

Journal of Policy and Practice in Intellectual Disabilities [Explore this journal >](#)

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Volume 14, Issue 1

March 2017

Pages 4–6

Quality of Life-New Directions

Editorial for Special Issue on Quality of Life: Exploring New Grounds

[Alice Schippers](#) , [Geert Van Hove](#)

First published:

1 March 2017 [Full publication history](#)

DOI:

10.1111/jppi.12228 [View/save citation](#)

Cited by:

0 articles



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This special issue on Quality of Life: Exploring New Grounds, is the second part of two special issues. The first one is published in the *Journal of Intellectual and Developmental Disability*, Brown & Schippers (Eds.) 2016, 4(4). The two issues are complementary and together give a broad overview of both developments and challenges in the field of quality of life and family quality of life.

Over the past decades, the concept of Quality of Life (QOL) has received an international or global perspective (Brown, Schalock, & Brown, 2009; WHO, 1993). Quality of life can be considered as a concept that gives a general idea of what is important in life, “what it is all about.” Living a quality life is equally important for people with and without disabilities.

General QOL research was in the early stages in the 1960s focussed on the sustainability of political systems (historical), the productivity of a state (economic) and achieving societal ideals (sociological) (Michalos, 2014; Veenhoven, 1998). Social indicators research reflects this systems oriented approach, for example, in describing poverty around the world (WHO, 1993). Developing individual QOL became more and more important, informed by psychological research and focus on personal outcomes.

In the field of intellectual and developmental disabilities (IDD) QOL, though based on research, is employed as a practical approach. Its end goals involve personal well-being and positive social and community interaction (see Brown & Faragher, 2014; Schalock et al., 2002). As in current QOL research generally, the emphasis on individual outcomes is viewed as critical and its roots in research and practice are important developments (Michalos, 2014). Contextual factors, for example, the social and economic system, provide preconditions for a good life, and are essential considerations both historically and presently in QOL (Veenhoven, 1998).

In the field of IDD from the beginning of the 21st century Family QOL (FQOL) became a major focus

espousing similar domains to individual QOL in order to obtain measures of importance, opportunities, initiative, attainment, stability, and satisfaction (Isaacs, Brown, Brown, & Wang, 2007). A major gap seems to be in the application of the results from this approach.

It is interesting to see that the new ideas and practical application as well as research, we looked for in the call for papers for this special issue was reflected in the majority of proposals which focussed on application of FQOL—specifically in cultural contexts—, while embedding the QOL concepts in ecological approaches.

But, history is not simply repeated but influences new developments in the present. The focus on the family in QOL research in the disability field can be seen as an increasing blend of different backgrounds and approaches including ecological and systems approaches as well as developmental work in psychology (e.g., positive psychology). In studying individual QOL, the importance of the family and the broader network of community (particularly friends and neighbours) are critical as seen in the innovative research of the Turnbolls (Turnbull, Brown, & Turnbull, 2004), where FQOL was viewed as a multidimensional social construct (Samuel, Rillotta, & Brown, 2012).

The importance of ecological aspects is reflected in the first World Report on Disability (WHO, 2011), where considerable attention is paid to the complexity of experiencing disability in different cultural contexts. Themes like war and conflict and living with a disability in or because of extreme poverty were less emphasized in the QOL measures and disability research agendas, but are presented in this special issue.

At the more individual side of the spectrum of disability, there are issues concerning inclusion and personal and societal outcomes, but there is also the pressing issue of practising inclusive and collaborative research—in other words: the method is the message, which is also presented in this special issue. In summary, we have attempted to provide a blend of new challenges and solutions.

One of our QOL “pater familias,” Roy **Brown**, opens this special issue and shares with us his reflections after many years studying QOL. He leads us through critical debates on subjectivity versus objectivity of QOL data, which currently results in confusing or even misleading interpretation and as a result devalues data labeled as subjective. For the author, such QOL or FQOL data are hard perceptual data which require serious and careful interpretation. The author then critically investigates issues around inclusion that in practice can often lead to individual and family exclusion. Consequently, these situations can “bounce back” on the concept of QOL because the extreme acceptance of inclusion at all costs can lead to further exclusion. He argues that QOL needs to be expanded into a paradigm which takes into account this type of variable impact. A paradigm that guides future research, policy, and practice.

Brown's article gives us insight into the solid grounds on which QOL has been built over the last decades. The fruitfulness of this soil is reflected in the broad palette of subjects in this Special Issue.

Four articles in this issue draw attention to the broad and hybrid nature of QOL and ways of conceptualising the breadth and complexity of the concept.

First of all, **Alborz** in her article steps back in time and provides a valuable overview of what our field has achieved in conceptualising QOL. The addition of multidisciplinary approaches in the proposed model of QOL is compelling and matches well with the aforementioned cultural view on disability, where outcomes are informed by both contextual and personal aspects. Alborz provides us also with the potential use of the model. Via application of Latour's Action Network Theory she shows the reader that because of the complexity and interplay of different elements greater and flexible ways of assessment can occur providing a more detailed and useful “snap shot” of QOL.

Furthermore, the concept of FQOL contains few indepth studies on the relation between the various

family members and general FQOL. Contributing to the foundation of FQOL, **Boelsma, Caubo, et al.**, conducted several individual family case studies. Relation dynamics were noted and described using the metaphors employed by the family members. One of the reflections by the authors is that the dynamic interplay between individual and family QOL can strengthen families and their members, but can also lead to tensions and conflicts between family members. A flexible way of assessing family QOL, as proposed by Alborz, might be one of the possible applications of these findings.

In the third conceptual article, **Faragher & Van Ommen** build further branches on the tree of QOL, namely Educational QOL. Education is a major life area, and certainly for persons with intellectual and developmental disabilities since the exponential rise of their life expectancy. The authors, from their practice and from the literature, detected the need for change in education for students with intellectual disabilities and propose—perfectly in line with the hybrid, blended model—a multidimensional model for educational QOL, that features individual and collective aspects and where the student's voice is central to the teaching process.

The next article by **Sauer & Lalvani**, develops a broader ecological circle of influence (cf. Bronfenbrenner, **1986**) on individual and family QOL, specifically community life. The authors apply concepts and principles in individual QOL as tools in developing collective activism. They illustrate this from their experience in educational settings where individual advocacy of parents leads to grass roots collective activism. Intellectual and developmental disabilities have a lifelong and lifespan nature and families are not only involved in their lives, but disability of one (or more) family member(s) has impact on the individual family members and each impacts the family as a whole and also the wider community (Brown & Faragher, 2014).

The other half of this special issue contains four articles where application of FQOL is discussed in several specific but different contexts.

First, the voice of persons with disabilities needs not only to be included in policy, but also in the practice of doing research. **Correia** conducted a study where the voices of persons with intellectual disabilities were not only heard and valued, but resulted in new knowledge about FQOL. In her article, that she wrote with I. Brown, the specific concerns of persons with intellectual disabilities are discussed in terms of aging of relatives. The impact of longevity and ageing on families is an important area of study in our field (National Task Group on Intellectual Disabilities & Dementia Practice, **2012**). The lived experiences and knowledge of persons with intellectual disabilities themselves add to our understanding of the impact of ageing in individuals and families.

In the following article, **Roth & I. Brown** consider social and cultural aspects in Israeli families. Here, the contextual impact on QOL becomes very clear. Specific aspects such as being a minority group and living in a conflict area are addressed. The authors discuss the importance of cultural issues, such as spirituality, values and beliefs, in measuring and applying the Family QOL concepts. The importance of alignment between policy and practice to improve the lives of families is stressed.

The importance of spirituality and cultural beliefs resonates in the third article by **Aldersey**, who takes us to the Democratic Republic of Congo. She explores Congolese conceptions of FQOL, which show many commonalities with international FQOL studies, but are different in their specific cultural views regarding self-support of families. The relationship between poverty and FQOL proved to be an important issue in Congolese families, and complements the FQOL literature, and reflects the global knowledge on disability and poverty described in the aforementioned World Report on Disability (WHO, **2011**).

In the final article, Schmidt, I. Brown & Schmidt inform us also on the importance of family relationships. In their Slovenian study, family relationships and community interaction proved to be important contributors

to FQOL, where support from (in)formal support was valued as highly desirable but not always available. Moreover, in families with a child with disabilities involving autism spectrum disorder, the contribution of (in)formal support was seen as even more necessary. This is an important finding, as it further informs policy and practice world wide, because it is consistent with previous international studies (Brown, 2012).

Acknowledgments

The authors would like to thank Roy Brown for reviewing this editorial and also for taking the lead in the partnering special issue in the *Journal of Intellectual & Developmental Disabilities*. Also, special thanks to Ivan Brown, who did a lot of 'native' editing. As non-native English speakers, we needed and appreciated his non-stop efforts. We thank Ralph Kober, who thought along with us in the initial phase of this issue. Finally, as guest editors we are grateful for the support from the previous Editor in Chief, Matt Janicki, who encouraged our Special Interest Research Group on Quality of Life to put forward this special issue. We also appreciated the smooth follow-through by Rhonda Faragher, the current Coeditor in Chief.

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