

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

Fiona Rillotta

B. Arts (Hons Psych), B. Soc. Sci.

Submitted for the award of  
Doctor of Philosophy  
in the School of Psychology  
University of Adelaide

December, 2010



## Table of Contents

Table of Contents .....	iv
List of Tables .....	xii
List of Figures .....	xii
Abstract .....	xiv
Declaration .....	xvi
Acknowledgements .....	xix
<b>Chapter 1: Introduction .....</b>	<b>1</b>
1.1 Overview of this Thesis .....	1
1.1.1 Chapters of this Thesis .....	3
1.1.1.1 Chapter 1 .....	3
1.1.1.2 Chapter 2 .....	3
1.1.1.3 Chapter 3 .....	4
1.1.1.4 Chapter 4 .....	4
1.1.1.5 Chapter 5 .....	5
1.2 Conceptualising Quality of Life .....	6
1.2.1 Quality of Life in the Intellectual/ Developmental Disability Field .....	7
1.2.1.1 Quality of Life Domains .....	9
1.2.2 Measuring and Applying Quality of Life .....	12
1.2.2.1 Historical Context .....	13
1.2.2.2 Needs Perspective .....	14
1.2.2.3 Systems Perspective .....	14
1.2.2.4 Multidimensional Properties .....	15
1.2.2.5 Methodological Considerations .....	15
1.2.2.6 Application .....	17
1.2.2.7 Summary .....	19
1.3 Family .....	20
1.3.1 Definition .....	20
1.3.2 Families with a Member with an Intellectual/ Developmental Disability .....	21
1.3.3 Family-Centred Research .....	21
1.3.3.1 Context .....	21
1.3.3.2 Health and Well-being of Carers .....	24
1.3.3.3 Transportation .....	26
1.3.3.4 Rural vs. Metropolitan Residents .....	28
1.3.3.5 Lifespan Perspective .....	30
1.3.3.6 Siblings .....	38
1.4 Conceptualising Family Quality of Life in the Context of Intellectual/ Developmental Disability .....	41
1.4.1 Measuring Family Quality of Life .....	44
1.4.1.1 Application of FQOL Measurement .....	46
1.4.1.2 Cultural Considerations .....	48
1.4.1.3 QOL to FQOL Domains .....	50
1.4.1.4 International Survey (FQOLS-2006) .....	51
1.4.1.5 Beach Center Survey .....	53
1.4.1.6 Comparing Measures .....	55

1.5 Family and Intellectual Disability Research in an Australian Context.....	56
1.5.1 Prevalence of Intellectual/ Developmental Disability .....	56
1.5.2 Importance of Family .....	57
1.5.3 Historical Overview.....	57
1.5.4 Current Perspectives .....	58
1.5.4.1 Primary Caregiver, Career, Income, and Gender Differences.....	59
1.5.4.2 Existing Issues for Australian Families.....	60
1.5.4.3 Informal Support and Interaction of Variables .....	62
1.6 The Current Study.....	63
1.6.1 Objectives.....	63
1.6.2 Research Questions.....	63
1.6.3 Outline of Thesis Chapters.....	64
<b>Chapter 2: Methodology.....</b>	<b>67</b>
2.1 Overview.....	67
2.2 Participants .....	67
2.3 Materials .....	72
2.3.1 International Survey (FQOLS-2006).....	72
2.3.1.1 Alterations and Additions to the FQOLS-2006 .....	75
2.3.2 Beach Center Survey .....	79
2.3.3 Comparing Measures.....	82
2.3.3.1 Internal Consistency of FQOL Surveys .....	82
2.3.4 Other Materials .....	83
2.4 Procedure.....	84
2.4.1 Ethical Considerations.....	84
2.4.2 Recruitment Organisation – Disability Service Provider in SA (DSP-SA) .....	85
2.4.3 Focus Groups .....	86
2.4.4 Pilot Study Using FQOLS-2006 and Training of the Interviewer.....	92
2.4.5 Process of Recruiting Participants.....	98
2.4.6 Response Rates .....	100
2.4.7 Interviews (Setting, Location, and Environment).....	102
<b>Chapter 3:.....</b>	<b>105</b>
<b>Intellectual Disability and Family Quality of Life in Australia: An overview of caregiver perceptions.....</b>	<b>105</b>
Statement of Authorship .....	107
3.1 Key Words .....	110
3.2 Abstract.....	110
3.3 Introduction .....	111
3.4 Methodology.....	116
3.4.1 Participants.....	116
3.4.2 Materials .....	117
3.4.3 Procedure.....	118
3.5 Results.....	119
3.5.1 Descriptive Data.....	119
3.5.2 Family Quality of Life Measures and Reliability of the FQOLS-2006.....	123
3.5.2.1 Importance, Attainment, Satisfaction.....	124

3.5.2.2 Influence of Values.....	125
3.5.2.3 Opportunities, Initiative, Stability .....	126
3.5.2.4 Financial Well-being .....	126
3.5.2.5 Careers.....	127
3.5.2.6 Siblings.....	128
3.5.2.7 Variance .....	129
3.5.2.8 Services .....	130
3.5.3 Practical and Emotional Support from Other People .....	130
3.6 Discussion.....	132
Prologue to Chapter 4.....	137
<b>Chapter 4:.....</b>	<b>139</b>
<b>A Comparison of Two Family Quality of Life Measures: An Australian Study.....</b>	<b>139</b>
Statement of Authorship .....	141
4.1 Abstract.....	144
4.2 Background.....	145
4.2.1 “Family” .....	146
4.2.2 Why Compare Two FQOL Measures?.....	147
4.3 Overview of Previous Research .....	148
4.3.1 FQOL Research in Australia .....	150
4.4 Measurement of FQOL .....	152
4.4.1 International Survey.....	152
4.4.2 Beach Center Survey .....	155
4.5 Methodology of the Current Study .....	157
4.5.1 Participant Demographics .....	157
4.5.2 Pilot Study: Modifications to Surveys and Cultural Considerations .....	159
4.6 Findings from Australian Data Comparing Two Measures.....	161
4.6.1 Survey Completion Time .....	165
4.6.2 Methodology and Survey Designs.....	166
4.6.3 Surveys’ Structures and Participants’ Experiences of the Interviews .....	168
4.6.4 More than one Family Member with a Disability.....	172
4.6.5 “Parenting” Domain - Beach Center Survey.....	173
4.6.6 “Influence of Values” Domain - International Survey .....	178
4.6.7 Transportation .....	182
4.7 Differences in the Measurement Concepts of Both Surveys.....	186
4.7.1 Importance and Satisfaction .....	187
4.7.2 Opportunities, Initiative, Attainment, Stability.....	191
4.7.3 Repetitiveness of Measurement Concepts and Limitations to Likert Scale.....	193
4.7.4 High Importance, Consistencies and Contradictions of Ratings .....	195
4.7.5 Summary and Conclusions Associated with Measurement Concepts.....	197
4.8 Past and Distant Future .....	200
4.9 Conclusions & Recommendations for FQOL Measures .....	205
4.9.1 Limitations to the Current Study and Further Research .....	210
<b>Chapter 5: General Discussion and Conclusions .....</b>	<b>212</b>
5.1 Overview.....	212
5.1.1 Acknowledgement of Forthcoming Research and Publications .....	212

5.2 Review of Thesis Aims.....	213
5.3 Summary of Thesis Findings.....	214
5.3.1 Important Areas for FQOL Measurement to Consider.....	216
5.3.1.1 Domains and Concepts.....	216
5.3.1.2 Parenting, Individual Family Member Needs, and Sibling Issues .....	220
5.3.1.3 Lifespan – Past and Distant Future.....	222
5.3.1.4 Practical and Emotional Support .....	224
5.3.1.5 Transportation.....	226
5.3.2 Methodological Considerations .....	228
5.3.2.1 Method of Survey Completion .....	228
5.3.2.2 Interview Setting, Location, and Environment.....	230
5.4 Practical Implications of FQOL Measurement .....	236
5.4.1 Unmet Service Needs .....	238
5.4.1.1 Reasons for Unmet Needs.....	243
5.4.2 Sensitivity to Differences between Family Circumstances.....	245
5.4.3 Differences in Support Services across the Lifespan .....	246
5.5 Limitations and Implications for Future Research.....	249
5.5.1 Lifespan Perspective.....	249
5.5.2 Disability Type and Additional Conditions .....	251
5.5.2.1 Control Group.....	253
5.5.2.2 Recruitment Organisations.....	254
5.5.3 Transportation .....	255
5.5.4 Random Nature of Participants.....	255
5.5.5 Cultural Relevance.....	256
5.5.6 Different Perspectives within the Family.....	256
5.5.6.1 User-friendly Terminology .....	258
5.5.7 Self-administered vs. Interview .....	259
5.5.8 Practical Usefulness of the FQOL Surveys.....	260
5.6 Conclusion.....	261
<b>Appendices.....</b>	<b>264</b>
Appendix A. Conference Presentations Associated with this Thesis.....	264
Appendix B. Information Sheet for Participants .....	266
Appendix C. Consent Form for Participants.....	270
Appendix D. FQOLS-2006 (electronic version – attached on disk).....	272
Appendix E. Feedback about the FQOLS-2006.....	274
Appendix F. Additional Questions to the FQOLS-2006 about the Past.....	284
Appendix G. Beach Center FQOL Scale (electronic version – attached on disk) .....	286
Appendix H. Alterations to Demographic Questions of the Beach Center FQOLS Scale .....	288
<b>References.....</b>	<b>292</b>

## List of Tables

Table 1.1 <i>Indicators and Descriptors of Core QOL Domains</i> .....	11
Table 2.1 <i>Demographical Details of all Participants (N = 53)</i> .....	69
Table 2.2 <i>Modifications to Demographics Section of Beach Center FQOL Scale</i> .....	81
Table 2.3 <i>Pilot Study Particulars</i> .....	94
Table 2.4 <i>Response Rates for Each Region of DSP- SA</i> .....	101
Table 3.1 <i>Family Characteristics</i> .....	120
Table 3.2 <i>Characteristics of the Person with a Disability</i> .....	122
Table 3.3 <i>FQOL Domains and Dimensions</i> .....	124
Table 3.4 <i>Outliers at the Lower End of the Scale</i> .....	129
Table 3.5 <i>Breakdown of Practical and Emotional Support from Other People Ratings</i>	131
Table 4.1 <i>Demographical Details of Participants who Completed Both Measures</i> .....	158
Table 4.2 <i>Summary of Face-Value Comparisons</i> .....	163
Table 4.3 <i>Most and Least Important and Satisfied Domains from Both Surveys (N = 15)</i> .....	190
Table 4.4 <i>Correlations between Specific Survey Items (Importance and Satisfaction)</i> ..	191

## List of Figures

<i>Figure 4.1. Average ratings for Beach Centre domain — “Parenting”</i> .....	174
<i>Figure 4.2. Individual scores on Parenting domain - Importance and Satisfaction.</i> .....	177





## **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.

I give consent to this copy of my thesis when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968.

The author acknowledges that copyright of published works contained within this thesis (as listed below) resides with the copyright holder(s) of those works.

I also give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library catalogue, the Australian Digital Theses Program (ADTP) and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

Rillotta, F., Kirby, N., Shearer, J., & Nettelbeck, T. (2010). Intellectual Disability and Family Quality of Life in Australia: An overview of caregiver perceptions. Manuscript submitted for publication.

Rillotta, F., Kirby, N., & Shearer, J. (in press). A comparison of two family quality of life measures: An Australian study. In R. Kober (Ed.), *Enhancing the Quality of Life of People with Intellectual Disabilities: From theory to practice*. New York: Springer.

Signed:

Dated: 19/12/10



## Acknowledgements

I would like to thank the following people who have made this thesis possible:

First and foremost, to my supervisors, Neil Kirby, Ted Nettelbeck and Jo Shearer. My gratitude for offering your generous time, support, advice and knowledge is immeasurable. I have learnt so much from you all and I am so grateful to have had the opportunity to work with you.

To my national and international colleagues, particularly the Quality of Life Special Interest Research Group. I have enjoyed our time together at conferences. You have been my greatest teachers and I admire your commitment to driving improvements to the Quality of Life of people with disabilities and their families.

To the International FQOL Survey team and the Beach Center team for the use of your instruments and for being prepared to promptly answer my queries at any time.

To the organisation that helped recruit participants and to the families who participated. Thank you for offering your time and for being so willing and open to share your experiences.

To my fellow PhD students and co-inhabitants of 111 (Annamaria, Julia, Roma, Kelly, Rakesh, Stacey, Sara and Tess) who have shared your experiences, and many words of wisdom. I would have become very isolated without all of you around.

To my work mates and students at the South Australian Learning Centre. I have been very grateful for the support, encouragement and excitement that you all shared.

To my last minute motivator, Megan Astill. Words cannot express how much I appreciate your motivational support. These final stages would not have been possible without you. Thank you for answering every single text message with just the right words. You believed in me all along. Together we have demonstrated that we can do anything we set our mind to.

To my special friend Leah Wilson for being there throughout the ups and downs of the entire journey. I have really appreciated your moral support and guidance. There is no one else out there quite like you, who would be willing to proof read for me while you were on holidays.

To my brothers for supporting me in your subtle ways and for always being so proud of me. To my amazing parents, who have had faith in me from the very beginning. Thank you from the bottom of my heart for your unconditional love and for believing in me and constantly providing me reassurance. This truly would not have been possible without your ongoing encouragement and support.

Finally, to my husband to be, Tom, for your ongoing love and immense patience. I am really looking forward to our future together, which has been a true motivator, and has now become a reality.

*You have all proven that no journey is too long or too hard with good support.*