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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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.

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Chapter 1: Introduction

1.1 Overview of this Thesis

This thesis advances the idea that an effective measure of Family Quality of Life (FQOL) is necessary to enable the construct to be used to better predict support needs of Australian families that have a member with an intellectual/ developmental disability. If support needs are accurately identified, then support services in Australia, as with other nations, could be better informed to provide quality support. This would encourage and better enable families to continue to care for their relative with a disability at home, whilst living a fulfilling life in accordance with the family's expectations.

It is well known that families that have a member with an intellectual/ developmental disability require additional ongoing support for their needs to be met in areas of life such as health, finances, and leisure and recreation (I. Brown, Anand, Fung, Isaacs, & Baum, 2003; R. I. Brown, Davey, Shearer, & Kyrkou, 2004; Schalock, 2004b). The support needed by such families could be formal, from services such as medical/ healthcare professionals, respite services or day options; or informal, from immediate/ extended relatives and friends. In addition, such support could be of a practical nature (e.g. babysitting, cleaning or financial support) or it could be emotional (e.g. having someone to confide in) (I. Brown et al., 2003). These various aspects that make up family life highlight the need for a holistic approach to FQOL measurement (R. I. Brown et al., 2004). However, existing measures of FQOL do not necessarily address all aspects of family life comprehensively.

The broad aim of this thesis is to utilise current Quality of Life (QOL) and FQOL and disability literature to investigate FQOL measurement issues. More specifically, it will evaluate the reliability and validity of two existing internationally developed FQOL

measurement tools (Beach Center on Disability, 2003; FQOLS-2006, I. Brown et al., 2006) in Australia. There is currently limited data available on the use of these two surveys in Australia. As such, little is known about their concurrent validity and cross-cultural applicability. In addition, this thesis will use those measurement tools to investigate the following ideas in the assessment of FQOL:

1. Transportation issues impact on FQOL.

2. Significant past events impact on current FQOL.

3. Practical and emotional support from others need to be assessed separately when measuring FQOL.

4. Families consider it important to address the individual needs of every child in the family.

5. When there is more than one family member with an intellectual/ developmental disability, it is necessary for FQOL measures to include provision for commenting separately on each member with an intellectual/ developmental disability.

Results of the current research will be discussed in terms of the best features of both surveys, and suggestions will be made for improvements to existing FQOL measurement tools. The methods used for collecting FQOL data (e.g. face-to-face interviews in the participants' homes; and mixed methods) will also be examined. The results presented in the thesis will be used to make suggestions for a more accurate and comprehensive measure of FQOL, incorporating established QOL domains in the disability field (i.e. family interaction; emotional well-being (e.g. support from other people); physical /material well-being (e.g. health/ financial); community interaction/ social inclusion; and disability-related support) to gain a more holistic picture of issues

concerning families that have a member with an intellectual/ developmental disability. Such a FQOL measure, if used correctly, can result in substantial quality of information relevant to the supports that families require in order to improve their QOL.

As will be highlighted in the following literature review, if the specific supports that families require are adequately identified through a practical, user-friendly measurement tool, researchers and practitioners will then be better able to accurately address the family's needs. This, in turn will facilitate the collective improvement of QOL for all members of the family.

The following section provides an overview of the five chapters of this thesis, which address the issues outlined above.

1.1.1 Chapters of this Thesis

1.1.1.1 Chapter 1

The first chapter consists of a critical evaluation of individual and family QOL and intellectual/ developmental disability literature. This literature review presents an overview of the historical context of QOL research, which drives the current conceptualization and measurement of QOL and FQOL. The content presented in Chapter 1 has formed the basis for a co-authored journal article submitted for publication: *The development of Family Quality of Life concepts and measures* (Samuel, Rillotta, & Brown, Submitted 31st July 2010). FQOL literature in an Australian context is also discussed to provide an introduction to the research presented in the remaining chapters of this thesis.

1.1.1.2 Chapter 2

The second chapter describes the methodology that was used to collect information about FQOL in Australia using two surveys (Beach Center on Disability,

2003; FQOLS-2006, I. Brown et al., 2006). It provides details about the modifications that were made to both surveys for use in Australia following focus groups and a pilot study (e.g. changes to the terminology used for demographical details). Ethical considerations, recruitment of participants, and details of the interview setting are also outlined in Chapter 2.

1.1.1.3 Chapter 3

Following the description of methodology in Chapter 2, Chapter 3, which has been submitted for publication, discusses the findings associated with the use of the FQOLS-2006 in Australia. The format of Chapter 3 reflects the layout required for journal manuscripts. It discusses such important findings as the fact that the main caregivers who participated in this study felt that Health, Family Relationships and Financial Well-being were more important to their FQOL than other areas. Chapter 3 also establishes that the FQOLS-2006 is a reliable measure for FQOL. However, the results of Chapter 3 are preliminary because they do not compare concurrent validity of the data from the FQOLS-2006 with other FQOL measurement tools. Therefore, the next chapter of this thesis (Chapter 4) presents results from comparing the FQOLS-2006 with the Beach Center FQOL Scale.

1.1.1.4 Chapter 4

Chapter 4 has been accepted for publication as a chapter in the book: *Enhancing the Quality of Life of People with Intellectual Disabilities: From theory to practice*, edited by Ralph Kober, in press 2010. It is therefore formatted according to the book chapter requirements. It was submitted in June 2009, and therefore does not include literature published beyond that date. Such additional literature can be found in Chapter 1 of this thesis. The results presented in Chapter 4 continue to support the superior

reliability of the FQOLS-2006; however, there are some areas of family life, such as transportation and parenting (taking care of the individual needs of every child), that were only included in the Beach Center Scale but are also paramount to FQOL. Chapter 4 therefore concludes with suggestions for further modifications to the measures of FQOL.

1.1.1.5 Chapter 5

The concluding chapter of this thesis both draws together the results of Chapters 3 and 4 and discusses the implications of the results to support services for families that have a member with an intellectual/ developmental disability. This chapter concludes by highlighting some important areas for further FQOL research, such as the need to:

- Undertake syndrome specific comparisons;

- Examine the impact of additional conditions;

- Test FQOL across the lifespan at different developmental/ transitional stages; and

- Assess sibling issues.

As mentioned previously, the following literature review provides an overview of the most recent and relevant research associated with conceptualisation, theory, and application of QOL and FQOL. Further reviews of relevant literature are also presented in the publications included in this thesis (see Chapters 3 and 4). Many authors have contributed several publications to the QOL and/ or FQOL literature over the years, and in each article, the authors have often reiterated findings from their own previous research. Therefore, following the process used in a literature review by Turnbull, Summers, Lee, and Kyzar (2007), and to avoid repetition, only the most recent publications of the same authors have been referred to in the following literature review.

1.2 Conceptualising Quality of Life

According to Wood-Dauphinee (1999) the earliest use of the term 'Quality of Life' (QOL) was in 1920 in a book about economics and welfare by Pigou, in which he discussed government support to lower class citizens. After that, 'QOL' seemed to have disappeared temporarily, but returned in the late 1940s when the World Health Organisation (WHO) expanded the definition of health to include physical, emotional, and social well being. Initially the term QOL was only used in the context of health. Since then, however, the term has been universally accepted as a valid and reliable indicator of what it means to live a good life in the many areas of human experience. Whilst there is no single definition for QOL, researchers and other QOL experts have generally accepted that QOL includes physical, mental, and social well-being, as well as an individual's perceived ability to live a fulfilling life, people's relationships, and their perceptions of life satisfaction (I. Brown & Brown, 2003; R. I. Brown, 1997; Schalock et al., 2002; Verdugo, Schalock, Keith, & Stancliffe, 2005; Wood-Dauphinee, 1999). The central focus is that the concept of QOL provides an indicator of the individual's perspective, and that QOL themes present a common language and systematic framework for applying QOL principles (Schalock, 2004a, 2004b; Schalock et al., 2002; Verdugo, Schalock, Keith, & Stancliffe, 2005). The "quality" aspect implies high levels of reported happiness, success, wealth, health and other human values; and the "of life" component comprises essential aspects of human existence (or access to basic human needs for survival) (Schalock et al., 2002)

Furthermore, QOL provides a rationale to facilitate changes to society that encourage the development of strategies for enhancing the quality of supports and service delivery. QOL is now also used as a basis for assessing the effectiveness of such

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strategies (Schalock, 2004a, 2004b; Schalock et al., 2002; Verdugo, Schalock et al., 2005). Research has also recognised that QOL reflects the need/ desire to have choice and personal control over aspects of one's life, including environments and activities, and this often results in the empowerment of the individual (I. Brown & Brown, 2009; Cummins, 2005; Schalock et al., 2002). Choice needs to be recognised in a structured way, relating to a person's developmental level, and in the context of needs, goals, activities, places and personnel (R. I. Brown & Brown, 2005). Thus, the study of different aspects of QOL in the field of intellectual/ developmental disability, including how to measure it, has become a major research objective over the past two to three decades (Schalock, 2004b; Verdugo & Schalock, 2009).

1.2.1 Quality of Life in the Intellectual/ Developmental Disability Field

QOL has been recognised in the intellectual/ developmental disability field since the 1980s (I. Brown & Brown, 2003; R. I. Brown, 1997; Goode, 1994). For example, the overall person-centred goal of deinstitutionalisation (normalisation or mainstreaming as it was known in the past) was to enhance the well-being and QOL of people with intellectual/ developmental disabilities. The introduction of inclusive education and compulsory continued training for teachers and healthcare professionals has led to wider acceptance of people with disabilities in the community (R. I. Brown et al., 2004). In addition, improvements to health services and medical treatments, better community and disability-related supports, early intervention provisions, and increased access to resources and facilities, have resulted in increased longevity for people with intellectual/ developmental disabilities (R. I. Brown & Brown, 2005; McConkey, 2005; Talley & Crews, 2007). Therefore, it has become increasingly important to evaluate the QOL of

people living with a disability, who have the right to the same level of QOL as other people.

The Quality of Life Special Interest Research Group (QOL SIRG) (I. Brown, Brown et al., 2000) stated that the study of QOL involves "an attempt to describe and understand the conditions that promote and enhance a good life" (p.7), and that the concept of QOL encompasses feelings of well-being, positive social involvement, and the chance to achieve personal potential. This international panel of experts developed the following five principles for conceptualising QOL in the intellectual disabilities field (Schalock et al., 2002):

1. Factors that are important to people with intellectual disabilities and their families are the same elements that make up QOL for individuals and families without disabilities.

2. QOL occurs when individual and family needs are fulfilled and when there is opportunity to pursue life enrichment.

3. QOL has objective and subjective components but is primarily accurately interpreted by the perspective of the individual themselves.

4. QOL is based on individual needs, choices, and control.

5. QOL is multidimensional and affected by personal and environmental factors including relationships, family life, work, neighbourhood, residence, housing, education, health, standard of living, and the state of the nation (Schalock, 2004b, p.13).

As such, QOL has been viewed as a holistic notion encompassing not only external features such as housing, health status, income and employment, but also social integration (which includes being satisfied with the state and nature of social

relationships), self-determination and, psychological and spiritual well-being, as well as acknowledging the interaction of all of these features and the ways in which they influence each other (Albrecht & Devlieger, 1999; Bailey et al., 1998; Bramston, Chipuer, & Pretty, 2005; I. Brown, Brown et al., 2000; Otrebski, 2005; Poston & Turnbull, 2004; Schalock, 2004a, 2004b; Schalock et al., 2002; Summers et al., 2005). Since QOL can be considered as being achieved when individual and family needs are fulfilled, it is important for services to support individuals and families to have their needs met. In order for support services to easily identify these needs, it is necessary to have an effective means for measuring QOL, within QOL "domains", as described in the following section.

1.2.1.1 Quality of Life Domains

Even though there has been much debate associated with how to define the dimensions of QOL, there is a consensus that domains (a set of factors that make up personal well-being) and indicators (domain specific perceptions, behaviours or conditions) are imperative to QOL measurement (Cummins, 2005; Schalock, 2004a; Verdugo, Schalock et al., 2005). These domains need to be intricately defined in order to be able to measure QOL holistically and to recognise that life is very complex.

The increasing popularity of QOL as a valid measurement concept has also been supported by the World Health Organisation (WHO). The WHO Quality of Life (WHOQOL) instruments (World Health Organisation, 1997; World Health Organisation (WHO), 2004) were designed to encompass the WHO's holistic definition of health, by measuring an individual's perception of the impact of disease on his or her life (Wood-Dauphinee, 1999). Hence, these QOL measures have been and continue to be used in the disability sector (Chou, Lin, Chang, & Schalock, 2007; Lin et al., 2009; WHOQOL

Group, 1998). The life domains incorporated into the WHOQOL are similar to the domains presented by Schalock et al. as relevant to QOL and intellectual disability. These include, physical, psychological, level of independence, social relationships, environments, and spirituality/ personal beliefs (Schalock et al., 2002).

In addition, the QOL SIRG on intellectual disability (I. Brown, Brown et al., 2000; Schalock, 2004a, 2004b; Schalock et al., 2002) came to a consensus that QOL includes eight domains, which are desired states of emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. Further details about these domains and their indicators are provided in Table 1.1. The term 'desired states' is used because different people have different ideas on what they consider or perceive to be "good" QOL.

As has been outlined previously, the complexities involved with the conceptualisation and measurement of QOL have created many debates within the disability field. Throughout the remainder of this thesis further issues pertaining to measurement and application of QOL principles will be outlined. This thesis employs the approach presented by international experts that QOL is measurable by adopting core principles and using key domains to guide the measurement process (Schalock et al., 2002). As shown in Table 1.1 these domains include: Emotional Well-being, Interpersonal Relations, Material Well-being, Personal Development, Physical Well-being, Self-determination, Social Inclusion, and Rights. The sections of this chapter on FQOL (see sections 1.4 and 1.5) and upcoming chapters of this thesis highlight the domains that are relevant and specific to FQOL measurement. However, the more general measurement of QOL, which is the foundation for FQOL measurement, is outlined first.

Table 1.1 *Indicators and Descriptors of Core QOL Domains*
(Schalock, 2004a, 2004b; Schalock et al., 2002; Verdugo, Schalock et al., 2005)

Domains	Indicators	Descriptors
Emotional Well-being	Contentment	Satisfaction Moods Enjoyment Positive feedback
	Self-concept	Identity Self-worth Self-esteem
	Lack of stress	Predictability Stability Control Safety
Interpersonal Relations	Interactions	Social networks Social contacts Affection
	Relationships	Affiliations Intimacy Friends Family Peers
	Supports	Emotional Physical Financial Feedback
Material Well-being	Financial Status	Income Benefits
	Employment	Work status Work environment
	Housing	Type of residence Ownership
	Possessions	
Personal Development	Education	Achievements Status Habilitation
	Personal competence	Cognitive Social Practical
	Performance	Success Achievements Productivity Purposive activities Assistive technologies
Physical Well-being	Health	Functioning Symptoms Fitness Nutrition Health care Wellness
	Activities of daily living	Self-care skills Mobility
	Leisure	Recreation Hobbies

Self-determination	Autonomy/ personal control	Independence
	Goals and personal values	Desires Expectations
	Choices	Opportunities Options Preferences Decisions
Social Inclusion	Community integration and participation	Integrated environments
	Community roles	Contributor Volunteer
	Social supports	Support network Services Natural supports
Rights	Human	Respect Dignity Equality Privacy Ownership Barrier free environments
	Legal	Citizenship Access Due process

1.2.2 Measuring and Applying Quality of Life

It is not only important to conceptualise QOL in the intellectual/ developmental disability field, it is also crucial to be able to measure QOL. Without an effective means for measuring QOL the conceptualisation would serve no practical purpose. Measures of level of QOL relate to (Schalock, 2004a; Schalock et al., 2002; Verdugo, Schalock et al., 2005):

- Personal appraisal, including satisfaction level;

- Functional assessment, such as level of adaptive behaviour;

- Lifestyle and social roles, including level of activities and social affiliations; and

- Social indicators including education, financial and health status.

The central purpose of measuring QOL, whichever approach is taken, is to enhance the lives of people with disabilities (Schalock et al., 2002). Measurement will result in an appreciation for quality within people's lives by maintaining elements already

considered good and improving aspects that detract from a life of quality (Schalock et al., 2002; Verdugo, Schalock et al., 2005).

1.2.2.1 Historical Context

Experts in the field of disability initially questioned whether measurement of QOL was possible and, if so, how to measure QOL to be useful in service development and evaluation (Vreeke, Janssen, Resnick, & Stolk, 1997). The following past considerations have influenced the way that QOL is now measured.

The earliest reported development of health-related instruments for measuring QOL was in the 1970s, and "methodological rigour" for measurement of QOL improved into the 1980s and 1990s (Wood-Dauphinee, 1999, p. 357). This involved a review of traditional views that the notion of QOL is the same for all people. Cummins (2005) noted that the questions included in earlier measures of QOL for people with a disability or medical condition emphasised the pathology and set the benchmarks too low relative to the general population. There was a tendency for assumptions such as, disability and physical difference being associated with an inferior QOL in the first place (Koch, 2000); or that QOL is higher for people who do not have some kind of pathology (Cummins, 2005). Consequently, there was a lack of recognition of the value of QOL for each unique individual, regardless of disability status. Previously, such measurement of QOL could also have led to lack of recognition of individual strengths and there would have been no focus on the support needed to achieve what the individual considers to be ideal QOL. The value of having an accurate measure of QOL is that it enables the identification of these areas of support.

1.2.2.2 Needs Perspective

Moreover, measurement of QOL should enable unmet needs of people with disabilities to be identified and subsequently remedied. Cummins (2005) argued that QOL should not be limited to consideration of needs, because needs highlight deficits in people's lives and having few needs does not necessarily equate to high quality of life. Arguably, however, assessment of needs could also be considered a positive outcome measure because satisfaction with (or fulfilment of) needs may indicate what is working well for the individual, and unmet needs may indicate areas requiring improvement. Therefore measures of QOL should be designed so that needs, in various areas of life, can be easily identified (see section 1.2.1.1 Quality of Life Domains).

1.2.2.3 Systems Perspective

According to Schalock, Verdugo, et al. measurement of QOL can be adopted at four levels of social systems:

1. People/ subjective nature (microsystem),

2. Programs/ objective nature (mesosystem),

3. Communities and

4. Nation/ external conditions (macrosystem)

(Schalock, 2004a, 2004b; Schalock et al., 2002; Verdugo, Schalock et al., 2005).

Examples of the benefits of clearly defined QOL measurement therefore include the fact that *people with intellectual disabilities* apply the concept of QOL by self-advocating for increased participation in the mainstream community. It also becomes possible for *support service providers* to employ techniques that enhance QOL by understanding QOL domains. Furthermore, *Communities* implement QOL enhancement techniques by demonstrating that a good QOL represents a fulfillment of needs and

wants, and by ensuring that the individual is appropriately matched to their environment. Lastly, there are several conventions developed by *nations* worldwide that have addressed the rights of people with disabilities to participate fully and effectively at all levels of society (Schalock et al., 2002).

1.2.2.4 Multidimensional Properties

As outlined previously, QOL has now been established as a multidimensional construct, with interrelated components, including both objective and subjective aspects (Cummins, 2005; Schalock, 2004b), and it is uncommon that "any single attribute independently defines life quality" (Koch, 2000, p.758). As such, currently it is widely accepted that measures of QOL factoring in these characteristics can provide reliable, accurate and important information for people with disabilities, practitioners, service providers and researchers. Similarly, it has been recognised that through QOL measurement it is possible to set an appropriate baseline in the evaluation of services and intervention programs. It has also become possible to set out a clear purpose related to improving policies, services and individual supports (Schalock et al., 2002; Verdugo, Schalock et al., 2005).

1.2.2.5 Methodological Considerations

However, although the purpose and benefits of QOL measurement have been established in terms of person-centred practice and strengths-based approaches, there are still a few inconsistencies associated with the content of QOL measurement domains (see section 1.2.1.1 Quality of Life Domains). There is also ongoing research associated with methodological issues such as the relative advantages and disadvantages of collecting quantitative and/ or qualitative data; and whether to assess QOL subjectively or objectively.

In terms of quantitative and/ or qualitative means of obtaining QOL information it has generally been accepted that a mixed methods approach is most effective (Schalock et al., 2002). For example, quantitative measures of QOL domains provide a rating from best to worst possible outcomes, highlighting aspects that individuals regard as a threat to their overall QOL; and qualitative measures are used further to explain, explore and describe key domains of QOL (Cummins, 2005; Schalock et al., 2002). This issue is discussed further in terms of FQOL measurement, because generally the same principles apply to QOL and FQOL measurement (see section 1.4.1 Measuring Family Quality of Life). Also, current results supporting a mixed-methods approach to FQOL measurement can be found in the upcoming chapters of this thesis.

Another methodological concern with respect to measuring QOL which has received substantial attention in the literature is associated with who should complete the survey, interview or questionnaire (i.e. the person with a disability, or a proxy – parent, spouse, carer, service provider). Moreover, it has been noted that measurement of QOL can be problematic when there is a discrepancy between reported measures of subjective QOL in comparison to objective indicators, which may show negative or low levels of QOL (R. I. Brown & Brown, 2005).

It has generally been found that proxy reports on behalf of people with intellectual/ developmental disabilities differ markedly from self-ratings, because proxies tend to underrate or guess QOL (R. I. Brown & Brown, 2005; Hatton, 1998; Shearer, 2000). For example, Albrecht and Devlieger (1999) found that even though people without disabilities perceived those with disabilities to be living an undesirable life, over half of the people with disabilities questioned reported good or excellent QOL. Therefore, every effort should be made to enable the person with an intellectual/ developmental

disability to speak for themselves (Schalock, 2004a; Schalock et al., 2002; Verdugo, Schalock et al., 2005; Wood-Dauphinee, 1999). This would then empower people with intellectual/ developmental disabilities to identify what is important in their own lives. At the same time, however, the objective views of others can "be useful for comparative purposes, or for presenting a new perspective" (I. Brown & Brown, 2004a, p.38).

Importantly, it is not always possible to obtain the opinions of the individual using standard QOL measures, because people with severe or profound disabilities have markedly lower than average communication skills (Hatton, 1998). Hence the opinions of such people must be represented by someone who knows them well, such as a family member (Verdugo, Schalock et al., 2005). In these cases, proxy reports or ratings should be supplemented with observations of the individual in various contexts to verify the information obtained (Schalock et al., 2002).

1.2.2.6 Application

This continuing methodological concern instigates a number of questions in the application of QOL principles. For example, there may be uncertainty about when an intervention should take place, if the individual reports a good QOL, but the objective measures indicate otherwise. It is for this reason that Brown and Brown (2005) emphasised that the application of QOL principles to intervention is a long-term ongoing and detailed process. The application process relies on thorough professional skills to prepare a plan for intervention, to implement the intervention in an effective manner, and to record and evaluate progress and changes (R. I. Brown & Brown, 2005).

The proposed practical usefulness and benefits (e.g. enhanced personal outcomes for people with intellectual/ developmental disabilities and their families) of QOL

concepts, measurements and frameworks (as summarised by Verdugo & Schalock, 2009) include:

- Using QOL to assess the effectiveness of particular interventions or programs, by exploring levels of QOL before and after the structure had been put in place (Werner, Edwards, & Baum, 2009);

- Undertaking cross-cultural research. For example, by using QOL measures, Chou and Schalock (2009) found that people with disabilities in Taiwan had lower QOL scores than those in other countries (e.g. USA and Spain), especially in the domain of social inclusion. Such research is important, in order to explore culture-specific factors such as the society's attitude to intellectual/ developmental disability that play a significant role in determining QOL (Chou & Schalock, 2009);

- Providing opportunities for people with intellectual disabilities and their families to have a choice in decision making, by acknowledging that choice is a critical aspect of QOL (I. Brown & Brown, 2009).

- Empowering family members and advocates to have proactive roles, so that staff recognise the importance of supporting the person with a disability and their social networks, including their family (Schippers & Van Boheemen, 2009); and

- Acknowledging that QOL has developed from a concept, to a measurable construct that can be used both to establish theories and apply to families (Zuna, Turnbull, & Summers, 2009).

The studies relevant to FQOL (Schippers & Van Boheemen, 2009; Werner, Edwards, & Baum, 2009; Zuna, Turnbull et al., 2009) are reviewed more comprehensively in the section on FQOL in this chapter (see section 1.4).

1.2.2.7 Summary

In summary, measurement of QOL is usually undertaken by identifying specific aspects that individuals report as being valuable in their own lives, and then matching these with their own perceptions of happiness and satisfaction in these areas (Schalock et al., 2002; Verdugo, Schalock et al., 2005). Measurement of QOL considers the experiences common to all humans as well as those unique to individuals; and results should serve as a guide for personal, service, or policy enhancement (in accordance with societal norms), rather than for classifying individuals and their systems (Hatton, 1998; Verdugo, Schalock et al., 2005).

The current thesis explores these issues further within the FQOL framework to shed further light on methodological considerations and how best to measure FQOL. This thesis supports the notion that by measuring FQOL the provision of additional resources, programs or interventions can then be justified and implemented. Throughout the upcoming chapters of this thesis it will also be acknowledged that nowadays the focus of QOL and FQOL research can no longer be mistaken for highlighting pathology and deficit in individuals with intellectual/ developmental disabilities and their families, as it has done in the past. In addition, as will be described in the upcoming chapters, the evidence from the current research supports the measurement of FQOL through face-to-face interviews using a multi-dimensional framework and mixed methods.

Previous research has heavily focused on assessing the QOL of individuals with disabilities, but it has become increasingly evident that implications for the family of these individuals (particularly when the family member with an intellectual/ developmental disability is living at home) are similarly imperative. Since many of the

QOL domains outlined in Table 1.1 involve the support of the individual's family, a shift in focus has occurred from person-centred to family-centred approaches, as described next (e.g. Bailey et al., 1998; R. I. Brown et al., 2004; Dempsey & Keen, 2008; Dunst, 2002; Poston et al., 2003; Raghavendra, Murchland, Bentley, Wake-Dyster, & Lyons, 2007; Riper, 1999). Prior to the description of family-centred research in the disability field, a description of 'family' is presented in order to set the context for FQOL. It is important to clearly establish this definition of family, because when assessing FQOL it is necessary to clarify to whom the assessment is referring.

1.3 Family

1.3.1 Definition

In today's society families are very diverse; therefore it is difficult to arrive at a universally accepted definition of "family". Individual interpretations often determine who one considers to be their own "immediate family" – whether their definition includes extended family such as aunties, uncles, grandparents, and others living in the household, or whether it is based on the traditional nuclear family structure of parents and offspring. Typically, a family consists of more than one person (Bailey et al., 1998), who think of themselves as part of the family, whether related or not and who support each other regularly (Poston et al., 2003). Families support one another in different ways. For example, families are required to provide different types of support throughout changes in life stage and conditions, such as economic hardship, separation, birth of a child, disability, or ageing (Australian Institute of Family Studies, Baxter, Gray, & Hayes, 2009). As such, families make up a significant structure important to maintaining the functioning and stability of human society (Isaacs et al., 2007). Therefore, significant life

events and having a relative with a disability clearly impact on the family unit. Empirical research into these impacts has only recently emerged.

1.3.2 Families with a Member with an Intellectual/ Developmental Disability

With respect to FQOL and intellectual/ developmental disability, 'family' has also been defined as a "formal arrangement where one, two, or more adults are the main providers of a home and community life for at least one person with an intellectual disability…" (I. Brown & Brown, 2004a, p.27). Family well-being can be described as "the extent to which there is a meaningful, congruent and sustainable family routine" (Llewellyn, Thompson et al., 2003, p.16). A clear definition of family is needed in order to create certainty about how to measure FQOL in a valid way. This is because the various components of a family need to be examined collectively and it is therefore essential to be certain about who is included. Additional information about families in Australia and other societies is presented in Chapters 3 and 4 of this thesis.

1.3.3 Family-Centred Research

The following section first presents an overview of the importance and benefits of family-centred research. There is also an explanation for why the family is considered to be such an important part in the lives of people with disabilities. Following on from that, various family-centred research topics (not specific to FQOL) are discussed. A detailed review of previous literature exploring FQOL-related issues is provided, and further information can also be found in the literature reviews in the upcoming chapters of this thesis.

1.3.3.1 Context

More and more people with intellectual/ developmental disabilities are living at home with their families and they are living longer (R. I. Brown et al., 2004). For

example, survival rates of children with Down Syndrome in their first year of life increased from 50% during the period of 1942 to 1952, to 91% during 1980 to 1996 (Talley & Crews, 2007). Historically, parents outlived their children with a disability; however, this is no longer the norm. This means that there is now an increasing need to research the impact of this lengthened life on the family. In particular, ageing family carers and end of life issues (e.g. what will happen to my child when I die?) have become the focus of recent intellectual/ developmental disability research (Davys & Haigh, 2007; Harwood, 2007; Jokinen, 2006; see section 1.3.3.5 Lifespan Perspective).

The importance of family-centred research is highlighted by the fact that the family is increasingly seen as responsible for the primary caring component of people with intellectual/ developmental disabilities (H. R. Turnbull, Beegle, & Stowe, 2001; Zuna, Turnbull et al., 2009). Families of people with disabilities are seen as an integral positive social resource contributing to the economy. This is because families make up a considerable part of informal community supports in all life domains for people with intellectual/ developmental disabilities (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009a; Isaacs et al., 2007; Zuna, Turnbull et al., 2009). Moreover, greater family involvement is related to increased community participation and independence for people with disabilities (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). Therefore, there is a need to further quantify the ways that the individual's family can potentially contribute to an enhanced QOL. In turn, there is a need to understand what this means for the family unit as a whole in all life areas (domains).

Moreover, researchers have acknowledged that families are the most knowledgeable in their own circumstances and needs (Davis & Gavidia-Payne, 2009; Parish, Pomeranz, Hemp, Rizzolo, & Braddock, 2001). Therefore, decisions about family

support service needs are best made in collaboration with families (R. I. Brown et al., 2004). Such decisions cannot be made without adequate supports in place. In order to provide this support, an adequate assessment tool aimed at family members is needed. By placing 'family' at the centre of intellectual/ developmental disability research, adequate FQOL measures can be developed and then used to improve the QOL and environmental circumstances of everyone involved.

Prior to the development of FQOL as a research concept, an extensive number of studies addressed particular elements of family life separately, such as the impact on caregivers' well-being. In fact, the long-term well-being of people with intellectual/ developmental disabilities is dependent on the continual maintenance of physical, mental, social and economic welfare of their family carers (Burton-Smith et al., 2009a). As such, it has been noted that family-centred practices are beneficial when all features in family life, such as social support, specific child characteristics (e.g. behaviour), and specific family characteristics (e.g. income) are considered (Davis & Gavidia-Payne, 2009). FQOL has then developed from the recognition that there is a need to assess all of those separate areas of family life collectively, because they interact with, and influence one another. Family-centred research topics have included the following areas as well as the complex interaction of some/ all of these variables:

- The impact on caregivers of having a child with an intellectual/ developmental disability (e.g. physical and mental health and well-being; stress and coping; and career opportunities and restrictions);
- The importance of reliable means for transportation.
- Family life across the lifespan of the child with a disability, including transitional stages and significant family or life events that may have impacted on QOL; and

- The impact on siblings (e.g. siblings taking on parental roles, or siblings aversive reactions and behaviour).

The following literature review considers the abovementioned family-centred research topics in the intellectual/ developmental disability field. Only those topics of family-centred research that have emerged as relevant to FQOL research are discussed. Utilising the method employed for a literature review by Turnbull, et al. (2007), constructs of well-being, stress, adaptation and family functioning have been separated from FQOL. This is because the literature associated with FQOL has used different conceptualisation and measurement; and other more general literature associated with family in the disability field is very extensive. Family-centred research not specific to FQOL is presented first, followed by literature associated with conceptualizing, theorising, measuring, and applying FQOL.

1.3.3.2 Health and Well-being of Carers

It has been found that clinical depression and significant mental health concerns are more likely to be experienced by parent caregivers of people with an intellectual/ developmental disability than parents whose child does not have a disability (Emerson, 2003; Oelofsen & Richardson, 2006; Olsson & Hwang, 2001). Burton-Smith et al. (2009a) attributed this to a break down in ability to maintain subjective well-being due to the additional pressures of care giving.

Caring for a family member with special needs over the long term can result in concerns, worries and anxieties, as well as general wear and tear of caregivers. These impacts have detrimental effects not only on main caregivers, but also on the family's general health (physical and mental) and behaviour as a whole (R. I. Brown et al., 2004).

Therefore, it is important to explore the health and well-being of family carers as a contributing factor to a positive family life.

Mackey and Goddard (2006, 2007) found that even though mothers with a child with an intellectual/ developmental disability reported being tired, burdened, and left to take on the majority of the primary care giving, they still paid greater attention to their child's health and other needs compared to their own health. Whilst this may result in a positive outcome for the individual with a disability because their health needs are being met, at the same time the mothers' adverse health and well-being would impact on the rest of the family. For example, if the mother develops an illness requiring hospitalisation, then she would no longer be able to support the relative with a disability (and others in the family). However, there was no indication in Mackey and Goddard's study about the impact of mothers' well-being on the family as a whole. There is a need to develop a measurement tool that considers outcomes not only for individuals but also for the whole family. Results from such a tool could then be used to identify difficulties that mothers experience. Mothers can then be better supported to access appropriate resources (e.g. information about health promotion strategies) for themselves and for their families (Mackey & Goddard, 2006).

The research associated with caregivers' health and well-being, described above, is limited in that it does not go further to assess the interaction of the caregiver's health and well-being with other areas of family life, such as financial well-being and career opportunities. For example, having a fulfilling career can influence satisfaction with life and self-worth. Moreover, restricted employment opportunities as a result of family caregivers accommodating the needs and schedule of their relative with a disability can be detrimental to the financial well-being of the whole family (R. I. Brown et al., 2004;

Burton-Smith et al., 2009a; Emerson, 2003). In this sense, there is also a need to assess the impact of disability services to identify their contribution to overall FQOL (Isaacs et al., 2007). For example, if sufficient respite services are put in place to support the person with a disability during working hours, parents would be able to continue working. In addition, with effective financial support in place, families would not have to deal with the hardships resulting from only one parent being able to work and earn an income. The interactions of a caregiver's health, employment situation, and financial well-being provide only a few examples of why it is important for disability research to evaluate all of these components together, and their collective impact on individuals as well as the whole family.

Further to the areas described above, financial burden can impact on other areas of life. For example, without sufficient funds, families cannot afford adequate means of transportation for their family. Reliable means of transport has been found to contribute to satisfaction with life, particularly for people who live in rural or remote areas.

1.3.3.3 Transportation

As stated by the Australian Human Rights Commission (2008), one of the biggest issues facing families that are attempting to balance their paid work and family/ carer responsibilities is time required for commuting/ travel. In fact, each week over 10% of parents in paid employment spend more time commuting than they do with their children. These facts are associated with families in general but it is important to note that commuting times are increased for families that have a member with an intellectual/ developmental disability. For example, there is an additional need to travel to doctors, specialists, and hospital appointments due to ongoing health concerns. People with intellectual/ developmental disabilities also have the additional need to travel to specialist

services (e.g. therapy centres, day options, special schools, and respite centres).

Sometimes these services may be located a considerable distance from the family home

and therefore families encounter additional pressures to get to such places.

In addition to concerns with commuting times associated with transportation,

families are also concerned about having to resort to walking as a mode of transport. As

noted by Bostock (2001), this concern is especially heightened in families of lower socio-

economic status, who cannot afford to own their own vehicle. Moreover, contrary to the

idea that walking was seen as a positive form of fitness, many mothers reported that they

became distressed that they could only access shops and services that were nearby

(Bostock, 2001). Although Bostock's research was not specific to families with a member

with a disability, it still highlights that mothers without a car had restricted access to

health services and social outlets, and hence their well-being was undermined. However,

Bostock's research did not explore the effects on the family as a whole.

Verdonschot et al. (2009) examined transportation issues in the context of

intellectual disability. They pointed out that lack of transport was a barrier to community

participation, especially with respect to leisure activities. Reported barriers to transport

included: lack of information about available transport options; inadequate public

transport; expensive taxis; and that specialist transport is often not on time (Beart,

Hawkins, Kroese, Smithson, & Tolosa, 2001). There is a need to understand what these

barriers mean for the family as a whole. For example, there is currently no research

examining the impact of transportation restrictions on siblings. This can be a problem

when parents do not have time to transport the sibling to their activities, because they are

too busy with the member with a disability.

1.3.3.4 Rural vs. Metropolitan Residents

Geographical location of families has been found to further impact on the life domains of family involvement, support from others (e.g. friends), leisure and recreation, community involvement and access to services. For example, in general terms, metropolitan residents in Australia have reported having more contact with close friends and family than rural farmers (Best, Cummins, & Lo, 2000). Rural farmers on the other hand were more involved in the community and exhibited more productive activities (Best et al., 2000). Further to this, Huntley and Perlesz (2008) reported that city-based clinicians viewed rural residents as having impoverished and lower QOL. Little is known as to why city-based clinicians were of this opinion. However, based on the results of Best et al. it is clear that there are relative advantages and disadvantages to living in both locations. While Best et al.'s research was not specific to families that have a member with a disability, the differences across the life domains can be partly explained by distance (i.e. for rural residents, members of their family live further away). Best et al. did not consider transportation as a predictor of contact with friends and families, or of community involvement. Clearly, however, for metropolitan residents, transportation can be more easily acquired and distance is not often an issue.

For families that have a member with a disability living in rural locations, this means that they may not have access to the same support from friends and relatives as those living in metropolitan areas. However, Raghavendra, et al. (2007) found that rural families in Australia with a child with a disability aged 6–12 years reported significantly higher levels of services providing specific information about the child than metropolitan families with a child aged 6–12 years. This means that whilst support from relatives and friends may not be as forthcoming in rural areas, specific support from services may in

some cases (e.g. 6–12 age group) be more accessible. However, these findings could be because families in rural areas received a different type of service (i.e. frequency of contact, formal consulting) than families in metropolitan areas (Raghavendra et al., 2007). These issues need to be explored further in terms of what families consider to be important to live a fulfilling life (e.g. the relative importance of support from other people compared with support from services). For example, if a family living in a rural setting with a child with a disability is able to cope adequately with the support of relatives and friends, then their QOL may not depend on specialised support services. However, access to services may depend on the level of disability and any additional disabilities, such as medical problems. This further demonstrates that QOL is a very complex phenomenon.

The literature outlined above supports the notion that financial well-being partly predicts whether or not families have access to adequate means of transportation. The concern of inadequate transport (as a result of financial hardship) may be greater for families living in rural/ remote areas, where public transportation is not as readily available and access to formal and informal support, goods and services are usually further away. In turn, the health and well-being of the family can be affected because there is restricted access to healthcare facilities. Moreover, there are likely to be restrictions on leisure and recreation activities for the family, because they cannot get to the appropriate venues. Once again, the need for a multi-element framework for exploring family-related issues is highlighted. The research outcomes described above also emphasise the need for FQOL measures to include questions specific to transportation and geographical location within the domains of physical well-being and supports from services or from others. The value of a FQOL framework is that it has

provision for these interrelated variables to be explored collectively in terms of their relative importance and satisfaction.

Supplementary to considering the interaction of FQOL variables, it is also important to note that transport needs of people with intellectual/ developmental disabilities may change over time. Hence, age, or more correctly age related effects, constitutes another variable influencing the quality of family life. For example, during school years the child mainly requires transport support to get to and from school; however, once the child leaves school other community venues, such as sporting organisations, will also need to be accessed. Community networks that the person with a disability is involved with at different times in their lives may or may not be close to the family home. Therefore, the family may be under additional pressure to meet the needs (transport or otherwise) of all family members at different times. This is especially so if the member with a disability is at a different developmental stage to their siblings. For example, while the sibling needs transport to get to school, the person with a disability may need to be supported to get to a vocational activity; not to mention that parents often have their own activities and work to get to as well. It is for these reasons that it is important to consider support needs of the whole family across the lifespan of the member with an intellectual/ developmental disability.

1.3.3.5 Lifespan Perspective

With respect to a lifespan perspective, it has been argued that families need support from key stakeholders including services, to plan adequately for the future, particularly in anticipation for significant transitions and events (R. I. Brown & Brown, 2005; R. I. Brown et al., 2004; Burton-Smith et al., 2009a; Schalock et al., 2002). It is imperative for efficient support services to be developed throughout the lifespan, because

of cumulative effects on QOL as a person develops (Schalock et al., 2002). Achieving success at one stage in life sets up opportunity for expectations and achievements at subsequent stages (R. I. Brown et al., 2004). Moreover, changes that are made at a particular time can impact on FQOL at a later stage (R. I. Brown et al., 2004). Even though it is widely accepted that there are changes that occur in family life across the lifespan of the member with a disability (Jokinen & Brown, 2005), little is known about the impact of past events on current FQOL.

For example, a longitudinal study of parents with a child with Autism found that over time, parents reported using fewer coping strategies than they had previously and they did not rely on services as much as they had previously (Gray, 2006). Gray found that over the course of 10 years, children were no longer attending a treatment centre for children with Autism, but instead they were using a variety of different services such as special education, community service support, or no services at all. However, Gray's study was unable to conclude whether fewer coping strategies were needed by parents over time because of changes to the child's circumstances (e.g. improved behaviour) or because appropriate services were attained (Gray, 2006). Gray also only focussed on parental perceptions and did not use a holistic FQOL perspective considering life circumstances for the family as a whole (e.g. Gray did not explore the impacts on siblings).

1.3.3.5.1 Early Childhood

Leaders in the early intervention field have emphasised the value of FQOL outcomes as influencing services and policies (Wang et al., 2006). For example, Summers et al. (2007) found that families with children in the early childhood age group (0 to 5 years old) believed they were receiving a sufficient amount of early-intervention

services for their child but they also believed that they were not receiving sufficient services for the family (Summers et al., 2007). Families reported that Disability-Related Support was one of the most important domains of family life and they needed further information about where to get services for their child. Summers et al. concluded that service adequacy can predict FQOL for families with a child in the early childhood age group.

Further to this, planning for school is particularly important for families in the early childhood stages. For example, Janus, Kopechanski, Cameron, and Hughes (2008) found that only 20% of families in their study with pre-school aged children had plans for school-based services for their children, and the rest were either uncertain or hoped to continue current services. This highlights that as a child develops to school age, there are additional pressures on the family due to lack of adequate information about predicted or planned school services and the transition process. Consequently, when the child commences school the family may be faced with problems that they had not expected. Therefore in order to ensure a smooth transition to school, services and community partners need to communicate effectively and work collaboratively with families prior to transition to school (Rosenkoetter, Hains, & Dogaru, 2007).

1.3.3.5.2 School Age

In terms of school aged children, families are often uncertain about which school environment is best for their relative with an intellectual/ developmental disability (e.g. inclusive mainstream education or special education classes, units and schools). This uncertainty and concern is escalated when appropriate educational services are not available. For example, it was reported in Australia that in 2003 nearly 30% of students with an intellectual disability did not receive extra educational support for their disability

(Australian Institute of Health and Welfare (AIHW), 2008). These findings were confirmed in Canada by Janus, et al. (2008) who found that only about 15% of children (aged up to 6 years old) were receiving all of the services and supports they required at school. This means that there is added pressure on the family to manage their child's educational needs along with the everyday functional needs of their child.

At the same time, however, Janus et al. (2008) found that parental stress is lower for families with children who have commenced school. This could be because parents now have more opportunities for social interaction because they have respite from their child with a disability while they are at school (Janus et al., 2008). Also, once suitable schooling has been found, parents are likely to feel that their child is securely supported throughout the upcoming 13 to 14 years of schooling. Coupled with this, however, is the fact that apprehension about future transitions begins to develop again when the child is nearing end of school age.

1.3.3.5.3 Post School, Adolescence and Early Adulthood

Significant concerns with respect to transition to adulthood after leaving school have been reported in the literature (Blacher, 2001; Glidden & Jobe, 2007; Jokinen & Brown, 2005; Nuehring & Sitlington, 2003). Blacher (2001) and Schneider, Wedgewood, Llewellyn, and McConnell (2006) found that in older adolescent years (approximately 17 – 25 years), since formal schooling ends, there are changes in family roles and relationships. Changes in residential, vocational, and social status are also likely, as well as being faced with the challenge of service discontinuity.

In Australia, for example, participation in the workforce for people with intellectual disabilities aged in their 30s was found to be far lower than among their peers of the same age group without disabilities (Australian Institute of Health and Welfare

(AIHW), 2008). This outcome emphasises the difficulties and pressures that people with intellectual disabilities may face with respect to retaining a job and finding alternative means of social participation (Australian Institute of Health and Welfare (AIHW), 2008). Consequently, families are faced with additional concerns, such as supporting the financial needs of the member with an intellectual/ developmental disability, and providing for their leisure activities. At the same time, if a person with a disability is employed in an inclusive setting with inadequate support services, then this precipitates constraints, worries, and frustration for the whole family (R. I. Brown et al., 2004). Sometimes it even results in failure in the upcoming years (R. I. Brown et al., 2004). It is therefore critical to assess FQOL during the developmental period of early adulthood, and for services to work with families to achieve favourable outcomes.

1.3.3.5.4 Late Adulthood and Ageing

The focus of previous FQOL research has been on families of children with disabilities, and less research has been associated with the families of ageing adults with a disability (Jokinen & Brown, in press). When considering the ageing adult years, positive impacts on the family of having a member with an intellectual/ developmental disability have been found. This could be because as the parent ages, their general health declines and they tend to become isolated; therefore, the adult family member with a disability who is still living at home may be providing essential support to enable their parent to continue to live in their family home (Jokinen & Brown, in press). This suggests the presence of a reciprocal support process promoting positive well-being for the whole family.

As such, the consensus is that, overall, families of people with intellectual/ developmental disabilities in older age groups are more satisfied than younger families

(Jokinen & Brown, in press). However, Jokinen and Brown questioned whether this is because of general changes in the family's circumstances over time – regardless of the presence of a relative with an intellectual/ developmental disability – or whether it is due to ageing and disability. Moreover, another possible reason for these effects could be the increased likelihood that older parents will have children who have been living in institutional settings for long periods. It has been argued that the FQOL framework provides an effective means for evaluating this research question, because it encompasses multiple family characteristics and circumstances, along with disability.

FQOL is also highly variable, so that even if the family is satisfied in one area of family life, they are not necessarily satisfied in other areas, as demonstrated in the following example associated with transition to out-of-home living.

1.3.3.5.5 Transition to Out of Home Living Arrangements

It has been acknowledged that 'out-of-home placement' (Llewellyn, Dunn, Fante, Turnbull, & Grace, 1999) overall can have positive effects on the family and on the emotional well-being of the parent caregivers (e.g. increased peace of mind, more freedom, improved relationships within the family, and enhanced FQOL) (Werner, Edwards, & Baum, 2009). However, worry for the relative with a disability has persisted; parents have remained highly involved in their child's life; and parents have felt guilty that they had an inability to fulfill the parental role (Baker & Blacher, 2002, cited in Werner, Edwards, & Baum, 2009). Irrespective of whether or not the family member with a disability is living at home or in out-of-home arrangements, the family generally still plays a key lifelong role in the lives of the individual with a disability (Davys & Haigh, 2007). By using the FQOL framework (as described in section 1.4), information about the impact on the family over time in various life areas can be found. The research

described previously has emphasised the need for practitioners to assess aspects of FQOL and to continue to work closely to support family caregivers at different transitional stages, such as when the child has recently moved out of home.

1.3.3.5.6 Future Planning

Linking with the idea of a lifespan perspective to explore the issues for older families, main caregivers have also expressed concern about the effects on present FQOL of anticipation and planning for the near or distant future (Burton-Smith et al., 2009a). Families are especially concerned about the housing and support options for their ageing family member with a disability when the parent caregivers die or are unable to cope with them at home (Davys & Haigh, 2007; McConkey, McConaghie, Barr, & Roberts, 2006). Jokinen and Brown (in press) concluded that family needs must be met prior to stress occurring, in order to prevent breakdown, and to stabilise FQOL so that families can continue supporting their member with a disability. Moreover, Schippers and Van Boheemen (2009) supported the idea that future planning is important because they found that the emphasis on planning, rather than the doing, empowered people with disabilities and their families. However, Schippers and Van Boheemen focussed on a wider array of variables in future plans, including perspectives on work/ day activities, leisure time, (re)building social networks, education, living conditions and personal development. These variables, along with information being provided to the family about various residential options for their relative with a disability (McConkey et al., 2006), are all seen as important elements to living a fulfilling life.

Furthermore, Burton-Smith et al. (2009a) suggested that support services should consider ways to reassure families, by working on planning for the future. However, they did not measure families perceptions of the future in their study and they also did not

assess the affect of any significant events of the past. Jokinen and Brown (in press) argued that by using the FQOL approach (see sections 1.4 and 1.5) these key details about future planning around ageing and its impact on families can be ascertained. Research emphasising the importance of future planning is especially valuable in Australia because most people with an intellectual disability in 2003 were aged under 65 years (Australian Institute of Health and Welfare (AIHW), 2008), and families may be uncertain about their future.

When significant changes occur, although higher or lower satisfaction with life may be initially reported, little is known about whether this satisfaction level remains or whether it returns to a level it was prior to the event. Therefore it is necessary for measures of FQOL to ask about the past, including any significant life events that have impact on the family, in order to test how families progress after a significant event. Previous family-related research assessing the differences across age groups has mainly used cross-sectional designs. However, similar results could be found by asking individual families about what life was like in the past, and how they anticipate it to be in the future. This topic is revisited in Chapter 4 of this thesis. If FQOL is not assessed over time, and if measures of FQOL do not question the impact of significant past events, little will be known about family resilience and it will be difficult to fully understand the family's current position. Potentially, without measuring perceptions of the past and future, research may reveal inaccurate impressions about service quality. For example, a family's disappointment with services during the adolescence of their family member with a disability may be partly due to the much more comprehensive services that were available during infancy. Hence the support provided to individuals and families will not accurately reflect their needs.

In summary, it is important to assess family conditions over time. The primary purpose of research associated with a lifespan perspective is to explore the idea that more support for the family is required at key transitional stages throughout the person's life (e.g. leaving school; entering work; ageing), because such events can have an impact not only FQOL at the time of the transition but also on future FQOL. The abovementioned research has not examined what life was like in the past for families of people with disabilities. Although this kind of information may be revealed by participants as part of general informal conversation during interviews, if it is not asked about directly, it may not be evident. Such information would also not be present in self-administered questionnaires without explicitly questioning what family life was like in the past. For example, in the past there may have been a death of a parent in the family which has now resulted in one of the siblings of the family member with a disability becoming a significant carer, or even the primary carer.

The ageing of the family member with an intellectual/ developmental disability can also significantly impact on the siblings of the person with a disability who are often left to take on the primary caring role of their brother or sister with an intellectual/ developmental disability after the parent caregivers die (Greenberg, Seltzer, Orsmond, & Krauss, 1999). Siblings may also be affected in various ways across the lifespan (Heller & Keiling Arnold, 2010). As such, research associated with siblings is recently emerging as an important area of study in the intellectual/ developmental disability field, as described in the following section.

1.3.3.6 Siblings

Siblings play an important role in the lives of people with intellectual/ developmental disabilities and they anticipate playing an even bigger role over time

(Heller & Keiling Arnold, 2010). Siblings are often affected in a variety of different ways by having a brother or sister with an intellectual/ developmental disability (R. I. Brown et al., 2004). For example, older siblings have been found to express anxiety about the future care of their brother or sister with a disability (R. I. Brown et al., 2004). Parents have also reported concerns related to the lack of attention and praise that siblings without a disability received from their parents; consequently, siblings may also become withdrawn or may have other behaviour problems (R. I. Brown et al., 2004; Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008).

Importantly, positive psychosocial outcomes for siblings have also been found. For example, siblings of people with disabilities may develop strong skills related to coping (R. I. Brown et al., 2004). In addition, generally siblings have a close long-lasting relationship with their brother or sister with an intellectual/ developmental disability (Heller & Keiling Arnold, 2010). However, this closeness in relationships between siblings was found to vary with diagnostic condition. For example, siblings of people with Down Syndrome were found to have similar adjustment strategies as siblings of people without disability (Cuskelly & Gunn, 2006). Siblings of people with Down Syndrome were also found to be more optimistic about their brother or sister's future and they experienced more emotional closeness than those with a brother or sister with Autism Spectrum Disorder (Orsmond & Seltzer, 2007). Furthermore, siblings of people with Autism and aggressive behaviours exhibited an emotional reaction of anger, yet they also reported emotional regulation (i.e. actively controlling their emotions) as a coping strategy (Ross & Cuskelly, 2006). Little is known about the impacts on the family as a whole of these syndrome-specific sibling reactions; and measurement of the impacts on

siblings has mainly focussed on coping and adjustment. As stated by Cuskelly and Gunn it is important for research associated with siblings to examine within-family processes.

Moreover, as noted by Heller and Keiling Arnold (2010) in their systematic literature review of sibling research in the intellectual/ developmental disability field over the past 40 years, previous studies have focussed solely on the impact on the sibling, and none of the studies addressed the impact of the sibling on the family member with a disability, in terms of their health, well-being, general ageing and community involvement. Importantly, none of the studies reviewed by Heller and Keiling considered the impact of siblings on FQOL as a whole. Giallo and Gavidia-Payne (2006) found that family factors, such as socio-economic status, and family problem-solving and communication were stronger predictors of sibling adjustment than siblings' own experiences of stress and coping. These results imply that the impact on siblings should be considered within the family context (Giallo & Gavidia-Payne, 2006). The factors that Giallo and Gavidia-Payne found to influence sibling adjustment are included in the Financial Well-being and Family Relationships domains of FQOL framework. However, Giallo and Gavidia-Payne did not mention FQOL in their study.

Since a family unit is made of several interacting components, it is necessary not only to explore siblings' well-being and need for support, but also the impact of the sibling on the rest of the family. Zuna, Summers, Turnbull, Hu, and Xu (in press) noted that a common theme in FQOL literature is that families consider it important to meet the individual needs of all family members, including having enough time for siblings of the member with a disability. This suggests that the FQOL measurement may be useful in evaluating the impact on siblings.

As mentioned previously, all of the abovementioned family-centred research areas have received separate attention in the literature, but the FQOL framework considers a multi-factorial model of QOL. That is, the various domains of family life as a whole interact with and influence one another. Moreover, A. P. Turnbull et al. (2007) found that only 15% of family-related studies associated with well-being, adaptation, and family functioning that they reviewed referred to supports; whereas all studies related to FQOL referred to supports. This also highlights the value of FQOL research because it considers both internal and external aspects relevant to family life (A. P. Turnbull et al., 2007). By using a FQOL framework that considers all aspects of family life together, research can gain a better understanding of what life is like for families that have a member with an intellectual/ developmental disability. In turn, services can be better informed on how to support such families.

Literature associated with conceptualising FQOL will be described next and, following that, an overview of FQOL measurement will be provided. The details provided about the two surveys used in the current study are brief in this first chapter, because they are reviewed in more detail in the upcoming chapters of this thesis.

1.4 Conceptualising Family Quality of Life in the Context of Intellectual/ Developmental Disability

The primary rationale for researching FQOL is that it provides a comprehensive and holistic framework for drawing together all of the abovementioned family-centred research topics in the disability field. The principles of conceptualising, measuring and applying FQOL are very similar to the principles of QOL outlined previously (Verdugo, Schalock et al., 2005). However, FQOL is an extension of QOL, in that the focus has shifted from meeting the needs of the individual with a disability, to meeting the

collective needs of their family as a whole unit (R. I. Brown et al., 2004). This also

includes incorporating the impact and interaction of individual members' QOL on the

whole family (Poston et al., 2003). In a practical sense FQOL outcomes ensure that

families feel supported, sufficiently so that every member of the family is able to lead a

fulfilling life (I. Brown & Brown, 2004b; Summers et al., 2005).

As with the concept of QOL, it is difficult to unanimously define FQOL;

however, there are some commonly established factors and domains. A clear definition of

FQOL is needed in order for the concept to be measured and then applied to improve

FQOL. One broad definition for FQOL is: the degree to which the family's needs are

met, and family members enjoy life together as a family and are able to engage in things

that the family consider to be important (Park et al., 2003). The current section will

therefore briefly describe how FQOL emerged from QOL. It will also review the

conceptual frameworks of FQOL and their application in terms of the support available to

families with a member with an intellectual/ developmental disability.

Schalock (2004b) outlined four premises for moving from individual QOL to

FQOL:

1. QOL is a social construct that impacts on program development and service

    delivery in education, health care, intellectual disability, and mental health;

2. QOL is being used for assessing service effectiveness;

3. Pursuing 'quality' is evident at three levels: individuals and families, providers,

    and evaluators; and

4. FQOL is greatly influenced by work in the area of individual QOL.

Therefore, since QOL is being used at many levels and in various life areas

(education, health, disability, mental health), and since the family plays a central part in

these areas, it makes sense to combine QOL and family. Further, service quality is partly determined by the perceptions and expectations of the people who are directly affected (i.e. service recipients). Hence, using a FQOL framework for assessing service quality ensures that the subjective opinions of family members themselves are taken into consideration.

Bailey et al. (1998) also outlined three ideas for why family-centred approaches are important:

1. There are individual differences across families in terms of culture, priorities and preferences (which may go beyond a focus on child development);

2. Families should work together with professionals to achieve desired outcomes; and

3. Families make the final decision and need to be viewed and empowered as adequate advocates for the member with disability.

Furthermore, Brown and Brown (2004a) outlined three main components of FQOL which are:

1. Attaining what other families attain and attaining what is *important* to the family;

2. Being satisfied with what one has attained; and

3. Being empowered to live as one wishes, as well as being able to use *initiative* to make the most of opportunities.

These components have been taken into consideration in FQOL research. For example, international perspectives and themes associated with FQOL include the following: (Schalock, 2004b, p. 20-21; A. P. Turnbull, Brown, & Turnbull, 2004):

- It is important for families to understand clearly the core domains of well-being, and to plan ahead to link self-image and expectations to level of satisfaction.

- Families with a member with a disability encounter challenges associated with the disability and with access to sufficient and appropriate supports and services, such as availability and cost.

- FQOL relates to specific life domains linked to individual QOL core domains, and personal and social-cultural factors significantly affect FQOL.

- It is assumed that a better understanding of the FQOL framework will contribute to the development of family-centred approaches to support.

The first step in the process of a better understanding of FQOL framework is to validate existing FQOL measurement tools. These measurement initiatives will be discussed in the next section. It is also important for internationally developed measures of FQOL to be assessed for relevance in different countries. The tools described next have not been used extensively in Australia and little is known about their concurrent validity. Outcomes from such research could be used to develop a more effective culturally relevant measure for FQOL. As mentioned previously, results from FQOL measurement could then be used to implement appropriate supports and services, incorporating the family's perspective. FQOL measures could then be used to evaluate the outcomes and for further revision of those supports and services.

1.4.1 Measuring Family Quality of Life

The abovementioned components have formed the basis for measuring FQOL. As with individual QOL, the general consensus is that it is necessary to obtain both qualitative and quantitative data (methodological pluralism); and subjective and objective

data (R. I. Brown & Brown, 2005; Felce, 1997; Schalock, 2004a, 2004b; Verdugo, Schalock et al., 2005). Subjective measures consist of the family member's perceptions of their own psychological well-being, personal satisfaction and happiness; while objective measures centre around external and environmental aspects of people's lives, such as income, housing or health (Bailey et al., 1998; Schalock, 2004b; Schalock et al., 2002). Accurate information about important aspects of family life should be obtained from the individual perceptions of each family member because ultimately it is these perceptions that determine the individual's values, approach to life, and satisfaction with life. (I. Brown & Brown, 2004b; R. I. Brown et al., 2004). Qualitative questions allow participants to explain their FQOL in terms they choose and this in turn creates a deeper understanding of the underlying issues of importance. In the case of measuring FQOL for families that have a member with an intellectual/ developmental disability, time and resources often do not make it easy for research to seek the opinions of all family members. Wang et al. (2006) did however use the Beach Center FQOL Scale (see section 1.4.1.5) in the USA to measure the perceptions of FQOL of mothers and fathers of children with a disability. They found no differences between mothers' and fathers' opinions of importance and satisfaction of the various family life domains. While their study needs to be replicated, particularly in different countries and cultures, the results suggest that it might be reasonable as well as most efficient for the perspective of the main caregiver, mostly a parent, and most frequently a mother, to be sought to represent the family as a whole in FQOL research. The benefits of such research are that FQOL can be better understood in terms of what is important to families. Outcomes can then be applied to implement programs accordingly.

1.4.1.1 Application of FQOL Measurement

FQOL should be measured so that it can be used to implement support services in a proactive way to improve the lives of individuals with disabilities and their families. Zuna et al. (2009) recognised that very few studies have researched the supports and services necessary to enhance overall FQOL (Zuna et al., in press; Zuna, Turnbull et al., 2009). Consequently, Zuna et al. proposed a framework for using a FQOL theory as the next logical step from the development and usage of FQOL instruments. The theory of FQOL presented by Zuna et al. included:

- Systemic concepts (i.e. systems – interrelated organised networks; policies – guidelines for procedures; and programs of support);

- Performance concepts (i.e. an action such as formal service delivery and support);

- Individual-member concepts (e.g. demographics such as age and gender); and

- Family-unit concepts (e.g. the size of the family; family income; or relationships within the family).

Zuna et al. argued that these elements are interlinked and in the application of FQOL research, all of these systems need to be considered. This theory was intended to inform systems, policies and programs on how to assess individual and family performance constructs.

Further to this, Brown, Schalock, and Brown (2009) proposed that the family is involved throughout the whole process of applying FQOL principles, as follows:

- Assessing the family's behaviours and needs holistically;

- Employing an appropriate intervention for support;

- Evaluating progress in the family's behaviour and evaluating quality outcomes; and

- Making any changes that were considered necessary as a result of the evaluation.

Therefore, measurement of FQOL also takes into account lifespan implications of any outcomes that have been applied. Current measures and theories of FQOL can be used to re-assess FQOL after an intervention has taken place. Theories can also be re-tested in the long term with the continued development of variables influencing FQOL as family circumstances change (Zuna et al., in press). However, existing measures of FQOL do not assess what life was like previously for the family. It is important to understand how issues from the past, such as the death of a significant other, may impact on the present.

The interlinking nature of the systematic components in the application process was also supported by Schippers and Van Boheemen (2009). They emphasised that FQOL measurement has revealed the increasing importance of partnerships between the individual with a disability, their immediate social environments (family and friends), generic social services, and disability specific services. As a result, changes have been made to the legislation associated with the support paradigm for 'vulnerable citizens' in the Netherlands. Previously, service providers were responsible for the total well-being of the individuals they support, but services are now seen as contributors, sharing the responsibility of maintaining QOL with the individuals and others in their lives (Schippers & Van Boheemen, 2009). This is one example of the practical implications of QOL research. By using the systematic components of the FQOL framework proposed by Zuna et al. (2009), it is possible to gain an increased understanding of these positive

partnerships that contribute to QOL. It must be acknowledged, however, that the results

of Schippers and Van Boheemen's research may only apply to their culture. As such a

number of cultural considerations need to be examined, as discussed next.

1.4.1.2 Cultural Considerations

When measuring FQOL, as with QOL, it is important to be mindful of a number

of cultural considerations. Even though the overall meaning of QOL or FQOL can be

universally understood and applied, when it is applied to different individuals, groups, or

cultures certain aspects may be more prominent over others (R. I. Brown & Brown,

2005). An individual's cultural identity can be very complex, encompassing ethnicity,

nationality, dual nationality, language, social class and personal interests (Harry, 2002).

In the current culturally diverse society it cannot be assumed that particular dimensions

considered critical to QOL or FQOL in one culture are the same as for other cultures (R.

I. Brown & Brown, 2005; Verdugo, Schalock et al., 2005). In order for FQOL research to

inform disability services in various cultures effectively, there is a need for measurement

tools to be sensitive to cultural differences. This is because there may be differences in

terms of sense of self and perceptions of others; or meaning may be lost in language

translations (Verdugo, Schalock et al., 2005).

For example, Chou and Schalock (2009) assessed eight validated QOL domains

(emotional well-being, interpersonal relations, material well-being, personal

development, physical well-being, self-determination, social inclusion, and rights) and

they found that Taiwanese people with intellectual disability had lower levels of QOL

than other cultures (Spain, Latin America, USA, Canada, China). This lower QOL was

especially evident with respect to social inclusion and irrespective of whether the person

was living in the community or in a residential unit. However, the meaning of community

living as opposed to residential unit may not be the same across cultures. This confirms that measurement of FQOL and QOL, as well as resulting support programs, need to be culturally relevant and culturally sensitive (Verdugo & Schalock, 2009).

Similarly, it must be acknowledged that there are some differences between Australian culture and other Western cultures. Even though the differences may be considered minimal (e.g. the common language is English), they do still need to be taken into consideration when measuring and interpreting QOL and FQOL. For example, in America the term 'mental retardation' continues to be used, but in Australia the same construct is known only as 'intellectual disability'. In addition, in Australia, children below the age of 6 years are classified as having a 'developmental disability', rather than 'intellectual disability'. Moreover, although support services and the health systems are quite similar across Western cultures, there are some differences in terms of criteria for government funding and the amounts of funding available. For example, in South Australia people with disabilities and their immediate carers are entitled to Disability Support Pension, Mobility Allowance, and Carer's Allowance; whereas, some other nations, and even different states of Australia, have implemented individualised funding to support people with disabilities.

Therefore, it is important to check the validity of any internationally developed QOL measurement tools in Australia. This will also mean that the results from measurement tools could then be directly transferred into better access to quality services that meet the culture-specific needs of the people involved. Although an earlier version of the FQOLS-2006 (I. Brown, Neikrug, & Brown, 2000) has been used in Australia (e.g. R. I. Brown et al., 2004), little is known about the validity of other FQOL measures (e.g. Beach Center FQOL Scale) in an Australian context. In addition, it is also important to

assess the relevance of established FQOL domains in Australia. These domains will be described next, followed by a discussion of current FQOL measurement tools.

1.4.1.3 QOL to FQOL Domains

Current measures of FQOL include an extension of the QOL domains described previously. The major addition to FQOL measurement is that support from other people, support from services, family relationships, and parenting have been allocated separate domains, rather than being incorporated into other life areas. The FQOL domains that have been identified in recent research include: health, finances, emotional state, vocational pursuits, social involvement, recreation, interpersonal relationships, personal values and potential (I. Brown, Brown et al., 2000; Schalock, 2004a; Schalock et al., 2002; Verdugo, Schalock et al., 2005), disability-related supports (I. Brown et al., 2006; R. I. Brown, MacAdam–Crisp, Wang, & Iarocci, 2006; Isaacs et al., 2007; Schalock, 2004b; Summers et al., 2005), parenting (Beach Center on Disability, 2003; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006); and family interaction or family relationships.

To date there are three major FQOL measurement instruments based on these domains, and each one has been used in various research endeavours (e.g. Aznar & Castanon, 2005; I. Brown, Isaacs, McCormack, Baum, & Renwick, 2004; R. I. Brown et al., 2004; R. I. Brown et al., 2006; Hoffman et al., 2006; Isaacs et al., 2007; Summers et al., 2007; Summers et al., 2005; Wang et al., 2006). Aznar and Castanon (2005) presented a diverse perspective about FQOL domains. They argued, contrary to other linear multi-factorial models of QOL, that QOL domains are not organised according to relevance or as a link of consecutive conditions. Instead, Aznar and Castanon proposed a QOL model which includes three interacting components: material (objective), personal

(subjective) and social (contextual). The domains included within this framework were: emotional well-being, personal strength and development, rules of cohabitation, physical/material well-being, family life, and interpersonal and community relations. The main difference between Aznar and Castanon's approach and that of the other two FQOL measures is in terms of items related to rules of cohabitation, such as being treated as equal and exercising citizen rights. Aznar and Castanon did not incorporate the domain of disability-related services into their measure of FQOL. This could be considered a favourable approach, because as noted by Zuna et al. (in press), since FQOL is considered an outcome for exploring the impact of services and supports, then measures of the FQOL outcome cannot include assessments of the quality of services and supports as a domain factor. On the other hand, by excluding a disability-related services domain, it becomes difficult to establish connections between the variables (e.g. satisfaction with support services, related to satisfaction in other areas of family life).

The other two FQOL measurement instruments did include a domain for support from disability-related services. These surveys (Beach Center FQOL Scale; and FQOLS-2006) continue to be used and refined as FQOL research continues to develop. Their multi-factorial nature means that they can be used to test whether attainment of support from services predicts satisfaction in other areas of life such as family relationships or financial well-being. Both surveys have been used in the current research to test further their reliability and validity. These instruments will therefore be described next and they feature in more detail in the following chapters.

1.4.1.4 International Survey (FQOLS-2006)

An international study exploring FQOL in the United States, Wales, Israel, Canada and Australia (R. I. Brown et al., 2004) showed similarities across cultures in

terms of parental concerns for their family and the life of the member with an intellectual/ developmental disability. The results were published in a book edited by A. P. Turnbull et al. (2004). These similarities included that the main burden was placed on the mother of the family, and parents' main concern for their child with a disability was social isolation. The researchers of this international study had previously identified nine domains, which formed the basis of the original FQOL Survey (FQOLS-2000) as follows: health; financial well-being; family relationships; support from other people; support from disability related services; spiritual and cultural beliefs; careers and preparing for careers; leisure and enjoyment of life; and community and civic involvement. These domains were based on in-depth discussions and input from research persons and a review of FQOL research.

The current version of the survey titled, *Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities* (FQOLS-2006) (I. Brown et al., 2006) contains the domains of: health; financial well-being; family relationships; support from other people; support from disability-related services; influence of values; careers; leisure and recreation; and community interaction. These domains are measured on a 5-point Likert scale with six measurement concepts: Importance; Opportunities; Initiative; Stability; Attainment; and Satisfaction. The FQOLS-2006 includes qualitative and quantitative questions, allowing respondents to elaborate or share further concerns about each topic.

With respect to methodology employed to administer the FQOLS-2006, only one study (I. Brown et al., 2003) found by the thesis author noted that interviews were conducted in a quiet room on the recruitment agency premises, and no details were presented about the benefits of such methodology. Therefore, little is known about the

advantages and disadvantages of self-administration as opposed to face-to-face interview, because there are no comparative data. However, it can be assumed that a quiet location with little to no distractions creates an environment for the most accurate responses to be revealed.

The FQOLS-2006 has not been used in Australia previously. It was used in the present study with some additions and slight amendments. These modifications included assessing FQOL in the past and separating practical and emotional support, both of which are exclusive to the current research. The following chapters of this thesis contain further details about the FQOLS-2006 and methodology (see Chapters 2, 3 and 4 for further information, including a description of changes that were made to the survey for the purpose of the current study).

1.4.1.5 Beach Center Survey

The Beach Center on Disability at the University of Kansas developed a scale specifically designed for measuring FQOL. Based on thorough analyses of the research literature, expert opinion and the data collected, five FQOL domains were identified and included in The Beach Center Family Quality of Life Scale. These were, family interaction; parenting; emotional well-being; physical/ material well-being; and disability-related support (Summers et al., 2005). Poston et al. (2003) acknowledged that confirmatory analysis of the data examination procedures used to develop this survey was not conducted; and, given that qualitative data were once-off with selected people, results may not necessarily have been generalisable to all families. However, Summers et al. concluded that this scale was an effective tool for assessing the impact of services on families. In a later study in the USA, Wang et al. (2006) reiterated the validity of the Beach Center FQOL Scale for use with both mothers and fathers, finding that perceptions

of FQOL of mothers and fathers were not significantly different. However, they also acknowledged that differences were not examined in relation to characteristics of the child with a disability, such as age, or disability type; and parents may have completed the surveys together.

Wang et al.'s study attempted to represent ethnic diversity by recruiting participants from various agencies, and encouraging participation by typically underrepresented ethnic groups (e.g. African American, Hispanic, American Indian and Asian). However, they did not obtain many participants of such cultural backgrounds, and little is actually known about cross-cultural validity of the Beach Center FQOLS-2006 because it had previously not been used outside of the USA. Davis and Gavidia-Payne (2009) collected data in Australia using the Beach Center FQOL Scale; however, they did not comment on any culture-specific considerations or measurement issues. Further details of the Beach Center FQOL Scale are presented in the following chapters of this thesis, along with the details about the FQOLS-2006. (See Chapters 2, 3 and 4 for further information and comparisons with the FQOLS-2006 domains).

Similar to the FQOLS-2006, previous studies using the Beach Center FQOL Scale reported that surveys were self-administered in the participant's own time and posted back to the researcher (e.g. Hoffman et al., 2006); self-administered in a group situation with a facilitator present (Werner, Edwards, Baum et al., 2009); or conducted by telephone interview (Zuna, Selig, Summers, & Turnbull, 2009). However, those previous studies did not discuss methodological issues in terms of how data were collected. Therefore, more information is needed about the relative advantages and disadvantages of the different completion methods for the Beach Center FQOL Scale.

1.4.1.6 Comparing Measures

The abovementioned two teams of researchers (authors of the FQOLS-2006 and the Beach Center FQOL Scale) continue to work collaboratively to examine FQOL measurement issues, and to provide feedback about the respective tools. It has been highlighted during informal discussions and conference presentations (R. I. Brown & Brown, 2006; Poston, 2006) that the FQOLS-2006 was being used in several countries, whereas the Beach Center Scale was only being used in the USA, and there is no research that has collected data using both FQOL measures. This means it has not been possible to examine concurrent cross-cultural validity in terms of the similarities and differences between the two surveys.

In 2007 Zuna, Hu, and their colleagues at the Beach Center on Disability produced a table for a conference presentation, which underscored the main differences between the two surveys (Beach Center on Disability, Zuna, & Hu, 2007). This table served as a basis for the current thesis, which has been developed from data collected using both measures in Australia. The current study is the only Australian study concurrently using the two measures of FQOL. The results of comparing the two measures are included in Chapter 4 of this thesis (Rillotta, Kirby, & Shearer, in press). The upcoming chapters of this thesis also provide further details about the importance of evaluating existing FQOL measures in order to develop a tool which could be used to apply the FQOL construct. The ultimate aim of this research is to develop a universal FQOL tool, which could be used to better predict support needs for families that have a member with an intellectual/ developmental disability, and as a result improve their QOL. The value of the current study is that it contributes to methodological considerations while FQOL measurement in the intellectual/ developmental disability field is still in its

infancy in Australia. The review of family-centred research topics in Australia will demonstrate that it is important to test these internationally developed surveys in Australia and verify that the outcomes are relevant to Australian families in terms of identifying service needs, and fundamentally improving FQOL.

1.5 Family and Intellectual Disability Research in an Australian Context

Since the current research is associated with validation of the previously described FQOL measures in Australia, it is necessary first to describe the relevance of FQOL measurement and research in the intellectual/ developmental disability field in Australia. This is done by providing some background about prevalence of intellectual/ developmental disability in Australia. Following that, early research associated with families that have a member with a disability is discussed, to set the context for current approaches.

1.5.1 Prevalence of Intellectual/ Developmental Disability

Approximately three percent of the Australian population is known to have an intellectual disability. Intellectual disability is the most prominent disability (36.4%) in Australia (Department for Families and Communities, 2007). Although it is often difficult to provide specific estimates of the prevalence of particular diagnoses in Australia, figures from various disability information sources estimate that, of those with intellectual/ developmental disability in Australia, 110, 000 (22%) have been diagnosed with Autism Spectrum Disorder, including autistic disorder, Asperger's disorder or atypical autism (Autism Spectrum Australia (Aspect), February 2006); and about 22,000 (4.4%) have Down Syndrome (Keeping Up with Down Syndrome NSW, January 2009).

1.5.2 Importance of Family

In Australia there has been an increasingly recognition that particular disability types mean that these people need to live with the support of others, mostly with their families. Furthermore, it has been argued that "the support provided by families is the thread that holds together the fabric of society" (Australian Institute of Family Studies et al., 2009, p.3). Research associated with the Family Support and Services Project (Llewellyn, 2004) has stated that, for parent carers in Australia, caring is a lifelong process that benefits society substantially, because previously family members with a disability would have been placed in institutional settings.

Chapter 3 of this thesis consists of a publication with details about the Australian component and contribution to the International FQOL project. Further details, facts and figures associated with intellectual/ developmental disability and families in Australia are provided in that publication.

1.5.3 Historical Overview

Reynolds (1979) indicated that early research associated with the impacts of intellectual disability[1] on the family dates back to the 1950s in Australia. Reynolds followed on from early research and found that generally having a child with an intellectual/ developmental disability had little effect on father's employment prospects. However, there was a reported need for the family to remain living in the vicinity of the child's school and so opportunity to receive promotions or change job were restricted. With respect to friendships, families reported making more friends as a result of having a child with an intellectual/ developmental disability, because such families valued meeting with other parents in similar situations. Overall, family friendships were not affected to a

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[1] Intellectual disability was previously, and in some countries still is, termed 'Mental Retardation'

large extent by having a child with an intellectual/ developmental disability. Overall, Reynolds' findings were quite positive, apart from lack of opportunity to receive promotions at work. These findings are an example of positive outcomes that can only be revealed by taking a family-centred approach.

1.5.4 Current Perspectives

Issues for Australian families seem to have increased since the 1970s. This may be because recent Australian studies have looked at the impact of a family member with an intellectual/ developmental disability more comprehensively. This means that past outcomes may not have been as well known in terms of detail as they are today. Consequently, issues facing families may have been underestimated, and appropriate support services were perhaps not provided. Many of the problems or concerns that families faced were not apparent from studies in the past (e.g. Reynolds, 1979) because they did not employ a FQOL framework; but rather, they considered particular aspects of family life, such as careers, in isolation. Thus, even though it may seem as though more issues have emerged for families since the 1970s, it is more to do with the measurement framework, which now considers several aspects of family life in a holistic sense.

In addition, there have been some changes to Australian legislation since Reynolds' study. For example, the focus of supporting people with disabilities is no longer limited to health-related needs. Society now acknowledges the rights of people with disabilities to live fulfilling lives and to participate in society to the same extent as others (Commonwealth of Australia, 2007, 2009; Department of Families, Housing, & Community Services and Indigenous Affairs (FaHCSIA), 2007). According to R. I. Brown, et al. (2004), consumer outcomes from Australian disability legislation in 1985 included having housing, employment, competence and self-reliance, community

participation, security, choice and a positive image. In 2004 State governments were responsible for services associated with accommodation, recreation, respite, case management, early intervention, education, community access, advocacy, transport, equipment, information, and research (R. I. Brown et al., 2004). With these expanding government support services also came increased family involvement and support in decision making to acquire these services. These changes to the support structures over the years highlight the need for revised assessment tools for family life that are in accordance with contemporary practices.

1.5.4.1 Primary Caregiver, Career, Income, and Gender Differences

Despite these changes, results similar to those of Reynolds' (1979) continue to be found. However, such issues as restricted employment options are also known to be confounded by other areas of family life, such as income and financial well-being. For example, Burton-Smith and colleagues (2009a) found similar results to Reynolds (1979) with respect to employment and career opportunities. However, Burton-Smith et al. also indicated that lack of work opportunities for the parents of the child with a disability impacted the family's economic circumstances as well as restricted the personal networks and social opportunities available to the parents through their work commitments.

Concordant with Reynolds findings, males in Burton-Smith et al.'s study indicated greater full-time employment than females. In addition, females were found to be more affected by caring for the member with a disability, with limited employment opportunities due to continuous caring activities, and well-being that fell significantly below population norms for Australian families (Burton-Smith et al., 2009a; Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009b; McVilly, 2007b). However, since females largely outnumbered males in the sample, findings related to females

having lower general health than males need to be interpreted with caution and further research is required. On the other hand, given that generally females are found to be the main caregivers in families that have a member with a disability, research in the FQOL and disability fields using predominantly males as participants is scarce.

A fundamental limitation in Burton-Smith et al.'s research is that they did not consider FQOL as a whole, but rather they explored the circumstances (feelings, health, and personal well-being) of the primary caregiver. Nevertheless, there is an impact of having a child with a disability on all members of the family, and therefore mothers, fathers and siblings all need to be represented. The FQOL framework allows for respondents to represent all members of the family holistically. This in turn means that services can better provide for the whole family.

1.5.4.2 Existing Issues for Australian Families

There have been a number of Australian studies exploring particular elements of FQOL where there is a family member with an intellectual/ developmental disability (R. I. Brown et al., 2004; Burton-Smith et al., 2009a, 2009b; Davis & Gavidia-Payne, 2009; Eacott, 2002; Kristine Peters Project Management Pty Ltd, 1998; Llewellyn, Thompson et al., 2003). These studies indicated that the child with a disability became the focal point of the family and influenced the family's QOL in terms of what the family could and could not do. In addition, each family member was reported as being affected in different ways (e.g. stress, health and employment of carers; sibling development; and degree of family social isolation and community involvement). Further research associated with how to measure all of these components adequately is required.

R. I. Brown et al. (2004) discussed a range of concerns reported by families in Australia including: lack of funding for respite and respite not available when needed;

little or no choice when it comes to decisions about the family member with an intellectual/ developmental disability; families experience of emotional issues; changed levels of intimacy between parents due to the apprehension of having another child with a disability; less opportunities for families to engage in social and leisure and recreation activities, due to lack of funding (and this can negatively impact on the mental health of family members); and many families experience financial difficulties, which then impacts on other areas of family life. These issues emerged as a result of using a measure similar to the FQOLS-2006 (see section 1.4.1.4). The value of the FQOL framework is that it enables such concerns to be researched effectively. Rather than assess each of those components separately, which could be quite time consuming, FQOL measurement provides a holistic measure examining the many elements collectively, and across the lifespan.

1.5.4.3 Informal Support and Interaction of Variables

Developing on from Brown et al.'s research which focussed on support services, there is a need to research further the importance that families place on informal practical and emotional support from other people (such as friends and relatives). Supporting this, in another Australian study, Davis and Gavidia-Payne (2009) found that support from extended family and professionals were stronger predictors of FQOL than family income. However, it remains unknown whether families considered practical and emotional support from others to be separate constructs that were attained at different levels. Nevertheless, Davis and Gavidia-Payne's study has also emphasised the interaction between income and family relationships, in the sense that increased income means that the family has access to more resources to support the child with a disability. Hence the family as a whole is better off, which in turn results in more harmonious marital

relationships and dual support from both parents to care for the child with a disability (Davis & Gavidia-Payne, 2009). However, these findings were based on a very low response rate; therefore, the conclusions drawn are not necessarily based on representative data from families that have a member with an intellectual/ developmental disability. The researchers also did not discuss FQOL measurement issues and they did not make any suggestions associated with how to assess FQOL further.

The importance and rationale for this kind of research lies in the fact that, if people with disabilities are to remain living with their families, then families need to be adequately equipped for this caring process. Empirical evidence is needed to provide a better understanding of the needs of all family members (Burton-Smith et al., 2009a), and this can only be done by using an adequate assessment tool.

1.6 The Current Study

As outlined previously, very few studies have explored FQOL for Australian families that have a member with an intellectual/ developmental disability. Of the FQOL research that has been conducted in Australia, none has discussed measurement issues in detail. Moreover, they have not examined the concurrent use of FQOL measurement tools. Such research is necessary because if some aspects of support that families require can be identified through a practical, user-friendly measurement tool, then this can assist in meeting family needs. This, in turn will facilitate the collective improvement of QOL for all members of the family.

1.6.1 Objectives

The current study investigates FQOL measurement issues in Australia. The specific objectives are to:

1. Examine factors that contribute to a satisfactory FQOL for various families.

2. Test the reliability/ validity of the internationally developed FQOLS-2006 in Australia.

3. Compare the FQOLS-2006 to the Beach Center FQOL Scale.

4. Explore the implications of FQOL research for support services.

1.6.2 Research Questions

The research questions that arise from the above aims and objectives are:

1. Can the two international surveys (FQOLS-2006 and Beach Center Family Quality of Life Scale) be used to measure FQOL comprehensively within an Australian context?

2. Is it necessary for FQOL measures to ask about and differentiate between practical and emotional support that families receive from others?[2]

3. Do significant life events of the past and apprehension about the distant future influence current FQOL?

4. Is 'Parenting' a valid FQOL domain, particularly with respect to taking care of the individual needs of each child in the family, and is it useful for exploring emerging sibling issues?

5. Is having means of transportation an important element influencing FQOL?

6. What are the best methods for collecting FQOL information (e.g. multidimensional; qualitative/ quantitative; face-to-face interview/ telephone/ self-administered).

Specifically, these research objectives and questions will lead to suggested improvements to existing FQOL measurement tools. Broadly, the outcomes of this thesis

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[2] This research question developed as a result of emerging ideas presented in the pilot phase of the current study (see Chapters 2 and 3).

will be used to offer service providers more knowledge about the specific service needs of families with an intellectual/ developmental disability in South Australia. Results can be used to encourage improvement of services, supports and FQOL for all members including the member with the intellectual/ developmental disability.

1.6.3 Outline of Thesis Chapters

The following chapters of this thesis include:

- *Chapter 2:* Comprehensive description of the methodology of the research.

- *Chapter 3:* Journal article publication on the use of the FQOLS-2006 in Australia, emphasising the differences between practical and emotional support from other people.

- *Chapter 4:* Book chapter comparing the FQOLS-2006 with the BC –FQOLS with 15 participants.

- *Chapter 5:* Conclusions, including an overview of implications for services.

See section 1.1 of this chapter for further details about the content of the upcoming chapters.

Chapter 2: Methodology

2.1 Overview

This section elaborates on the methodology described in the publications, which make up Chapters 3 and 4 of this thesis, and it provides further comprehensive information with respect to the early developmental stages of the current research. This chapter also describes a review of the draft form of the *Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities* (FQOLS-2006; I. Brown et al., 2006) undertaken by the thesis' author, and an explanation of changes that were made to the FQOLS-2006 for the current study. Further details associated with ethical considerations, the results from two focus groups, and the pilot study are also outlined. Data from interviews have been drawn upon to illustrate relevant points related to the methods employed for the study. In order to meet the objectives outlined in the previous chapter and attempt to answer the research questions, the study was operationalised as described in the following sections.

2.2 Participants

There were 53 main caregivers (i.e. one or both parents, grandparents, or siblings) of family members with an intellectual/ developmental disability who participated in this study, which included four participants from the pilot study. Staff from the government's main disability service provider in South Australia (DSP-SA)[3] acted as liaison persons and randomly selected families from their client database to recruit as participants for the study. Families were telephoned to discuss participation in the study. They were asked to nominate who they considered to be the main caregiver of the family member with an

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[3] The name of the government's main disability service provider has not been disclosed in this thesis for confidentiality reasons. It is referred to throughout as DSP-SA (Disability Service Provider SA).

intellectual/ developmental disability in their household. The main caregiver completed the questionnaires and/ or participated in interviews. Information sheets (see Appendix B) informed participants about the nature of the study and other relevant considerations, such as voluntary participation, confidentiality of individual responses, and the fact that they were free to withdraw at any time. They were also required to sign an informed consent form (see Appendix C) before taking part in the study (see section 2.4 Procedure, for further information about Pilot Study, Recruitment Organisation, Ethical Considerations, and the Process of Recruiting Participants). Of the 53 participants, 15 family members participated in both the FQOLS-2006 and the Beach Center FQOL Scale, nine completed only the Beach Center Survey,[4] and 29 completed only the International FQOLS-2006. Not all participants completed both surveys because, as will be described in the upcoming chapters, the Beach Center FQOL Scale was introduced at a later stage of the study, and some participants specified that they did not have time to complete both surveys. Note that the demographics of 42 people who completed the FQOLS-2006 will be detailed in Chapter 3 of this thesis; and descriptive details of the 15 who completed both surveys will be outlined in Chapter 4.

As shown in Table 2.1, the main caregivers were mostly biological mothers and they varied considerably in age from mid twenties through to almost 80 years. It can also be seen that the members with an intellectual/ developmental disability varied in age from early childhood through to nearly 50 years, and that the majority were male. As their primary disability, most family members were diagnosed with 'Intellectual Disability' ($n = 19$; 36%); followed by 'Autism Spectrum Disorder' ($n = 16$; 30%); then

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[4] The data of these nine participants who completed only the Beach Center Survey were not used directly in the reporting of results throughout this thesis, but these data served to endorse the information and evidence provided in the comparisons of the two measures (Chapter 4).

'Developmental Delay' or 'Early Childhood Disability' ($n = 5$; 9%); 'Down Syndrome'
($n = 4$; 8%); 'Cerebral Palsy' ($n = 2$; 4%); Fetal Alcohol Syndrome ($n = 2$; 4%); and other
rarer diagnoses and conditions, such as Prader-Willi Syndrome and Rhett Syndrome
made up the remaining nine percent ($n = 5$). Almost all had one or more of a variety of
secondary conditions including behavioural problems, physical impairments, or speech/
language/ communication difficulties. In fact, 25 participants (47%) identified that their
family members had five or more additional conditions. Previous research has indicated
that approximately half of all Australians with an intellectual disability had a combination
of two or more disabilities or conditions (Australian Institute of Health and Welfare
(AIHW), September 2009), indicating that participants in the current study were
representative in this regard.

Table 2.1 *Demographical Details of all Participants (N = 53)*

	Age Range	Mean (SD) Age in years	Gender	Relationship to person with disability
Participant (Main Caregiver)	25 – 78	45 (11.87)	Female = 50 Male = 3	Mother = 47 Father = 2 Grandmother = 1 Brother = 1 Other = 2
Member with intellectual disability	2 – 46	15 (10.41)	Female = 20 Male = 33	N/A*

*N/A = not applicable

While all families resided in the Western, Northern and Southern metropolitan
areas of Adelaide (the capital of South Australia), some lived further away from the
central business district than others. It was beyond the resources of this study to involve
families living in rural areas of South Australia. However, this is considered another
important area for future investigation because service provisions can be influenced by

geographical location and, in rural areas where the population is fewer than in metropolitan areas, support services are usually quite different. Sometimes there is a heightened sense of community responsibility and intimacy or familiarity among rural communities. For further information about families and QOL in Rural Australia see Chapter 1 of this thesis.

In response to the FQOLS-2006 survey question about total family income relative to the rest of the country (n=44), more than half (55.8%) of the participants in the current study indicated that they had "average" total family income including pensions; followed by "below average" family income (23.3%). Fewer families (16.3%) indicated that they had family incomes that fell "above average"; and only two families (4.7%) fell "well below average". None were "well above average". Some families were from suburbs considered to be wealthier or to have higher socio-economic status than others. In addition, it is worth noting that all family members with an intellectual/ developmental disability were receiving the 'Disability Support Pension' from the government, and 66% of families also indicated that the main caregiver was receiving 'Carer's Allowance' from the government. Further details, such as suggestions on how to ask about family finances in FQOL surveys, are outlined in Chapter 4 of this thesis, as part of the comparison of the two FQOL surveys.

With respect to family type (two-parent; single-parent; other) and marital status of participants, fewer than three quarters (69.8%) of participants were partnered (including married or de facto relationships) and the remainder (30.2%) were single (including divorced, separated or widowed). Furthermore, just over half of the participants (54.7%) were not employed (including a few who were retired and a couple who were students, but most specified that they were stay-at-home full-time mothers/ carers), and the

remainder (45.3%) of main caregivers were employed (mostly on a part-time or casual basis, but some were full-time). The remaining demographic variable to discuss is cultural and/ or religious affiliations of the families involved in this study, as indicated in the 'Values' section of the FQOLS-2006 and the 'General Individual and Family Information' section of the Beach Center Survey. Whilst most participants were Australian, a few had various European backgrounds (including German, Italian, Croatian, English and Irish). Two families associated themselves with the Aboriginal culture; one of which was a foster situation, whereby the main caregiver (who was not Aboriginal) was a voluntary carer to several Aboriginal children with Fetal Alcohol Syndrome. In another family the biological mother of the member with a disability (who was not identified as the main carer, and hence did not participate in the study) was of Aboriginal descent. One family was from an Asian background; however, the member with disability had been born in Australia. Another family originated from New Zealand and the member with a disability was born in New Zealand.

More families considered themselves to be aligned with a particular religion (59.1%) than those who did not specify being associated with a particular religion (40.9%). Of those who specified religious affiliations ($n = 26$; 59.1%), the religions included Christian (88.5%), such as Catholic, Baptist, Lutheran, Anglican, Uniting, and Orthodox; followed by Mormon (7.7%) and Muslim (3.8%). This diversity in the sample represents typically what might be expected from a cross section of urban, middle-class Australians (Australian Bureau of Statistics (ABS), 2004, 2010).

2.3 Materials

2.3.1 International Survey (FQOLS-2006)

Participants ($n = 44$) were interviewed using the *Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities* (FQOLS-2006; I. Brown et al., 2006; see Appendix D). Additional relevant comments made by family members during interviews were also recorded by the researcher. The FQOLS-2006 was designed and developed by nine professionals who are experts in the fields of disability and quality of life (QOL), and it had been revised several times prior to final publication in 2006. Based on the results and feedback from data collected using the first version of the survey in 2000 (FQOLS-2000; I. Brown, Neikrug et al., 2000), changes were made to the terminology within the domains. Such changes included simplifying the wording of the demographics section, allowing for families to discuss FQOL with respect to more than one member with a disability, and changing 'Community and Civic Involvement' to 'Community Interaction', because official civil duties in organisations were reported as irrelevant to many families (Isaacs et al., 2007). Chapter 4 of this thesis contains further details regarding the differences between the 2000 version and the FQOLS-2006 version. There is also a short version of the FQOLS-2006, but it was not used in the current study.

While the FQOLS-2006 was still in its final draft form in October 2005, the current researcher contributed a critical analysis of the survey's items. As can be seen in Appendix E, most of the suggestions were incorporated by the authors of the survey into a revised version of the FQOLS-2006. The current researcher's feedback was considered critical to aid the user-friendliness of the survey and in order to gain an accurate insight into FQOL. As a result of the current researcher's feedback and feedback from various researchers, the authors of the FQOLS-2006 added an open question at the end of each

section/ domain, asking participants if they had any extra information or further explanations. When administered in an interview format this was useful, to clarify any misinterpretations of the questions, as well as to allow participants to elaborate on the quantitative options they had selected.

The FQOLS-2006 includes both qualitative and quantitative questions. As mentioned in the Introduction to this thesis (Chapter 1), the areas of family life questioned in the FQOLS-2006 are:

- Family Background

- Health

- Financial Well-being

- Family Relationships

- Support from Other People

- Support from Services

- Influence of Values (personal, spiritual, religious, cultural)

- Careers and Preparing for Careers

- Leisure and Recreation

- Community Interaction

These areas (referred to as domains) formed the basis for the sections of the FQOLS-2006. Each section contained a Part A and a Part B. Part A serves to obtain background information about the family with respect to the domain in question. For example, in the Financial Well-being section the following open question was asked, *"Does your family receive any financial support from sources other than employment (such as gifts, pensions, investment income)?"* Part B was consistent across all domains

asking about, Importance, Opportunities, Attainment, Initiative, Stability, and

Satisfaction, rated on a 5-point Likert scale. As an example, the Initiative question from

the Leisure and Recreation section was, *"To what degree do your family members engage*

in leisure and recreation activities" (A great deal, Quite a bit, Some, A little, Hardly at

all)? The complete survey is attached in Appendix D. Chapter 4 of this thesis elaborates

on, and provides critical insight to, the measurement concepts of the FQOL-2006.

      In Australia, the diagnosis of '*intellectual* disability' is not provided until after the

age of 6 years. Prior to that age, such children are considered to have a developmental

delay, given the difficulties of accurately indentifying intellectual disability before that

age. The manager of the early childhood services of the DSP-SA, who was consulted

prior to commencement of the study, stated that it would be very confronting for

participants to read the term intellectual disability when their child had not yet been

diagnosed as such. Similar issues were later recognised by researchers using the

International FQOLS-2006 in Taiwan (Wang, S., 2006; as cited by I. Brown, 2006).

Since their sample was primarily families who had a member with Autism Spectrum

Disorder, some participants noted that their sons or daughters did not have an *intellectual*

disability. The same might be true of people with Down Syndrome and other conditions

that are usually, but not always associated with intellectual disability (Ivan Brown, 2006).

Accordingly, around 10 months after publication (i.e. October, 2006), the survey

developers added the words "or developmental" to the title of the FQOLS-2006 and to

the questions throughout. The FQOLS-2006 was then republished, so that where ever

"intellectual disability" was previously stated, it now reads, "intellectual or

developmental disability". This wording change acknowledges that terminology may

differ from country to country (Ivan Brown, 2006), and it is also more encompassing of

early childhood disabilities (such as 'Global Developmental Delay') and other disabilities that do not always include intellectual disability. For the purpose of the current study, open questions in addition to the FQOLS-2006 were also asked to gain further information about the FQOL variables under consideration. These modifications are outlined in the next section.

2.3.1.1 Alterations and Additions to the FQOLS-2006

Additions to the FQOLS-2006 for the current study (see below and Appendix F) were based on focus group discussions (see section 2.4.3 Focus Groups for further information) and on the Australian study conducted in 2002 by J. Shearer (unpublished), using the previous version of the FQOLS (I. Brown, Neikrug et al., 2000). For Shearer's unpublished study, follow-up interviews with 11 questions expanding on the FQOLS-2000 were undertaken with 10 of the 55 participants. These questions included, the impact of the child with disability's health care needs on the family (health); what the family would like to do with any money left after living expenses are paid (financial); how family members relate to each other or work together (family relationships); any groups in the community that should help the family (community involvement); services not available in the area (support from disability related services); importance of respite to FQOL (support from disability related services/ support from others); most effective means of advocating (support from disability related services/ support from others); family activities most enjoyable for the family (leisure and recreation); leisure activities they would like to do that they were not currently doing (leisure and recreation); most pressing needs of the child with disability; and what is needed to improve FQOL. In the previous Australian study (reported in, R. I. Brown et al., 2004), participants mentioned additional family life concerns, not covered in the FQOLS-2000. For example, one

interviewee expressed the need to talk about whether their child with an intellectual/ developmental disability was in an intimate relationship or not, because this had an impact on their FQOL insofar as the partner to the member with a disability was an extra support – both emotionally and in a practical sense (e.g. the partner was able to provide moral support to the person with a disability and was a significant part of the their social life). Thus, whether or not the family member with a disability was in a relationship was also added to the demographic questions in the current study. It was, however, not found to be a useful question in this study, because only two families (4.5%) indicated that their family member with a disability "may" be in a relationship and, for these, it had very little impact on the lives within the family or the member with a disability.

As outlined previously, the changes between the 2000 and 2006 versions of the FQOLS incorporated all of the above mentioned follow-up interview questions into qualitative/ open questions within each section of the survey. However, some additional open questions were included in the current study, in order to address any aspects that had not already been mentioned in qualitative responses. These additional questions were also useful for more reserved respondents who required prompting to provide further details about their FQOL. For example, in the Financial Well-being section of the FQOLS-2006, there was already a question asking whether the household has money left over to do with as they wish and whether or not the absence of such money presents a hardship to the family, and so the questions, "what is it that your family would wish for?" and "how is it a hardship to the family financially?" were added. At the end of the Family Relationships section the question was added: "what things are likely to create/ reduce a sense of harmony/ unity within the family?" Furthermore, in the Support from Disability-Related Services section, there may have been a need to also ask: "are the services

appropriate in making a difference to your child's/ family's life?" With respect to Community Interaction, in order to obtain further information, the questions added were: "which groups in the community do you think should help your family?" and "what would you like that help to be?" Finally, in the overall FQOL section of the FQOLS-2006, additional prompt questions were: "are you satisfied with the current living arrangements of your family member with a disability?" and "is family life the way you intend it to be?" The question about whether FQOL meets the family's expectations was found to be fully covered in the 'attainment' question for each domain of the FQOLS-2006 and so it was not found necessary to ask about it specifically. As outlined in sections of this thesis that report results from the current study, these additional questions were mostly not required, given that the FQOLS-2006 was very comprehensive, and when administered in an interview format there was ample opportunity for participants to explain or elaborate on their quantitative responses. However, whenever the FQOLS-2006 is self-administered, follow-up interviews should contain the additional questions outlined above, as per the research conducted by J. Shearer in Australia in 2002. Moreover, the main advantage of administering the survey as an interview in the current study meant that additional questions could be incorporated at the appropriate time during the interview. Such questions included, "could you please explain why that is the case?", "can you please clarify what you mean by that?", or "can you think of any examples of...?" These additional questions served as prompts to ask participants for further information if they had not already provided extra details about FQOL.

Alterations and additional questions to the FQOLS-2006 for the current study were also based on the ideas and suggestions of the current researcher that had not been taken up by the authors of the FQOLS-2006 (see Appendix E). The focus groups and

pilot study for the current study also confirmed the importance of these changes. For example, results showed that it was necessary to ask about practical and emotional support from other people separately, because they are two different concepts and are acquired at different levels. The reader is referred to the "pilot study" section of this chapter (see section 2.4.4) and Chapters 3 and 4 of this thesis for more detail and evidence associated with dividing practical and emotional support.

The only other alteration to the FQOLS-2006 that was considered necessary was to add questions about FQOL in the past in each domain. These questions were designed to gain perspective into the impact of developmental/ transitional stages of the child with a disability on the various areas of FQOL. As discussed in the Introduction to this thesis (Chapter 1), there is a wealth of recent literature that discusses a lifespan perspective and how life for the family is different at different times throughout the life of the member with a disability. Since it was not possible to undertake longitudinal analyses within the scope of the current research, in order to explore how FQOL may change over time, additional questions were added, asking families about the past. Results from the current study emphasised that it was imperative to gain an understanding about issues from the past that may affect current FQOL. For example, the fact that some services may have been more readily available and accessible when the child was younger can have an effect on the family's current expectations of, and satisfaction with, support services. This may be because the same services may no longer be available to the same extent and with the same quality as they were previously. Chapters 3 and 4 of this thesis cover more detail and evidence associated with asking about FQOL in the past or about significant life events.

Results from the current study supported the notion that topics and responses to questions in the different FQOL domains/ dimensions can overlap with one another and that research needs to focus on the many aspects that make up a good family life (as discussed in Chapter 1). For example, in response to a question in the Health domain of the International FQOLS-2006, one participant from the current study had specified that there were *no* major physical and/ or mental health concerns for other members of the family; however, in the "Leisure and Recreation" domain the participant talked about her husband's arthritis and that he was on the waiting list for hip replacement surgery and this had implications for the Leisure and Recreation activities that the family could now engage in together. The question that prompted this participant to talk about a major physical health issue in the family was about how the family's leisure and recreation was different in the past (see Chapter 4 for more detail about the importance of asking about the past). If this question had not been added then this critical information would not have been included in the participant's responses.

2.3.2 Beach Center Survey

The Beach Center Family Quality of Life Scale (Beach Center on Disability, 2003; See Appendix G) was the other FQOL measurement tool used for this research. This scale had been developed in the USA and had not been applied to an Australian population until the current study. A small sample of 24 participants completed this survey for comparative purposes in the current study. The authors of the survey have recommended that the scale can be used for pre and post evaluations of the effectiveness of interventions; and as an outcome measure for programs and/ or services. It was also explicitly stated on the information accompanying the Scale that it is not to be used as a clinical diagnostic tool or to exclude people from particular services. The three phase

development of the scale undertaken in the USA involved literature reviews, focus groups and interviews with family members, people with disabilities, and people representing the services. The first phase of interviews resulted in 10 domains: Family Interaction, Parenting, Daily Life, Financial Well-being, Emotional Well-being, Social Well-being , Health, Physical Environment, Advocacy, and Productivity (Poston et al., 2003). A scale with items based on these domains was then piloted and exploratory factor analysis resulted in a 5-factor solution (Park et al., 2003). As mentioned in Chapter 1 of this thesis the final scale contains five subscales, which were determined from further confirmatory factor analyses:

- Family Interaction

- Parenting

- Emotional Well-being

- Physical/ Material Well-being

- Disability – Related Support

There were 25 items randomly presented, which covered these areas of family life and each was questioned in terms of Importance and Satisfaction on a 5-point Likert Scale (a little important to critically important; and very dissatisfied to very satisfied). For example: *"For my family to have a good life together... How important is it that... My family members teach children how to get along with others?"* and *"For my family to have a good life together... How satisfied am I that... My family has the support we need to relieve stress?"* A comprehensive description of the scale and critique of the survey items with respect to comparing the Beach Center Survey to the FQOLS-2006 (described previously) can be found in Chapter 4 of this thesis.

There were no major changes required to the Beach Center Scale for the purpose of this Australian study. However, it was necessary to modify the wording of the demographical questions (see Appendix H). Specifically, the terminology needed to be changed from suiting an American population to suit an Australian sample. Table 2.2 shows that these changes were minor, but they were nevertheless important. In terms of ethnicity in Australia, it was essential to ask whether the family was of Aboriginal descent. In terms of employment status, 'public assistance pay' was equated to 'Centrelink' in Australia. Changes were also associated with education and terms such as 'year 12', 'university', 'TAFE', and 'honours' were used for the Australian sample.

Table 2.2 *Modifications to Demographics Section of Beach Center FQOL Scale*

Original Beach Center Scale - American Samples	Modified Beach Center Scale - Australian Samples
Are you of Hispanic or Latino origin?	Are you Aboriginal/ Torres Strait Islander origin?
What is your race? American Indian or Alaskan Native Asian or Pacific Islander Black or African American White	*What is your cultural background?* Australian, English, Asian, Italian, Greek, German, Other
What is your marital status?	
Married/ Living with someone	Married/ De facto
What is your employment status?	
Not employed (for example, stay-at-home parent or care-giver, retired, public assistance pay, disability)	Not employed (for example, stay-at-home parent or care-giver, retired, Centrelink pay, disability)
What is the highest level of education that you have completed?	
Formal schooling but no high school diploma or GED -- High school graduate (diploma or GED) Some college or other post-high school, but no degree Associate degree (AA, AS, etc.) Bachelor's degree (BA, BS, etc.) Graduate Degree --	Formal schooling but no high school (only primary school) Some high school but not completed High school graduate (Year 12 or equivalent) Some University/ TAFE/ other post-high school/ no degree TAFE Certificate Bachelor's Degree Graduate Degree (e.g. Honours or other Higher Degree) Doctorate degree
What is the nature of your family member's PRIMARY disability?	
Mental retardation	Intellectual Disability (cause unknown)

2.3.3 Comparing Measures

Chapter 1 has provided an overview of literature that has compared the FQOLS-2006 and the Beach Center FQOL Scale at face-value. Upon initial examination of the two surveys (i.e. without considering the actual data) it is clear that there are differences in the presentation, design and methodology of both surveys. The Beach Center Survey is much shorter, consisting of only quantitative questions and the FQOLS-2006 is longer, with both quantitative and qualitative questions. Furthermore, the Beach Center Survey is not structured in sections/ domains like the FQOLS-2006. A small sample of participants ($n = 15$) in the current study were interviewed using both surveys and data were analysed to evaluate similarities and differences between the two surveys. The overall outcomes of the study comparing the two measures (presented in the following chapters) resulted in suggestions for revisions to these measures and / or for the development of future FQOL measures. Chapter 4 provides an overview of the basis for conducting this research with the two surveys in South Australia and a thorough analysis and presentation of these results can be found in the book chapter (see Chapter 4).

2.3.3.1 Internal Consistency of FQOL Surveys

Based on 42 participants who completed the FQOLS-2006 in the current study, Cronbach's Alpha was found to be low to moderate across the six concepts for the FQOL domains. Specifically, Importance = .24, Attainment = .69, Opportunities = .79, Stability = .45, Satisfaction = .82, Initiative = .48. The reason for the low Cronbach Alpha value associated with Importance was because all FQOL domains were already shown to be important to families that have a member with a disability in the development of the survey. This meant that there was very little variability between the importance scores

across domains. Arguably this item could therefore be removed from the survey except where there was a specific reason for assessing importance, as discussed in Chapter 4 (see Chapter 4, section 4.7.4). In addition, the lower Cronbach Alpha for the Stability concept was the consequence of little variability in scores for Stability. This supports the theme often found in research involving families that have a member with a disability; that is, apprehension and uncertainty for the future. Many participants in the current study indicated that they simply "do not know" whether certain aspects of family life will improve or decline, particularly with respect to support from services.

From the 24 participants in the current study who completed the Beach Center FQOL Scale, Cronbach Alpha was found to be high for the two measurement concepts that were included in the scale – Importance (.69) and Satisfaction (.88) – for the 25 survey items. These results are consistent with those reported by Hoffman, Marquis, Poston, Summers, and Turnbull (2006), who found reliability to be .94 for importance and .88 for Satisfaction. This indicates that the survey measures elements of FQOL as intended.

2.3.4 Other Materials

The other materials necessary for the implementation of this research were Information Sheets for participants and Consent Forms for participants to provide authorisation that they wished to participate in the research (see section 2.4.1 Ethical Considerations and Appendices B and C). Following participant's verbal consent and permission, all interviews were voice recorded in order to later obtain further details, confirm any missing information from the written notes during interviews, and retrieve verbatim statements. This also proved useful to ensure that interviews did not take longer

than they should as result of the interviewer taking time to write complete notes during interviews.

2.4 Procedure

2.4.1 Ethical Considerations

Prior to commencement of data collection for this study, the research proposal was approved by the University of Adelaide, School of Psychology Human Ethics Subcommittee and by the Chair of the research committee of the DSP-SA. The research proposal was accepted, and all ethical essentials were adhered to throughout the course of this research. This included, providing research participants with an information sheet (see Appendix B) detailing the research and the nature of the study, as well as providing details of who to contact should participants require further assistance. It was also important to indicate that the research would have no known adverse effects on its participants; to obtain informed written/ signed consent (see Appendix C) from all participants; and to ensure that the participants had the freedom to withdraw from the study at anytime, and that they were aware of the confidential and voluntary nature of their participation. In addition, should the participants have raised any significant issues of concern about themselves or their families, they could be referred to appropriate services. Moreover, the number for DSP- SA was provided for any personal concerns about disability – related services, living conditions or previous stress that may have arisen as a result of participating in this study. Whilst there were no issues of this nature during the current study, it was important to have these ethical procedures in place given the potential for sensitive family related issues to be raised during the interviews.

For the current research additional ethical considerations included: making sure that data were stored in a secure location and that only the researcher had access to it, as

well as ensuring and maintaining the safety of the researcher during visits to family homes to conduct interviews. This involved taking recommended precautions[5] for interview studies in people's homes, such as, always carrying a charged mobile telephone; avoiding interviews taking place in the kitchen or in locations where there are potentially dangerous instruments, such as knives; and not parking in the driveway because other cars may block the interviewer, making it impossible to depart in case of an emergency. In the present study, no issues related to the safety of the interviewer occurred during any of the interviews. However, given the random nature of recruiting participants and the fact that participants were not screened prior to participation, researchers must be mindful of these precautions.

2.4.2 Recruitment Organisation – Disability Service Provider in SA (DSP-SA)

The South Australian government's generic disability service provider (DSP-SA) assisted with recruiting participants. This organisation provides a range of specialist services to people with disabilities and their families, and funds other organisations that provide support to people with a disability. It also leads strategic planning, the development of policies, and resource allocation throughout the disability sector in South Australia (Government of South Australia, 2009). Services are provided to approximately 12,000 South Australians with a disability and their families. These services include: service coordination; aboriginal inclusion, exceptional needs, independent living, continence resources, social, recreation and support groups, as well as disability specific or age specific information. Prior to assisting with contacting potential participants, staff members from the DSP-SA supported this research by contributing to two focus groups

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[5] These precautions were outlined at a Postgraduate Induction in the School of Psychology at The University of Adelaide for commencing PhD students. I wish to acknowledge that these precautions were developed by the School of Psychology Occupational Health and Safety Officer, Lynda Klopp.

and they assisted in facilitating a pilot study, as outlined in the next sections of this chapter.

2.4.3 Focus Groups

Two focus groups with staff from the DSP-SA were conducted to discuss the aims and suitability of the project. The staff members who were involved included, a Project Officer, the Manager of Early Childhood Services, a Team Coordinator, an 'Options' Coordinators, and Social Workers. Regional Managers were also consulted about the project, and they assisted with the pilot study (outlined in the next section of this chapter). These focus groups came together on two occasions approximately one month apart. Both focus groups were tape recorded (with participants' permission) and noted. The intention of the first focus group was to introduce the research proposal and the background details of the international study using the FQOLS-2006. This also included highlighting the importance of the research given that families were becoming increasingly responsible for the care of their family member with a disability and it was important to explore the impact that this has on the family as a whole. Benefits to participants, such as the overall aim of improving services to their family, and the fact that results would contribute to international data on the newly established research topic of Family Quality of Life (FQOL) were also outlined. Discussions took part about ideas for the implementation of the study, based on the experiences of DSP-SA staff members working with families. The FQOLS-2006[6] was also distributed to participants at the first focus group. Some important questions and opinions expressed by staff members are

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[6] At the time of these focus groups – the beginning of this research, the researchers did not yet have access to the Beach Center FQOL Scale and there were no existing plans to use the Beach Center Scale as yet. Therefore the focus groups were only consulted about the FQOLS-2006.

stated below. These points were consistent with the research literature, as detailed in Chapter 1 of this thesis.

- Which age groups would be included in the study? Staff members indicated that it is important to gain a lifespan perspective, because family life can be different at different times in the child's life and when the member with a disability is at different developmental stages.

  [The researcher agreed to have as many participants as possible and to invite participants of any age group, including early childhood and aged carers]

- Will participants be asked about what was life like before the child was born? Or how has family life changed over the years? Many families have claimed to these staff members that their family was coping well before the child with a disability was born and now they are not coping so well.

  [The researcher added questions about family life in the past to each domain of the survey]

- Will data only be collected in metropolitan Adelaide or will families from rural South Australian regions be invited to participate as well? Staff members suggested that it would be good to compare FQOL of people from the two areas (metropolitan and rural). In the staff members' experiences, people living in the country are most likely to be willing to participate in the research, and they express more of a sense of community than metropolitan residents.

  [Assessment of rural families was not feasible within the scope of this study because of issues related to the time required and cost of travel and accommodation associated with interviews in rural areas]

- Would the primary researcher (author of this thesis) be conducting all interviews? Will the FQOLS-2006 be administered face-to-face, or will the researcher at least be present whilst participants complete the survey? This was considered important for consistency in the interviewing and the quality of the data to be obtained. [The researcher agreed to undertake all interviews face-to-face, unless the response rate was excessive, or if participants asked to self-administer the survey]

- Depending on the response rate, if the primary researcher personally did not have sufficient time to conduct all interviews, the suggestion was made that it might be possible to train other people in various locations and from various agencies (e.g. rural locations) to administer the survey. [This was not feasible or necessary within the scope of this study]

These questions and comments were taken into consideration by the researcher and new proposals were brought to the second focus group. For example, several possible additional questions to the FQOLS-2006 were proposed, based on the suggestions of the previous focus group participants. After each staff member/ focus group participant had thoroughly assessed the FQOLS-2006, including sampling it on their own family life, there were further concerns and comments expressed and these were then discussed at the second focus group. A summary of these concerns and comments, and the actions taken in response to these follows.

- As outlined in section 2.3.1, during the focus group meetings, the manager of Early Childhood Services and DSP-SA staff members agreed that an altered version of the FQOLS-2006 was necessary for use with families with members under the age of six years, to account for the early provisional diagnosis of

"developmental delay". This was because children below the age of 6 years who appear to be delayed in intellectual development mostly have not yet been identified as having an *intellectual* disability because of difficulties associated with assessing it accurately at such early ages. Since it was the draft version of the FQOLS-2006 that was presented at the focus groups, the researcher and manager of Early Childhood Services collaborated on the changes that would be necessary for use with the early childhood group. However, as stated previously, this change was also later incorporated by the authors of the survey who added the words "intellectual *or developmental disability*" throughout the survey. The manager then confirmed that this change in wording took into account the early provisional diagnosis of "global developmental delay", for families with young children.

- One staff member at the second focus group expressed the concern that family members would decline to participate because they would not be able to see any direct benefits to their families. Consequently, the following statement was included under the heading of 'Benefits' on the Information Sheet (see Appendix B) provided to participants: *"Whilst outcomes of this study may not be of direct benefit to you or your family, your contribution is valuable and it is expected that results will contribute to improving service provisions and support available to families with member(s) who have an intellectual/ developmental disability.".* It was also verbally explained to participants when they were phoned and invited to participate that their contribution is important to gain a consensus from as many South Australian families as possible, and to be able to report group results related to particular FQOL matters.

- Staff members also expressed a concern that some families may have been contacted several times to participate in various research projects and may no longer be interested or may have become overwhelmed with being invited to participate in similar projects. Staff members stated that there was a need to be cautious that the current research did not clash with other research. For example, at the time of commencement of the current study, there was another larger scale study underway, inviting all DSP-SA clients to participate. Therefore, focus group participants recommended that in order to consider not overloading, confusing or inconveniencing family members and to ensure a better response rate, it would be a good idea to liaise with other researchers who were using the DSP-SA client database to recruit participants for their research. The current researcher/ thesis author accepted this advice and collaborated with a researcher evaluating the relationship between time spent caring and the psychological, social and physical well-being of parents of pre-school children with developmental delays (Crettenden, 2008). Even though Crettenden's research was only being conducted on the Early Childhood group, it was still necessary to ensure that there was no overlap. This meant commencing the current research in the region that Crettenden had not yet used for recruiting her participants. The current researcher and Crettenden also established the appropriate procedures for contacting participants (as outlined in section 2.4.5 Process of Recruiting Participants).

Further additional questions asked and opinions expressed by staff members at the second focus group included:

- Would the research include various languages and cultures? Staff members stated that the largest group of non-English speaking people on the DSP-SA client database were of Vietnamese background. The survey had been translated into various languages (not including Vietnamese), but there was a risk that people of non-English speaking backgrounds in South Australia might misinterpret the questions.

- How culturally appropriate is this research and the FQOLS-2006 for Aboriginal families? In the opinions of the staff present at the focus groups, research with these families would need to be approved by the Aboriginal ethics committee, and significant alterations may be needed. In addition, most Aboriginal families live in rural South Australia, and due to the exclusion of rural participants it was likely that the current study would have had an under representation of Aboriginal families.

All members of the focus groups agreed that the research would be worthwhile and beneficial, and that the outcomes could be used to advise service providers. The ideas that arose from these focus groups and were considered feasible within the scope of the current study were incorporated in the research. For example, supplementary questions were added to the FQOLS-2006 to encompass the feedback from the DSP-SA staff members. These additions have been detailed in section 2.3.1.1 of this chapter. Unfortunately there was insufficient time, money and resources for travel and accommodation of the interviewer to include families from rural locations in South

Australia or those with non-English speaking or Aboriginal backgrounds. However, the thesis author recognises these as important areas for future research to address, as discussed in the final chapter of this thesis (see Chapter 5).

2.4.4 Pilot Study Using FQOLS-2006 and Training of the Interviewer

A pilot study was conducted in order to assess the appropriateness of the research methods and design. Pilot participants were selected specifically by two regional managers of DSP-SA. Seven families were approached because they were likely to be interested, available and able to contribute constructive critical feedback on the FQOLS-2006, the FQOL topic, and the interviewing technique. Three of those family members replied to the regional managers and agreed to participate. Therefore the response rate for the pilot study was 42.9%. There was also a fourth opportunistic pilot study participant, drawn upon from the researcher's family network, who provided an example for self-administered interviews.

As a result of discussions between the thesis author, the supervisory panel, and the previous FQOL researcher in South Australia, it was considered useful to have the previous researcher, who had conducted similar research in 2002 (J. Shearer, 2002) with the previous version of the survey (FQOLS-2000), model the first pilot study interview to begin the study. Shearer aimed to demonstrate how to manage any difficulties that may arise during interviews, such as misinterpretations or clarifications of the survey questions, as well as to demonstrate professional interview techniques directly to the current researcher/ thesis author. The previous researcher, who is also one of the authors of the FQOLS-2006, has extensive experience in interviewing a variety of families, is very familiar with the topic of FQOL, and has considerable knowledge of the content and questions of the FQOLS-2006. In addition, when she commenced conducting her FQOL

research in 2000, she had also first observed a more senior researcher administering the survey as an interview, and therefore she had learnt from demonstration how to conduct the interviews and manage any difficulties that may arise. This training and observation process was useful to increase new researchers' personal confidence and awareness of self-care issues when conducting interviews. For example, the current researcher was able to learn to be mindful of not becoming anxious or distressed by adverse responses or emotional stories from respondents, whilst still displaying empathy and understanding but without turning the interview into a counselling session.

Another benefit of this modelling procedure was to test inter-rater reliability and to ensure consistency and reliability in terms of administration of the interviews and in data collection. For the first two interviews in the pilot study the previous South Australian FQOL researcher and the current thesis author both wrote notes and filled out the FQOLS-2006 during the interviews. Both researchers consistently marked the same responses throughout the FQOLS-2006 (inter-rater reliability = 100%). Both the previous and current researchers had also recorded similar comments. This also displayed consistent interpretation of what the participant had said, and it confirmed the ease of use of the FQOLS-2006 for researchers using it in an interview format.

The process, methodology and outcomes from the four pilot interviews are outlined in Table 2.3 and in the information following the table.

Table 2.3 *Pilot Study Particulars*

Case Number	Interviewer	Time Taken to Complete
1	Previous Researcher – observed by current researcher	2 hours 10 minutes
2	Current Researcher – observed and guided by previous researcher	2 hours 17 minutes
3	Self-administered opportunistic – researcher not present	52 minutes
4	Current researcher independently	3 hours 13 minutes

The following four questions were asked at the end of the pilot interviews:

1.) Did you feel comfortable answering all the questions asked of you? Why/ why not

2.) Did you feel that the survey covered all elements of your FQOLS? Why/ why not?

3.) Do you have any suggestions or recommendations for anything else that the survey

needs to include?

4.) Was there anything from the FQOLS-2006 that you felt was particularly irrelevant to

your family?

Respondents indicated that they were comfortable with the questions, and that they were

provided with the opportunity to discuss all features of their family life that they

considered essential to QOL. As evident by the participants' qualitative information

provided in interviews, the open questions at the end of each section/ domain were

especially useful so that participants could 'tell their story'.

The pilot study also provided an indication of how long interviews using the

FQOLS-2006 would take. As can be seen in Table 2.3 self-administering the survey was

considerably shorter, and the average time taken for interviews was 2 hours and 45 minutes. However, the length of these pilot interviews can also be attributed to the fact that it was essential to introduce the pilot study and, in particular, explain why there were two researchers present. A general conversation introducing the survey took place at the beginning of each pilot interview so that both researchers were in agreement, as well as to establish rapport with the interviewee who may have otherwise felt intimated by having two researchers present. The information sheet had previously specified that interviews would take one hour and so this had to be changed to "approximately two hours". In addition, it was noted by the third pilot interview, that some degree of discipline with additional conversation and interjecting questions needed to be put in place, because otherwise interviews could take much longer than anticipated. Consequently, the current researcher also developed a short introduction to use at the beginning of interviews if necessary, *"Please answer each question specifically and try to leave your extra comments to a minimum. You will have the chance at the end of each section to elaborate a little more on the topic."* This was designed to ensure that there was sufficient time to respond to all sections of the FQOLS-2006 within the designated time frame for interviews.

Another conclusion from this pilot study was that there was much less quality detail obtained in the self-administered interview. Although the participant selected a response option to all survey questions that provided quantitative rating options, most of the open questions throughout contained only one or two words with no elaboration. The final section of the survey about 'overall FQOL', which contained four open questions consecutively, did contain slightly more information in the form of a sentence, and this confirmed the usefulness of these final qualitative questions, especially for self-

administered surveys. It was therefore concluded that, wherever possible, data collection for this survey should be in the form of an interview. Further information and justification for this approach are outlined in the following chapters of this thesis and in the section 2.4.7 Interviews (setting, location, and environment).

One of the issues that arose in the very first interview was how to define 'family'. This concern was also anticipated by previous researchers (see Chapter 1 of this thesis). In the first section of the FQOLS-2006 there is an introduction, which states: *"Around the world people think of families differently. When completing this survey, we ask you to think of your immediate family – those people who are closely involved in the day-to-day affairs of your household. Family members may be related by blood or by close personal relationship."* It proved to be important to reiterate this in the first interview because the participant questioned in the financial well-being section: *"are you just asking talking about the four of us who live here or all six [including offspring who had moved out]"?* The current researcher also observed and noted the importance of the interviewer not making assumptions or providing leading statements during interviews. For example, in response to the above question, the previous and experienced FQOL researcher stated *"this is up to your interpretation of who you consider to be your family"*. At another point in the interview, when asking for a rating to one of the questions in Section B of the survey, the respondent continued to provide qualitative explanations. Rather than making her own decision based on the respondent's comments, the interviewer drew the participant back to the quantitative options by stating, "which option fits for you?" and "which option would you like to select?"

Results from the pilot study also confirmed the need to divide practical and emotional support from other people because these forms of support are acquired at

different levels. The published version of the FQOLS-2006 asks about these two combined into a single question. However, as one pilot participant explained, *"its [support from others] somewhat [important] because most of it I have to do myself... Emotionally it's [all] me... I do get occasional practical help... accepting it is a problem".* Further details about the distinction between practical and emotional support are presented in Chapter 3.

The main additional comments from participants during discussions in the pilot interviews were associated with how circumstances had been different for the family in the past. For example, *"David[7] [member with disability] was destroying the family when he couldn't talk he would scratch and kick and bite... absolutely paralysed the whole family..."* and *"Jim's [member with disability] behaviour... affected all of us, so we all had to have the ability to bring him in to control... we had to teach them [siblings of member with disability] to use it [behaviour modification] at a very very early age, so that [Jim] didn't destroy everybody... and the boys [siblings of member with disability] now use it [behaviour modification] on their own children so consequently their own children are beautifully behaved".* Therefore, as a result of the member with a disability's behavioural concerns approximately 24 years prior to this pilot interview, family life was now far more harmonious for everyone. One pilot participant also expressed concerns for the future, and all mentioned significant life/ family events that resulted in changed FQOL, such as the death of an extended relative who had provided significant support in the past. As stated previously and as outlined in upcoming chapters, there are existing FQOLS-2006 questions (i.e. 5a. 5b. of Section B) in every topic about

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[7] In order to protect the confidentiality of participants, pseudonyms have been used to replace actual names in all direct quotations when reporting results.

perceptions for the near future (stability), but there are no questions that ask about family life in the past. Accordingly, conclusions from the pilot study also indicated the need to add some questions about the past (see Chapters 3 and 4 for further detail).

One final outcome of the pilot interviews was that in the Support from Disability-Related Services Section A, Questions 1 and 2 (see Appendix D for the FQOLS-2006) ask about services that are *available in the area* and services that members of the family *have used*, respectively. The 29 options provided (e.g. service coordination, paediatrician, behavioural support, etc.) are repeated for both questions, and it was found useful to ask about 'availability' and then 'use' together (i.e. each of the stated options in turn), as opposed to going through whole list twice.

The current researcher was able to use the pilot study interviews as a guide for the study proper. All of the abovementioned factors were considered and changes were implemented accordingly, and then the remaining interviews could commence. Since there were no major alterations or differences between the pilot survey and the survey used in the study proper, the data from the pilot study respondents could be used in the study proper.

2.4.5 Process of Recruiting Participants

Following ethics approval, various meetings, focus groups and the pilot study, each region of DSP- SA was contacted one by one, commencing with the Western region. A liaison person (usually a social worker) from the DSP-SA at each regional office was nominated to work with the researcher in contacting prospective participants from their client database on a random basis. This liaison person first sent out an initial letter, along with the information sheet of the study (see Appendix B). The letter introduced and endorsed the study to potential participants and informed them that they would receive a

telephone call from the DSP-SA staff member soon. The information sheet detailed the study further, and provided information such as, the aims and benefits of the study, that participation was entirely voluntary and confidential, the estimated time interviews would take, as well as the contact details of the researcher and ethics committee that had approved the study. Potential participants were not required to take any action on that initial letter. The staff member then telephoned the nominated family a few days after letters had been sent firstly to confirm that they had received the letter and then to ask interested people for permission to pass their telephone number onto the researcher. The DSP- SA worker was not required to take any further action, other than ask for this permission to release telephone numbers – further questions about the study and a formal verbal invitation to participate were handled by the researcher. Once permission was obtained, the researcher called the family and explained the study further, and then invited them to take part, and to nominate who they considered to be the main caregiver of the person with a disability in their family. The family members who were contacted by the researcher still had the right to decline this invitation to participate and they were informed that they were free to withdraw at any stage. However, almost all participants who had given permission for their telephone number to be passed on agreed to participate. Those who declined to participate mostly provided the reason that they had too many time restraints or that it was a stressful/ inconvenient time. This procedure, as summarised below, was considered necessary in order to maximize the response rate for this type of study, which may have been considered to be too personal and addressing sensitive issues, or too time consuming for carers who may already be under many time pressures (Crettenden, 2008). For family members who agreed to participate, a mutually convenient time and location (the participant's home where possible) was arranged for

the researcher to administer the survey as an interview. As stated in the ethical considerations section of this chapter (see section 2.4.1), all safety concerns associated with home interviews were always followed by the researcher when undertaking interviews. The 'Interviews (setting, location, and environment)' section of this chapter outlines details associated with the setting of the interviews (see section 2.4.7). There was only one interviewer (the primary researcher/ thesis author) responsible for administering all interviews, to enhance validity and to limit researcher bias or inconsistent responses as a result of different interviewing techniques.

Summary of recruitment procedure:

1.) DSP- SA worker selected families randomly from their database.

2.) DSP- SA worker posted out cover letter and information sheet.

3.) DSP- SA worker telephoned potential families asking for permission to release their phone number to the researcher.

4.) Researcher telephoned families and explained the study further then invited participation.

5.) A mutually convenient time and the location for the interview were arranged.

2.4.6 Response Rates

For research of this nature, and considering the time needed for interviews, the number of family members who agreed to participate was encouraging, relative to the number of people who were invited to participate. Overall 166 people were contacted and 59 agreed for their telephone number to be passed on to the main researcher (35.5%). Of those 59 approached by the researcher, 53 interviews took place (89.8%). Further information regarding the breakdown of this response rate for each region of Adelaide is provided in Table 2.4.

Table 2.4 *Response Rates for Each Region of DSP- SA*

Region	Number of letters sent to potential participants	Number of people consenting to releasing their telephone number	Response Rate
West	55	20	36.4%
North	28	12	42.9%
Early Childhood Services North	63	15	23.8%
South[8]	20	12	60%

Because the Western region of Adelaide was the first region to commence recruiting participants, the researcher and the DSP-SA staff member discussed the process of contacting families (Oudshoorn, 2006). The staff member explained that recruitment of participants involved filtering through all families on the database (approximately 800 to 900 clients for the Western region). It was also noted that elderly carers were less keen to participate, because they may not have realised exactly what was involved with the interview, or they had their adult child with a disability living at home with them; therefore it was not feasible to participate. Consequently, the sample obtained consists of only a small number of aged people with disabilities. In order to ensure that the sample is representative, this population should be purposefully sampled. Recruiting of participants in the following regions ensured that any concerns about participation expressed by elderly carers had been adequately addressed.

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[8] In the Southern region, the DSP-SA staff member who was originally contacting potential participants went on leave. Therefore, another staff member was nominated to continue the process. The first liaison person had not kept detailed records of whom she had contacted. Consequently, the response rate for this region has been estimated.

2.4.7 Interviews (Setting, Location, and Environment)

All interviews in the current study were conducted in the family home (as opposed to an interviewer's office or interview room). This was so that participants could feel as comfortable as possible, and it lessened the inconvenience of participant's needing to travel to the interview location. In approximately 40% of cases for the current study the family member with a disability was home during the time of the interviews. This was good because, when the participant was describing the level of communication of the member with a disability, the researcher was able to observe the member with a disability communicate throughout the course of the interview. In addition, the researcher informally assessed the overall quality of the living environment of the family. This was rated by the researcher as low – defined as 'poorly maintained' (16%); moderate – defined as 'well maintained' (41%); or high – defined as 'immaculately maintained' (27%). In 16% of cases this process did not apply because surveys were self-administered or interviews were conducted over the phone.

The following chapter presents results associated with using the methodology described in this chapter. It consists of a paper submitted for publication as a journal article, which details the use of the FQOLS-2006 in South Australia. It provides an overview of the main caregiver's perceptions of their FQOL and discusses important issues pertaining to measurement of FQOL, such as asking about practical and emotional support from others separately. The results that will be presented also describe disadvantages to considering mean quantitative results in isolation from qualitative explanations from individual participants. The following chapter also demonstrates that families were generally satisfied with all domains of FQOL; however, they were more

satisfied with Family Relationships than they were with their Financial Well-being. The use of the Beach Center Scale and results associated with the data obtained, as well as a comparison of the two surveys are outlined in Chapter 4 of this thesis.

Chapter 3:

Intellectual Disability and Family Quality of Life in Australia: An overview of

caregiver perceptions.

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Statement of Authorship

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Fiona Rillotta (Candidate)

Performed the research work associated with this paper; including study set up, data collection, analysis on samples, interpreting data, writing of the manuscript and acting as corresponding author. Fiona Rillotta contributed 80% of the work for this article.
I hereby certify that this statement of contribution is accurate

Signed   *Date   19/10/10*

Neil Kirby (Co-author)

Supervised development of research work, contributed to planning of the article and provided critical evaluation and editing of the article to the amount of 10%.
I hereby certify that this statement of contribution is accurate and I give permission for the inclusion of this paper in the candidate's thesis

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Contributed to the editing of the final draft of the article to the amount of 5%.
I hereby certify that this statement of contribution is accurate and I give permission for the inclusion of this paper in the candidate's thesis

Signed   *Date   19/10/10*

Ted Nettelbeck (Co-author)

Contributed to the editing of the final draft of the article to the amount of 5%.
I hereby certify that this statement of contribution is accurate and I give permission for the inclusion of this paper in the candidate's thesis

Signed   *Date   19/10/10*

Chapter 3: Intellectual Disability and Family Quality of Life in Australia: An overview of caregiver perceptions (Paper submitted for Publication).

3.1 Key Words

Family Quality of Life, practical and emotional support, Australia, caregiver perceptions, FQOLS-2006

3.2 Abstract

Background. Family Quality of Life (FQOL) is a recent concept in intellectual/ developmental disability research. Outcomes for the family are important to the provision of services because families, rather than institutions, are increasingly considered the primary care unit. This article presents Australian findings using the international measure *Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities* (FQOLS-2006; I. Brown et al., 2006), to assess the quality of life of families who have a member with an intellectual/ developmental disability. *Method.* Forty-two main caregivers of people with an intellectual/ developmental disability in South Australia were interviewed using the FQOLS-2006. The FQOL domains assessed were Health, Financial Well-being, Relationships, Support from Others, Support from Services, Values, Careers, Leisure and Recreation, and Community Interaction. These domains were measured in terms of Importance, Opportunities, Attainment, Initiative, Stability, and Satisfaction. Questions about practical and emotional support from other people were separated, and questions about the past were added.

Results. Results indicated that families considered all the FQOL domains to be important. However, Health, Family Relationships and Financial Well-being were regarded as slightly more important than other areas such as Practical and Emotional Support from Other People. The attainment of Family Relationships, Health, Values and Leisure were rated as "quite a bit", but Practical Support from Others was only rated as "a little". Families were generally satisfied with all family life areas, but they were "satisfied" with their Family Relationships and they were "neither satisfied or dissatisfied" with their Financial Well-being. Results also indicated that there was a need to distinguish between the provision of practical and emotional support within the Support from Other People domain, because the attainment of emotional support was rated at a slightly higher level than practical support.

Conclusions. This study found that the FQOLS-2006 provided a comprehensive measure of FQOL, which, with some additional modifications, could be used to better inform service provisions and ultimately enhance the QOL of people with intellectual/ developmental disabilities and their families.

3.3 Introduction

Although Quality of Life (QOL) has been researched widely in the human services since the early twentieth century, it is only over the past few decades that there has been a growing interest in QOL in the disability field. QOL encompasses objective and subjective measures concerning life domains such as an individual's health, financial situation, emotional state, vocational pursuits, social involvement, recreation, interpersonal relationships, and personal values and potential (I. Brown, Brown et al., 2000; Schalock, 2004a; Schalock et al., 2002; Verdugo, Schalock et al., 2005). Core QOL domains in the disability field also include the availability of and access to supports; both

formal, like disability service providers, and informal, like extended family and friends (I. Brown et al., 2006; R. I. Brown et al., 2006; Isaacs et al., 2007; Schalock, 2004b; Summers et al., 2005).

The concept of Family Quality of Life (FQOL) has recently been recognised as an important extension of QOL in the field of intellectual/ developmental disability (e.g. Aznar & Castanon, 2005; Davis & Gavidia-Payne, 2009; Hoffman et al., 2006; Isaacs et al., 2007; Jokinen & Brown, 2005; Poston et al., 2003; Schippers & Van Boheemen, 2009; A. P. Turnbull et al., 2004). See Samuel, Rillotta and Brown, this issue, for a review of QOL/ FQOL literature. The importance of FQOL came from an awareness of the increasing numbers of people with an intellectual/ developmental disability who were living at home, with family members playing a central role in supporting them, and the realisation that an individual's environment, including their family environment, contributes significantly to their QOL (I. Brown & Brown, 2004b). Therefore families are seen as a significant social resource (Burton-Smith et al., 2009a; Isaacs et al., 2007; Llewellyn, Thompson et al., 2003; Zuna, Turnbull et al., 2009).

Additional domains in FQOL research have included, Parenting (e.g. taking care of every child in the family, and helping children to make friends) (Beach Center on Disability, 2003; Hoffman et al., 2006); and Family Interaction or Family Relationships (e.g. harmony within the family unit – support, trust, and companionship). These domains, along with the abovementioned QOL domains, form the basis for conceptualising, measuring and applying FQOL. Park et al. (2003) defined FQOL as the opportunity for families to have their needs met, to enjoy life together, and to engage in things that they consider important. Family-centred approaches to service provisions focus on supporting and empowering families as a whole (I. Brown & Brown, 2004b;

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Dempsey & Keen, 2008). A Canadian study (I. Brown et al., 2003) found that families placed more emphasis on immediate (internal) family relationships and supports than on extended family (external) supports. Families commonly received very little practical support from other people (excluding service providers); however, there was more variation in the emotional support they received (I. Brown et al., 2003). Research of this kind has not been conducted in Australia and, in fact, there has been relatively little FQOL research in Australia.

From an Australian perspective FQOL is relevant to current disability legislation, policy, and practice. There are over 500,000 people with an intellectual/ developmental disability in Australia (approximately 3% of the population) (Australian Institute of Health and Welfare (AIHW), 2008). Over recent decades there has been a wider acceptance of people with disabilities in the community, together with increased pressure on families to care for their child or children with a disability at home, rather than placing them in institutional settings (R. I. Brown et al., 2004). For example, in 1998, the majority of people with an "intellectual impairment" in Australia lived with their parents (49%), or in supported accommodation (22%) (Australian Bureau of Statistics (ABS), 1998). More recent statistics have indicated that, 76% of people with disabilities (all types) live with family, with about 18% living on their own (Department for Families and Communities, 2007).

The Australian Disability Discrimination Act 1992 and the Disability Services Act 1986 (Commonwealth of Australia, 2007, 2009) are similar to those of other developed nations, and were intended to enhance QOL by ensuring that people with disabilities have the same rights as other people to access all aspects of society. In Australia this has led to people with disabilities and their families being given more

control over their lives (R. I. Brown et al., 2004). In particular, people with disabilities now have more access to, and participation in, education and vocational programs, in less restrictive environments. At the same time, however, these changes have, in some cases, significantly affected the whole family of the person with a disability. It is therefore important for services to acknowledge associated personal issues of all family members and their collective impact on FQOL (R. I. Brown et al., 2004).

In Australia, as in other countries, there have been changes in the structure of families. For example, from 1996 to 2006, couple families with children decreased; couple families without children increased; and single parent families also increased (ABS, 2001, 2006). This means that what constitutes or defines "family" is open to interpretation and changes over time. However, in spite of such diversity, families across societies are consistently expected to nurture children, to financially support their members, and to transmit cultural and moral values (Australian Institute of Family Studies et al., 2009). The changing nature of families and society makes it important to research the FQOL of families that have a member with an intellectual/ developmental disability in Australia.

Only a few studies in Australia have explored particular aspects of FQOL in the intellectual/ developmental disability field (R. I. Brown et al., 2004; Browne & Bramston, 1996; Burton-Smith et al., 2009a, 2009b; Davis & Gavidia-Payne, 2009; Skok, Harvey, & Reddihough, 2006). The earliest of these studies (Browne & Bramston, 1996) found that life priorities (i.e. what was considered important) did not differ between families having a member with an intellectual disability and families without a member with an intellectual disability. However, families having a member with an intellectual disability reported lower levels of satisfaction with QOL than those without, particularly

in the areas of material well-being, health, and productivity (Browne & Bramston, 1996).

More recently, Burton-Smith et al. (2009a) have presented Australian results from an

international, multi-centre investigation of burden of care, mental health and life

satisfaction. They found that people caring for a family member with a disability reported

levels of well-being and general health that were lower than the norm. However, carers

did not consider care giving as burdensome (Burton-Smith et al., 2009a). In their study,

Burton-Smith et al. assessed the circumstances of the primary caregiver, rather than

considering FQOL as a whole.

Skok et al. (2006) and Davis and Gavidia-Payne (2009) found that Australian

parents of children with an intellectual/ developmental disability (school-age and early

childhood respectively) who received significant social support, experienced lower levels

of stress, increased levels of well-being, and better FQOL. These authors therefore

suggested that service providers needed to adopt a family-centred approach, including

involving the extended family to ensure that caregivers have adequate social supports in

place. Similarly, R. I. Brown et al. (2004) proposed that families often felt excluded from

society and community/ leisure/ recreation activities because of restrictions resulting

from having a member with an intellectual/ developmental disability. These authors

suggested that, if opportunities for friendship networks and supports were expanded, then

community supports for families would also grow. Furthermore, since friendships and

supports may change over time, new valued relationships may be made through

involvement in the disability sector with people who have had similar experiences (R. I.

Brown et al., 2004). R. I. Brown et al. also discussed families' concerns associated with

the relationship between the family and support staff from disability services. Davis and

Gavidia-Payne (2009) also explored this issue and found that, while family experiences

with service providers were generally quite positive, parents' perceptions of, and experiences with, services were significantly related to their satisfaction with FQOL. These findings suggest that family-centred professional support has a significant influence on FQOL.

While FQOL has been accepted as an important construct in disability, questions remain concerning the extent to which FQOL issues are similar in different countries and the extent to which existing measures of FQOL can be used effectively in different countries. The aim of the present study was therefore to investigate the FQOL of Australian families who have a member with an intellectual/ developmental disability, using the *Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities* (FQOLS-2006; I. Brown et al., 2006). This measure of FQOL was developed with the intention of being appropriate for use in different countries. The findings of the present study will contribute to cross-cultural comparisons, which will be presented in a separate paper in this special issue, evaluating the universal properties of the FQOLS-2006.

3.4 Methodology

3.4.1 Participants

Of approximately 150 people randomly selected from the South Australian government's main disability service provider client database, 42 agreed to participate (response rate = 28%). Even though the sample was random, it seems likely that those who agreed to participate may have been those who had the time, support in the home and interest in participating. Thus, the results may underestimate the family related difficulties and consequent FQOL of families having a child or children with a disability. A majority were mothers aged between 25 to 78 years. Family members with a disability

were aged from 2 to 46 years and a majority had an intellectual disability (cause unknown) or Autism Spectrum Disorder. All participating families were from metropolitan Adelaide, the capital city of South Australia. However, some families lived further from the central business district than others, and some were from wealthier suburbs and had higher social economic status than others. These demographic details are shown in the results section (Tables 3.1 and 3.2).

3.4.2 Materials

Face-to-face interviews were conducted using the FQOLS-2006 (I. Brown et al., 2006). Nine domains of FQOL were assessed (health, financial well-being, family relationships, support from other people, support from disability related services, influence of values, careers, leisure and recreation, and community interaction). These domains were measured using the concepts of Importance, Opportunities, Attainment, Initiative, Stability, and Satisfaction on a 5 point Likert scale. (For further details about the psychometric properties of this survey see Isaacs, et al., this issue). Based on information provided during the pilot phase of the current study, practical and emotional support from other people were divided into two separate measurable components, rather than dealing with them together as specified in the FQOLS-2006. Questions pertaining to FQOL in the past were also added to each domain (see Rillotta et al., in press). Participants were required to sign a consent form and they were provided with an information sheet about the study. With participants' permission, a voice recorder was used in order to obtain further information and verbatim statements.

3.4.3 Procedure

Ethics approval was obtained from the researchers' university and from the South Australian government's main disability service provider. An important ethical

consideration was to ensure the safety of the first author while conducting interviews at family homes (e.g. having access to cell phone). The use of the FQOLS-2006 in Australian was first discussed by two focus groups, each with four professionals working for the government's main disability service provider, and two regional managers were also consulted individually. Main concerns were, the need to use the wording 'developmental disability' for those in early childhood who do not receive the diagnosis of *intellectual* disability until after 6 years of age; to divide practical and emotional support from other people, because they could be attained at different levels; and to add questions about FQOL in the past, to gain more of a lifespan perspective. Study participants were recruited through the disability organisation which first posted out a letter. Staff then phoned prospective families to request permission to forward their phone number to the first author. Subsequently, the first author contacted families directly. Four pilot interviews were conducted to test the methods of inquiry, to gauge how long interviews would take, and to check for any concerns from participants. Results from the pilot study confirmed issues previously raised by the focus groups. In particular, the separation of practical and emotional support was confirmed when these participants were asked, *"Would you say the emotional support is different to the practical support"?* One participant responded, *"yeah it is… some people can handle helping you out if you need to go somewhere or you need to get something [practical support], and others are probably better for the emotional side of things… I guess that's why you'll ring a certain person for this and then you'll ring somebody else for something else because you know they're better at doing that"*. No further changes to the FQOL-2006 or to the study methodology were required. Interviews generally took between 1 to 3 hours and were conducted in three regions of metropolitan South Australia. A universal SPSS database

was used for data analysis, to enable cross-cultural comparisons with international data. Qualitative data were analysed into themes.

3.5 Results[9]

3.5.1 Descriptive Data

Table 3.1 displays the demographical characteristics of participants (main caregivers of people with intellectual/ developmental disabilities), and their family characteristics. Participants were mostly mothers and the majority were aged in their mid to late 40s. Approximately two thirds were part of two parent families. Seven families had more than one member with an intellectual/ developmental disability and each was engaged in different activities and had different levels of disability-related support needs, which impacted on overall FQOL in different ways. For example, one family had a member with an intellectual disability who was a Paralympics athlete, was studying through correspondence with tutor support, and did volunteer work. The other member with an intellectual disability in the same family was in her final year of school, and her mother expressed deep concern about what she could/ would do when she finished school. In another case a mother explained, *"they're very different; John, he's more laid back; if you were in a crowd he'd just stand back and watch, whereas Stephen, he goes in for the kill."*

Table 3.2 shows that the majority of family members with intellectual/ developmental disabilities were male and their ages varied from 2 to 46 years, with most in their late teens. The most common disability type was intellectual disability (cause unknown), followed by Autism Spectrum Disorder. All family members with disabilities

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[9] In order to protect the confidentiality of participants, pseudonyms have been used to replace actual names in all direct quotations when reporting results.

had a number of additional conditions. A little under half (46%) had five or fewer

conditions, and just over half (54%) reported six or more conditions. The most common

reported condition, for all except 10 people, was behavioural problems, followed closely

by speech and/ or language difficulties; just over half had mood/ expression/ anxiety

problems and just over half had general problems with motor control/ coordination. The

least frequently occurring additional conditions were severe psychiatric disturbances (e.g.

schizophrenia), and two people with a disability had heart problems.

Table 3.1 *Family Characteristics*

Gender of Respondent	
Male	4.8% (2)
Female	95.2% (40)
Relationship to member with ID	
Mother	88.1% (37)
Father	2.4% (1)
Grandparent	2.4% (1)
Sibling	2.4% (1)
Others (Foster Mother, Voluntary Carer)	4.8% (2)
Age of respondent in years	
Mean	47.2
Age range	25 - 78
Employment status of respondent	
Employed (full-time or part-time)	43%
Not Employed	57%
Family structure	
One Parent	31.0% (13)
Two Parent	66.7% (28)
Other	2.4% (1)
Number of siblings to member with disability	
One	33.3% (14)
Two	21.4% (9)
Three	21.4% (9)
Four or More	12% (5)
Families with >1 person with a disability	16.7% (7)

Table 3.2 *Characteristics of the Person with a Disability*

Gender	
Male	64.3% (27)
Female	35.7% (15)
Age in years	
Mean	17.3
Age Range	2 - 46
Type of Disability	
ID unknown	38.1% (16)
Autism	26.2% (11)
Down's syndrome	9.5% (4)
Developmental Delay	9.5% (4)
CP	4.8% (2)
Fetal Alcohol Syndrome	4.8% (2)
Rhett Syndrome	2.4% (1)
Others (cru du ca chat; sensory processing disorder)	4.8% (2)
Additional Conditions	
Behavioural	76.2% (32)
Speech/ language	73.8% (31)
Mood/ expression/ anxiety	59.5% (25)
Motor control/ coordination	59.5% (25)
Feeding/ eating	50.0% (21)
Sensory integration	47.6% (20)
Seizures	38.1% (16)
Vision	33.3% (14)
Gastro-intestinal	28.6% (12)
Asthma	19.0% (8)
Hearing	19.0% (8)
Severe psychiatric disturbances	14.3% (6)
Heart	4.8% (2)
Level of Disability Related Support Required	
Almost all aspects of life	9.5% (4)
Most but not all aspects of life	23.8% (10)
Some aspects of life	23.8% (10)
Only a few aspects of life	31.0% (13)
Does not require disability-related support	11.9% (5)
Level of Communication	
Very little meaningful communication	9.5% (4)
Basic needs and wants	26.2% (11)
Needs, wants, & some ideas in a meaningful way	21.4% (9)
Within limited range of topics in a meaningful way	33.3% (14)
About a wide variety of topics in a meaningful way	9.5% (4)

It can also be seen in Table 3.2 that there was a wide spread of disability-related support required, with nearly a third requiring support for "only a few aspects" of life and nearly a quarter requiring support for either "some aspects" or "most, but not all, aspects" of life. The question concerning level of disability-related support from the FQOLS-2006 was ideal for the Australian sample, because in Australia people with disabilities are described in terms of their support needs and not their disability severity level. Furthermore, Table 3.2 shows that the level of communication that best described the family members with a disability varied; one third were able to communicate "within a limited range of topics in a meaningful way", and just over a quarter were able to communicate "basic needs and wants". These results indicate that the sample was representative of people with a variety of conditions, support needs, and communication levels.

3.5.2 Family Quality of Life Measures and Reliability of the FQOLS-2006

Table 3.3 shows the mean scores and standard deviations for each measurement concept in each of the FQOL domains. The reliability of the FQOLS-2006 in terms of Cronbach Alpha was found to be moderate to high across the measurement dimensions, indicating good internal consistency. Qualitative explanations and common themes associated with these FQOL domains are discussed to provide a more in-depth understanding of the quantitative results. Practical and Emotional Support from Other People were assessed separately to evaluate any differences between them.

Table 3.3 *FQOL Domains and Dimensions*

Domains	Dimensions of Family Quality of Life (Mean and SD) Possible Score Range: 1 to 5					
	Importance	*Attainment*	*Satisfaction*	*Opportunities*	*Initiative*	*Stability*
Health	4.88 (.40)	4.08 (.69)	3.78 (.82)	3.63 (1.25)	3.87 (1.03)	3.11 (.83)
Financial	4.50 (.78)	3.05 (1.15)	3.30 (1.02)	2.57 (1.09)	3.39 (1.33)	2.89 (.66)
Relationships	4.85 (.43)	4.34 (.63)	4.36 (.90)	3.72 (.97)	4.13 (.84)	3.38 (.71)
Practical Support/others	3.49 (1.52)	2.08 (1.28)	3.59 (1.12)	2.68 (1.40)	2.53 (1.48)	3.00 (.59)
Emotional Support/others	3.97 (1.18)	2.77 (1.33)	3.75 (1.11)	3.36 (1.10)	3.03 (1.33)	3.03 (.56)
Support/services	4.40 (1.03)	3.17 (1.34)	3.54 (1.07)	3.19 (1.31)	3.66 (1.34)	3.26 (.66)
Values	4.14 (1.11)	3.91 (1.07)	4.17 (.70)	3.71 (1.03)	3.38 (1.23)	3.11 (.32)
Careers	4.24 (.96)	3.43 (1.43)	3.94 (.80)	3.55 (1.12)	3.59 (1.43)	3.45 (.62)
Leisure	4.38 (.71)	3.47 (.86)	3.78 (.86)	3.50 (1.06)	3.77 (.93)	3.51 (.72)
Community	4.00 (1.14)	3.18 (.94)	3.71 (.83)	3.56 (.99)	3.24 (1.13)	3.21 (.60)

3.5.2.1 Importance, Attainment, Satisfaction

With respect to *importance*, as shown in Table 3.3, all domains were considered to be "quite important" or "very important" (rated between 4 and 5). Health of the Family and Family Relationships were closest to "very important"; and Practical and Emotional Support from Others was rated between "somewhat important" and "quite important" (3 to 4). The health of the whole family was seen as important as the following respondent explained; *"life's certainly easier if everybody is well, if someone's sick, then you're limited to what you can do… if someone isn't well, well you do what you have to do to get by…".* All aspects of family life were thought to be *attained* by families. Family Relationships and Health were enjoyed "quite a bit" to "a great deal" (4 to 5); Practical and Emotional Support from Other People was received "a little " to "some" (2 to 3); and all other domains were rated as being attained "some" to "quite a bit" (3 to 4). Families were also generally *satisfied* with all aspects of family life. For example, Family

Relationships and Influence of Values were rated between "satisfied" and "very satisfied" (4 to 5); and the other domains were rated between "neither satisfied or dissatisfied" to "satisfied" (3 to 4), with Financial Well-being closest to the "neither satisfied or dissatisfied" rating of 3. Despite the average results indicating satisfaction with practical and emotional support from others (Table 3.3), as can be seen in Table 3.5 a relatively large percentage of participants indicated that they were not satisfied (including neither satisfied or dissatisfied) with practical and emotional support from others. This result should be considered with respect to possible improvements to this factor affecting FQOL.

In the concluding section of the FQOLS-2006 participants were asked to rate overall (globally) how satisfied they are with their FQOL using a five point scale (1 = "very dissatisfied" to 5 = "very satisfied"). Overall satisfaction ratings that were equivalent to a rating of "satisfied" ($M = 3.9$, $SD = .91$) were found to be consistent with the mean of the total of satisfaction ratings for the individual domains. Overall satisfaction with FQOL and the mean of the combined satisfaction of all domains were also highly and significantly correlated ($r = .64$, $p = .000$). Overall (global) satisfaction also correlated with overall attainment (the mean of the total attainment scores) in all areas of FQOL ($r = .46$, $p = .005$). Furthermore, the mean of the total of satisfaction ratings for all FQOL domains was significantly related to the mean of the total attainment scores ($r = .58$, $p =.000$).

3.5.2.2 Influence of Values

Values were rated at the higher end of the satisfaction scale. The following quote illustrates the influence of values on FQOL:

"You never can anticipate what it's like unless you live with a person [with a disability]… I didn't understand before I had Nicole the depth of the effects that it can have on your family… we're all God's children and we're all equal… [but] value judgments can be made incorrectly because of just misunderstanding… they've [people who are not caring for someone with an intellectual disability] only got their own experiences to go by…."

3.5.2.3 Opportunities, Initiative, Stability

Table 3.3 also shows that, on average, families reported that there were "a few" to "some" *opportunities* with respect to Financial Well-being and Practical Support from Other People; whereas there were "some" to "many" opportunities in all other life areas. Participants also considered that they made effort *(initiative)* in all areas of life to a certain extent. They felt that they made "quite a bit" to "a great deal" of effort with Family Relationships; "a little" to "some" effort with Practical Support from Other People; and "some" to "quite a bit" of effort with all other life areas. All elements of family life were generally predicted to "stay about the same" or "improve" *(stability)* in the near future; except Financial Well-being which was rated as likely to "decline" or "stay about the same" (between 2 to 3).

3.5.2.4 Financial Well-being

Financial Well-being was rated at the lower end of the satisfaction scale and likely to decline. The following comments illustrate why this may be the case:

"[Maintaining financial well-being] all hinges on Jackson and Helen [members with disabilities]… At the moment we both care and we both work; if they end up being too higher need then… one of us might have to take on the wholly and solely caring… we don't want to go back that way, but sometimes you can't help it."

"...lack of financial well-being and the struggle to make ends meet and the struggle to deal with the unexpected... is a very significant part of the stress... and you're not looking at luxuries, you're just looking at necessities... You don't always have control over what expenses are incurred on various things... this quarter it will be an enormous gas bill, because I've been home more, because I've been ill more and so things like that are out of my control..."

3.5.2.5 Careers

As can be seen in Table 3.1, just under half of the main caregivers were employed either full-time or part-time. Of the mothers who were in the workforce, over 65% indicated that they valued work as their social outlet, or as a break from the family. In addition, 65% of working main caregivers were in a disability-related field, including personal carers, support officers, or teachers. Of the caregivers who gave up their career to care for the member with a disability (59%), most (44%) predicted that they would not work again; 28% indicated that they might work again, depending on the progress of the person with a disability; and a further 28% predicted that they would commence working again (when the family member goes to school, or to vocational activities; or they move to out of home accommodation). Therefore, when participants predicted an improvement in their family's ability to pursue and prepare for careers, they were likely to be referring to their children, because they are finishing school and pursuing additional study, or are maturing and developing work skills. This suggests that it may be important to ask about caregivers' careers separate to their children's career prospects.

The following quote represents the impact on the family of the main caregiver either working or leaving work to care for the member with a disability. This participant discussed both the benefits and disadvantages associated with working or not;

"When you've got other stuff to cope with during the day... it's a lot more pressure actually, working full time and dealing with a family member with a disability as well, because you don't have the time... it's a bigger rush... financially it's probably better because we're both working..., but... it makes the family a lot busier, you are working harder... Emotionally it's better, but physically it's not... You have to be better at making choices... because you can't do everything... making the balance... having the outlet is good".

3.5.2.6 Siblings

Table 3.1 shows that one third of families consisted of one sibling to the member with an intellectual/ developmental disability; just under a quarter had two siblings; and just under a quarter had three siblings. Even though participants generally described their family relationships as good, all families who had siblings of the member with an intellectual/ developmental disability (37 families; 88%) discussed the impact on siblings and/ or the importance of having time for all children in the family. This included siblings feeling that they did not get enough attention from parents, or it could include being given increased responsibility for siblings. For example,

"Because Daniel [member with intellectual disability] is so demanding it makes it difficult to have time… Sheree [Sister] doesn't understand things either… I guess Sheree feels that we don't love her as much…"

"...we've made an effort to make sure that the other two [brothers] haven't suffered because of it [the disability of the family member]... They were given the opportunity and the responsibility of discipline for a sibling that would normally never be granted in a family... and they respected it... They [brothers] love John [member with intellectual disability] dearly... but they just have had enough of him."

3.5.2.7 Variance

It can be seen in Table 3.3 that the standard deviations were generally quite low across all the FQOL domains and measurement concepts. It is important to consider variance from the mean in order to assess the capacity of the measure to detect individual differences and identify families with very low domain scores. Table 3.4 shows the domains and the number of participants who selected at the lower ends of the attainment (i.e. hardly at all), and satisfaction (i.e. dissatisfied or very dissatisfied) scales.

Table 3.4 *Outliers at the Lower End of the Scale*

Measurement Concept and FQOL Domains	Number of Participants
Attainment (hardly at all)	
Practical Support from Other People	17 (40.5%)
Emotional Support from Other People	8 (19%)
Support from Services	6 (14.3%)
Financial Well-being	6 (14.3%)
Careers	5 (11.9%)
Values	2 (4.8%)
Community	2 (4.8%)
Satisfaction (dissatisfied, very dissatisfied)	
Financial Well-being	9 (21.5%)
Support from Services	6 (14.3%)
Practical Support from Other People	5 (11.9%)
Leisure and Recreation	4 (9.5%)
Health	4 (9.5%)
Emotional Support from Other People	3 (7.1%)
Family Relationships	2 (4.8%)
Community Interaction	2 (4.8%)

3.5.2.8 Services

Table 3.4 shows that, in spite of the generally high mean scores on the FQOL domains shown in Table 3.3, there were a significant number of participants who scored at the lower end of some of the domain scales. In particular, it can be seen that 41% said they attained practical support from other people "hardly at all" and 19% said the same with respect to emotional support. In terms of satisfaction, 22% were "dissatisfied" or "very dissatisfied" with their financial well being, 14% said the same with respect to support from services, and 12% also said this about practical support from other people.

In terms of dissatisfaction with support from services, nearly a quarter of participants indicated that they did not know where to go to obtain particular services. For example,

"You're not actually given information like 'here are all the services you need'... a lot of it's word of mouth... there needs to be a bit more information... When someone's got a child diagnosed with a disability automatically they should be given all this information that they need... [and] sent to the right department."

In addition, nearly one third of participants said that they often did not bother with services because of waiting lists, or the services just do not help enough. For example, *"I found... that these things are available if you use them all along, but if you suddenly want some service and you've never used it before then... you're on the waiting list and so I don't look into that very often, unless it becomes so desperate".*

3.5.3 Practical and Emotional Support from Other People

As discussed previously, in this Australian study, a differentiation was made between practical and emotional support from other people, including relatives, friends and neighbours. Generally it was found that relatives and friends were more willing to

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provide emotional support than practical assistance. Table 3.5 shows the differences between the two kinds of support in each of the measurement concepts. It can be seen that emotional support was considered to be generally more important and attained more, with more opportunities and initiative associated with it. There was, however, not much difference in rated stability and satisfaction with the two types of support. It should also be noted from Table 3.5, as already mentioned, that 46% of respondents were not satisfied (including neither satisfied or dissatisfied) with practical support. Thus, there would seem to be considerable scope for improvements in practical support from others.

Table 3.5 *Breakdown of Practical and Emotional Support from Other People Ratings*

	Practical	Emotional
Importance		
Hardly/ A little	27%	14%
Somewhat	14%	19%
Quite/ Very	59%	67%
Opportunities		
Hardly any/ A few	40%	22%
Some	34%	36%
Many/ Great many	26%	42%
Initiative		
Hardly at all/ A little	55%	36%
Some	14%	28%
Quite a bit/ A great deal	31%	36%
Attainment		
Hardly at all/ A little	70%	43%
Some	11%	26%
Quite a bit/ A great deal	19%	31%
Stability		
Greatly decline/ Decline	11%	8%
Stay about same	75%	78%
Improve	14%	14%
Satisfaction		
Very dissatisfied/ Dissatisfied	14%	9%
Neither satisfied or dissatisfied	32%	33%
Satisfied/ Very satisfied	54%	58%

In commenting on the two types of support, a participant explained, *"I guess we don't look to friends… we don't expect practical things from other people… we do things ourselves… that's why we've survived… but emotionally, yes, it is important for us to be in contact with other people and not just in the disability sector"*.

3.6 Discussion

Participants gave relevant answers to all questions in the FQOLS-2006 and the fact that they did not mention any other family-related issues suggests that it may be a comprehensive measure of the FQOL of Australian families having a member with an intellectual/ developmental disability. However, despite a careful administration and comprehensive interview, it is unknown if other family issues remain that would be representative of FQOL. One way to address this would be to include a follow-up question at the end of the interview that asks families whether there are any other family issues that were not addressed on the FQOL survey or discussed in the interview that they feel should be included in order to better understand their FQOL. Practically all domains - health, finance, relationships, support from others, services, careers, values, leisure, and community interaction - were rated of high importance (i.e. quite important or very important), and qualitative comments confirmed that the questions asked within each domain were relevant to the QOL of the families concerned. The lack of variation in importance across domains, which was expected because the FQOLS-2006 was developed to represent aspects of high relevance to FQOL, suggests that it may not be necessary to ask this question, except where there might be a specific reason for doing so. Omitting the importance concept would have the benefit of reducing the time required to administer the questionnaire. The results also supported the only major change made in

administering the FQOLS-2006, which was to separate the questions on practical and emotional support from other people.

In terms of satisfaction with aspects of FQOL, the results of the current study are consistent with those of Burton-Smith et al. (2009a) concerning aspects of life that Australian families value. Burton-Smith et al. found that family carers of people with disabilities were most satisfied with safety, standard of living, personal relationships and health; whereas they were less satisfied with community involvement, future security and achievement in life. In the current study families were "satisfied" to "very satisfied" with family relationships (personal relationships), and values (standard of living) and "neither satisfied or dissatisfied" to "satisfied" with health (health); and community interaction (community involvement). However, financial well-being was rated slightly lower, being closest to "neither satisfied or dissatisfied" in the current study, whereas standard of living, which arguably could include financial well-being, was rated high on satisfaction in Burton-Smith et al.'s study. This may reflect genuine differences between participants in the two studies or it may reflect differences in the wording of questions concerned with these related QOL domains. Another domain assessed in the present study was support from disability-related services and support from other people, both of which were rated between "neither satisfied or dissatisfied" and "satisfied".

Overall, the results of the current study provide further evidence of the validity and reliability of the FQOLS-2006. Findings suggest that that all the FQOL domains were relevant to the Australian families in the study and they were able to answer questions using all the measurement concepts (importance, opportunities, attainment, initiative, stability, and satisfaction). Consistent with previous QOL/ FQOL literature (e.g. R. I. Brown et al., 2004; Schalock et al., 2002; Summers et al., 2007), there was

evidence that the various life domains and measurement concepts were interlinked. For example, practical support from others was not as attained to the extent of other aspects of FQOL. Qualitative comments suggested that some families made less effort to obtain practical support because they did not want to burden other people, in spite of evidence that families having a member with a disability generally have higher physical and emotional demands and therefore need more support from other people (I. Brown et al., 2003).

The different results obtained from asking about practical and emotional support from other people separately is consistent with the research of I. Brown et al. (2003) in their Canadian FQOL study. They found that families with a member with an intellectual disability generally received very little practical support from relatives, friends and neighbours, and there was more variance in the emotional support that families received. A further worthwhile distinction might also be made between support from extended family such as grandparents, aunties and uncles and from other people such as friends, colleagues or neighbours, as discussed by I. Brown et al. (2003). Davis and Gavidia-Payne (2009) found that families rated the support they received from extended family higher and more likely to impact on various aspects of FQOL than the support received from friends, which was only found to influence emotional well-being. In the current study, qualitative comments accompanying quantitative ratings made it possible to identify the source of the support that was valued by families. For example, main caregivers who were working indicated that they valued the social aspects of work, and colleagues provided valuable support. This is consistent with comments by Burton-Smith et al. (2009a), that lack of employment opportunities not only impacts on the family financially but also decreases the opportunities for personal/ social networks of the family

members. Consistent with I. Brown et al. (2003), the value and priority placed on internal or immediate family, and the efforts made to uphold strong relationships within the family, suggests that families needed to rely on each other rather than other external means of support for their FQOL to be fulfilled. This is also consistent with the findings of Llewellyn et al. (2003) that elements external to the family unit were more likely to be seen as being a burden.

The findings associated with sibling issues in the current study are relevant to a separate area of research associated with the impact of having a member with an intellectual/ developmental disability on siblings (e.g. Giallo & Gavidia-Payne, 2006; Hodapp, Glidden, & Kaiser, 2005; Mulroy et al., 2008; Orsmond & Seltzer, 2007; Strohm, 2002). Further analyses of the qualitative data from the current study are warranted. Themes from the qualitative data associated with siblings are in accordance with previous research. For example, consistent with the work of R. I. Brown et al. (2004), in the current study main caregivers explained that siblings presented as feeling second to their sibling with a disability. In some cases this was associated with positive reactions, such as feeling enriched and learning important lessons but, in a few instances, it was associated with delinquent or problem behaviours because they had not received enough attention from their parents. These results suggest that this is an important area of FQOL to be assessed and that it deserves separate attention from service providers.

Although mean ratings of satisfaction with FQOL domains were relatively positive in the present study - suggesting that the majority of participants were moderately to highly satisfied with FQOL domains - evidence that the FQOLS-2006 is sensitive to individual differences across families was provided by the fact that some families rated their satisfaction with and attainment of some FQOL domains, such as

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financial well-being and support from services, at the lowest rating levels. This means that mean results should not be taken to imply that the services were satisfactory in all cases, and the FQOLS-2006 can be useful for service providers to identify families with low FQOL that might require additional support. There is also the possibility that FQOL measures could be subject to social desirability responding such that respondents might feel obliged to answer in a positive way. Specific concerns for service delivery that were expressed by families with higher support needs in the current study included sibling issues; families at risk of relationship breakdown; significant financial concerns and uncertainty about where to go to obtain services.

There were a number of limitations to the present study. It used a sample of primary caregivers from the metropolitan region of one disability organisation in South Australia. However, this organisation provided a generic disability support service, meaning that the sample was representative of all intellectual/ developmental disability types, rather than being restricted to the clientele of organisations for specific diagnoses such as Autism or Down Syndrome. Further research is needed to expand the present assessment of the FQOLS-2006 to organisations with different types of disabilities and to rural areas that may have different support services (e.g. see, Best et al., 2000; Eley, Boyes, Young, & Hegney, 2009; Lee & Browne, 2008; Mackey & Goddard, 2006; Raghavendra et al., 2007). Further research should also endeavour to assess FQOL from multiple perspectives in the family, such as fathers, siblings, grandparents and, importantly, the personal views of the person with a disability (e.g. I. Brown et al., 2003; I. Brown & Brown, 2004b; Hoffman et al., 2006; Werner, Edwards, & Baum, 2009). Finally, more research is needed into the practical usefulness of the FQOLS-2006 for assessment and service delivery.

Despite the above limitations, the present study has suggested that the FQOLS –
2006 has the potential, with some modifications, to provide a reliable and comprehensive
assessment of FQOL in an Australian context. Its capacity to discriminate between
families with different levels of FQOL in different domains and concepts also suggests
that it could be a useful practical measure for service delivery.

Prologue to Chapter 4

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International Survey and the entire chapter contains American English spelling.

Chapter 4:

A Comparison of Two Family Quality of Life Measures: An Australian Study

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Performed the research work associated with this chapter; including study set up, data collection, analysis on samples, interpreting data, writing of the manuscript and acting as corresponding author. Fiona Rillotta contributed 85% of the work for this book chapter.
I hereby certify that this statement of contribution is accurate

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Supervised development of research work, contributed to planning of the chapter and provided critical evaluation and editing of the book chapter to the amount of 10%.
I hereby certify that this statement of contribution is accurate and I give permission for the inclusion of this paper in the candidate's thesis

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Contributed to the editing of the final draft of the book chapter to the amount of 5%.
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Chapter 4: A Comparison of Two Family Quality of Life Measures: An Australian Study (Book Chapter Publication).

4.1 Abstract

        Family Quality of Life (FQOL) research partly stemmed from government policies in the 1970s promoting deinstitutionalization, resulting in increasing numbers of families becoming responsible for the primary care and support of their relative with an intellectual disability. Research has indicated that families have not necessarily been prepared for the duration and intensity of this care, leading to added demands on disability services to provide such families with support. Consequently, there has grown a need to evaluate FQOL. This chapter describes two internationally developed FQOL survey measures; the *Beach Center Family Quality of Life Scale* (Beach Center on Disability, 2003) and the international *Family Quality of Life Survey: Main caregivers of people with intellectual disabilities* (I. Brown et al., 2006), and discusses their concurrent use within Australia. Both surveys made use of similar FQOL domains associated with Emotional, Material, and Physical Well-Being; Family Relationships; and Disability Services, but there are also some differences throughout the scales. While both surveys resulted in relatively comprehensive FQOL data, some components relevant to FQOL were included in one survey but not the other, such as "Transportation", "Parenting", and "Influence of Values". In addition, while both surveys used the measurement concepts Importance and Satisfaction, the International Survey also measured Opportunities, Initiative, Attainment, and Stability. The evaluation of these two instruments carried out in the present study supports the importance of measuring FQOL using mixed-methods in an interview format where possible, and it also provides suggestions for how these

measures could be improved to better identify what makes up a life of quality for these families as well as the support needed to improve the QOL of families who have a member with a intellectual disability.

4.2 Background

From the 1970s, widespread acceptance of deinstitutionalization together with growing demands for government sponsored community-based services, and rising costs for these services, led to an increase in the number of people with an intellectual disability living quasi-independently in the community or at home, with their families taking responsibility for their primary care throughout their lifespan (I. Brown et al., 2003; R. I. Brown et al., 2004; Llewellyn, Gething, Kendig, & Cant, 2003). Given that many families have not been prepared for the duration and intensity of this care giving role (Isaacs et al., 2007) a multitude of issues and concerns have arisen for these families and for the services that support them. These issues and concerns have led to the need for research in how they affect Family Quality of Life (FQOL).

Quality of Life (QOL) has been a concept studied and developed within the field of disability since the mid 1980s (e.g., I. Brown, Brown et al., 2000; R. I. Brown, 1988; Browne & Bramston, 1996; Cummins, 1991; Dennis, Williams, Giangreco, & Cloninger, 1993; Goode, 1994; Rapley, 2003; Schalock, 2004a; M.M. Seltzer & Krauss, 2001; A. P. Turnbull et al., 2004). FQOL developed from the work of individual QOL (Schalock, 2004b), but focused on quality within the family unit as a whole, including the impact of disability services on outcomes for the family (Isaacs et al., 2007). The importance of a multi-element QOL framework encompassing the desired states of emotional, material, and physical well-being; interpersonal relations or interactions; personal development; self-determination; social inclusion; and rights, has become widely accepted (I. Brown,

Brown et al., 2000; Hoffman et al., 2006). Understanding the potential of the QOL model and its application has also become important to social policy, support services and programs (e.g., education, health and social) and their evaluation (I. Brown, Brown et al., 2000; Schalock, 2004a). Moreover, the value of researching FQOL is recognized insofar as the family constitutes a structure that is important to society's functioning and stability, and because well functioning families and good FQOL are viewed as a positive social resource (Isaacs et al., 2007). The ultimate purpose of FQOL research is to focus on, and understand, global, positive and universal aspects of family life (Isaacs et al., 2007; Poston, 2006); and to use the QOL framework to influence service outcomes aiming to improve the general well-being of people with intellectual disabilities and their families.

4.2.1 "Family"

In today's society the definition of a "family" has become complicated partly due to the changing nature of family structures. In Western societies "family" has traditionally been based on the nuclear model of biological parents and offspring. However, it now may include: step, foster, adoptive, or single parent families; a non related group of people; blended families; extended families residing together; etc. For example, the Australian Bureau of Statistics (ABS, 2001, 2006) census results showed that between 1996 and 2006, there was a 4.7% drop in couple families with children; a 3.2% rise in couple families without children; a 1.9% rise in single parent families; and a 0.1% drop in 'other' families. Currently in the USA, only about a quarter of all households consist of nuclear families (24.1% in 2005 compared to 40.3% in 1970), due to a rise in other family arrangements such as blended families, binuclear (step) families, and single-parent families (Williams, Sawyer, & Wahlstrom, 2005). The definition for

"family" used in this chapter is based on a combination of those presented in the two FQOL surveys considered in this chapter (Beach Center on Disability, 2003; I. Brown et al., 2006): *"People who are closely involved in the day-to-day affairs of your household and support each other on a regular basis; whether related by blood, marriage or by close personal relationship"*.

4.2.2 Why Compare Two FQOL Measures?

This chapter does not summarize all findings associated with family-centered research within the field of disability because it focuses primarily on the use of two measures of FQOL (Beach Center on Disability, 2003; I. Brown et al., 2006). However, a brief overview of such findings is presented, including specific reference to Australian research. At the 2006 E-IASSID conference, Quality of Life Special Interest Research Group presenters (N. Baum, I. Brown, D. Poston) explained that the International FQOL Survey was being used in several countries (including in Australia by the authors of this chapter) and with families that had members with various intellectual disability types and ages, whereas the Beach Center Survey was only being used in the USA, mostly for families with children younger than 12 years of age, and was not disability specific (i.e., not only intellectual disability). Since the two surveys had essentially the same purpose, it was considered useful to explore convergent validity by comparing the information collected using both measures with the *same* families, as suggested by Isaacs et al. (2007). The study described in this chapter aimed to do this, using both surveys with a sample of families in Australia.

Given that FQOL is a relatively new area that is considered critical to policy, service and research for enhancing the QOL of people with a disability and their families, the aims and benefits of comparing the two surveys are to identify the best features of

each and contribute to the future developments of improved FQOL measures. The research discussed in this chapter also investigated FQOL more generally in order to identify important features that may not currently be included in either of the existing measures, and which may also contribute to an increased understanding of FQOL. Further development of FQOL measures will assist in applying the FQOL concepts to program planning, service delivery and evaluation. It will also facilitate further research into FQOL, moving from conceptualizing a QOL "model" (inputs, activities, outputs, outcomes) to a "framework" (factors, domains, indicators) applying the principles of QOL (Schalock, 2007).

The practical benefit of this study was to provide main disability service providers with relevant service information on FQOL issues. Previous family-centered research in Australia (e.g., see Brown et al., 2004; Eacott, 2002; Kristine Peters Project Management Pty Ltd., 1998; Shearer, 2000; and refer to section of this chapter 'FQOL Research in Australia') did not use such comprehensive FQOL measures. Management and staff of the disability service provider that facilitated recruitment of participants were interested in applying research findings to their services for families with a member with an intellectual disability. The longer term benefit of this study was to have a FQOL measure that could be used to identify service needs of families and evaluate their effectiveness.

4.3 Overview of Previous Research

Recent Australian and international literature has supported the idea that FQOL is a useful construct in the field of disability (Aznar & Castanon, 2005; I. Brown & Brown, 2004b; R. I. Brown & Brown, 2006; Davis & Gavidia-Payne, 2009; Hoffman et al., 2006; Isaacs et al., 2007; Neikrug, Judes, Roth, & Krauss, 2004; Poston, 2006; Summers et al., 2007). Research has shown that the member with a disability becomes the focal point of

the whole family. For example, a study concerned with family spontaneity in recreation activities found that the member with a disability often played a decisive role in determining the activities that the family could and could not undertake, because of skill limitations, challenging behaviors, difficulties in coordinating busy schedules, and limits in availability of service information (Mactavish & Schleien, 2004). There also appears to be a lack of congruence in everyday family life between meeting the needs of the child with a disability and those of other family members; such that the child with a disability is often not integrated into everyday family life or into the wider community (Llewellyn et al., 1999; Owen, Gordon, Frederico, & Cooper, 2002). Variables such as the age of the member with a disability and/ or the age of parent carers and the type of disability (or 'diagnosis') have also been found to influence stress levels in the family as well as the family's coping mechanisms for dealing with the challenges that come with having a child with a disability (Blacher, 2001; Eisenhower, Baker, & Blacher, 2005; Jokinen & Brown, 2005; Schneider et al., 2006). It has also been found that parents' own health and well-being becomes second to their child with a disability's needs; and parental carer well-being falls significantly below the population norms for Australian families (Mackey & Goddard, 2006, 2007; McVilly, 2007a, 2007b). Parents caring for children with an intellectual disability also display poorer states of mental health and vitality than Australian norms (Llewellyn, Thompson et al., 2003; McVilly, 2007b). These findings are consistent with the theory that poor personal well-being is an indicator of a breakdown in homeostasis regarding life satisfaction and subjective well-being, and also indicates the emergence of psychopathology (Cummins, 2003, 2005; Cummins, Eckersley, Pallant, Van Vugt, & Miasjon, 2003).

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4.3.1 FQOL Research in Australia

A number of studies in Australia associated with families that have a member with a disability have focused on particular aspects of FQOL, such as parents' health and stress levels, caregiver burden, parent- professional relationships, or sibling issues (R. I. Brown et al., 2004; Cummins, 2007; Eacott, 2002; Llewellyn, 2004; Mackey & Goddard, 2006; McVilly, 2007b; Owen et al., 2002). In a very recent Australian study, Davis and Gavidia-Payne (2009) found that parental experiences and perceptions of family-centered professional support was a strong predictor of FQOL; and support from extended family, the child's behavior problems, and family income also had an impact on FQOL. These findings highlighted the need for professional supports to respectfully consider family-centered outcomes to service provision. The current study is the only Australian study using two established measures of FQOL and their associated FQOL domains (Beach Center on Disability, 2003; I. Brown et al., 2006). As indicated by Llewellyn, Thompson et al. (2003), policy makers and service providers in Australia are interested in finding effective and efficient processes that will encourage families to continue caring for their children with disabilities at home.

There have been a few studies exploring FQOL issues and intellectual disability in the state of South Australia (R. I. Brown et al., 2004; Eacott, 2002; Kristine Peters Project Management Pty Ltd, 1998; Shearer, 2000). Roy Brown and his colleagues began research in FQOL in South Australia in 1997, using a similar tool to the current International Survey (I. Brown et al., 2006. See Section on 'Measurement of FQOL' in this chapter). They found similar results to other studies from Australia and to those of international FQOL studies. In particular, having a member with an intellectual disability significantly influenced FQOL, and each family member was found to be affected in

different ways. Examples included; stress and poor health of carers whose child's needs were paramount in the family and who were physically, mentally and emotionally demanding; restricted employment options for carers to accommodate the needs and schedule of the member with a disability, which often resulted in financial constraints for the family, and was especially difficult due to the additional and sometimes excessive expenses involved for some people with disabilities; and family social isolation with an associated lack of community involvement (R. I. Brown et al., 2004; Eacott, 2002; Kristine Peters Project Management Pty Ltd, 1998; Shearer, 2000). With respect to sibling development and individual attention to all family members, some families reported the positive impact of respite services or recreational services that take the person with a disability away from the family every so often, to give siblings a break from the demands that accompany caring for a person with a disability (R. I. Brown et al., 2004; Kristine Peters Project Management Pty Ltd, 1998). Dissatisfaction with the supports and services available for the family and for the individual with a disability, including insufficient amounts of respite, childcare and funding, was also expressed in these studies. Results from the current Australian study, using a similar measure for FQOL, have revealed similar service issues as those identified by R.I. Brown et al. (2004) and Eacott (2002). However, current results also contribute additional information about implications for the measurement of FQOL.

4.4 Measurement of FQOL

There is a consensus in the QOL literature that it is necessary to obtain both qualitative and quantitative data when conducting QOL research (I. Brown, Brown et al., 2000). Qualitative measures are useful to assess family outcomes involving personal experiences that can only be explained by considering the perceptions of the family

members themselves, because ultimately it is these subjective perceptions that determine the individual's approach to life and how satisfied they are with life (Bailey et al., 1998; I. Brown & Brown, 2004b). There are many measurement tools that have been used for research involving families, but most tend to measure aspects of family life as separate issues; such as financial well-being, caregiver/ parental health, and burden or stress. They do not draw together these various components or encompass the holistic notion implied in the concept of FQOL and its frameworks (Isaacs et al., 2007). The FQOL framework attempts to bring together a wide range of objective and subjective aspects of family life, including family income and the amount spent on disability related needs; the number of hours friends/ relatives spend supporting the family; employment; and clubs/ organizations to which family members belong (Isaacs et al., 2007). The two surveys described next aimed to integrate these and other aspects of FQOL within concepts commonly accepted for individual QOL research, such as levels of satisfaction.

4.4.1 International Survey

The Family Quality of Life Survey (I. Brown, Neikrug et al., 2000) was originally developed by experts in the field of QOL and stakeholders (Isaacs et al., 2007). Nine domains of FQOL were identified, forming the basis of the survey: "Health", "Financial Well-Being", "Family Relationships", "Support from Other People", "Support from Disability Related Services", "Spiritual and Cultural Beliefs", "Careers and Preparing for Careers", "Leisure and Enjoyment of Life", and "Community and Civic Involvement". These domains were formed by reviewing FQOL research; input from researchers from nine institutes and universities; feedback from family members (with and without a family with an intellectual disability); and feedback from prospective users of the tool, professionals and academics (Isaacs et al., 2007).

The original version of the survey (I. Brown, Neikrug et al., 2000) was also later field tested. It was piloted internationally over the course of four years with over 300 family members (mostly mothers and fathers of relatives with various intellectual disability types including Down Syndrome and Autism). It was used as a measure of FQOL in Australia (R. I. Brown et al., 2004; Shearer, 2000), Canada (I. Brown et al., 2003; I. Brown et al., 2004), Israel (Neikrug et al., 2004), South Korea, and Taiwan. The survey resulted in similar findings across these different cultures in terms of main caregiver's concerns for their family and the life of the member with an intellectual disability. For example, it was consistently found that the main burden of care was placed on the mother of the family, and that the main concern for the relative with a disability was social isolation. As described by Isaacs et al. (2007), analysis of the international data also indicated high reliability and validity of the first version of this scale, and the nine domains were deemed feasible subscales for measuring different aspects of FQOL. However, due to the small sample size, confirmatory factor analysis was not conducted. Some wording changes and clarification of the Likert scales were found to be necessary. Respondents also indicated their desire to provide supplementary qualitative information, to explain their quantitative ratings. Subsequent work on the FQOL domains was conducted accordingly and participants' interpretations of the concepts were analyzed. For example, "civil involvement" was considered to be irrelevant to some families because they interpreted it to mean involvement in official civic duties. Also, there was a need to elaborate on what was meant by "stability" in terms of the anticipated future for disability supports, which may have been viewed as either a positive or negative element of family life (see Isaacs et al., 2007 for further detail). The older version of the survey was also deemed to be quite long (1.5 to 2 hours) and while that was appropriate for

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research purposes, it was less appropriate for other purposes such as outcome evaluation or administering large numbers of surveys in order to statistically compare groups (Isaacs et al., 2007).

An updated version of the survey was published in 2006 (I. Brown et al., 2006) with revised FQOL domains; "Health", "Financial Well-Being", "Family Relationships", "Support from Other People", "Support from Disability Related Services", "Influence of Values", "Careers and Preparing for Careers", "Leisure and Recreation", "Community Interaction", as well as two extra sections of the survey – "Family Background" and "Overall Family Quality of Life" (See Isaacs et al., 2007). The assessment concepts associated with the questions in each of these domains include: *Importance* (the degree of value the family places on that particular element), *Opportunities* (the options that are available to families), *Attainment* (the degree to which the family is able to accomplish or obtain what they need), *Initiative* (the degree to which families take advantage of available opportunities), *Stability* (the degree to which circumstances are likely to improve, decline or stay the same), and *Satisfaction* (overall perception about important aspects of family life) (See Isaacs et al., 2007). In the current study, the International Survey took between 1 and 3.5 hours to administer by interview. It is currently being used in 19 countries and has been translated into 12 different languages.

4.4.2 Beach Center Survey

The Beach Center Family Quality of Life Scale (Beach Center on Disability, 2003)[10] was developed at the Beach Center, The University of Kansas. It was trialed in three States of America (Kansas, Louisiana, and North Carolina) and was developed in

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[10] For some of the data collected in the present study, The Beach Center Partnership and Family Quality of Life Survey was used, which included a preliminary section on Support and Services (disability related or otherwise). For the purpose of this chapter, only FQOL data are presented. Results from Partnership and Support Services sections of the survey are relevant for other analyses.

three phases in order to be used for both research and program or policy evaluation. The first phase sought to understand people's perceptions of the meaning of FQOL with or without having a member with a disability. Qualitative interviews were conducted with over 100 people including family members of children and youth with and without disabilities, service providers, and administrators (Poston et al., 2003). The second phase was undertaken to develop 10 specific domains of FQOL. During this phase focus groups and interviews were conducted with family members, including those with disabilities, and service providers. The domains were: "Family Interaction", "Parenting", "Daily Life", "Financial Well-Being", "Emotional Well-Being", "Social Well-Being", "Health", "Physical Environment", "Advocacy", and "Productivity" (Summers et al., 2005). The third phase was dedicated to developing a statistical model based on the qualitative data and field tests, using exploratory factor analysis to form subscales from a 5-factor solution; Family Interaction, Parenting, General Resources, Health and Safety, and Support for Persons with Disabilities (See Hoffman et al., 2006; Park et al., 2003 for more detail). Items that were rated low on importance were removed; however, the literature does not report what these items were, or any possible reasons why they were not rated as being as important as other items. The end result of these statistical analyses and rewording of items was a 25 item survey (plus a section on General and Individual Family Information), including five FQOL domains: "Family Interaction", "Parenting", "Emotional Well-Being", "Physical/ Material Well-Being", and "Disability-Related Support". Questions in the survey were designed to also assess these domains in terms of the concepts of Importance and Satisfaction.

Poston et al. (2003) outlined preliminary limitations in the initial study used to develop The Beach Center FQOL Scale, including the fact that confirmatory analysis of

the data examination procedures by a professional peer was not conducted. Also, given that it was based on a qualitative analysis with selected people, results may not necessarily be generalized to all families. However, in a later study with 280 family members (mostly mothers) of children with mostly 'moderate' levels of disabilities (including but not limited to Autism, Developmental Delay, learning difficulties, emotional disorders and physical health conditions) Hoffman et al. (2006) confirmed (from psychometric evaluation) the five-factor solution for the FQOL domains. They concluded that, the scale is an effective tool for researching FQOL, as well as for applied research to examine the outcomes of family services and policies.

The Beach Center Survey has so far been used with over 1000 participants in American populations, including a translated Spanish version used in Colombia (Verdugo, Córdoba, & Gómez, 2005; Wang et al., 2006; Wang et al., 2004), and it has been used in a multi-survey study self-administered by 64 families in Australia assessing the impact of child, family and professional support characteristics on FQOL for families with young children aged 3 to 5 years (Davis & Gavidia-Payne, 2009). No other uses of the Beach Center Survey are known to the authors. Studies describing the data obtained from using this measure (e.g., Hoffman et al., 2006) did not specify how long participants took to self-administer the survey. However, the Spanish version (Verdugo, Córdoba et al., 2005), administered by interview, was reported to have taken 45 minutes. Similarly, in the current study interviews took between 30 minutes and 1 hour.

4.5 Methodology of the Current Study

The data discussed in this chapter ($n = 15$) came from a larger sample of 53 main caregivers of people with a disability who participated in the Australian FQOL study. Main caregivers were interviewed in their homes in a semi-structured manner using one

or the other, or both of the surveys. Not all families completed both surveys; depending

on how much time they had available. Most completed the International Survey only ($n =$

29) and the remainder completed the Beach Center survey only ($n = 9$). The data from the

15 families who had time to complete both surveys were considered a useful indication of

the similarities and differences between the two measures. Further observations on each

measure could also be made from the results of the 38 participants who only completed

one of the measures, as well as from responses to any additional questions asked during

the time spent with these families.

4.5.1 Participant Demographics

Table 4.1 shows demographic details of the 15 main caregivers who completed

both surveys. Main caregivers were all biological mothers and they varied in age from 25

to 76 years. Nine families were two-parent families and six were single-parent. The

Beach Center Survey question about financial income, asking participants to select from

10 options (from $15,000 to above $75,000), was found to be too personal or challenging

for some to answer; therefore it was not usually asked. One mother responded, *"Nope,*

I'd rather not answer that…I don't like them asking that question…I don't even know

how much my husband earns". Pilot study participants indicated that they preferred the

equivalent question from the International Survey, which requested that participants

select from five options ("well below average" to "well above average") based on the

average income of their country. The vast majority (87%) of participants selected an

"average" income level; one participant selected above average, and another selected

below average). This suggests that asking about level of income may not be a useful

question. However, this needs to be explored in larger samples, along with qualitative

data about financial well-being. In addition, the vast majority of families had an

Australian cultural background, with a few who were English, German or Croatian descendants.

Table 4.1 *Demographical Details of Participants who Completed Both Measures*

	Age	Gender	Marital Status
Participant (Main Caregiver)	**Range:** 25 – 76 **Mean:** 45 years **SD:** 12.64	F = 15 M = 0	Married = 8 Divorced = 2 Separated = 2 Not Married = 2 Widowed = 1
Member with intellectual disability*	**Range:** 2 – 39 **Mean:** 16 years **SD:** 12.20	F = 6 M = 9	N/A

* Six families had more than one member with a disability. Since the Beach Center Survey did not ask about each family member with a disability separately (the International Survey did) the family member with the most impact on the family has been discussed for comparison purposes (See section of this chapter on 'More than one family member with a disability').

Table 4.1 also shows that members with an intellectual disability varied in age, and that there were slightly more males than females. The 'diagnoses' for the 15 family members with a disability varied; Autism Spectrum Disorder $n = 4$; Intellectual disability $n = 3$; Developmental Delay or Early Childhood Disability $n = 3$; Down Syndrome $n = 3$; Cerebral Palsy $n = 1$; and Chromosomal Disorder III $n = 1$. Almost all had one or more secondary conditions including behavioral problems, mood or expression challenges, physical impairments, or speech/ language/ communication difficulties. The Beach Center Survey asked about level of disability (mild, moderate, severe, unknown) whereas the International Survey did not. Based on responses of the participants, asking for this information did not prove to be useful, because most participants found level of disability difficult to describe. This was not surprising since Australian disability services describe a person in relation to their service needs rather than their level of disability and they no longer classify level of disability. The equivalent International Survey background question asking about level of disability support required was more suited to the

Australian participants. The mean score from the participants in the current study was 2.15 (equivalent to "requires disability-related support for most, but not all, aspects of life"); no participants selected "does not require disability-related support"; two participants selected "only a few aspects of life"; three selected "some aspects of life"; three selected "most, but not all, aspects of life"; and five selected "almost all aspects of life" (two respondents did not indicate a level of disability-related support). Therefore, this question was useful in discriminating between participants in terms of differing levels of support needs.

4.5.2 Pilot Study: Modifications to Surveys and Cultural Considerations

A pilot study was conducted with four families selected by a regional manager of the disability service provider. The pilot study resulted in adding supplementary questions about relevant *past* family circumstances to each section/ domain of the International Survey (See section on 'Past and Distant Future' of this chapter). It was also considered necessary to distinguish between the provision of practical (or material) support and emotional support in the "Support from Other People" domain of the International Survey because pilot study participants identified these as two separate constructs. For example, practical support referred to monetary support or assistance with babysitting or housework, etc., whereas emotional support included listening when needed or being "a shoulder to cry on" at times of grief or distress. The Beach Center Survey questions about support from others were broader in that they did not specify "practical" or "emotional" support. However, questions were worded so that it was left up to the individual's interpretation. For example, the Beach Center Survey asked about the importance of, and satisfaction with, "the support we need to relieve stress", "friends or others who provide support" and "outside help… to take care of special needs of all

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family members". Generally participants in the current study responded to these Beach Center Survey questions about support from others without asking for clarification of the *kind* of support. Results of the pilot study suggested that modifications to the Beach Center Survey (with the permission of the survey's authors) were only required in terms of culture specific demographic questions to fit with Australian terminology (e.g., educational qualifications and race/ cultural background). These changes were necessary because the Beach Center Survey had only been used in the United States, and it was not originally designed for international use.

With further respect to cultural context, Aznar and Castanon (2005) suggested that Latin American families may have different values, understandings and priorities than those encompassed in commonly reported FQOL 'domains' developed in Anglo-American cultures, such as the International Survey. Aznar and Castanon (2005) therefore developed a FQOL measure, including domains worded appropriately for their culture; "Emotional Well-Being", "Personal Strength and Development", "Rules of Cohabitation", "Physical/Material Well-Being", "Family Life", and "Interpersonal and Community Relations" (See Aznar & Castanon, 2005, for further information). Also, S. Devi from India (Devi, 2006), who had hoped to use the International FQOL survey in her country, indicated that an additional domain associated with superstitions and religion would be necessary because these elements help guide the people of India through their everyday lives and hence their family life (Devi, 2006). Therefore, if research is to effectively inform policies associated with disability in different cultures, there is a need for FQOL measures to be sensitive to cultural differences.

To the best of the authors' knowledge, no further culture specific (or other) changes have been made to the published surveys, and there is no evidence from previous

studies or from the current pilot study suggesting any other necessary rewording for either of the surveys.

4.6 Findings from Australian Data Comparing Two Measures

While both surveys attempt to measure the same construct (i.e., FQOL), and they seek similar information from families about their FQOL in slightly different ways, they also differ considerably in various elements including: length; user-friendliness; time taken to administer; methodology (i.e., self-administered vs. face-to-face; and qualitative vs. quantitative); and the expertise or personal traits required to administer the surveys. Comparisons between the two measures were also considered in terms of the FQOL aspects that were included in one survey but not the other, such as: provision to report information about more than one family member with a disability (in the International Survey). As noted by Poston et al. (2003) the Beach Center Survey 'domains' were broader; and whilst the Beach Center Survey included the domain of "Parenting", the International Survey included the domain of "Influence of Values"; The overarching measurement 'concepts' that the Beach Center Survey used within each domain were the same as the major measurement concepts used in the International Survey (i.e., Importance and Satisfaction), but the International Survey also assesses Opportunities, Initiative, Attainment and Stability. Table 4.2 summarizes the main differences between the two surveys, and these differences are then discussed in light of the Australian data.

Table 4.2 *Summary of Face-Value Comparisons*

Comparison Area	International Survey	Beach Center Survey
Development	Researchers (9 institutes/universities) Field Tested 300+ International Sample 3 Countries (Canada, Australia, Israel)	Qualitative Inquiry Field Tested 150+ Sample 3 States of USA (Kansas, Louisiana, North Carolina)
Number of Pages	39	15
Time to Administer Interview	45 minutes to 3.5 hours	20 minutes to 1 hour
Number of Items Per Survey Section	**121** About Your Family (13) Health of Family (10) Financial Well-Being (13) Family Relationships (10) Support-Other People (12) Support-Disability Related Services (10) Influence of Values (12) Careers & Preparing for Careers (13) Leisure & Recreation (10) Community Interaction (11) Overall FQOL (7)	**69** Support and Services (28) FQOL (25) Physical/ Material Well-Being (5) Emotional Well-being (4) Family Interaction (6) Disability-Related Support (4) Parenting (6) General Individual & Family Information (16)
Comparison of FQOL Domains in the two surveys (Adopted with permission from Beach Center on Disability, Zuna, & Hu, 2007)	Health of Family →	Physical/ Material Well-Being (2 items; medical care, dental care)
	Financial Well-Being →	Physical/ Material Well-Being (1 item; take care of expenses)
	Family Relationships →	Family Interaction (whole domain; 6 items)
	Support from Other People →	Emotional Well-Being (3 items; support to relieve stress, friends or others who provide support, outside help available)
	Support from Disability Related Services →	Disability-Related Support (whole domain; 4 items)
	Influence of Values →	Parenting *Questionable** (1 item; teach children to make good decisions)
	Careers and Preparing for Careers →	Emotional Well-Being *Questionable** (1 item; pursue own interests)
	Leisure and Recreation →	Family Interaction (1 item; enjoy spending time together) Emotional Well-Being (1 item; pursue own interests)

	Community Interaction →	Physical/ Material Well-Being (1 item; feel safe at home, work, school, neighborhood) Emotional Well-Being (2 items; friends or *others* who provide support, outside help available)
Provisions For…..	More than one family member with an intellectual disability (up to 3) State siblings and any other people considered to be immediate family (i.e., not just parents of the relative with intellectual disability)	The member with a disability who has the *most* impact on family life (despite how many family members there are with a disability). Only asks about the participant in the study (i.e., main caregiver/ usually the mother).
Measurement	Quantitative with some provision for Qualitative explanations	Quantitative only; no opportunity for Qualitative explanations (other than in the General Information/ demographics section)
Measurement Concepts	Importance Opportunities Initiative Attainment Stability Satisfaction	Importance Satisfaction
Five Point Likert Scale (Importance)	Very important Quite important Somewhat important A little important Hardly important at all	Critically important (Blank) Important (Blank) A little important
Five Point Likert Scale (Satisfaction)	Very satisfied Satisfied Neither satisfied or dissatisfied Dissatisfied Very dissatisfied	Very satisfied (Blank) Neither (Blank) Very dissatisfied

* *Questionable* means that it is debatable as to whether or not these items from the Beach Center Survey fit into the equivalent International Survey domain.

From Table 4.2 it can be seen that there are considerable similarities between the

five Beach Center Survey domains and the nine International Survey domains (domain

comparisons were adopted with permission from Beach Center on Disability et al., 2007).

For example, certain items from the "Emotional Well-Being" domain of the Beach

Center Survey align with three of the International Survey domains; "Support from Other

People", "Leisure and Recreation" and "Community Interaction" (See Table 4.2). The International Survey has separate domains (and more detailed survey sections) for "Influence of Values", "Community Interaction", "Leisure and Recreation" and "Careers", but the Beach Center Survey only had one survey item which could be linked to these domains respectively; "teach the children to make good decisions", "safety at home, work, school and in the neighborhood", and "time to pursue own interests" (which could be interpreted to represent either International Survey domains of "Leisure and Recreation" or "Careers" or both). This implies that the Beach Center Survey questions are not as extensive in their coverage of these issues as those in the specific sections of the International Survey, which means that participants cannot expand on issues associated with quality and quantity of education, leisure, involvement in groups or clubs, and careers as they can in the International Survey.

4.6.1 Survey Completion Time

Interviews with the International Survey took between 45 minutes to 3.5 hours (average 1 hour and 55 minutes, $SD = 50.86$), which is similar to the results reported by Isaacs et al. 2007 with the first version of the survey (i.e., 1.5 to 2 hours to administer). The Beach Center Survey interviews took between 20 minutes to 1 hour (average 55 minutes, $SD = 13.78$). Previous literature reporting use of the Beach Center Survey has not specified the time taken, so comparison was not possible. Surveys that were self-administered by the main caregiver were estimated (by means of the researcher filling out the survey based on their own family life, prior to distributing it to participants) to take less time than the face-to-face interview format (i.e., approximately 40 minutes for the International Survey and 20 minutes for the Beach Center Survey). However, of the total 15 participants in this study, only three chose to complete the surveys on their own and

they were not asked to record how long they took to complete the survey. The International Survey took longer to complete because it contained more items, and due to the open nature of some of the questions, participants were more stimulated to add comments and explanations than they were with the Beach Center Survey.

4.6.2 Methodology and Survey Designs
(Qualitative vs. Quantitative; Interview vs. Self-Administered)

The Beach Center Survey is predominantly quantitative, requesting that participants *only* mark a circle for their responses without providing comments on the form (other than in the General Information section). The International Survey has some open questions and allows for participants to elaborate on the information in each domain. However, when participants self-administered the surveys (n = 3), they provided relatively little qualitative information in the International Survey, even though they were given the opportunity to do so. For example, in response to the question about disability related services needed that they were not currently getting, a self-administered response was: *"Social Skills training. Friendship Groups";* and the response from another participant who was interviewed face-to-face was more detailed: *"more support from talking to people… groups and things like that… some more friends… and some friends for [member with intellectual disability]… Someone like him, some other kids that he can have to play with, he's got no one… go somewhere and meet other kids with special needs and be able to play with them and communicate with them".*

When both surveys were conducted in an interview format, far more qualitative information was obtained. During the interview with the Beach Center Survey, the same participant as in the above example provided the following explanation; *"I haven't got*

many friends... could do with a bit more... he [member with intellectual disability] needs a lot more support [to make friends]... I don't know how to work with him... I think he needs more friends". Although the response to the Beach Center Survey question was not as detailed as the explanation given in response to the International Survey question, it was more than what was provided from self-administered surveys. Another critical point was the wording of the survey questions which led to these explanations by the participant. The first example given above was in response to the International Survey item, "disability related services you need that you are not currently getting", and hence the participant may have felt motivated to explain more in the hope that the information might be fed back to the services and something would be done about it, whereas the Beach Center Survey did not specifically ask about services needed. The comparative Beach Center Survey questions only asked about the importance of, and satisfaction with, "friends or others who provide support" and "family member with a disability has support to make friends". Thus, participants were asked to provide a more general explanation of their situation and not refer specifically to disability services.

Therefore, both surveys, as currently worded, elicited detailed qualitative information and feedback for services when administered in a face-to-face interview format, but only minimal or no qualitative data when self administered. There were benefits to both qualitative and quantitative data collection approaches. For self-administration, quantitative methods were appropriate and convenient for the participant (with respect to time to complete and ease of completion). However, if time and resources permit, the face-to-face interview format has been preferred by the developers of the surveys (e.g., See Park et al., 2003) and by those using the surveys, because it can provide supplementary qualitative information concerning the unique needs of family

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members, including clarification of certain questions, to prevent misinterpretation. This method also assists family members who may not be able to read the surveys – a group who could have been excluded if self-administration was the only option (Park et al., 2003). An advantage of the quantitative method of the Beach Center Survey is its scanning technology, which can be used for convenient and easy entry of the quantitative data points. Both surveys provide quantitative data that can be used for statistical analyses as part of FQOL assessment, but the International Survey also requires expertise in qualitative analysis.

4.6.3 Surveys' Structures and Participants' Experiences of the Interviews

The Beach Center Survey was not split into sections according to FQOL domains, and questions were in random order; therefore, participants were not as aware of the question that was to come next; whereas in the International Survey all questions regarding the same domain were grouped together, meaning that participants felt comfortable once the domain was mentioned to adjust their responses accordingly and provide information about their family situation concerning whatever issue was being asked about. This may have been partly why the International Survey took longer and stimulated more comments. Some participants were uncertain about the exact content of the survey at times. For example, one participant said, *"do you want me to talk about that now, or will it be asked about later?"*. Another participant specified (in the "Health" domain of the International Survey) that there were *no* major physical and/ or mental health concerns for other family members; however, at the end of that section she stated, *"I was just going to say, with health... would that [include] depression and stuff like that, because I've been on antidepressants for a while - I just thought of that as well."*

Although some participants seemed initially to be apprehensive about providing information (evident by their short answers at the beginning of interviews), once rapport had been established with the interviewer, they seemed to enjoy the opportunity to express their feelings about family life in the context of having a member with a disability. For example, participants made comments after completing the International Survey such as; *"it was good to let everything out"*. Although responses from the Beach Center Survey were generally not as detailed, one mother who only had limited time for the interview with the Beach Center Survey nevertheless commented at the end, *"there we go, we got it done in time after all and I got to tell you all about the family"*, indicating that she felt the survey had adequately considered her FQOL.

Empathy and listening skills of the interviewer were important, in order to create a more pleasant experience for the participant. A number of participants had moments of tears and/ or deep reflection during the interviews with the International Survey. Firstly, this seemed to be due to the personal and emotional nature of the topics such as, "Support from Other People", which may or may not have been forthcoming. The questions added to the International Survey by the current authors about the past also triggered emotional reactions as family members often reflected on life before the child with a disability, or what family life might be like without the member with a disability. Secondly, the time spent elaborating on the quantitative questions of the International Survey with qualitative responses enabled participants to reflect on the support (or lack of) that they received, as well as to consider their satisfaction with each FQOL domain. For example, in one case, the interviewer decided not to ask questions associated with "Support from Other People" but instead moved straight on to the next section of the survey, because this participant began to cry as soon as the topic was mentioned. She explained that she

did not wish to talk about that aspect of family life because all her relatives were overseas and she did not have anyone else. There were less emotional reactions of this kind to the Beach Center Survey, because questions were all quantitative in nature and did not ask about one topic with additional qualitative questions before moving on to another topic. For the same participant as described immediately above, quantitative questions in the Beach Center Survey concerning, "have friends or others who provide support" or "outside help available to take care of special needs of all family members" did not elicit the same emotional reaction. Perhaps this was because the participant did not associate either of these Beach Center Survey questions with her overseas relatives, or perhaps these questions led her to think more in terms of formal service provisions. Neither question specifies who "others" or "outside help" may include. Also, since the next item in the Beach Center Survey that follows these questions was not related to the same topic, the participant was not given much opportunity to reflect on the issue that saddened her when she was answering the equivalent International Survey questions.

Empathy and interviewing expertise was also needed for the Beach Center Survey since one person did cry during the interview with it. However, in this case, the tears were due to the participant raising a topic that was not part of the survey; in particular, she expressed feelings of resentment related to having a child with a disability, and how different life could otherwise be. The survey question that was asked prior to this reaction concerned the importance and satisfaction related to "family members talk openly with each other". After giving her quantitative response, the mother went on to explain that it was important for her to have talked with her other children when she was at a very low point in life and that is when she began to cry; *"and I told them my concerns of… leaving her…they have seen me at my worst"*. She also explained that *"when we moved into this*

*house… I remember thinking; now, should I put [sibling without disability] in that room
or should we put [member with disability] in that room, because what if a car went
through…?"* Here the mother was referring to the fact that she would have preferred her
daughter with a disability to have endured the consequences of an accident, over her
other children without disabilities. Therefore, interviewing and basic counseling skills
were required to deal with the extent to which FQOL questions, whether quantitative or
qualitative, elicited emotional reactions of this kind. If controlled and dealt with
appropriately these emotional reactions can make service providers aware of the severity
or sensitivity of some FQOL issues. This information might be extremely useful for
evaluative purposes in prioritizing different kinds of services for certain families. A
suggested addition to the analysis of data from the two surveys would be to record the
degree of emotion that arose about particular FQOL issues.

In summary, interviews conducted with both surveys indicated that their structure
in terms of FQOL topics was logical and appropriate. However, the International Survey
was slightly better in this regard since all items associated with a particular FQOL
domain were grouped together, enabling participants to elaborate more easily on that
particular aspect. During the development process of both surveys, only those domains
considered important to families involved in the pilot studies were included. The current
study also confirmed the relevance and importance of the domains insofar as most
participants had something to say about each of the FQOL issues. Interpersonal and
professional interview skills were also important with respect to ethical considerations in
the delivery of both surveys. It is recommended that interviewers receive specific
training, and that information be provided to participants about who they could contact to
obtain appropriate advice and assistance (e.g., the government's main disability service

provider). These ethical considerations were put in place for the current study and proved

to be effective, although no one asked for, or was considered in need of, additional

counseling. It should be noted that even though participants became emotional when

reflecting on their family life during interviews with the International Survey, there was

no evidence to suggest that they felt particularly uncomfortable in the interview situation,

because no one chose to withdraw from the study, despite being free to do so.

4.6.4 More than one Family Member with a Disability

Six of the 15 (40%) families who completed both surveys had more than one

member with a disability. A major advantage of the International Survey is that it has

provision for this family demographic by asking participants to talk about each family

member with an intellectual or developmental disability separately. The Beach Center

Survey does not provide an option for participants to discuss how FQOL is affected by

more than one family member with a disability. Instead, it specifies that participants

should "consider the one who has the most impact on your family life." Of the six

families that had more than one member with a disability, it was notable that all members

of the family with a disability had an impact on the family and in different ways. For

example, it was revealed in responses to the International Survey, that one family had an

18 year old child with a developmental disability and behavioral problems including

physical aggression towards his mother, whilst his 10 year old brother who also had

developmental disability did not have any behavioral issues, but was in and out of

hospital due to his physical health conditions. This participant also explained that: *"[10*

year old] has always been jealous of [18 year old brother]". These facts and

explanations were not evident in the same participant's responses to the Beach Center

Survey. Also, another participant who had two children with a disability was not able to

choose one satisfaction rating for the question about "family member with a disability having support to make friends" from the Beach Center survey, because, *"[daughter with disability] does alright… but [son with disability] needs a lot more… [Daughter with disability] is slowly making friends, but [son with disability], needs a lot more support"*. Even though the Beach Center Survey asked about the family as a whole, there was no opportunity to comment on both family members with a disability and the separate impact of their disabilities on the family. These results indicate that when assessing FQOL, it is necessary to ask about all members with a disability and their individual affects on the family.

4.6.5 "Parenting" Domain - Beach Center Survey

The Beach Center Survey included the FQOL domain "Parenting" while the International Survey did not. The six Beach Center Survey items associated with "Parenting" were: "help children learn to be independent"; "help children with schoolwork and activities"; "teach children how to get along with others"; "teach children to make good decisions"; "adults in my family know other people in the children's lives (friends, teachers, etc.)"; "adults in my family have time to take care of the individual needs of every child". As can be seen in Figure 4.1, on the Importance scale of 1 to 5 (1 = a little important, to 5 = critically important), all participants from the current study rated 3 and above for all of these items except for, "knowing other people in the children's lives", for which one participant specified "a little important". Figure 4.1 also shows that in terms of Satisfaction, the majority were "very satisfied" with "helping children learn to be independent", "helping children with schoolwork", "teaching children to get along with others". There was more variation in the responses for "teaching good decisions"

and "knowing others in the children's lives", but with both still having an average rating of 4 (equivalent to "satisfied").
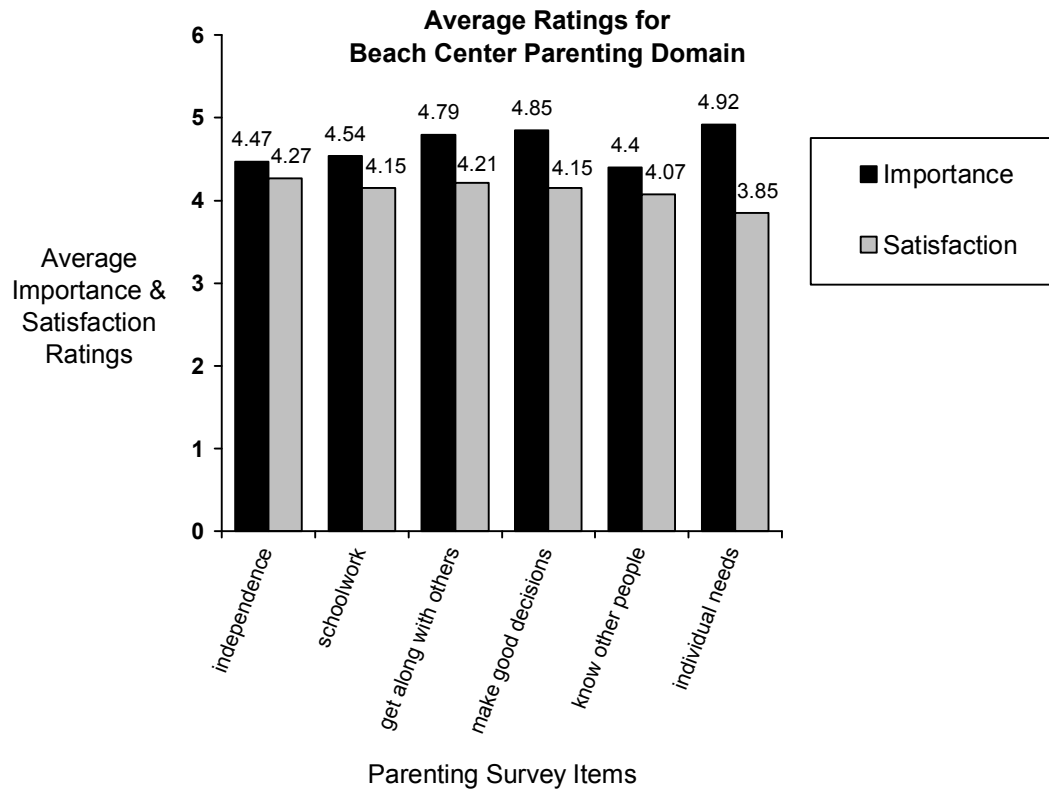
Figure 4.1. Average ratings for Beach Centre domain — "Parenting"

Whilst all other items associated with "Parenting" were important to participants, the item associated with having "time to take care of the individual needs of every child" in the family was rated the highest in importance yet lowest in satisfaction, suggesting that it is an area of concern in some families, which should be asked about in FQOL measures. In general, participants provided slightly lower satisfaction ratings (Mean = 3.85) to this item, despite the fact that all participants rated it as "critically important" (except one who rated it just below "critically important"). The impact of this issue on

FQOL was also evident in the qualitative comments that accompanied these ratings to the Beach Center Survey; for example:

"It is absolutely vital [to take care of the individual needs of every child]… but it's not practical… it is extremely hard to make sure that all 3 are totally satisfied, especially when you've got a high needs child."

"[For] so many months we look[ed] after [member with intellectual disability] but we have another son, we love him too… [Member with intellectual disability] needs more care but he [older son] needs love too."

Throughout interviews using both measures almost all participants referred to their other children (i.e., siblings of member with a disability), even though the International Survey did not include any direct questions about this issue. These results suggest that it is very important to explore the impact of having a family member with a disability on siblings - an area of research which has received separate attention in the literature (for example, Hodapp et al., 2005; M. M. Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997; Strohm, 2002). In many cases, examples were provided by participants in the current study of drastic effects on siblings, which in turn had impacted on FQOL. For example, in response to the Beach Center Survey question a mother explained that it was a very emotional time for her whole family when she started working again and the second sibling had some concerns that she had spoken to a person who ran a siblings support group about; *"[sibling 1] had her baby and moved on; [father] was at work; I [mother] was sort of finding my pathway; and all of a sudden she [sibling 2] found out that she was home and [member with disability] was all she had left really, so she was a*

*bit lost, it was the first time that she had seen her sister [member with disability] for who she was and there was no one to talk to… it was emotional for us **all.***"

Participants also expressed their concerns for siblings when responding to the International Survey, mostly in response to the demographics question that asked participants to state who their other children were. For one mother, the biggest cause for concern for her FQOL was the sibling of the member with an intellectual disability. For example, *"they say when somebody in your family has got cancer everybody has got cancer, it's the same… he [sibling] gives me a hard time… he's [sibling] doing some bad things…it's affecting him [sibling] too..."*. She went on to explain in the section about "Family Relationships" that *"I don't receive enough help for [member with intellectual disability] … I think sometimes if I receive enough support for [member with intellectual disability's] health, then I'll spend more time with my other son [sibling] when he plays sport… maybe I should be there more often… things might be different… but I can't go… can't bring [member with intellectual disability] because he's in a nappy…"* and *"he's [sibling] full of anger"*. This participant continued to raise this issue throughout the interview with the International Survey. While there was no comparable data from the same participant using the Beach Center Survey it was clear when comparing these comments to those previously described in response to the Beach Center Survey question, "time to take care of the individual needs of every child", that responses to the Beach Center Survey were a lot shorter and less detailed, but presented the same kinds of issues.

Ratings and averages for groups need to be interpreted with caution, because in this study there were only 15 participants, but for larger samples there may be more variation around the mean. Therefore, it is important to consider not only mean scores, but also any outliers or cases that particularly deviate from the norm. For example, in

Figure 4.2, which shows the individual scores of participants for importance and

satisfaction in the Beach Center parenting domain, it is clear that participant 3, who had a

learning disability herself, stands out from the other participants. She had indicated that

all parenting domain items were "critically important", but she was "dissatisfied",

implying that she would require further support, as displayed in her response to the

question about adults in the family teaching children to make good decisions; *"I try but*

probably it's not perfect enough, but I do try...I suppose that's probably why I'm seeing a

doctor too, because I don't get enough credit for myself for anything...".
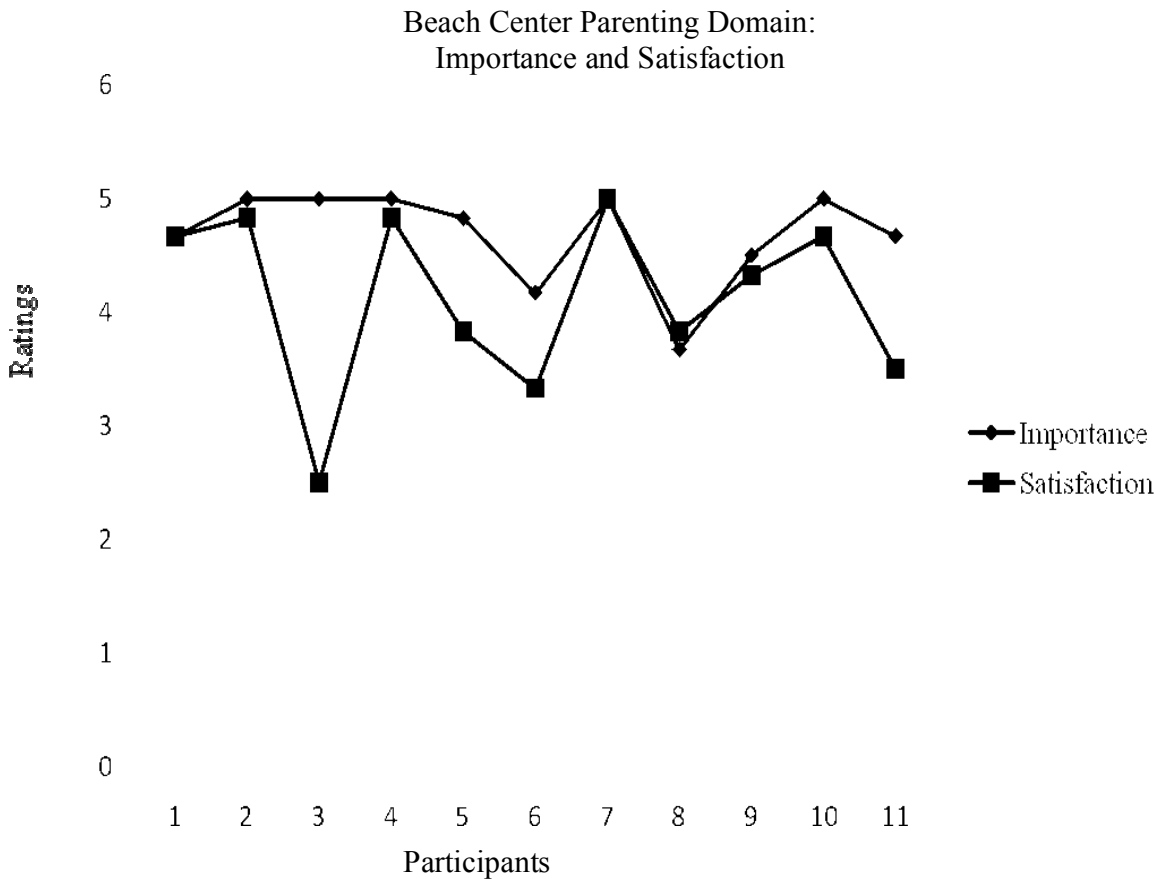
Figure 4.2. Individual scores on Parenting domain - Importance and Satisfaction.
NB: N = 15, but only 11 are displayed on this graph, because some cases had missing data in this domain.

In summary, results show that the Beach Center Parenting domain is an important element of FQOL. However, the most interesting results were in terms of "taking care of the individual needs of every child" and exploring the cases who presented as outliers. FQOL measures should question those elements of Parenting that are important to families. This can be done in a briefer manner than the six questions of the Beach Center survey of presenting. It is suggested that FQOL measures include an open question asking participants to explain any impact of parenting on their FQOL; for example, *"are there any elements of raising/ bringing up the children that are particularly important to your FQOL, such as taking care of the individual needs of every child; if there are, please explain."*

4.6.6 *"Influence of Values" Domain - International Survey*

The International Survey included the domain "Influence of Values", whilst the Beach Center Survey did not contain any questions associated with this aspect of FQOL. Every participant who completed the International Survey and responded to the "Influence of Values" section indicated that they held personal values, including personal morals such as; knowing right from wrong ($n = 11$, 73%), but less participants specified that the family had religious ($n = 6$, 40%), spiritual ($n = 4$, 27%) or cultural ($n = 4$, 27%) values. These values were, on average, using a scale of 1 to 5, rated as "very important" to FQOL ($M = 4.40$, SD $= 1.27$); and most participants were "satisfied" with the degree to which values contributed to FQOL ($M = 4.00$, $SD = .67$). There were no apparent outliers for satisfaction with Values from the 15 participants - all participants had selected from the middle satisfaction option and above. For importance, one participant differed to most of the others in that they selected "hardly important at all" and then went on to select "neither satisfied or dissatisfied", whereas most others had selected "quite" to "very"

important. With larger samples, participants who differ substantially from the mean would need to be considered further. Two participants stated that their family held all four areas of values (i.e., personal, religious, spiritual, and cultural), and they provided detailed explanations placing more emphasis on the importance of the "Influence of Values", to their FQOL. For example, one participant explained that *"[religious values] has very little to do with... our beliefs except that it helps you to understand... It [values] has a profound effect on decisions that you make; just for example, having a child with disability, some people would have sought out the information before she was born and terminated the pregnancy, but that is not even [an option for consideration] for us... and even if it wasn't a choice we made for religious or spiritual reasons, we would have made it anyway, for moral reasons"*. This participant further qualified the family's view by saying, *"Our appreciation of who she [member with disability] is... comes from those values"*. This participant did not mention any of this critical detail throughout the interview with the Beach Center Survey. The only hint of any reference to values was in response to the "Emotional Well-Being" domain question "having friends or others who provide support", in which the participant referred to the importance of having someone to *love and care* for the member with a disability.

For another family, attending church regularly was important; however, the participant expressed her disappointment throughout the interview with the International Survey at not being able to attend church at the same time as her husband, because one of them had to look after the member with a disability; *"the opportunities are there, except that there are a lot of things that we have to do alternately because we both can't go at the same time, which we'd like to do... when he [member with disability] goes to [respite] we go together"*. In this case the presence of a member with a disability in the

family led to restrictions on the family being able to do what they would like to do to maintain their values. This same participant did not refer to their family's values to the same extent during the interview with the Beach Center Survey, despite their obvious importance to the family. The only reference throughout the Beach Center Survey that was associated with religious values was in response to the "Emotional Well-Being" domain of "family members being able to pursue their own interests", in which the participant stated that they belonged to a church choir and a church group, but there was no further detail provided, other than that these groups were "critically important" to them and that they were "very satisfied" with having time to pursue their own interests. Thus, there was an apparent discrepancy between the International Survey qualitative response and the Beach Center Survey Satisfaction rating, insofar as the participant had explained in the International Survey domain on "Influence of Values" that she was disappointed that she could not go to church together with her husband, yet still reported being "very satisfied" with "having time to pursue own interest" in the Beach Center Survey. This suggests that the differences in wording between the two surveys allows for differences in interpretation. Questions therefore need to be as specific as possible, so that participants are prompted to provide specific informative details in their responses.

These results suggest that even though the Beach Center Survey did not have a specific question related to "Influence of Values", participants still had the opportunity to raise issues associated with the "Influence of Values" domain in response to certain questions, (for example in the "Emotional Well-Being" domain) but not to the same extent as was provided by the direct questions on values in the International Survey. There also seemed to be some implied emphasis on values in the Beach Center Survey "Parenting" domain item: "adults in my family teach the children to make good

decisions", because at least two participants responded to this question in relation to teaching personal *values*, such as right from wrong; and choices, such as experimenting with illicit substances; for example, *"I've done my best… I've always taught them good values… I trust my kids…none of them are [alcohol] drinkers or on drugs or nothing"*. This information was provided from extra qualitative questions asked by the interviewer, which emphasizes the importance of the interviewer seeking clarification, and it also suggests that all domains of FQOL can be interlinked, depending on the wording of survey items. The difference with placing this item in the "Parenting" domain is in the words "adults in my family *teach* children…"; if the question purely asked for the importance and satisfaction of "making good decisions" then it would be more appropriately placed in a "Values" domain. The words "adults in my family" also indicate that this is referring to perceived competency of the *adults*, whereas in the International Survey, items related to personal values (which may include personal values of making good decisions), referred to the *family* as a whole.

Given that only 13% (2 out of 15) discussed the "Influence of Values" comprehensively in their responses to the International Survey, it is not necessarily the case that a whole domain or section of the survey should be dedicated to values. However, since participants did mention church groups, religious morals, or personal values such as knowing right from wrong, throughout the International Survey, it is necessary to at least provide the participants with some explicit opportunity to comment directly on how these may or may not influence the ways in which the family deals with disability or copes with stress, etc. For example, participants could be asked: "does your family hold personal, spiritual, cultural, and/ or religious values that are important to your FQOL (yes or no)?" and then "if yes, please comment or discuss how they affect FQOL".

If the answer is "no" then there need not be a whole domain of questions dedicated to family values.

4.6.7 Transportation

The topic of "transportation" was incorporated into both surveys, but it was not considered in as much detail throughout the International Survey as it was in the Beach Center Survey. During the Beach Center Survey participants were asked "does your child currently need transportation and/ or mobility services" (item 9) and "does your family currently need transportation" (item 19). Both were followed by "if yes, how much service does your family get?" In the FQOL section of the Beach Center Survey under the domain of "Practical/ Material Well-Being", the questions "how important is it that my family members have transportation to get to the places they need to be", followed by "how satisfied am I that my family members have transportation to get to the places they need to be" (item 6) elicited much discussion by family members. The International Survey did not specifically ask about transportation, but it was a response option included in the "Health" domain as a possible barrier to the family accessing health care; and then in the "Support from Services" domain as an option for why the family was not receiving the disability related services they need.

Four (27%) participants mentioned transportation as an issue affecting FQOL during the interview with the International Survey. Of these four, only one also mentioned the same specific transportation issue in the interview with the Beach Center Survey and the other three cases (see examples below) did not present any concerns with transportation throughout the Beach Center Survey.

1. "Support from Services" domain:

   In response to the question: "Are there disability related services you need that you are not currently getting?", the participant explained a need for transportation training; *"Bus training... anytime that she had to go anywhere by bus...".* This mother explained that she had to train her daughter herself to be able to independently catch public transport, but she would have liked some formal assistance from the services with incorporating this critical skill into her child's life. This was not discussed in any part of the interview with the Beach Center Survey, but instead lack of funding and the need for more mobility allowance was mentioned with respect to transportation.

2. "Support from Services" domain:

   In response to the question "Why are you not receiving the disability related services you need?" the participant had at first said that transportation was not a problem, but later recalled; *"Come to think of it, transport can be a problem; one of the reasons is because they need 10 days notice to change anything for the transport to and from school if we use it... and the other thing is that you never quite know when they're going to arrive... the kids have to go to two separate schools... the issue I have is... how do I coordinate?"* [PCM0032]. There was no mention of transportation issues in any part of the interview with the Beach Center Survey for this participant.

3. "Financial Well-Being" and "Leisure and Recreation" domains:

   "The car I had, I had problems with it, then I brought this one, now I've got problems with it… as it is now, I've got to borrow the money so I can go get the starter motor and things fixed…" and then later on the participant was talking about the activities that the family takes part in, such as going to the Christmas pageant; *"At the moment… I can't live without a car… when you do have transport, life's a lot easier".* Once again, these issues were absent from comments and explanations in the Beach Center Survey.

Results from the Beach Center Survey showed that twelve (80%) family members considered transport as "critically important"; two (13%) rated it just below "critically important", and one (7%) indicated that it was "important". There were more varied responses for participants' satisfaction with transport; just over half (eight participants, 53%) were "very satisfied", three (20%) were "satisfied", three (20%) were "neither satisfied nor dissatisfied", and one (7%) was "very dissatisfied". Of the six (40%) participants who presented problems or negative concerns associated with transportation, only one of these same issues had also been mentioned in the interview using the International Survey. This means that these problems with transportation would not have otherwise been presented by participants with just the International Survey, suggesting that even though "transportation" was incorporated into other domains of the International Survey, the wording of such questions elicited different interpretations and hence different responses from participants.

Fifty-three percent of participants commented on the importance of having a family car to get around and that it was critical for at least one of the parents to have a

driver's license; *"I couldn't imagine catching buses... if I had to catch a bus I just wouldn't go anywhere"*. All of these families, except one who selected "neither" satisfied or dissatisfied, indicated that they were "satisfied" or "very satisfied" with respect to transportation at the moment. For example, two participants discussed how it may become more difficult once the father of the member with a disability becomes too old to be able to drive a car; *"Having a car to get around is important and as long as [father of member with disability] can still drive then it's okay"* and, *"One day when [father] loses his license... at the moment we don't need [help]... in future, yes [we will need help with transport]"*. These comments suggest that there is a need to ask about any future concerns with respect to family issues although neither survey specifically asked about this. Even though many (40%) commented on the availability of public transport (i.e., trains and buses), some (33% of participants who commented on public transport) expressed dissatisfaction with certain elements of it, such as running late or not being able to read timetables easily; for example, *"There could be more transport at a lot of different places... places where I can't go, which I'm too frightened to go because I don't think there's any bus routes there... so if there's not bus routes and you don't know how to get there well you can't go"*. Furthermore, a few participants (33%) discussed the use of Taxi services, particularly to and from school, which was usually a service that families considered critical and was free to families having a child with a disability. Some children's access to school is provided for by the public education system but not all, and adults do not receive such assistance with transport to work or day activities. Another cause for dissatisfaction with respect to transportation was that there was no extra funding to help pay for transportation. A few participants (20%) talked about "mobility allowance" and the little amount of government support they received to help

cover the cost associated with transporting the family member with a disability; *"we have got two cars, it's more just the cost associated with them that is a problem"*. For another participant, the school bus, which used to be a free service, was no longer being provided to her daughter due to her behavior and her refusing to wear a seat belt correctly, so now she was expected to pay for transportation herself; *"...she [member with disability] played up last week and the bus driver said 'nup [nope] she's not coming back at all'... they won't have her back on the bus... she got booted off [the school bus]... it's costing me 80 dollars a week in petrol at the moment"*. These results suggest that there should be some questions concerning the costs of family transport in the financial section of FQOL surveys, as well as an opportunity for participants to discuss transportation openly as an issue impacting FQOL. In conclusion, judging from responses to the Beach Center Survey items associated with transport and the few comments received in response to the International Survey, transportation and its associated costs are important elements of FQOL that should be directly incorporated in to FQOL surveys, either in a separate domain or in the domains "Support from Services" or "Financial Well-Being".

4.7 Differences in the Measurement Concepts of Both Surveys

The measurement concepts of Importance and Satisfaction were used in both surveys; however, measures for Opportunities, Attainment, Initiative, and Stability were only used in the International Survey. Results from the current study are discussed mainly in terms of comparisons in the use of the Importance and Satisfaction ratings, but comments are also provided on the Opportunities, Attainment, Initiative and Stability concepts.

4.7.1 Importance and Satisfaction

Table 4.3 shows that for the 15 participants in the current study there were some consistencies and inconsistencies between the responses from the two measures in terms of what was considered to be most and least important, and elements of FQOL that families were most and least satisfied with. Consistencies included high importance placed on: "Family Interaction" ("Family Relationships") and "Physical/ Material Well-Being" ("Health"; "Financial Well-Being"). Participants also consistently reported that "Support from Other People" (including service providers) was slightly less important, although it was still well above an average rating. The results were less consistent with respect to satisfaction insofar as the International Survey showed highest satisfaction with "Family Relationships", while the Beach Center Survey showed highest satisfaction with "Disability-Related Support: To accomplish goals at home". Similarly, the lowest satisfaction scores were in the domain of "Financial Well-Being" for the International Survey, and "Emotional Well-Being: Outside help available to help the family" for the Beach Center Survey. However, as with importance, all satisfaction scores were above an average rating. Some of the varied responses between the two surveys for satisfaction and importance ratings of FQOL can possibly be attributed to the different wording used in each survey. For example, participants reported that they were "satisfied" with "Leisure and Recreation" in the International Survey, but this was not a domain included in the Beach Center Survey. Similarly, for the Beach Center Survey participants reported that teaching their children to learn to be independent was important, but this was not a question in the International Survey. Importantly, even though these variations between the two surveys exist, participants generally reported that all FQOL domains were important. Even though participants were "dissatisfied" in some areas, the mean

satisfaction ratings were still reasonably high for most of the domains in both surveys. However, these data are based on only 15 participants from Australia. More data need to be collected and further comparisons need to be made in order to generalize results about the concepts of Importance and Satisfaction. When interpreting quantitative results, however, it is important to consider not only mean scores and standard deviations, but also individual differences and any outliers. In practical terms, there may be "outlier" families who might be in desperate need of urgent assistance. For service providers, just looking at high mean satisfaction scores for a group might suggest there is no need for any urgent interventions or any change in services; whereas investigating cases who stand out from the rest (e.g., those who score low satisfaction in domains that other participants are satisfied with), can enable further support and assistance to be provided and/ or facilitate changes in service provision. A particular strength of both surveys' measurement concepts is that they allow participants to express dissatisfaction in elements of FQOL that they have indicated as being important to their families.

In spite of some inconsistencies in relative ratings, the generally high mean Importance and Satisfaction ratings in both surveys support their concurrent validity. In order to assess their concurrent validity further, correlations were run on the survey items that were directly related. Table 4.4 shows three areas of FQOL that were included in both surveys and it can be seen that they correlated highly, with Pearson's Correlation Coefficients between .5 and .9. While definite conclusions cannot be drawn on the basis of only 15 participants, the results do suggest that the surveys measure similar constructs within the FQOL domains.

Table 4.3 *Most and Least Important and Satisfied Domains from Both Surveys (N = 15)*

	Importance		Satisfaction	
	MOST	LEAST	MOST	LEAST
International Survey	1. Health *M* = 5.00 *SD* = .000	1. Practical Support from Other People *M* = 3.60 *SD* = 1.647	1. Family Relationships *M* = 4.77 *SD* = .439	1. Financial Well-Being *M* = 3.15 *SD* = .899
	2. Family Relationships *M* = 5.00 *SD* = .000	2. Emotional Support from Other People *M* = 4.09 *SD* = 1.221	2. Practical & Emotional Support from Other People *M* = 4.09 *SD* = .831	2.Community Interaction *M* = 3.89 *SD* = 1.054
	3. Financial Well-Being *M* = 4.58 *SD* = .515	3. Support from Services *M* = 4.38 *SD* = 1.121	3. Leisure & Recreation *M* = 4.08 *SD* = .669	3. Support from Services *M* = 3.92 *SD* = .760
Beach Center Survey	1. Family Interaction: Love *M* = 4.93 *SD* = .258	1. Emotional Well-Being: Outside help available to help the family *M* = 4.00 *SD* = 1.363	1. Disability-Related Support: To accomplish goals at home *M* = 4.46 *SD* = .519	1. Emotional Well-Being: Outside help available to help the family *M* = 3.25 *SD* = 1.288
	2. Physical/ Material Well-Being: Medical *M* = 4.93 *SD* = .258	2. Disability-Related Support: Relationships with the service providers *M* = 4.40 *SD* = .910	2. Physical/ Material Well-Being: Medical *M* = 4.27 *SD* = 1.100	2. Emotional Well-Being: Time to pursue own interests *M* = 3.46 *SD* = 1.56
	3. Physical/ Material Well-Being: Safety *M* = 4.93 *SD* = .258	3. Parenting: Learn independence *M* = 4.47 *SD* = .743	3. Parenting: Learn independence *M* = 4.27 *SD* = 1.100	3. Physical/ Material Well-Being: Having a way to take care of expenses *M* = 3.47 *SD* = 1.302

Table 4.4 *Correlations between Specific Survey Items (Importance and Satisfaction)*

		Medical (Satisfaction)	Take Care of Expenses (Importance)	Take Care of Expenses (Satisfaction)	Time to Pursue Own Interests (Importance)	Time to Pursue Own Interests (Satisfaction)
INTERNATIONAL SURVEY DOMAINS	Health (Satisfaction)	r = .744 p = .004**	-	-	-	-
	Financial Well-Being (Importance)	-	r = .683 p = .014*	-	-	-
	Financial Well-Being (Satisfaction)	-	-	r = .597 p = .031*	-	-
	Leisure and Recreation (Importance)	-	-	-	r = .553 p = .077	-
	Leisure and Recreation (Satisfaction)	-	-	-	-	r = .842 p = .002**

*significant at the p < .05 level   **significant at the p<.01 level

NB: Health/ Medical (Importance) has not been included here because for the International Survey all participants selected "Very Important", meaning that the variable was constant.

4.7.2 Opportunities, Initiative, Attainment, Stability

A few participants did not seem to know how to respond to, or they did not understand what was meant by, the International Survey's concepts; Opportunities, Initiative, Attainment, and Stability. Certain questions such as: "are there opportunities for members of your family to…?" (Opportunities) or "to what degree do members of your family enjoy good health?" (Attainment) resulted in participants asking *"what does that mean?"*. These International Survey questions sometimes required further explanations by means of the interviewer elaborating on exactly what was being asked and re-wording the question. For example, "are there opportunities for your family to…?" was changed to "is it possible for your family to...?" or "are there restrictions on…?" and

only then was the participant able to select from the quantitative options. This lack of understanding the question at first could be due to vagueness of the words "opportunities" or "enjoy". While these difficulties in interpreting the concepts only occurred to a limited extent in the current study, with larger samples it could be problematic, particularly if the survey is being self-administered because there is no opportunity available for an interviewer to explain the concepts.

Furthermore, three of the 15 (20%) main caregiver participants from the current study stated that they had learning disabilities themselves, and these participants needed to be carefully considered and accommodated accordingly. For example, the items associated with the measurement concepts in the International Survey needed to be reworded, but this was not the case for any of the Beach Center Survey questions. For people self-administering the surveys who may have difficulties reading and/ or understanding the questions due to their own disability, it is important to provide easily understood questions and ratings. For example, one participant stated at the very beginning of the interview using the International Survey that *"we [participant and her 9 year old daughter] have problems understanding what people say… so you have to explain it over and over again so we understand what you mean…"*. In order to ensure ease of understanding, it is important for individual questions to only address a single issue. Future research needs to explore this issue further to ensure that questions are worded so that participants are capable of providing accurate FQOL information and that missing data and/ or very low scores indicate a real need for support, and not just a misunderstanding of questions.

4.7.3 Repetitiveness of Measurement Concepts and Limitations to Likert Scale

During interviews using the International Survey, when responding to questions

from Section B of each domain (i.e., the six measurement concepts), many participants

found the concepts and their associated quantitative options repetitive. For example, by

the time the survey reached Section 6 ("Values" domain) and after two hours of being

interviewed, one main caregiver said *"this is getting a bit repetitive isn't it?"*. Problems

with the repetitive nature of parts of the International Survey were also illustrated by one

mother, who when phoned and invited to participate in the Beach Center Survey, after

having completed the International Survey previously, stated that she was happy to

participate again, *"as long as it is not as repetitive as the last one"*. When questioned

about this comment, the participant indicated that she was referring to Section B (the six

measurement concepts) of each part of the International Survey. This participant did not

make similar comments about the Beach Center Survey, but instead commented at the

end of the interview: *"that was OK"*. However, participants did express some concerns

about the repetitiveness of the quantitative questions for *both* surveys. To avoid the

Beach Center Survey also becoming tedious due to its predominantly quantitative nature

involving ratings, the interviewer found it necessary, in order to maintain rapport and to

supplement the quantitative information, to ask extra questions, such as "what do you

mean by that?" or "can you please explain that?" For example, the interviewer added to

the Beach Center FQOL question about support to relieve stress, "what sorts of avenues

do you go to for that kind of support, when you need to relieve stress?" and the

participant responded, *"I just talk to family that's all... my mum... and friends"*. It is

recommended that such questions be added to the surveys, not only to avoid

repetitiveness, but also in order to check that participants have understood and interpreted

the questions correctly, as well as to better understand the details associated with satisfaction or dissatisfaction. In the above example, it was unclear until the additional open question was asked, as to who or which service the participant was referring to when she stated that it was "critically important" and that she was "very satisfied" with having support to relieve stress.

Many participants found the 5 point Likert scale options in both surveys to be limiting, and most chose to explain their situation further whether or not there was a direct qualitative question being asked of them. "Missing data" from the current study was not necessarily the result of participants misunderstanding the questions, or from accidentally missing questions when completing the surveys themselves, but may have also been because participants found it difficult to select a rating. For example, for the Beach Center Survey FQOL question asking about the degree of satisfaction with the family enjoying spending time together, one participant chose not to select a satisfaction rating, but instead differentiated by saying that when the family does get the chance to spend time together it is good; *"Are you talking about the quality or quantity?... I am happy with the quality, not happy with the quantity"*. This same participant also broke down his satisfaction ratings for the Beach Center Survey FQOL question about outside help to take care of the family; *"Are we talking about [disability service provider/ Autism service provider] or are we talking about family wise...? The services we are very happy... [but with relatives, friends and neighbors we are] neither [satisfied or dissatisfied]...they are too busy"*. In some instances participants decided not to select a general satisfaction rating for the whole family, because it was very different for different family members. For example, in the interview with the Beach Center Survey, one mother explained that she was "very dissatisfied" with having time to pursue her own

interests, because she needed sleep and was doing housework whenever she had a free moment; but she was "neither" satisfied or dissatisfied with the kids having time to pursue their own interests, because they were all able to do what they wanted to. Similarly, in response to the Careers - Opportunities question from the International Survey, one participant felt that she could not select a rating, because it was different for her and her husband; *"very limited for me… with my husband yes [there are opportunities] and that's our choice that it would be him that would pursue it rather than me… the reality is that there aren't too many three day a week jobs where we can each have a three day a week job… and he can probably earn more in his one job pursuing his career than we could doing that anyway"*. These results once again emphasize the need for questions in both surveys to be revised and worded carefully to avoid perceived ambiguity as much as possible. These issues also support the use of the interview format whenever possible, which enables additional questions to be asked to clarify the participant's interpretation, and to understand participant's family experiences more clearly.

4.7.4 High Importance, Consistencies and Contradictions of Ratings

Consistent with the literature and previous results using both surveys, participants in this study often selected at the high importance end of the scale (i.e., "very important" or "critically important") for almost all elements of FQOL in both measures. As explained by Hoffman et al. (2006) the little variation in responses to importance was expected, given that the surveys were designed to efficiently represent factors that were of high relevance to FQOL. The same result is evident in the sample Standard Deviations in Table 4.3 where it can be seen that all FQOL items were relevant to all families, because there was very little dispersion around the mean and the mean was usually

closest to the highest importance rating. As a result, responses tended to become quite repetitive. Arguably, since we already know (from the background development of both surveys and the current results) that the FQOL indicators presented to participants are important to FQOL, the value of continuing to ask participants about importance is questionable. However, the case for continuing to ask about importance is that it is useful to explore outliers, in which particular caregivers stand out from the rest, because they have specified that certain elements were not important to their family. In these instances it is critical to obtain explanations of why certain elements are not so important to FQOL. For example, for one participant, Support from Services was *"not very [important] but it's nice to know it's there... For me... individually it's nice to know that it's there but for others it'd be very important...".* This participant was viewing her family's situation in light of what it could be like or in comparison to other families, and this critical explanation may not have been obtained if the survey was self-administered.

An advantage of the International Survey was that participants had the chance to explain their family story or circumstances first in each of the domains, and then they were able to reflect on how important various elements were and how satisfied they were with them. In addition, the second to last question of the International Survey asked participants to rate how satisfied they are with their FQOL overall (from 1 = "very dissatisfied" to 5 = "very satisfied"). Overall satisfaction ratings were found to be consistent with the satisfaction ratings that participants chose for the individual domains. The Beach Center Survey did not allow for participants to explain their situation first, nor did it ask for an overall FQOL rating. This resulted in some notable inconsistencies between quantitative ratings and qualitative explanations. For example, one mother selected "very satisfied" to the Beach Center Survey FQOL item "family enjoys spending

time together", but then went on to explain that, *"[sibling 1] is jealous of [sibling 2] and they don't get on too well. This disappoints [their father]"*, and even though the participant had responded with the quantitative option just before "very satisfied" about family members supporting each other to accomplish goals, the participant then went on to state: *"sadly I don't think it happens"*. These comments would be more consistent with a rating at the "dissatisfied" end of the scale. There were some contradictions between quantitative and qualitative responses to the International Survey too. For example, one respondent did not select an Importance rating for the domain of "Leisure and Recreation", because *"I don't know how important it is because I don't have it"*, but then went on to indicate "satisfied" for the satisfaction rating of the same domain. The extent of such inconsistencies needs to be explored with larger sample groups, since they only occurred for a few individuals in the present study. These examples once again indicate the need, whenever possible, to obtain qualitative explanations to accompany the quantitative ratings in both surveys, in order to check the accuracy of ratings and to better understand FQOL.

4.7.5 Summary and Conclusions Associated with Measurement Concepts

Questions concerning Opportunities, Initiative and Attainment (in the International Survey) were designed to determine whether participants made efforts or were actually able to acquire particular elements of FQOL, such as socializing outside the family and receiving practical and emotional support. However, some participants had problems understanding some of these concepts and their ratings. The usefulness of asking about Opportunities, Initiative and Attainment *separately* was also found to be questionable, because most participants indicated that the opportunities do exist but restrictions placed on the family by having a child with a disability mean that the

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opportunities cannot be taken up. For example, one mother explained that when it comes to socializing outside of the family, *"often you decline invitations because... then you think about will [member with disability] be home alone... tend to not bother, it's too hard"*. Accordingly, quantitative results need to be interpreted with caution; and interviews are recommended whenever possible in order to clarify the participants' understanding of the measurement concepts; and to obtain further explanations of why participants chose certain options for each of the additional measurement concepts.

The Initiative concept was designed partly to determine whether the reason for not obtaining certain elements of FQOL was due to lack of effort by the family to acquire them. For example, one mother became very emotional when responding to the Support from Other People section as she indicated that the family makes "a little" bit of effort ('Initiative') to get practical and emotional support; and followed again by explaining in response to the 'Attainment' question that the family does not receive as much support from others as they would like, *"...but then that's probably our fault as well, because you don't tend to... you don't ask for it."* This was a common theme for many participants, particularly those who indicated that they were more likely to put in the effort to make themselves heard, resulting in obtaining what they required. These participants commented that they believed that they can attain particular elements of FQOL if they make the effort. For example, when talking about Support Services one mother said, *"...I've done it all... if I wasn't the sort of person that I was, [my son with a disability] would have fallen through the cracks, because there isn't enough out there... I worry so much for the ones that just don't give a damn about their kids... there must be a lot of children falling through the cracks, which is a damn shame"*. This discussion about the amount of effort or initiative needed in order to obtain required services was also present

in the qualitative responses to the Beach Center Survey, even though it was not directly asked about. Generally when participants were provided with the opportunity to discuss obtaining their service needs they would mention that they personally had to put in a lot of effort. For example, with respect to physical/ occupational therapy, one participant explained that *"they [special school] do [provide it], but only if you ring up and say you want something..."* These results suggest that the measurement concepts of Opportunities, Initiative, and Attainment the International Survey are interrelated and should continue to be asked about and assessed in FQOL measures. However, they may be more accurately assessed by not asking them as separate constructs and not as quantitative ratings. Such a question could be reworded as, "Discuss what is *possible* and what is *difficult* to obtain with the *effort* your family makes to *obtain* the *desired* outcome for [each FQOL domain]?" With the key words (in italics in the above statement) in place, FQOL surveys could add qualitative questions such as "please comment" or "please provide examples".

The Stability concept served the purpose of finding out about the families' perceptions of their future, with respect to whether they think certain areas of FQOL will improve, stay the same or decline. While all participants understood this question, a common response was "I don't know". The majority also indicated that while they would *like* and *hope* for it to improve, they were uncertain as to whether or not that would be the case. Uncertainty about the future was found to impact on present FQOL, particularly with respect to *"fear of the unknown"*. This supports the inclusion of questions about Stability to fully understand present FQOL (See section on 'Past and Distant Future' of this chapter for further details and evidence).

Overall, questions on Opportunities, Initiative, Attainment and Stability enabled the International Survey to cover FQOL far more comprehensively than the Beach Center

Survey, which needs to incorporate similar types of questions. However, while the current results support the validity of the Importance and Satisfaction measurement constructs, it also confirmed that all FQOL domains were generally important to most families. Accordingly, it is questionable whether it is worth the additional time required to repeat this question for all domains. It might be worth considering a more general question as to whether there are any of the domains, or aspects of them, that are particularly important to the participant and if so, why? It could then be asked if there are any domains, or aspects of them, that are of little importance to them, and if so, why not? For domains indicated as being of little importance there may be no need to continue to ask about them, once it has been explained as to why/ why not that area is/ is not important to the family.

4.8 Past and Distant Future

> *"As [member with intellectual disability] gets older it's harder to*
> *get respite from the responsibilities of caring for her, it's harder*
> *to get people to be willing to take caring for her on. And that in*
> *turn affects all of us…when she was younger she was just a baby*
> *like any other baby to care for…"*.

Previous research has not explored the effects on present FQOL of significant events in the past, or those anticipated in the more distant future. Family well-being is subject to change (for better or worse) depending on events or transitions that may enhance, disrupt or unsettle everyday family routines (R. I. Brown et al., 2004; Llewellyn, Thompson et al., 2003; Owen et al., 2002; Rapanaro, Bartu, & Lee, 2008). Esbensen and Benson (2006), who conducted their research on individuals with

disabilities and not their families, found that people with intellectual disabilities who experienced more life events, such as changes associated with family, work, and social activities, reported more depressive symptoms and more behavior problems. These results highlight the importance of gaining information about life events or issues in the past and anticipated for the distant future. Research to date has not explored these issues in relation to FQOL; and neither the International Survey nor the Beach Center Survey questioned how elements of the family may have changed over time, particularly with respect to the significance of past events.

Based on comments made by family members in the present pilot study, asking about past circumstances or events was important, and in some cases essential, to understand how FQOL had changed over time and how present FQOL continued to be affected by past events. Accordingly, the following questions concerning the past were added to the interviews:

1. Has your immediate family changed over the past few years and, if so, in what ways?

2. In the past, has your family's [Health/ Financial Situation/ Relationships/ Support from Others/ Support from Services/ Values/ Careers/ Leisure and Recreation/ Community Interaction – i.e., for each domain/ section of the International Survey] been any different to what it is now? If yes, please explain when and why (including before children were born)?

3. In the past, has your *overall* family quality of life been any different to what it is now (including before the child with a disability was born, or at relevant transitional periods)?

In the current study all except one of the 15 participants (93%) presented issues about significant past family event/s that impacted negatively on their present FQOL including, a major health concern for any family member; a change in career, such as

main caregiver giving up their job in order to care for the member with a disability; or illness/ death of close relative who had provided support in the past, leading to a decrease in FQOL. Seven participants (47%) described a change for the better including, a new partner to the main caregiver, resulting in extra support for the whole family; or more support services now, such as extra respite. These concerns were raised in response to the additional questions added by the current researchers, and not in response to direct questions as part of the existing surveys. Of the 15 participants, only about 4 (27%) raised these issues incidentally, during informal discussions throughout interviews. This indicates that participants are not likely to mention such points, unless the additional direct questions about the past are asked. Nevertheless, issues of the past can impact on present FQOL. For example, a father explained that *"if you came to me, say 5, 6 years ago this [answers to the survey] would have been totally different"*. This participant explained that he was very stressed out in the past, due to being home constantly with his son who has an intellectual disability and significant behavioral issues. Under the doctor's advice, this participant stated that *now* FQOL is far better, because he has returned to work and the member with an intellectual disability participates in day activities. Therefore a significant change made in the past resulted in better present FQOL.

With respect to the possible effect of concerns about the future on present FQOL, the International Survey did ask participants about their perceptions of the Stability of FQOL domains in the *near* future (e.g., over the upcoming couple of years), in terms of whether they anticipated improvement or decline, but neither survey directly asked about how participants anticipated the *distant* future (e.g., over the next 10 to 20 years). In the current pilot study, none of the participants mentioned issues about the distant future and

so no questions of this kind were added to the two surveys. However, such issues about the distant future did emerge, suggesting that questions about concerns related to the distant future need to be added to FQOL surveys. In response to questions about the future in the International Survey and/ or as part of general comments throughout interviews, most participants in the current study mentioned that in their experience, medical, vocational and accommodation services, which are more important in adulthood and which can be expensive, must be sought out by parent-caregivers and paid for by the family. For example,

"We [parents] can get a bit down from time to time because we have anxieties for the future of the children. Will they get jobs or the careers they want? Where will they be?... People have told them just to take their pension and be happy with that... that crushes any hopes of being able to work 'normal' jobs... they can work with normal people and not just earn a measly $10 per week... people give the impression that because they have a disability then they cannot work in the mainstream."

Present FQOL was also found to be negatively affected by the belief that fewer resources would be available when the member with a disability is older, than were available when the child with a disability was younger. These concerns were only raised incidentally throughout interviews. The following examples from interviews illustrate how concerns for the near and distant future, including transition from school to adulthood (a separate area of research e.g., Blacher, 2001; Glidden & Jobe, 2007; Jokinen & Brown, 2005; Nuehring & Sitlington, 2003); accommodation; and what will happen to the child when the parents dies, can impact on current family life:

"[When member with disability leaves school] I've pretty well been told that she won't get anything - none of the workshops, because of her behavior… Options [disability service] won't do anything until she's actually ready to leave school".

"They [disability-related support services] will be somewhat important later I think… when he's out on his own… because that's a bit of a problem… we [main caregivers] can't live forever and whether it's more important to get [member with disability] settled before we 'move on' [die]… I don't know… we've already got his name down for housing trust and accommodation…"

*"I want *** [member with disability] to go [die] before me coz [because] then I won't have to worry about her… Do I take her with me [when I die]?… how do I take her with me?… who can look after her?… who's gonna [going to] put up with her?…They [sisters] know that they won't be left with caring for ***."*

These examples show that parents were worried at the present time about these anticipated future issues, and a considerable amount of time was being spent looking for viable options for the future. Supports from services for these areas of future need (e.g., careers and accommodation) were often not forthcoming. Despite their apparent influence on current FQOL, especially evident by the fact that family members felt the need to talk about these issues during the interviews, neither survey addressed such issues concerning the distant future and their possible affects on present FQOL. Instead, these issues were raised incidentally in response to other questions. For example, in response to the Beach Center Survey question about making friends, which did not specify anything

about the past or the future, one participant said, *"when he gets to a group home it'll be important"*. This indicates that the participant was concerned about introducing something new (help with making friends) into the life of the member with intellectual disability in the future.

For the purpose of service provision, measures of FQOL need to include questions about the past and the distant future in order to more fully understand present FQOL and the way it has changed and is likely to change at different developmental stages. This information can also help current disability services provide more appropriate support, including relevant information about disability services for the future of the family. Such information might also enable disability services to schedule future specific support resources for families and to plan transition services that can prepare families to better cope with the developmental transitions when they occur. Being aware that such services will be available might also reduce the anxiety felt by parents about the future of their child with a disability and hence improve their present FQOL.

4.9 Conclusions & Recommendations for FQOL Measures

FQOL is an important area of research, because more people with disabilities are now living at home with their family rather than in alternative care settings. Results from the current study show support for a multi-dimensional framework to measure FQOL, including domains that encompass a wide range of objective and subjective aspects associated with family life such as; support from disability- related services; leisure activities; involvement in the community; and material or physical well-being. This was to be expected given that both the International Survey and the Beach Center Survey were developed on the basis of the practical experiences of families having a member with a disability, and relevant statistical analyses by the developers have shown that the

surveys are reliable. The current study contributes to cross cultural validation of the surveys, because both were found to be culturally relevant to issues concerning families that have a member with a disability in Australia. This was demonstrated by the acceptance of the questions by participants with relatively little rewording required and by the fact that no cultural issues were raised concerning the nature of any of the questions. Both surveys also demonstrated good face validity insofar as all participants readily answered the questions concerning their family and did not raise any issues about the relevance of the questions (even though some were seen as of very personal nature) to their FQOL. It can therefore be recommended that both surveys continue to be used as measures of FQOL. Within both surveys there were considerable similarities between the domains, and in each survey participants were asked to indicate their responses to Importance and Satisfaction levels on a 5-point Likert Scale. However, the International Survey also asked about Opportunities, Attainment, Initiative and Stability, which, despite some issues with interpretation and understanding of the wording, provided additional useful information relevant to FQOL; even though it did make the International survey more repetitive than the Beach Center Survey. As a result, the International Survey does provide a more comprehensive assessment of FQOL domains, although its greater number of items means that it takes longer (average of 1hr. and 55 minutes compared with 55 minutes) than the Beach Center Survey to complete. The International Survey also elicited more qualitative comments because it presented all items in a domain/ topic consecutively before moving on to the next domain/ topic, with survey items organized into logical sections (as opposed to the Beach Center Survey design of items being presented in a random order).

Each survey may be more or less appropriate for research purposes or service provisions depending on the amount of detailed information required, the time available, the cost to administer, and/ or the number of families to be assessed. Some research projects may only require particular information from the shorter Beach Center Survey, whilst some service assessments may find the longer, International Survey useful for individual families in crisis. The shorter Beach Center Survey may be more desirable for service providers undertaking outcome evaluations. However, the Beach Center Survey elicited less detailed responses, and did not result in the substantial qualitative information required for other types of research that was provided by the International Survey. The International Survey developers have taken these different requirements into consideration by developing a short and long version of their survey. Since the short version was not used in the current study, it requires further research to evaluate its relative advantages and disadvantages. The extra qualitative data obtained from interviews with the Beach Center Survey in the current study cannot be compared with qualitative data from other studies using the Beach Center Survey, because they mostly used self-administration and have not specified whether follow up interviews were conducted.

While all domains of FQOL were considered by participants to be important, Transportation was found to be a particularly important issue for many families. The Beach Center Survey covered this issue in detail and resulted in families explaining that having means (e.g., a family car, or taxi/ bus service) for transporting the member with an intellectual disability around was critical to making life easier for the family. Another area of particular concern was being able to take care of the individual needs of every child in the family; for example, participants described the often negative effects on the

siblings of the member with a disability, which in turn impacted the whole FQOL. For the six participants who had more than one family member with a disability, it was found to be necessary to provide them with the opportunity to talk about all family members with a disability (as allowed for by the International Survey) and not just the one who has 'the most impact on the family' (as required in the Beach Center Survey). It was critical to understand the impact that more than one member with a disability can have on the family as a whole. Further to this, the Beach Center Survey item, "knowing others in the children's lives (i.e., friends, teachers)" from the "Parenting" domain did not appear to be as important as other items such as "teach the children to make good decisions" or "have time to take care of the individual needs of every child". Likewise, the International Survey domain "Influence of Values" was found to be of some importance to participants, but not of as high importance as other domains, such as "Health of the Family" or "Family Relationships". Revisions of these survey measures and future FQOL measures need to consider incorporating all of the abovementioned elements in order to provide a more comprehensive and useful assessment of FQOL.

During interviews with both surveys it was found useful, and in some cases necessary, to ask additional questions about family life in the past and in the anticipated future in order to adequately understand present FQOL issues. In many cases significant family events in the past were found to have an impact on present FQOL, and apprehension about anticipated FQOL issues in the distant future was also of present concern for many families. These concerns about the past and the future were raised in almost all domains of FQOL. For example, many Australian families were very concerned about the support from services that would be available in the future, because the amount and quality of support was perceived to vary according to the age of the

member with a disability, with early childhood receiving the most family based support. The results of the present study suggest that it is important to consider service provision, and information provided about such service provision, across the lifespan, because the impact of having a member with a disability can be different for different family members at different times.

Overall, the results of the present study suggest that both surveys are efficient measures of FQOL. However, both measures could be improved by some modifications, revisions and refinement. For example, interview results suggested that it is critical to supplement quantitative data with qualitative information, and self-administered surveys should be followed up with face-to-face interviews where possible. Such interviews might involve asking questions about relevant past events and any concerns about the future. This is particularly important to clarify any apparent inconsistencies in the results. In a practical sense, it is not sufficient for service providers to acquire information that families are dissatisfied with respect to disability related support; service providers need to know *why* main caregivers are expressing this dissatisfaction, and in order to obtain this information qualitative methods are required. Hence, it is suggested that face-to-face interviews using the surveys (rather than self-administration) should be preferred, in order to obtain more detailed, in-depth qualitative information. However, further research is needed with a larger sample of participants self-administering the surveys, in order to more accurately compare the user-friendliness, amount and quality of information obtained between the self-administered and interview formats.

4.9.1 Limitations to the Current Study and Further Research

The main aim of the current study was to compare the results of the two measures for the purpose of understanding the surveys' validity and applicability in an Australian

context. This study did not consider the practical use of the surveys by service providers or policy makers. Internationally, both surveys have been found to be useful for service delivery and policy making, but these applications are yet to be demonstrated in Australia, where there has been little research reported on the practical usefulness of FQOL measurement.

FQOL is a relatively new area of research in the disability field and further research is needed, particularly in the following areas:

- To assess not only the reliability and validity of FQOL measures but also their practical usefulness in different countries, including Australia.

- To assess the capacity of the measures to obtain relevant FQOL information from more varied family demographics and family circumstances (in the present study most families were lower middle class, two-parent families living in metropolitan areas).

- To compare both FQOL measures in larger groups using self administered and interview formats in order to determine how the self administered questions can be refined to obtain more of the critical qualitative information available from interviews.

- Conduct cross-cultural comparisons of the two measures controlling for different variables including the age(s) of member(s) with a disability and the types, levels and combinations of disabilities. Such studies are needed to determine the extent to which family issues related to disability are similar across different countries and cultures.

- Evaluate the extent to which the practical use of FQOL measures by disability services advances the delivery of their services in terms of significant improvements in FQOL.

This study aimed to contribute to the evaluation of two existing FQOL measures and to investigate associated issues that might have implications for improved FQOL measures that could assist in appropriate provision of services to families having a member with a disability. Results suggested that the two measures of FQOL in the present study are both useful for the assessment of FQOL, but that both can and should be improved to facilitate the research, service provision, and policy development, that are required to improve the quality of life of individuals with an intellectual disability and their families.

Chapter 5: General Discussion and Conclusions

5.1 Overview

This chapter first explains how the thesis aims were achieved. Secondly, it revisits the literature presented in the previous chapters in light of the current findings associated with Family Quality of Life (FQOL) measurement. Thirdly, this chapter discusses the practical implications of the thesis results to support services for families that have a member with an intellectual/ developmental disability. Lastly, it highlights limitations in the current research and generates suggestions for future FQOL research. At times throughout this chapter data that is supplementary to those presented in the previous chapters have been drawn upon to further illustrate the points made.

5.1.1 Acknowledgement of Forthcoming Research and Publications

Although previous research has highlighted a need to understand better the concurrent validity of existing FQOL measurement tools (e.g. Isaacs et al., 2007), to date there have been no studies published that have collected information from families by using both the FQOLS-2006 and the Beach Center FQOL Scale. The author acknowledges, however, that similar unpublished preliminary research is currently being conducted in the United States by P. Samuel. To date Samuel has collected data from 44 participants using both the FQOLS-2006 and the Beach Center FQOL Scale (P. Samuel, personal communication, July 14, 2010). However, these data were not available to make comparisons with the current data at the time of thesis submission. The current research has contributed valuable and unique information towards the improvement of current measures of FQOL.

The author also acknowledges a forthcoming FQOL Special Issue of the Journal of Intellectual Disability Research, due to be published in late 2010. At the time of thesis

submission, the author had submitted (as primary author and co-author) three papers for this special issue. The first co-authored paper (Samuel et al., Submitted 31st July 2010) consists of a literature review of FQOL, including a comparison of the two FQOL measures as detailed in this thesis. The second paper is the article which has been included in Chapter 3. It presents the Australian results, using the internationally developed FQOLS-2006. The third paper is a cross-cultural validation of data from various countries using the international FQOLS-2006. The cross-cultural research was conducted by researchers in the US, and hence has not been included in this thesis. The thesis author contributed the Australian data and served an editorial role in the formation of the paper.

5.2 Review of Thesis Aims

The broad aim of this thesis was to use existing literature associated with conceptualising, measuring, and applying Quality of Life (QOL) and Family Quality of Life (FQOL) in the intellectual/ developmental disability field as a basis to further investigate FQOL measurement issues. The research reported in this thesis has addressed this aim by providing some evidence concerning the cross-cultural reliability and validity of the two internationally developed measurement tools (Beach Center on Disability, 2003; FQOLS-2006, I. Brown et al., 2006). While more research on these issues is required, the present study did show significant correlations between those items from each survey that were similar. The relatively small sample size in this study means that these results must be treated with caution with respect to their generalisability.

The rationale for this research was that over the past couple of decades new research directions have added further evidence to support the recognition that individuals with intellectual/ developmental disabilities have needs that are beyond those

required by typically developing peers (Schalock et al., 2002). Coupled with this, it has been recognised that, in order to address those additional needs, support services need to consider the environment of the person with a disability, including the critical support from families, (Park et al., 2003; Schippers & Van Boheemen, 2009). Moreover, family-centred research has become increasingly important because of heightened awareness that people with intellectual/ developmental disabilities and their families have the same right to live a life of quality as everyone else. Also, the family needs to be supported to continue to care for their relative with a disability at home if they wish to do so. Hence, for these rights and needs to be fulfilled, it is important to be able to measure FQOL effectively. Throughout the thesis, the author has highlighted that, by effectively measuring factors that contribute to satisfaction with FQOL, support services can be better informed about the specific support needs of families that have a member with an intellectual/ developmental disability.

Previous FQOL research has mostly occurred in countries other than Australia. However, as outlined in Chapters 1 and 3, families are just as important to the lives of people with intellectual/ developmental disabilities in Australia as with other countries. Moreover, cross-cultural comparisons are important because particular dimensions considered critical to QOL or FQOL in one culture are not necessarily the same as for other cultures (R. I. Brown & Brown, 2005; Verdugo, Schalock et al., 2005).

5.3 Summary of Thesis Findings

In answering the research questions outlined in Chapter 1, this research found that:

- Practical and emotional support from others are separate constructs attained by families at different levels;

- Having means of transportation is an important element influencing FQOL;

- Significant past events and apprehension about the future impact on current FQOL;

- Families consider it important to address the individual needs of every child in the family; and

- When the family has more than one member with an intellectual/ developmental disability, these members each impact on the family in different ways.

Consequently, when measuring FQOL there is a need to assess separately practical and emotional support provided to the family from friends and relatives; transportation issues; the impact of significant past events on current FQOL; the impact of having a family member with an intellectual/ developmental disability on siblings; and the separate impact of each member with an intellectual/ developmental disability on the family.

With respect to the methodology used for collecting FQOL information, the current results have supported the use of a multi-domain FQOL framework. The current results have also found that it is necessary to incorporate both qualitative and quantitative questions in FQOL measurement and to address the outcome measures of attainment and satisfaction. Furthermore, face-to-face interviews should be conducted. However, if this is not possible then self-administered questionnaires should be supplemented with additional qualitative questions in order to further understand the meaning that families assign to their FQOL. Both the FQOLS-2006 and the Beach Center FQOL Scale were found to be useful for measuring FQOL comprehensively within an Australian context.

Furthermore, high correlations were found between the two surveys, indicating that they measure similar constructs within the FQOL domains.

The abovementioned main findings will be summarised briefly in the following sections, and then discussed in further detail in section 5.4 with respect to practical implications. Chapter 4 compared the two FQOL measures; therefore the following discussion does not consider the two FQOLS measures separately, but the results that have transpired from using the two measures. The following section considers FQOL measurement in a holistic sense. It describes critical characteristics of family life that FQOL measures need to address, in order for assessment findings to be translated to improved support services for families.

5.3.1 Important Areas for FQOL Measurement to Consider

5.3.1.1 Domains and Concepts

The current study confirmed the multidimensional nature of QOL and FQOL (Cummins, 2005; Schalock, 2004b). It also confirmed the relevance of existing FQOL domains. All participants in the current study were able to respond to the quantitative questions and comment on their FQOL in each domain. These domains were:

- family interaction/ relationships and parenting;

- emotional well-being (e.g. support from other people);

- physical /material well-being (e.g. health/ financial);

- community interaction/ social inclusion; and

- disability-related support.

(Beach Center on Disability, 2003; I. Brown et al., 2006; I. Brown, Brown et al., 2000; R. I. Brown et al., 2006; Hoffman et al., 2006; Isaacs et al., 2007; Schalock, 2004a; Schalock et al., 2002; Summers et al., 2005; Verdugo, Schalock et al., 2005).

The FQOLS-2006 provided a comprehensive measure of FQOL because families in the current study were able to rate importance, opportunities, initiative, attainment, stability, and satisfaction in light of the domains of health, finance, relationships, support from others, services, careers, values, leisure, and community interaction.

Chapter 3 has reported that families were "satisfied" with family relationships, and values, but their responses ranged between "neither satisfied or dissatisfied" and "satisfied" for domains of health, community interaction, disability-related services, support from other people, and financial well-being. Since mean scores were generally quite close together across domains, these ratings did not permit clear conclusions about whether some domains were being more adequately achieved than others. As will be described throughout the current chapter, qualitative comments provided a clearer picture about the family's priorities and needs than ratings.

Previous research has also indicated that measurement domains and concepts are interlinked (e.g. R. I. Brown et al., 2004; Schalock et al., 2002; Summers et al., 2007). For example, the opportunity to enhance QOL is not necessarily an outcome, but more likely a contributing factor to a life of quality. Therefore, opportunity should be considered in light of other causal variables (Cummins, 2005). The current research also found that the FQOL measurement domains and concepts related to each other; therefore endorsing the measurement constructs that were used in the FQOLS-2006.

However, the current research also provided further considerations regarding the structure of the FQOLS-2006 with respect to the six measurement concepts (importance, opportunities, initiative, attainment, stability, satisfaction). Chapter 4 concluded by suggesting that the measurement concepts do not necessarily need to be considered

separately. This is because most participants indicated that opportunities do exist in each of the life domains, but restrictions placed on the family by having a child with a disability mean that the opportunities cannot be taken up. Moreover, particular aspects of family life were identified by families as having been obtained in light of the initiative and effort that they invested.

Therefore, as suggested in Chapter 3, it may be preferable to include a qualitative question in the FQOLS-2006 that asks about attainment of FQOL domains such as good health and support from services in light of the opportunities that exist and the effort the family makes to acquire their needs. Such a question would also prevent the survey from becoming too repetitive for participants. As was reported in Chapter 4, if measures of FQOL only include quantitative questions then reliability may be challenged, and participants may be discouraged from completing the whole survey accurately because it may become tedious.

Notwithstanding these findings, it is important to note that the results associated with the measurement constructs of the FQOLS-2006 (Chapter 3) were preliminary because they did not compare the FQOLS-2006 with other FQOL measurement tools. Although the developers of the FQOLS-2006 considered their domains and measurement constructs in light of previous FQOL literature, they did not attempt to collect data with other surveys while they were still in their pilot phase. This could have been because both the FQOLS-2006 and the Beach Center FQOLS Scale were at early developmental stages at the same time. This meant that little was known about the relative benefits and disadvantages of the measurement constructs and domains.

Consequently, the current research collected data using both the FQOLS-2006 and the Beach Center FQOL Scale in Australia (Chapter 4). As already discussed in

Chapters 3 and 4, the need to measure the construct "importance" is questionable in both FQOL measures because generally all domains were reported as being of high importance. This is because during the developmental phase of the two surveys the authors removed items that were considered of low importance to the majority of families (Wang et al., 2006), and only items considered to be of high relevance to families were included (Hoffman et al., 2006).

With further respect to FQOL domains, the FQOLS-2006 showed that satisfaction was highest with "Family Relationships" and lowest with "Financial Well-Being", while the Beach Center showed highest satisfaction with "Disability-Related Support: To accomplish goals at home" and lowest with "Emotional Well-Being: Outside help available to help the family". These differences, as described in Chapter 4, could be due to the fact that the different wording used between the FQOL surveys elicited different interpretations of the questions. Nevertheless, the results to both surveys indicated that, on average, families reported reasonably high satisfaction in all domains of FQOL, despite dissatisfaction in some areas.

A major finding from comparing the two measures was that the domain of "Parenting", which has been considered in detail in the Beach Center Survey but not explicitly in the FQOLS-2006, was found to be important. It should therefore be included in FQOL measurement, as is discussed next.

5.3.1.2 Parenting, Individual Family Member Needs, and
Sibling Issues

As was discussed in Chapter 4, Parenting was found to be an important domain in FQOL measurement. As confirmed in the current study and in previous research (Zuna et al., in press) having sufficient time to take care of the individual needs of every child in

the family, irrespective of whether or not they had a disability, was rated as being of highest importance, yet was clearly a need that was not being met satisfactorily. This result therefore suggests that, in accordance with previous literature (e.g. Llewellyn et al., 1999; Owen et al., 2002), caregivers were concerned that they could not provide equal care and support to all family members, despite wanting to. It was clear from the current findings that caregivers were concerned that inequality of care could result in the family member with a disability not being fully integrated into family life. Furthermore, it could also result in siblings' feelings of non inclusion in family life, which could lead to delinquent or attention seeking behaviours. In order to emphasise the individual nature of QOL, future measures of FQOL, or refinements to existing measures, would need to provide qualitative questions that allow participants the opportunity to discuss all family members.

The FQOLS-2006 was advantageous in this sense, because it asked about all adults in the participant's immediate family who take a parental role, as well as any other people considered to be members of the immediate family, including siblings and extended relatives who take on a care giving role (e.g. grandparents). The FQOLS-2006 also asked participants to indicate if a sibling was considered to be a caregiver and this question usually generated much discussion about the impact on the sibling of the family member with an intellectual/ developmental disability. For example, some caregivers described that siblings felt responsible for their brother or sister with a disability and some also reported that siblings felt ashamed to have a brother or sister with a disability. Similarly, the Beach Center FQOL Scale question associated with the importance of taking care of the individual needs of each child in the family resulted in participants explaining the impact of having a member with a disability on the sibling(s).

Moreover, when there was more than one member with an intellectual/ developmental disability in the same family, each was found to have an impact on the family and in different ways. For example, as described in Chapter 4 while one member with a disability may have engaged in maladaptive behaviours, which disrupted the emotional well-being of others in the family, another may have had physical health concerns, which meant that the family was occupied by attending medical appointments or the family was restricted in accessing places in the community. In addition, one family member with a disability may need more support than the other in areas such as social and recreational activities or education. As reported in Chapter 2, given that approximately half of the people with intellectual disabilities in Australia have secondary disabilities or conditions (Australian Institute of Health and Welfare (AIHW), September 2009), families may also be confronted by the fact that each member with a disability might have different additional conditions. Added to that, there would also be personality differences that might require different types and levels of support. In this sense the FQOLS-2006 was found to be preferable to the Beach Center FQOL Scale because the demographics section in the former included provision to discuss each family member with a disability separately. On the other hand, as reported in Chapter 4, families with more than one member with a disability found it difficult to select one option that represented the opportunities, attainment, initiative, and satisfaction for all members with a disability, because they could be very different.

Furthermore, the Parenting domain in the Beach Center FQOL Scale was useful in that it also resulted in participants being able to explain the individual impacts of disability. However, as already suggested in Chapter 4, consideration should be given to the possibility that information relevant to the Parenting domain in the Beach Center

FQOLS Scale could be obtained from one qualitative question that would present opportunity for addressing similar issues to those linked to the several items in the Beach Center FQOL Scale.

Sibling issues are particularly relevant when considering what will happen to the member with a disability when the parent-caregiver dies. Most participants in the current study reported that they did not expect the siblings to take on the caring role, but, given the findings associated with concerns for future support (see section 5.4.3) it was apparent that viable, alterative options were not already in place. The following section will discuss the findings associated with the lifespan perspective and end-of-life concerns.

5.3.1.3 Lifespan – Past and Distant Future

The current study found that FQOL varied according to the age of the family member with a disability. Given the connection between FQOL and support services, this may in part be because the amount and quality of support services that families received depended on the age of the member with a disability, with participants indicating that they received the most in depth support when their child with a disability was in early childhood. As reported in Chapters 3 and 4, and in accordance with previous literature (I. Brown et al., 2003; R. I. Brown et al., 2004; Davis & Gavidia-Payne, 2009), most families were aware that they would not necessarily obtain the same services once their child grew older, but there was a lot of uncertainty and anxiety as to how the services would be supplemented to accommodate changing needs.

The current results have confirmed that FQOL can change under particular circumstances across the lifespan, such as during transitions to/ from school, or events that may enhance, disrupt or unsettle everyday family routines (Blacher, 2001; R. I.

Brown et al., 2004; Jokinen & Brown, 2005; Llewellyn, Thompson et al., 2003; Owen et al., 2002; Rapanaro et al., 2008). However, previous research has not explored the impact of past events on current FQOL. The current responses to the question added to the FQOLS-2006 about family life in the past implied that present FQOL can be affected by knowledge about previous access to different kinds of services.

As discussed in Chapter 4, it is necessary to understand how FQOL may have changed over time and how present FQOL continues to be affected by past events. This finding highlights the possibility that some families may need counselling for previous issues that are still having an effect on the family (e.g. parental grief, or the need to discuss and resolve previous disappointments with service delivery). This type of support may be needed to create a positive approach to the new support rather than a cynical resignation that it probably will not help either. Existing FQOL measures, including those examined in the current research, have not incorporated this important consideration asking about issues of the past. Therefore the current results present unique information about issues from the past that are important for FQOL measures to address, particularly for those families whose service needs vary according to the age of the member with an intellectual/ developmental disability.

Across the lifespan the amount and quality of support received from other people (e.g. immediate and extended family, friends, work colleagues and neighbours) may also change. The FQOLS-2006 asked about practical and emotional support from such people together. By dividing the concepts of practical and emotional support, the current study was able to make clear distinctions between the types of supports that were valued by families. Hardly any previous research has considered practical and emotional support separately, and this distinction is not reflected in any existing FQOL measure.

5.3.1.4 Practical and Emotional Support

As was discussed in Chapter 3, families that have a member with a disability generally have higher physical and emotional demands and therefore they need more social support from other people including relatives, friends, and neighbours if they are to experience lower stress levels, and increased well-being (I. Brown et al., 2003; Davis & Gavidia-Payne, 2009; Skok et al., 2006). Even though there is no legal requirement for immediate or extended family, friends and neighbours to support families that have a member with a disability, their voluntary support was reported by families as being invaluable. At this same time, however, formal support services should not base the level of support they provide on whether or not the family has access to informal social supports. It may also mean that services need to support the provision of informal support, perhaps by providing support to extended family members to enable them to provide the support needed by the family with the member with a disability.

The need to distinguish between practical and emotional support from others was firstly identified in the pilot study of the current study (see Chapter 2) and then it continued to be emphasised by participants throughout the study. Evidently, practical support includes such things as financial assistance, babysitting, and housework; and emotional support includes having someone who will listen and be there for consultation at times of grief or sorrow. According to participants' ratings, practical support from others was not attained to the same extent as other aspects of FQOL, including emotional support from others. As noted in Chapter 3, qualitative comments suggested that this could be because some families made less effort to obtain practical support because they did not want to burden other people. This means that services may need to support

families to understand how to, and to feel comfortable to acquire practical support from others.

Surprisingly, only one other study (I. Brown et al., 2003) has discussed the important distinction that should be drawn between practical support and emotional support obtained from others. The current results strongly support I. Brown et al.'s (2003) finding, that families with a member with a disability in their study received little practical support from other people, and considerable variation in the amount of emotional support received. Other research using the FQOLS-2006 has used the approach of the survey developers without further researching the differences between these two separate areas of support. Given the differences that were found in the current study and by I. Brown et al., it is essential that future FQOL measures seek information about these two separate areas of support, to gain a more accurate picture not only of the amount of support that families receive from others, but also the type and quality. Such an approach should make it possible to ascertain reasons for lack of support in either area, and how such support might be provided.

Due to fewer opportunities for involvement outside of the family home, friendships and professional relationships of members of families with a child with a disability may become smaller or disappear over time (Breitenbach, 2004). Consistent with this suggestion, the current study found that during early childhood ages practical assistance like babysitting was easier to access because the child with a disability was a baby and often not discernibly different from any other baby. However, as the child developed, their disability-specific needs became more apparent and other people were less likely to be available and willing to provide practical support of this kind.

Overall, these results imply that practical and emotional support may not be adequate substitutes for each other. That is that, even if a family receives adequate support for practical aspects of caring for a member with a disability, there may still be negative effects on their FQOL if they do not receive adequate emotional support as well. Support services therefore need to consider the separate impacts of practical and emotional support from others on FQOL.

Sometimes whether or not families have contact with and support from relatives, friends and neighbours can be due to restrictions in transportation. Thus, transportation limitations can result in the family becoming more isolated and/ or not accessing the support services needed.

5.3.1.5 Transportation

The current research has emphasised that family members with a disability often have additional needs to get to disability-specific appointments because the services that they require are often not available locally. For such families transportation was often a problem. Consistent with the findings of previous research (Beart et al., 2001), participants in the current study discussed transportation issues, such as the importance of having a family car because public transport was often unreliable and not on time. Other caregivers also reported that their family member with an intellectual/ developmental disability had difficulty understanding timetables for public transport; hence, they needed to rely on their family for transport to services and other activities.

Furthermore, Chapter 4 highlighted that families felt that there was a problem with limited government funding for mobility assistance for the family member with a disability. Some participants also reported that they were unaware of government financial supports like "Mobility Assistance", which is available for people with

disabilities in Australia. These results confirmed those of Beart et al. (2001), who also found that service users did not receive information about available transport services.

Once again, the interlinking nature of the various FQOL domains is underscored by the fact that, consistent with previous literature (Verdonschot et al., 2009), participants in the current study reported that lack of transport restricted community participation and leisure/ recreation activities for all members of the family (see section 5.4.1).

Although the FQOLS-2006 and the Beach Center FQOL Scale attempted to assess the impact of transportation restrictions on FQOL, they did not include specific questions that allowed the families to explain the importance of transportation for the family. The findings of the current research therefore suggest that information about transportation and its associated costs should be directly sought by incorporating appropriate questions into FQOL surveys. This should be achieved either by including a separate domain or by locating additional questions within the domains "Financial Well-Being" or "Support from Services". It is also recommended that transportation be addressed with open ended questions enabling families to explain the impact of transportation on FQOL.

Coupled with the need for FQOL measurement to incorporate additional questions about the past and distant future, to separate practical and emotional support, and to address transportation, it is also necessary to consider the manner in which such questions are asked. Further methodological considerations of this kind will therefore be discussed next.

5.3.2 Methodological Considerations

5.3.2.1 Method of Survey Completion

The face-to-face interview method employed in the current study was found to be beneficial for many reasons. During interviews participants often commented on how much they appreciated the chance to tell their story. As stated by R. I. Brown, et al. (2004), the approach that a research interviewer adopts can be uplifting for the participant. Family caregivers who have participated in FQOL research have emphasised that they consider it important to be heard and listened to (R. I. Brown et al., 2004), an outcome which indicates that perhaps service providers have not sufficiently considered the family's desire to retain the responsibility for being decision makers about family needs. This observation is also consistent with the previous claim that services providers sometimes do not enable families to feel empowered to the extent that most families would wish (Bailey et al., 1998).

Another advantage of the interview method is that it allowed the interviewer to clarify questions and responses and therefore prevent misunderstandings. For instance, as reported in Chapter 4, some participants found it challenging to limit their response to one of the 5-point Likert scale options and it was therefore useful for the interviewer to encourage the participant to explain why they had not selected an option. Without this method there would have been considerable missing data.

The value of the interviewer being able to clarify a participant's responses is further demonstrated in the following example of the difference between a self-administered response and an interview response to the FQOLS-2006 question about changes to family life:

- Self-administered response: *"siblings are now leaving home"*.

There was no indication as to whether or not this was a positive impact or what implications it had for the family.

- During an interview another participant spoke for nearly two minutes about how life had changed for the family when her mother (grandmother to the member with a disability) had passed away. The interviewer was also able to ask what that meant in terms of changes in the practical and emotional support that the family received.

These results emphasise that it is important that FQOL measurement tools be used by experienced interviewers, with appropriate qualifications and knowledge about disability as well as training in survey administration and in-home interviews. The results also confirm the importance of assessing FQOL over time and of obtaining supplementary qualitative information during interviews by providing participants with the opportunities to elaborate on their responses. The fact that some questions on the FQOLS-2006 required elaboration for the family members raises a question of consistent presentation of questions to ensure consistency across participants. This suggests a need to standardise follow-up questions and the order in which they are presented.

To summarise, previous studies (Hoffman et al., 2006; Werner, Edwards, & Baum, 2009; Zuna, Selig et al., 2009) have used a self-administration format for the surveys. However, the evidence as described in Chapter 4 has underscored the necessity of collecting information about FQOL through a face-to-face interview, to ensure that qualitative data that elaborates on ratings can be obtained. If it is not possible to conduct interviews, for example, due to limited time and resources, then self-administered surveys

should be followed up with a short, informal interview (face-to-face or telephone) to clarify the responses recorded in the rating scale.

5.3.2.2 Interview Setting, Location, and Environment

With respect to the location of the interviews, it was found that conducting interviews in the family home had both advantages and disadvantages. An advantage was that this enabled the researcher to establish rapport in a comfortable, relaxed and convenient environment for participants. This was found to encourage conversations to flow freely.

As described in Chapter 4, throughout interviews with the FQOLS-2006 many participants expressed their emotions through tears. Given that sensitive family issues are likely to be raised and discussed it is important for an interviewer to be trained in managing such responses throughout interviews. As was the case in the current study, interviewers should receive hands on instruction and modelling from someone skilled in interviewing families with a child with a disability.

It is important to note also that, although participants became emotional when reflecting during interviews on their family life, no one chose to withdraw from the study. However, this does not mean that participation could not lead to subsequent stress. For example, at some stage after the interview, participants may discuss the content of the interview with other family members, and the distress about the issues which triggered emotional reactions during the interview might reoccur. Therefore it may be important for future research to investigate the longer term impact of participating in FQOL research. If the participant felt that there were negative outcomes, then they may refuse to be reinterviewed about FQOL, or it may lead to a generalisation that FQOL assessment is not a pleasant experience.

In future it may also be useful to record and analyse information about the trigger for these emotional reactions during the interviews. This could be useful for the future measurement of FQOL if different ways of wording the questions could be found to ensure that participants feel comfortable. Observing and recording such reactions could also be useful for the more effective provision of services, because if it is known which FQOL issues trigger adverse reactions, then changes to support procedures could be put in place to counteract those adverse responses. This information may also be useful for prioritising different kinds of services for particular families. It is unknown to what extent the FQOLS-2006 may trigger emotional reactions when not conducted as an interview in the family home.

As discussed in Chapter 2, another benefit of conducting interviews in the family home was the possibility that the interviewer would meet family members other than the interviewee, including the member with an intellectual/ developmental disability. This was beneficial because it provided the researcher with opportunities to understand and verify the details provided by participants. Once again this highlights the need for the interviewer to be appropriately trained and to have experience with disability so that they are familiar with how to interact appropriately with a person with an intellectual/ developmental disability.

During interviews it was also possible to observe the level of communication between family members and the in-home activities of the family member with a disability. For example, in one instance the mother reported that her child loved to be on the computer, and that he loved music and movies. During the 2 to 3 hour interview the family member with a disability was on the computer the whole time whilst listening to music thereby directly confirming the mother's report. In another instance, the mother

explained that the member with a disability, aged in his early childhood, was most calm and content while watching children's television programs. Once again, this was confirmed by the child's behaviour throughout the whole interview, which also meant that he did not interrupt the interview.

Interviews being conducted at the family home also had the advantage that the researcher was able to observe living conditions and the lifestyle of the family. The assessments of living conditions carried out in the homes (and rated by the researcher as either low, moderate or high) enabled subsequent correlation of data with the circumstances reported by the participants during interviews. For example, as stated in Chapter 2, the majority of families reported "average" family financial circumstances relative to others in Australia. The validity of these reports was reflected in the fact that the majority of families were rated by the researcher, based on direct observation, as living in good ("moderate") conditions.

There were, however, some notable disadvantages of conducting interviews at family homes. These included unavoidable general distractions such as the telephone or door bell ringing; another family member coming home from school or work and interrupting an ongoing interview; or family members (with or without a disability) requiring the attention of the main caregiver during an interview (particularly those who were younger or more dependent). Such disruptions obviously had the capacity to influence the reliability of the interview process and also meant that some interviews lasted much longer than anticipated.

It is also possible that during interviews at the family home the participant was reluctant to discuss issues pertaining to family members who were home at the time of the interview. For example, if a sibling who was home at the time of the interview was

seen as a significant problem for the family, the main caregiver may have been hesitant to reveal this for fear that the person involved would overhear what was being said. In one instance, as soon as the sibling of the member with a disability left the room, the mother explained in a very quiet tone that the sibling was struggling and has severe depression because of her brother with a disability. In another instance the mother later informed the interviewer that the fact that her daughter's boyfriend had moved in to live with their family had been very unsettling for the family member with a disability and hence for the whole family. However, the mother had not felt able to explain this during the interview until the daughter had left the house.

These important details, which impacted on FQOL, would not have been revealed if the sibling had been present in the interview for the entire duration. Clearly, too, it is unknown whether or not similar issues could have been raised by families where siblings were present in the room or house throughout the entire interview. The possibility of the influences of such considerations highlights the importance that interviews be conducted in privacy, preferably with no one else home, or in a private room of the house so as to avoid any adverse effects of the interview on other members of the family. Alternatively, if the interview is conducted elsewhere, such as in an office or interview room, the participant may reveal further information about siblings and other family members.

Another possible disadvantage of interviews being conducted in the participant's home is that the safety of the researcher could be compromised in an unfamiliar environment with an unknown person. For example, a participant may become angry and/or aggressive toward the researcher when expressing their opinion about inadequate services. Although this did not occur in the present study, it is worth acknowledging as a possibility. Therefore, researchers interviewing in family homes should first ensure that

appropriate contacts are established before undertaking a visit, with a recognised protocol in place that ensures the interviewer's safety. An interviewer also needs to be alert to any changes in the participant's behaviour and to be prepared to terminate an interview if necessary (as discussed in Chapter 2). Such protocol should be included in the training the interviewer receives.

As another example of adverse reactions to the interview, participants may presume that the information being sought is too confidential or that the interview had some undeclared, underlying purpose, like a government service checking up on them. This only occurred in one case during the current study, where the participant had asked a few times throughout the interview, *"what do they [government] want to know that for?"*(despite having been told that the interview was for research purposes). However, in larger samples, there may be more instances where the interviewer needs to be mindful of this type of reaction to a survey. This possibility also highlighted the importance of describing the purpose of the study clearly and of referring participants back to the information sheet provided. A reluctance to reveal information of this kind might also occur when a person self-administers the survey, particularly since it is not possible for an interviewer to reassure the person about the purpose of the interview and how the information will be used.

Training and appropriate interpersonal skills such as listening, understanding and empathy of the interviewer were also found to be important in the current research because, without them, interviews may have resulted in minimal qualitative information, with participants feeling uncomfortable about elaborating on their responses. Moreover, interview sessions could take much longer than originally anticipated and become tiring

if the participant was allowed by an untrained or inadequately trained interviewer to wander off the immediate topic.

Results from the current study showed that the interviewer required skills to keep participants on track and prevent interviews from becoming far longer than anticipated. In order to achieve this, the interviewer needed to prevent the interview from turning into a counselling session, or information/ advice seeking, or just friendly conversation. For example, throughout one interview with the FQOLS-2006, the participant questioned on at least four occasions things like, *"can I go to….?"* or *"is there a service for….?"*. To help avoid these tendencies, information about the aims and design of FQOL research provided to participants should include details about services that participants can contact, to obtain appropriate advice and assistance. Chapter 4 provided further details about the characteristics that are required to conduct an effective interview, such as empathy, listening skills, and interviewing expertise.

In summary, further detail and evidence about whether or not there are differences in the amount or quality of information obtained from participants when interviews are conducted in an office or testing room, as opposed to the family home, is a question for future research to address. However, experience in the current study has suggested that a face-to-face interview format, using appropriate interviewing techniques for both FQOL measures, has elicited detailed responses that helped to clarify family circumstances. Summers et al. (2005) recommended that for a measure of FQOL to be useful for practical, rather than just research purposes, it should be short, easy to administer and compatible with other service-related measures. Current experience supports these recommendations but adds that to be useful in a practical sense, developing good interviewing skills beforehand is worth the additional effort, not only to ensure that

participants are treated with respect and sensitively, but also because more detailed and accurate qualitative information can be obtained, generating a better understanding of FQOL.

The results from the research reported above have provided valuable insights into FQOL measurement issues, and particularly the concurrent validity of measures provided by comparisons between the FQOLS-2006 and the Beach Center FQOL Scale. Further, the findings, in conjunction with the literature reviewed, have pointed to numerous important practical implications associated with the support needs of families who have a member with an intellectual/ developmental disability. Additionally, results have also raised for consideration issues associated with the refinement of existing FQOL instruments, to be used for service provision.

5.4 Practical Implications of FQOL Measurement

As mentioned in Chapter 1, Zuna et al. (2009) recognised that FQOL scales have not yet been used for intervention research or for program revision and improvement, but FQOL should nonetheless be measured in a way that enables results to shape improved support services. The current study did not attempt to fill this gap; however, several suggestions for support services can be made on the basis of the results. In accordance with previous national and international literature (Davis & Gavidia-Payne, 2009; Park et al., 2003; Schippers & Van Boheemen, 2009; Werner, Edwards, & Baum, 2009), the current thesis has emphasised the practical benefits of FQOL research to inform support services in Australia and elsewhere.

These implications will be discussed in light of Zuna et al.'s (in press) FQOL theory including:

- Individual-member concepts such as age, disability type, and parent's employment status;

- Family-unit concepts including having more than one member with a disability, geographical location of the family residence, and number of siblings;

- Performance concepts associated with support services.

However, as outlined in section 5.5, the current conclusions need to be considered in light of further analyses that are required on the variables of interest.

FQOL research plays a key role in ensuring that people with intellectual/ developmental disabilities and their families have an opportunity to describe what they need to improve their FQOL. This is important because by providing such opportunities to consumers of services to voice their opinions and knowledge, service providers will empower families. Service providers will also be able to make use of the expert opinions from within the family to assist them to access the same places and resources that are available within the wider community (Wood-Dauphinee, 1999; Zuna, Turnbull et al., 2009). Although Cummins (2005) argued that QOL should not be considered in terms of needs, current results support the notion that, by identifying needs, support services will not only be alerted to what is working well for families, but they will also be better placed to implement programs to support families effectively.

The FQOL measures used in the current study were successful in identifying service needs. In fact, the current research reiterated the findings of previous research (R. I. Brown et al., 2004; Davis & Gavidia-Payne, 2009) that adequate support from disability-related services (in terms of amount and quality) is regarded by families as being highly important. Moreover, service support is often vital to the functional

effectiveness of the family and it can contribute to a more satisfactory FQOL in all life domains (I. Brown et al., 2003; R. I. Brown et al., 2004; Summers et al., 2007). The practical implications of FQOL measurement and the application of the current results will be reviewed in the following section. First, however, an overview of the service needs reported by families is outlined.

5.4.1 Unmet Service Needs

As reported in Chapter 3, although most families were generally satisfied with support services, nearly one fifth reported being dissatisfied. In addition, through qualitative analyses it was possible to identify that about two thirds of the participants in the current study felt that there were services that they needed that they were not currently receiving. These results therefore confirm results from previous FQOL research in Australia (R. I. Brown et al., 2004; Davis & Gavidia-Payne, 2009).

The current research has drawn attention to the fact that families reported needing the following disability-related supports, which they were not receiving:

- Social, leisure and recreation activities for the member with an intellectual/ developmental disability;

- Reliable/ experienced staff to work with the family to manage the special needs of the family member with a disability;

- Respite for carers and siblings;

- Nutritionist advice; and

- Speech therapy.

With respect to leisure and recreation – one of the most crucial areas identified as requiring further attention from services – the current results were consistent with previous literature that has reported that the family member with a disability often

determined/ limited the activities that the family was able to undertake (Mactavish &

Schleien, 2004). Moreover, if the family member with a disability was not engaging in

meaningful leisure and recreation activities, then other members of the family may also

miss out on opportunities for leisure and recreation activities. Siblings were particularly

affected if, as was frequently the case, parents/ caregivers were committed to attending to

the functional needs of their child with a disability. This result confirms that having a

family member with an intellectual/ developmental disability can have detrimental effects

on the mental health of other family members because they do not get sufficient

opportunities to engage in meaningful social contact (R. I. Brown et al., 2004). It also

confirmed that respite and other community supports are beneficial to the well-being of

the whole family (R. I. Brown et al., 2004).

The findings related to a need for more respite were not surprising, given that a

recent South Australian government report found that in the past 12 months the unmet

need for respite care had increased by 81%, leaving nearly 500 families still waiting for

these supports (Martin, 2010). These results appear contrary to R. I. Brown et al.'s (2004)

earlier claim that support services in South Australia had improved, although this report

was completed 6 to 7 years prior. However, although current findings have supported

Martin's government report based on statistical demographic information, the difference

with R.I. Brown's research results may reflect different criteria for "unmet need" for

respite care, because the term "support services" can represent various areas of support,

including education, accommodation, and is not limited to respite.

At the time of R.I. Brown et al.'s report (R. I. Brown et al., 2004) Australian

families were concerned with lack of adequate community accommodation. However,

accommodation support was less frequently mentioned by participants in the current

study. This may be because accommodation is an age-specific service and, as reported in Chapter 2, many of the participants in the current research were outside of the older age groups who generally require such services. The current results may also be due to the most frequently used service in the Disability Sector Profile in South Australia being reported as accommodation support (47%). This suggests that accommodation support needs are more likely to be met than the less frequently used services like Community Support, Community Access, and Respite (17%, 16% and 10%, respectively) (South Australian government National Minimum Data Set report; Department for Families and Communities, 2007).

With respect to educational needs, the Australian Institute for Health and Welfare (AIHW, 2008) reported that in 2003, of all students with an intellectual disability in Australia, 45% were attending ordinary (mainstream) classes, 38% were attending a special class, and 17% were attending a special school, suggesting that formal support for educational needs were being met. However, the current research found that this was not necessarily always the case, with a few families reporting that appropriate education was an area of need for their family member with a disability.

If educational support for the person with a disability is not appropriate, then the family can be left to take on an educational role in addition to the many other responsibilities and pressures. If a child has more complex learning needs this can affect the family because parents will need to consider the most appropriate educational setting for the family member with an intellectual/ developmental disability, as the following example illustrates.

"When Mark [a child with an intellectual disability] was in year 10 and Sophie [a second child with an intellectual disability] in year 8, they [the school] told the family that they

couldn't help Mark and Sophie anymore and they tried to send them to a special school."

This situation was particularly stressful for this mother and her family, because she felt that her children were functioning academically at a level beyond that which could be provided by a special school, yet below the level of mainstream schooling. Thus, there was no appropriate education for these children. In this case, there were also no alternative appropriate local schools near to the family home where they had lived for 22 years, meaning that the family may have had to relocate to meet the educational needs of the children with a disability. Relocating their home would also have meant that the family would be further away from the father's workplace and so they were faced with the prospect that he may have had to change jobs as well, which may have generated additional financial losses for the family. Although the outcome for this family did not in the end result in them having to move house or change jobs, it was a stressful event that at the time caused anxiety to the family.

This example demonstrates the interlinking nature of various FQOL domains, as well as the restricted employment options for caregivers, considerations that have been raised in other studies (R. I. Brown et al., 2004; Burton-Smith et al., 2009a). As described in Chapter 1, previous research exploring the impact of a child with a disability on caregiver's employment status (e.g. Burton-Smith et al., 2009a) has been limited by not using a FQOL framework and by focussing principally on female caregivers. The current results have demonstrated that through FQOL measurement it is possible to consider the family as a whole, including consideration of the father's situation and the impact of employment status on family well-being.

According to Zuna et al.'s (in press) theory the abovementioned example demonstrates the interaction between individual-member concepts (education and

employment status) and family-unit concepts (financial outcomes), which make up FQOL. The results also demonstrate that nowadays FQOL examines various life domains holistically, and support needs for people with disabilities are not merely considered in terms of treatment, as has been the focus of disability service provision historically.

In terms of the current results, if family support needs had only been explored in terms of the Support from Services domain, the highest reported area of unmet need would have been leisure and recreation. However, when assessing other FQOL domains along with Support from Services, it has clearly been revealed that satisfaction with and attainment of Leisure and Recreation falls somewhere in the middle, with other life domains of Family Relationships, Influence of Values and Health taking precedence. This illustrates that, the value of a holistic, family-centred approach is that support services can prioritise areas of need.

In summary, the current findings have supported previous research with respect to family-unit and performance concepts of FQOL (Zuna et al., in press). These findings have emphasised that adequate supports are required so that family dynamics can be balanced. Where this is achieved the family's energy is not focussed solely on supporting the family member with a disability. Where the level of support is sufficient then spousal relationships will be maintained and there will be sufficient resources to fulfil the needs of every family member, especially siblings (Breitenbach, 2004; R. I. Brown et al., 2004).

5.4.1.1 Reasons for Unmet Needs

Comprehensive measurement of FQOL using the Support from Services domain also successfully identified families' perceptions about why they were not receiving the services they needed. Reasons included long waiting times; not knowing where/ how to

access the services needed; inadequate services; inadequate funding; and transportation issues. Each of these is now discussed in turn.

5.4.1.1.1 Long Wait/ Knowing Where to Obtain Services

The most common reason advanced by families with a child with a disability for not receiving disability-related services was long waiting lists, which often led families to feel unmotivated to ask for support. This result is consistent with a recent report which stated that in South Australia over 1000 people remain on waiting lists for supported accommodation places, and some were waiting for more than five years (Martin, 2010).

Concern about long waiting times were followed closely by the fact that families were uncertain about where to go to get the services they need (e.g. *"...there could be millions of things out there, but I don't know about them... They [main disability service provider] don't make enough contact and don't tell me about things [services]"*). This result is consistent with previous research that has reported that parents in various countries encounter problems when seeking access to information and practical advice (Breitenbach, 2004). Similarly, I. Brown et al. (2003) found that families demonstrated poor levels of initiative to access services because of uncertainty about where to go to obtain the services that they needed.

In accordance with findings of Knox et al. (2000), current results found that receiving up to date information about the child with a disability is critical to FQOL. Family-centred support should therefore aim to treat families respectfully by providing the information that they need to make decisions in line with what they consider important to their family (Freedman & Boyer, 2000, cited in Davis & Gavidia-Payne, 2009).

5.4.1.1.2 Inadequate Services

Families in the current study indicated that the services they were using were inadequate. For example, it was reported that health professionals did not have specialist disability/ autism knowledge. These results were similar to those from a Canadian study that found that, even though support services were available to people with intellectual/ developmental disabilities and their families, those services were reported as not being appropriate to meet the needs of the family (I. Brown et al., 2003). Some families have therefore concluded that service staff do not understand their child's disability and that consequently they do not understand what life is like for the family (R. I. Brown et al., 2004).

5.4.1.1.3 Inadequate Funding

Another commonly reported reason in the current research for not receiving the services needed was insufficient funding to access the required services. Burton-Smith et al. (2009a) found that standard of living (which arguably includes financial well-being) was an area of life in which families were most satisfied. In the current study, however, although as reported in Chapters 3 and 4 the vast majority of families reported having an 'average' income relative to the rest of the country, financial well-being was reported at lower levels of satisfaction than was the case for other FQOL domains. This result therefore suggests that some families still struggle to receive adequate funding in accordance with their expectations.

Financial restraints are also important to consider in light of their impact on family relationships (Davis & Gavidia-Payne, 2009). As reported in Chapter 3, more than half of the main caregivers in the current study had given up their careers to support their family member with a disability. What is more, just under half stated that they did not

expect to return to work in the near future. If there is a sole income earner in the family, or if the family need to rely on government pensions there may be implications for what the family can and cannot do. In addition to financial implications, since many caregivers in the current study reported that their job was their main social outlet, giving up their career would decrease opportunities for personal/ social networks (as was also found by Burton-Smith et al., 2009a).

Once again these reports highlight the complexities associated with FQOL measurement, emphasising that the domain of financial well-being should not be considered in isolation from other FQOL domains. As already considered in Chapter 1, financial concerns can also impact on other areas of life, like access to adequate transportation (see section 5.3.1.5). Clearly, support services need to consider the relevance of employment careers and of financial well-being on FQOL.

5.4.2 Sensitivity to Differences between Family Circumstances

In addition to identifying unmet service needs and the reasons for discrepancies between the ideal and actual, FQOL measurement makes it possible to identify emerging differences between families. Chapters 3 and 4 have emphasised that it is important for support services to consider a general consensus (i.e. mean results of FQOL measurement) about the needs of families with people with intellectual/ developmental disabilities. However, the qualitative data in the current study has further underscored that support services need to identify, understand, and cater for the individual, unique and changing issues, needs, and coping mechanisms of every family (see also I. Brown et al., 2003; R. I. Brown et al., 2004). In particular, those families that deviate from the norm require special attention. The implication of this is that services need a measurement tool that will enable them to provide flexibility in their services offered to families, rather than

having to act only in response to very large problems and to pay less attention to the many minor challenges that families may face regularly (R. I. Brown et al., 2004).

5.4.3 Differences in Support Services across the Lifespan

The current study found that not only do services need to be more aware of differences between families that are caring for a family member with a disability; they also need to be equipped for supporting families across the lifespan of the member with a disability. As stated in previous literature, families should be supported to continue to care for their relative with a disability at home for as long as possible (Llewellyn, Thompson et al., 2003). However, as described in section 5.4.1 a common theme that emerged in the current interviews and in previous research was apprehension or anxiety about future out-of-home accommodation options and end-of-life decisions. Specifically, older caregivers were often uncertain and insecure about what will happen to the child with a disability when the main caregiver dies (Davys & Haigh, 2007; Harwood, 2007; Jokinen, 2006).

Consistent with previous research (e.g. R. I. Brown et al., 2004; Burton-Smith et al., 2009a; Schippers & Van Boheemen, 2009; Werner, Edwards, & Baum, 2009), current results have emphasised that, in order to avoid excessive apprehension about the future, families need additional support to be prepared for the future transitional stages of the family member with a disability (Burton-Smith et al., 2009a), such as information about out-of-home accommodation options. Services should be flexible in response to changes over time and family carers need to be provided with positive reassurance for the future of their child with a disability as the parent/ caregiver ages and may no longer be able to support their child (Breitenbach, 2004; R. I. Brown et al., 2004).

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The current study has supported previous research indicating that, in addition to preparing families for the future in a practical sense, service providers also need to protect and sustain the mental/ physical health needs of caregivers throughout the lifespan of the member with a disability (Mackey & Goddard, 2006; Werner, Edwards, & Baum, 2009). This is especially important because, compared with their counterparts in the wider community, on average family caregivers with a child with a disability have a mental health status that falls significantly below the norm (Burton-Smith et al., 2009a). Caregivers' mental health can be affected by decreased levels of well-being, which relate to concerns about the future security of their child with a disability. The health and well-being of family carers impacts on the family as a whole (R. I. Brown et al., 2004). The FQOLS-2006 was useful for identifying apprehension about the future because it questioned future stability. Therefore, the FQOL framework provides an indication of anticipated changes that may occur in the family and services that may be needed in the future.

Furthermore, in two separate previous studies it was found that families with a member with an intellectual/ developmental disability in the older age groups reported inadequate support (R. I. Brown et al., 2004), yet they were more satisfied than younger families (Jokinen & Brown, in press). The current results confirmed such findings, highlighting that the individual-member characteristic (Zuna et al., in press) of age needs to be considered in light of other variables. The current research therefore emphasises the benefits of the FQOL framework as an effective means for evaluating multiple individual and family characteristics such as age, along with the impact of disability.

In summary, the current results imply that service providers need to measure FQOL at different times throughout the lifespan to gain a better understanding about how

issues of the past and anticipation for the distant future influence present FQOL. Service providers also need to be aware that some services that were previously required may, at a later time, be no longer appropriate for the family, but instead the family will require something else. This information can also help services to provide more appropriate support, incorporating services for the family that will be available in the future. An added benefit of measuring FQOL at different times is that it becomes possible to determine whether or not particular programs, services or interventions have been successful in enhancing QOL (Verdugo, Schalock et al., 2005).

The abovementioned suggestions, which relate to the practical implications of FQOL measurement, require further critical discussion amongst key disability services in Australia and beyond. Prior to attempting to apply the current suggestions limitations in the methodology of the current research need to be considered. However, despite the limitations discussed in the following section, the current research findings contribute to the understanding of the measurement of FQOL and the process of identifying and addressing support needs of families that have a member with an intellectual/ developmental disability. The results also make it possible to identify avenues for future research, as will also be discussed in the next section.

5.5 Limitations and Implications for Future Research

This section provides further details about the limitations to the current study that have been presented in Chapters 3 and 4, and it concludes with suggestions for future research. Perhaps the most obvious further consideration is the need to collect more FQOL data. With a larger sample it will be possible to make further comparisons in areas such as: different syndromes and additional conditions; different age groups across the lifespan of the member with a disability and of the caregiver; self-administered versus

face-to-face interview format; and from different perspectives within the family, including siblings. Furthermore, even though the current research could be used to make suggestions for service providers, little is known about the practical use of the surveys by service providers to identify support needs of families.

5.5.1 Lifespan Perspective

As suggested in the current results and by previous research (e.g. Davis & Gavidia-Payne, 2009; Jokinen, 2006), it is important to explore the differences in FQOL across different age groups of the family member with a disability, such as when they are leaving school. Although the current study recruited participants from various age groups, the older age groups were under represented. The cross-sectional qualitative data from the current study enabled preliminary conclusions associated with differences across the lifespan of the person with a disability. However, with a larger overall sample size it would have been possible to statistically compare various age groups.

As explained in Chapter 2, many elderly parent caregivers were reluctant to participate in the current study because they were unsure about what was involved and they wondered if they were required by their service provider to do so. Consequently, the older age group was not represented well in the current study. This emphasised that there is a need to explain the research requirements in a manner where the participants are able to fully understand the purpose of the research (Hatton, 1998). In future, in order to acquire participants who represent a wide range of age groups, any concerns about the study expressed by caregivers need to be carefully considered. Alternatively, families in the older age groups may need to be purposefully sampled in future, in order to ensure representativeness.

For research purposes, since longitudinal analyses are often not within the scope of the study, it is important for future measures of FQOL to include an assessment of the impact on FQOL of significant life events in the past, as well as the anticipated distant future. As stated in Chapter 4, for the purpose of service provision, measures of FQOL need to include such questions to address the effects of the past and anticipated events. Services would then be better able to assess and reassess FQOL at different developmental stages, and at times when FQOL is likely to be affected by events such as the death of a significant other who provided support to the family previously.

The current study benefitted from the additional questions that were asked about family life in the past, enabling cross-sectional comparisons associated with lifespan issues. However, longitudinal follow up of participants, although not possible here, is highly recommended and would provide further insight into the differences in FQOL and support provided to families across the lifespan.

Current participants were asked to tick a box on their consent form as to whether or not they would agree to be contacted in future to participate in further research. The vast majority of participants selected "yes". Therefore, it is possible to conduct follow-up interviews in future. The nature of the FQOLS-2006 and the Beach Center FQOL Scale makes it possible to collect further data at different points in time and to make comparisons with relative ease.

In addition to age or developmental stage, the current study found that there are other demographic variables that support services need to take into consideration because of their impact on the family; however, there were limitations in addressing the differences across different diagnostic conditions, as discussed next.

5.5.2 Disability Type and Additional Conditions

Research has shown that different types of disabilities (or diagnoses) or having additional/ secondary conditions, such as challenging behaviours or mental health conditions, impact on FQOL in different ways (Blacher & McIntyre, 2006; Davis & Gavidia-Payne, 2009; Eisenhower et al., 2005). Previous international research has shown that Down Syndrome does not present as many concerns to families as do other disabilities (Ricci & Hodapp, 2003). Moreover, more behaviour problems were found to be associated with Autism than Down Syndrome, Cerebral Palsy or other intellectual/ developmental disabilities, and more maternal depression and lower morale were also found among mothers of young adults with autism, compared to mothers of young adults with other disabilities (Blacher & McIntyre, 2006; Olsson & Hwang, 2001).

Research associated with different disabilities and/ or additional conditions is relevant in Australia, because it is common for people with intellectual disabilities to have other types of disabilities and/ or conditions (e.g. psychiatric issues or communication difficulties) in addition to their intellectual disability (Australian Institute of Health and Welfare (AIHW), 2008). Therefore, the type of disability and support needed – ranging from cognitive or emotional support to assistance with daily living activities (Australian Institute of Health and Welfare (AIHW), 2008) – can influence stress levels in the family as well as how families cope with the challenges that come with having a child with a disability. Research similar to the international studies described above is required in Australia.

Even though the current study collected information from families with children with a variety of disabilities including Autism, Down Syndrome and Cerebral Palsy, there were still insufficient numbers in each diagnostic category to make statistical

comparisons. Given that over half of the people with disabilities represented in the current study were reported to have six of more additional conditions such as behavioural concerns or speech/ language difficulties, it is important for future research to separate any apparent impact of particular conditions.

Access to support services may also be complicated when there are additional disabilities because there may be uncertainty about which support agencies are equipped to deal with particular cases. For example, services have previously been reported to lack resources to help families with dual disabilities (R. I. Brown et al., 2004). Consequently, since support from disability-related services has been found to be important to FQOL, this in turn can have a major impact on the well-being of the family, but further research is required to support these assumptions.

In the early stages of the current research, the author presented information about the effects of additional conditions on FQOL at an international conference (Rillotta, Kirby, & Nettelbeck, 2006). Preliminary data from 17 participants in the current study were analysed. Three case studies were presented – one with additional major disabilities, another with a single additional minor condition, and also one with more than one additional minor condition. Results suggested that the number, type and severity of additional conditions impacted on the family's perceived QOL with respect to support from disability-related services. However, these results are considered preliminary because the analysis was based only on qualitative data from three participants and there were insufficient participants to provide specific conclusions. As suggested by previous researchers (e.g. Davis & Gavidia-Payne, 2009), it is important for future research to consider the different impacts on FQOL and support needs of various diagnoses. It is also

important to understand levels of FQOL relative to the general population for families that have a member with an intellectual/ developmental disability.

5.5.2.1 Control Group

FQOL for families with a member with particular disabilities and/ or additional conditions may or may not differ from FQOL for families that do not have a member with a disability. For example, families with a member with Down Syndrome have been found to be more closely linked to families that do not have a member with a disability, than is the case for families where there are other disabilities (Blacher & McIntyre, 2006).

It is often assumed that families with a member with a disability have lower levels of satisfaction with QOL than families without a member with a disability. However, although Browne and Bramston (1996) supported this assumption, research that has compared family life for families that do and do not include a member with an intellectual/ developmental disability is limited. Further research is needed to assess whether the existing measures of FQOL can be used to reveal similar results for families that do not have a member with an intellectual/ developmental disability.

As stated by Schalock et al. (2002), QOL is important for all people, regardless of whether or not they have a disability. As emphasised in Chapters 3 and 4, future research should endeavour to compare the current results to results obtained from families that do not have a member with a disability, in order to determine how FQOL is different for these different groups. Wherever possible, demographics of the participants should be matched closely, to enable comparisons in terms of the developmental stage of the child.

5.5.2.2 Recruitment Organisations

The families from the current study were recruited from one service provider in South Australia. Even though this is a generic disability support service, there are many other services that are specific to particular diagnoses or areas of need (e.g. Autism, Down Syndrome, early intervention, accommodation, occupational activities, day options, challenging behaviours, etc.). Future research should seek to liaise with most, if not all, of these organisations for participant recruitment. This may maximise the overall response rate and enable the research to include more variety in the family demographics. It will also make it possible to investigate the impact of support from various agencies.

As mentioned in previous chapters, most families in the present study were lower middle class, two-parent families living in metropolitan areas of South Australia. Further research should explore families nationwide and include single parent families and families living in rural areas. In particular, correlations between FQOL performance and family-unit concepts (Zuna et al., in press): transportation; geographic location; and financial well-being, warrant further research. Transportation issues are particularly relevant to families who live in rural regions where service access may be at a distance.

As noted in Chapter 1 specific support services for younger age groups were found to be more readily accessible for rural families than metropolitan families (Raghavendra et al., 2007). On the other hand, in another study, families living in rural areas were reported as having a higher need for formal support from services than metropolitan residents because, generally speaking, metropolitan residents have more contact with close friends and family than those living in rural areas (Best et al., 2000). However, it was beyond the scope of the current study to test the abovementioned findings with respect to rural and metropolitan dwellers.

5.5.3 Transportation

There is some indication in previous research of differences between rural and metropolitan residents in terms of the support that families received. However, previous research associated with intellectual/ developmental disability and transportation issues in rural regions is scarce. Therefore, future research needs to explore the notion that transportation can be more easily acquired and the distance travelled to gain support is not as much of an issue for metropolitan residents as it is with rural residents. Whilst the current research did not conduct these analyses, it has ascertained that transportation and additional demographical details such as residential location are issues deserving inclusion in FQOL measurement.

Further research using FQOL variables needs to be conducted with more participants in various geographical locations. In order for it to be feasible to conduct such research, in future it may be necessary to train researchers in various locations, including rural areas, to administer the surveys as an interview. This approach may benefit from including a DVD that demonstrates the interview techniques.

5.5.4 Random Nature of Participants

Although the current sample was identified as "random" by the disability workers who randomly selected participants from their client database, it is important to note the possibility of "self selection" bias. That is, it is possible that those who agreed to participate were more likely to be extroverted caregivers with enough time to complete the interview, or they were not as stressed out and were not under as much pressure as others. This became evident in the sorts of responses that the liaison persons received when inviting people to participate. Some people who were invited to participate also indicated that they did not feel that there was any point in participating because it would

not change anything in terms of the services they received. Such people were more likely to be those who had additional support needs.

Therefore future research may need to purposefully sample families with lower morale, lower socio-economic status and/ or higher support needs. It may also be possible in future to check the client database for the number of times that families have used the service recently and then recruit participants accordingly, in order to gain a broader picture of those who use the service less frequently and those who use it more often.

5.5.5 Cultural Relevance

With further respect to the demographical details of the participants in the current study, it is important to note that Aboriginal families were not represented very well, and nor were families of non-English speaking backgrounds living in South Australia. It is important for future research to consider inviting people from diverse backgrounds to share information about their FQOL in order to further assess the cultural relevance of the FQOL domains and the two surveys. This is important because, as identified by Chou and Schalock (2009), culture-specific factors such as society's attitude to intellectual/ developmental disability can play a significant part in determining QOL. As mentioned in Chapter 2 the FQOLS-2006 has been translated into several different languages and so it would be possible to investigate further, the FQOL of more diverse Australian families.

5.5.6 Different Perspectives within the Family

The current study found that FQOL can be represented by the main caregiver in the family. However, in considering the importance of obtaining both subjective and objective measures (Schalock et al., 2002) of FQOL, future research needs to expand the invitation to all members of the family, including fathers, grandparents, and siblings.

As discussed in the previous chapters, measurement of FQOL needs to address concerns related to siblings of the person with an intellectual/ developmental disability. Previous research associated with siblings (Cuskelly & Gunn, 2006; Heller & Keiling Arnold, 2010; Orsmond & Seltzer, 2007) has not assessed sibling concerns in light of the rest of the family, nor has it included a FQOL framework, but rather it has focussed primarily on the impacts on the sibling.

As discussed in section 5.3.1.2, it could be argued that both FQOL measurement tools used in the current research attempted to include an opportunity for participants to explain sibling issues. However, this was limited to quantitative response options and the true impact on the sibling may not have been revealed, especially for self-administered interviews. Information obtained about sibling issues needs to be assessed further. Support services will need to address the additional support that siblings may require, such as a desire for information about their sibling with a disability, and/ or support groups (Heller & Keiling Arnold, 2010). Therefore, in future, FQOL research outcomes should be used in a manner that focuses on supporting the whole family, in addition to supporting siblings directly (Giallo & Gavidia-Payne, 2006).

Another important consideration for future research is to include the direct perspective of the member(s) with an intellectual/ developmental disability in FQOL research. This consideration is especially important because as identified in previous literature, proxy reports on behalf of people with intellectual/ developmental disabilities can often differ markedly from self-ratings (R. I. Brown & Brown, 2005; Hatton, 1998; Shearer, 2000). Obtaining various perspectives will also enable research to verify the details obtained from the main caregiver. It will also make it possible to assess any

additional components that family members consider important to their FQOL but which perhaps another family member was unaware of, or forgot to report.

As suggested by Schalock et al. (2002), where it is not possible to obtain the opinions of the person with a disability, it may be necessary for future research to supplement the information collected from the main caregiver with observations. This was considered in part in the current research because during interviews at the family home the researcher was able to make an informal assessment of the living conditions (see section 5.3.2.2). However, future behavioural observations might be extended to include an established measure of environmental conditions, or a standardised checklist.

5.5.6.1 User-friendly Terminology

It should be acknowledged that caregivers of people with disabilities may have disabilities themselves or they may have additional learning support needs, as was the case here. In the current study participants did not appear to encounter any problems in understanding the questions from the Beach Center FQOL Scale; however some of the FQOLS-2006 questions needed to be reworded. Therefore, as overviewed in Chapter 4, for participants with learning difficulties there is a need for the FQOLS-2006 to be converted to simple, user-friendly language and each separate question should only address a single issue.

These considerations are very important, because if the surveys are used to predict support needs of families, assessors need to be certain that excessively high or low scores are indicative of the level of support needed and are not the result of the questions having been misunderstood. Despite this possibility for misinterpretation of the results, previous research has not considered translating surveys to user-friendly or simple language. It may be assumed that people who have trouble filling out the surveys will seek assistance

from the researchers, but sometimes this may not be the case. In future, it would also be

important to covert the terminology to simple English if the surveys are to be

administered to the people with disabilities themselves, as suggested previously.

5.5.7 Self-administered vs. Interview

Participants in the current study who chose to self-administer the surveys may

have selected this option because they did not feel comfortable with the researcher going

to their home, or perhaps it was inconvenient to arrange a specific time to complete the

surveys. As was discussed in Chapter 4, it was difficult to make comparisons between

self-administered and interviewed responses to surveys in the current study, because very

few elected to self-administer the surveys. Although the interviewer in this study found

both surveys straight forward to complete, and not requiring any particular specialist

knowledge about FQOL, it cannot be concluded that the surveys were simple, clear and

user-friendly for participants to complete on their own, because only a few were

completed in this way. Moreover, follow-up interviews evaluating the ease of use of the

self-administered surveys were not conducted.

However, from the small sample of participants who chose to self-administer the

surveys it was possible to make preliminary comparisons. Much less qualitative

information was obtained from participants who self-administered the surveys than from

those who were interviewed. This evidence, consistent with previous literature (I. Brown,

Brown et al., 2000; Cummins, 2005; Schalock et al., 2002) indicated that qualitative data

should be obtained in order to clarify that the participant has understood the questions

accurately. Qualitative information is also useful to further understand quantitative

ratings in light of the family's circumstances. As mentioned in previous chapters, further

research needs to be conducted with larger samples to make conclusions about the relative adequacy of each method for completing the survey.

5.5.8 Practical Usefulness of the FQOL Surveys

Particularly in Australia there has been little research reported on the practical uses of FQOL measurement. As outlined in Chapter 4, the current study did not consider the practical use of the surveys by service providers or policy makers. As stated by Wood-Dauphinee (1999), QOL instruments need to be carefully chosen, dependent on the purpose of the data collection. That is, if assessment of QOL is to be used for service provision, then it is necessary to conduct research with the goal of applying the results in order to adopt strategies to enhance QOL. Furthermore, as Schalock (2004a) proposed, in moving forward with the concept of QOL, it is important for policy makers to be aware that measurement of QOL has shown enhanced QOL when people live and work in culturally typical environments.

In the current study this kind of research was not conducted. Even though the main disability service provider in South Australia (DSP-SA) facilitated the recruitment of participants, and they will be provided with a summary of the research results, they did not directly intend to use results at an individual or family-centred case management level. Nor will the results from the current study be used as evidence for changes at a policy level. As stated by R. I. Brown and Brown (2005) these uses of QOL and FQOL conceptualisation and measurement need to be explored further. Hoffman et al. (2006) concluded that the Beach Center FQOL Scale was useful for applied research that examines the outcomes of family services and policies; however, the current study was not able to make similar conclusions.

Services that contemplate using QOL and FQOL frameworks need to work closely with researchers who are aware of both research and application needs, and not simply adopt an academic approach. As emphasised previously, the ultimate aim of QOL and FQOL research is to enhance the lives of people with intellectual/ developmental disabilities and their families. In order for this to occur, evidence-based research outcomes need to be communicated to service providers in a manner which convincingly highlights the support that families need to improve their QOL.

5.6 Conclusion

In conclusion, this thesis has demonstrated that effective measurement of QOL and FQOL provides a valid and reliable indicator of what it means to live a good life according to the individual family's perceptions of their experiences. This is crucial because in the disability field there is a need to strive to ensure that people with disabilities and their families are treated equally and that they can access the same places, services and resources as the rest of society.

In recognising that families that have a member with a disability have additional, and often complex, support requirements, this thesis has found that through face-to-face, multi-dimensional, mixed methods measurement of FQOL the provision of these additional resources, programs or interventions can then be justified and implemented. The purpose of measuring FQOL is to more accurately reflect what life is like for families who have a member with an intellectual/ developmental disability.

Family-centred practices are beneficial when all features in family life, such as social support, specific child characteristics (e.g. behaviour), and specific family characteristics (e.g. income) are considered (Davis & Gavidia-Payne, 2009; Zuna et al., in press). Outcomes from the current study imply that through the use of reliable and

accurate measurement of FQOL it becomes possible to assess the interacting nature of FQOL variables.

Such research is in its infancy in Australia. Therefore, the current results contribute an important step in the shift to providing appropriate services to support families that have a member with an intellectual/ developmental disability. Moreover, if the outcomes of the research are taken seriously by service providers, then they will be able to directly improve the lives of people with disabilities and their families.

With respect to the measurement tools that were evaluated, this thesis concludes that it is not necessary to develop a new measure of FQOL. Both the FQOLS-2006 and the Beach Center FQOL scale have been found to be reliable measures of FQOL in Australia. However, it is necessary to make some modifications associated with practical and emotional support from others, family life in the past, transportation, and parenting. In light of the current recommendations future research is required to investigate how to incorporate these elements into FQOL measurement. Once these elements have been included in existing FQOL measurement instruments, cross-cultural reliability and validity will need to be retested, so that FQOL tools can better inform support services about family support needs.

Finally, the results of the current study, along with the literature reviewed in this thesis, may be of direct benefit to society as a whole, because the principles of QOL and FQOL can be applied across the board to generic services. Also, if families are better supported in their journey as caregivers to relatives with intellectual/ developmental disabilities then not only will individual members and the whole family benefit substantially, but so too will the general community.

Appendices

Appendix A. Conference Presentations Associated with this Thesis

Rillotta, F., Kirby, N., Nettelbeck, T., & Shearer, J. (July, 2009). *Family Quality of Life and Intellectual Disability: Implications for Support Services.* International Society for Quality of Life Studies (ISQOLS) IX Conference, Florence, Italy. 20th July 2009.

Rillotta, F., Kirby, N., Nettelbeck, T., & Shearer, J. (June, 2009). *Results from Nine Domains of Family Quality of Life in South Australia.* 2nd International Association for the Scientific Study of Intellectual Disability (IASSID) Asia Pacific Regional Congress, Singapore. 24th June, 2009.

Rillotta, F., Kirby, N., Nettelbeck, T., & Shearer, J. (November, 2008). *Family Quality of Life and Intellectual Disability: The impact of significant life events in the past and in the anticipated future.* Poster Presentation at the 43rd Australasian Society for Study of Intellectual Disability (ASSID) Conference, Melbourne, Australia. 25th November, 2008.

Rillotta, F. (October, 2008). *Family Quality of Life and Intellectual Disability.* Seminar to Clinical and Organisational Masters Students. School of Psychology, The University of Adelaide. October 17th 2008.

Rillotta, F., Kirby, N., Nettelbeck, T., & Shearer, J. (August, 2008). *Quality of Life of South Australian Families when the Member with an Intellectual Disability is at Different Developmental Stages.* 13th International Association for the Scientific Study of Intellectual Disability (IASSID) World Congress, Cape Town, South Africa. 26th August, 2008.

Rillotta, F., Kirby, N., Nettelbeck, T., & Shearer, J. (December, 2007) *Family Quality Of Life and Intellectual Disability: A Comparison Of Two Measures in South Australia.* 8th Conference of the International Society for Quality of Life Studies (ISQOLS). San Diego, California, USA. 7th December, 2007.

Rillotta, F., Kirby, N., & Nettelbeck, T. (August, 2006). *Family Quality of Life: The Effect of Additional Disabilities.* 2nd International Congress for the Europe - International Association for the Scientific Study of Intellectual Disability (E-IASSID), Maastricht, The Netherlands. 2nd – 5th August, 2006.

Appendix B. Information Sheet for Participants

<u>INFORMATION FOR FAMILY MEMBERS:</u>

Family Quality of Life and Disability

General Information:
My name is Fiona Rillotta and I am a PhD student in Psychology at the University of Adelaide. My research project is about the quality of life of Australian families who have a member/ members with an intellectual disability. This research project is part of the requirements for my degree and it is supervised from within the School of Psychology.

The Aim:
The goal of this study is to alert service providers to factors which contribute to family satisfaction and; whether different circumstances such as age of family members or type of disability make a difference to family quality of life and consequently to service support needs. Additionally two survey measures will be compared to assist in the development of a universal measure for Family Quality of Life. The results of this research will have implications for support provided by services to families.

Participation:
Participation in the study is voluntary. Should you agree to participate, you will first be asked to give informed consent and then will be invited to be involved in an interview about aspects of your family's life and well-being, with one (or both) of the 2 surveys:

1.) *Family Quality of Life Survey: Main caregivers of people with intellectual disabilities.*
- Approximately 2 hours;
- Family Background; Health; Financial well-being; Family Relationships; Support from Other People/ Services/ Values; Careers; Leisure; and Community Interaction.

2.) *Beach Center Partnership and Family Quality of Life Survey.*
- Approximately 40 minutes;
- General and Individual Family Information; Family Quality of Life (the things that make your life together as a family good); Partnership (how you feel about the main person who works with you and your child); and Supports and Services.

Benefits:
Whilst outcomes of this study may not be of direct benefit to you or your family, your contribution is valuable and it is expected that results will contribute to improving service provisions and support available to families with member(s) who have a disability.

Confidentiality:
Your responses will be kept confidential. All data will be analysed in group form and no participant will be identified in any results provided to independent bodies. Names on consent forms will be kept separate to surveys and all will be stored securely.

Your family has not been selected to participate for any particular reason other than criteria related to the study; for example, having a family member with an additional disability along with intellectual. I (the researcher) do not personally have access to contact details of potential participants.

Time and Assistance:
The interview is expected to take about two hours, but there is no time limit. *If you feel that time constraints may be an issue for you, please notify me and I can make alternate arrangements.*

It is intended that I will be present interviewing you with the survey, but if I am not present and you would like assistance filling out the survey, please contact me, Fiona Rillotta on my office phone 8303 4674 or mobile 0421882107.

Additional Information:
You may have participated (or been invited to participate) in a similar study in 2002. If this is the case, please indicate in the space provided on your consent form.

Whilst there are no known adverse affects of participation in this study, please note that the researcher is not qualified as a counsellor and so should any personal concerns about living conditions arise as a result of participating in this study you are urged to contact:

Disability Services SA (formerly IDSC)
Phone: (08) 8282 5500
Email: idsc.central@dfc.sa.gov.au

or previous supports or other existing resources you may have (e.g. counsellor, psychologist, options coordinator)

From Here:
You are not required to take any action on this letter. Your family will be contacted shortly by a Disability Services SA (IDS) staff member, seeking your permission to release your telephone number to me, Fiona Rillotta. If you agree, I can then call you and explain the study further, answer any questions you may have and invite you to participate. Please note that your consent to releasing your phone number does not mean that you must participate in the study and you are free to withdraw at any stage.

Ethical Considerations:
This study has been approved by the University of Adelaide School of Psychology Human Ethics Subcommittee. For any ethical concerns feel free to contact the Convenor of the committee:

Dr Paul Delfabbro
Convenor of the School of Psychology Human Ethics Subcommittee
Phone: 8303 5744
Email: paul.delfabbro@psychology.adelaide.edu.au

For More Information:
Thank you for considering this. If you have any queries about this study or require further information please do not hesitate to contact me, or one of my supervisors:

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Ms Joanne Shearer
External Supervisor
Ministerial Advisory Committee: Students with Disabilities
Phone: 8226 3632
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Appendix C. Consent Form for Participants

CONSENT FORM
Family Quality of Life and Disability
For participants in a research project in psychology

1. I ……………………………………………… (please print your name)

   consent to take part in the research project.

2. I acknowledge that I have read the attached Information Sheet entitled:

   ……………………………………………………………………………………..

   and I am satisfied that I understand the aims of the project and how these will affect me or my family. My consent is given freely.

   IN ADDITION, I ACKNOWLEDGE THE FOLLOWING:

3. Although I understand the aims of this research project, I also understand that involvement may not be of direct benefit to me or my family.

4. I have been informed that the information I provide will be kept confidential.

5. I understand that I am free to withdraw from the project at any time and that this will not affect my access to services now or in the future.

6. Have you participated or been invited to participate in a similar study?

   ☐ **Yes**   ☐ **No**

7. Do you consent to being contacted and invited to participate in another survey in the near future?

   ☐ **Yes**   ☐ **No**

……………………………………… (signature)

………….……… (date)

**You can obtain a copy of this completed Consent Form from
Fiona Rillotta, if you wish.**

Appendix D. FQOLS-2006 (electronic version – attached on disk)

Appendix E. Feedback about the FQOLS-2006

FAMILY QUALITY OF LIFE SURVEY:

Family Quality of Life Survey: Main caregivers of people with intellectual or developmental disabilities (FQOLS-2006)

**Comments and Suggestions by Fiona Rillotta and Neil Kirby
(Submitted October 2005)**

Questionnaire topics

Background: Family Members
Health of the Family
Financial Well-Being
Family Relationships
Support from Other People
Support from Disability Related Services
Support from Values
Careers and Preparing for Careers
Leisure
Community Interaction
Summary

✖ = Suggestion not taken up by the survey's authors

✔ = Suggestion taken up by the survey's authors

👎 = Dismissed altogether

👍 = Included in the current study

☹ = Not found to be considered crucial

😐 = Found to be an important point useful to other parts of the study

☺ = Found to be an all round important/ valid suggestion

Concerning "other" responses

✖👎☹
Only 2 "other" spaces are provided. Might this restrict respondents? Would it be better to have a general "others" category with a number of lines to allow more than two if necessary?
Not taken up – not considered necessary, plus there were opportunities to discuss in the qualitative comments during interviews.

Information to respondents

✖👍😐
Should the approximate time taken to fill in the questionnaire be given as the questionnaire might otherwise seem quite daunting in terms of its length?
Not taken up – but included on information sheets to participants in the current study.

✖👍😐
An explanation is given of the use of the term "intellectual disability". Should a brief explanation be given of the term "quality of life"?
Not taken up because "Quality of Life" can be very individualistic and the way that one family defines a life of quality may be very different to what another family considers to be a "good life". - Explained verbally to participants when conducting interviews in the current study.

✓👍☺

Should information be given as to whom respondents can contact for assistance if they have any problem in understanding the questions or filling out the survey?

Taken up – added a section on the first page of the survey for 'Correspondence and Information', including general inquiries contact and data sharing contact. - Local contacts for the current study are also on the information sheets to participants.

Background; Family Members

✓👍☺

Q 2 and Q4. Should the respondent be asked to tick a box to indicate that they have included additional information on the reverse side of the paper to ensure that it is not overlooked? Plus, the survey may be copied double-sided.

Taken up – changed to "Use the space to the right of the table to add others if needed" and "Add others if needed".

✓👍☺

Q3b. Should some category for mild or moderate behavioural problems be included in addition to severe, or just a category of behavioural problems, since mild or moderate behavioural problems or particularly, a number of them, might also affect family quality of life.

Taken up – changed to just 'Behavioural problems'.

✗👎😐

Q6. Should there be an additional question of this kind concerning anything the respondent might want to say about other family members, e.g. a family member that is particularly helpful or unhelpful? (e.g. a sibling)

Not taken up – this information could be provided in response to other sections of the survey, and in the following questions about the family, such as when talking about siblings. In the current study, participants revealed this information in their qualitative explanations, without additional questions needing to be added.

✗👍☺

Q7. Is there a need to ask if the immediate family has changed over the last few years (or specify a time like the last three years) and if so, in what way? For example, family quality of life might at the present time be severely affected by a recent divorce.

Not taken up – added questions about the past in each domain and to overall FQOL in the current study.

✗👎😐

Q8. The question says 'in your immediate family', but what if the respondent's ex-husband has remarried and so the child(ren) has/ have a step mother who takes on a parental role sometimes. The respondent might not consider this person to be 'immediate family'.

Not taken up – was still a valid point, but it only occurred in a few cases and in those instances participants were able to qualitatively explain the immediate family situation throughout interviews in the current study.

✓👍☺

Q8 Is there a need to include Siblings in this list since older siblings sometimes take on, or are required to take on, a parental role, e.g. in a single parent family. This can affect family quality of life if the sibling finds this role stressful.

Taken up – added Siblings to the list

✔👍☺

Q9. Further to the comment on question 8, should an additional column be added to this question to indicate whether the sibling(s) assist(s) with the care of the member with an intellectual disability?
Taken up – added another column for "Act as caregiver? (check ✔ if yes)"

✔👍☺

Q10. The same point can be made as for Q9 since family friends might also take on a role in assisting the member with an intellectual disability, e.g. respite, taking them on outings etc.
Taken up – added another column for "Act as caregiver? (check ✔ if yes)"

✘👎😐

Q11. Would it be useful to also ask who else is significantly involved with the member having an intellectual disability, e.g. a sibling?
Not taken up – this is already included in the response options to this question (e.g. "parents, siblings, and other members")

✘👍😐

Q13b. Would it be better to write this question as for Q6 on page 2, i.e. is there anything else you would like to tell us about your immediate family? - As this may be more likely to prompt a response that just "comments"
Not taken up – an additional question was added for the current study asking about anything else to tell about the family e.g. how it may have changed.

1. Health of the family

Section A

✔👍😐

Q1 and Q2. Should there be a question concerning whether major health concerns are ongoing at the present time as this may affect present quality of life whereas a previous but now resolved health concern may not.
Not taken up directly, but changed the wording from "*have there been*… health concerns…" to "*are* there… health concerns…" – Also added questions about the past (e.g. in the past has you family's level of health been any different to what it is now?") in each domain and to overall FQOL in the current study.

Section B

✘👎☹

Q2a Does "your area' need to be defined more specifically, e.g. local area or suburb? This also applies to
p.19 Q1.
p.20 Q3a.
p.21 Q4a.
p.22 Q6.
Not taken up – no problems arose with leaving the interpretation of "in your area" up to the participants. Plus qualitative comments from interviews in the current study verified any issues with this terminology.

✘👍😐

Does there also need to be a "none" category rather than just "hardly any" Should this be instead of the top category "a great many"? This would also apply to:

P10, Q2
P13, Q2
P17, Q2A
P20, Q3A
P21, Q2
P24, Q2
P28, Q2
P31, Q2A
P34, Q2.

Not taken up – probably due to the need to emphasize positive elements and avoid including negative connotations where ever possible. The option "none" was included in each Section B of every domain of the current study and it was necessary, because some participants did indicate "none" or "not at all".

✘👍😐

Should the two questions asking for examples of opportunities and barriers in Leisure section B Q2b and 2c be used here in each domain?

Not taken up directly – these were removed as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent. Plus the final question of Section B in every domain now asks for any additional qualitative comments. This proved to be necessary to obtain additional explanations

✔👍😊

Q2b. Should this read "your family's health needs" as it might be interpreted as referring to the respondents own individual health needs.

Taken up – and also was altered, reworded, and relocated as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent.

✘👎☹

Q4. Is "enjoy good health" what is wanted here since this could be interpreted to mean more than average health and it could be interpreted as either on a continual basis or as occasional good health. Would it be better to work it in the negative, i.e. in terms of continual poor health?

Not taken up – was not considered necessary.

2. Financial Well-being

Section A

✔👍😊

Q1. Should this question be separated into personal income and government benefits since it asks for total income, which might be interpreted as just personal or personal plus government benefits. Question 4 then asks about any additional financial support, which may or may not have been included in the answer to question 1. Should this question also ask about who contributes to the family income, e.g. siblings who work or receive government benefits.

Taken up – and also as a result of other feedback from other researchers, and this question's potential problematic nature, it was removed.

✘☞☹

Q3. Should "Managing well with some extra" be accompanied by "please indicate source"?
Not taken up – was not considered necessary. Plus the following question asks about sources of income other than employment.

✘👍☺

Q7c Should this question include an "if yes, please explain why? This might give some indication as to what the family would do with additional money.
Not taken up – a question was added in the current study asking about what it is that the family would wish for. This was considered necessary to gauge exactly what it was that the family desired in addition to acquiring the necessities.

Section B

✘👍😐

Q2. Should the two questions asking for examples of opportunities and barriers in Leisure section B Q2b and 2c be used here?
Not taken up directly – these were removed as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent. Plus the final question of Section B in every domain now asks for any additional qualitative comments. This proved to be necessary to obtain additional explanations.

✘☞😐

Q3a Is there a need to give examples of activities, such as sharing a house; otherwise, respondents might not know what is meant.
Not taken up directly – but this question was reworded as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent.

3. Family Relationships

Section A

✘👍😐

Q2. Should the "other" column be accompanied by a "please specify" column, e.g. grand parent, neighbor, family friend?
Not taken up – added "who" to the current study, because e.g. many times 'maintenance and repairs' was done by the Housing Trust and this was the only time in the survey that it was revealed that the family's house was owned by the Housing Trust.

Section B

✘👍😐

Q2. Should the two questions asking for examples of opportunities and barriers in Leisure section B Q2b and 2c be used here?
Not taken up directly – these were removed as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent. Plus the final question of Section B in every domain now asks for any additional qualitative comments. This proved to be necessary to obtain additional explanations.

4. Support from other people

Section A

✖☝😐
Q 4a. Should this question include "if some or more, please specify?
Not taken up – not considered necessary, plus there were opportunities to discuss in the qualitative comments during interviews and in the final open question of Section B.

Section B

✖👍🙂
Q1. Should practical and emotional support be separated because one could be provided without the other?
Not taken up – this was done in the current study for all 6 measurement concepts and it was considered important, because family members did indicate difference between practical and emotional support.

✖👍😐
Q2. Should the two questions asking for examples of opportunities and barriers in Leisure section B Q2b and 2c be used here?
Not taken up directly – these were removed as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent. Plus the final question of Section B in every domain now asks for any additional qualitative comments. This proved to be necessary to obtain additional explanations.

✖☝😐
Q4. Should this question include "if some or more, please specify"?
Not taken up – not considered necessary, plus there were opportunities to discuss in the qualitative comments during interviews and in the final open question of Section B.

✖☝😐
Q5a. Should there be separate sections for improve and decline as both might occur. For example a close neighbor who provided strong emotional support might move overseas (and therefore emotional support would decline), but a sister moving into a house nearby might provide practical support (and therefore practical support would improve).
Not taken up – not considered necessary, plus there were opportunities to discuss in the qualitative comments during interviews and in the final open question of Section B.

5. Support from Disability Related Services
  (remove capital from "From"?) **[Taken up]** ✔👍🙂

✖☝😐
Q2. Is there a need to assess how satisfied the family is with any of these services that they have used?
Not taken up – not considered necessary, plus there were opportunities to discuss in the qualitative comments during interviews and in the final open question of Section B.

Section B

✖👍😐

Q2. Should the two questions asking for examples of opportunities and barriers in Leisure section B Q2b and 2c be used here?
Not taken up directly – these were removed as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent. Plus the final question of Section B in every domain now asks for any additional qualitative comments. This proved to be necessary to obtain additional explanations.

✓👍😊

Q3. Does "work' in this question mean "employment" or "make a lot of effort to"? Should this question also include a Please specify?
Taken up – reworded to be consistent with Section B of all other domains

6. Support from Values

✖👍😐

Personal, Spiritual, Cultural are all included in the same questions but there could be different answers to each of them. Should they be separated or separate options for answers be given?
Not taken up – but there was opportunity to comment on these in qualitative comments during interviews and in the final open question of Section B.

✓👍😊

Q1 and Q4 do they need to be reworded to clarify the difference between them?
Taken up – these questions were reworded and another first question was added for participants to qualitatively explain their family's values – probably as the result of other feedback from other researchers as well.

✖👍😐

Q1-4. Should these questions include a Please comment section to indicate the kind of help received?
Not taken up, but there was opportunity to comment on these in qualitative comments during interviews and in the final open question of Section B.

Section B

✖👍😐

Q2 Should the two questions asking for examples of opportunities and barriers in Leisure section B Q2b and 2c be used here?
Not taken up directly – these were removed as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent. Plus the final question of Section B in every domain now asks for any additional qualitative comments. This proved to be necessary to obtain additional explanations.

✖👎😐

Q5a. and 5b. Should separate improve and decline options be provided since one (e.g. personal) might improve and another (e.g. Cultural) decline?
Not taken up – not considered necessary, plus there were opportunities to discuss in the qualitative comments during interviews and in the final open question of Section B.

7. Careers and Preparing for Careers

✓👍😐

Q6a. Should this question include an If yes, please specify? For example, Technical Training College, Sheltered workshop, Special employment service.

Not taken up directly – but this question was reworded as a result of other feedback from other researchers – to specify "does member with an intellectual disability engage in the daily activities he/ she/ they wants?" and then "what daily activities does your family member with an intellectual disability engage in?" [with a list including those suggested]

Section B

✗👎😐

Q 1-4 Is the intention here to include the member with an intellectual disability? If so, should this be stated? Also, is it important to ask the respondent to indicate which members of the family these questions refer to?

Not taken up – not considered necessary, plus there were opportunities to discuss in the qualitative comments during interviews and in the final open question of Section B.

✗👍😐

Q2. Should the two questions asking for examples of opportunities and barriers in Leisure section B Q2b and 2c be used here?

Not taken up directly – these were removed as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent. Plus the final question of Section B in every domain now asks for any additional qualitative comments. This proved to be necessary to obtain additional explanations.

✗👎☹

Q5b. Should this include improve and/or decline since it might improve for one family member but decline for another.

Not taken up – not considered necessary

8. Leisure

✗👎😐

Q1. Is there a need to ask additional questions concerning people outside of the family? Is there also a need to ask how satisfactory these activities are?

Not taken up – not considered necessary, plus there were opportunities to discuss in the qualitative comments during interviews and in the final open question of Section B.

Section B

✗👍😐

Q2b and 2c. Should these two questions also be used in the other sections concerning opportunities and barriers with respect to education and work etc., i.e.
p.6 Q2
p.10 Q2
p.13 Q2
p.17 Q2a
p.21 Q2
p.24 Q2
p.28 Q2

Not taken up directly – these were removed as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent. Plus the final question of Section B in every domain now asks for any additional qualitative comments. This proved to be necessary to obtain additional explanations.

9. Community Interaction

✖👍😐

Q1. Should the respondent also be asked how satisfied the family is with the groups, clubs or organizations?
Not taken up – but there were opportunities to discuss satisfaction in the qualitative comments during interviews and in the final open question of Section B.

Section B.

✖👍😐

Q2. Should the questions concerning what opportunities and what barriers be asked here as in Q2b and Q2c in section B of Leisure?
Not taken up directly – these were removed as a result of other feedback from other researchers, and to make sure that Section B of every domain is identical and consistent. Plus the final question of Section B in every domain now asks for any additional qualitative comments. This proved to be necessary to obtain additional explanations

✖👍😐

Q 3 and 4. Should the respondent be asked for examples?
Not taken up – but there were opportunities to discuss examples in the qualitative comments during interviews and in the final open question of Section B. Question 3 was changed to "make efforts" rather than "take steps" so that Section B of all domains would be consistent.

10. Summary

✔👍😊

Q3. & Q4. While '*add*' might be easily understood, would "detract" be more easily understood as "decrease" or "reduce"?
Taken up – this was changed to "take away from"

Appendix F. Additional Questions to the FQOLS-2006 about the Past

p.4 Q14
Is there anything else you would like to tell us about your immediate family?
(e.g. has your immediate family changed over the past few years and in what ways)?

p.6 Q 5c.
In the past has your family's level of health been any different to what it is now?
Yes □ No □

p.6 Q5d. If yes, please explain when and why (including before child(ren) were born)?

p. 10 In the past has your family's financial situation been any different to what it is now?
Q5d. If yes, please explain when and why (including before child(ren) were born)?

p. 13 In the past have your family relationships been any different to what they are now?
Q5d. If yes, please explain when and why (including before child(ren) were born)?

p. 18 In the past has the practical support your family receives from other people (excluding service providers) been any different to what it is now?
Q5d. If yes, please explain when and why (including before child(ren) were born)?

p.18 In the past has the emotional support your family receives from other people (excluding service providers) been any different to what it is now?
Q5d. If yes, please explain when and why (including before child(ren) were born)?

p.23 In the past has the support your family receives from disability related services been any different to what it is now?
Q5d. If yes, please explain when and why (including before child(ren) were born)?

p. 27 In the past have the personal, spiritual, religions and/or cultural values that contribute to your family's quality of life been any different to what they are now?
Q5d. If yes, please explain when and why (including before child(ren) were born)?

p. 31 In the past has your family's ability to pursue and prepare for the careers they want been any different to what it is now?
Q5d. If yes, please explain when and why (including before child(ren) were born)?

p. 33 In the past has your family's leisure and recreation been any different to what it is now?
Q5d. If yes, please explain when and why (including before child(ren) were born)?

p. 36 In the past has your family's interaction with people and places in your community been any different to what it is now?
Q5d. If yes, please explain when and why (including before child(ren) were born)?

p. 38 Q4a. In the past has you family's quality of life been any different to what it is now?
(e.g. including before the child with intellectual disability was born, or at relevant transitional periods of their life).

Appendix G. Beach Center FQOL Scale (electronic version – attached on disk)

NOTE:
This appendix is on a CD included
with the print copy of the thesis held in the
University of Adelaide Library.

Appendix H. Alterations to Demographic Questions of the Beach Center FQOLS Scale

General Individual and Family Information

Here are a few questions about you and your family. We will use this information to generally describe the people who responded to our survey. We will describe people in groups, never as individuals, so your answers will be kept confidential. Please answer these questions about **yourself**.

1. What is your gender?

   O Male   O Female

2. What year were you born? _____ Your age: _____

3. Are you of Aboriginal or Torres Strait Islander origin?

   O Yes   O No

4. What is your cultural background? (Shade all that apply.)
   O Australian

   O English   O Asian   O Italian

   O Greek   O German   O Other (Please specify)

5. What is your marital status?

   O Married/ De facto (Living with someone)   O Not married (widowed, divorced, separated, never married)

6. What is your employment status?

   O Working **full-time** for pay or profit for a company or family business

   O Working **part-time** for pay or profit for a company or family business

   O Student **full-time**

   O Working and studying

   O Unemployed but looking

   O Not employed (for example, stay-at-home parent or care-giver, retired, Centrelink pay, disability)

7. What is the highest level of education that you have completed?
(Please shade *ONLY* one.)

   O No schooling completed   O TAFE Certificate

   O Formal schooling but no high school (e.g. only primary school)   O Bachelor's Degree

   O Some high school but not completed   O Graduate Degree (e.g. Honours or other Higher Degree)

   O High school graduate (Year 12 or equivalent)   O Doctorate degree

   O Some University, TAFE or other post-high school, but no degree   O Other (Please specify)

Now we want to ask you a few questions about your **family member with a disability.** If you have more than one family member a disability, please consider the one who has the most impact on your family life. Remember, your answers will be kept confidential and only reported as a group, not as individuals or families.

8. What is your relationship to the family member with a disability in your family?

O Parent (Biological, Step, Foster or Adoptive)

O Spouse or partner

O Other relative (child, grandparent, aunt, uncle, sibling, etc.)
Please specify: _____

O Other non-relative (family friend, etc.)
Please specify: _____

9. What is the gender of your family member with a disability?

O Male   O Female

10. What year was your family member with a disability born? _____

Family member with a disability's age: _____

11. What is the level of your family member's disability?

O Mild   O Moderate   O Severe   O Unknown

12. What is the nature of your family member's **PRIMARY** disability? (Please shade *ONLY* one.)

O ADD or ADHD

O Autism spectrum disorder

O Developmental delay or early childhood disability

O Emotional or behavioral disorder

O Hearing impairment including deafness

O Learning disability

O Intellectual Disability (cause unknown)

O Physical disability

O Speech or language impairment

O Traumatic brain injury

O Vision impairment including blindness

O Health impairment (Please specify) _____

O Other disability (Please specify) _____

O No specific diagnostics

13. Does your family member have any **SECONDARY** disabilities in addition to the primary disability?

O Yes   O No

The following questions pertain to your family. Remember, your answers will be kept confidential.

14. Which of the following best describes the size of the community in which you live?

○ Large city or metropolitan area (population greater than 200,000)

○ Urbanized area (between 50,000 and 200, 000)

○ Town or small city (between 2,500 and 50,000)

○ Rural area or town with population less than 2,500

15. What was your total household income from all sources for the past year? Be sure to include income from all sources (such as Centrelink payments, disability pension, carer's allowance, or child support).

○ Less than $14,999   ○ Between $35,000 and $39,999

○ Between $15,000 and $19,999   ○ Between $40,000 and $49,999

○ Between $20,000 and $24,999   ○ Between $50,000 and $59,000

○ Between $25,000 and $29,999   ○ Between $60,000 and $74,999

○ Between $30,000 and $34,999   ○ Over $75,000

16. How many people are supported on this income?

○ 1   ○ 5

○ 2   ○ 6

○ 3   ○ 7

○ 4   ○ 8 or more

☺ Thank you! ☺
If you have any questions, concerns or comments, please contact
Fiona Rillotta 8303 4674

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