

## Editorial

# Embracing an era of rising family quality of life research

Inquiry into family life has been an intriguing topic for multiple disciplines for many decades. The field of disability has especially witnessed a growing interest of research in understanding the needs of families of individuals with disabilities and the means of supporting them to attain enhanced quality of life. Rooted in a rich literature of individual quality of life research, family quality of life (FQoL<sup>1</sup>) has emerged as a field of study since the dawn of 21st century (Turnbull *et al.* 2004; Brown *et al.* 2009; Wang & Brown 2009).

From its early stage of development, fundamental issues surrounding conceptualisation, measurement and applications of family quality of life have been considered and debated. Over the years, FQoL research has been burgeoning in all these three dimensions. Despite the pluralism of FQoL definitions, there is a growing consensus on the underlying principles of conceptualising family quality of life. Zuna *et al.* (2010, p. 262) put forth a definition that sheds light on such an emerging consensus: 'Family quality of life is a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact.' However, they have made a call to the field for further theo-

rising about family quality of life. In addition, numerous measures of family quality of life have been developed in different cultures and languages and tested for validity and reliability. These measures assess family needs or family outcomes for the purpose of service programme planning or evaluation. They do this via the collection of either qualitative or quantitative data, or both. The fruitful applications of FQoL concepts, propositions and measures in developmental disability service system, which have led to a paradigm shift of service models, suggest that we are embracing an era of rising research in understanding family quality of life so as to better support families of individuals with disabilities through service systems that are family-centred.

Against this background, we believe that JIDR has, without doubt, chosen a perfect time to dedicate a special issue on the topic of family quality of life. We, as guest editors, are absolutely honoured to be invited to co-edit this special issue, and are thrilled to be able to glean a wonderful collection of 16 articles in this special issue. This special issue has several unique features. First of all, it's truly international. The 16 articles in this issue represent the most current FQoL empirical research from scholars from a wide spread regions of the world.

From Asia, the article by Hu, Wang and Xiao presents the results of an extensive survey of 442 Chinese families of middle school or high school students with intellectual disabilities (ID). The

<sup>1</sup> We acknowledge the different abbreviations for Family Quality of Life used in the literature: FQOL in the US literature and FQoL used in the international literature. We have used FQoL given the international focus of the Journal of Intellectual Disability Research.

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article by Clark, Brown and Karrapaya focuses on a FQoL survey study of 52 Malaysian families of children with intellectual and developmental disabilities (IDD).

We are especially pleased to have an article from Africa, a region in which family quality of life has definitely been under researched. The article by Ajuwon and Brown presents the results of the first systematic study in sub-Saharan Africa using a FQoL instrument. In addition to this paper focusing solely on Nigeria, the FQoL survey data from Nigeria is also included in the international comparative paper authored by Isaacs, Wang, Samuel, Ajuwon, Baum, Edwards and Rillotta.

This special issue contains papers from six European countries (Belgium, Bosnia and Herzegovina, Israel, Italy, Slovenia and Spain) that span both conceptualisation and measurement issues related to family quality of life and employ both quantitative and qualitative research methods. Belgium is especially well represented with two studies. Steel, Poppe, Vandeveld, Van Hove and Claes report on the results of a study on family quality of life of 25 Belgian families associated with a large project focusing on the development of support strategies for young and adolescent siblings of individuals with ID. Moyson and Roeyers adopt a qualitative research design and employ in-depth and phenomenology-based interviews to understand and interpret the life experience of a sibling of children with ID from the sibling's own frame of reference. Svrlak, Loga and Brown contribute a paper that reports the preliminary findings of a FQoL survey of 35 Bosnian families of adult school students with ID. Neikrug, Roth and Judes present the results of a FQoL survey of 103 Israeli families of children with IDD. The paper by Bertelli, Bianco, Rossi, Scuticchio and Brown reports the results of a survey conducted in Italy on 27 individuals with ID and their family members regarding both individual quality of life and family quality of life. Likewise, the study by Cagran, Schmidt and Brown reports the preliminary findings of an FQoL survey of 20 Slovenian families of children with IDD. Somewhat differently, the paper by Balcells-Balcells, Giné, Guàrdia-Olmos and Summers presents the results of a validation study of three FQoL related measurement instruments (i.e. the Beach Center Family Quality of Life Scale, the Beach Center Family-

Professional Partnership Scale and the Service Inventory) by using a sample of 202 Spanish families of young children with IDD.

From North America, data from Canada and the United States of America are reported in two articles. The Canadian FQoL data are reported in the article by Isaacs, Wang, Samuel, Ajuwon, Baum, Edwards and Rillotta as a part of international comparative study to examine the factor structure of the Family Quality of Life Survey-2006 (FQOLS-2006). The paper by Samuel and Hobden reports on the findings of a FQoL survey study involving 149 American low-income minority families of children with developmental disabilities (DD).

Last but definitely not least, from Oceania, there are two studies by Australian researchers. In the first article, Miller, Buys and Woodbridge present the results of a qualitative study that focused on exploring the grandparent's perspective of family quality of life. Through semi-structured interviews, 22 grandparents were asked to share their caregiving experiences for their grandchild with a disability and the impact on their family relationships and quality of life. The second paper, by Rillotta, Kirby, Shearer and Nettelbeck, reports the results of a survey of 42 Australian families of individuals with IDD with respect to their ratings of different domains of FQoL in different dimensions such as importance, opportunity, initiative, stability, attainment and satisfaction.

In addition to the above empirical papers, this special issue also includes two papers that provide a thorough literature review on the key conceptualisation and measurement issues of family quality of life. The conceptual paper by Samuel, Rillotta and Brown presents a comprehensive literature review on the evolution of family quality of life research for families of individuals with IDD, the origins of which lie in the related areas of study of: (i) family and family support research; and (ii) individual QOL research. In particular, the authors have provided useful comparisons of the two widely recognised conceptual frameworks and associated measurement tools of FQoL: The International FQoL Project and the FQoL initiative of the Beach Center on Disability in U.S. Therefore, this paper serves the purpose of providing a conceptual background to the other papers in this special issue. The

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other paper by Hu, Summers, Turnbull and Zuna provides a very thorough literature review on sixteen measurement tools commonly used in the area of disability studies, healthcare studies and general family research that can quantitatively measure the FQoL construct or related constructs such as family well-being and family satisfaction. Three summative tables are presented in this article illustrating the theoretical basis, scale characteristics and psychometric properties of these 16 measurement tools.

In addition to the strong international flavour represented by the wide coverage of work from respected international scholars, this special issue also highlights the spirit of collaboration apparent by researchers in the field of FQoL studies. The vast majority of the articles included in this special issue are coauthored by the scholars from different countries. This attests to a unique and noteworthy trend of international FQoL research.

Another important feature of this special issue is related to the emphasis of family voices. Turnbull *et al.* (2004, p. xv) eloquently stated it, in that you understand 'nothing about family quality of life without the voices of the families.' It is evident that many studies reported in this special issue explore the voices of parents (both fathers and mothers), siblings and grandparents of individuals with IDD. Historically most research conducted on families has focused on mothers as a 'spokesperson' of the family in order to understand their perspective and opinion of family life and wellbeing. It is likewise true for FQoL research, where mothers (for most of the cases) and fathers (for some of the cases) are often the target of inquiry given that they usually assume the main caregiver role in the family. In this special issue we are delighted to be able to present two qualitative studies that extend the voice of the family. Both articles seek to understand family quality of life, one by listening to the voices of grandparents of individuals with IDD (the paper by Miller, Buys and Woodbridge) and one by seeking the opinions of siblings of individuals with IDD (the paper by Moyson and Roeyers). Embracing pluralism of family perspectives for understanding family quality of life is definitely needed in this area of study, and it is of importance to deepen our understanding of issues regarding family quality of life as well as to lead the FQoL research into a new horizon.

Yet another unique feature of this special issue is the methodological richness of the papers. The studies in this special issue employ a variety of research methods, such as a meta-synthesis literature review, qualitative methods, quantitative methods and mixed method (i.e. using both quantitative and qualitative data). Different analytical techniques are also used to analyse both qualitative and quantitative data. For instance, in addition to the use of conventional descriptive and inferential statistics for data analysis, some more advanced statistical techniques such as structural equation modelling have been adopted in the FQoL studies. All of these indicate that this special issue has assembled some of the most cutting-edge research to date in the area of FQoL studies.

In addition, there are a couple of other observations that we want to share regarding the studies reported in this special issue. This special issue includes an article by Isaacs, Wang, Samuel, Ajuwon, Baum, Edwards and Rillotta that reports the first validation study of FQoLS-2006 based on the data from four countries. Given that the FQoLS-2006 has been translated to in excess of 20 languages and is being widely used in a number of countries, the reporting of psychometric properties of this scale has long been awaited. Although the preliminary findings of the scale validation in terms of its validity and reliability seem satisfactory, two problems still remain. Some dimensional measures of the FQoLS-2006 (e.g. Importance and Stability) seem to be unreliable and questionable as suggested by this study. This *red flags* the use of nine FQoL domain scores since each FQoLS-2006 domain score is generated on the basis of six dimensional rating scores. So each domain of the nine FQoL domains in the FQoLS-2006 require real indicators (component items). The current dimensional measures of the FQoLS-2006 can then be refined as six sub-scales of the FQoLS-2006 (e.g. Attainment and Satisfaction sub-scales as the real outcome measures of FQoL and other four explanatory measures of FQoL as the supplementary sub-scales of FQoL).

Aside from the validation study of the FQoLS-2006, it is evident in this special issue that a series of studies conducted through international collaborative projects have focused on investigating both etic and emic properties of the FQoL construct by

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adopting the same measurement tool (FQoLS-2006) in their respective countries. The tables presenting the mean scores of all the FQoL domains in the majority of those country studies provide an overall picture about what family domains appear to be important to families of individuals with IDD in different cultures or countries. This information also provides a good platform for some comparative analysis across countries to occur which could have important international policy implications. However, what seems to be missing in most of these country studies is the *Why* and *What* questions. That is, why families of individuals with IDD regard some domains as more important than others with respect to their family quality of life, and what influencing factors might be mediating or moderating their satisfaction with FQoL.

As mentioned earlier, we are delighted about the balanced coverage of both qualitative and quantitative studies in this special issue. Two qualitative studies that explore different family member perspectives of FQoL (e.g. perspectives of grandparents and siblings) deserve additional attention from readers. Not only have these two studies provided important and useful information to help us understand the perception of grandparents and siblings regarding family quality of life, they also raise important questions regarding FQoL conceptualisation and measurement: Is there any discrepancy of domain structures for different family members of the family? How can different family members' perceptions be included into the assessment or evaluation of FQoL by the use of FQoL scales?

Additionally, the paper by Samuel, Rillotta and Brown and the one by Hu, Summers, Turnbull and Zuna have made pertinent points regarding future directions for conceptualisation (or theorising in a broader sense) and measurement of family quality of life. In particular, the call of some researchers for a 'unified theory of family quality of life' for families of children with intellectual and other disabilities resonates with us. Based on the work of Zuna *et al.* (2010), a unified theory should view family quality of life as 'an interactive process in which individual family member demographics, characteristics, and beliefs interact with family-unit dynamics and characteristics within the context of individual-level and family-level supports, services, and practices' (Kober 2010, p. viii). This internal FQoL

framework is always impacted by external factors such as: policies, federal, state, and local service systems, and programmes of support. Therefore, an established theory or theoretical framework of FQoL can guide the researchers' decision in determining what domains or/and dimensions of FQoL represent an underlying construct – family quality of life.

As for the future directions of FQoL measurement development, there are several issues deserving of further attention by the field. Since family quality of life is usually defined as a multidimensional construct with a strong functional focus on family activities and responsibilities (as suggested in the Hu, Summers, Turnbull and Zuna paper), it would seem reasonable that different FQoL measures should have similar core domains. However, this is not currently the case, and there exists an inconsistency of core domains and indicators across the different FQoL measures. Future efforts on theorising FQoL should help address this issue at both the conceptual and measurement levels. In addition, it is interesting to note that no current FQoL measure considers family dynamics. We believe that future measurement development should consider creating a new sub-scale or adding a domain to FQoL scales reflecting family dynamics to measure the interactions and transactions among different family members and their reciprocity and patterns of mutual influence. In particular, from the point of view of unit of analysis, researchers need to develop specific versions of measures for various family sub-systems or members. More advanced analytical techniques such as the Multilevel Modelling approach (e.g. hierarchical linear modelling or growth latent curve modelling) provide promising means of analysing nested family data (e.g. family members nested in the family, and families nested in the community or culture etc.) at different layers. It also provides a more appropriate statistical means to tackle scoring choices of the FQoL scales (e.g. summative scores or family mean scores etc.).

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