

# Quality of life in Disability Studies

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*Disability Studies as an area of research, training and education, was recently launched as an organization in The Netherlands (November 6, 2009). The organization Disability Studies in the Netherlands (DSiN) aims to promote and advocate social change by means of research, education, and by supporting an integrated knowledge network. One important aspect of this development is the concept of quality of life (QoL) and its application in disability studies and disability related research. QoL can be seen as an anchor or framework for DSiN.*

*This paper focuses on the nature and application of QoL in disability research and practice and in DSiN in particular. First, a sketch of the QoL concept from an international perspective is provided. Then, the possible application of the concept of QoL in DSiN is considered along with the implications for disability studies in the Netherlands*

*[disability studies, quality of life, disabilities, the Netherlands]*

## Background

Although studies in the field of disabilities within the Netherlands has developed over a considerable number of years and has been prominent in research and practice, the idea of an overarching organization with the status of a discipline is relatively new. Disability Studies in the Netherlands (DSiN) was launched on 6 November 2009. DSiN hopes to promote and advocate social change by means of research, education and by supporting a knowledge network available to those involved in some shape or form in the disability field.

In the emerging field of disability studies in The Netherlands, several concepts are of importance. One of the core concepts is the concept of Quality of Life (QoL), integrated in the mission statement of DSiN in the following way (Kool 2009: 7):

DSiN aims to contribute to:

- the effective quality of life for people with disabilities, including self-directing their choices and life;

- the full participation of people with disabilities, optimizing their talents, qualities and lived experience;
- an inclusive society with diversity, space and opportunities for everyone;
- a research and developmental tradition including people with disabilities (and their organizations) in several roles, according to the adage: ‘Nothing about us, without us’.

This paper focuses on the concept of QoL in disability related research, and its possible and potential application in the Dutch context. It sketches the concept from an international perspective followed by a discussion about the application of the concept of QoL in DSiN.

A large amount of work on QoL is available in the field of intellectual and developmental disabilities. A large group of researchers from the International Association of the Scientific Study of Intellectual Disabilities (IASSID) produced a consensus document (Schalock et al. 2002) that formed the basis for further research and practice. Of importance for the purpose of this article is the fact that IASSID views the development of QoL from a multidisciplinary perspective. QoL is as a social construct involving community, social and family concepts, including health (Kober 2010; Turnbull, Brown & Turnbull 2004; Schalock et al. 2005). The multidisciplinary and inclusive perspective in this article is a description of quality of life as developed in the field of intellectual and developmental disabilities. This includes intellectual disabilities arising in the developmental years either through genetic causation or environmental damage such as poverty, abuse or physical accident. It also includes such conditions such as cerebral palsy, which may or may not involve a degree of cognitive disability.

In promoting research and education DSiN adopts the following set of guidelines.<sup>1</sup>

#### Disability Studies:

- views disability contextually, proposing a hybrid model involving an understanding of impairment as an interaction between the individual and the environment (WHO 1993);
- is an emerging interdisciplinary field of research ‘targeted at enhancing enablement and preventing disablement’ (Turnbull & Turnbull 2002);
- has a ‘cross-disability’ perspective, its accent is not on specific disabilities such as intellectual disability or deafness, but on domains and principles that are important for all people with and without disabilities (Van Hove 2009);
- should actively encourage participation by students with disabilities and promote leadership positions for people with disabilities.

DSiN uses three perspectives following Albrecht et al. (2001) who outline: (1) the historical background of disability studies, including definitions, classifications, scientific paradigms and theory; (2) the experience of specifically focusing on disability and local community, the role of professionals and social network; and (3) disability in context, addressing culture, rights, education, work, policy and technology. The three perspectives are consistent with the arguments put forward in the IASSID consensus

QoL document by Schalock et al. (2002). Within these three perspectives, DSiN states that the QoL of people with disabilities within society is a major focus or anchor point for disability studies (Kool 2009).

In (Western) international disability studies the concept of QoL has become a core concept, because it is central to people's lives and society. This is critical because Western society frequently devalues people with disabilities, and associates their existence with a lower QoL (Barber 1990; Jones et al. 2008; Wolf 1990, cited in: Lyons 2010: 75). Cummins (2001), for instance, has noted that people in restricted environments, including institutions, may not have opportunities to explore normal and wider ranging environments. Some articles have, however, reported contradictory findings. For instance Albrecht and Devlieger (1999) concluded that, notwithstanding the severity of their disabilities, some people with disabilities reported their QoL as being good to excellent. Such a contradictory finding highlights that perception is a critical aspect of QoL (Brown et al. 1992) and as researchers have recognized, perception is what drives people's behaviour (e.g. Andrews 1974).

## **Quality of life**

QoL can be considered as a concept that identifies what is important, necessary and satisfying in human existence. The concept dates back many hundreds of years. The earliest known reference to QoL is made by Aristotle who used the term 'eudemonia' or 'the good life'. However, this notion did not enter into social sciences, particularly sociology and psychology, as a defining concept until the beginning of the 20th century and only began being researched in the field of disability in the 1980's and 1990's. Since this time there has been a large growth in the use of the concept and its application within the field of intellectual and allied disabilities (Brown et al. 1989; Schalock 1990; Goode 1994; Felce & Perry 1996; Cummins 1996).

Searching the worldwide web for QoL, one comes up with millions of hits, indicating the present widespread use of the concept, many of which are vague, confusing or at first glance contradictory. In the field of intellectual and developmental disabilities there has been an attempt to define and consolidate ideas about QoL (see for example Schalock et al. 2002). Quality of Life is an integrating concept, which takes into account a number of previous approaches and concepts such as normalization, inclusion, and empowerment, though the development of QoL is resulting in some modification to those practices. For example, the application of personal choice within a developmental framework may set limits for some individuals on the degree to which they wish or feel comfortable with inclusion. Thus it is important to recognize individual and family variability. In addition, in the QoL model described here, there are further principles integrated within this holistic concept including, for example, self-image, lifespan, perception, inter and intra personal variability (Schalock & Verdugo 2002; Brown & Brown 2003; Turnbull et al. 2004). Domains cover all areas of individual and family living. Examples are health, finance, community, family, employment, education (see Felce & Perry 1996; Brown et al. 2003, 2006). It is recognized that

all of the domains are linked and are activated through such principles as choice. For example, recreation and leisure may for some people the best way to improve physical health and employment. It is this notion of holism that makes QoL an interesting prism through which to examine policies and practices for individuals with disabilities, their families and social network (Brown & Brown 2003).

Although different researchers have categorized QoL of comprising of different domains, each set of QoL domains cover the major areas of life functions. Much used in international public policy are the domains used by the World Health Organization: physical health, psychological well-being, social relations and environment (Murphy et al. 2000). Brown & Brown (2003) consolidated these ideas for practice in disability services into three core domains and nine sub-domains: Being (namely physical, psychological and spiritual well-being), Belonging (namely physical, social and community belonging) and Becoming (namely practical, leisure and growth becoming). Another widely used set of domains is described by Schalock & Verdugo (2002), namely: emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. The various domains discussed by different researchers have a wide degree of commonality though different labels are sometimes employed. All the recent domain structures cover similar ground and reflect the particular context involved.

### *The concept of QoL in the context*

Over the past three decades, in the disabilities field, the concept of QoL has received an international perspective, and has been applied in several ways, for example as a *sensitizing*, *organizing* and *reflecting* concept (WHO 1993; Brown et al. 2009; Schalock et al. 2007). As a sensitizing concept, in the last quarter of the 20th century the concept of QoL began to be studied in depth as a conceptual model and applied in research and social policy (Brown, Bayer & MacFarlane 1989). The 1980's was a decade of international focus on disability, for example, the United Nations proclaimed 1981 the International Year of Disabled Persons (Schalock et al. 2007). The concept was developed to encourage stakeholders in the disabilities field to be aware that both people with and without disabilities want to live a quality life.

As an organizing concept QoL provides a framework at several levels. For example, the WHO uses the concept in describing poverty around the world (WHO 1993). In the United States the Americans with Disabilities Act of 1990 and other legislation emphasizes greater access to services and encouraged full involvement of people with disabilities in community life (Schalock et al. 2007). From the mid-1990s the concept of QoL was used throughout Europe as an organizing concept in designing programs and support, with a strong influence on personal advocacy (cf. Schippers 2010). Many aspects of QoL in the last quarter of the 20th century are described in Romney et al. (1994). Furthermore QoL as a reflecting or evaluating concept provides a reference for evaluating policy and practice, e.g. legislation or care provision. Emphasis in QoL research and practice is on applying the QoL concept for multiple purposes, including personal development, personal well-being and quality improve-

ment. In the coming years the focus will be on sustaining and improving QoL outcomes (Schalock et al. 2007).

The interest in QoL is derived from several sources. Brown & Schalock (2009) describe how research and then application can improve the QoL of both individuals and families when disability occurs. The impact of pressure groups and self-advocacy and parents organizations has grown over the years, and has become closely linked to the notion of improved living conditions and well-being, e.g. inclusive education. Further, movements such as The Association for Community Living in Canada (see <http://cacl.ca>), and in general the empowerment and rights movements have had an increasing effect on the development of services and support in terms of well-being and QoL for people with disabilities.

In the above context Van Gennep (2007) places the concept of QoL in his social objectives in the historical perspective of social responsibility towards people with disabilities. These include amongst others: dignity of and respect for people with disabilities (QoL), integration in society (inclusion), emancipation of people with disabilities (empowerment), which provide the means by which people with disabilities can be sustained and enabled to help themselves (support). Van Gennep (2007) describes QoL as a useful concept in realizing the above-mentioned social objectives for people with disabilities. QoL is not only the QoL of the individual, but also the means of supplying informal and professional support, which reflects the individual's personal choices.

Scientific paradigms, including QoL, advance over time and ideally are later reflected in public policy. Public policy based on QoL principles including equity, living and working conditions, and personal empowerment, will continue to be a significant factor in the evolution of disability reform (Brown et al. 2009). In understanding disability the emphasis has changed from individual causation, reflected in the biomedical and functional models, to an understanding of disability from an ecological perspective. Recently a hybrid approach has been advocated, integrating environmental perspectives on disability within a cultural model that emphasizes individual and personal aspects along with culture (Devlieger et al. 2003, 2006). An ecological perspective, e.g. cultural mores, is likely to influence QoL, both for people with disabilities as well as the rest of the population, and therefore it is critical in the future design of individual support and intervention programs.

### ***QoL: Research criteria***

Research on QoL has played a role as a '*change agent*' during the past few decades, primarily as a sensitizing notion, broadening to a conceptual framework for assessing quality outcomes and enhancing quality of life through understanding, support and intervention (Lyons 2010; Schippers & Tubben 2008).

In 2004 an international group of QoL researchers who were member of the Quality of Life Special Interest Research Group (QoL SIRG) of IASSID developed a set of criteria for Quality of Life research. This particular set of criteria is a useful format for considering the different aspects of QoL, and as such can be an effective model

in designing policy and developing intervention and support (see also Brown et al. 2009).

The first criterion for QoL research is the use of a multidimensional framework using several domains, with anticipated cross-cultural validity that allows research to be more clearly directed to specific areas. The QoL SIRG formulated a set of operational principles for QoL research. The principles are outlined in three major components in the model of QoL, presented in box 1. The first component is conceptualization, and describes what QoL is, namely a multidimensional construct, influenced by personal and environmental factors and their interactions (Schalock & Verdugo 2002). As described earlier, components or domains cover all important areas in life and are interrelated (although it is recognized that there is variability from person to person), result from individual perception and choice, and change over an individual's lifespan (Brown & Brown 2003). Consistent with a hybrid model on disability, QoL is considered to be enhanced by self-determination, within resources available from family, friends and other people, as well as from professional support. Further, principles on assessment and measurement include the recognition and measurement of individual QoL, including the recognition of valued personal experiences and circumstances, which reflect domains that contribute to a full and interconnected life. The important aspects of the physical, social and cultural environment need to be taken into account. The third component of application focuses on the enhancement of well-being within the context of those involved, thus implying a wide variety of settings as well as a variety of individual and group purposes. Professional practices should reflect QoL principles resulting in personally valued QoL outcomes that are based on sound professional skills and methods such as observation and the measurement of choices that are important to the person (see also Brown et al. 2009; Brown & Brown 2009).

It is important to recognize that the three components are interactive. Working in any of the components requires effective assessment and feedback for adjustment to a total research or support program. This requires that the approach much be fully interdisciplinary from a research or a professional perspective. For example, what professionals learn from application often has an impact on measurement strategies and technique, and can result in re-conceptualization (cycle of iteration).

A second criterion for effective QoL research is a balance of qualitative and quantitative methods and triangulation of those methods, using assessment of both subjective (perceptual) and objective parameters.

Furthermore, a systems perspective is helpful, integrating the micro-, meso- and macro-levels in which persons with disabilities live, so that predictors and causal factors in their lives may be identified (Lyons 2010).

The criteria of methodological pluralism and a systems perspective make clear that QoL research requires active involvement of people with disabilities and their social network. As argued above, inter and intra variability in perceived QoL is critical in QoL research. Also QoL research requires phenomenological approaches with partnerships between subjects and researchers.

<b>Premise</b>		
Quality of Life provides an organizing framework to promote wellbeing at the personal, family, service delivery, community, national and international levels		
<b>Conceptualization</b>	<b>Measurement</b>	<b>Application</b>
1. Quality of Life is multi-dimensional and influenced by personal and environmental factors, and their interactions	1. Measurement in Quality of Life involves the degree to which people have Life experiences that they value	1. Quality of Life application enhances well-being within cultural contexts
2. Quality of Life has the same components for all people	2. Measurement in quality of Life reflects the domains that contribute to a full and interconnected life	2. Quality of Life principles should be the basis for interventions and supports
3. Quality of Life has both subjective and objective components	3. Measurement in quality of Life considers the contexts of physical, social and cultural environments that are important to people	3. Quality of Life applications should be researched in practice and evidence-based
4. Quality of Life is enhanced by self-determination, resources, purpose in life, and a sense of belonging	4. Measurement in quality of Life includes measures experiences both common to all humans and those unique to individuals	4. Quality of Life principles should take a prominent place in professional education and training

## Quality of Life in Disability Studies in the Netherlands

Having described the concept of Quality of Life in the previous section, the possibilities of the QoL concept are now explored in depth for application in disability studies in the Netherlands.

First, there is a great similarity between the concepts and principles of QoL as stated above and the mission statement of DSiN. QoL research is a change agent in the disability field, influencing public policy and professional practices. Thus, a QoL framework is useful to DSiN in advocating for social change, contributing to the first part of the organization's mission statement, namely 'an effective quality of life for people with disabilities, including the self-directing of their life'. Such practice-based research is at the core of disability studies, reflecting amongst others on the relationship between science and activism (Kool 2008: 10; see also Gabel & Peters 2004). Brown (1997) and Brown et al. (2009) noted that there is currently a shift in the study of disabilities, from 'group' to individual focus, from external to internal levels of control. Better understanding and knowledge about self-image, choice and self-control are important and need to be on the current research agenda. These aspects

need to be fully explored in partnership with people with disabilities, using theoretical concepts such as QoL. Future research in the disability field should be directed by a framework that promotes wellbeing not only at the personal, but also at the 'systems' level, including changes within society.

Second, the criteria of QoL research seem to be an effective fit with the guidelines for disability studies research mentioned in the background section of this paper and also applied by DSiN. Like the guideline of using a hybrid model in disability studies research, the models of QoL represents many concepts and ideas within a changing environment (Brown 1997), including not just the disabilities field but also the general population in both western and non-western countries (Rapley 2003). Keeping the characteristics of disability studies research in mind, QoL appears to be a useful concept in a hybrid and cross-disability perspective. Brown et al. (2009: 2) indicate that "QoL is increasingly being informed by the ecological model of disability, which sees disability as the expression of individual limitations within a social context, and by the social model which views disability as a core aspect of society and as such should be accommodated fully by society." Like Disability Studies QoL is influenced by many disciplines in the social sciences: health and life sciences, humanities, education, gender studies, economics, and history. Moreover, disability studies research, as well as "QoL studies, resides at the interface between art and science" (Clarke & Clarke in Brown 1997: xii) and represents an interactionist approach (Gleeson 1997), indicating that research influences policy and practice, e.g. the interaction between the disability movement and self-advocate groups.

However, every model represents a reductionist view (Rioux 1997). This is the case for integrated, cosmologic models (Devlieger et al. 2006) as well as for QoL models (Brown 1997; Rapley 2003). Within this structure there are other important issues such as ethical and professional considerations. Rapley (2003: 63), for example, raised the question "whose quality of life is it anyway?" which indicates issues about focus, ethical and professional responsibilities that influence the ways in which practitioners and researchers carry out their work. For example, if data is collected involving people with disabilities how should they be acknowledged in publications? Such issues are not only of a quantitative nature but are also and perhaps essentially qualitative. Debates on such issues will continue, and will deepen and broaden our understanding of disability, leading to the development of further concepts and models in disability studies. This is especially relevant in the Dutch context, where disability studies is an emerging field, aiming to enlighten and integrate research policy and practice (Hoppe et al. in press).

QoL is a theoretical construct with major practical implications. It is also an evidence-based concept and provides direction for constructing and evaluating disability related policies and practices. It is critically important that QoL applications are measured. However, it is important to first determine what are the components of any QoL application. This has to be determined by people with disabilities and their social network. Recommendations may come from professionals but the aim is to heighten the chances that support and interventions will in fact improve the individual's perception of their QoL, and this should include measures based on the individual's responses

whether verbal or non-verbal. It is personal reactions to change that are critical in this context (see Lyons 2010).

Furthermore, as the QoL concept is a significant concept within disability studies, and as such influences and is influenced by disability policy and practices, the concept should be further validated from a cross-disability perspective, including an interdisciplinary and participatory approach. In the Dutch context, this is even more important, because most QoL research is driven by health care policy and practice. Moreover, most QoL research is not derived from a multidisciplinary and inclusive perspective, which is critical from consumers' and modern disability studies views of application and personal need. Started as an emancipatory discipline, disability studies is according to Gleeson (1997) in a state of 'theoretical underdevelopment'. Therefore, not only should the concept of QoL be validated from a cross-disability and interdisciplinary context, but it should also be examined further in developing a theoretical framework for DSiN, intertwined with other important theoretical issues such as identity, disability culture, and social/cultural model analysis.

DSiN recently launched its first research program, which reflects the mentioned (disability studies and QoL) research criteria (See <http://disabilitystudies.nl>). Building theory and applied research will be on the agenda so that disability studies will be in a better position to impact public policy and disability reform (Brown et al. 2009). Lyons (2010: 108) stresses the need to promote the synchronizing of research and practice in such areas as support and intervention as well as policies. According to Lyons (2010), it is both necessary and possible to move from the rather isolated studies in the disabilities field towards an integrated body of knowledge. Such a move would be of importance in the development of QoL services in the Netherlands. As Lyons (2010: 108) concludes, it is the 'ultimate benchmark to make a difference in the lives of individuals with, which is also the ultimate goal DSiN is striving for in the Netherlands.

## Notes

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1 Retrieved from [http://www.Disstudies.org/guidelines\\_for\\_disability\\_studies\\_programs](http://www.Disstudies.org/guidelines_for_disability_studies_programs);  
See also Van Hove 2009: 305, 306.

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