

Special issue: Quality of life and family quality of life: Recent developments in research and application

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EDITORIAL

Special issue: Quality of life and family quality of life: Recent developments in research and application

This special issue on quality of life (QOL) and family quality of life (FQOL) is the first part of two special issues, with the second to appear in the *Journal of Policy and Practice in Intellectual Disabilities* (JPPID) in 2017. Studies concerning QOL in the field of intellectual and developmental disability (IDD) started in the late 1980s and 1990s (see Brown, Bayer, & MacFarlane, 1989; Goode, 1994; Renwick, Brown, & Nagler, 1996) and the major themes were pulled together in 2002 (Schalock et al., 2002). FQOL was a development from the earlier field of QOL, and in 2000 a symposium prior to, and in conjunction with, the IASSIDD conference in Seattle summarised the work to date. This family research was further developed and published in 2004 (Turnbull, Brown, & Turnbull, 2004). Development started slowly in both areas and is now seen as important for research, policy, and practice. The major themes have been published in both article and book format.

This issue of the *Journal of Intellectual & Developmental Disability* (JIDD) is built around age samples particularly because QOL is seen as a lifespan topic both for individuals with IDD and their families. Brown and Faragher (2014), with a number of colleagues, have argued that both QOL and FQOL contain fundamental aspects of social living, including the needs of individuals for support, and these have relevance way beyond IDD. For example, it is in the family and community relations that perceptions play major roles in driving the behaviour of individuals, and this is accented within the first few articles of this special issue.

Luijkx et al. provide us an insight into siblings' perceptions in living with a brother or sister with profound disability. Proxies are considered in most cases parents of persons with IDD, and their perceptions are taken into account in Sigstad's article, focusing on friendships as an important topic in adolescents' lives. In planning for the future, parental perspectives are also important, but in directing their future lives, the choice of young adults with IDD themselves is a critical requirement, as van Heumen and Schippers concluded in their article, while Simões and Santos explain the similarities and differences between perceptions of persons with IDD themselves and their proxies.

Sexton and colleagues examine the use of QOL scales with older adults; a critical aspect of which is the comparison

between ageing adults with and without IDD. The authors review specific measures through the lens of Schalock's QOL framework. In a large sample study, Lombardi et al. stress the importance of aligning specific personal needs and goals. Intervariability is thus highly relevant and the requirement for individual targeting of supports.

Taub and Werner have taken on a challenging area. Examining FQOL from the perspective of religious beliefs and spirituality has not been studied in much depth, and the authors raise important issues in terms of the connection between different aspects of family relations and domains of FQOL. In doing so they stress the relevance and importance of religious and spiritual belief. The authors carry out an interesting and in-depth analysis, which raises many questions regarding methodology and interpretation.

The article by Krishnasamy and her colleagues is a conceptual paper. We have placed it as the final article because the authors employ QOL as a lens to construct a model for the important issue of transition for youth with IDD. This has been a challenge for many years, and the authors use the framework of QOL based on the prior work of many notable colleagues who have contributed to this field over many years. Krishnasamy et al. take the ideas in QOL a step further by providing an approach for moving forward on this critical issue.

The messages contained in the above articles include a validation of much of earlier work in the field of individual and family QOL. While confirming and further investigating the general principles of such concepts as choice and variability among people with similar challenges, the articles note that there remains a need for policymakers and practitioners to take account of such findings in research in ensuring that relevant "tailor-made" supports are available to maintain and improve individual and FQOL.

We acknowledge the support of Michael Arthur-Kelly and Matthew Janicki, the editors of JIDD and JPPID, respectively, for permitting us to move, with author consent, articles across the journals to make effective balance in both of the issues on QOL. We also thank Michael for his willingness to take on this special issue, along with his advice and support during development. Genevieve Farrell, Assistant Editor, kept us up to date and provided

publishing support throughout the process. We are much impressed!

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