Family Quality of Life of Australian Families with a Member with an Intellectual/Developmental Disability: Measurement issues

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Abstract

The main aim of this thesis was to investigate factors that affect the quality of life (QOL) of families with a member with an intellectual and/ or developmental disability. A second aim was to compare the validities of two established instruments designed to assess Family Quality of Life (FQOL): the international *FQOL Survey: Main caregivers of people with intellectual or developmental disabilities* (FQOLS-2006; I. Brown et al., 2006) and the *Beach Center FQOL Scale* (Beach Center on Disability, 2003). Qualitative and quantitative FQOL data were collected by interviewing main caregivers of family members with an intellectual/ developmental disability in South Australia.

Results confirmed the need for multi-dimensional measures of FQOL, as contained in both surveys. The results also suggested that FQOL is more accurately assessed using the surveys in an interview format. The need for a combination of measurement concepts including satisfaction and attainment of FQOL, as in the FQOLS-2006, was also supported. Suggested improvements to the surveys included separating questions about practical and emotional support for other people and asking about the past, as well as parenting issues. The FQOL of Australian families assessed in this study was found to be significantly affected by having a member with an intellectual/ developmental disability. For example, families reported concerns such as not knowing where or how to obtain particular services, and the need for medical professionals specialising in intellectual/ developmental disability.

The results confirmed the need to measure FQOL of families with a member with an intellectual/ developmental disability in order for disability-related services to be better informed to support such families. Results also suggested ways in which existing and new measures of FQOL could more comprehensively assess the QOL of families with a member with an intellectual/ developmental disability. The outcomes of such measurement could lead to significantly improved individual and FQOL.
Declaration

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution to Fiona Rillotta and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

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