



MONASH University

Family Quality of Life When There is a Child with Disability

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*Bachelor of Science (Occupational Therapy); Masters of Biomedical Science
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This PhD is dedicated to

Mrs Vira Bhopti
who loved me unconditionally

Mr Roop Lal Malhotra,
my grandfather, who whispered to me
when I was 6 months old
that I would do great things
I hope you are proud!

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Abstract

Having a child with disability has an influence on parents, family members, and family quality of life (FQOL). Disability-related services and supports become a part of the family's life. Many parents give up their previous occupations such as self-care, and paid work to be able to provide long-term caregiving. This research investigated parent perspectives of their family quality of life when there is a child with disability. Relationships between early childhood intervention services (ECIS), parent occupations, and FQOL were also examined. The overall aim was to inform research, practice, and policy for families, and ECIS providers.

Two mixed methods studies were conducted including 122 participants, and 24 in-depth interviews. The first study included parents of children with disability in ECIS. The quantitative aspect ($N=72$) used the Beach Center family quality of life survey (BC-FQOLS) and a demographic questionnaire. Twelve semi-structured interviews were conducted from a purposefully selected sample. The second study included parents of school-aged children with disability. The same tools were used. Fifty parents participated in the quantitative study, and 12 interviews were completed. Data for each individual study were analysed using Spearman's correlations, descriptive scores, and qualitative coding analyses. Results and findings from each study were triangulated and discussed.

A two-way analysis of variance (ANOVA) was conducted to compare the quantitative scores from the BC-FQOLS, and the demographic questionnaire items from both studies. A comparative analysis of findings from both qualitative studies was also conducted. The final results and findings were triangulated, integrated, and synthesised to answer the research questions.

This research found associations between parent occupations, ECIS/disability-related support, and FQOL in both study groups (ECIS and school-age).

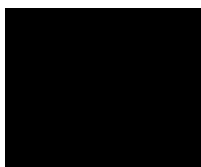
The significant differences in the ANOVA scores on total FQOL, and all the subscales of the BC-FQOLS between the two groups indicated that FQOL scores reduced as children got older. The qualitative findings further illuminated the quantitative results.

Positive adaptations, positive beliefs and values, and positive transformations contributed to better levels of FQOL in both groups. Parents in the ECIS group were hopeful that their child would continue to progress to mainstream school. They anticipated being able to return to their previous occupations when their child went to school. Due to the long-term caregiving, most parents/caregivers from the school-aged group were unable to return to their previous occupations, especially work. Necessary occupations such as sleep and health care continued to be compromised. Family-centred care and supportive staff had a positive influence on FQOL. Respite care, periods of short-term residential care, and spending small amounts of time away from caregiving for the child with disability were crucial for parents to be able to return to some of their previous occupations and in turn improve their FQOL.

This doctoral research further adds to the body of knowledge in FQOL research by demonstrating relationships between parent occupations and FQOL, and concludes that even though parents are happy to adopt the caregiver role, loss of occupations such as work and looking after their own health (self-care) can have detrimental impacts on their long-term well-being, and consequently on their FQOL. This research concludes that even though families feel satisfaction with their FQOL, the hardships and challenges of caregiving increase, as the child gets older.

Declaration

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



Signature:

Print Name: ANOOPAMA BHOPTI

Date: March 2018

Publications During Enrolment as a Doctoral Student

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes two original papers published in peer-reviewed journals and one submitted publication. The core theme of the thesis is *Family Quality of Life*. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the Department of Occupational Therapy, under the supervision of Associate Professor Ted Brown and Dr Primrose Lentin.

Thesis Chapter	Publication Title	Status (<i>published, in press, accepted or returned for revision, submitted</i>)	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
1	<i>Viewpoint - Promoting the occupations of parents of children with disability in early childhood services - building stronger families and communities.</i>	Published <i>Australian Occupational Therapy Journal.</i> doi:10.1111/1440-1630.12297	90%	5% - Dr Ted Brown 5% - Dr Primrose Lentin	No
2	<i>Family quality of life: a key outcome in early childhood intervention services—a scoping review.</i>	Published <i>Journal of Early Intervention</i> , 38(4), 191-211. doi: 10.1177/10538151166731	80%	10% - Dr Ted Brown 10% - Dr Primrose Lentin	Monash academics and supervisors

2	<i>Relationships between early childhood intervention services, family quality of life and parent occupations: a mixed methods study</i>	<i>Submitted to Journal of Occupational Therapy, Schools and Early Intervention</i>	80%	10% - Dr Primrose Lentin 10% - Dr Ted Brown	<i>Monash academics and supervisors</i>
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**If no co-authors, leave fields blank*

I have not renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

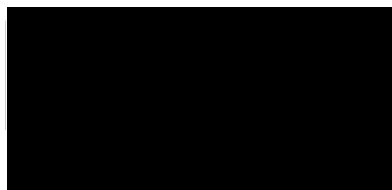
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The undersigned hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author I have consulted with the responsible author to agree on the respective contributions of the authors.

Main Supervisor signature:



Date: 28-03-2018

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List of Acronyms

ABS – Australian Bureau of Statistics

BC-FQOLS – Beach Center Family Quality of Life Survey

CIW – Canadian Index of Well-being

CWD – Child with Disability

DHS – Department of Human Services

DET – Department of Education and Training

ECEI – Early Childhood Early Intervention

ECIS – Early Childhood Intervention Services

FCP – Family Centred Practice

FQOL – Family Quality of Life

GDP – Gross Domestic Product

NDIS – National Disability Insurance Scheme

QoL – Quality of Life

SEL – Subjective Experience of Life

SWB – Subjective Well-being

WB – Well-being

WHO – World Health Organization

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Chapter 1: Introduction to Thesis – Family Quality of Life when there is a Child with Disability

This doctoral thesis is titled “Family Quality of Life when there is a Child with Disability”. The focus of the doctoral research was to investigate parents’ perspectives of their family quality of life (FQOL) when they have a young child with disability (CWD), and the impact of having a CWD on their FQOL and their occupations. This research was also interested in investigating whether early childhood intervention services (ECIS) provided to families of a CWD in the early years had any influence on the FQOL of family members, and whether there were any emerging implications for service providers working in ECIS.

Two completed mixed methods studies are incorporated within this thesis. These two studies will be presented as separate chapters (Chapters 2 and 3) with subsections detailing the method, results and findings, and discussion for each study. Chapter 4 will synthesise and integrate the findings from both the completed studies and present these integrated findings. The final chapter (Chapter 5) will present a discussion from the completed studies to arrive at implications for policy, practice and further research, and the final conclusion will be a culmination of both studies. Some refereed publications were also written as part of this doctoral research and the published and “under review” papers are also enclosed within the thesis.

This chapter presents an overview of quality of life (QoL), its definition, theories, and models. Following this section, the concept of family and FQOL is presented which constitutes the main topic for this research. The research within this thesis is also concerned with the influence of having a CWD on the changes in parent

occupations, and the relationships this has with FQOL. An overview of parent occupations and the classification of occupations used for this research are also presented. The last section presents a brief overview of the ECIS system in Melbourne, Australia.

1.1 Quality of Life, Family Quality of Life and Disability

Quality of life (QoL) has emerged as an important term in policy and in research because it represents the conditions individuals require to flourish as human beings (Soutphommasane, 2011). QoL has also generated interest as an outcome within the field of disability, including QoL of people with disability and their families. Over the last decade, family outcomes such as family functioning and FQOL started attracting recognition from numerous disciplines including social sciences, health, and disability (R. Brown, Kyrkou, & Samuel, 2016; Turnbull & Turnbull, 2002). The significance of QoL for families gained recognition as research indicated that well-functioning families were important to the functioning and stability of human societies. QoL theories have influenced the concept and development of FQOL as an outcome measure for service delivery and understanding of family well-being (Kober, 2010; Zuna, Summers, Turnbull, Hu, & Xu, 2010).

1.2 An Overview of Quality of Life (QoL)

Quality of life is recognised as an important outcome in measuring service delivery and guiding policy (Schalock, 2010; Seed & Lloyd, 1997). QoL incorporates individual factors like health, personal beliefs, emotional, social, and financial states, as well as level of independence (Schalock, 2004). In the last two decades, QoL has emerged as an indicator of not only well-being for the individual, but also as an

indicator of a country's social and economic growth, sustainability, and community, rather than just gross domestic product (GDP) (Hoegen, 2009). Since the 1930s, GDP was used as a standard benchmark for a country's standard of living; however, GDP does not inform one about the distribution of wealth or the income gap between the rich and poor in a certain country (Soutphommasane, 2011). Several countries have taken national initiatives to measure their development and progress in a new, more comprehensive way and Australia is one of the pioneers in this regard (Hoegen, 2009). According to an Australian political theorist and philosopher, Soutphommasane (2011), QoL is important, because it highlights the conditions required for individuals to enjoy well-being and prosperity at an individual level. Amartya Sen (2009), an economist and philosopher argues that even though income, wealth, respect, and recognition are instrumental in value, the true criterion of overall progress for human beings is improvement in the actual opportunities of living and being able to do the different things that they value, without restraint.

Many policy makers around the world consider happiness and well-being as priorities, rather than GDP. In 2008, France commissioned a body of leading economists to consider ways to measure their nation's progress in terms beyond economic growth. In 2010, the United Kingdom Office of National Statistics announced the development of a *national happiness index* (Soutphommasane, 2011). The Canadian government is now considering GDP against the Canadian Index of Well-being (CIW) to measure how the Canadian population is faring as a whole (Smale, 2016). The Australian Commonwealth Treasury developed a "Wellbeing Framework" to primarily reflect the importance of a person's substantive freedom to lead a life they have reason to value, alongside analytical and measurement frameworks from economists and statisticians (Commonwealth Treasury of Australia,

2004). Deakin University's Australian Centre on Quality of Life has also compiled the Australian well-being and happiness index that is being used to regularly measure how satisfied Australians are with their own lives and with life in Australia (Cummins & Mead, 2010).

In the health and disability arena, traditional biomedical outcomes (such as frequency and severity of disease) do not capture how the individual is truly affected by illness; however, including QoL brings a holistic dimension to measuring outcomes (Waters et al., 2009). The World Health Organization (WHO) in 1997 incorporated the concept of health into QoL implying that QoL is affected by a person's health, emotional state, level of independence, social relationships, and personal beliefs. The measurement of health and the effects of health care must therefore include not only an indication of changes in the frequency and severity of diseases, but also an estimation of well-being by measuring the QoL related to health care (WHOQOL, 1997). The next section assists in the further understanding of the development of QoL, its theory, and applications.

1.3 Definition of QoL

The World Health Organization (1997) defines QoL as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (p. 1). QoL is affected by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment (WHOQOL, 1997). According to the WHO, there are six domains of QoL and 24 facets. The six domains are physical health, psychological, level of independence, social relationships, environment, and

spirituality/religion/personal beliefs (WHOQOL, 1997). Each domain has corresponding facets that assist in understanding the domain; for example, the domain of physical health can be further described by understanding the person's level of energy and fatigue, pain and discomfort, and sleep and rest (Szabo, 1996). The facets are linked to the domain; for instance, within the domain of 'level of independence' reduced mobility or inability to perform activities of daily living would affect a person's level of independence and this would in turn affect their QoL. Table 1.1 presents the six domains with the corresponding 24 facets.

Table 1.1 *The WHOQOL: Domains and Facets of Quality of Life (1997)*

Domains	Facets
1. Physical health	Energy and fatigue Pain and discomfort Sleep and rest
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Thinking, learning, memory, and concentration
3. Level of independence	Mobility Activities of daily living Dependence on medicinal substances and medical aids Work capacity
4. Social relationships	Personal relationships Social support Sexual activity

5. Environment	Financial resources Freedom, physical safety, and security Health and social care Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation/leisure Physical environment (pollution/noise/traffic/climate) Transport
6. Spirituality/religion/personal beliefs	Religion/spirituality/personal beliefs

WHOQOL = World Health Organization Quality of Life. Source: WHOQOL, 1997.

1.4 Theories and Models of Quality of Life

The concept of QoL is primarily used in three ways: as a framework for service delivery, as a basis for evidence-based practices, and as a vehicle to implement quality improvement strategies (Schalock, Kenneth, Verdugo, & Gomez, 2010). This section presents some theories and models of QoL.

The Schalock et al. (2010) QoL model. According to Schalock et al. (2010), “Individual QoL is defined as a multi-dimensional phenomenon composed of eight core domains influenced by culturally-sensitive indicators that identify personal characteristics and environmental factors” (p. 21). Schalock et al. (2010) published their model based on individual-referenced QoL research over two decades. According to this model, QoL is multidimensional and the eight core domains are measured on the basis of personal and culturally relevant indicators, and influenced by personal and environmental factors (Schalock, 2010). These factors act as potential moderators or mediators (see Figure 1.1). The eight domains are emotional well-being, interpersonal relations, material well-being, personal development, physical

well-being, self-determination, social inclusion, and rights (see Table 1.2). QoL indicators are QoL-related perceptions, behaviours, and conditions that define each QoL domain and their measurement results in personal outcomes (Schalock, 1996, 2010; Schalock et al., 2010). A moderator variable can be a qualitative (e.g. gender or race) or quantitative (e.g. intelligence quotient or socio-economic status) variable that alters the direction or strength of the relation between a predictor and an outcome (Schalock et al., 2010). A mediator variable influences the relation between an independent variable and an outcome, and exhibits indirect causation, connection, or relation; for example, policies, practices, services, and supports (Schalock et al., 2010). Table 1.2 and Figure 1.1 provide the conceptual basis for this operational QoL model.

Table 1.2 *QoL Conceptual and Measurement Framework*

Domain	Indicators
Emotional well-being	Contentment, self-concept, lack of stress
Interpersonal relations	Interactions, relationships, supports
Material well-being	Financial status, employment, housing
Personal development	Education, personal competence, performance
Physical well-being	Health and health care, activities of daily living, leisure
Self-determination	Autonomy/personal control, goals and personal values, choices
Social inclusion	Community integration and participation, community roles, social supports
Rights	Human (respect, dignity, equality) and legal (citizenship, access, due process)

Source: Schalock R., Kenneth, K., Verdugo, M., & Gomez, L. (2010). Quality of life model development and use in the field of intellectual disability. In R. Kober (Ed.),

Enhancing the quality of life of people with intellectual disabilities (Vol. 41, pp. 17-32). Vic: Springer.



Figure 1.1. Quality of Life Operational Model by Schalock et al. (2010).
Schalock, R., Kenneth, K., Verdugo, M., & Gomez, L. (2010). Quality of life model development and use in the field of intellectual disability. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities* (Vol. 41, pp. 17-32). Vic: Springer. Schalock et al. (2010)

Schalock et al. (2010) state that the use of this model has three implications and potential impacts for practice, namely that:

1. there should be increased confidence that this QoL model provides a valid framework for service delivery, policies, and program practices
2. the program's inputs, processes, and external factors should act as moderator or mediator variables that impact QoL domain referenced personal outcomes, and

3. this model should provide an application and research framework for emerging transdisciplinary approaches to research and applications that involve researchers and practitioners working jointly (Schalock et al., 2010).

Quality of life model by Granzin and Haggard (2000). This QoL was presented in a book chapter (Granzin & Haggard, 2000). The authors claimed that greater QoL is associated with more education, emotional support, physical functioning, housing satisfaction, community identity, and mental health, and the absence of leisure/boredom. This model was centred around the person, environment, and subjective experience of life to understand the theory of QoL. It was based on an interactionist perspective and holds that human behaviour is influenced by the interaction between the organism and the environment (Granzin & Haggard, 2000). It comprises three segments, namely person, environment, and the subjective experience of life (SEL). The flow of influence proceeds recursively from the person segment, through both the environment and SEL segments. The model (see Figure 1.2) uses four person constructs (age, education, income, and physical functioning), four environment constructs (home ownership, emotional support, housing satisfaction, and community/neighbourhood identity) and three SEL constructs (leisure, boredom, mental health, and QoL) (Baker & Palmer, 2006; Cummins, 2000; Osborne, 1992).

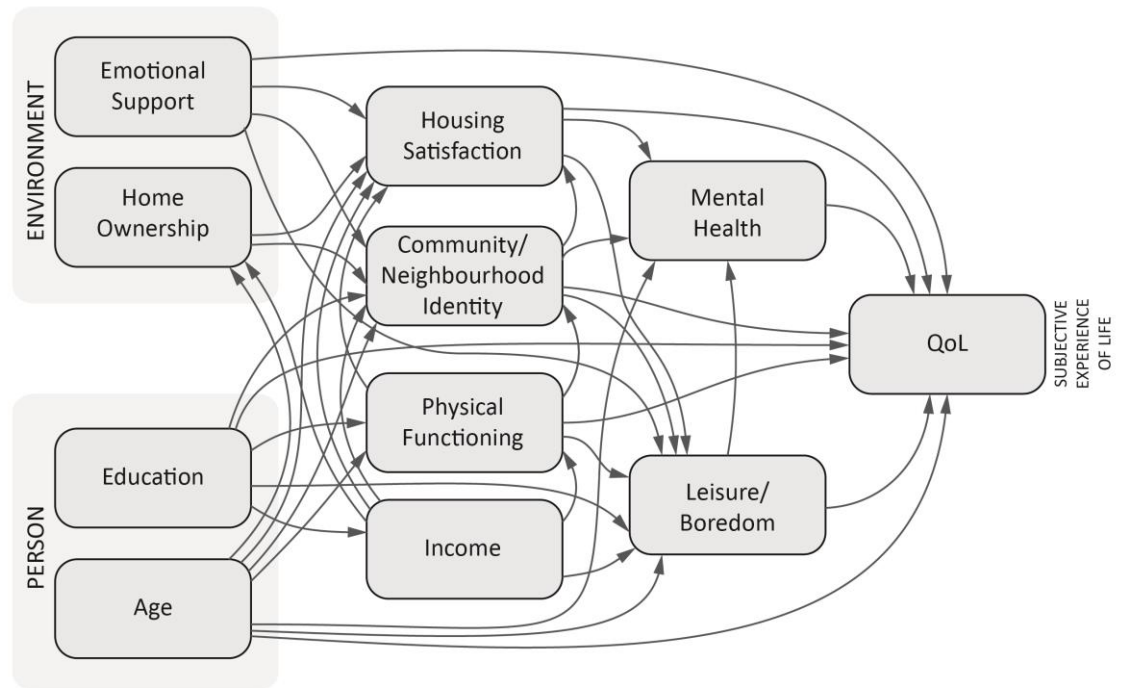


Figure 1.2. Granzin and Haggard’s model showing the influences of person and environment on QoL and subjective experience of life. Source: Granzin & Haggard, (2000).

QoL is the output or criterion construct of this model within the SEL segment. It is subjective in nature, representing a person’s overall sense of well-being. This model (see Figure 1.2) proposes a complex flow of influence among the constructs and offers an integrative explanation for QoL (Baker & Palmer, 2006; Granzin & Haggard, 2000).

Cummins’ model/ theory of QoL. Cummins presented an “Explanatory theory of QoL” rather than a model, as he argued that there was a need for simpler

propositions that could be tested empirically (Cummins, 2005). He presented three propositions in his theory: (a) that all measures relevant to QoL be characterised as either indicator variables (measured as outcome) or causal variables (that generate outcome); (b) that the indicator variables be hierarchically organised from general (life as a whole) to specific (friendships); and (c) that both QoL models and instruments reflect this hierarchical structure. Cummins (2005) proposed the use of this theory in four ways, namely:

1. for the purpose of monitoring service quality
2. to use subjective well-being (SWB) as the global indicator variable (if SWB lies below its normative range this signals homeostatic failure and a high probability of depression)
3. to use domain-level indicators for diagnostic purposes (to indicate those aspects of life which the person regards as threatening to their overall life quality)
4. to use SWB values to guide intervention (if SWB values lie below the normative range then the provision of appropriate additional resources will increase SWB and homeostasis) (Cummins, 2005).

After years of work and a multitude of QoL conceptualisations by researchers from different perspectives, and from different disciplines, a consensus has been reached among an international team of researchers on some key components of QoL conceptualisation. Some of these key concepts and principles include values, lifespan, holism, self-image, choice, personal control, empowerment, rights, and antidiscrimination (Cummins, 2005; Schalock et al., 2002; Schalock et al., 2010). Although the functional areas of QoL may be labeled differently, most agree that the

common QoL domains are physical well-being, material well-being, social well-being, and emotional and productive well-being.

1.5 From QoL to Family Quality of Life in Disability

QoL has been established as an important outcome in the field of disability with an increasing focus on providing individualised supports within inclusive environments, an emphasis on key performance indicators and evidence-based practices, and the use of best practices (Schalock, 2010). Recently, researchers in the international disability field have been interested in the concept of FQOL in families of CWD (Park et al., 2003; Zuna et al., 2010). Over the last two decades, the disability field has gradually come to a consensus that providing family support and delivering services using family-centered approaches are important core concepts of disability policy and practice (Dunst, Johanson, Trivette, & Hamby, 1991; Kennedy, McLoughlin, Moore, Gavidia-Payne, & Forster, 2010; Turnbull & Turnbull, 2002). The collaborative work of several researchers and professionals further suggests that disability impacts the whole family, and that professionals collaborating with families can better serve the needs of children with disability, and achieve better outcomes, if they consider the well-being of all family members (I. Brown, 2006; Dunst, Trivette, & Hamby, 2007; Turnbull, Brown, & Turnbull, 2004; Turnbull & Turnbull, 2002). The value of research in FQOL is further recognised because the family constitutes a structure that is important to society's functioning and stability, and well-functioning families and a good FQOL are seen as a positive social resource (Isaacs et al., 2007). The next section presents an overview on family and FQOL.

1.6 Overview of the Constitution of Family

Family – definition and context. “Family is defined as those people that consider themselves a family (whether or not they are related by blood or marriage), and support and care for each other on a regular basis” (Turnbull, 2011, p. 8). Within the Australian Bureau of Statistics (ABS), family is defined as “two or more persons, one of whom is at least 15 years of age, who are related by blood, marriage (registered or de facto), adoption, step or fostering; and who are usually resident in the same household” (ABS, 2010, p. 5). Families may include step and blended siblings, and may be headed by single parents, adoptive or foster parents, grandparents, or same-sex partners, along with married couples. More married women are in the workforce and mother-only households have become more common as a result of the postponement of marriage and increases in lifetime levels of divorce (Department of Human Services, 2002). According to a report by the ABS, there are six million families in Australia and 45% of these families are couples with children, 38% are couples without children, and 16% are single parent families (ABS, 2015). Almost 47,000 same-sex couples live in Australia, an 81% increase since 2006. The significance of the diversity of family forms is a central theme emerging in other research and needs consideration when conducting studies within the family context.

1.7. Definitions and Theories of Family Quality of Life (FQOL)

Family quality of life emerged as a separate concept to QoL following the strong emphasis in the disability field on a family-centred practice (FCP) approach. The FCP approach is used mainly when working in the field of childhood disability, more so in the early childhood disability area of practice. The FCP approach involves the family in service delivery as a team member. Child-focused goals as well as family-focused goals are set for achieving better family outcomes (Dunst, 2010;

Dunst et al., 1991; Moore & Larkin, 2005). The concept of FQOL for families who have a CWD was also rooted in principles of positive psychology where researchers began to focus on positive development, strengths and coping strategies that families use rather than examining the impact of disability on families on assumptions of negative factors such as stress and depression, divorce, and maladjustment (Chiu et al., 2013). Around the same time, the paradigm shifted from the medical model, where disability was seen as impairment within the person, to a social model, where disability was being measured as an interaction of the person with their environment (Turnbull & Turnbull, 2002). Measuring meaningful life for a person with disability was related to the supports that they were provided with. Thus, disability researchers who were seeking a more positive orientation to exploring family outcomes adapted the concept of individual QoL to FQOL. In thinking about family outcomes, FQOL started emerging as an important outcome to measure the effectiveness of service provision.

According to Brown et al. (2016), FQOL is a combination of the individual family members' QoL and factors that affect the whole family. There are seven areas of individual life that are particularly important for describing FQOL, namely, physical well-being, emotional well-being, environmental well-being, social well-being, advocacy, enrichment, and productivity (I. Brown & Brown, 2003). FQOL can be considered the place where the individual QoL of each family member meets.

Zuna et al. (2010) defined FQOL as “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact” (p. 262). Their definition was based on a literature review that aimed to theorise and conceptualise FQOL. A book chapter on FQOL definitions and concepts includes the work of many researchers who have

contributed to the development of FQOL, and six of these definitions of FQOL from Kober (2010) are presented in Table 1.3.

Table 1.3 *Family Quality of Life Definitions*

Author	FQOL Definition
Bayat (2005)	FQOL refers to the family's overall well-being and ability to meet the family's needs and enjoy life.
Brown et al. (2006)	FQOL is a combination of the individual family members' QoL, and factors that affect the whole family. There are seven areas of individual life that are particularly important for describing FQOL, namely physical well-being, emotional well-being, environmental well-being, social well-being, advocacy, enrichment, and productivity.
Gupta & Sharma (1998)	Enrichment of life, a socio-economic and socio-psychological process running through social production, social distribution, and social perception of values concerning QoL.
Rettig & Bubolz (1983)	Integration of human needs, economic and psychological resources, and interpersonal satisfaction as a basis for development of perceptual indicators for family well-being.
Rettig & Leichtentritt (1999)	An individual's experience of family life will depend on the extent to which personal needs are met, as judged by the personal values, standards, and aspirations one has for an ideal family life.
Weigel et al. (1995)	Three variables represent FQOL: family satisfaction, family cohesion, and family decision making.
Zuna et al. (2010)	FQOL is defined as "a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact".

(Adapted from Kober, 2010)

1.8 The Unified Theory of FQOL

After reviewing FQOL definitions, conceptualisations, and models, Zuna et al. (2010) proposed a unified theory of FQOL to help inform and organise an interdisciplinary agenda. The theory was based on four clusters of concepts identified from a review of 24 studies on FQOL (Zuna et al., 2010). These four concepts are

- family-unit concepts
- individual family-member concepts
- performance concepts, and
- systemic concepts.

Family-unit concepts. Family-unit concepts comprise family characteristics and family dynamics. The family-unit is the collective number of individuals who consider themselves to be a part of a family and who engage in some form of family activities together on a regular basis (Zuna et al., 2010). Family characteristics include traits of the family as a whole; for example, family income, size of family, geographic location, religious preference, ethnicity, or family form. Family dynamics are the aspects of interactions and ongoing relationships among two or more family members. Family dynamics include variables such as family sense of coherence, family hardiness, satisfaction with division of family labour, and work-family conflict.

Individual family member concepts. Three types of family member concepts include demographics, characteristics, and beliefs of family members who may reside in the home. Individual demographics are basic traits, such as the age and sex of the person with disability, the parents' education levels, ethnicity, or employment status, or siblings' age or sex. Individual characteristics are complex and might vary over time, such as the behaviour of the individual with disability, parental depression, or sibling health status (Zuna et al., 2010). Beliefs are a family member's attributions of

meaning, expectations, or understanding about a phenomenon, such as the meaning of the individual's disability, expectations about the individual's future, or expectations about parental roles with professionals.

Performance concepts. Performance concepts imply an action, something that is delivered or acted upon on behalf of the individuals with disabilities and their families. The three performance concepts include services, supports, and practices. Services include a range of educational, social, and health-related activities expected to improve family outcomes such as respite care, counselling, or occupational therapy. Supports are less concrete resources and include emotional support or knowledge provided through parents' interactions with a service provider such as an early childhood intervention service (ECIS) provider, or information provided via attending a parent support group (Kyzar, Turnbull, Summers, & Gomez, 2012). Practices are specific procedures or processes through which services and supports are delivered such as family-centred practice, inclusive practices, or child-specific interventions (Zuna et al., 2010).

Systemic concepts. Three systemic concepts that influence FQOL are systems, policies, and programs (Zuna et al., 2010). Systems are a collection of interrelated networks organised to meet the various needs of the society such as health and education systems (Phillips, 2006). Systems and programs are formal or informal organised entities that provide services to an identified population. Policies are guidelines establishing, organising, and regulating the procedures for implementing programs (Phillips, 2006; Zuna et al., 2010). Without policies in place there would be very few programs, services, and supports for families of a CWD and this would affect their FQOL. Hence systems, policies, and programs need to be included as the backdrop for FQOL.

Figure 1.3 is a representation of the unified theory of FQOL as depicted by Zuna et al. (2010). A few related linkages that are drawn from this proposed theory include the interaction of family characteristics and dynamics with individual characteristics to influence FQOL outcomes. Zuna et al. (2010) state that family and individual factors like supports and services act as mediating or moderating variables on the effectiveness of family-unit or individual member factors to predict FQOL. Lastly, the theory highlights that program quality predicts implementation of best practice, that in turn impacts individual factors and therefore FQOL (Zuna et al., 2010). Figure 1.3 illustrates the distal impacts of systems, policies, and programs, represented by the dashed lines of the outer circles around the edge of the interactive cogs, to emphasise their role as indirect influences on the directly interactive elements within the inner circle (Zuna, Selig, Summers, & Turnbull, 2009; Zuna et al., 2010; Zuna, Turnbull, & Summers, 2009).

According to Zuna et al. (2010) the systems, policies, and programs indirectly impact individual and family-level supports, services, and practices; individual demographics, characteristics, and beliefs, and family-unit dynamics, characteristics, and beliefs are direct predictors of FQOL, and also interact with individual and family-level supports, services, and practices to predict FQOL. Singly or combined, this model's predictors results in a FQOL outcome that produces new family strengths, needs, and priorities which re-enter the model as new input resulting in a continuous feedback loop throughout the life course of the family (Zuna et al., 2010). If one of the system factors changes, it disrupts the smooth running of the cogs leading to changes in FQOL until adaptation or homeostasis occurs within the individual or family. For example, if a child is transitioning from early childhood services to school and needs to be served by another service system, FQOL will be

impacted while a whole new set of performance factors with new services, practices, and supports is activated.

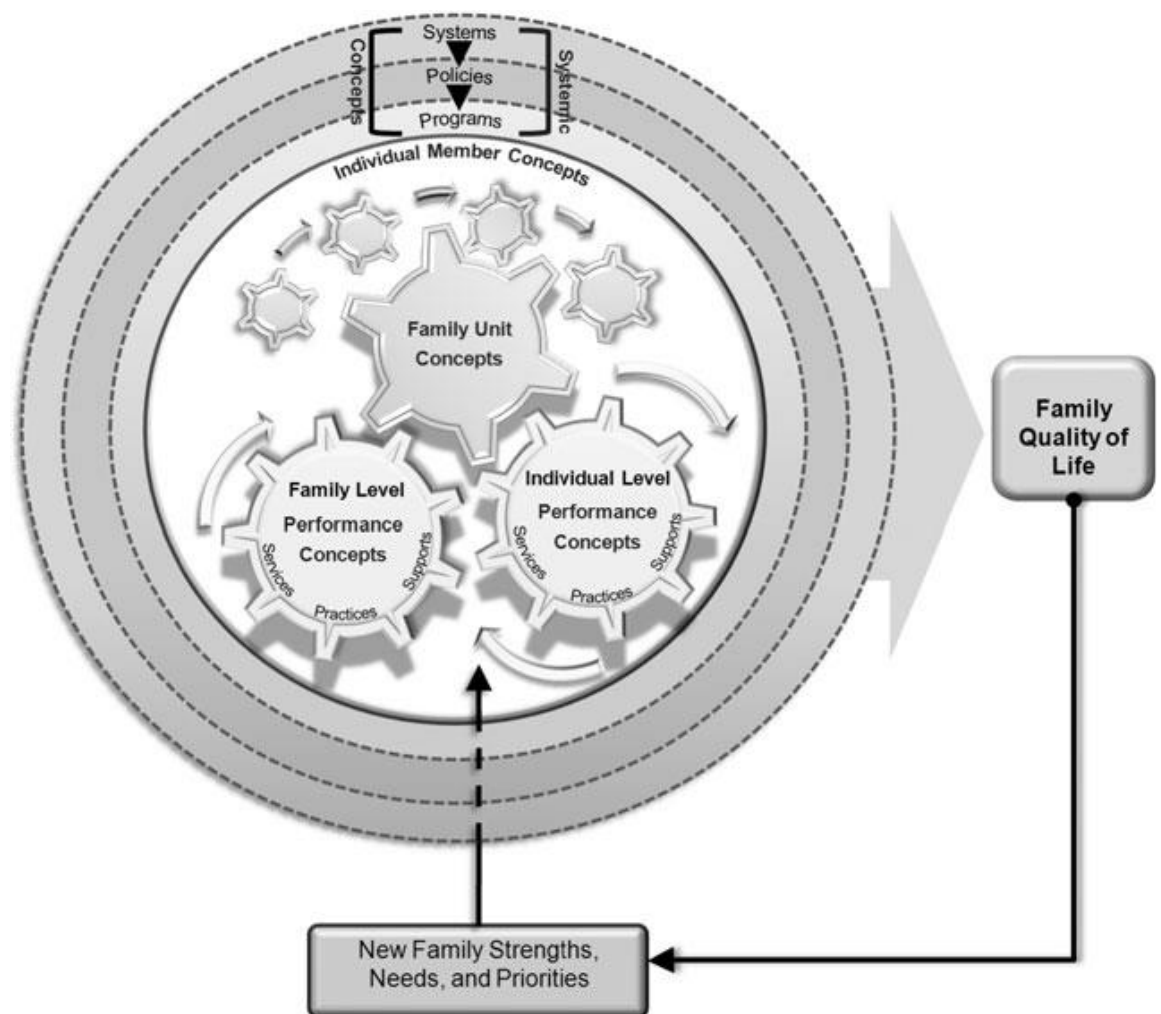


Figure 1.3. Unified Theory of FQOL. Source: Zuna et al. 2010, p. 268. (Zuna, N., Summers, J., Turnbull, A., Hu, X., & Xu, S. (2010), p. 268)

According to the authors of this unified theory, it is acknowledged that FQOL is difficult to measure and complex to articulate, due to it being dependent on many factors, and not just at one given time (Zuna et al., 2010). Disability is only one aspect of families who have a CWD, and the theory of FQOL must address the multiple aspects of families' lives. The model considers a number of components that influence FQOL. It presents a useable model for researchers to generate multiple

testable theoretical statements and clearly illustrates that systemic concepts are distal inputs while the family-unit, individual family-member, and performance factors are the key predictors of FQOL as mediators and moderators (Kyzar et al., 2012; Zuna, Selig, et al., 2009).

This model can be compared to the QoL model by Schalock et al. (2010) as it uses similar concepts to explain the theory of FQOL. The concepts in both models are represented as cogs in a gearbox. The core concepts are similar to the domains in Schalock's model as they represent the family and the individual within the family, and they affect FQOL. The difference in this model is the outer circles that represent the systemic concepts like systems, programs, and policies that have an indirect influence on the interactive cogs in the inner circle. Even though it seems to have its roots in Schalock's model, it is a simpler representation of the concepts that denote the effect on FQOL and is easier to utilise in practice. This unified FQOL model also seems to derive its concepts from the domains in the WHOQOL (WHOQOL, 1997) such as physical health, social relationships, and environment. The strengths of this model lie in its simplicity for use and its visual representation that makes it easy to use in practice. It has been previously used in research and even though several conceptual frameworks proposing domains of FQOL circulate in the field, this seems to be the only model of FQOL that is theorised; therefore, it will be used as a guide for this doctoral research (Kober, 2010; Rillotta, Kirby, & Shearer, 2010).

QoL and FQOL have been extensively researched in general populations and in specific populations in the literature; however, in individuals with disability and families of individuals with disability, QoL and FQOL have largely been researched only in the past decade. A focus of this research is the influence of having a CWD on parent occupations and their FQOL. Many parents give up their previous occupations

in order to be involved in the caregiving role (Bourke-Taylor, Howie, & Law, 2010; DeGrace, 2004). Having a young child with disability has an influence on the FQOL of all family members and can lead to consequences like the loss of engagement in activities that earlier gave meaning and purpose to life, and loss of previous occupations such as employment, leisure, activities of daily living, rest, sleep, and free time (Hammell, 2004). Parents of a CWD have to address the long-term needs of their children, who sometimes require up to 24 hours of caregiving. This can impact parents' immediate and long-term aspirations and occupations (Downs, 2008). At the time of writing, the research base on parent occupations was not fully developed and the next section introduces some of the literature on parent occupations relevant to this research.

1.9 Parent Occupations

Parenting is an important occupation and being a caregiver is an important occupational role for a parent. The way a mother perceives her care-giving role and executes mothering tasks, or how a father perceives his occupational roles and contributes to parenting, can offer insight about the home environment within families (Hauari & Hollingworth, 2012). In a phenomenological study conducted in Florida of seven women and their perspectives on the occupation of mothering, a common theme was that mothering was a lifetime occupation and mothering does not end; the tasks may change as children grow and develop, but the occupation of mothering continues (Dunbar & Roberts, 2006).

QoL is connected to how one lives and performs one's daily life activities, for example being able to independently care for one's physical needs, social needs, and productivity needs such as paid work. If these daily activities are disrupted due to

illness or long-term disability it can have an impact on the individual's QoL (Christiansen & Townsend, 2004; Hammell, 2004; Townsend & Polatajko, 2007). Thus, evaluation of QoL involves capturing the living of one's life in terms of what is done (occupations) and how much time is spent doing it (Wilcock, 2003). Parenting occupations are important for most parents when they have a child and include being able to do a number of things for their home and their family (Beatty & King, 2008; Bourke-Taylor, Pallant, Law, & Howie, 2012; DeGrace, 2004). Consideration of parents' occupations and the meaning that routine tasks have is worthy of study to enable occupational therapists to better address family needs in a variety of service areas such as community health, early intervention, and education (Dunbar & Roberts, 2006).

Classifications used in occupation. Occupation is classified according to what people do and includes self-care (looking after themselves), leisure (enjoying themselves), and productivity (contributing to social and economic aspects of their community) (Townsend & Polatajko, 2007). The Canadian Association of Occupational Therapy (CAOT) referred to occupation as “groups of activities and tasks of everyday life and as everything people do to occupy themselves, named, organized, and given value and meaning by individuals and a culture; occupation is everything people do to occupy themselves; the domain of concern and the therapeutic medium of occupational therapy” (CAOT, 2007, p. 20). Studies in occupational science consider the concept of time allocation across occupations, and discuss how this time allocation is important to achieve a balance in life (Pentland & McColl, 2008). “A primary assumption underlying occupational therapy intervention is that peoples' use of time, or their participation in activities, is related to their overall well-being and quality of life” (Farnworth, 2003, p. 116). One classification of

occupations based on time allocations from the early 1980s (Aas, 1980) was later published and four categories of occupations were identified (Harvey & Pentland, 2004). These four categories are pertinent to understanding how carers around the person with a disability or acquired illness spend their time, and are especially relevant to this research (Aas, 1980; Harvey & Pentland, 2004). This classification will therefore be considered for this research and is presented in Figure 1.4. The four categories of occupations are:

- necessary occupations
- committed occupations
- contracted occupations, and
- free-time occupations

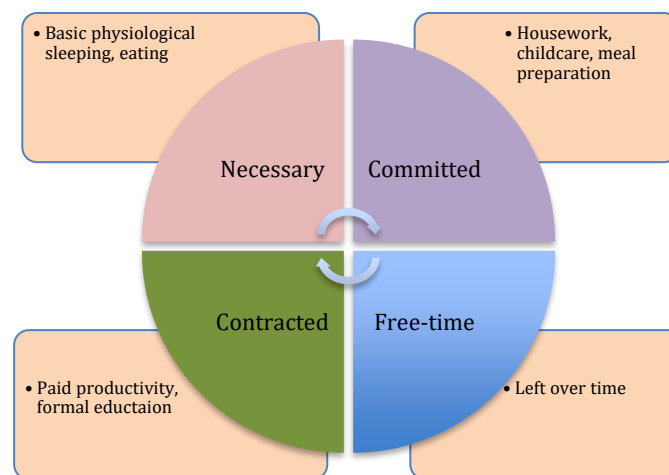


Figure 1.4. Classification for Occupations (Aas, 1980; Harvey & Pentland, 2004).

Necessary occupations comprise necessary time and are aimed at meeting the basic physiological and self-maintenance needs such as eating, sleeping, resting, sex, and personal care activities related to health and hygiene (Harvey & Pentland, 2004). Contracted occupations occur in contracted time and typically involve paid

productivity or formal education. These occupations generally have a start time, finish time, and amount to a pay or a reward like a formal graduation or certification.

Committed occupations occur during committed time and even though they have a productivity or work character are typically not remunerated, and the duration of work is diffuse and unspecified such as housework, childcare, meal preparation, home and vehicle maintenance, or shopping (Harvey & Pentland, 2004). Time for committed occupations can be purchased as a service by paying others to do these occupations to gain time for free or contracted occupations. Free-time occupations occur in the time that is left over after necessary, contracted, and committed occupations are accomplished. Free-time occupations can be increased by reducing some contracted or committed occupations like attending an office gathering instead of cooking a meal at home one evening a week (Harvey & Pentland, 2004).

Childcare and caregiving falls under the category of *committed* occupations and being a parent of a young child can lead to an increase in time used around the *committed* occupation of childcare and a decrease in *contracted* and *free-time* occupations (Christiansen & Townsend, 2004; Harvey & Pentland, 2004). Having a CWD can have a significant impact on the time spent by parents in the *committed* occupation of caregiving for their CWD for longer durations. Although only a few studies have been undertaken focusing on the occupations of parents of CWD, they have reported the impact of the caregiving role on the health of the parents, especially the mother as 94-98% of CWD primary caregivers are mothers (Bourke-Taylor, Law, Howie, & Pallant, 2009). There is a high risk of clinical depression in mothers of CWD associated with the caregiving role. The family is also affected financially given the costs of special care and equipment required for a CWD (Bourke-Taylor et al., 2009).

There are very few studies examining the occupations of parents of a young CWD and the impact of having a CWD on parent occupations is unclear (DeGrace, 2004). Parents of children with disability, are involved in the process of diagnosis, looking for therapy, ECIS, and worry about the developmental needs of their CWD. This can lead to loss of their previous occupations more so than parents of children without disability. It is unclear whether loss of occupations has any relationship with FQOL or whether services such as ECIS should help families to engage in their previous occupations. Parents need to find a balance between their *committed* occupations of caregiving for their CWD and *contracted* and *free-time* occupations. As part of scoping this study, the first paper published for this thesis presented a viewpoint to promote occupations of parents as an important outcome when working with a CWD in ECIS. This paper is included as an appendix to this chapter. (See publication 1: Appendix 1.1.: Bhojti, A. (2017). Promoting the occupations of parents of children with disability in early childhood intervention services – Building stronger families and communities. *Australian Occupational Therapy Journal*, 64(5), 419 -422. doi: 10.1111/1440-1630.12297).

According to the unified theory of FQOL, services, supports, practices, systems, and programs have an influence on FQOL (Zuna et al., 2010). This research is concerned with ECIS as a service/program for families and children with disability/developmental delay, and whether receiving ECIS influences FQOL and parent occupations. The next section provides an overview to and how ECIS are offered in Australia.

1.10 Early Childhood Intervention Services (ECIS) in Australia

Within Australia, ECIS support children with a disability/developmental delay from birth to school entry, and provide therapy, education, counselling, service planning and coordination, and support to access services such as kindergarten and childcare (ECIA, 2012). Services are focused on supporting the child in their natural environments and in their everyday experiences and activities. Parents are provided with knowledge, skills, and support to meet the needs of their child and optimise the child's development and ability to participate in family and community life. Services use a family-centred practice approach, recognising the importance of working in partnership with the family.

This research was conducted in Melbourne, Australia. Most ECIS within Melbourne use a transdisciplinary model of practice wherein every family is assigned a keyworker as part of a transdisciplinary team of allied health professionals and specialist educators (Alexander & Forster, 2012). Goals are set in collaboration with the family at the start of the service delivery and the keyworkers work closely with the family, allied health professionals, and other staff. They provide strategies for participation via visits to the kindergarten or childcare, at home, and within the family's natural environments. Since 2016 within Australia, the National Disability Insurance Scheme (NDIS) has been rolling out and is intended to be fully operational by 2019. The NDIS is a way of supporting people with disability and currently supports 100,000 Australians with disability. Funding for ECIS provision in the future will be provided via NDIS. Within the NDIS, the early childhood early intervention (ECEI) approach has been identified as the recommended service delivery approach for ECIS. The ECEI approach strongly recommends the use of family-centred practice and is tailored to support every family and child individually and to enhance

community participation. For further details about the NDIS and the ECEI approach, please follow the link to their website, <https://www.ndis.gov.au/ecei>

Conclusion - Chapter 1

This chapter provided an overview of FQOL, parent occupations, and ECIS as background for this research. It presented theories of QoL that were a precedent for FQOL, theories and definitions of FQOL, and classification of occupations that will be used in this research to aid understanding of parent occupations. The chapter gave a brief overview of ECIS and how these services are offered in Melbourne. The next chapter presents the first study in this thesis.

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Chapter 2: Study 1 – Family Quality of Life of Families of Children in Early Childhood Intervention Services

This chapter introduces Study 1, the rationale for the study and the aims and research questions. It is made up of six sections, namely:

2.1 Study Rationale and Aims

2.2 Literature Review - Publication 2 – Scoping Review

2.3 Method

2.4 Results and Findings

2.5 Discussion

2.6 Conclusion of Study 1

2.1 Study Rationale and Aims

Having a child with or without disability leads to constant family adaptations and influences the family-unit dynamic (Zuna, Turnbull, & Summers, 2009). The model of family quality of life (FQOL) by Zuna, Summers, Turnbull, Hu and Xu (2010) demonstrates that the everyday occupations of parents, their beliefs, and their family characteristics are important family-unit concepts, and individual member concepts have a direct mediatory influence on FQOL. Systems, policies, and programs are also noted as important systemic concepts that have an indirect influence on FQOL according to the unified theory by Zuna et al. (2010).

Several studies have shown that caregiving for a child with disability (CWD) can impact the life trajectories, family functioning, and everyday occupations of parents, and have demonstrated some relationship with FQOL (Caples & Sweeney, 2010; Epley, Summers, & Turnbull, 2011; Leiter, 2004; Rillotta, Kirby, Shearer, & Nettelbeck, 2012). However, it is unclear whether parents/caregivers within Australia feel that the loss of their previous occupations after having a CWD has any influence on their FQOL, or whether the services and supports they receive in the early years via early childhood intervention services (ECIS) have an influence on their FQOL. It is also unclear whether the style of ECIS service delivery, and practices used within Australia are indirect mediators of FQOL as indicated by the FQOL model (Zuna, Summers, Turnbull, Hu, & Xu, 2010). Besides, the majority of previous studies on FQOL have been quantitative and lack in-depth reports of parents' perspectives of their FQOL in the early years when they have a CWD (Bhopti, Brown, & Lentin, 2016; Davis & Gavidia-Payne, 2009; Rillotta et al., 2012). Parental perspectives about their adaptations to family life of having a CWD, the relationships between receiving

ECIS and their FQOL, and the subsequent changes to their everyday occupations within the Australian context needs further investigation.

This study was planned to investigate parental perspectives about the influence of having a CWD on their FQOL. The relationships between two factors (eg factor 1 - receiving early childhood intervention services –ECIS, and factor 2 - the changes to parent occupations upon having a child with disability) that mediate FQOL according to the model of FQOL (Zuna et al., 2010) were also selected for further investigation. The aim of this study was to explore parents’ perspectives of FQOL when they have a young CWD and to look for relationships between FQOL and receiving ECIS, and between FQOL and changes to parent occupations (upon having a CWD), within an Australian context. The research questions that guided this study were:

- 1) What are the perspectives of family quality of life, of parents of children with disability, receiving early childhood intervention services?
- 2) What are the relationships between parent occupations and FQOL, and receiving ECIS and FQOL as per parents’ perspectives?

2.2 Literature Review - Publication 2

The second publication in this thesis was a scoping review. Before choosing a method and the outcome measures for this study, a scoping review was conducted to summarise the known factors that influence FQOL, and to find within the literature appropriate scales and methods to measure FQOL within ECIS. The first page of the publication is pasted into Chapter 2 and the publication is available as Appendix 2.8 or by following the link below

Publication 2: Bhopti, A., Brown, T., & Lentin, P. (2016). Family quality of life: a key outcome in early childhood intervention services – a scoping review. *Journal of Early Intervention*, 38(4), 191-211. doi:10.1177/1053815116673182

Family Quality of Life: A Key Outcome in Early Childhood Intervention Services — A Scoping Review

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Abstract

A scoping review was conducted to identify factors influencing the quality of life of families of children with disability. The review also explored the scales used to measure family quality of life (FQOL) as an outcome in early childhood intervention services (ECIS). Multiple databases were searched from 2000 to 2013 to include studies pertinent to ECIS. Results were charted and summarized based on scoping methodology. Eighteen articles were chosen for the review based on the selection criteria. Results were summarized as five factors that affect FQOL, namely, (a) disability-related support, (b) family interactions/family relationships, (c) overall well-being, (d) support from services, and (e) severity and type of disability. The review also identified two FQOL scales that were used most frequently within ECIS: (a) the *Beach Center Family Quality of Life Survey*, and (b) *Family Quality of Life Survey: Main Caregivers of People With Intellectual or Developmental Disabilities*. It is recommended that those responsible for evaluation decisions within ECIS programs should consider using a FQOL scale to measure family outcomes. Furthermore, professionals working with families within ECIS should consider the factors affecting FQOL to further enhance their service provision.

Keywords

Family quality of life, family, early childhood intervention, child with disability, scoping review, ECIS, FQOL

Introduction

The quality of life of family members of individuals with disability has a tendency to be neglected in practice and in research. It is important to work closely with family members when there is a child with disability (Dunst, Trivette, & Hamby, 2007). Caring for a child with disability, in addition to the usual child care practices, can add to the challenge of raising a young child (Bourke- Taylor, Howie, & Law, 2010). This additional caregiving can affect the quality of life of all family members. Improving the quality of life of families can have a positive effect on child and family outcomes (Bailey et al., 2006; Turnbull & Turnbull, 2002). Measuring positive family...

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<http://journals.sagepub.com.ez.library.latrobe.edu.au/doi/pdf/10.1177/1053815116673182>

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2.3 Method

The first section presents the rationale for selecting the mixed-methods approach for this research and is used for both the studies incorporated within this thesis. The next section details the procedures within the methods for the quantitative and qualitative aspects of the Study 1. Most of the methods are the same for Study 1 and Study 2 with a few alterations in the qualitative aspect of Study 2 (These differences will be detailed in Chapter 3).

2.3.1 Rationale for a mixed-methods approach. The main questions in this research were around investigating the parents' perspectives of their FQOL when they have a CWD (research question 1) , and also finding out if there were any relationships between the services they received and their FQOL, and between their occupations and FQOL (research question 2). For question 1 regarding parents' perspectives on FQOL, firstly a quantitative method was selected using the Beach Center Family Quality of Life Survey (BC-FQOLS) from the Beach Center of Disability (BCD) as the tool for collecting quantitative data about perceived FQOL (BCD, 2002; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Summers, Poston, Turnbull, & Marquis, 2005). This tool also provides an understanding of the subscales or factors that comprise FQOL and has already established a correlation between these factors and FQOL (Zuna, Selig, Summers, & Turnbull, 2009). Before finalising the use of the BC-FQOLS for the study, it was trialled with eight parents (of a CWD) to gain their feedback related to the language and readability. All eight parents reported that they were able to complete the survey with ease. Six out of the eight parents provided feedback that it would be helpful to have a section for comments, or to have a further interview to enable them to explain how they perceived their FQOL in further detail. So adding a qualitative aspect to the Study 1 was considered.

The second question was related to the relationships between parent occupations, ECIS and FQOL. A questionnaire was added to gain information about the participants' occupations and details about their demographics such as work status, education level, annual income, the type of disability of their child and about the duration of ECIS service they received. The BC-FQOLS has a subscale

“disability-related support” that was representative of ECIS and would provide quantitative information about services received and if they were related to FQOL. However, there were no available tools that measured parent occupations in relation to FQOL. The BC-FQOLS has a number of subscales or items that can be considered as describing parent occupations, to some extent. For example, (as per Harvey and Pentland’s (2004) classification of occupations) necessary occupations that involve meeting the basic physiological and self-maintenance needs such as eating, sleeping, and personal care activities related to health and hygiene can be described by the subscale of physical/material well-being and emotional well-being (refer to Table 2.1 for details and for other occupations and relation to the scale). These items and subscales were not enough to represent parent occupations and it was felt necessary that parent occupations would be understood better by adding a qualitative aspect to Study 1.

Table 2.1 *Relating Subscales of BC-FQOLS to Parent Occupations*

Parent Occupations – Classification used (Harvey & Pentland, 2004)	BC-FQOLS (Subscales) (BCD, 2002)
Necessary occupations	Physical/material well-being Emotional wellbeing
Committed occupations	Parenting
Contracted occupations	Physical/material well-being
Free-time occupations	Family interactions

BC-FQOLS = Beach Centre Family Quality of Life Survey. BCD = Beach Center on Disability.

Sources: (Harvey, A., & Pentland, W. (2004). What do people do? In C. Christiansen & E. Townsend (Eds.), *Introduction to occupation: The art and science of living* (pp. 63-90). Old Tappan, NJ: Pearson Education;

BCD. (2002). *The Beach Center Family Quality of Life Scale* (Survey). Kansas: Beach Centre: The University of Kansas.)

In choosing a method for the study, the unified theory of FQOL by Zuna et al. (2010) was also considered. This FQOL theory informs us that FQOL is dynamic and that individual demographics, characteristics, beliefs, family-unit dynamics, and characteristics are direct predictors of FQOL, and that systems, policies, and programs are indirect mediators of FQOL (Zuna et al., 2010). In considering the dynamic nature of FQOL, the importance of the individual perspectives of families, and its direct effect on FQOL, it was deemed pragmatic that individual family voices be heard and that their experiences be gathered in a qualitative way along with using the quantitative BC-FQOLS. According to Creswell (2009), within a pragmatic philosophical worldview the researcher emphasises the problem (in this study it is FQOL) and uses all approaches available to understand the problem (Creswell, 2009). So it was again felt necessary to add a qualitative aspect to study 1 and then to triangulate the results and findings as are consistent with mixed methods study (Greene, 2006; Teddlie & Yu, 2007).

Lastly, the scoping review results regarding the methods used in past studies were also considered. These results confirmed that previous studies mainly used quantitative methods to study FQOL, with 14 of the 18 studies on FQOL being quantitative, three studies being mixed-methods and only one qualitative (Bhojti et al., 2016). Only one study was conducted in Australia, a quantitative study (Davis & Gavidia-Payne, 2009). The social, historical, and political contexts in Australia are different from most countries and it was necessary to fill the knowledge gap about the perspectives of FQOL of families within an Australian context. The pragmatic worldview is of the opinion that research needs to occur in different contexts, and gathering quantitative and qualitative perspectives from parents that reflect the

Australian context would provide a deeper understanding of their FQOL, and the factors that have a relationship with FQOL (Creswell, 2009).

The combining of elements from quantitative and qualitative research approaches for the purpose of understanding the perspectives of participants in depth, and analysing and integrating the findings, seemed necessary to answer the research questions within this study. This type of method is consistent with mixed-methods research (I. Brown, 2006; Creswell, 2009; Johnson, Onwuegbuzie, & Turner, 2007). Within the mixed-methods research, the concurrent triangulation approach as listed by Creswell (2009) was most suited to this study. The qualitative sample was selected purposefully from the quantitative sample simultaneously, as the surveys started rolling in, to include a variation within the sample (for example, to include children with varying diagnoses, mothers and fathers, varying socio-economic status, and geographical location). Data were analysed using rigorous quantitative and qualitative methods as the data were coming in. Then both qualitative and quantitative results and findings were triangulated, compared and integrated to answer the research questions, consistent with mixed methods using a concurrent triangulation approach (Creswell, 2009; Johnson et al., 2007; Taket, 2011). See Figure 2.1 for a representation of the mixed methods used for this study.

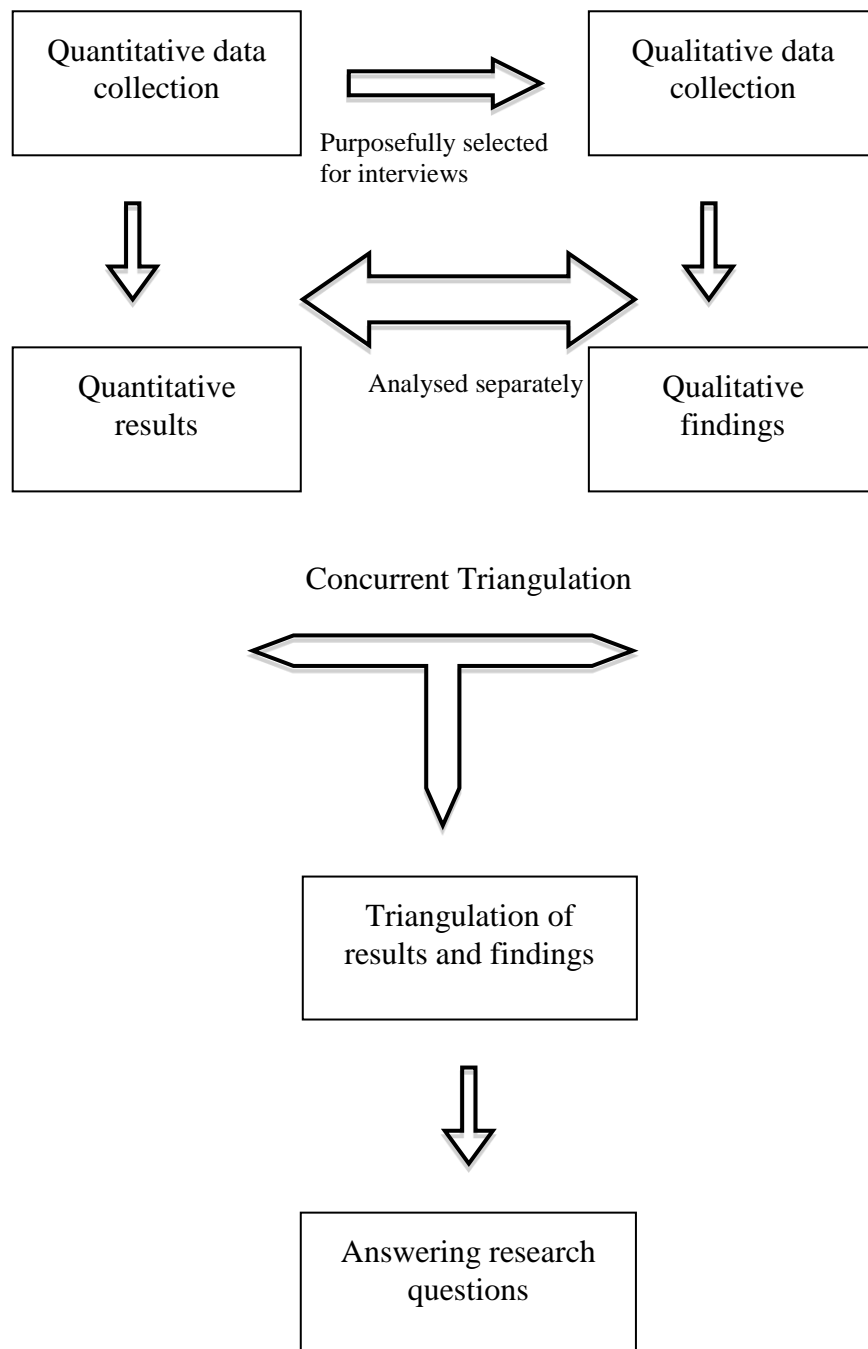


Figure 2.1. Mixed Methods Used in this Study.

2.3.2 Inclusion criteria for quantitative and qualitative study.

1. Parents/caregivers of children with disability or developmental delay and enrolled in Yooralla's ECIS service;

2. Parents/caregivers with a working knowledge of English for completion of the BC-FQOLS (English version), demographic questionnaire, and participation in the semi-structured interview; and
3. Parents/caregivers provide informed consent to participate in the study.

2.3.3 Exclusion criteria for quantitative and qualitative study.

Parents/caregivers who did not fit within the definition of “family” as defined in the study were excluded (for example, a birth father with no custody or relationship with the child or family).

2.3.4 Quantitative study details.

2.3.4a Instruments. Demographic data from participants were recorded on a demographic questionnaire. The demographic questionnaire provided information about the background of the family members participating in the study including age, sex, relationship to the child, languages spoken at home, educational levels of main carer and partner, duration of ECIS, and annual income (see Appendix 2.1).

The BC-FQOLS was used to collect quantitative data regarding FQOL. The BC-FQOLS (BCD, 2002) is a 25-item survey composed of five subscales (e.g., *family interaction, parenting, emotional well-being, physical-material well-being* and *disability-related support*) and was designed at the Beach Center on Disability (BCD) in Kansas (BCD, 2002; Turnbull & Turnbull, 2002). The BC-FQOLS was developed using a participatory action research methodology involving the families. Families of CWD were the primary stakeholders, valued participants, and beneficiaries in the research (Turnbull & Turnbull, 2002).

According to the Beach Center of Disability, (BCD, 2002), the BC-FQOLS has good internal consistency with a Cronbach’s alpha coefficient reported of .88 on

the satisfaction ratings. In the current study, the Cronbach alpha coefficient was .94, indicating good internal consistency reliability for the scale with this sample ($N=122$).

The BC-FQOLS has been used with over 1000 participants in North and South American populations including translated versions – the Spanish version was used in Colombia (Verdugo, Córdoba, & Gómez, 2005), and a Chinese version (Hu, Wang, & Fei, 2012) . It has been used in a multi-survey study self-administered by 64 families in Australia assessing the impact of child, family, and professional characteristics on FQOL for families of young children (Davis & Gavidia-Payne, 2009). See Appendix 2.2 for a copy of the BC-FQOLS.

Park et al. (2003) presented the process of developing the BC-FQOLS tool using a total of 1197 respondents in a national field test. Through factor analysis, the survey was refined in several ways including reducing the domains from 10 to five domains, using 41 items and clarifying the wordings of the items to a grade six level (Park et al., 2003). Following the work by Park et al. (2003), Hoffman et al. (2006) conducted a two-part study including a total of 488 families with CWD to complete the development of the BC-FQOLS and to assess the psychometric properties of the survey. The BC-FQOLS was refined through confirmatory factor analyses into 25 items that assess five domains of FQOL. The authors used single-factor measurement models for each of the subscales and also examined the factor loadings and overall model fit. They used three indices to evaluate the quality of model fit in the factor analyses, namely the obtained χ^2 , the comparative fit index (CFI), and the root mean square error of approximation (RMSEA) to examine the conceptual and statistical fit of the BC-FQOLS items within each subscale. Items demonstrating poor internal

consistency as measured by Cronbach's alpha (a value above .80 was considered acceptable) were deleted. After psychometric analysis, a five-factor solution was finalised with a final 25-item survey, and the five factors became the domains of the BC-FQOLS. Test-retest reliability was examined in both importance and satisfaction responses for each of the FQOL subscales at an interval of three months, with all correlations significant at the .01 levels or beyond (Hoffman et al., 2006). For importance, the correlations between time points were .54 for "Family interaction", .66 for "Parenting", .69 for "Emotional well-being", .41 for "Physical/material well-being", and .82 for "Disability-related support". For satisfaction, the correlations between time points were .74 for "Family interaction", .70 for "Parenting", .75 for "Emotional well-being", .77 for "Physical/material well-being", and .60 for "Disability-related support".

In the Hoffman et al. (2006) study for convergent validity, the BC-FQOLS subscales were correlated with related existing measures within subsamples of participants. The "Family APGAR" (Adaptability, Partnership, Growth, Affection and Resolve), a five-item measure of family functioning, was significantly correlated with the satisfaction mean for the BC-FQOLS and the "Family Interaction" subscale, $r = .68, p < .001$ (Smilkstein, Ashworth, & Montano, 1982). Similarly, the "Family Resource Scale" (Dunst & Leet, 1986), a 30-item measure of family resources, was significantly correlated with the mean of the five items on the BC-FQOLS and the "Physical/Material Well-Being" subscale, which was most similar in content to the "Family Resource Scale", $r = .60, p < .001$ (Hoffman et al., 2006).

2.3.4b Participant recruitment and data collection. All nine of the ECIS sites within the ECIS agency (Yooralla) were provided with information and explanatory

notes regarding the study from the outset. ECIS within this agency were provided in a transdisciplinary style, where every family had an assigned keyworker (Alexander & Forster, 2012). The service provision used a family-centred practice (FCP) approach and had a strong emphasis on involving the family at all stages of service provision, from goal setting to service delivery (Dunst, Trivette, & Hamby, 2007). The keyworker was the main contact for the family and coordinated the ECIS delivery for every family they were assigned.

The researcher organised a meeting with the site managers prior to data collection, and explained the steps in data collection. These steps included selecting the sites for the study, organising dates and times for the researcher to visit the sites to hand over the information packs and surveys to the site managers, and organising collection of the completed surveys. Suitable procedures were discussed with and confirmed by the managers. Site managers were requested to provide the approximate number of families enrolled in their program with a working knowledge of English, or availability of assistance to complete the survey in English. The ECIS agency was also requested to send out information regarding the study and surveys to the families via their newsletters to alert the families of this event. As per the numbers from all sites, the researcher distributed 300 information packs. The packs included a covering letter, a consent form, an explanatory statement, a withdrawal form, the demographic questionnaire, and the BC-FQOLS form. Participants were assured regarding the confidentiality of the information collected, and were guaranteed anonymity by the process of de-identification in the cover letter.

The researcher delivered the packs at each site and the managers forwarded the packs to the keyworkers for distribution to their respective families at the ECIS. A cover letter addressed to the keyworkers was also provided to the site managers.

This letter explained the details of the study and procedures for inclusion and data collection to be followed by the keyworkers. The site managers emailed this letter to the keyworkers prior to their home visits for data collection. A sealed postbox was provided at each site for return of the surveys along with postage paid return envelopes.

The information packs were hand delivered to most families during the keyworkers' follow-up visits. A mail self-completion administration method was used where the participants completed the surveys and mailed them back in a reply paid envelope (Liamputtong, 2013). A weekly email was sent to the site managers to ensure an acceptable return rate; however, at the end of eight weeks only 30 surveys had been received.

Due to the part-time nature of keyworkers, they were unable to deliver the surveys by hand at a few sites. After consultation with the site managers, it was decided that because the keyworkers were restricted for time, the researcher should visit a couple of sites with the lowest return rates and post out blocks of surveys to the eligible families accessing ECIS. The researcher did not have permission to access the database of the families at these sites, so the site manager assisted the researcher with family details for posting out the surveys. The researcher posted the information packs including the surveys to approximately 60 families. At the end of this step, the agency managers reported that all families considered eligible for participation had been contacted and they did not think that any more surveys would be returned. The agency was also concerned about research fatigue for the participants, as there was another large research project occurring at the same time; therefore, no further surveys were posted, and quantitative data collection was stopped after nine months.

2.3.4c Quantitative data analysis. The Statistical Package of Social Sciences (SPSS) version 22.0 was used for data entry and analysis of the quantitative data (IBM, 2013). A codebook was created with all the variables from the demographic questionnaire and items from the BC-FQOLS (see Appendix 2.3). Variables were labelled and defined, and numerical codes added. A data file was created and data from all the participants were entered. Data screening was completed to check for errors and any errors detected were corrected before starting data analysis (Pallant, 2013).

Descriptive analysis was done first to gain an understanding of the characteristics of the sample. The distribution of scores assisted with analysis of the sample for a range of variables such as age, gender, relationship to the child, other family member details, level of education and employment status of both parents, and annual income. Recoding of some categories was done to reduce the complexity of the rating scale structure for the demographic questions. The raw data from the BC-FQOLS scale (satisfaction) was then manipulated to address the research questions around correlations of FQOL, and subscales of FQOL with the descriptive data. The five subscales, namely family interaction, parenting, emotional well-being, physical-material well-being, and disability-related support, were summed up as per the instructions for scoring the BC-FQOLS (BCD, 2002); for example, six items were computed for the total value for family interaction, namely, time spent together, talking openly to family members, helping family to solve problems, helping family members to accomplish goals, being loving and caring with family members, and being able to handle ups and downs (see Tables 2.2 and 2.3).

Table 2.2 *Items and Summation for Subscales of BC-FQOLS (BCD, 2002)*

Item	Code	Sum
Total FQOL	TFQOL	Total of 25 items on BCFQOLS
Family interaction	TFamilyInteraction	Total of 6 items (1+7+10+11+12+18) TFamilyInteraction=timetogether + talkopenly + problemsolving + accomplishgoals + lovecare + upsdowns.
Parenting	TParenting	Total of 6 items (2+5+8+14+17+19) TParenting=childindependent + schoolwork + teachestogetalong + gooddecisions + otherpeople + individualchildneeds.
Physical/material well-being	TPhysmaterialWB	Total of 5 items (6+16+21+15+20) TPhysMaterialWB=transport + expenses + safety + medicalcare + dentalcare.
Emotional well-being	TEmotionalWB	Total of 4 items (3+4+9+13) TEmotionalWB=supportstress + friendsother + owninterests + outsidehelp.
Disability-related support	TDisabSupport	Total of 4 items (22+23+24+25) TDisabSupport=CWDsupportoutside + CWDsupporthome + CWDsupportfriends + RelationSP

Note: CWD = Child with disability; BC-FQOLS = Beach Center Family Quality of Life Survey; T = Total; PhysmaterialWB = Physical material well-being; Disbsupport = disability-related support; WB = Well-being; SP = Service provider

As the research questions were about the relationships between FQOL and ECIS service provision and between FQOL and parent occupations, the Spearman's Rho correlation was chosen as the statistic for the analysis. The Spearman's Rho is suitable for ordinal or ranked data (such as a Likert scale that is used in the BC-FQOLS) and is also being used increasingly in the health and medical literature (Pallant, 2013). This correlation can be used to explore the strength of the relationship between two variables with an indication of the direction of the relationship. A

positive correlation indicates that as one variable increases the other does too; for example, a positive correlation between the annual income of a family with FQOL would indicate that the higher the annual income, the better the FQOL.

Research Question 1:

For research question 1, regarding parent perspectives on FQOL, the total FQOL (TFQOL) score was calculated using descriptive analysis. The five subscales that are validated as factors of FQOL by the authors of the BC-FQOLS (see Table 2.3) were also summed up for correlations, to provide an understanding regarding each of the factors and their relationship to the total FQOL (Summers et al., 2005; Zuna et al., 2010).

Table 2.3 *Item Description and Subscales from the BC-FQOLS (BCD, 2002)*

Beach Centre Family Quality of Life Survey – (BC-FQOLS) – Detail
<p>Subscale 1- Family Interaction – Items 1, 7, 10, 11, 12, 18</p> <p>Item description</p> <ul style="list-style-type: none"> 1 - My family enjoys spending time together 7 - My family members talk openly to each other 10 - Our family solves problems together 11 - My family members support each other to accomplish goals 12 - My family members show that they love and care for each other 18 - My family is able to handle ups and downs <p>Subscale 2 - Parenting – Items 2, 5, 8, 14, 17, 19</p> <p>Item description</p> <ul style="list-style-type: none"> 2 - My family members help children to be independent 5 - My family members help children with schoolwork and activities 8 - My family members help children how to get along with others 14 - Adults in our family teach children to make good decisions 17 - Adults in my family know other people in the children's lives 19 - Adults in my family have time to take care of the individual needs of every child <p>Subscale 3 - Physical Material Wellbeing (PMWB) – Items 6, 16, 21, 15, 20</p> <p>Item description</p> <ul style="list-style-type: none"> 6 - My family members have transportation to get to places 16 - My family has a way to take care of our expenses 21 - My family feels safe at home, work, school, and in our neighborhood 15 - My family has medical care when needed 20 - My family gets dental care when needed

Subscale 4 - Emotional Well-Being (EWB) – Items 3, 4, 9, 13

Item description

- 3 - My family has the support we need to relieve stress
- 4 - My family members have friends or others who provide support
- 9 - My family members have time to pursue own interests
- 13 - My family has outside help available to us to take care of special needs of all family members

Subscale 5 - Disability – Related Support – Items 22, 23, 24, 25

Item description

- 22 - My family member with disability has support to accomplish goals at home
- 23 - My FMWD has support to accomplish goals at home
- 24 - My FMWD has support to make friends
- 25 - My family has good relationships with the service providing services and support to our FMWD

PMWB = Physical material well-being; FMWD = Family member with disability

Research Question 2:

For research question 2, regarding the relationships between ECIS and FQOL, the item from the demographic questionnaire ‘duration of ECIS’ was correlated to BC-FQOLS item 25 (My family has good relationships with the service providers). This item was chosen because families within the ECIS received a higher frequency of service (weekly or fortnightly visits) at the onset of services and then reduced. (A question asking parents about their perspectives on the relationship between ECIS and FQOL was included during the interviews to triangulate with these results).

Regarding relationships between parent occupations, ECIS and FQOL there were no available assessment tools relevant to parent occupations. Some items from the BC-FQOLS were deemed fit to represent parent occupations and for inter-item correlations. Before selecting items for correlations from the BC-FQOLS, a face

validity and agreement exercise was carried out with seven occupational therapists. All seven therapists were working as practitioners for 7-15 years. The four types of parent occupations (see Table 2.4) were defined in a handout, namely necessary occupations, committed occupations, contracted occupations, and free-time occupations (Harvey & Pentland, 2004). The 25 items from the BC-FQOLS were also listed in random order and presented to the therapists to allocate to any of the four categories of parent occupations. There was 90% agreement within the item allocation from BC-FQOLS items to parent occupations as in Table 2.4 (Fawcett, 2007). Four items with maximum agreement were selected for correlations (in bold in Table 2.4). These four items were then selected for correlation with the subscale “disability-related support” (representing ECIS) on the BC-FQOLS. These four items are not included in the “disability-related support” subscale. For committed occupations, item 1 (My family enjoys spending time together) and item 19 (Adults in my family have time to take care of the individual needs of every child) were correlated with the subscale “disability-related support”. Necessary occupations, item 16 (My family has a way to take care of our expenses) and free-time occupations, item 9 (My family members have time to pursue own interests) were correlated with “disability-related support”. For contracted occupations, the work status of carer (from the demographic questionnaire) was correlated with subscales and total scores from the BC-FQOLS subscales. (Parents participating in the qualitative interviews were interviewed about their perspectives on parent occupations, ECIS and FQOL to triangulate the findings for this question.)

Table 2.4 *Parent Occupations Represented by Items from the BC-FQOLS*

Parent Occupations - Adapted from Harvey & Pentland (2004)

Necessary Occupations - aimed at meeting the basic self-maintenance needs

Items 3, 6, 12, 15, 16, 20, 21

3 - My family has the support we need to relieve stress

6 - My family members have transportation to get to places

12 - My family members show that they love and care for each other

15 - My family has medical care when needed

16 - My family has a way to take care of our expenses

20 - My family gets dental care when needed

21 - My family feels safe at home, work, school, and in our neighborhood

Committed Occupations - typically not remunerated such as housework, childcare, home maintenance

Items 1, 2, 5, 7, 8, 10, 11, 14, 19, 17

1 - My family enjoys spending time together

2 - My family members help children to be independent

5 - My family members help children with schoolwork and activities

7 - My family members talk openly to each other

8 - My family members help children how to get along with others

10 - Our family solves problems together

11 - My family members support each other to accomplish goals

14 - Adults in our family teach children to make good decisions

19 - Adults in my family have time to take care of the individual needs of every child

17 - Adults in my family know other people in the children's lives

Contracted Occupations - paid productivity or formal education

Not related to any item on the BC-FQOLS

Within demographic questionnaire – related to work status of carer (working or non-working)

Annual income of household (< \$50000 or > \$50000)

Free-Time Occupations - occur in the time that is left over, such as going out with friends or doing things of interest for self

Items 3, 4, 9, 13

3 - My family has the support we need to relieve stress

4 - My family members have friends or others who provide support

9 - My family members have time to pursue own interests

13 - My family has outside help available to us to take care of special needs of all family members

BC-FQOLS = Beach Center Family Quality of Life Survey. Source: Harvey & Pentland, 2004.

Lastly, results from all correlations were considered and triangulated with the qualitative findings to investigate whether there were any associations between the three variables in the question.

2.3.5 Qualitative study details. Semi-structured interviews were used within the same agency, using the same inclusion and exclusion criteria, and ethics approval as the quantitative study as above.

2.3.5a Participant recruitment and selection. Participants for the interviews were purposefully selected from those in the demographic data (quantitative sample) who consented for interviews. To gain a diverse and representative sample, the participants for the interviews included mothers and fathers from different geographical areas and varying socio-economic backgrounds. The annual household income was considered based on the Australian Bureau of Statistics (ABS) figures, indicating high average income as approximately \$96,000 and low average income as \$20,800 or less (ABS, 2015). The diagnosis of the children was also considered and included varying diagnoses such as cerebral palsy, Down syndrome, and autism.

Prior to the interview, the participants received written information via email or via text message about the interview's purpose and the researcher's interest in understanding the parent's perspective on the relationship between receiving ECIS, their FQOL, and their occupations. A brief written definition in simple language about what FQOL means was also provided (Appendix 2.4). An interview guide listing a few questions was also either emailed to all participants or presented prior to commencing the interviews (Appendix 2.5).

2.3.5b Qualitative data collection methods. This section presents the data collection details.

Data collection and data management. Qualitative data was collected over a period of 10-12 months alongside the quantitative data collection, as there was a closed time period for data collection from the agency. A folder was created on a

password protected computer for each participant to record field note observations and impressions, interview recordings and transcripts, and records of documents and other notes (Lincoln & Guba, 1985; Minichiello, Sullivan, Greenwood, & Axford, 2004). Hand written field notes after each interview were also kept in a reflective journal and later transferred into the participant's folder on the computer. Immediately after an interview all recordings were numbered, dated, and filed in each participant's folder. All audio interviews were transcribed verbatim and the recordings as well as transcripts were stored in the individual folders. (Minichiello et al., 2004). A table was also constructed in Microsoft word to record participant details and demographic information such as relationship to child, diagnosis, income, siblings and so on (see Table 2.5 in findings). Other tables that were constructed included common codes and themes related to quotes which displayed the combined findings of all participants and which are presented within the Appendix 2.6 or within this chapter as they are referred to (Miles & Huberman, 1994).

After the first two interviews were conducted and transcribed verbatim, the researcher met with the university supervisor to discuss the preliminary analysis of the raw data. According to Creswell (2009), the iterative nature of qualitative research allows data analysis to inform and guide upcoming data collection within one study. Data from the two interviews were independently analysed by the researcher and the supervisor, and emerging themes were discussed to determine if any changes to the interview guide were needed or if any questions needed further exploration. These initial themes were compared across participants during the process of analysis. Selection of further participants was also guided by these emerging themes, as the supervisor and researcher were able to determine the gaps in the information gathered based on the research questions. The next participant selection would assist in filling

out these gaps and provide richer data. For example, including participants from a lower socio-economic group, including participants with children with varying diagnoses and including fathers as well as mothers.

Data saturation was discussed between the researcher and the supervisor after every two to three interviews, and emerging codes were constantly compared to check for variability and effective saturation (Liamputtong, 2013). This process was repeated for every two to three interviews. By the tenth interview, data saturation seemed to have occurred, with a varying participant group, and it was jointly decided that more information might not add to new understanding about the aims of this study. A sample from the interview is presented in Figure 2.2. Two more interviews were conducted to ensure data saturation was reached.

Researcher: So you're happy to give up work yea? It's helped you and your child and your family members as well?

Parent: Even M [husband] you know, he after a while with me being off work... I was back 2 days a week, but even when I took time off he said "Oh we need to look at a way for you not having to go back to work." Like it made such a difference to our family. Yea.

Researcher: So can you tell me a bit more of what difference it made to your family, like some examples?

Parent: I mean obviously we've... we've seen results with E [child with disability] so those things that we're seeing achieved I think is sort of speaking for itself. And the other thing is just... it's just a better quality of family life, you know like the nutrition and meals that you can cook, and the you know with my husband, he had his own stresses and things and it just alleviated him... Or even have plants that stay alive or you know, it's those things that create a home ...

Figure 2.2. Interview Transcript Sample.

The researchers. The student researcher conducted all the interviews. She had over 20 years of experience working in the area of ECIS, and being a part of the family setting and context. The families within this research were not known to the researcher, however, in the past she had worked with children and families within ECIS for several years within the same agency. Prior to the interviews, the researcher had also undertaken training modules on qualitative studies with an emphasis on interviewing techniques, as she did not have experience of interviewing participants for research studies. One of the university supervisors was highly experienced in qualitative research and the researcher regularly debriefed with her throughout the research process to maintain trustworthiness.

The interviews. Semi-structured interviews were used for the qualitative aspect of this study. This allowed the researcher to elicit information from prepared questions, and at the same time allowed participants to elaborate on their responses (Liamputtong & Serry, 2011). All interviews took place in the family home and lasted between 45–90 minutes. The interview questions were based on the research questions and aimed to understand the participant's perspectives of their FQOL, and to find out if there were things that influenced their FQOL. Six broad questions were used as a guide to prompt participants, such as “How would you describe your family quality of life at present?”; “What are some of the things that you think have impacted or influenced your current family quality of life? Can you explain why?”; “Do you think that your family quality of life was different before having [name of child with disability]? Did you work? Or are you able to do things you did before? Can you give

me some examples?"; "Has receiving ECIS had any influence on you or your family? Could you tell me a bit more about that?"

Prior to the interview, participants were asked to think about how they considered having a CWD and receiving services such as ECIS had influenced their FQOL. If the participants had not read the information provided, the researcher presented a copy of these documents and gave the participant some time to read them before commencing the interview. During the interview participants were prompted to think about things that influenced their FQOL and if they felt that their FQOL was related or associated with their previous occupations (necessary, committed, contracted, and free-time) and/or with ECIS services.

All interviews were recorded on a digital recorder and backed up with iPad recordings using an application called "My Memos". No written notes were taken during the interview as the researcher wanted to engage in active listening and follow-up with prompts as they came up (Liamputtong & Serry, 2011).

Following each interview the researcher made notes in a reflective journal (Creswell, 2009). These notes included aspects about the environment, the mood of the participant, and any other detail that was not included in the recorded interview, but the researcher felt was important to note as contextual information. For example, the appearance of the participant, presence of other members at home, and the influence of them on the participant, and any other significant contexts such as the condition of the home, the mood of the members at home, and any specific routine that might influence the interview such as lunch time or breakfast time.

2.3.5c Qualitative data analysis. Data collected in the semi-structured interviews were analysed using Creswell's (2009) six steps of qualitative analysis (see

Figure 2.3). The work of several other researchers in qualitative research was also referred to and guided the steps and are included within the detail of the six steps (Liamputtong & Serry, 2011; Lincoln & Guba, 1985; Patton, 2002).

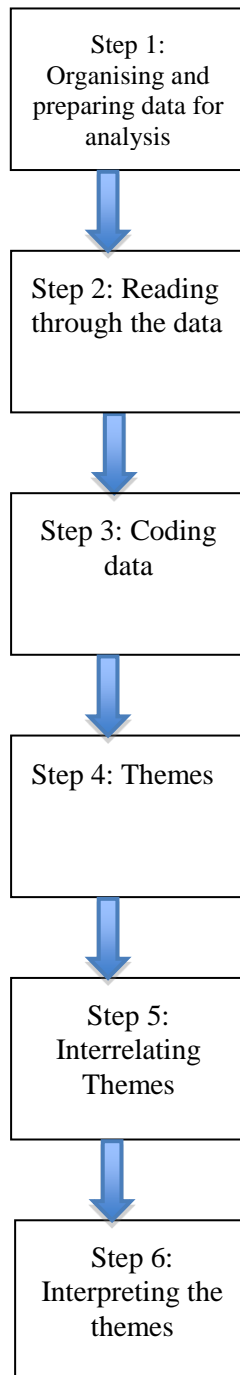


Figure 2.3. Six Steps of Qualitative Data Analysis (Creswell, 2009).

Steps of the analysis. The six steps that were used for the analysis were as follows:

Step 1: Organising and preparing data for analysis. All interviews were transcribed verbatim. The audio recordings, typed transcripts, and fieldnotes were stored in a folder assigned for each participant on the computer. A large sectioned binder was also maintained with sections assigned to every participant and included a printed copy of the transcripts with marginal notes, emerging codes, and fieldnotes. A number coding system was used where all interviews were assigned line numbers and each interview was coded numerically from 1–12 to report the data with dependability and confirmability, and to enable location of participants later (Lincoln & Guba, 1985; Minichiello et al., 2004). For example, **I2**: L23 corresponded to the second interview participant (**I2**) and the quote on line number 23 was represented by L23. All participants were assigned pseudonyms (in alphabetical order) and any other family members were also assigned either pseudonyms or an initial that did not match their actual name initial to maintain confidentiality. To aid retrieval of data, individual folders for each participant contained all their information including completed transcripts, fieldnotes, and any other material folders set up. All relevant quotes were colour coded using coloured sticky notes with line numbers to aid retrieval of quotes later on for analysis.

Step 2: Reading through the data. Interview transcripts were read one at a time and a general sense of the transcripts was gathered regarding the overall meanings of what the participants were saying and whether the data represented the information that was sought. The researcher cross-checked the interview questions and transcripts with her university supervisor after two interviews had been conducted to ensure that the questions were not leading or biased. This was a way of further informing the interview protocol to gain a better idea of the data for dependability. The interview questions did not change; however, the exploration of certain questions was deemed

necessary to obtain richer data. The researcher also reflected on her interviewing style, noting that the interruptions needed to be limited and the flow of the interview needed to be facilitated in order to get richer data.

Step 3: Coding data. Each paragraph of the transcripts were subjected to a detailed coding process to incorporate concepts used by the participants and the researcher (Patton, 2002). Eight steps based on the work of Tesch (1990) were followed for the coding process (see Figure 2.4). The first step of coding according to Tesch involved a general reading of all the data were completed in the above step two of the analysis. The next step involved recording overall meanings from the interview and making notes about the emerging topics alongside the margins. The aim was to build a picture of the complexities involved in dealing with having a CWD and to look for recurring or evolving patterns over time. Step three of coding involved listing topics and clustering common topics together (Tesch, 1990). The clustering process involved looking for common participant perspectives, their way of thinking about certain topics (such as their changed parent role and changed occupations), or even looking for expected codes (such as factors that influence FQOL including supports, finances, emotional well-being, or relationships between family members), as well as any surprising or unusual codes (for example, when participants felt that their FQOL is not much different following having a CWD to having a typical child, and that their FQOL will get better when they go to school).

The fourth step of the coding (Tesch, 1990) involved assigning headings to each topic. Step five grouped these headings that related to each other to form categories of data or the codes. The codes were constantly compared between the two researchers to avoid losing significantly meaningful information while reducing the data. Sixteen codes were labeled in step six of the coding process. Step seven

involved assembling data from the 12 interviews to each code as the preliminary analysis. A coloured sticky note was assigned to each participant and the line numbers for quotes that contributed to each code were recorded on the sticky note (for example, participant 1, Alice, was represented by a yellow, heart-shaped sticky note while participant 2, Bob, was represented by a pink, square-shaped sticky note).

All the sticky notes were displayed on a large whiteboard and the researcher started grouping the sticky notes into the respective codes. This step led to further reassembling of the codes. The researcher ensured that there were no leftover quotes or codes. Each code was then written on a separate page in the qualitative codebook, and the sticky notes with the quotes were placed on the corresponding code page. Recoding was considered the last step; however, it was not needed. Sixteen codes were created and the summary of the information that contributed to the code was written in dot point form under each code page. Photographs of these pages with the 16 codes were taken for audit trail purposes (see Appendix 2.7) to provide evidence and ensure credibility and dependability (Lincoln & Guba, 1985).

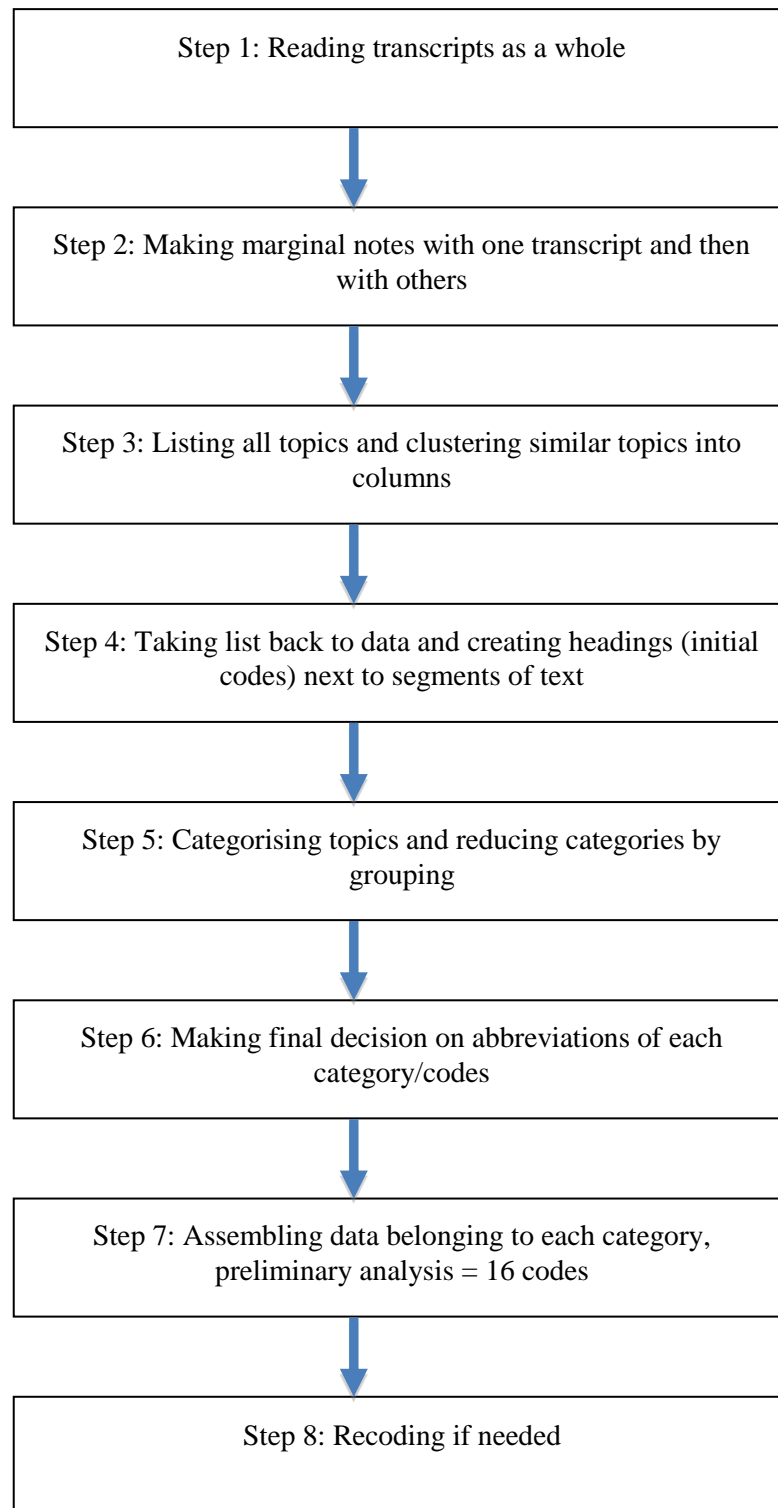


Figure 2.4. Eight Steps of Analysis based on Tesch (1990) for Coding Data. Source: Creswell, 2009, p. 186.

Step 4: Themes. This process required constant re-organising of codes, collapsing codes together, constant comparison of data, and weekly meetings between the researcher and university supervisor to discuss and re-assemble the codes or collapse them. The 16 codes were laid out alongside the quotes and connections were made between the differences, similarities, and the emerging themes with regard to the questions. Codes that contained parent perspectives about their FQOL were grouped together as a theme, and those that were about challenges to their FQOL were grouped as a separate theme. The codes that described things that supported their FQOL were clustered together for another theme and codes that were about consequences of having a CWD to their FQOL were grouped together. This led to the generation of four themes. These themes were checked for each individual participant and then compared across participants. A table was created in Microsoft Word to group these four themes across the rows with the participants' pseudonyms along the columns. This table (Table 2.11) will be presented in the findings section.

Step 5: Interrelating themes. This step involved interrelating the four themes in answering the study questions. The research questions that guided this study were placed on a whiteboard and links and connections were made with the four themes. Some themes seemed to relate to more than one research question. It was necessary to use iterative, deductive, and constant comparison methods to work back and forth between the emerging themes and the research questions (Lincoln & Guba, 1985; Miles & Huberman, 1994). The research questions were used as a guide to understand the connections between the themes, and at the end of this step, relations and connections were made between the research questions. (Glesne & Peshkin,

1992). Figure 2.8 in the findings section presents these connections between the themes and the research questions.

Step 6: Interpreting the themes. This final step in data analysis was valuable as within this step, the researcher asks further questions about the data with the aim of capturing the essence of the study (Creswell, 2009). It also compares the analysis to literature or theories to confirm past information or divergence from it. This step will be used for clarifying and developing recommendations for practice and policy and further help with understanding FQOL and the factors that impact on FQOL of parents/caregivers in this sample group. This was a challenging step as it required the researcher to feel confident about her data analysis and interpretation, and then argue or concur with existing literature. It was important for the researcher to be immersed in the data to affirm her judgment and to feel a sense of rightness and coherence about the process of working with the data (Glesne & Peshkin, 1992). This step would lead to emergent conclusions that would contribute to research in the field of early childhood intervention and FQOL. As this analysis is more like a discussion, it will be covered in the discussion section.

2.3.5d Trustworthiness. The process of trustworthiness mentioned within this section applies to this entire research. It will be described in this chapter but is also applicable to Chapter 3, study 2. There are a number of key features that support the trustworthiness and authenticity of a study. Levels of trustworthiness were regularly discussed with the supervisor. The level of trustworthiness within the qualitative parts/components of the research can be further described by examining the four criteria of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). See Figure 2.5.

Credibility. Credibility involves establishing that the results of the qualitative research are believable or credible from the participants' perspective (Lincoln & Guba, 1985). A number of steps were taken to maintain credibility within this study.

The data collected for this study was comprehensive, collected over almost a year, in collaboration with research participants (Glesne & Peshkin, 1992; Lincoln & Guba, 1985; Minichiello et al., 2004). The rigour was built into the ongoing data collection by maintaining reflexive field notes, using authentic methods for interpretation of codes and themes, and for reporting findings in the writing process.

Sampling: For sampling, the inclusion and exclusion criteria were adhered to and participants were purposefully selected from the quantitative sample to include a diverse sample. For Study 1, even though the participants were from the same agency, they were from different socio-economic groups, different geographical areas, and included children with varying diagnoses. Study 1 included two fathers and 10 mothers. In study 2, initially there were very few fathers who completed the surveys, with no fathers for the interviews. However, some mothers who were interviewed expressed that their spouses (fathers) would also like to be interviewed. Four of the fathers who consented were then included in the qualitative interviews to give study 2 a diverse sample of mothers and fathers. Thus, both studies had mothers' and fathers' perspectives to add to the diversity. According to Curtin and Fossey (2007) using a diverse sample maximises the range of data and contributes to a better understanding of the phenomenon (in this research this phenomenon is the parent perspectives of their FQOL). Comparing similarities and differences from the perspectives of a diverse sample provides richer data for triangulation as it presents different viewpoints and the researcher can cross-check for consistency, as well as differences during triangulation (Curtin & Fossey, 2007).

Within the methods section each step of the data collection, sampling procedures, and methods used for the analysis were written in detail. Wherever possible, tables and figures were used to further clarify the methods either in the text or within appendices, to demonstrate credibility and dependability. Constant comparison methods between the researcher and supervisor were consistently carried out during each step of data analysis. The researcher met with the supervisor after every two interviews and both analysed the data separately and compared notes before arriving at the final codes and themes. Triangulation was also incorporated when the interview data was linked with field notes, observations recorded, and connected back to the transcripts before finalising codes and themes (Miles & Huberman, 1994; Minichiello et al., 2004).

According to Curtin and Fossey (2007), across-method triangulation refers to the use of both qualitative and quantitative approaches in a study to investigate the same phenomenon (FQOL when there is a CWD). The quantitative findings were also considered for triangulation because combining multiple methods and data sources can overcome intrinsic bias and enhance the validity or trustworthiness of a study (Curtin & Fossey, 2007). The quantitative scores from the BC-FQOLS were often congruent to findings from the interviews; however, the interviews detailed extra information that sometimes added an understanding of the high scores but were also surprising. For example, participants had high scores on their total FQOL and triangulating this with the interview data helped in understanding that there were times when they were feeling better about their FQOL but at other times they felt challenged and experienced a poor FQOL. Such triangulation added to the richness of data for the results and findings but needed to be accurate and not pre-empted during the interviews. The researcher stayed authentic to the interview questions and the

supervisor checked the transcripts periodically to ascertain avoidance of leading questions.

Member checking is a crucial step for ensuring credibility and includes testing the data, interpretations, and conclusions with the members from whom the data was originally collected (Lincoln & Guba, 1985). The researcher prepared a summary from all the interview transcripts, and from the codes and themes after analysis. This summary was emailed or texted via mobile phones to all participants to gain any further comments or feedback before finalising the themes. The researcher used member checking to check her interpretations and reconstructions of the participant responses while she was constructing her own understanding (Lincoln & Guba, 1985). For example, the participants' comments on their commitment to the parenting/caregiving role as a contributor to their FQOL was surprising for the researcher, as she was of the opinion that caregiving would be exhausting and detrimental to FQOL. Lastly, for member checking, all interview transcripts and codes were cross-checked by the researcher for use of participant language and quotes when reporting the findings.

Peer debriefing is useful in establishing credibility and exposes the researcher to peers for exploring aspects of the inquiry that might otherwise remain implicit. Regular confidential debriefing with the university supervisors was essential and valuable given the parent experiences that were being exposed to the researcher. There were sensitive and occasionally emotionally distressing and challenging issues that were raised during the interviews that were discussed during these debriefing meetings. Other methods used included debriefing with other doctoral students and peers at the university during postgraduate meetings. These colleagues were not engaged in the study, but were presented with study details and asked to pose

questions relating to methodological, ethical, legal, or any other relevant issues that would help the researcher to be more objective to enable next steps. The researcher also presented her research at seminars, conferences, and within occupational therapy course subjects related to children and families experiencing disability. Such discussions helped in gaining insights from peers to strengthen credibility (Lincoln & Guba, 1985)

Transferability. Transferability is achieved by providing detailed and accurate descriptions of the time, context, participants, and settings in which the study occurred. These thick descriptions enable future researchers to conclude whether the same circumstances and descriptions can be created if they were to conduct a similar study (Lincoln & Guba, 1985). In this study, transferability was achieved by providing descriptions of the settings and context of the interviews. Most interviews were held at participants' homes and a description of the home environment and context is noted. Descriptions of each participant have been provided in the text, describing the context and background, the setting, and a short story, to enable the reader to form a representation about the participant. Many quotes are listed in the findings that allow the reader to subjectively share the experience of the participant, and make their own judgments about the findings as well (Lincoln & Guba, 1985; Minichiello et al., 2004; Tesch, 1990). Tables are also included listing the participants' relation to the child, diagnosis of child, siblings, marital status, and work status in both studies. All participants were either parents of children in ECIS or parents of school-aged children with a disability. A clear description of the ECIS system and the school system within Melbourne is provided.

Dependability. According to Lincoln and Guba (1985), there can be no credibility without dependability. If the methods for the entire research process are

outlined clearly for credibility, it is not necessary to demonstrate dependability separately. Auditability – the ability to track variance and consistency is also associated with credibility and has been maintained during this study. Triangulation of all data, cross-checking of codes as well as provision of clear figures and descriptions of the research methods were used in this study. All tables representing triangulation of findings from the qualitative and quantitative studies are presented in the appendices to demonstrate the process used for triangulation. Details about the analysis from the interviews and quotes and the processes for the emerging codes and themes are stored in the folders and are available for audit trail.

Stepwise replication is also a part of dependability and requires an inquiry team of at least two persons who conduct their own inquiries (Creswell, 2009; Lincoln & Guba, 1985). For this study, the researcher and one of the university supervisors were engaged in separate analysis of the qualitative data. All decision points regarding the data collection and analysis were discussed between the researcher and the university supervisor. Inquirer bias was reviewed and early closure of the interviews was resisted to ensure all reasonable areas were explored. Premature judgments were avoided and sampling decisions were constantly reviewed during the data collection process. This led to a range of participants from across Melbourne with variations in their socio-economic backgrounds, gender, and the diagnoses of their children (see findings sections). All methodological, analytical, and interpretive decisions are reported for dependability so that others can evaluate the research (Miles & Huberman, 1994; Minichiello et al., 2004). Lincoln and Guba (1985) say that with such research as in this study, it is important that the data can be tracked to their sources, and the logic used to organise the data into coherent wholes is both explicit and implicit in the narrative of the study. This is achieved by using line numbers on

transcripts and numerical codes for the interviews to track every quote in the study. The methods of triangulation and documenting evidence also add to the confirmability of a study. For example, the ongoing interviews and repeated use of the interview questions as a guide across all interviews were used in this study. During the interviews, she used the pre-written questions diligently as a guide to avoid leading the participants to answers that may reflect her own views or past experience of work with families or lead the research in a desired direction (Cumming-Potvin, 2013).

Confirmability. All of the above processes are important to establish confirmability and to ascertain that the integrity of the findings was grounded in the data. Confirmability also involved checking whether the findings were the results of the perspectives of the parents rather than the preferences of the researcher, a process that was consistently checked by the university supervisor. Another strategy supporting confirmability is related to the concept of the researcher as a research instrument. The researcher was aware of reflexivity issues associated with her 20 years of experience of working with children and families, and she therefore used self-reflection and took detailed field notes and recorded written reflections in a journal after each interview (Barry, Britten, Barber, Bradley, & Stevenson, 1999). A qualitative codebook was maintained by the researcher throughout the process of coding and all methodological decisions for coding were recorded to maintain reflexivity throughout the analysis process (Barry et al., 1999).

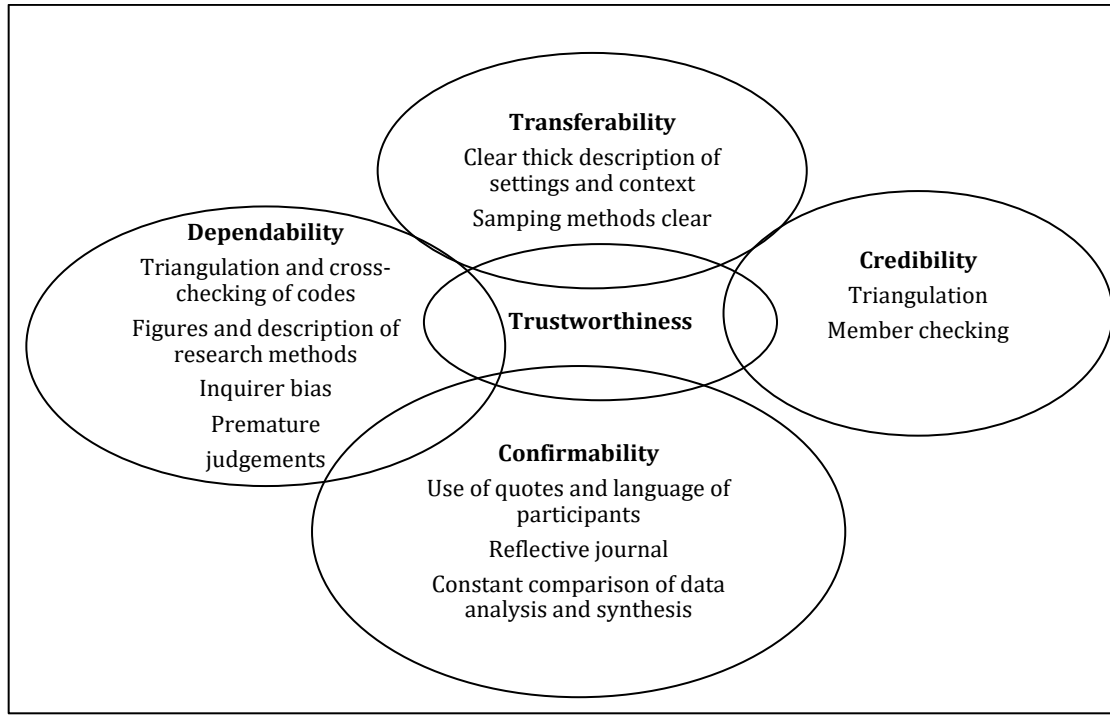


Figure 2.5. Trustworthiness (adapted from the work of Lincoln & Guba, 1985).

2.4 Results and Findings

This section presents the results from the quantitative BC-FQOLS and demographic questionnaires, and the findings from the 12 qualitative interviews. All the quantitative results will be presented first, followed by the qualitative findings and to end the section a summary of both the results and findings will be triangulated and presented.

2.4.1 Quantitative results. The *Beach Centre Family Quality of Life Survey* (BC-FQOLS) was used to collect quantitative data from the participants of this study regarding their satisfaction with the items on the survey (BCD, 2002; Turnbull & Turnbull, 2002). Besides the BC-FQOLS, demographic data was also recorded on a demographic questionnaire. This data included age and diagnosis of the CWD, relationship of participant with CWD, background regarding origin of family, family members living at home, gender of participant, partnership status, employment status of participant and their partner, level of education of participant and partner, income status of family, and the duration of time they were enrolled in ECIS. Three hundred BC-FQOLS surveys and demographic questionnaires were handed out over five sites from a single ECIS agency, Yooralla, and another 60 surveys were posted out by the researcher after three months.

Seventy-two participants returned the completed surveys. The researcher estimated that 150-200 surveys were distributed from Yooralla and this infers a response rate of between 36%–48%. All 72 participants were parents or caregivers of a CWD attending Yooralla ECIS. The data collected was entered into the Statistical Package of Social Sciences software (*SPSS, version 22*) for analysis (IBM, 2013). No missing data was recorded. Two participants did not return the BC-FQOLS along with the demographic questionnaire but consented for the interview and returned the forms after an email request was sent to them via their contact details.

2.4.1a Descriptive scores - demographic questionnaire. All demographic data are presented in Table 2.5. The majority of the participants (N = 72) were mothers (80%) followed by fathers (16%) and two grandmothers (see Table 2.5). The distribution of the sample was from five main areas of metropolitan Melbourne, Victoria, Australia divided as Outer South, Inner South, West, North, Outer East, and

Inner East. The majority of participants were from the Outer South and West area (27%) and the distribution was between 7%–15% over the areas.

Table 2.5 *Demographic Questionnaire Results*

Demographics of Quantitative Sample			
		Frequency	Percent
Relationship	Father	12	16.7
	Mother	58	80.6
	Grandmother	2	2.8
Age of child	0-2.1 years	9	12.5
	2.2-4.1 years	34	47.2
	4.2-6+ years	29	40.3
Father living at home	Father lives at home	58	80.6
Languages spoken	English	67	93.1
	Other	5	6.9
Diagnosis of child	Developmental delay	11	15.3
	Cerebral palsy	10	13.9
	Down syndrome	5	6.9
	Autism ASD	19	26.4
	Congenital issues	8	11.1
	No clear diagnosis	8	11.1
	Speech and language delay	5	6.9
	Other	6	8.3
Annual income	Not working (nil income)	13	18.1
	\$30,000-\$50,000	16	22.2
	\$50,001-\$70,000	11	15.3
	>\$70,001	31	43
	Not stated	1	1.4
Work status	Not working due to my child's health	22	30.6
	Not working due to my health	1	1.4
	Looking for work outside home	2	2.8
	Working full-time	3	4.2
	Working part-time	25	34.6
	Full-time home maker	14	19.4
	Student	3	4.2
	Other	2	2.8

English was the first language of 93% of the participants. The other 7% did speak another language but had sufficient English (spoken and reading) to take part in the study and were included. Nearly 13% of the children with disability were between the ages of 0–2.1 years, 47% were between 2.2–4.1 years and 40% were between 4.2–6+ years (see Table 2.5). The primary diagnosis of the children ranged from autism (26%), developmental delay (15%), and cerebral palsy (14%) through to congenital issues (11%), Down syndrome (7%), and speech and language delay (7%) while nearly 20% had no clear diagnosis or some other rare diagnosis. There are no clear statistics available comparing types of disability within ECIS to consider whether this is a representative sample however it is comparable to the statistics reported in an ABS report from 2016, the incidence of Autism is highest as compared to other disabilities with 1 in 150 children (nearly 0.7%) having a diagnosis of Autism, compared to 2 per 1000 (0.002%) of children with cerebral palsy and 1 per 1100 children with Down syndrome (ABS, 2016).

The annual income was reported in five categories with nearly 22% earning between \$30,000 and \$50,000, 15% between \$50,001 and \$70,000, and 43% reported their annual family income as \$70,001 or higher. Only one participant did not state their income and 18% were not working so had no income except from Centrelink payments. In terms of work status of the main carer, 54% of the participants were not working and 31% of these were not working due to their child's health needs. Only 4% were working in full-time jobs and 35% were working in a part-time capacity. Seven percent were either studying or looking for some work or chose the 'other' option (see Table 2.5).

2.4.1b Results from the BC-FQOLS. Descriptive analyses and correlational analyses were conducted with the subscales and items from the BC-FQOLS. For the

correlation analysis, the total FQOL score was summed up by adding the scores from the 25 items on the BC-FQOLS. The relationships between FQOL and ECIS and parent occupations as per the research questions were analysed using the Spearman's Rho correlation.

Research Question 1: For the first research question regarding parents' perspectives of their FQOL, the descriptive analysis scores indicated that the distribution of scores on the continuous variable, 'satisfaction with total FQOL' (TFQOL), had a range of 64 ($M = 100.56$, $SD = 14.15$); the subscales of 'total family interaction' had a range of 20 ($M = 24.6$, $SD = 4.87$); 'total parenting' had a range of 15 ($M = 24.31$, $SD = 3.57$); 'total physical material well-being' had a range of 13 ($M = 20.67$, $SD = 3.29$); 'total emotional well-being' had a range of 16 ($M = 14.38$, $SD = 3.61$); and 'disability-related support' had a range of 9 ($M = 16.94$, $SD = 2.19$). Please refer to Table 2.6 for these scores. The scores from the BC-FQOLS indicated strongest association for total FQOL (TFQOL) with the 'parenting' subscale ($\rho = .86$, $p = .01$), followed by 'emotional well-being' ($\rho = .85$, $p = .01$), 'family interaction' ($\rho = 0.85$, $p > .01$), disability-related support ($\rho = .70$, $p = .01$), and, lastly, 'physical material well-being' ($\rho = .61$, $p = .01$). The BC-FQOLS does not provide standard scores and norms for comparisons so it was not possible to comment on these scores with normative data, however in the discussion section these scores are compared to scores from other studies to compare the study results to the literature.

Table 2.6 *Descriptive Scores for Total Subscale Items on BC-FQOLS*

	Total FQOL (TS = 125)	Total Family Interaction (TS = 30)	Total Parenting (TS = 30)	Total Physical Material WB (TS = 25)	Total Emotional WB (TS = 20)	Disability- related support (TS = 20)
Mean	100.56	24.26	24.31	20.67	14.38	16.94
Median	99.50	25.00	24.00	21.00	15.00	16.50
Std. Deviation	14.15	4.87	3.57	3.29	3.61	2.19
Range	64	20	15	13	16	9

The total FQOL score on the BC-FQOLS sums up to a maximum score of 125. The scores on TFQOL indicate that the majority of the sample had high scores and were satisfied with their total FQOL. There was only one outlier that had a score of 61, indicating low satisfaction with their total FQOL. The skewness score of $-.091$ indicates a clustering of the scores at the high end of the graph, which means that in this sample the number of families satisfied with their ‘Total FQOL’ was higher compared to the families less satisfied with their ‘Total FQOL’ (TFQOL). The histogram (see Figure 2.6) illustrates a representation of this distribution.

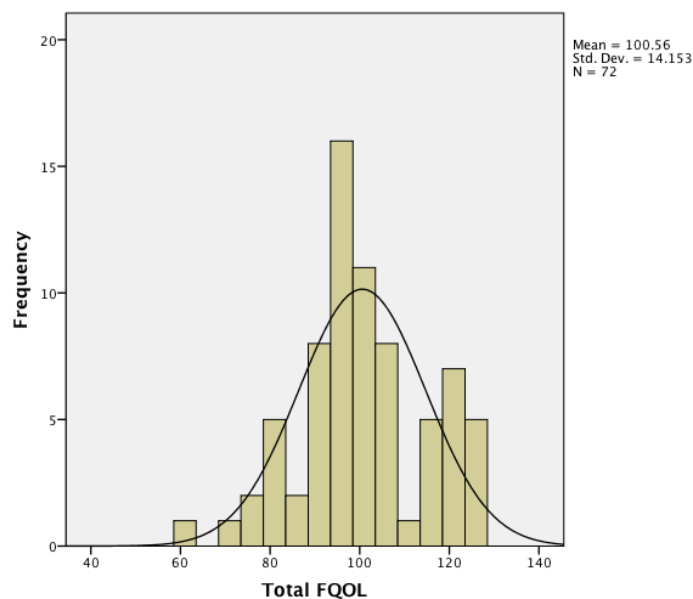


Figure 2.6. Total Family Quality of Life (FQOL) Satisfaction.

Research Question 2: Research question 2 concerned relationships between parent occupations, ECIS, and FQOL. For contracted occupations or paid employment, the descriptive scores from the demographic questionnaire indicated that over half (54%) of the participants

were not working and 31% of this group were not working due to their child’s health needs, 4% were working in full-time jobs, and 35% were working in some part-time capacity. For free-time occupations, 59% of the participants were either satisfied or very satisfied with the time they could spend on pursuing their interests, and 41% were either not sure or not satisfied. For relationships between parent occupations and ECIS, four items from the BC-FQOLS were selected based on maximum agreement scores of therapists (see above) and correlated with the BC-FQOLS subscale ‘disability-related support’. These four items represented parent occupations as per the classification used in this study. For example Item 1 – Spending time together and item 19 – taking care of individual needs of every child, were both representative of committed occupations, and were correlated with the subscale “disability-related support”. Item 16 – taking care of expenses was representative of necessary occupations and item 9 – time to pursue own interests was representative of free time occupations and both these items were correlated with the subscale “disability-related support”. See Table 2.7.

Table 2.7 *Parent Occupations and Disability-Related Support (ECIS) – Correlation scores (N = 72)*

Parent Occupations		Disability-related Support (ECIS)
<hr/>		
Committed occupations		
Item 1: Spending time together		
	Correlation coefficient	.383**
	significance	
Item 19: Taking care of individual needs of every child		
	Correlation coefficient	
	significance	.545**
Necessary occupations		
Item 16: Taking care of expenses		
	Correlation coefficient	.330**
	significance	

Free-time occupations		
Item 9: Time to pursue own interests		
	Correlation coefficient	.463**
	significance	
Contracted occupations		
Work status (from demographic questionnaire)		
	correlation coefficient	.111
	significance	

** Correlation is significant at the 0.01 level (2-tailed); * Correlation is significant at the 0.05 level (2-tailed)

For committed occupations, there were strong positive correlations between item 1 – spending time together as a family ($\rho = .38, p < .01$) and item 19 – taking care of the individual needs of every child ($\rho = .54, p < .01$), and ‘disability-related support’ indicating that such committed occupations were associated with the support the families were receiving from their ECIS. For necessary occupations there was a strong positive correlation between item 16 – taking care of expenses for family ($\rho = .33, p = .00$) and ‘disability-related support’ and for free-time occupations item 9 – time to pursue own interests with ‘disability-related support’ ($\rho = .46, p < .01$). For contracted occupations, there was no significant correlation between the work status of the main carer (from demographic questionnaire) and ‘disability-related support’ ($\rho = .11, p = .35$).

Regarding the relationship between ECIS and FQOL, the descriptive scores indicated that 96% of the participants were satisfied with the relationship they had with their service provider. Six significant correlations were found between time to pursue own interests (occupations of parents, Item 9 on the BC-FQOLS) and items from the BC-FQOLS that indicate support provided by ECIS. The satisfaction a family felt with the amount of time they had to pursue their own interests (Item 9) was significantly correlated to having a good relationship with their ECIS provider (Item 25) ($\rho = .337, p = .004$). The satisfaction a

family felt with the amount of time they had to pursue their own interests (Item 9) was also significantly correlated to disability-related support that they receive from their ECIS ($\rho = .463, p = .01$). The satisfaction a family felt with the amount of time they had to pursue their own interests (Item 9) was significantly correlated to having support for their child to make progress at home (Item 23) ($\rho = .497, p = .01$). The satisfaction a family felt with the amount of time they had to pursue their own interests (Item 9) was significantly correlated to having support for their child to make friends (Item 24) ($\rho = .315, p = .007$).

The satisfaction a family felt with the amount of time they had to pursue their own interests (Item 9) was significantly correlated to having support to relieve stress (Item 3) ($\rho = .634, p = .01$). The satisfaction a family felt with the amount of time they had to pursue their own interests (Item 9) was significantly correlated to spending time together as a family (item 1) ($\rho = .427, p = .01$). There was a strong negative correlation between duration of ECIS and relationship with ECIS provider (Item 25) ($\rho = -.33, p > .00$) indicating that the relationships with ECIS providers may be associated with the frequency of visits from the keyworker (the frequency of visits by keyworkers reduced as the duration of time a family spent within ECIS increased).

In terms of the relationships between all three variables, namely ECIS, parent occupations, and FQOL (research question 2), all of the above strong correlations between items and subscales of the BC-FQOLS, and items from the demographic questionnaire, demonstrate associations between parent occupations, disability-related support, and FQOL. The descriptive scores indicated high scores on the TFQOL with the strongest association with the subscale of parenting. See Table 2.8 for all the correlations for the research questions.

Overall, to summarise the quantitative results, there were strong correlations between a number of variables that comprised ECIS (good relationship with service provider, duration of

ECIS, support available at home and kinder, support available to relieve stress, disability-related support) and parent occupations (time spent together as a family, time to pursue interests) with total FQOL, indicating that satisfaction with ECIS is related to FQOL and participation in certain parent occupations is also related to FQOL.

Table 2.8 *Correlations for Research Questions*

			Work Status Carer	ECIS Duration	Good Relationship with SP	Total FQOL	Time for Own Interest	CWD has Support Make Friends	CWD has Support at Home	CWD has Support at Kinder	Support for Stress	Enjoy Time Together
Spearman's Rho	Work status carer	Correlation coefficient	1.000	.105	-.073	.182	.138	.180	.152	-.029	.101	.171
	ECIS duration	Correlation coefficient		1.000	-.334**	-.139	-.174	.048	-.209	.051	-.143	-.188
	Good relationship with SP	Correlation coefficient			1.000	.399**	.337**	.235*	.485**	.330**	.305**	.254*
	Total FQOL	Correlation coefficient				1.000	.663**	.478**	.733**	.498**	.788**	.559**
	Time for own interest	Correlation coefficient					1.000	.315**	.497**	.283*	.634**	.417**
	CWD has support make friends	Correlation coefficient						1.000	.453**	.549**	.376**	.176
	CWD has support at home	Correlation coefficient							1.000	.561**	.567**	.398**
	CWD has support at kinder	Correlation coefficient								1.000	.384**	.306**
	Support for stress	Correlation coefficient									1.000	.477**
	Enjoy time together	Correlation coefficient										1.000

CWD = child with disability; N = 72;

** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

2.4.2 Qualitative findings. Semi-structured interviews were conducted with purposefully selected participants from those in the agency quantitative participant sample who consented to be interviewed. Twelve participants were selected to include participants from different areas of Melbourne and mothers and fathers of CWD. A diverse sample to maximize and capture the breadth of the phenomenon of interest provides rich data (Minichiello et al., 2004).

2.4.2a About the participants. All twelve participants were parents of CWD attending Yooralla ECIS, and their demographic details are listed in Table 2.9. They were selected from diverse regions of metropolitan Melbourne and included ten mothers and two fathers. The diagnoses of their children aged between 3–7 years included autism, cerebral palsy, Down syndrome, and developmental delay. The main carer for 11 out of 12 children was the mother, and 10 out of the 12 main carers were not working in a paid job. The remaining two participants were working in a part-time capacity. The annual income details were gathered from the demographic questionnaire that all participants filled out at the start of the quantitative study. The annual household income ranged from low to high average and was determined using the Australian Bureau of Statistics (ABS) categories, indicating high average income as approximately \$96,000 and low average income as \$20,800 or less for the year ending in 2014 (ABS, 2015).

All interviews took place at the participants' homes upon their request. The information below introduces participants and presents some observations made by the researcher during and after the interviews. These descriptions present the context of the interviews, highlighting the additional parenting responsibilities of parents caring for CWD. These descriptions also provide a further understanding of the

diversity, yet similarities, in their experiences. The participants were de-identified and pseudonyms were assigned. The code in parenthesis next to the name of each participant denotes the order of the interviews; for example, **I1** means that this participant was the first interviewee where ‘**I**’ stands for the interviewee.

Table 2.9 *Demographic Data – Qualitative Study*

Participant Pseudonyms	Area/Region	Diagnosis of Child/ Severity (according to parents)	Age of Child	Siblings	Marital Status	Other Child has Disability or Delay or Undiagnosed	Family Income	Main Carer Working
I1 - Alice	Outer South	Autism (mild)	Approx 4 years	2 siblings	Married	No	High average	No
I2 - Bob	Outer South	Cerebral palsy – spastic quadriplegia (severe)	4 years	One sibling	Married	No	Low	No
I3 - Cassie	Inner East	Cerebral palsy (moderate)	3 years	1 sibling	Married	Unsure - may have autism	Average	No
I4 - Dee	Outer East	Autism (mild with behaviour challenges)	Approx 7 years	None	Married	N/A	Average	No
I5 - Ellie	Inner East	Down syndrome (moderate)	4 years	1 sibling	Married	No	High average	No
I6 - Fran	Outer East	Autism (mild with behaviour challenges)	Approx 5 years	3 siblings	Married	Yes – two have autism, one visual condition	Low average	No
I7 - Grace	Outer South	Cerebral palsy (moderate)	4 years	None	Married	N/A	Average	No
I8 - Hannah	Inner East	Autism (moderate with behaviour challenges)	6 years	1 sibling	Separated	Yes	Low	No
I9 - Irene	West	Global developmental delay (mild)	Nearly 3 years	None	Married	N/A	Average	Part-time
I10 - Jenny	Outer South	Autism (moderate with behaviour challenges)	5 years	3 siblings	Single	Yes - one with autism and other unclear diagnosis	Low	No
I11 - Kerry	West	Down syndrome (mild)	2 years	None	Separated	N/A	Average	No
I12 - Liam	West	Autism (mild-moderate)	4 years	1 sibling	Separated	Yes - autism	Average	Part-time

Alice (I1) has three children less than 4 years of age and her oldest son has a diagnosis of autism. Her husband works full-time and is a tradesperson. Alice is a full-time homemaker and the main caregiver for her children. She described being very content with her parent and homemaker role. During the interview her son with the diagnosis of autism was at childcare, and the other two siblings were present. Both were under 3 years of age. Alice was constantly attending to their needs such as providing them with snacks or adjusting the programs on the television, as they requested. According to Alice, her son with autism is high functioning and can express his needs well. Alice reported the family annual income within the high average category in the demographic questionnaire. She also reported that she has a supportive extended family and gets a lot of support from her mother.

Bob (I2) has 4-year-old twins, a boy and a girl, and lived with his wife and an older adult uncle. His son has a diagnosis of cerebral palsy, spastic quadriplegia. His son was at home, in another room, with his mother but would occasionally crawl out of the room, to be in the lounge room. His daughter was at childcare and was developing typically. Bob also cared for his uncle who needed support for some of his daily living tasks. Bob's son required full-time care, with Bob having to meet his needs for mobility, feeding, communication, and self-care routines. He had low cognitive abilities, was not walking, and communicated minimally. He had no comprehensible speech, but communicated his needs by making sounds. He used a percutaneous endoscopy gastrostomy device (PEG) for night feeds and his main difficulty was oral feeding according to Bob. Both parents took turns to provide him with oral feeds twice a day. The feeding took between a half to two hours. Bob had given up his work due to his poor health and his son's high support needs. His wife was a full-time homemaker. According to Bob she suffered from post-natal

depression. Bob expressed having financial difficulties and was receiving ECIS and funding from a funding initiative for his son's therapy needs.

Cassie (I3) has two boys and lived with them and her husband. Her younger 3-year-old son has a diagnosis of cerebral palsy. He was crawling and beginning to walk with some support. He communicated with single words and gestures. Cassie was his main carer and helped him with most daily routines such as self-care and mobility. Cassie reported that her older son may have autism; however, he was not diagnosed as they were unable to find time to take him through the assessment processes with the specialists. Both the boys were present during the interview and Cassie was managing them by assigning tasks to the older son. She asked him to play blocks with his younger brother and then allowed him to play games on his tablet (iPad) for 10 minutes. Her younger son, with the diagnosis of cerebral palsy, sat at the table with us during the interview and played with his toys. He seemed like a bright and bubbly boy who enjoyed the social interactions. His speech was difficult to understand but Cassie could follow what he said. She had to constantly attend to his requests such as getting toys, playing with blocks, or getting him in and out of the chair. Cassie's husband worked full-time as a tradesperson and she had stopped working in order to look after her younger son's needs. She was working in a well-paid job so the family was facing some financial strain. However, she was determined not to return to work for a few years, to look after her younger son's needs. She mentioned that not going back to work placed a huge strain on her relationship with her husband, as he found the pressure of work difficult and his single wage was not enough for meeting the family's needs.

Dee (I4) lives with her husband and their 7-year-old daughter, who has a diagnosis of autism. Her daughter had just started school transition and she was at school during the interview. Dee reported that as a baby and preschooler, her daughter

had significant sensory issues and challenging behaviours such as aversion to certain foods, loud noises, and she would have huge ‘meltdowns’, around 10–15 a day, dropping down to the floor, and was extremely difficult to manage. Dee reported that at that time she expressed her concern to the doctors and nurses on several occasions; however, she felt she was not listened to and was asked to change her behaviour management strategies with her daughter. This had an impact on her and she felt that she lost her confidence in parenting her daughter. Her daughter received a diagnosis of autism after 5 years of age and this delay in diagnosis was an extremely difficult time for the parents to manage, especially the challenging behaviours, and the financial requirements of visiting specialists. She did not qualify for ECIS in the early years due to delayed diagnosis and the family accessed community health and private psychology services. Dee had to stop working because of her daughter’s high needs and challenging behaviours. Due to a single wage she expressed some financial difficulties. Dee’s parents and her husband’s family supported them financially. They were currently living at her in-laws home. Dee expressed that both she and her husband felt obligated to their parents for helping them and would like to be more financially stable to repay them. Dee planned to start working part-time again when her daughter went to school next year and mentioned that she seemed to be settling at school transition; however, she still had sporadic meltdowns.

Ellie (I5) lives with her two boys and husband. Her older son was 4-years-old with a diagnosis of Down syndrome and had high needs for medical care. He also had significant speech delay and difficulties with motor skills and cognitive abilities. The younger son was 2 years old and Ellie reported that he was “quite a handful”. Both the children were at a relative’s place and not present during the interview. Her husband, a tradesperson, worked long hours. He helped with home chores occasionally and on the weekends spent time with his sons so Ellie could have a break

to do tasks such as grocery shopping. Their annual income was in the high category. Ellie stopped working after her first son was born and has since been a full-time homemaker. She was unable to return to work due to her son's high care needs and several medical appointments. He underwent surgery for a congenital heart condition as a baby and needed regular follow-ups. Her younger son also needed care, as he was only 2-years-old, and Ellie felt that he was very active and did not sit still, seeking her attention all the time, more so than her older son. She said that she found his needs exhausting and it was hard to cope on some days with the two sons' needs. She received occasional support from her mother. She missed work and adult interaction, and would like to return to work after her children went to school.

Fran (I6) lives with her partner at her parents' home and is the main carer for four children between the ages of 3 and 17 years. Three out of the four children have additional needs. The eldest, her 17-year-old son, has a degenerative visual impairment and two other children have been diagnosed with autism. One daughter was at school and the other daughter with autism was preschool age and due to be going to school the next year. Her youngest daughter was 3-years-old and was present during the interview, and Fran was attending to her by playing with her toys or getting her snacks when she requested. Her partner (children's father) suffered from a health condition and was not working. He was unable to support and care for the family's daily and financial needs. Fran's parents supported the family with accommodation and childcare. Fran and her family resided in a house in the backyard of her parents' property. Fran and her children were usually at her parents' home and shared some cooking duties, and the children had play spaces in their grandparents' home. Fran commented on how busy her life was, mainly as she was looking after the home chores and dropping off and picking up her children most times of the day. She also occasionally did some paid work for her father's business. She commented several

times on how she was disappointed with having to run around to find services for her older children with additional needs at school, and being unable to afford the costs. She would prefer for her children with disability to attend special school, as she felt that this would meet all their therapy needs.

Grace (I7) lives with her daughter, who is nearly 4-years-old, and husband. Her daughter has a diagnosis of cerebral palsy, and walks with support. She was present for the interview and was very chatty and talked to us all the time. Grace was constantly attending to her requests such as changing the television channels, or providing snacks, or getting her toys out for playing. She needed assistance for mobility and needed to be supported by using special furniture for sitting or standing for long periods. She was walking around the room holding onto furniture. Grace was very vigilant and aware of her needs, especially as she was at risk of falling over. Grace was not working; however, she was in a well-paid job before the birth of her daughter. She resumed work a few months after her delivery but due to the high support needs of her daughter, she decided to quit her job and focus on her daughter's therapy. She felt that the therapy input was helping her daughter to improve her skills. She engaged in a lot of therapy and had recently been overseas to participate in a therapy program for her daughter. Her partner worked full-time and his family was supportive and occasionally offered help with caring for their daughter. However, Grace spoke about how she found it hard to ask for or accept help. Her family was overseas and she valued and missed her mother.

Hannah (I8) lives with her two children and a partner (who is not the father) and had recently been through a separation with the children's birth father. Both her children have autism. Her daughter was at school and her son was in school transition. Both children were away during the interview. Hannah was studying and hoped to make a career as a teacher. She also thought that being a teacher would help her

understand her children's needs better. She reported that she was in a financial crisis due to the recent separation, and that had had an impact on her well-being. Her mother helped financially and they were living in her mother's home. Hannah mentioned that she was taking medication for her own health issues but did not elaborate on this further. She commented several times on how busy her life is and reported that she had no time for any of her own needs as she had to organise all home chores, and look after the children's additional needs as well. Her main difficulty was managing her children's challenging behaviours, such as fixation with routines, watching the same television programs, having issues with organising themselves to get ready for school and meltdowns at home. This meant that she was constantly juggling with their demands and trying to meet each one's needs. This made her feel exhausted. She valued the support from her partner as he occasionally offered to care for the children; however, the children did not get along with him and this led to further frustration for her. She seemed to be going through a hard time.

Irene (I9) lives with her preschool aged son and husband. Her son is diagnosed with global developmental delay. Irene is a health professional and had been working part-time since the birth of her son. Her husband also worked in the health industry and worked full-time. Irene was the main carer and her son was at childcare during the interview. He presented with moderate difficulties in all areas of development like mobility, speech, communication, and learning. He was not yet walking independently and needed full support with his daily needs, mobility, and communication. Irene said that his speech was very limited and incomprehensible, and she was the only person who can understand him. Her husband could comprehend his speech to a small extent, however she did not feel that he fully understood what their son was asking for. She spent a lot of time working on developing skills in mobility and speech with her son and felt that he was improving in all areas.

Jenny (I10) lives with her four children and her partner in a rental home. Three of her children have additional needs with one having a diagnosis of autism. She was pregnant with her fifth child. The children ranged from one to 7 years of age, and two of the children attend a mainstream school. The youngest child was nearly 1 year old and was present during the interview. Jenny was feeding her a bottle and she had to be carried around, as she was not yet walking. Jenny and her partner did not work, and she was the main carer of all the children. Her partner had a mild intellectual disability and he supported Jenny in the care of the children; for example, he would give the baby a bottle, or help in feeding the other children when needed. He was also present during the interview and often added comments when Jenny was talking; however, he was out of the room for most of the time. The family had significant financial difficulties and struggled with paying bills and looking after the therapy support and medical needs of their children. Jenny often referred to the lack of support for her children with additional needs at school. She also mentioned that two of her children had no diagnosis, but she felt that they had a range of challenging behaviours and sensory issues consistent with autism. She felt not listened to by health professionals in regards to the diagnosis of her two children. She thought that they missed out on receiving funding for specialist therapy services due to a lack of diagnosis. The family received a number of services and supports via ECIS and other services for one child who was preschool age. Jenny said that she loved being a mother. She used to work casually before her first born, however that was 8 years ago and she did not feel like she wanted to, or was able to, go back to work due to the children and their needs.

Kerry (I11) lives with her 2-year-old son who has a diagnosis of Down syndrome. Kerry had her son at a later age and was not working currently. She was extremely satisfied with her decision not to work and appreciated that she was

financially capable of staying at home to look after her son's needs. During the interview, her son was in his bedroom and did not call for her attention for the entire time. His godmother was present for the interview, but she did not participate. Kerry was very appreciative of ECIS services, however she also wanted to try private contemporary therapies for her son. She mentioned that using different therapies for her son at an early age would help him to improve in areas of development such as mobility and talking. She also reported that she would like to continue to work on improving her son's skills, so he could be ready for school, as this would allow her to return to work. She mentioned spending time on the Internet looking for therapy and cures for children like her son, and was determined to try different therapy techniques to help him. She and her partner recently separated and this was a mutual decision. The family did not seem to have financial difficulties and she mentioned that she worked from home occasionally on some accounting and book keeping for their family business.

Liam (I12) shared care for his two boys with their mother as they had recently separated. Both the boys were preschool age, and both had a diagnosis of autism. Liam felt the financial strain as he had to maintain two households. His ex-wife was working and contributed to the expenses before the separation. He said that he valued his home and cared for the boys three days a week. Both boys were present during the interview. They were playing with Lego toys and often came to Liam to help with finding lost pieces of Lego. Liam was deeply engaged with them, and throughout the interview he moved around the house to be able to attend to the boys' requests. The boys seemed very comfortable and happy around their father. He was able to understand their speech, even though it was quite unclear. He organised their lunches and ensured that they sat and ate their lunch during the interview. We also moved to the backyard towards the end of the interview as the boys wanted to have a

play on the trampoline. Liam reported strongly about how his ex-wife and he were dissatisfied with the health professionals during the times of diagnosis of their children. He felt that this had a huge impact on his wife's well-being at the time. He valued ECIS, but he did not feel assured that the services helped the family or his boys with their therapy needs fully. He reported that his parents and his wife's father help with caring, picking up and dropping the children to childcare, and he values this support as it allowed him to work when the children are in his care.

2.4.2b Qualitative analysis findings. The findings are reported in this section based on the qualitative analysis presented in the methods section (Creswell, 2009, Tesch, 1990) and a number of tables and figures will be used to report the codes and themes. See Figure 2.7 for application of the method of analysis to this study. The initial steps in the qualitative analysis led to 16 codes that were numbered from 1 to 16 in no particular order. Steps one and two were described in the methods section and were used to read and check the transcripts and assign initial numbers to interviews. Step three involved coding.

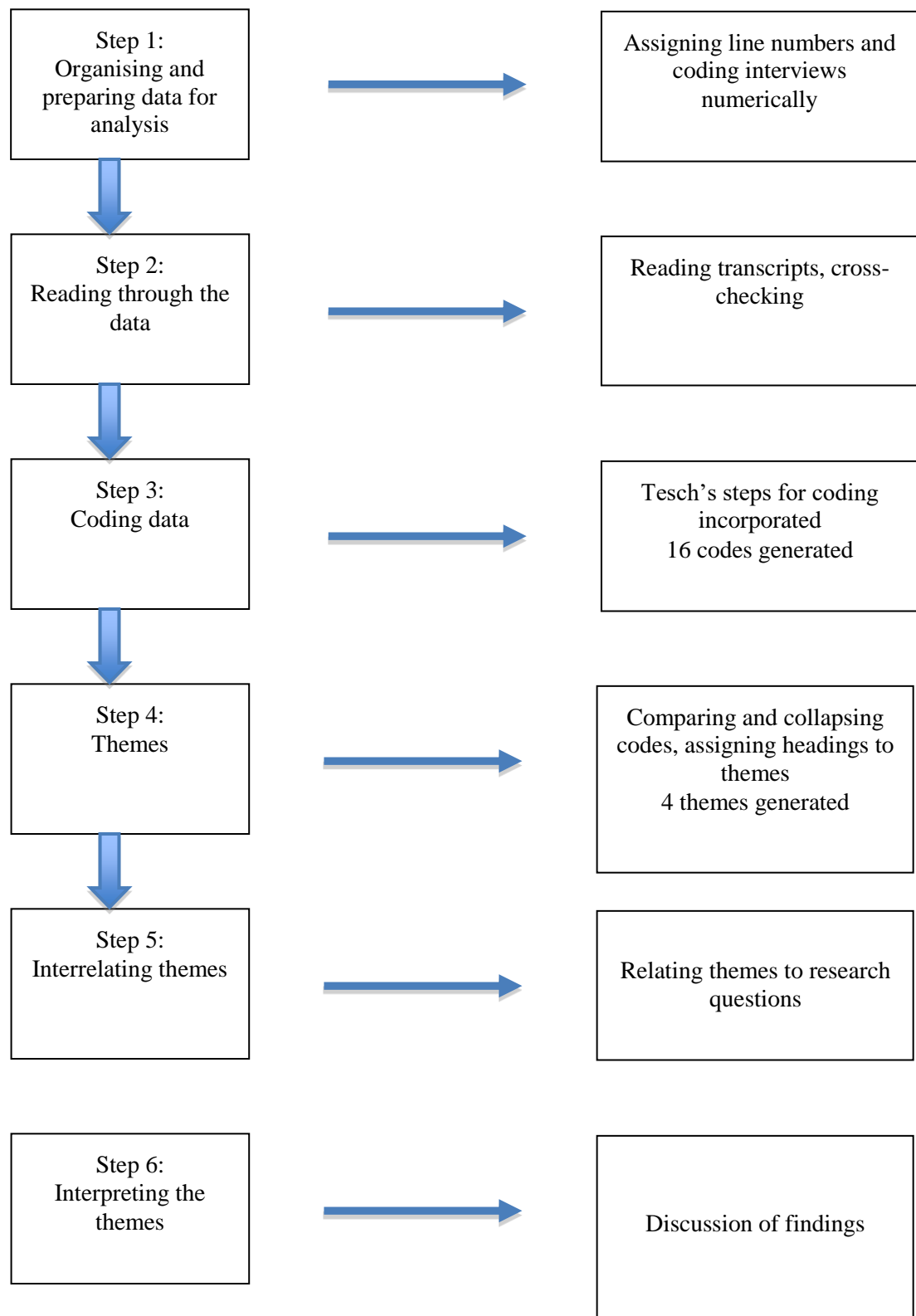


Figure 2.7. Applying the Steps of Coding in Current Study (from Creswell, 2009).

Step 3 – Codes. This section presents the 16 codes. The codes were placed numerically and the quotes were added next to the codes in a large table form before finalising this step. A snapshot of this table is presented in Appendix 2.6, Table A2.1 where the codes are represented in a table alongside some relevant quotes.

Code 1: My FQOL is okay... different, reasonable, however is hard and difficult at times. It is constant adaptation, ups and downs. Most participants started the interview by stating that their FQOL was okay or quite good; however, they later elaborated on how difficult it was at certain times and was different to what they had expected. During the interview many participants reflected on the extent to which having a CWD had impacted their day-to-day life. They had not expected to have a CWD and were constantly adapting to the needs as they arose. When asked about how they would describe their FQOL, they started to talk about incidents, events, and transitions that they had to adapt to, and when they adapted and moved ahead, their FQOL felt good. There were ups and downs that were related to how they were adapting to the needs of their child and family.

Okay. I think our quality of life is reasonable. You know, not 100% but not terrible... I suppose that some days are more stressful than others. But overall [FQOL] good – I11: L13–L15 (Kerry)

I mean it definitely has its moments but I don't think, I don't think our quality of life is... FQOL is less, less in life. You know what I mean? Like we do have a couple moments where its higher stress times or demanding kinda times but overall I still think, family life's pretty good – I7: L517–529 (Grace)

... because only thing is ... sometimes the expectations are not going our way ... so, every time we get to that situation it's like is galvanising us... but once we go through these shallow areas and we clear them, then we go back to a normal life. Once we start that positive situation I am very positive we can bring the family back to a normal lifestyle. Two three things are holding us - to have... a good quality of life that we had in the past... – I2: L587–590 (Bob)

Code 2: Financial support for accessing services helps reduce the financial burden and helps FQOL. Most participants talked about their financial status as being average, and that receiving financial support for services helps FQOL. According to the demographics of the qualitative sample, 8 out of 12 participants were in the average or high average income category based on Australian Bureau of Statistics (ABS, 2015). Most participants were able to access funding from ECIS and through funding packages, and this helped with reducing the financial burden of paying for therapy or early intervention services for their child. These packages included *Better Start* and/or the *Helping children with autism* (HCWA) package that assist children with disability/developmental delay in preschool years (0-6 years) by paying for ECIS and therapy services within Australia (Betterstart, 2015; HCWA, 2014). The *Better Start for Children with Disability* initiative is determined by the Department of Social Services (DSS) and provides funding for early intervention services including audiology, occupational therapy, physiotherapy, psychology, and speech pathology (DSS, 2015). Children registered with *Better Start* can access up to \$12,000 (maximum \$6,000 per year) to pay for early intervention services. The HCWA funding is for children with a diagnosis of autism spectrum disorders (ASD) and is similar to *Better Start*. It funds up to \$12,000 of early intervention therapy and services for children with ASD until their seventh birthday (DSS, 2015). Financial support from these different funding packages was most appreciated by all participants, and families valued this support for their child's therapy needs, more so than any other need.

The participants who were not eligible for these funding packages, due to their delay in acquiring diagnosis, felt that they were not able to afford as much therapy or

services as they would like for their child, and felt angry and frustrated about this.

Most of the participant mothers had given up their paid work and reported that this impacted their family income.

But I've got the Better Start for 8 months. So we didn't feel the pressure – I11: L230 (Kerry)

Going to private speech therapy has really helped Mark and his behaviour, and I've used that \$12,000 from the government [Better Start] for that so I need that money – I5: L 585–L588 (Ellie)

We're just making do, like we, whatever money that we get. ... I mean I've got bugger all gas in the car. I just finished the last big lot of gas this morning ... which I'm lucky just to get the carers allowance – [family not receiving Better Start or HCWA for two children who are older than 7 years] – I10: L80–L94 (Jenny)

... and the fact that we had to fork out [money] before she was diagnosed was really hard, because you know ... we couldn't find any help – I4: L157–L159 (Dee)

I just don't have the money now and I don't have the resources or the time or the energy. I've got no energy left – I8: L405–407 (Hannah)

...so it is a double ended sword, not able to go to work – financially although we are going backwards... It is a negative not having an income, and a positive being able to stay at home – I3: L698–L703 (Cassie)

Code 3: Physical well-being of parent/caregiver is not a priority, due to the child's needs and financial responsibility. Many participants commented that their own health and well-being was not a priority, as they were too busy looking after the care needs of their family and their CWD. Participants reported being exhausted and bogged down. Despite financial difficulties, some mothers did not want to return to paid work as they wanted to concentrate on their child's therapy and everyday needs. They also mentioned that their partners did the “outside job” of earning income, so they had to keep going with their child and home care, even if it affected their health. Some of the parents had chronic health issues such as cancer, chronic back pain, or cardiovascular issues, but deferred their treatment due to caregiving. The two fathers who were interviewed also reported little time for self-care or enough sleep. Most

participants were concerned about their partner's well-being, especially as some partners had mental health issues. Most participants did not have time to go out together as a couple and even though a few reported that they felt this would be positive for their well-being and FQOL, they had no time or money for it.

I also have a personal health problem ... but somehow we are managing, too much stress ...a person only has the chance to sleep around 4-5 hours and you can see the stress – I2: L57–58; L260–262 (Bob)

...when I got to the point of exhaustion, and I spoke to carers Victoria [respite care service, hoping to get some respite]. He [husband] would just... he'd get up and go to work. He also has depression as well, but what can you do... – I11 L427–430 (Kerry)

I kind of should have a mastectomy, but umm I am going to delay that a little bit longer, cos I will be out of action for a little while... If it's health issues for myself, then I'm in trouble, or even Tim [husband], cos then we would have a wage reduction – I3: L611–618 (Cassie)

Code 4: Early years are similar to having a typically developing child. Many participants compared having a young CWD as similar to having a new baby in the family, or to a “normal” child. The adaptations that they made to their life and everyday occupations were similar to what they would have made irrespective of the disability. Most parents felt that they would be back to their previous job and life after their child went to school, similar to parents of children without disability. Most of the parents felt that having a young baby involves a lot of caregiving and they felt that the amount of time they spent in caregiving for their young CWD was no different to another young child of that age.

Well I think, I suppose diagnosis or no diagnosis; life prior to a child and after a child is very different... She didn't really start doing things until probably the tail end of that year, most part of it was caring for her like, for want of a better word, a normal child. So in that period, there's not too much to my day that was different to the next mum... I7 L26–27; L 92–92 (Grace)

You know... any child you've got to, you basically have to stop for 12 months you know and get nothing done. It's just with him it's a little bit longer – I3: L251–L254 (Cassie)

... we stopped going out, then having babies – you want to be home by 8 o'clock ... nothing to do with autism or – I1 L319–321 (Alice)

Code 5: Ownership and adoption of parenting role (occupational role of care-giving) come about after having a child. The majority of participants had taken ownership of their parenting role and talked about the factors that led them to adopt this role. Ten out of 12 participants were mothers, who felt that it was their role to provide the primary care and therapy support for their child rather than the father and took ownership of the role. Even though they were tired or sad on certain days, they did not want the fathers to give up work due to loss of income, so they had developed an ownership of this role. They felt that owning this role helped their child's development, because they knew the needs of their child better than the father, or anyone else. Some mothers said that they were not sure if the father would be able to follow up with their child's therapy needs or caregiving and this further helped them to adopt and accept the role. Some mothers were fearful of their partners leaving the relationships due to the pressures of caring for their CWD. They had clear expectations of the fathers to provide for the family financially, and in some ways, this helped them to accept and adopt the caregiving role in which they felt content. Even if the fathers got time for a break and went out with their friends for a beer or a football game, the mothers did not feel resentful. They rationalised this by saying that the fathers needed a break due to the pressure of their family being on a single wage. Most mothers mentioned that they did not get time to go out with friends or have time for a break and they would have liked to have some time off from household chores. The two fathers in the study were not the primary caregivers but shared care with the mother. They had also adopted well to their caregiver and parent role; however, they managed to get a break from home duties and caregiving because the mothers assisted with the role, so they did not have a strong ownership of the role.

But I think now I've kind of accepted that, I just don't think I would be able to juggle it [work and home] – I7: L232–237 (Grace)

We agreed that one of us would need to stay home, we would want to stay home, to raise him... And then it just naturally came out that it was me, because I was carrying him... and that was fine, that was something that I was happy to do – I9: L320–L326 (Irene)

He works, you know could be leaving at 5:30 in the morning or 6 in the morning and getting home at 6 or 7 o'clock. So um... I do the kids and expect that he's not going to be around to help me during the working week – I5: L85–89 (Ellie)

He does have a beer I think with the boys, and I think he needs that time ... and I think, well that's probably fine. You know, he obviously needs it... So... um he does come home and I don't hound him – I5: L341–350 (Ellie)

Phillip [husband] could still do his football and his cricket, his training and leaving the house at the time as well ... And well I was playing netball and I soon got sick of leaving the house... I had to feed him and get him ready for bed and it was easier to give up – I1: L240–L242, 246 (Alice)

I guess, I feel that most of the time the caring of M [CWD] and the extra things I need to do because he has a disability um is, is my job, and my husband... he doesn't know what they're like and that's um difficult at times – I5: L116–L119, L124–L130 (Ellie)

Code 6: Adaptations are made/previous parent occupations change. This code is related to Code 5 because following on from developing an ownership to the main caregiver role and adopting this role, many caregivers talked about the adaptations they made to their everyday activities and occupations. They were ready to embark on the parenthood journey before the child was born, and had mentally adapted their life to be ready for this change. They mentioned that they had done the partying and outings and were ready to have a family and change their lifestyle. They talked about missing their previous lifestyle and occupations (self-care, work, and hobbies) but most of them felt that they would be able to return to these occupations in a few years. They also felt privileged that they didn't have to return to work to earn a wage, as this gave them time to look after their child and family needs. A few participants talked

about taking on occupations related to the CWD, such as researching about disability and therapy.

But we've already done all the partying, we are quite happy to stay at home and do the KID thing – I3: L585–587 (Cassie)

I'd definitely be back at work now if he wasn't special needs ... feeling like I've got all these supports, it's sort of justifies not going back to work. So I feel in some ways more privileged than other women that you know, because all kids are needy like at this age, and so Jake's [CWD] getting a really good quality of life I think – I11: 308–L312 (Kerry)

I would probably be at work... and I wouldn't um... I feel like Jim [CWD] is my work and I kind of resent that a bit... pre-Jim, I had a great job and I loved work and I haven't worked since he was born um... we've got to do some things first – I5: L421–L423 (Ellie)

I used to dance on Friday nights. I don't do that because they (her children) don't like it when I'm out of the house. They don't settle. I have trouble settling them anyway. So there's a lot of choices, a lot of things that you just can't do – I8: L123–L126 (Hannah)

I worked in a disability field but I didn't know a lot then about early intervention because we worked with adults. And the more I got online and researched and heard about early intervention and neuroplasticity and all sorts of things, it was like, oh wow. You can make an impact now – I11: L342–347 (Kerry)

Code 7: Waiting for the diagnosis leads to stress, but knowing the diagnosis is also stressful, sad, and devastating. A few participants reported very strongly that they felt that the time of diagnosis was particularly difficult and devastating for their quality of life. They expressed resentment with the attitude of the health professionals at this time and a lack of support. They felt not listened to by their doctors when they expressed concern with their child's behaviour and occasionally felt incompetent as parents. They stayed close to their partners and family members to cope with this difficult time. Some mothers reported that they were not sure how the fathers were feeling as they were quiet or did not discuss the diagnosis at all. Both of the fathers from the interviews reported how the time of diagnosis left their wives devastated, and led to mental health issues for them. This time was extremely difficult for the

families and most participants were glad that it was over. However, some participants felt that the time after the diagnosis was also filled with sadness. Not knowing what to expect, left them stressful and sad.

It was part of that whole early... process upon diagnosis... some psychologists and paediatricians who were especially oblivious to, even factoring in ... and I know this is a quality of life matter... the sort of mental health of parents. And so it degraded her [wife] quality of life – I12: L205–L211 (Liam)

He [paediatrician] said that there was nothing wrong with him and I remember saying ‘autism’ and he said – na na na – he is doing fine – I sort of said to my mum – that if the doctor says he is fine – he must be fine... I was still concerned ... [and he was diagnosed with autism later] – I1: L162–L165 (Alice)

I suppose early days were more the not knowing. You know and then your mind’s running wild and your thoughts run away with you of what the possibilities could be or the lack of possibilities for our daughter... And I suppose that those days were probably much harder because you’ve got the worst-case scenario – I7: L274–251; L307–L309 (Grace)

... but you know hearing the diagnosis was obviously a bit stressful and sad... just cause neither of us wanted to really say the effects that it had had on us, we felt humiliated and struggle – I7: L34–39 (Grace)

Actual parental mental health is probably paramount actually..., because no matter what the diagnosis, it’s always gonna be devastating for the parents no matter what – I12: L592–L597 (Liam)

Code 8: Progress and development of child is energising and uplifts parents and helps FQOL. Many participants were very hopeful about their child’s skill development and felt happy when their child with disability/delay learnt new skills or progressed developmentally, such as learnt to walk, or started speaking, or achieved toilet training. Their child’s progress helped the parents to see positive possibilities in the future and gave them hope that they would be able to have a more “normal” life like other families when their children were older. They wanted to provide their child with as much input as was necessary in the early years, because they felt that this was a critical period in their child’s development, and if not capitalized on, their child may

miss out on learning important skills. They were happy to make changes to their lifestyle and to give up their work and social life to be able to see these successes in their child. This hope for their child's development and progress was uplifting for families as most of the participants felt that their quality of life would be better in the future.

We have to see his developments in a positive way and we are able to see positive signs ... he is going in the right direction... We know that one day K is going to walk ... many many parents don't have that hope. ... our situation is more fortunate compared to a lot others – I2: L439–L442 (Bob)

I look at it in the way that a lot of his needs that have needed me around for a longer period of time, like the balance, like the not being able to play so well by himself are just delayed really. But he's getting there and I'm beginning to find silver linings for things like that – I9: L354–L359 (Irene)

She's [CWD] so determined, she's so independent and she's got that motivation, she's got the spirit to succeed kind of thing... I think you take, you take strength in the fact of the person that she is – I7: L310–314 (Grace)

Oh he's saying these words, and with the signs, like his vocab (vocabulary) was 100s of words ... So, so I am seeing results and I think that's really much more encouraging – I11: L523, L528 (Kerry)

I'm up and down and it's dependent on J and where he is at in his development, coz everything is very slow with him and... um when he starts to do some great things that's when we have a great... I guess... quality of life... um... when things go wrong or he's sick, um, or things, he's not doing anything, he's just stagnating, um, that's when things become a little bit more difficult – I5: L26–33 (Ellie)

Code 9: Support from partner, family, and friends varies but is valued, however reluctant to ask for support. Most participants reported that their partners were their main support. Three participants were separated from their partners and still received some caregiving and financial support from them. Most of the mothers had taken ownership of the caregiving role and felt that it was their role to help with their child's therapy and daily needs, and not the father's role. Many mothers also reported that the amount of support from their partners varied and the fathers did not

support them enough in the caregiving. Hence, they did not expect a lot of support from the father in the care provision of their child. Some participants also talked about the support they received from their parents and this was highly valued.

Many grandparents helped with financial support and some helped in providing childcare to siblings during medical appointments. However, many participants also mentioned that they were reluctant to ask for support for fear of being refused or for not wanting to be a burden on others. Many participants reported that they were not in touch with their friends because their life was very different after having a CWD. Most parents of children with a diagnosis of autism, or with challenging behaviours, or with severe physical disability were particularly reluctant to ask for support from their extended family or friends because they felt it was too hard to manage their child's needs. Some participants missed their friends and felt isolated.

Wooo a little bit but not quite [not receiving support from partner]. At the start was better... as time goes on, the empathy is wearing down... in the first 18 months I got a bit of empathy from him [partner] but then the novelty wore off and it was a bit of bad luck. And dare he wake him in the night. Oh he wouldn't cope with that – I3: L764–L768 (Cassie)

He's a great dad. He loves S to bits and he is co-operative, but he's happy to hand ball when it's... He likes to visit more than actual caring – I11: L183–L185, L236–L238 (Kerry)

Yeah and so it's a bit of a vicious cycle... you lose your patience and are exhausted and um... yeah so I would say, that is the time when I have a bad quality of life, and that's the time when I need the support from the family – I5: L179–L183 (Ellie)

Well I've got mum – she comes at the drop of a hat, so she babysits – while I was pregnant [with third child] taking C [son with autism] in her care while his dad... well he's got his own business so he can walk away – I1: L178–181 (Alice)

... even though there's a lot of people that are ... are willing to lend support; not just immediate family... and you know are always offering to help with, whether it's come over and help clean or cook a meal or take L [child with disability] for half a day... I wasn't one to. As much as I need it, I was always one to say no – I7: L407–412 (Grace)

For us to move out and go and associate with them [friends] ... is not going to be suitable for them... so we can't interfere with their normal day to day life... even if they are understanding... we don't want to trouble them... we are isolated – I2: L282–287; L492 (Bob)

Code 10: Support from services is important and valued. Most of the participants valued the support they received from their ECIS, valuing experienced keyworkers for being respectful, and for providing information regarding their child's progress, and the services and supports to access. They also valued the visits by the keyworkers to their child's early childhood services (such as childcare and kinder). These visits helped the childcare staff to work in collaboration with the family, and provided the staff with strategies to use within their services that would help achieve their child's goals. This was a relief for them, as they did not have to worry about how their child was participating at their childcare or kinder. A few participants like Liam and Jenny were not sure about the value of the ECIS or keyworker because they felt that most of the follow-up strategies provided by the keyworker had to be done by the family members. This was difficult if the family had other children that needed care, or if the parent was not feeling well, or had a different style of learning.

Eleven out of the 12 participants were receiving funding from *Better Start* or the *Helping Children with Autism* (HCWA) packages that assist children with a disability/developmental delay towards ECIS and therapy services within Australia (Betterstart, 2015; HCWA, 2014). Most participants indicated how difficult it would be to access the services and supports if they had to pay for them. They highly valued these funded supports for their child's therapy, aids, and equipment or recreational activities. These packages also helped a few parents to access respite care services. Most parents had not yet considered respite care services, as they felt it was their role to provide care for their children. Asking for respite support was not an expectation,

as they felt some guilt in asking for time off for themselves, and they considered childcare an important role for themselves. Overall, receiving services and supports was appreciated and valued by most participants.

Having Berta [keyworker] provides not just practical support, but she provides different ways to think about problem solving ... she does really good practical things like that and she sorts out funding and things like that – I9: L223–224, 226 (Irene)

Chris [keyworker] has been fantastic with them. She's been amazing ... She talks ... to us and she makes us feel better about everything we do. Because you end up feeling so guilty about every choice you make – I8:L504–510 (Hannah)

and ECI ... they already have experience in this field and they have experienced staff to treat children like mine so at the first point we get the right person at the right time – I2: L493–495 (Bob)

So Yooralla [ECIS] suggested the childcare and um that has really helped with J [CWD] in the way that he plays with some toys here and helps D [younger brother] as well, coz D was seeing the way J played with toys ... So it has definitely helped and then given me a break – I5: L605–610 (Ellie)

yeah cos when you have a child, there is chaos and the keyworker – they are there to help you. Once you are in there [referring to ECIS] you go – I am starting to feel better. It is really important absolutely – I4: L715–718 (Dee)

Oh yea, it's moderately useful [ECIS]. Fiona [his wife] didn't really get on ... I mean she struggled with almost all. She's almost had this reaction to all care workers and then struggled and not wanted to have anything to do with Yooralla [ECIS] but ultimately I've found they're moderately useful ... they don't seem to take that into consideration ... all the early intervention sort of springs off the parents – I12: L574–L575; L580–L585; L597–L601 (Liam)

Code 11: Support after exiting ECIS is scarce. Two participants had older CWD who had transitioned from ECIS to the school system, and another one of them had missed out on the funding packages from ECIS for her child. These participants were not looking forward to their child transitioning from ECIS to a mainstream school because of their negative past experience with their older children. They reported a lack of funding and therapy services for their children at mainstream school, and mentioned that all therapy services needed to be paid for by the family

when at school. They were not looking forward to losing the funding and the support from their keyworkers. One of the two participants wanted to send her child to a special school due to more support being available there. The other participants were not yet thinking of services at school because they were in ECIS for a few more years.

but I know as soon as she starts school that's it. Yooralla's [referring to their ECIS] gone and what their school system offers, that's disappointing and there's so many other kids that need sort of support to keep going – I6: L293–295 (Fran)

Like I said, there's just no chance of that happening [getting admission into special school] but they've got smaller class sizes, as you know in special schools. They've got like 6 kids and 2 adults, 3 adults ... speech therapists um occupational therapists. It's just so much more support and the mainstream can only offer you know once a fortnight – I6: L400–403 (Fran)

I know the school can offer a little bit, but yeah. Because what B [son with autism] struggles right through the whole day. I mean he gets up, goes to school and he ... I mean he's in a classroom with another aid, but the aid's not for him, the aids for sharing. Yeah so needless to say, you've gotta share between three and he just can't get that help – I10: L264–267 (Jenny)

I mean I'm already disappointed. I've got to go through the school system because it's a real let down ... when we've received so much help I mean ... and just because I've seen what happened with C as in um yeah – I6: L373–L375 (Fran)

It's just so much more support and the mainstream can only offer you know once a fortnight ... Coz you know a teacher can't ... the teacher says do this this this, and um then she will be like – I don't know what to do – I6: L402–L414 (Fran)

Code 12: Positive attitudes, beliefs, religion, faith, and family values help families. Many participants talked about their positive attitudes that helped them get past everyday and through difficult times. Some talked about their belief systems or faith and religion that helped them cope with the difficulties that having a CWD brings. Whenever they talked about difficult times because of their CWD, they immediately talked about positives associated with their child. Participants talked about the strengths of their CWD and how this was a joyful and rewarding experience. They expressed how they were luckier than many other families who had

children who were of higher severity or couldn't do all the things their child was doing. They mentioned the positive energy and joy that their CWD brought to their life. They mentioned their positive attitudes that helped them cope with whatever came by. One of the positives they talked about was how resourceful they had become in learning new things about disability. They were more educated about resources that help them to understand their child better. Some mothers talked about how they were lucky to be able to spend so much time with their child due to the extra support needs, and felt that all children deserved this time.

A few families talked about how their religious beliefs, religious institutions, or their family's cultural upbringing and values helped them cope. Their values about being instrumental in raising their children helped them accept the challenges of caregiving. These positive attitudes, beliefs, and values helped them to adapt everyday and move ahead with their life.

I'm a very positive person so ... I think we are very grateful ... I mean he's just got a physical disability rather than intellectual, and because they said to us that if he survives he will be severely handicapped when he was first born ... but hey ... look what we have got ... a spunk! – I3: L166–177 (Cassie)

from the beginning to now I have turned all the negative things or whatever impact I am having to positive, that's how I've to go that's it ... and my mum always used to say whatever happens is for good ... and that's turning to positive – I2: L580–582 (Bob)

I am Christian and ... I wouldn't be here if it wasn't for my beliefs ... I believe that God doesn't give you anything that you can't handle ... – I4: L315–318 (Dee)

I knew that if I wanted to have a child, then I'd have to be around to raise him. There was no point, I didn't wanna put my child in full-time child care and let somebody else be instrumental in raising him because he's my child and I wanted to make a difference – I9: L436–443 (Irene)

Code 13: Having multiple children with a disability and family members with health issues impacts FQOL. Three participants had other CWD and a fourth

participant had an older child who was also likely to have autism, awaiting an assessment. Some participants' partners had mental health issues and needed care as well and one participant had an older family member with high-care needs. Most of these participants felt that having multiple family members with caregiving needs impacted their individual quality of life and well-being, and thus detracted from a good FQOL.

About FQOL ... oh well we're happy but it's one of those things. But my partner's not coping, I don't know what his reasons are. He's going through a lot of mental issues. He's been a couple of times in the last 6 months to the emergency department ... I got four kids and I just told you what they're going through [three have been diagnosed with some form of disability] and I don't need another one to look after – I6: L148–152 (Fran)

After a week of getting them to school because neither of them want or care ... they don't like it [both children have autism]. So after spending all that time getting them there, and getting them home, and doing all the stuff and fighting them through dinner, because they're both horrible eaters, and baths, they hate baths; I'm just exhausted – I8: L410–413 (Hannah)

You've got three with additional needs, um it is really really hard, like you know B swells himself up when he gets all upset, emotional and all the rest of it – I10: L348–350 (Jenny)

Code 14: Severity of disability, especially challenging behaviours impact

FQOL. For most participants, the impact of the disability was not yet evident, unless they had a physical disability such as cerebral palsy, or challenging behaviours, because most of the children were young. Many of the participants felt that their child's diagnosis did not impact their FQOL, because according to them, their child was not severe, or did not have high support needs. Please note in Table 2.9, the severity of disability reported as per the parents. Two out of the three children with cerebral palsy were showing consistent improvements, so the parents did not feel that the severity was high. One child with cerebral palsy had very high support needs, and it was evident that this caused social isolation, as it impacted on their family outings

and social life. Participants with children with challenging behaviours seemed to have a higher impact on their FQOL, because these behaviours were hard to manage when they arose. Some mothers said that their partners were still in the relationship because their child was not “severely disabled”, otherwise they would have left the relationship, and their FQOL would be worse.

So what we do is daytime ... we do oral feeding, takes 20 minutes – 2.5 hours and depends on his mood ... So if really we want to go out we can but ... he has to lose his daily intake ... or sacrifice something. Normally my life was ... if Friday comes ... and Sat night we go and spend time with friends and things and now, isolated ... our world is inside the house ... whatever we had, the joyful life, turned in a different way – I2: L70–71, 88–90, 100–102, 137–138 (Bob)

He [partner] always said before E, that he would not do a disabled child ... but I think if E would have been worse I would have been in trouble keeping him here ... cos it's a bit of a fight for the relationship to keep him happy and not feel stressed – I3: L304–306, 309–311 (Cassie)

M self-harmed and like did everything. I mean like she was two and half, ram her dummy down her throat, put her hand down there and strangle herself, she didn't want to be here ... do you know what I mean – I4: L584–587 (Dee)

Code 15: Siblings/family relationships are impacted. Some participants talked about siblings having to adjust their everyday routines and outings because of a brother or sister with disability. However, only two participants felt that having a sibling with a disability impacted on the typically developing sibling. Most participants felt that siblings have to adjust when a new child enters the family, irrespective of disability, so were not particularly concerned. Adjustments were mostly around choosing television programs (especially if the child had autism, they got to choose the program to avoid meltdowns), not being able to go to the local park or play dates (too difficult to pack things for the CWD) and not being able to invite friends for “sleepover” nights. This led to relationships between family members becoming strained. Overall, most participants thought that having siblings was a

positive, rather than a concern. One participant was concerned about the sibling missing out on activities that typical children do, and also expressed that he did not want the sibling to have the burden of care for their CWD in the future.

We always know that if C [brother with autism] wants to watch this movie and ... she's like I don't wanna watch this movie. She's had to adjust cause it's not worth the tantrum from C. She will get upset – she'll cry, she will run to her room but then 10 minutes later she will come out again and forget. That's easy to deal with but C's tantrums can go on for hours – I1: L51–55 (Alice)

I thought I can't take J [child with disability] to this [church mass], coz he is very loud, and he won't understand that you have to sit, stay in your seat, stand up or sit down ... and it's awful to think that I can't bring J to something like that, when it's going to be his brother's baptism – I5: L 401–408 (Ellie)

Really we are worried about the future once we are not living ... If he can't [be independent] then is it fair to put all burden on twin sister or better to have another sister or brother... I am really worried about her because normally other kids they are enjoying ... even her friends ... she is trying to find her own way to associate, trying to find time to go to their house or bring her friends in. Already two parents approached us to have time to get together with her ... she is missing a lot and she is trying to find her own way to get herself, but we are struggling – I2: L470–473, 517–521 (Bob)

Code 16: Triggers/events in life can impact FQOL. Four families out of the 12 had recently experienced a significant event that had impacted on their FQOL. Three participants had just been through a separation and one participant had an incident in their home that had destroyed a small part of their house. These participants talked about these events having an impact on their FQOL and were working out ways to adapt or adjust to these events. It was particularly difficult for two participants who had been through a mutual separation, because of the financial impact the separation had caused, along with some emotional impact. The third participant who had separated seemed to be relieved because she talked about how she was always exhausted with being the carer for her child, and her partner (with a mental illness). She was financially secure so did not feel this impact. The fourth participant who had the home incident was quite shaken by it; however, she had come to adapt to the incident, and was talking about how they were going to move ahead and repair the damage to their property. However, at the time of the incident the

family was quite shocked and their daughter with a diagnosis of autism did not cope well, adding to the parents' concerns.

But I suppose after the separation, just the costs of running two households and of course I've gone down financially ... The financial concern is that I may go back to having a mortgage which we don't have at the moment – I12: L124–125, 148–149 (Liam)

[After their recent separation] *but then my ex defaulted on a loan that my name was on, and I had to pay the loan. So now we don't have a lot of money ... I've paid back so much money that was his – I8: L217, 218, 223 (Hannah)*

And also the incident that was like two weeks after we moved in and she now goes – mum what if we go to school and the house burns down and we die and all this sort of stuff – I4: L257–259 (Dee)

Step 4 – Themes. Based on the 16 codes, four themes were generated from the major findings. This step involved re-assembling the codes or collapsing them (Creswell, 2009). The emerging themes were guided by the codes as well as by the research questions. For example, the codes that contained parent perspectives about their FQOL were grouped together as a theme, and would be used to answer the first research question regarding parent perspectives about their FQOL. The codes that were related to the challenges that the families talked about, such as the time of diagnosis, the challenging behaviours, were grouped together under a common theme. The codes that were related to the supports that families felt helped their FQOL were grouped together, such as supports from services, from their partners, watching their child make progress, having a positive attitude and so on. Lastly the codes that were related to the consequences of having a CWD, were grouped together, for example, codes about their physical well-being not being a priority, the adaptations they made after having a CWD that led to loss of their occupations, their adoption of the parent role and the caregiving along with that, formed the codes under this theme. This led to the generation of four themes. The four themes are presented in Table 2.10. The relation of the codes to the themes and the corresponding quotes, for maintaining dependability and credibility are displayed in Appendix 2.6, as Table A2.2 (Lincoln & Guba, 1980).

Table 2.10 *Themes – Study 1*

Theme	Description
Theme 1	My FQOL is okay, but ... different, hard, with constant ups and downs
Theme 2	FQOL is better when we feel hopeful and supported

Theme 3	FQOL feels challenged during difficult times
Theme 4	Having a CWD has consequences for the family and FQOL

These themes were then again checked against each individual participant and then compared across participants. A table was created in Microsoft Word to group these four themes and the 16 codes across the rows with the participants' pseudonyms along the columns and is presented in Table 2.11.

Table 2.11 *Codes and Themes in Relation to Participants – Study 1*

Themes	1 Alice	2 Bob	3 Cassie	4 Dee	5 Ellie	6 Fran	7 Grace	8 Hannah	9 Irene	10 Jenny	11 Kerry	12 Liam
Theme 1: My FQOL is okay, but ... different, hard, with constant ups and downs	X	X	X	X	X	X	X	X	X	X	X	X
Theme 2: FQOL is better when we feel hopeful and supported												
Code 2: Financial support for accessing services helps reduce the financial burden and helps FQOL	X	X	X	X	X	X	X	X	X	X	X	X
Code 4: Early years are similar to having a typically developing child	X		X	X	X		X		X		X	
Code 8: Progress and development of child is energising and uplifts parents and helps FQOL		X	X	X		X	X		X	X	X	
Code 9: Support from partner, family, and friends varies but is valued, however reluctant to ask for support	X	X	X	X	X	X	X	X	X		X	
Code 10: Support from services is important and valued	X	X	X	X	X	X	X	X	X		X	
Code 12: Positive attitudes, beliefs, religion, faith, and family values help families	X	X	X	X	X	X	X	X	X		X	

Theme 3:
FQOL feels challenged during difficult times

Code 7: Waiting for the diagnosis leads to stress, but knowing the diagnosis is also stressful, sad, and devastating	X		X	X		X	X			X
Code 11: Support after exiting ECIS is scarce					X		X		X	
Code 13: Having multiple children and family members with a diagnosis/illness impacts FQOL		X	X		X				X	X
Code 14: Severity of disability, especially challenging behaviours, impact FQOL	X	X		X	X				X	X
Code 16: Triggers/events in life can impact FQOL				X			X		X	X

Theme 4:
Having a CWD has consequences for the family and for FQOL

Code 3: Physical well-being of parent/caregiver is not a priority, due to the child's needs and financial responsibility		X	X	X		X	X	X		X
Code 5: Ownership and adoption of parenting role comes about after having a child	X		X	X	X		X	X		X

Code 6: Adaptations are made/previous parent occupations change	X	X	X	X	X	X	X	X	X	X	X	X
Code 15: Siblings/family relationships are impacted	X	X	X			X			X			X

Theme 1: My FQOL is okay, but ... different, hard with ups and downs. This theme came out of code 1 that concerned most participants' perspectives of their FQOL. Most of the participants felt that their FQOL was okay; however, there were difficulties and struggles and ups and downs. They felt that having a CWD was different to what they had expected, demanding, and difficult at times, but overall, if they looked at their FQOL, *it seemed okay*. As the conversations continued, it seemed that they started to understand what FQOL meant, and what things were influencing their own FQOL. Some felt that it was *too exhausting and stressful on some days*. Most participants commented on hardships they faced, but would come around quickly and state that they felt this was a part of their life anyway. One participant said that they did not expect to have a CWD, so *life had taken a different path*, and they were trying to follow this new path which made him feel that his life *was uprooted*. Another participant felt that because *the younger children didn't know any other way* and have always had their older brother with autism around, their FQOL seemed fine to her. Many participants expressed that they felt rushed and exhausted due to the extra running around to access medical appointments, and this impacted their FQOL. Overall, most participants felt that they had *ups and downs*, feeling better and hopeful when they were supported and feeling down when they were experiencing difficulties.

Theme 2: FQOL is better when we feel hopeful and supported. This theme was generated from all the codes that helped in understanding the factors that supported the FQOL of the participants. Codes 2, 4, 8, 9, 10, and 12 contributed to this theme. Code 2 was related to the financial support that families received and how this supported their FQOL. It was also related to the financial status of families and many

participants expressed that they were earning average or high average income. They also received funding from *Better Start* and HCWA and this reduced their financial burden. Code 4 was about participants feeling that the experiences during the early years with having a CWD were similar to the experiences of most families when they have a new child in the family. This belief helped their coping in a positive way, and supported their FQOL. They did not feel different or pressured by the extra duties of caregiving involved in looking after a CWD as it was early years, and they felt hopeful for the future.

Code 8 was about progress and development of their CWD. Parents of younger children between 2–5 years were more focused on their child's developmental goals, more so than their own needs. Progress with their child's goals was very important to them, and they felt that the early years were *a time to work hard on the developmental goals*, for a better future. Some goals that parents mentioned included toilet training, walking, oral feeding, and speech. Seeing possibilities in the future was dependent on their child's progress with these goals, and supported their FQOL.

Code 9 was about support from partners, family members, and friends and these supports had a favourable impact on their FQOL. Code 9 highlighted that support from partners and extended family was inconsistent, but valued by the main caregivers. Ten out of the 12 participants were mothers, and seven out of these 10 mothers had partners who assisted with some household chores or playing with the children, even though this was not consistent. Many grandparents and extended family members also helped occasionally with the caregiving and this supported the parents and helped their FQOL.

Code 10 was about supports from services, mainly ECIS, and how this supported their FQOL. Participants valued the services provided by the keyworker through home-visits and childcare visits. They felt this was instrumental in building parental confidence about sending their child to kinder or childcare. They valued the knowledge and information provided by the keyworkers around their child's condition, and specifically valued being guided about services available for their child and their family. Parents trusted their keyworkers more if they helped them see ahead in relation to their child and family needs. They appreciated that the keyworkers treated them with respect and guided them towards the next steps for their child, and also for themselves and their family, and that this was supportive of their FQOL. They valued the support groups and networks that they found via the keyworker.

All 12 families received funding from ECIS, *Better Start* and/or the HCWA package. Financial support from these different funding packages was most appreciated by all participants, and families valued this support for their child's therapy needs, more so than any other need.

Code 12 was about the positive attitudes, beliefs, religion, and value systems that parents used to feel positive and adapt to their life of living with childhood disability. Six out of 12 participants commented on how their positive attitudes, beliefs, and coping systems helped their FQOL. They talked about the adaptive process and alluded to the constant need to adapt to the situation and learn to cope as challenges came forth, and this supported their FQOL.

Theme 3: FQOL feels challenged during difficult times. This theme consists of all codes that contributed towards the challenges that the parents talked about when having a child with developmental delay/disability. Codes 7, 11, 13, 14, and 16

contributed towards the generation of this theme. Code 7 was about the time of diagnosis being stressful for most parents. Seven out of 12 participants had negative experiences around the time of diagnosis. Delayed diagnosis was a leading cause of anxiety, anger, frustration, and self-doubt for many families and this impacted their FQOL. Participants reported that they felt health professionals *did not listen to their concerns* and they had to wait longer than necessary to get through the process of diagnosis. Two participants mentioned that they started doubting their parenting skills because the diagnosis was unclear.

A few participants expressed resentment with the attitude of the health professionals at this time, and a lack of support. One participant said that he and his partner *were devastated* with the health professionals' way of explaining the diagnosis to them, especially because they were given incorrect guidance. This made them lose confidence in health professionals and was detrimental to their FQOL at the time. Some participants felt that the time after the diagnosis was also filled with sadness, devastation, *and not knowing what to expect*, and was stressful.

Code 11 was about support being scarce after exiting ECIS. Lack of services and support at school and the lack of financial and emotional support from ECIS and from their keyworkers were mentioned as being challenging. Some parents preferred special school to mainstream school due to a lack of services in the mainstream education system. Six out of 12 participants had children going to school in the near future and were very apprehensive about support for their child when at school. Three out of these six participants had older CWD at school and were very unhappy with the lack of support and funding available at school. Lack of parental support and large class sizes with busy teachers were common concerns for them. Funding therapy services was another concern and these participants clearly indicated that their

children would miss out on therapy, as they were unable to afford therapy costs. This was detrimental and challenging for their FQOL.

Code 13 was about having multiple family members with a disability or a chronic illness that impacted their everyday life, increased caregiving needs, and challenged their FQOL. Five participants had other children with concerns or a diagnosis and felt that the caregiving needs of multiple family members impacted their individual quality of life and physical and financial well-being, and thus detracted from a good FQOL. Code 14 was related to severity of disability, especially challenging behaviours impacting FQOL. As it was early years, many participants had not yet felt the severity of the disability, so only a few participants contributed to this code. Most participants felt that if their child were more severe, then it would impact their relationships and FQOL more. Participants with children who had challenging behaviours seemed to be more exhausted and struggled when the behaviours occurred, and this impacted their FQOL.

Code 16 was about triggers and uncontrollable events that occur that have a negative impact on FQOL. Two participants were coming to terms with a recent separation, and also dealing with two children with diagnoses of autism. The separation had had an impact on their finances, emotional well-being, and impacted their FQOL. A third participant had recently suffered an incident at their new home and this had left the family shaken. These events were challenging and impacted FQOL detrimentally.

Theme 4: Having a CWD has consequences for family and for FQOL. Many factors were related to this theme from several codes and even though most participants did not clearly express the consequences of having a CWD, their

responses when clustered gave a clear indication that having a CWD had consequences for family and FQOL. Codes 3, 5, 6, and 15 help with understanding these consequences. Code 3 was about the physical well-being of the parent/caregiver not being a priority due to the child's needs. Many participants commented that their own health and well-being did not take precedence, as they were too busy looking after the care needs of their family, and their CWD. Participants reported being *exhausted and bogged down*, but continued to provide the caregiving as it was necessary for their child.

Codes 5 and 6 were important for understanding the consequences of having a CWD on parent roles and occupations. Code 5 was about the ownership and adoption of the parenting role that comes about after having a child and Code 6 was about adaptations that are made and how previous parent occupations change after having a child and more so a CWD. Most participants were committed to the occupation of being a parent, and participating in occupations such as caregiving, housework, and looking after children's needs, and they took ownership of these new occupations. Parents were ready for starting a family and were adapting to the parenting role and added responsibilities. Ten out of 12 mothers had taken on their role as the main caregiver, and fathers were the income earners for the majority of the families. Participants missed time for their everyday occupations such as meeting their basic self-maintenance needs and doing things for themselves, due to the commitments of caring for their CWD and also their home. Many participants missed time for their everyday occupations such as self-care, sleep, and doing things for themselves and talked about having no *me-time*.

The other occupation that was impacted as a consequence of having a CWD was to resume or be able to participate in paid work or formal education. Eight out of

10 mothers had given up their paid work, two were working part-time and one of the dads was working part-time due to the caregiving needs of their child. Most participants recognised that staying off work or going part-time reduced career prospects for them, and some mothers missed their work. It also had an impact on the family income. However, most participants agreed that it was necessary to take this break from paid work due to having a child with added needs and the increased need for caregiving attached to this, and that going back to work would be stressful. Most participants had accepted that they would have to wait for a longer time before resuming work and even when they resumed, it would be part-time or from home. They missed the working environments and their colleagues. This highlighted that having a CWD impacts on the main carer's ability to engage in paid work for longer.

Some participants also talked about the impact of having a CWD on family occupations such as outings, vacations, and family get-togethers. A few participants felt that they were unable to engage in previous family outings and parties with friends. Most participants felt that this was quite typical when families have young children, but a few participants who had children with higher severity felt that they would not be able to engage with their friends or family in the near future. This led to feelings of isolation.

Code 15 was about relationships between family members and the impact of having a CWD on siblings. Most parents mentioned that the siblings had to adjust to having a sibling with disability, even though they felt that it was a positive to have siblings who understood the needs and dynamics of their family, and this was a support to the parents. Some participants worried about sacrifices that siblings were making, like not being able to attend family outings or *invite friends for a sleepover* and thought that this impacted their FQOL. Most parents did not expect the siblings to

be involved in sharing the care of their sibling with disability; however, a few of them were concerned that the CWD *would be a burden* on the sibling in the future.

Step 5 – Interrelating themes. Step 5 interrelates, interprets and triangulates the four themes with the research questions. As this is a mixed methods study, the quantitative results also need to be triangulated with the qualitative findings to arrive at a conclusion (Greene, 2006; Johnson et al., 2007). Since this is the beginning of the discussion for this study, this step is presented in the next subsection along with the triangulation of quantitative results.

2.5 Discussion – Study 1

This section will present a discussion, and implications for future policy, practice and research. Finally the conclusion summarises study 1.

2.5.1 Discussion. The discussion interrelates and interprets the four themes (Step 5) from the qualitative data with the research questions and compares and triangulates the quantitative results with the qualitative findings. The findings are also compared with other studies and implications for future policy, practice, and research (part of Step 6) are presented.

2.5.1a Parent perspectives of family quality of life. The first question was about investigating parent perspectives of their FQOL. All four themes from the qualitative data contributed to answer this research question and Figure 2.8 shows the relation of all the themes to this question.

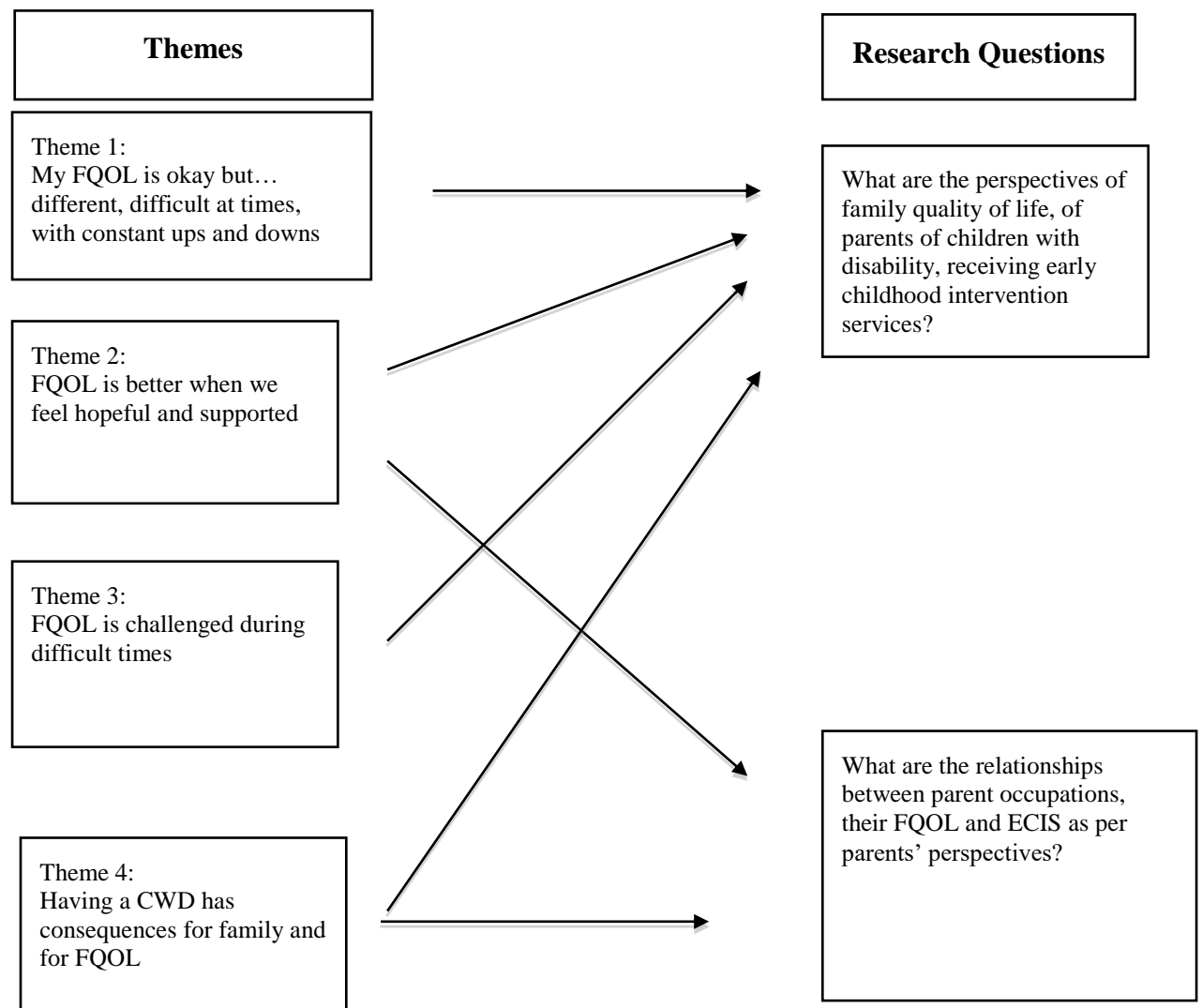


Figure 2.8. Themes in Relation to Research Questions.

The high scores from the quantitative results in this study indicated that the majority of respondents were satisfied with their total FQOL. The qualitative codes explained that parents were using positive attitudes despite the challenges of having a CWD. Theme 1 suggested that even though most parents initially responded that their FQOL was satisfactory, during the interview all participants commented on a variety of difficulties that they faced, and that their life was different to what they had expected. They commented on how their FQOL was *not bad*, but also added that they were constantly adapting to the challenges of having a CWD, and there were constant ups and downs. Within Appendix 2.6, Table A2.3 demonstrates the process of triangulation of the quantitative and qualitative findings from this study for understanding parent perspectives on their FQOL.

Despite reporting their life being stressful, different, *and a struggle at times*, *with many ups and downs*, most participants felt that they were managing their everyday activities and moving on. From their perspective their FQOL was not low at all times and, overall, they felt positive about their FQOL. Within the FQOL literature, high satisfactory FQOL scores and positive attitudes related to having a CWD are common (R. Brown, Schalock, & Brown, 2009; Chiu et al., 2013). The early work of Turnbull, Summers, Lee and Kyzar (2007), in the conceptualisation of FQOL, focused on the positives seen in families of CWD, such as positive adaptation. Their findings about parents adapting along the way and feeling a high sense of satisfaction with their FQOL are similar to the findings in this study. The results from this study are also in concurrence with a review presented in a book chapter by Chiu

et al. (2013) that studied trends in family research related to FQOL over the past 20 years. The review concluded that parents adapt in a positive way and develop strengths that help them feel positive about living with disability, rather than feeling negative (Chiu et al., 2013).

Another important parent perspective in the current study that supported their FQOL was related to the inherent qualities that parents possess, mainly their positive attitudes, their beliefs such as their duty of being a parent, their religious beliefs, and their value systems (Theme 2, code 12). Parents appreciated the positives in their child and were optimistic about the future. Positive parent perspectives regarding their FQOL in the current study are similar to Breen's (2009) findings in a paper about children with disability. Breen's paper highlighted that parents of a child with CWD felt joyful, optimistic, and resourceful more so than feeling grief, depression, or stress (Breen, 2009). The findings in this study can also be explained by the research on FQOL by Brown and colleagues relating to positive outcomes felt by parents and caregivers. The authors collated research findings related to FQOL for the past 20 years to provide a map for practice and policy (R. Brown, Kyrkou, & Samuel, 2016). They indicated that families use specific positive strategies such as problem solving, positive coping, and find ways to stay positive to manage their everyday life, and feel a good sense of their FQOL (R. Brown et al., 2016).

Within this study, many parents reported that their positive attitudes, family values, and religious beliefs were supporting their FQOL. Similar results are reported in a study with 187 parents and siblings of individuals with intellectual and developmental disabilities, where families perceived spirituality, well-being, and participation in religious communities as beneficial to their FQOL (Poston et al., 2003). Parents in this study were interviewed or participated in focus groups, and the

findings were similar to the current study, where most parents felt that having spiritual beliefs helps parents to have faith and to attribute meaning to disability (Poston et al., 2003)

Within theme 2, many parents compared the caregiving needs of their CWD to the caregiving needs of a typically developing child at a young age (Code 4). They felt that all young children were dependent for their everyday needs such as feeding and dressing, and this was no different for their CWD. Parenting their CWD did not make them feel different to other parents, possibly explaining their high scores on “parenting” in the quantitative study. Comparing their life to other families with typically developing children helped normalise their FQOL experience. This phenomenon of “normalisation” in parents of children with chronic illnesses, with medically fragile conditions and in children with developmental disabilities has been discussed in past literature (Deatrick, Knafl, & Walsh, 1988; Rehm & Bradley, 2005) and is usually considered a useful coping strategy for families of children with chronic conditions, and with developmental disabilities. In 1999, Deatrick, Knafl, and Murphy-Moore reviewed 33 articles using normalisation constructs and concluded that families acknowledge the condition of the child. However, they also adopt a normalcy lens to define the child and family and like to engage in parenting behaviours, and routines that are consistent with a normalcy lens, based on a view of the child and family as normal (Deatrick, Knafl, & Murphy-Moore, 1999). In another study, 48 parents of children with a genetic condition participated in a study related to normalisation (Knafl, Darney, Gallo, & Angst, 2010). The participants reflected two groups, normalisation present (NP) and normalisation absent (NA). Similar to this study the participants in the Knafl et al. (2010) study that used normalisation (NP) adapted successfully to the challenges of having a child with a chronic genetic

condition and were competent in their parenting style. However, the parents in the other (NP) group talked about the difficult and atypical nature of their lives and pointed to the negative impact of their child's condition on their lives. Within this study, parents used "normalisation" as a way to feel better about their FQOL and this could be because their children were still young and required caregiving like other children their age.

Another parent perspective in this study that supported their FQOL was the parents' hope that their CWD would continue to progress and improve into the future (Theme 2, code 8). Parents were hopeful and believed that their CWD would continue to achieve skills developmentally and would follow the trajectory of attending a mainstream school in the future. This hopeful perspective has been reported in past studies on FQOL as "stability" and is helpful for a better FQOL (I. Brown, Neikrug, & Brown, 2006). "Stability" is achieved when parents of CWD feel that circumstances are likely to improve over time, and helps parents' FQOL (Neikrug, Roth, & Judes, 2011). Neikrug et al. (2011) conducted their study in Israel with 103 main caregivers of CWD and used the Family Quality of Life Survey – 2006 (I. Brown et al., 2006). The results suggested that parents in their study were able to manage family challenges, and were able to see opportunities and initiate actions for the future (Neikrug et al., 2011), further confirming the relation between high satisfaction with FQOL and a feeling of "stability". The concept of "stability" is not measurable within the BC-FQOLS, so was not picked up in the quantitative aspect of this study; however, most participants in the qualitative interviews mentioned feeling hopeful about their child in the future, and this helped their experience of FQOL.

In terms of the subscales of the BC-FQOLS, parents were most satisfied with their parenting, emotional well-being, family interaction, and disability-related

support, more so than their physical/material well-being. This is consistent with an Australian study on FQOL in ECIS, that had similar results when the BC-FQOLS was used to measure satisfaction with total FQOL (Davis & Gavidia-Payne, 2009). This is also consistent with past literature where family relationships and values are reported as very important to families, and high scores on parenting and family interactions are common (R. Brown et al., 2016).

However, contrary to this study, satisfaction with disability-related support has been shown as low in past studies (Bhopti et al., 2016; R. Brown et al., 2016). This maybe because families in this study were getting supportive transdisciplinary and family-centred type of services that provide child and family supports, and were also receiving support from their extended family, and their spouses. Nearly 81% of the participants had both mother and father living at home. It is possible that the mothers (majority of the participants) were feeling supported and all these reasons lead to a high score. Physical/material well-being rated lowest on satisfaction and this is also prevalent in past studies and relates to parents feeling the financial burden and loss of income due to inability to work and being on a single wage (Bhopti et al., 2016; Caples & Sweeney, 2010).

Lastly, parents' perspectives of their FQOL in this study are compared with constructs within the unified theory of FQOL. Zuna et al. (2010) within their theory of FQOL, define beliefs as "individual family members' attributions of meaning, expectations or understanding about a phenomenon" (p. 264), such as the meaning of a child's disability for the family, expectations of the child's future, or understanding about parental roles. These beliefs have a mediatory influence on FQOL. The qualitative findings from the current study related to the constant process of adaptation, owning the parent role, their positive attitudes, and family beliefs (Code

12). This concurs with the theoretical frameworks of FQOL by Zuna et al. (2010) and confirm the application of this theory in the Australian context.

These qualitative findings, along with the high scores on the overall FQOL scores on the BC-FQOLS, concur with past literature regarding FQOL of families across different countries. The discussion to this section concludes that despite having a CWD and facing difficulties, and constant ups and downs, most families report a sense of satisfaction with their overall FQOL.

2.5.2b Relationships between parent occupations, their FQOL, and receiving ECIS. The themes that contributed to this question from the qualitative data are presented in Figure 2.8 above. Within the quantitative data there were positive correlations, indicating an association between items representing committed occupations and the support the families were receiving from their ECIS. There were also positive correlations between necessary occupations, free-time occupations, and “disability-related support” confirming an association between support provided from ECIS and the ability of parents to feel satisfaction with these parent occupations. It can be argued that these items were not clear representations of parent occupations, so the qualitative findings were considered in-depth to understand the relationship between parent occupations, disability-related supports, and FQOL. The qualitative findings concur with most of these quantitative results and further illuminate details about parent perspectives. Within Appendix 2.6, Table A2.4 shows the triangulated data and the relationships between parent occupations, ECIS, and FQOL.

Becoming a parent was seen as an important committed occupation, and most mothers felt that being the main caregiver was their role, and they were ready to adopt this role (Theme 4, code 5). Most of the mothers reported that they received support

from their partners, friends, and family, but still felt it was their role to be the main caregiver and they would prefer the father to be the income-earner (Theme 2, Code 9). These findings are supported by results presented in a gender report by the Australian Institute of Family Studies (AIFS) from a survey of Australian households completed in 2005. In this report 41% of the men and 36% of the women agreed that it is better for the family if the husband is the principal breadwinner outside the home, and the wife has primary responsibility for the home and children (Baxter, 2014). This possibly explains why many Australian mothers in this qualitative study wanted to stay at home and be the caregiver for their child and felt privileged that their partners were able to work and earn money so they were able to stay at home.

In terms of free-time occupations, the descriptive scores suggested that the majority of participants were either satisfied or very satisfied with the time they could spend on pursuing their interests. This was surprising because it meant that most caregivers were able to pursue their interests. However, most parents, especially mothers in the qualitative aspect of the study, indicated that they were unable to find time for activities like going to the gym, or going dancing. They reported that they were committed to the occupation of being a parent (Theme 4, code 6) and did not feel that having free-time for pursuing their interests was important to them. This could explain why nearly 60% of the participants in the quantitative study felt satisfied with the time they had to pursue their interests, an important free-time occupation. However, in contrast to this study, past studies with parents/main caregivers of CWD indicate that parents regard opportunities to engage in recreation as important, and lack of opportunities for leisure and community participation detract from a good FQOL (Caples & Sweeney, 2010; Clark, Brown, & Karapaya, 2012; Steel, Poppe, Vandeveld, Van Hove, & Claes, 2011). It is possible that the parents in

this study had young children (0–6 years) and felt that they would be able to return to their free-time occupations in the near future, further explaining the finding in this study.

For necessary occupations, the quantitative data did not pick up on whether parents were able to look after their basic needs such as their own health, including sleep. However, the qualitative data indicated that most mothers were unable to look after their own health and well-being. Financial pressures, lack of sleep, and being exhausted from caregiving were also mentioned. This finding was not reflected in the quantitative data, but it can be compared to previous studies.

In a study on occupations of mothers, Crowe and Florez (2006) compared the time use of 30 mothers of CWD to 30 mothers of children without disability. Mothers of CWD spent significantly more time in childcare activities and significantly less time in recreational activities (Crowe & Florez, 2006). Even though the findings from this study are similar to the above results related to less time being available for parents for their own needs and occupations, the acceptance and adoption of the parenting role became a primary occupation for most parents in the early years in this study, and doing their role well had a positive influence on their FQOL.

For contracted occupations, the majority (54%) of the quantitative sample were not working in paid employment. There was no significant correlation between the work status of the main carer and disability-related support on the BC-FQOLS; however, the qualitative data made it clear that loss of work (parent occupations) had an impact on parent well-being and on their FQOL. Many participants said that loss of paid work led to most families being on a single wage, thus impacting the family income and financial well-being of participants in this study (Theme 4, code 6). It also impacted parent physical well-being, and many participants reported that they

had suspended their own health needs due to financial restrictions and the caregiving needs of their child (Theme 4, code 3). Loss of paid work seemed to have a detrimental impact on the financial status of families and, indirectly, their FQOL in the qualitative aspect of this study.

These findings about losing one wage (most mothers were not working) and its impact on financial income can be compared to findings from a scoping review of 18 studies that looked at relationships between loss of occupations and FQOL (Bhopti et al., 2016). The review indicated that many family members reported that restrictions on their employment opportunities and professional growth led to a reduction in family income, and impacted their financial and emotional well-being and their FQOL (Caples & Sweeney, 2010; Neikrug et al., 2011). In the study by Caples and Sweeney (2010), 49 parents of CWD were surveyed using the FQOL-S, 2006 and the results indicated that financial status was strongly correlated to FQOL. In another Malaysian study with 52 parents of CWD (age between 2–18 years), financial well-being and careers were considered important for a better FQOL (Clark et al., 2012).

In summary, relationships between parent occupations and FQOL are not reported in past literature and the findings from this study add to the body of knowledge about how parent occupations change when they have a CWD, and how parents adapt to these changes in a positive way. It also confirms the relationship between parent occupations and FQOL and identifies engagement in these occupations as an important contributor to FQOL.

In terms of the second part of the question related to ECIS and FQOL, the majority of participants were satisfied with the ECIS services they were provided with. Since the early nineties studies have reported similar findings about ECIS, highlighting that families ascribe most of their positive experiences to the supportive

behaviours of professionals, and bad experiences are related to difficulties in finding out about and monitoring services (McWilliam et al., 1995) .

The correlations in the current study demonstrated associations between the time they had to pursue their own interests with the disability-related support. This support included support for their child to make progress at home and at kinder, and to make friends. It also included support they received to relieve stress and spend time together as a family (both are family-centred goals). Within Australia, a study about families perceptions of family-centred practice reported overall satisfaction with their ECIS and similar results to the current study, concluding that parents value coordinated and comprehensive care and receiving information from their ECIS providers (Ziviani, Feeney, & Khan, 2011). Similar findings from a scoping review, including 18 studies about FQOL and ECIS, concluded that parents valued experiences of family-centered support from service providers and support for navigating services, and this contributed positively to their FQOL (Bhopti et al., 2016). Parents in this qualitative study also reported similar experiences to all the above studies; that they valued the information provided by the keyworkers around their child's condition, and the visits and support provided by the keyworker within their child's home, childcare, and kinder. They were also grateful for the funding packages that the keyworkers helped them source for their child's needs. In an early National Early Intervention Longitudinal Study (NEILS), 3338 parents were asked to rate their satisfaction with early intervention in the United States (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004). A total of 75% of the respondents said they were receiving the "right amount" of services, 61% rated the quality of their child's therapies as "excellent", and 99% had "good feelings" about the professionals serving them. However, it was unclear in the study whether the family ratings of service

satisfaction or adequacy are related to other family outcomes, such as FQOL.

These collective findings concur with studies on parent perspectives of early intervention services that report high levels of parental satisfaction with their ECIS if the services are responsive to family concerns and needs, are family-centred in their approach, and make parents feel positive about the future for their child (Bailey et al., 2004; Konstantina et al., 2014).

Within this study, there was also a negative strong correlation between duration of ECIS and relationship with the service provider. Duration of ECIS in this study was the number of years a family participated in ECIS and ranged from 0–5 years. This can be attributed to the reduced frequency of visits by the keyworker in the latter years of service delivery. It is possible that families who were new to the service felt a greater satisfaction with their relationship with the ECIS provider as they had more frequent visits, and hence a stronger relationship with their keyworkers. Similar results in a past study reported a strong association among adequacy of services and family–professional partnerships and with FQOL (Summers et al., 2007). Similarly, in another study on first experiences of early intervention, it was concluded that the beginning of early intervention services is usually highly successful (Bailey et al., 2004) and explains why families who were early on in the program felt a higher satisfaction with their ECIS in the current study. Another study reported on data from a large-scale assessment using the family outcomes survey, with families participating in early intervention concluding that the time spent in early intervention was related to positive family outcomes, FQOL being one such outcome (Raspa et al., 2010).

When looking for associations between parent occupations, ECIS, and FQOL, the qualitative findings (Theme 2, code 10) explained that parents valued the support

and childcare/kinder visits from ECIS providers because it freed up some of their time to do things for themselves and helped their FQOL. Most parents in the qualitative study did not expect ECIS to help them get back to their previous occupations. Most parents felt that helping their child's developmental progress was the main role for ECIS, and when they considered that their child was making progress (Theme 2, code 8) they felt they could look after their own needs better. Similar findings were reported in an Israeli study that compared mothers of children with and without disabilities and concluded that mothers' satisfaction with their daily occupations might be enhanced when clinicians consider the developmental needs of their children, and this positively effects their family well-being (Gevir, Goldstand, & Weintraub, 2006).

The lack of services and support after leaving ECIS and entering the school system was hard for some of the families, and they were anxious that they would miss the financial and emotional support, and communication from ECIS and their keyworkers. This finding is further supported by a Canadian study about children transitioning from early intervention to kindergarten, where in-depth interviews with three parents highlighted the challenges that parents face when their CWD transitions to kindergarten (Villeneuve et al., 2013). Within the Canadian study, parents perceived a lack of communication from the educators about their child's experiences at school and felt they had been left to navigate their child's entry to school alone. Another study by Curle et al. (2017) investigated the experiences of transition to school from early intervention of 10 parents of children who were deaf or hard of hearing and reported a lack of funding and specialised professionals as a barrier to the transition to school for the children.

In summary, regarding the relationships between parent occupations, ECIS, and FQOL, the current study demonstrated associations between the three question components – FQOL, ECIS, and occupations of parents – and concluded that receiving family-centred and timely ECIS is positive for FQOL. Caregiving and parenting were important occupations for most parents and performing the parent role well helped their FQOL. Families valued the family-centred approach and respectful and experienced keyworkers within ECIS. Most parents were highly satisfied with their ECIS services and appreciated the input from ECIS towards family supports and family needs, and this indirectly helped their FQOL.

Lastly, the study findings also fit with the unified theory of FQOL, and the model of FQOL proposed by Zuna et al. (2010). According to Zuna et al. (2010) the unified theory of FQOL is presented based on the theoretical model (see Figure 1.3 in Chapter 1) and states that systems, policies, and programs indirectly impact individual and family-level supports, services, and practices. The model also further states that individual demographics, characteristics, and beliefs, and family-unit dynamics, characteristics, and beliefs are direct predictors of FQOL and interact with individual and family-level supports, services, and practices to predict FQOL (Zuna et al., 2010).

Within the current study it was clearly evident that the family characteristics and beliefs along with support from family, friends, and ECIS providers were significantly helping them to adapt to the changes in their life of living with childhood disability. Parents adapted to changes in their previous occupations, and were satisfied with their current occupation of caregiving for their child and looking after their family. Once they adapted to the changes, their FQOL felt better. There was a definite association between receiving ECIS and FQOL, and between the impact of loss of occupations and FQOL. The model of FQOL also states that the resulting FQOL

outcome produces new family strengths, needs, and priorities which re-enter the model as new input, resulting in a continuous feedback loop throughout the life course (Zuna et al., 2010). This was similar to findings from the current study where families felt resourceful and continued to move ahead with new strengths and resources while using their internal qualities, positive attitudes, and family values.

2.5.2 Limitations. There were several limitations within this study. One limitation was the lack of multiple ECIS agencies where different models of practice are used. The agency that was selected used the family-centred practice model for delivering their ECIS and it would be worthwhile to include participants receiving ECIS using different models of service delivery. The majority of participants (97%) were mothers and capturing perspectives of fathers as well would have increased the variability and illuminated the results further.

Another limitation could be the Likert style of responding used in the BC-FQOLS. This style sometimes fails to measure the true attitudes of respondents, and possibly the high scores on their total FQOL may be attributed to this. However, the interview data contributed to understanding the parent perspectives in detail. High positive scores can also be attributed to social desirability bias, the tendency of survey respondents to answer questions in a manner that will be viewed favourably by others, however may pose a serious problem with conducting research with self-reports, especially questionnaires (Stoeber, 2001). This bias can take the form of over-reporting desirable behaviour or under-reporting undesirable behaviour. The high scores on FQOL may have been influenced by this bias.

The BC-FQOLS does not provide normative and standard scores for comparisons thus lack of norms against which a comparison could be made for this study was a limitation as well.

Not having a clear outcome measure for parent occupations was another limitation. Majority of the data related to parent occupations was gathered from the qualitative analysis. Some items from the BC-FQOLS and the demographic questionnaire also helped in capturing an understanding of occupations and their relationships to FQOL.

Finally, the parent perspectives of their FQOL highlighted that they foresaw their FQOL would get better when their child went to school; however, no longitudinal study was planned to see if this would happen and the data seemed incomplete. This limitation in the current FQOL data led the research team to conclude that the true perspectives of FQOL would be more significant if parents at school could be included in further studies and their data compared. This limitation resulted in a positive outcome and helped in planning a further study for this doctoral research to include the perspectives of parents of school-aged children with disability.

2.5.3 Implications for Practice, Policy and Research.

Implications for ECIS practice. There are several implications for ECIS service providers and practitioners. Certain attributes of a keyworker/family service coordinator were identified by most parents as important and supportive of their FQOL. These attributes included using a family-centred approach, establishing positive partnerships with the parents, and providing information and support to the family, and the early childhood services (kinder/childcare). Supporting families in spending time together and providing support to relieve stress were important to

parents. ECIS providers need to consider provision of such support or referring parents to such supports. The coping process whereby families feel that the burden of caregiving for their CWD is similar to that of a typical child in the early years (normalisation) needs to be considered.

Most parents in ECIS are not ready for looking at the disability as a long-term issue and ECIS providers need to be mindful of the parents' journey, but continue to present information to families related to better family outcomes. The findings also highlight that parental involvement in meaningful occupations helps their overall well-being and can contribute to a better quality of life. ECIS providers need to include re-engagement in meaningful occupations, and suggest this to parents as a part of their individual goal plan.

Implications for research. There are some implications for further research from this study. Many parents felt that health professionals (mainly doctors and psychologists) were not honest about the diagnosis and the future, and this impacted their trust of health professionals. This is a significant issue that has its roots in the “medical” model of practice. Further research needs to examine and evaluate perspectives from other health professionals to gain an understanding of their views, and to further support and advocate for working in a family-centred model of care. Most families in this study had young children, and most parents felt that their FQOL would get better as their child got older and progressed into school. Further studies need to be conducted to investigate whether parents of children with disability attending school report FQOL outcomes similar to the current study.

Implications for policy. It is evident from this study that FQOL is related to receiving family-centred ECIS. Within Australia, the National Disability Insurance Scheme (NDIS) was established to provide services and support to people with

disability nationwide (NDIS, 2013, 2016) and will roll out nationwide in 2018. The results from this study strongly recommend that the NDIS should encourage ECIS providers to provide supports to children and families using a family-centred approach, and within a range of mainstream early childhood settings to ensure a good FQOL for parents. Policy makers need to consider family support, counselling, capacity and skill building related to the disability, and need to consider FQOL as a family outcome. Lastly, opportunities for returning to work or engaging in leisure activities for parents/carers are important and are currently not apparent in supports identified by the NDIS. These need to be considered to ensure a better FQOL.

2.6 Conclusion of Study 1

This study demonstrated high scores on FQOL in the quantitative section; however, the qualitative part of the study was able to illustrate that the increased FQOL was due to a number of reasons. The internal qualities of parents/caregivers such as positive attitudes, beliefs, resilience, and the ability to constantly adapt to change helped them manage the challenges of having a child with disability/delay. Parents were resourceful and managed their family needs, but needed support with their child's specific needs. Achieving positive outcomes for their child were instrumental in having a better FQOL. Early childhood intervention services (ECIS) that were family-centred in their philosophy, and keyworkers who were respectful, helped FQOL. Receiving services such as ECIS helped families with knowing how to care for their CWD, and this helped their FQOL. Within ECIS parents looked for information provision by the ECIS providers, tangible resources for therapy needs for their CWD, and knowing what to do next. Most families did not have strong expectations to be supported by ECIS for the entire family's needs.

In contrast to previous studies, and to the quantitative data from the BC-FQOLS, the qualitative findings in the current study bring new knowledge about the impact of having a CWD on parent occupations. Loss of previous occupations for the main caregiver, such as careers and time for self-care, seem to have a detrimental impact on their FQOL, mainly on their financial and emotional well-being. However, family support and information about their child's disability and for helping the family look after their child, reduced their caregiving burden and in turn improved their FQOL.

The loss of previous occupations was not felt strongly in the early years of having a CWD. Parents were ready for starting a family and accepted either giving up

their work or their own health care to look after the needs of their CWD. They strongly believed that this was their role. Being able to continue successfully in their occupation of caregiving and looking after their child's needs helped their FQOL. Support from family and friends also helped FQOL, but most parents did not depend on this support due to a fear of being refused. Finally, the experiences of "normalisation" and "stability" into the future helped families of young children in ECIS cope with early childhood disability, and the belief that achievements would continue into the future helped with having a sense of a good FQOL. But what happens when their child goes to school? Is the FQOL of parents of school-aged children different to parents of children within ECIS? This question led the research team to the second study in this doctoral research.

Note: Please note that Study 1 has been written up as a publication and the peer-review draft is attached as Appendix 2.9. It is currently under review for publication in the *Journal of Occupational Therapy Schools and Early Intervention*.

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Chapter 3: Study 2 – Family Quality of Life of Families of School-aged Children with Disability

This chapter introduces Study 2, the rationale for the study, background, the aims and research questions, method, results and findings, discussion, limitations, and conclusion of Study 2. It comprises five sections with several sub-sections, namely:

- 3.1 Study Rationale, Background and Aims
- 3.2 Method Overview
- 3.3 Results and Findings
- 3.4 Discussion –Study 2
- 3.5 Conclusion – Study 2

3.1 Study Rationale, Background, and Aims

3.1.1 Rationale for study 2. At the start of this doctoral study, the broad aim of the research project was to explore parents' perspectives of family quality of life (FQOL) when they have a young child with disability (CWD), and to look for relationships between early childhood intervention services (ECIS), their occupations, and their FQOL, within an Australian context. It was anticipated that this would require conducting two studies. One mixed-methods study comprising a quantitative study (using the BC-FQOLS, and demographic data), a qualitative study (interviews) with parents of children attending ECIS, and a second quantitative study to further investigate the relationship between parent occupations, FQOL, and receiving ECIS in parents of CWD, using quantitative tools, and completing correlations between the results.

At the end of study 1, the findings indicated that most parents of children in ECIS reported that they would be able to return to their previous occupations and lifestyle when their child went to school. They also anticipated that their FQOL would get better and that they would have more time for looking after their own needs, when their CWD attended school. Triangulating the findings in study 1 answered most aspects of all questions identified at the start of the study. However, it raised critical questions on whether the long-term caregiving needs of having a CWD changes the perspectives of parents when their child is at school, and whether this impacts their FQOL.

It was anticipated from the findings, and from the researcher's background of working with disability, that adding the school-aged cohort group to the second study would strengthen the first study further. It would also add value and depth to the doctoral research, inform service delivery in ECIS, and also inform policy especially

in the new environment of the National Disability Insurance Scheme (NDIS). It would be valuable to know if parents needed more support when their children were of school age, whether they felt the same about their FQOL, and whether they were able to return to their previous occupations as they reported when their children were preschoolers in ECIS. Thus study 2 was proposed to gain an insight from parents of CWD attending schools about their perspectives on FQOL.

3.1.2 Background – Families of school-aged CWD.

3.1.2a. Caregiving for school-aged CWD. The model of FQOL by Zuna, Summers, Turnbull, Hu, and Xu (2010) in conjunction with several studies on FQOL have reported that life transitions (such as moving to school from ECIS) can have a negative influence on the FQOL of all members of the family (Chiu et al., 2013; Villeneuve et al., 2013). Parents/caregivers need to be well-equipped with resources to ensure a smooth transition of their CWD to school (Epley, Summers, & Turnbull, 2011). The health, development, and opportunities enjoyed by CWD are largely dependent on the availability and support of a healthy, capable, and well-resourced caregiver (Bourke-Taylor, Howie, Law, & Pallant, 2012). Bourke-Taylor, Pallant, Law, & Howie et al. (2013) investigated the relationships between sleep, health, and care responsibilities of 152 mothers of school-aged CWD. They concluded that these mothers experienced chronic sleep interruption, poor maternal subjective health, and lower participation in health activities (Bourke-Taylor, Pallant, Law, & Howie, 2013). Parents undergo considerable levels of stress at the time of transition to school, but family involvement is often missing from the transition process (Raghavan, Pawson, & Small, 2013).

In a longitudinal study, stress attributed by parents to their family member with intellectual disability was investigated over a period of seven years in relation to

parental worry (Baxter, Cummins, & Yiolitis, 2000). The results of the Baxter et al. (2000) study reported that the stress parents attributed to their family member with a disability (sample consisted of school-aged CWD) was about double that attributed to the youngest sibling without a disability. In a study by White and Hastings (2004), 33 parents of adolescent children with intellectual disability completed measures of parental well-being (stress, anxiety, caregiver satisfaction), social support (formal and informal) and child characteristics (problem behaviours). Correlation analyses reported that parents' ratings of the helpfulness of informal sources of support (spouse, extended family, friends, etc.) was most reliably associated with parental well-being, and remained so after controlling for child characteristics (White & Hastings, 2004). The authors concluded that parents of CWD are particularly vulnerable to the disruption of their informal social support networks during their child's adolescence (White & Hastings, 2004). Such social supports are mediators of FQOL, and need consideration when children transition to school (Zuna, Summers, Turnbull, Hu, & Xu, 2010).

However, despite the challenges that parents/caregivers continue to face when living with childhood disability, many studies have reported the positive adaptation that families undergo during times of such transitions. Scorgie and Sobsey (2000) identified "transformations" or life-changing experiences of parents of CWD aged between 3–25 years. They reported that parents undergo "personal transformation" and gain new acquired roles in the family and community, such as an ability to advocate for their CWD (Scorgie & Sobsey, 2000). They also undergo "relational transformation", evident in the ways that they interact with or relate to other people, and often end up with healthy family outcomes and new friendship networks (Scorgie & Sobsey, 2000). In 2007, Turnbull, Summers, Lee and Kyzar conducted a literature

review using 28 articles examining outcomes of family well-being, family adaptation, and FQOL when they have a CWD. The review focused on positive family outcomes of families of children from birth to adult age, and concluded that there was a lack of such research (Chiu et al., 2013). Very few studies report the positive impacts of adaptation when families live with disability, and it is unclear whether such positive adaptations influence the FQOL of families of CWD in schools. The next study conducted within this research is pertinent to parents of school-aged CWD. The school system within Melbourne, Australia is presented in the next section.

3.1.2b Overview of the school system in Melbourne, Australia. According to the Department of Education and Training (DET), a child is eligible to start school in Melbourne when they turn five years of age (DET, 2017). The Department of Education identifies six types of primary schools for children transitioning from the early childhood programs to school (DET, 2017). These are Prep-year 12 (P-12) schools, special schools, multi-campus schools, English language schools, alternative schools, and community language schools. The P-12 schools include state, Catholic, and independent schools and provide a unified approach to schooling by combining primary and secondary school education at the same school (DET, 2017).

Special schools are considered if the child has a disability and may cater for a specific disability or different types of disability. Multi-campus schools are made up of several campuses in more than one location, all of which operate under the management of one school council. English language schools offer intensive English language programs to students who use English as an Additional Language (EAL) at home, or who do not use English at home. Alternative schools offer a different philosophical approach to education such as the Steiner approach or the Montessori approach (DET, 2017).

There are currently 1375 schools in Melbourne and the majority of these are government or state schools, followed by Catholic and independent schools (AustralianSchoolDirectory, 2017). According to the Association of Children with Disability (ACD), there are more than 80 government specialist schools in Victoria, including specialist schools for students with mild, moderate, and profound intellectual disabilities, for deaf and hearing impaired students, for students with autism spectrum disorder, and for students with a physical disability (ACD, 2017). Class sizes at specialist schools are smaller than at mainstream schools, with a lower ratio of teaching and support staff to students. Specialist schools generally have therapists, an accessible environment, and curriculum for their student population. Students who live within the specialist school's designated transport area are eligible for travel support (school bus) to that school (ACD, 2017).

Special schools encourage families to work in collaboration with the staff to support the child's learning. They also encourage parents to look after themselves, and provide access to parent support groups (ACD, 2017). In comparison, parents of children in government or state schools (P-12) are encouraged to participate in school life both formally and informally, through school councils, parent clubs, and volunteering (DET, 2017). Within volunteer programs parents can directly participate in school activities like helping in the school canteen, helping with school excursions and events, assisting with reading and maths programs, and participating in environment committees and cultural groups (DET, 2017). This section provided a brief overview of the school system in Victoria, as the next study is concerned with parents of school-aged CWD.

Aims and Research Questions

The aim of study 2 was to gain perspectives from parents of school-aged children about their FQOL and of the impact of having a CWD on FQOL, when children are within the school system. It was hoped that the parent perspectives from this study would add to the findings from study 1 and assist service providers in ECIS to guide parents on what to expect in the years ahead and guide policymakers to consider the needs of CWD at school to make the process of transition to school less stressful for families.

The aims of study 2 were:

- To investigate the FQOL of parents of school-aged CWD
- To investigate the relationship between parent occupations and FQOL in parents of school-aged CWD
- To investigate parent perspectives of the differences in their FQOL from ECIS to school.

The research questions in study 2 were similar to those in study 1, with the addition of question 3:

1. What are the perspectives of FQOL of parents of school-aged CWD?
2. What are the relationships among parent occupations, their FQOL, and disability-related supports, as per parent perspectives?
3. Are there any differences between the perspectives of school-aged parents of CWD, when compared to parents in ECIS in relation to their FQOL, parent occupations, and disability-related supports?

3.2 Method Overview

The method used for the second study is outlined here. It is the same method as in study 1, hence some sections of the methods are not repeated in detail. The methods for trustworthiness are also the same as in study 1 and can be located in Chapter 2. The procedures pertinent to the quantitative and qualitative aspects of study 2 are described within this chapter.

3.2.1 Method. The method for study 2 was the same mixed-method as for study 1. For detailed method, please refer to the *Rationale for mixed-methods* section of Chapter 2 and the publication attached in appendix 2.7. An ethics amendment was sought and granted from the Monash University Human Research Ethics Committee, as changes were made to the age group of the participants and services (school-related) in the demographic questionnaire and participant recruitment. One interview question was also revised to reflect the changes in age groups.

3.2.2 Quantitative study details.

3.2.2a Quantitative study procedure. Similar to Study 1, a demographic questionnaire and the Beach Centre Family Quality of Life Survey (BC-FQOLS) from the Beach Center of Disability (BCD) in Kansas, were used for the quantitative component, and semi-structured interviews were used for the qualitative component (BCD, 2002). The participants included parents of school-aged CWD.

3.2.2b. Participant recruitment and selection. A convenience sampling method was used and participants for the second study were recruited via privately run parent support groups within Metropolitan Melbourne, via their group facilitators and via snowball sampling (Liamputtong, 2013). These support groups met every fortnight and were attended by 8-10 parents in 9-10 locations. The researcher found information about these parent support groups via parents she interviewed during study 1. The researcher provided the explanatory statement and information packs including the survey, demographic questionnaire, and consent forms to the group facilitators (who were also parents) of these groups, to disperse to the group members from three groups. As these groups were run privately they did not require permission for recruitment from any agency, and recruitment mainly occurred via snowballing (parent to parent).

The group facilitator provided the researcher with a time and date for distribution of the surveys, and the researcher attended at these times to distribute the surveys to the parents within the group. The researcher provided reply-paid envelopes or a locked mail-box to collect the surveys. Extra copies were also provided for gaining participants via the snowballing method. Some parents from the support groups took copies of the surveys and packages to distribute to their friends (other parents of CWD). Approximately 150 surveys were supplied across the parent support groups, and a further 50 copies were supplied to a parent for distribution as requested. It is estimated that between 75-100 surveys were distributed to families.

3.2.2c Inclusion criteria. The inclusion criteria for the quantitative and qualitative parts for study 2 were the same and included the following:

4. Parents/caregivers of school-aged CWD
5. Parents/caregivers with a working knowledge of English for completion of a standardised survey, demographic questionnaire, and participation in the semi-structured interview; and
6. Parents/caregivers provided informed consent to participate in the study.

3.2.2d Exclusion criteria. The exclusion criteria for the quantitative and qualitative parts for study 2 were the same. Parents/caregivers who did not fit within the definition of “family” as defined in the study were excluded (for example, a birth father with no custody or relationship with the child or family). Participants in this study consisted of people that considered themselves a family (whether or not related by blood or marriage), and who supported and cared for each other on a regular basis (Turnbull, 2011). An overview of what constitutes a family is available in Chapter 1 and includes the Australian inclusions of a family according to the Australian Bureau of Statistics.

3.2.2e Instrumentation. Demographic data recorded from participants included age, gender, relationship to the child, other family member details, level of education, employment status of both parents, and annual income. It also included two new questions. The first question compared whether the participants felt that they received more services now, than when they were in ECIS: “What describes the services and supports you receive for your child’s needs best?”, with choices from “I get more services and support for my child now compared to when they were in preschool (early intervention)” to “I get less service and support for my child now compared to when they were in preschool (early intervention)”.

The second question was about whether they were able to manage the expenses for their CWD now that their child was at school, and how they felt about these expenses: “Are you able to afford services and supports for your CWD?”, with choices including “Yes fully”, “To some extent but that’s OK”, “To some extent but that is not OK”, or “No I am unable to”. Both questions had room for adding comments. The BC-FQOLS was again used in study 2 to collect data about FQOL. It is a 25-item survey consisting of five subscales:

1. Family interaction
2. Parenting
3. Emotional well-being
4. Physical/material well-being, and
5. Disability-related support.

More detail about the BC-FQOLS is provided in Chapter 2 and within the publication attached in Chapter 2 (Bhopti, Brown, & Lentin, 2016). Evidence of the BC-FQOLS’ convergent validity and internal consistency have been reported (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Summers, Poston, Turnbull, & Marquis, 2005).

See Table 3.1, for item descriptions and subscales of the BC-FQOLS. See Appendix 2.2 for a copy of BC-FQOLS and Appendix 3.1 for the demographic questionnaire used for study 2.

Table 3.1 *Item Description and Subscales from the BC-FQOLS*

Beach Centre Family Quality of Life Survey – (BC-FQOLS) – Items and Subscales
<p>Subscale 1 – Family Interaction – Items 1, 7, 10, 11, 12, 18</p> <p>Item description</p> <p>1 – My family enjoys spending time together</p> <p>7 – My family members talk openly to each other</p> <p>10 – Our family solves problems together</p> <p>11 – My family members support each other to accomplish goals</p> <p>12 – My family members show that they love and care for each other</p> <p>18 – My family is able to handle ups and downs</p>
<p>Subscale 2 – Parenting – Items 2, 5, 8, 14, 17, 19</p> <p>Item description</p> <p>2 – My family members help children to be independent</p> <p>5 – My family members help children with schoolwork and activities</p> <p>8 – My family members help children how to get along with others</p> <p>14 – Adults in our family teach children to make good decisions</p> <p>17 – Adults in my family know other people in the children’s lives</p> <p>19 – Adults in my family have time to take care of the individual needs of every child</p>
<p>Subscale 3 – Physical Material Well-being (PMWB) – Items 6, 16, 21, 15, 20</p> <p>Item description</p> <p>6 – My family members have transportation to get to places</p> <p>16 – My family has a way to take care of our expenses</p> <p>21 – My family feels safe at home, work, school, and in our neighborhood</p> <p>15 – My family has medical care when needed</p> <p>20 – My family gets dental care when needed</p>
<p>Subscale 4 – Emotional Well-Being (EWB) – Items 3, 4, 9, 13</p> <p>Item description</p> <p>3 – My family has the support we need to relieve stress</p> <p>4 – My family members have friends or others who provide support</p> <p>9 – My family members have time to pursue own interests</p> <p>13 – My family has outside help available to us to take care of special needs of all family members</p>

Subscale 5 – Disability-Related Support – Items 22, 23, 24, 25

Item description

22 – My family member with disability (FMWD) has support to accomplish goals at childcare/school

23 – My FMWD has support to accomplish goals at home

24 – My FMWD has support to make friends

25 – My family has good relationships with the service providing services and support to our FMWD

Footnote: Items 3, 6, 12, 15, 20, 21 = Necessary occupations; Items 1, 2, 5, 7, 8, 10, 11, 14, 19, 17 = committed occupations; Items 3, 4, 9, 13 = Free-time occupations

3.2.2f Quantitative data analysis. The same analysis as in study 1 was used for study 2. The Statistical Package of Social Sciences (SPSS) was used for the data inputting and analysis of the quantitative data (IBM, 2013). Descriptive analyses were calculated for the BC-FQOLS subscales and the demographic questionnaire. Spearman's Rho correlation was chosen as the statistic to look for associations between FQOL, parent occupations, and disability-related supports. For question 1, regarding parent perspectives on FQOL, the total FQOL (TFQOL) score and the total subscale scores were calculated using descriptive analysis.

For question 2, regarding the relationships between disability-related support and FQOL, the item from the demographic questionnaire "amount of services received" was correlated to item 25 ("My family has good relationships with the service providers") and to the total disability-related support score from the BC-FQOLS. Even though the adequacy of services received does not necessarily indicate the quality of service, this item was correlated because some families reported that they were receiving less services now than ECIS, and it would be worthwhile to find out if this was related to their satisfaction with the disability-related support.

Regarding relationships between parent occupations and FQOL (for research question 2), similar to study 1 items from the BC-FQOLS were compared with topics that were analogous to parent occupations such as necessary occupations (meeting

basic needs), committed occupations (typically not remunerated but a commitment), contracted occupations (paid productivity), and free-time occupations (doing things of interest to self or in free-time) (Harvey & Pentland, 2004).

These items were then compared to the items and the subscales of the BC-FQOLS to choose the best representation of parent occupations. During study 1 analysis, these items were presented to seven experienced occupational therapists to independently allocate or assign the survey items to parent occupations, to check for face validity and to check for agreement (Fawcett, 2007). Five out of the seven therapists were working in ECIS for more than 15 years and the others were working as practitioners for a period ranging from 7-10 years. The parent occupations were defined in the handout and the scale items were presented randomly. There was 90% agreement within the item allocation to parent occupations. These BC-FQOLS items were then selected for calculating associations or relationships between parent occupations and ECIS.

Table 3.2 presents those BC-FQOLS items that best represent parent occupations based on the classification of occupations identified by Harvey and Pentland (2004) and on feedback gathered from occupational therapists. There were no items unanimously representing contracted occupations (paid productivity), so one item from the demographic questionnaire (“Work status of carer”) was recoded for inclusion in the Spearman’s correlations with the BC-FQOLS subscales. Please refer to Table 3.1 and footnotes and Table 3.2.

Table 3.2 *Parent Occupations Represented by Items from the BC-FQOLS*

Parent Occupations (from Harvey & Pentland, 2004)
Necessary occupations – aimed at meeting the basic self-maintenance needs Items 3, 6, 12, 15, 20, 21 Related to the BC-FQOLS Subscales 3 and 4 – PMWB and EWB

Committed occupations – typically not remunerated such as housework, childcare, home maintenance

Items 1, 2, 5, 7, 8, 10, 11, 14, 19, 17

Related to Subscales 1 and 2 – Family interaction, Parenting

Contracted occupations – paid productivity or formal education

Not related to any item on the BC-FQOLS

Within demographic questionnaire – related to work status of carer (working or non- working)

Annual income of household (<\$50,000 or >\$50,000)

Free-time occupations – occur in the time that is left over, such as going out with friends or doing things of interest for self

Items 3, 4, 9, 13

Related to subscale 4 – EWB

EWB = Emotional Well-Being; PMWB = Physical Material Well-being; BC-FQOLS = Beach Centre Family quality of life survey

For question 2 about the relationships between disability-related support and parent occupations, the BC-FQOLS subscale “disability-related support” was correlated with items representing parent occupations with highest agreement (see Table 3.2). For committed occupations, item 1 (“My family enjoys spending time together”) and item 19 (“Adults in my family have time to take care of the individual needs of every child”) were correlated with the subscale “disability-related support”. For necessary occupations, item 16 (“My family has a way to take care of our expenses”) was correlated with “disability-related support” and free-time occupations item 9 (“My family members have time to pursue own interests”) was correlated with “disability-related support”. For relationships between all the above disability-related support, parent occupations, and FQOL the results from all correlations were considered to investigate whether there were any associations between the three.

For the final question related to whether the parent perspectives were different now to when they were in ECIS, the two new questions listed on the demographic

questionnaire were considered. However, answering this question required comparative analyses of the results and findings from both the studies, and will be presented in the next chapter.

3.2.3 Qualitative study details.

3.2.3a Qualitative study procedure. Semi-structured interviews were conducted with purposefully selected participants from the quantitative participant sample who consented to be interviewed. The same inclusion and exclusion criteria, and ethics approval as the above quantitative part of study 2 applied.

3.2.3b Participant recruitment and selection. The demographic data available to the authors upon return of the completed demographic questionnaire informed the selection of participants to be interviewed. To gain a diverse sample that represented the participant families in the larger quantitative sample, the participants for the interview included mothers and fathers from different geographical areas and varying socio-economic status. At the start of recruitment, most of the participants who consented for interviews from the quantitative sample were mothers. For diverse sampling and data triangulation similar to study 1, study 2 needed the perspectives of fathers as well. During the interviews, four of the mothers expressed that their spouses (fathers) would also like to be interviewed. These mothers were given copies of the surveys and the four fathers who consented for the interviews were contacted for participating in interviews. All four of these fathers were spouses of the mothers who were also interviewed and were included in the participants to be interviewed. Please refer to the trustworthiness section in Chapter 2 about this sampling. The annual household income, was considered based on the Australian Bureau of Statistics (ABS) figures, indicating high average income as approximately \$96,000 and low average income as \$20,800 or less (ABS, 2015). The diagnosis of the children was also

considered and included varying diagnoses such as cerebral palsy, Down syndrome, and autism, similar to study 1.

3.2.3c *Qualitative data collection methods.* This section provides details about the data collection.

Data collection and data management. Qualitative data was collected over a period of 8-10 months. All selected participants were contacted via email or telephone to obtain informed consent and to make arrangements for the interview. A brief definition of FQOL was emailed or presented to the participants before the interview. A folder was created on a password-protected computer for each participant to record fieldnote observations and impressions, interview recordings and transcripts, and records of documents and other notes (Lincoln & Guba, 1985; Minichiello, Sullivan, Greenwood, & Axford, 2004). Handwritten fieldnotes after each interview were also kept in a reflective journal and later transferred into the participant's folder on the computer. Immediately after an interview all recordings were numbered, dated, and filed in each participant's folder. All audio interviews were transcribed verbatim and the recordings as well as transcripts were stored in the individual folders. A table was also constructed in Microsoft Word to record participant details and demographic information such as relationship to child, diagnosis, income, siblings, and so on (see Table 3.6 in findings). Other tables (Tables A3.1, A3.2, A3.3, A3.4, and A3.5) that were constructed included common codes related to quotes and themes related to quotes displaying the combined findings of all participants. These are available within Appendix 3.2 (Miles & Huberman, 1994).

According to Creswell (2009), the iterative nature of qualitative research allows data analysis to inform and guide upcoming data collection within one study. The process of the researcher and supervisor regularly meeting to examine the

interview data, discuss emerging themes, and consider the selection of participants continued until the end of data collection. After each interview the first step of the constant comparative analysis method was applied and the audio-recorded interview data was compared with that of other participants. Keywords, concepts, codes, reflections, and issues requiring exploration were recorded in the reflexive journal (Minichiello et al., 2004). Any changes to the interview guide were discussed and applied based on this analysis. Selection of further participants was also guided by this analysis, as the supervisor and researcher were able to determine the gaps in the information gathered based on the research questions. The next participant selection would assist in filling out these gaps and provide richer data, for example, including participants with children with cerebral palsy was missing and added later.

Data saturation was discussed between the researcher and the supervisor after every two to three interviews, and emerging codes were constantly compared to check for variability and for effective saturation (Liamputtong, 2013). This process was repeated for every two to three interviews. Through this process of participant selection in relation to the developing codes, at the end of 10 interviews no new data seemed to be emerging. However, it was observed that parents of children with cerebral palsy were missing from the sample; therefore, two more interviews were conducted to include these. No variability was seen with these new additions, confirming data saturation.

The researchers. The student researcher conducted all the interviews. She had over 20 years of experience working with children and families. The researcher knew some families from her past work with their children in ECIS and was conscious of this bias with her past knowledge of their children. Prior to the interviews within the first study, the researcher had undertaken training modules emphasising qualitative

interviewing techniques, and this training and experience of interviewing participants in study 1 was helpful in reducing reflexive bias and facilitating deeper conversations with participants. The university supervisor was experienced in qualitative research and the researcher regularly debriefed with her throughout the research process to check for bias and to maintain trustworthiness of research process.

The interviews. Semi-structured interviews were used for the qualitative aspect of this study. This allowed the researcher to elicit information from prepared questions, and at the same time allowed participants to elaborate on their responses (Liamputtong & Serry, 2011). All interviews were conducted by the researcher and took place in the family home or participants' workplace as desired and lasted between 45–90 minutes. The interview questions were based on the research questions and aimed to understand the participant perspectives of what their FQOL was, and to find out if there were things that influenced their FQOL. Six broad questions were used as a guide to prompt participants, such as “How would you describe your family quality of life at present?”, “What are some of the things that you think have impacted or influenced your current family quality of life? Can you explain why?”, “Do you think that your family quality of life was different before having your child (name of CWD)? Did you work? Or are you able to do things you did before? Can you give me some examples?” One question was added to capture the differences that the parents reported from their time in ECIS to the present: “*Do your recall if receiving ECIS had any influence on you or your family? Could you comment on the differences between your FQOL now when your child is at school, compared to when in ECIS?*”

Prior to the interview, participants were asked to think about how they considered having a CWD had influenced their FQOL. If the participants had not read the information provided, the researcher presented a copy of these documents and gave the participant some time to read them before commencing the interview. During the interview they were prompted to think of things that influenced their FQOL and if they felt that their FQOL was related to or associated with their occupations (necessary, committed, contracted, and free-time) and/or with disability-related services/supports. All interviews were recorded on a password-protected digital recorder and backed up with iPad recordings using an application called “My Memos”. No written notes were taken during the interview as the researcher wanted to engage in active listening and follow-up with prompts as they came up (Liamputtong & Serry, 2011).

Following each interview the researcher made fieldnotes in a reflective journal (Creswell, 2009). These notes included aspects about the environment, the mood of the participant, and any other detail that was not included in the recorded interview, but the researcher felt was important to note as contextual information. For example, the appearance of the participant, presence of other members at home, and the influence of them on the participant, and any other significant contexts such as the condition of the home, the mood of the members at home, and any specific routine that might influence the interview such as lunchtime or breakfast time.

3.2.3d Qualitative data analysis. Data collected in the semi-structured interviews were analysed using steps from the framework of Creswell’s (2009) six steps of qualitative analysis, similar to study 1. Some of the steps from the eight steps of Tesch’s (1990) work on coding were also used to analyse and generate codes. The

work of several other researchers in qualitative research was also referred to, to provide credibility and a more detailed guide as required to Creswell's analysis, and are included within the analysis (Lincoln & Guba, 1985; Patton, 2002; Tesch, 1990).

Steps of the analysis. The steps used for the analysis were as follows:

Step 1: Organising and preparing data for analysis. Data were transcribed verbatim after each interview. The audio recordings, typed transcripts, and fieldnotes were stored in a folder assigned for each participant on the computer. A large sectioned binder was also maintained with sections assigned to every participant and included a printed copy of the transcripts with marginal notes, emerging codes, and fieldnotes. A number coding system was used where all interviews were assigned line numbers and each interview was coded numerically from 1–12 to provide dependability and confirmability, and to enable later location of participants' data (Lincoln & Guba, 1985; Minichiello et al., 2004). For example, **I2: L23** corresponded to the second interview participant (**I2**) and the quote on line number 23 was represented by L23. All participants were assigned pseudonyms (in alphabetical order of their inclusion into the sample and interview) and other family members were also assigned either pseudonyms or an initial that did not match their actual name initial to maintain confidentiality.

Step 2: Reading through the data. Interview transcripts were read one at a time, following each interview, and a general sense of the transcripts was gathered regarding the overall meanings of what the participants were saying and whether the data represented the information that was sought. Tesch's steps of coding were also referred to and involved a general reading of all the data and making notes about the emerging topics alongside the margins. The aim was to build a picture of the complexities involved in dealing with having a CWD and looking for recurring or

evolving patterns over time (Tesch, 1990). Handwritten marginal notes also included interesting, significant, or important data. The researcher cross-checked the interview questions and transcripts with her university supervisor after two interviews had been conducted to ensure that the questions were not leading or biased. This was a way of further informing the interview protocol to gain a better idea of the data for dependability. The interview questions did not change but the exploration of certain questions was deemed necessary to obtain richer data; for example, the question about parent occupations was explored further by asking the participants to think of examples. The researcher also reflected on her interviewing style, noting that the interruptions needed to be limited and the flow of the interview needed to be facilitated in order to get richer data.

Step 3: Coding data. Each paragraph of the transcripts was subjected to a detailed coding process to incorporate concepts used by the participants and the researcher (Patton, 2002). Step 3 of coding involved listing topics and clustering common topics together (Creswell, 2009; Tesch, 1990). The clustering process involved looking for common participant perspectives, their way of thinking about certain topics (such as their changed occupations of advocacy), or even looking for expected codes (such as factors that influence FQOL including support from respite, and from friends and family members) as well as any surprising or unusual codes (for example, when participants were worried about the future residential care for their CWD but not about their own health). All relevant quotes were colour-coded using coloured sticky notes with line numbers to aid retrieval of quotes later on for analysis.

The fourth step of Tesch's coding process involved assigning headings to each topic. These headings were then taken back to each transcript and written next to the appropriate segment of the transcript. Step five grouped the headings that related to

each other. Throughout this coding process all codes were generated independently and were constantly compared between the two researchers to avoid losing significantly meaningful information while reducing the data. At the end of step six 17 emerging codes were identified. Within step seven, a coloured sticky note was assigned to each participant and the line numbers for quotes that contributed to each code were recorded on the sticky note (for example, participant 3, Caitlin, was represented by a yellow, heart-shaped sticky note while participant 7, Gary, was represented by a pink, square-shaped sticky note – see Figure 1 in Appendix 3.3).

In the second part of Tesch's step seven the research moves into Creswell's Step 4 identifying themes. All the sticky notes were displayed on a large whiteboard and the researcher started grouping the sticky notes into the respective codes. Each code was then written on a separate page in the qualitative codebook and the sticky notes with the quotes were placed on the corresponding code page. These codes were then collapsed during recoding, the last step in Tesch's analysis based on grouping common codes together under a larger code. At the end of this step six final codes including the 17 subcodes were generated (see Table A3.1 in Appendix 3.2). The summary of the information that contributed to each code and its subcodes were written in dot point form under each code page. Photographs of these pages (see Figures 2 and 3 in Appendix 3.3) with the six codes were taken for audit trail purposes to provide evidence and ensure dependability and confirmability (Lincoln & Guba, 1985).

Step 4: Themes. One aim of study 2 was to gather and explore perspectives of FQOL from parents of school-aged CWD. This topic was highlighted as theme 1 – *Parent perspectives of FQOL*. Since this research question was also about parent perspectives of their FQOL in relation to disability-related supports and parent

occupations, the subthemes were created accordingly from the codes. Under subtheme 1.1 – *FQOL is better when we feel supported*, all codes that included supports were grouped together; for example, disability-related supports. Under subtheme 1.2 – *FQOL is challenged during difficult times and when we think about the future*, all codes that presented challenges were grouped together; for example, challenging behaviour (see Table A3.4 in Appendix 3.2). To find out about the influence of having a CWD on parent occupations and FQOL, subtheme 1.4 was titled – *Having a CWD has consequences for families and on FQOL* and all codes pertinent to consequences were grouped under this subtheme. The last research question was about comparing the FQOL from the time in ECIS to now, as per the perspectives of parents in study 2. All the codes pertinent to the parent perspectives about how their FQOL was different now as compared to when they were in ECIS were grouped under theme 2 – *Comparing early years to now*. Under theme 2, codes that were pertinent to the differences were included and were placed under four subthemes: *FQOL then and now*, *Caregiving then and now*, *Supports and services then and now*, and *Parent occupations then and now* (see Table A3.4 in Appendix 3.2). For credibility and dependability, the themes, subthemes, and codes were checked against each individual participant and then across participants. A table was created in Word to chart these four themes across the rows and the participant pseudonyms along the columns, as seen in Table 3.8 in the results and findings section of this chapter. An ‘X’ across the participants’ column denotes their contribution to this theme. The details of this process along with the qualitative findings are presented in the findings section of this chapter, and a snapshot of this analysis process can be seen in table form within Appendix 3.2 (see Tables A3.6, A3.7, A3.8, A3.9, A3.10, A3.11, and A3.12).

This chapter presents the findings from study 2 that include themes 1 and 2. The next part of the analysis pertains to the final aim of this doctoral study, to compare whether the FQOL of parents of school-aged children is different to parents of children within ECIS. The comparison of the perspectives of parents of children in ECIS (study 1) to school-aged children (study 2) are presented in Chapter 4. The method used for comparing the qualitative data and answering this question is also presented in Chapter 4 where comparative analysis and integration of both studies has been reported. The final two steps of analysis by Creswell involving interrelating and interpreting the themes to answer the research questions were modified because both studies were considered and compared for the final analysis. These steps included a synthesis from both the studies and are presented in Chapters 4 and 5.

3.2.3e Trustworthiness. The same steps as study 1 for trustworthiness were carried out in study 2. Please refer to Chapter 2, section 3.2.3d for trustworthiness details that are applicable to study 2.

3.3 Results and Findings

This section presents the results from the quantitative BC-FQOLS and demographic questionnaires, and the findings from the 12 qualitative interviews. All the quantitative results will be presented first, followed by the qualitative findings and to end the chapter a summary of both the results and findings will be triangulated and presented.

3.3.1 Quantitative results. Fifty participants completed and returned the demographic questionnaires and surveys. It was estimated that between 75–100 surveys were distributed to families with a response rate between 37%–50%. Demographic data are presented in Table 3.3.

3.3.1a Descriptive scores – Demographic questionnaire. The majority of participants were mothers (84%) followed by fathers (12%), and (4%) others. Nearly 58% of the CWD were between the ages of 10–15 years, 38% were between 7–10 years, and 6% were between 15–18 years, with the primary diagnoses of the children including autism spectrum disorder (46%), cerebral palsy (12%), congenital issues (16%), Down syndrome (18%), no clear diagnosis (4%), and other (4%). English was the main language spoken in 96% and 4% spoke a different language. The annual income of 22% was between \$30,000–\$50,000, 26% between \$50,001–\$70,000, and 28% earned more than \$70,000. About 24% were not working and had no income except from social welfare. In terms of the schools their CWD attended, 76% of children attended special schools, 14% attended mainstream school, and 28% attended a dual combination school which means that their CWD attended a few days per week in a mainstream school (2–3 days) and the rest of the days in the week in the special school. In terms of work status and employment, 16% of the main caregivers were not working due to their child’s health, 24% were homemakers, 36% were working part-time, and 12% worked full-time.

Table 3.3 *Demographic Data Scores for Study 2 – Quantitative sample (N = 50)*

Demographics of quantitative sample		Frequency	Percent
Relationship	Father	6	12.0
	Mother	42	84.0
	Other	2	4.0
Parents together	Father lives at home	37	74
Siblings	Sibling/s lives at home	45	90
Age of child	7–10 years	19	38
	10.1–15 years	28	56
	15.1–18 years	3	6
Languages spoken	English	48	96
	Other	2	4
Diagnosis of child	Cerebral palsy	6	12
	Down syndrome	9	18
	Autism ASD	23	46
	Congenital conditions	8	16
	No clear diagnosis	2	4
	Other	2	4
Annual income	Not working (nil income)	12	24
	\$30,000–\$50,000	11	22
	\$50,001–\$70,000	13	26
	>\$70,001	14	28
Type of school	Mainstream	7	14
	Special school	38	76
	Combination school	4	8
	Other	1	2
Work status	Not working due to my child's health	8	16
	Not working due to my health	1	2
	Working full-time	6	12
	Working part-time	18	36
	Full-time home maker	12	24
	Student	2	4
	Other	3	6

3.3.1b Results from the BC-FQOLS. For the first research question regarding parents' perspectives of their FQOL, the descriptive analysis scores indicated that the distribution of scores on the continuous variable, 'satisfaction with total FQOL' (TFQOL) had a range of 91 ($M = 90.96$, $SD = 16.90$) and on the subscales of 'total family interaction' a range of 22 ($M = 22.26$, $SD = 5.09$); 'total parenting' had a range of 24 ($M = 21.88$, $SD = 4.74$); 'total physical material well-being' had a range of 17 ($M = 19.40$, $SD = 3.62$); 'total emotional well-being' had a range of 15 ($M = 12.46$, $SD = 3.65$); and 'disability-related support' had a range of 14 ($M = 14.96$, $SD = 3.21$). Please refer to Table 3.4 for these scores. The scores from the BC-FQOLS indicated strongest association for total FQOL (TFQOL) with the subscale of 'family interaction' ($\rho = 0.90$, $p < .01$), followed by 'parenting' ($\rho = .88$, $p > .00$), 'emotional well-being' ($\rho = .78$, $p < .01$), 'physical material well-being' ($\rho = .69$, $p < .01$), and disability-related support ($\rho = .64$, $p < .01$).

Table 3.4 *Descriptive Scores for Subscale Items on BC-FQOLS – Study 2; (N = 50)*

N = 50	Total FQOL (TS = 125)	Total Family Interaction (TS = 30)	Total Parenting (TS = 30)	Total Physical Material WB (TS = 25)	Total Emotional WB (TS = 20)	Disability- Related support (TS = 20)
Mean	90.96	22.26	21.88	19.40	12.46	14.96
Median	93.00	23.00	22.00	19.50	13.00	15.00
Std. Deviation	16.90	5.09	4.74	3.62	3.65	3.21
Range	91.00	22.00	24	17.00	15.00	14.00

FQOL = Family Quality of Life; WB = Well-being; TS = Total score; IQR = Interquartile range

Regarding the relationship between disability-related supports and FQOL (for research question 2), the descriptive scores indicated that 76% of the participants were satisfied with the relationship they had with their service provider, 8% were not satisfied, and 16% chose neither. The quantitative results indicated that there was no significant correlation between satisfaction with adequacy of services received (from the demographic questionnaire) with disability-related support ($\rho = -.125$, $p = .39$), and with total FQOL satisfaction (BC-FQOLS) ($\rho = -.061$, $p = .68$).

The second part of research question 2 was about parent occupations. In terms of contracted occupations or paid employment, descriptive scores from the demographic questionnaire indicated that 16% of the main caregivers were not working due to their child's health, 24% were homemakers, 36% were working part-time, and 12% worked full-time. About 10% selected being students, or other, and 2% were not working because of their own health issues.

For free-time occupations, 54% of the participants were either dissatisfied or very dissatisfied with the time they could spend on pursuing their interests, and 20% were satisfied or very satisfied, with the remaining 8% choosing neither. For relationships between parent occupations and disability-related support, four items from the BC-FQOLS were selected based on maximum agreement scores and correlated with the BC-FQOLS subscale “disability-related support”, similar to study 1. See Table 3.5.

Table 3.5 *Correlation Scores – Parent Occupations and Disability-related Support – Study 2; N = 50*

Parent occupations	Disability-related support (ECIS)
Committed occupations	
Item 1: Spending time together	
Correlation coefficient	.587**
Item 19: Taking care of individual needs of every child	
Correlation coefficient	.446**
Necessary occupations	
Item 16: Taking care of expenses	
Correlation coefficient	.263
Free-time occupations	
Item 9: Time to pursue own interests	
Correlation coefficient	.434**
significance	
Contracted occupations	
Work status (from demographic questionnaire)	
Correlation coefficient	-.073

For committed occupations, there were strong positive correlations between item 1: spending time together as a family ($\rho = .59, p < .01$) and item 19: taking care of the individual needs of every child ($\rho = .45, p < .01$) and “disability-related support” indicating that such committed occupations were associated with the support the families were receiving from their disability-related supports. For necessary occupations there was no significant correlation between item 16: taking care of expenses for family ($\rho = .26, p = .07$) and “disability-related support”. However, for free-time occupations item 9: time to pursue own interests and “disability-related support” there was a strong positive correlation ($\rho = .43, p < .01$). For contracted occupations, there was no significant correlation between the work status of the main carer and “disability-related support” ($\rho = -.07, p = .62$).

In terms of the relationships between all three variables, namely disability-related support, parent occupations, and FQOL (research question 2), all the above strong correlations between items and subscales of the BC-FQOLS, and items from the demographic questionnaire, demonstrate associations between parent occupations, disability-related support, and FQOL. There were no significant correlations between work status of the main carer and total FQOL ($r = -.05, p = .73$). The descriptive scores indicated high scores on the TFQOL of the participants in this study.

3.3.2 Qualitative findings

Qualitative data was collected in the form of semi-structured, in-depth interviews, and analysed for perspectives and themes. Twelve participants were selected to include mothers, fathers, and families with varying socio-economic status and a range of diagnoses.

3.3.2a About the participants. All 12 participants were parents of CWD who were attending school. The demographic details are listed in Table 3.6. They were

selected from diverse regions of metropolitan Melbourne and included eight mothers and four fathers.

Table 3.6 *Demographic Data – Qualitative Study 2*

Participant	Area/region	Diagnosis of child/severity (according to parents)	Age of child	Siblings	School	Marital status	Other child has disability or delay or undiagnosed	Family income	Work status
I1 – Amanda (married to Harry)	South East	Down syndrome (Mild)	17 years	2 siblings	Mainstream till year 7, now special school	Married	No. But issues related to puberty	Average	Part-time
I2 – Bianca (married to Eli)	South	Autism (moderate)	12 years	2 siblings	Special school	Married	No	Average	Part-time
I3 – Caitlin (married to David)	South	Cornelia de Lange syndrome (severe)	15 years	2 siblings	Special school	Married	Unsure – one may have learning difficulties	Average	Part-time
I4 – David (married to Caitlin)	South	Cornelia de Lange syndrome (severe)	15 years	2 siblings	Special school	Married	Unsure – one may have learning difficulties	Average	Full-time
I5 – Eli (married to Bianca)	South	Autism spectrum disorder (moderate)	12 years	2 siblings	Special school	Married	No	Average	Part-time
I6 – Fiona (married to Gary)	East	Autism spectrum disorder (severe)	15 years	1 sibling	Special school	Married	No	High average	Part-time

I7 – Gary (married to Fiona)	East	Autism spectrum disorder (severe)	15 years	1 sibling	Special school	Married	No	High average	Part-time
I8 – Harry (married to Amanda)	South East	Down syndrome (mild)	17years	2 siblings	Mainstream till year 7, but now in special school	Married	No. But issues related to puberty	Average	Part-time
I9 – Isla	South	Autism spectrum disorder (moderate)	8 years	1 sibling	Special school	Married	No	Average	Part-time
I10 – Jemima	East	Autism plus rare metabolic disorder (severe)	12 years	2 siblings	Special school – and residential care	Single	Yes. Other 17-year-old has autism and rare metabolic disorder	Low	Part-time
I11 – Kate	South	Cerebral palsy (severe)	15 years	3 siblings	Special school	Married	No	Average	Part-time
I12 – Lisa	South	Cerebral palsy (severe)	10 years	3 siblings	Special school	Single	Yes. Other 10-year-old has mild intellectual disability and anxiety	Low	Not working

The main carer was the mother, and 10 out of the 12 participants were working part-time in a paid job. The annual income details were gathered from the demographic questionnaire that all participants filled out at the start of the quantitative study. The annual household income ranged from low to high average and was determined using the Australian Bureau of Statistics (ABS) categories, indicating high average income as approximately \$96,000 and low average income as \$20,800 or less for the year ending in 2014 (ABS, 2015).

Eight interviews took place at the participants' homes, two in the participants' office, and two in the researcher's office upon their request. The information below introduces participants and presents some observations made by the researcher during and after the interviews. These descriptions present the context of the interviews highlighting the additional parenting responsibilities of parents caring for CWD. These descriptions also provide a further understanding of the diversity yet similarity in their experiences. The four fathers interviewed were spouses to four mothers (also interviewed) and were selected to gain the fathers' perspectives of their FQOL and to check for any consistencies or differences between the two parent responses. Surprisingly, during analysis of their data there were more similarities than differences between their perspectives. Common responses from the fathers were grouped together during coding, as there were some similarities noted between the four fathers. Any specific differences between the parents' perspectives are also highlighted in the analyses.

The participants were deidentified and pseudonyms were assigned. The code in parenthesis next to the name of each participant denotes the order of the interviews;

for example, **I1** means that this participant was the first interviewee where ‘**I**’ stands for the interviewee.

Amanda (**I1**) was interviewed at the researcher’s office. She has three sons, the oldest of whom, Eddie, has a diagnosis of Down syndrome. He is 17 years of age and his brothers are 16- and 15-years-old. Eddie was in mainstream school throughout his primary school years and since the start of secondary school he had changed a few schools as the schools were unable to manage some of his behaviours. Eddie is fully independent in all daily skills. He often runs away from home to busk on the streets, and most of the area police are involved with the family and are aware of his escapist episodes. Amanda very reluctantly placed him in a special school two years ago. She reported that the special school did not challenge him enough, and that he was capable of being in a mainstream school because of his high cognitive capabilities. She wanted him to attend the same school as his siblings; however, this was getting harder mainly due to the escapist behaviours at school which were hugely concerning to the school and they requested that he be sent to a different school. Amanda currently works part-time, and prior to having her children she worked full-time in a senior project management position managing employees for a large company. She was unable to return to work after her son Eddie was born and diagnosed with Down syndrome. She tried to return to work on several occasions but due to his medical needs or callouts from his school she was not able to pursue her career as a project manager. She worked as a childcare assistant in the early years and continues to do casual childcare work. She sews costumes and assists with managing school events such as concerts on a voluntary basis. Her husband is a tradesperson who works part-time and she reported having average income. The family have experienced periods of financial difficulties through their life and on occasions her parents have helped with

finances. Her main support is her husband Harry, as she was not comfortable asking for help from extended family or friends. Harry (I8) was interviewed later for this study. It seemed from some of Amanda's comments that the family was going through a difficult period with the other boys, who were beginning to show resentment towards their brother, Eddie. However, Amanda reported that this was related to their age because they were all reaching puberty and she was reluctant to talk further about the issues between the brothers. She also expressed that she wished to go back to study and do research that would help children and families with disability, but was unable to find time for study or work.

Bianca (I2) was interviewed at her home. Bianca has three children, the eldest of whom is 12-years-old James, with a diagnosis of autism, followed by Joel and Lauren. James started school in the mainstream but was soon changed to dual schooling (part-time mainstream and part-time special school), and in the last two years he is attending an autism specialist school. James is dependent for most of his daily activities and will assist with dressing or showering; however he needs supervision. He uses communication books and visuals to communicate and uses very little speech. Bianca was a schoolteacher and worked full-time before the birth of James. She had recently started to work at a school part-time as a teacher after a gap of 12 years. Her husband Eli (I5) worked full-time. She would have liked to work more hours; however, she said that the days she worked were hectic and she had to organise her parents to pick up the children from school on those days. Bianca apologised for the house being messy a few times during the interview and also complained about how tired she felt doing housework. She said that she spent most of her free-time researching for services and supports to help James achieve his goals. She expressed a sense of guilt at not being able to spend time with the other two

children or give them the support they needed, or be able to go out with them, without thinking about James' needs. The family had an average annual income; however, Bianca mentioned feeling stressed about finances due to her inability to work more hours.

Caitlin (I3) was interviewed at her home. She has three boys, the eldest, Mick, is 15-years-old and diagnosed with a congenital condition. He has very high medical needs. He has no speech and uses some gestures to communicate. He has attended a special school since he started school. Most of the time his needs are anticipated by his family members or school staff. Her other two boys are 12- and 11-years-old and attend mainstream school. Caitlin reports that the siblings have a wonderful relationship with their brother and involve him in all play activities. However, of late the 12-year-old has been expressing the need to be with his friends more. The family is very aware of Mick's high caregiving needs, and the impact of his caregiving on all family members. They often plan holidays and outings without Mick to be able to spend time with others, without the worry of caregiving. Caitlin was a full-time hairdresser before the birth of Mick, but was not able to return to work for several years after he was born. She reported that she suffered from post-natal depression and had found the initial years with Mick extremely hard and challenging. She trained to become a childcare assistant and worked part-time as an assistant for many years when her sons were at school. Her husband David (I4) is very supportive and helpful. Caitlin reported that the best thing she found on the journey of disability was the support of other parents of CWD. Over the years she developed an interest in supporting other parents via parent support groups. She currently facilitates and runs parent supports groups and advocates and researches information related to supports and services for CWD. She reported having average annual income and mentioned the

difficulties with finances due to loss of income. However, she seemed happy with her new work, even though it was not remunerated well. She missed hairdressing and the income, but said that she still did a bit of hairdressing for her friends to keep her skills.

David (I4) was Caitlin's (I3) husband and the interview took place in their home. During the interview a respite worker was present and was looking after their eldest son (with disability) Mick. David worked part-time as a salesperson and started his work day very early to be able to return in time to pick up the children from school. He expressed how his priorities changed after having a CWD, and that prior to that he had high ambitions and wanted to be wealthy. However, he seemed happy with his current work and he loved spending time with his family. He said that he felt "bogged down" by the expenses and mentioned how they had refinanced their home several times to be able to manage finances. However, working full-time was not an option for him as Mick needed lots of support for, caregiving, and he shared the caregiving with his wife. He reported that he had suffered from depression in the past (after Mick's birth) and talked about how difficult it was to come to terms with the challenges of having a child with severe disability. He enjoyed taking trips with his family and planned trips with or without their son with disability to balance the other family members' needs. He mentioned that the family still found some of Mick's behaviours hard to manage and these behaviours impacted all family members. He was very proud of his wife's role as an advocate and researcher and was grateful to her, as he was unable to find time for such things and appreciated how she helped them source funding and supports, especially respite care.

Eli (I5) was Bianca's (I2) husband and was interviewed at his home. He worked full-time and would have liked to reduce his work hours to help his wife with

caregiving. However, he expressed that he had to work due to financial needs. He was grateful that his wife was able to drop her work and look after the children, especially their son James and his high needs. He valued the support that they received from Bianca's family in caring for the children, picking them up from school if needed, and felt bad that his own family members could not help because they lived in a different state. He loved spending time with his children and wife but was not able to get enough time with them due to the caregiving needs of their son James, and household chores. He planned a trip each year with his family and valued spending this time together with them.

Fiona (I6) has two children, Samuel, 15-years-old and Jane, 11-years-old, and was interviewed at her home. Samuel has a diagnosis of autism and he displays several behaviours of concern including violent and aggressive behaviours towards family members and friends. Fiona works part-time and prior to her son's birth she worked full-time as an academic. She was unable to return to full-time work due to the high demands of caregiving. Samuel has attended specialist school since prep but recently was refused school attendance as he was displaying extremely violent behaviours. A few weeks prior to the interview Samuel had displayed violent aggression towards Fiona and she had to be hospitalised. Due to this serious consequence, the family was able to get him placed in interim residential care and this had changed their home life completely. Fiona showed me her home that was destroyed in several places, and she was relieved that the family would be able to sit and relax without the fear of having something hurled at them. Her daughter Jane also experienced her brother's aggression frequently which had resulted in her getting a lock for her room, so he couldn't enter. This family was severely impacted by their son's behaviours and the interim care was a big relief to all the family members.

Fiona mentioned that they had not used cutlery or crockery for several years and were looking forward to entertaining friends at home. The family had high-average annual income.

Gary (I7) is Fiona's husband and was interviewed at his office. His experiences were similar to those of Fiona; however, he seemed deeply hurt that the family had received such little support during the past years and was concerned about his wife's and his own health. He reflected on how hard it was for the family to manage a child with severe behavioural challenges. He found their life extremely challenging and hard, with not much support. He worked part-time and was in a health care profession. He was unable to work full-time due to caregiving needs and expressed that he felt frustrated that he was not able to think about his career progress, as it required time commitment and energy. He was looking forward to spending time with his family (their son was recently moved into interim residential care) doing everyday things like cooking a meal together, or sitting together and watching television, as these were activities they were unable to do in the past due to their son's behaviours. He seemed horrified with the health system and would have liked coordinated care for the family from the start so that they would know what services to access. It is interesting to note that their family did not receive family-centred care during ECIS years.

Harry (I8) was Amanda's (I1) husband and was interviewed in the researcher's office. Harry worked part-time as a tradesperson. He was very concerned about his second son Tom, reporting that Tom was resentful of his brother Eddie (Down syndrome) and did not want to be in the same space as Eddie. Tom was supposedly a bright and enterprising young boy who liked science. Harry said that Tom found Eddie's behaviours hateful and asked for his own room and refused to

share with Eddie. Harry was worried that this was also impacting the youngest son, Clint, who had now started refusing to share with Eddie. Harry's perspectives on the relationships between the siblings were different to his wife Amanda (I1) and he felt strongly that the brothers were not getting along. He was quite saddened and also tearful at times during the interview when thinking about the future when he would not be around to care for Eddie. He seemed frustrated and helpless about Eddie's future and was concerned about abandonment of his son by the brothers. Even though he did not expect them to look after Eddie in the future, Harry seemed concerned about Eddie's future. He also did not trust his extended family members, or the service system, to support them. He said that he wished he could see the future and help Eddie. He spoke about how he would like to spend time with adults with Down syndrome to be able to see what lies ahead for Eddie.

Isla (I9) is a mother to two children, Alex, who is 8-years-old with a diagnosis of autism and her younger daughter, Jessica who is nearly 4-years-old. She was interviewed at her home with Jessica, who was very demanding for attention. The interview had to be paused several times to address her requests for food, and other activities such as television, drawing, and play. Isla's son was the youngest in this study and had entered school two years ago. He started in a mainstream school; however, within a year he was moved to a special school. Isla was still coming to terms with the daily routines, schooling, and therapy appointments and invested a lot of time in private speech therapy for Alex. She talked about not being able to spend time with Jessica, and it seemed that she felt guilty about this issue. Isla worked in accounting and had a very high paying job prior to having Alex. She was not able to return to her work and missed it, especially the income. However, she had no time for work because her son's needs were quite high. He needed support for all daily

activities and was not using speech for communication. He displayed unsafe behaviours, and she had to stay very alert as he would often run on the main street if the door was not locked or wander away in shopping centres. Jessica was also demanding of her mother's attention, as was evident throughout the interview, and Isla commented that she had lost 20 kilos of weight since the birth of her son Alex as she had no time to eat a proper meal. Her husband had recently started his business from home and worked long hours and on weekends, so was unable to help her with household chores or caregiving. She also helped his business with accounting and seemed to like doing this work. The family had average annual income; however, Isla reported that they often received financial help from the extended family as finances were tight and her husband was trying to settle into his new business. She seemed to also spend a lot of time looking for services and supports for her son and was grateful to be part of a parent support group that helped with such information. She was not able to attend these groups as often as she liked due to emergency callouts from the school to take Alex home as he often demonstrated challenging behaviours at school.

Jemima (I10) has three children, two boys of 17 years (John) and 12 years (Peter), who are both diagnosed with autism, and one youngest daughter of 11 years (Rose) at school. She was divorced and lived with her two children. Her 12-year-old son Peter was placed in residential care last year due to extreme violent and aggressive behaviours, posing several threats to her life and to the safety and well-being of her daughter, Rose. His aggressive behaviours had continued for several years in the past with the involvement of police on several occasions; however, she was not eligible for interim residential care because of his young age. John, the elder son (autism), was also suffering from severe depression and was often found by the police trying to take his life on a bridge. Jemima was extremely exhausted with the

caregiving needs of her children and had no support systems except for her mother. But as she said, *she kept going*. Jemima was a lawyer prior to having her children and worked in a large law firm where she earned a high income. However, she was unable to return to her work due to having two CWD. Her husband was abusive towards the boys and she had to separate from him, and this led to her being the sole caregiver with no job. She experienced huge financial difficulties and reported that she received some financial and emotional support from her mother. Her property and savings were gone. After Peter was placed in residential care last year, she had started her own business six months ago and hoped to be able to become financially independent. She was currently living in her parents' home with her two children and had rented an office space. Her daughter had seen Peter's aggression towards their mother and was highly alert and fearful that something would happen to her mother. Jemima was recently diagnosed with cancer and needed to start treatment; however, she had put this on hold. She was aware of her daughter's fears and worried about her cancer as well. Jemima had received very little respite support or support for managing her sons' challenging behaviours and reported that her quality of life was extremely poor.

Kate (I11) has four children, three daughters and the youngest son. Two of her daughters are twins and are 15-years-old. One of the twins, Kara, has a diagnosis of cerebral palsy and attends special school. The eldest daughter is 21-years-old and is at university. The youngest son is in primary school. Kara needs assistance for all daily activities and uses a wheelchair. She is able to communicate her needs but refuses to communicate consistently, choosing who she wants to communicate with. Kate said that she is able to use many words and short sentences and also uses a communication book when she wants to. Kate feels that her family has always been well supported. Her husband is very helpful and since the twins were little they received family-

centred services. She said that they were able to manage all family members' needs well due to the ongoing support. Kate worked in a paid job earlier but wasn't able to return to work. However, when the twins were at school, she started to work as a family support worker, and continues to work part-time supporting other families. She is very satisfied with her work status. The family earn an average annual income and even though Kate talked about financial difficulties, she can access supports and aids and equipment for her daughter as needed. She feels that she is lucky because she has had responsive therapists and services and has not felt the challenge of caregiving, even though it is time consuming. Her eldest daughter helps with caregiving and all the siblings get along very well. The family has access to occasional respite care, and recently received a funding package for home and car modifications.

Lisa (I12) has four daughters, one at 14 years, 10-year-old twins, and a 6-year-old in school. One of the twins, Maddie, has a diagnosis of cerebral palsy and the other twin Anna, has a mild intellectual disability. Maddie requires assistance for all her daily activities and uses a wheelchair. She has very little speech but communicates well and attends special school. Anna has learning difficulties and finds it hard to make friends, often displaying anxiety, hiding, and becoming quiet when asked to communicate. She is in mainstream school, but according to Lisa she is struggling, and Lisa would like to move her to a special school as well. Prior to having children Lisa worked, but has never worked since having the children due to the high caregiving needs of the twins. She separated from her husband a few years ago and she said that her life was extremely difficult after the separation. She had no money and had to start from the beginning again; however, she was happy with her decision. She received some financial support from her family and had recently found a place to rent and seemed happy with her current situation. She found it hard to

manage the caregiving but said that she used “tight schedules” around school pickups and home routines to help her get through everyday activities along with the added caregiving. Lisa suffers from poor health, has severe back pain, and has no time for looking after her health, but she hopes to do so in the near future. She is not receiving any respite care or other support at home. She was not aware of such supports and was surprised to hear during the interview that she could apply for respite care and other services. She had an appropriate wheelchair for Maddie and also felt supported in terms of receiving aids and equipment for Maddie from the school therapists. She had not asked for home or bathroom modifications and thought that that was something she would need in the future, even though she was finding it really hard to manage Maddie in the shower and toilet currently. She had very positive values and beliefs and believed that all the siblings would continue to love and support each other. She had received family-centred support in the early years and was aware of the importance of looking after siblings’ needs as well. Even though she had very few resources, her family related well to each other and helped her in caregiving.

3.3.2b Qualitative analysis findings. The findings are reported in this section based on the analysis. The initial steps in the qualitative analysis led to six codes that were numbered from 1 to 6 in no particular order with numerous subcodes.

Step 3: Codes. The six codes and subcodes are presented next and are also presented in Table 3.7.

Table 3.7 *Codes in Numerical Order with Subcodes - Study 2*

Code	Description and subcodes
Code 1	Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting; however, there are positives about having a CWD.
Code 2	<p>Sharing good times as a family is important for FQOL.</p> <p>2.1 Family time is important for FQOL.</p> <p>2.2 Recreation for the CWD is important but is difficult for parents due to lack of time and resources.</p>
Code 3	<p>Caregiving for the CWD is an ongoing and long-term challenge and impacts all family activities and family members.</p> <p>SUBCODES</p> <p>3.1 – Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings.</p> <p>3.2 – Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being.</p> <p>3.3 – Caregiving for a CWD impacts parent occupations; parents are unable to return to paid work, with lack of time for self-care or meaningful occupations. Most parents become advocates and researchers.</p> <p>3.4 – Caregiving for a CWD impacts socialisation with friends/family, and most family activities are adapted to suit the needs of the CWD. Siblings miss out and parents feel guilty.</p> <p>3.5 – Parents worry about the future caregiving needs of their CWD, especially residential care. Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future.</p>

Code 4	Having a CWD impacts financial/material well-being due to extra costs and reduced income.
Code 5	<p>Services and supports are valued and help FQOL.</p> <p>SUBCODES</p> <p>5.1 – Special schools provide support for therapy needs and are a respite for parents due to long hours.</p> <p>5.2 – Respite care is valuable because it provides parents time away from caregiving and the CWD enjoys the time in respite too</p> <p>5.3 – Help is available from family and some others, and is valued, but parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older. Partners and spouses are the main support.</p> <p>5.4 – Support groups are valued because they provide information, research, and friendships.</p>
Code 6	<p>Families miss the ECIS family-centred support and the keyworkers, the financial support, and fun and engaging activities for their CWD, but the early years were raw and hard. Parents adapt and become advocates for their CWD.</p> <p>SUBCODES</p> <p>6.1 – Parents miss the ECIS services and family interaction.</p> <p>6.2 – Funding for services after ECIS is difficult. Disability support services are difficult to access. NDIS is helpful.</p> <p>6.3 – Inclusion of CWD into mainstream school is difficult and challenging for parents due to lack of supports in schools and lack of ECIS-like support.</p> <p>6.4 – Dads need support in the early years, but the support they seek is different to mothers.</p> <p>6.5 – Early years are raw and hard and more focused on the here and now and on child's therapy rather than parental well-being.</p> <p>6.6 – Parents become advocates for their CWD and for other families.</p>

FQOL = Family quality of life; CWD = child with disability; ECIS = early childhood intervention services

Code 1: Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting, however there are positives about having a CWD. Most participants reported that their FQOL was difficult and fluctuated as needs arose. They mentioned that dealing with the ups and downs and adapting to ongoing changes and challenges was a part of their life. Amanda (I1) said that her FQOL was hard. For Bianca (I2), a good FQOL meant that she could “make everything happen and fit” and she reported that her FQOL was limited because of the lack of time.

Yeah it’s hard [FQOL], yes I would agree that it’s hard. I1: L11 (Amanda)

So the quality of it, really, it’s just about making everything happen and fit. I2: L13 (Bianca)

Bianca mentioned how their FQOL was limited and the family members just dashed past each other at home with very few opportunities to sit back and ask each other about how their day was going. She stated that her life was absorbed with the routine activities, getting through all the needs of the family, along with caregiving for her son with autism. She said that they had to make adjustments all the time and she wished inwardly that it would be different but had learnt to accept it.

I guess for us ... it’s pretty limited for us. Our ... family life is, I guess, really just full of um ... busy-ness that is sort of dictated by the clock. There are times when you sort of get to the end of the day and realise you haven’t actually sat and had a conversation with someone else in the family; ... we just like, it’s sort of like that quick dash past each other in order to, you know, meet a deadline or work commitments or kids to places and things like that but particularly James [CWD], you know, he has additional needs ... quality time um is still just absorbed into routine activities. Because everything takes longer. I2: L5–14 (Bianca)

You just make adjustments as you go. You know, inwardly you wish it would never be like this, but you just learn to be okay with it because that’s just how it is. I2: L733–750 (Bianca)

Caitlin (I3) reported that their FQOL was hard and fluctuated, feeling good when her son with disability was having a good day. She compared her life to a ground hog day repeating over and over again.

In this particular moment [FQOL] ... quite hard at times ... I think that it fluctuates [FQOL]. It depends if he's [CWD] having a good day or a bad day or maybe he's gone to the respite house for the weekend or something ... but it's ... it's... it's like ground hog day. It's over and over and over again. I3: L4–5; L25–29 (Caitlin)

Having a good FQOL for David (I4) meant constant adjustments and dealing with the needs of his son with disability. He mentioned that he was not able to do things such as home maintenance tasks, mowing the lawns, and work in their backyard due to the busy family life. He was not pleased with how his home looked, and this was important to his FQOL; however, he also mentioned that this had to take a back seat because the parents were busy in caregiving.

But we just take every day as it comes and deal with ... with the ups and downs as it goes ... I've always said to myself that I didn't ask to have Mick [CWD], it's just that we've had Mick and we'll deal with it. We have to adjust our lives and it is constant adjustment. I4: L16–17; L616–618 (David)

You can't plan, I guess, to do things. Oh just your normal maintenance, like mowing the lawn, house maintenance and things like ... yeah and just prepare the backyard and so forth, get that finished ... yeah more time to do that yeah ... It's very hard to get outside to do whatever you need to do ... I have to be here and I have to look after the other kids so that can be hard. I4: L53; L60 (David)

Fiona (I6) reflected on her life and her family life as being terrible because they had to constantly manage their son's disruptive behaviours. As a family they were not able to enjoy doing things together because their son with autism did not like to do things together, and most times at home the parents were taking turns to supervise him. Their home and cupboards needed to be secured at all times.

Well so we've had terrible family quality of life for many years ... we had to have everything locked and we couldn't, there were very few things that we could actually do together as a family ... because he [son with autism] didn't want to be a part of

anything that we were doing ... anything at all. Someone always had to be with Samuel, to be watching Samuel, to be doing whatever um, Samuel needs ... all those doors are locked ... **I6:** L16–18, 24–26, 70–76 (Fiona)

Gary (**I7**) reported that their family life was dreadful due to his son's caregiving needs. Isla (**I9**) also said that her FQOL was hard, but they took one day at a time and hoped that things would get better. Jemima (**I10**) said that their FQOL was hard and it was difficult to find quality moments. Lisa felt that balancing between all the things that her children needed done was hard, and her quality of life even though good was a struggle.

... [FQOL] it was dreadful, because it was totally dominated by his care needs, ... taking time away from us personally. **I7:** L17–21 (Gary)

At the end of the day, yeah, it's got its challenges, it's hard. But you know what, you just keep going. You take it a day as-a day at a time. Um, and hope that it'll get better, knowing that it probably won't. **I9:** L1179–1186 (Isla)

... our family life it's very difficult to find quality moments. **I10:** L19 (Jemima)

... we have good quality of life but we struggle with things like one at 11 years old, should be doing more sports, interacting with other children whereas I'm struggling with having the two special needs kids. I find the other two don't want to participate because I can't be there at a certain time, I can't make it to her... Yeah there's no balance at the moment ... I'm struggling... like I can't be at two places at the same time. **I12:** L4–15 (Lisa)

A few participants mentioned that their FQOL was challenging because of the challenges of a growing family. Along with the CWD, the siblings were growing older too and brought their own challenges and the parents had to balance these challenges. Amanda (**I1**) said that her 17-year-old son with Down syndrome wanted to do things that his brothers could do such as watching M-rated films and playing violent games.

And he wants to play violent games and that sort of thing coz he says you know, "I'm 17 now. I'm older than 15 [his brother's age], I can watch all the M stuff". **I1:** L24–25 (Amanda)

Her husband Harry (I8) expressed how the siblings, because they were growing up and had to share spaces and activities around the home with him, were feeling disappointed. The second sibling wanted his individual room, but the parents wanted them to learn to live together and play and laugh together like in the past. Harry was reminiscing how the siblings used to play together in the past and were friends and compared those times to the present time.

Well at the moment Tom [sibling], when he wants to come into the kitchen to eat, if Eddie's [CWD] there he'll walk out again ... he [sibling] hates it. He wants to be in his own room like he used to be ... so it wasn't always like that ... those kids they used to play and laugh together. I8: L37–38, L52–53, L70–74 (Harry)

Bianca (I2) mentioned new challenges because the siblings were acquiring new interests and going to the park was not enough to satisfy their interests like in the past. She reported that their FQOL was difficult to balance as the children got older because everyone had different interests. Due to the needs of the CWD, the other family members were not able to enjoy family time together because their son with autism was unable to sit for long, and most activities were focused on his needs.

The kids are growing older and have new interests and things like that ... they're sort of launching out to do different things and stuff like that ... James [son with autism] is not moving out and launching into new things ... when he was younger we would all go and that would become family quality time, but now Joel and Carla [siblings] are needing to do other things and to make that happen James still needs Eli [dad] or I to go ... so that actually lessens the amount of time we're all available to do something as a family. It doesn't become a family thing it becomes a James focused thing. I2: L604; L623–624 (Bianca)

However, despite the challenges and difficulties, a few parents mentioned that having a CWD was a positive experience for them and their family members. David (I4) expressed that having a CWD brought joy for their family and he said that it changed

his perspective in many ways. He said that he had understood the value of family and was not pursuing wealth and money but wanted to have a good life with his family.

He said that having a CWD had made him stronger.

I mean it just changes your perspective. You know, you value change, your way of thinking changes, the way you want to progress with your lives changes. ... Like I know kids are a big thing as it is. But having a child with special needs is like ... I hear customers moaning and groaning about cars and I'm going they have nothing to moan about ... it puts things back in place It makes you strong as a person and you find out about yourself... a little truer I guess. I4: L482–488 (David)

Caitlin (I3) had become an advocate for disability. She reported that she had established many friendships with other parents of CWD, and she valued these friendships immensely. She called the parents group an 'elite club' because it was made up of parents with children with additional needs and no one else was experiencing this.

I've always said that it's um an elite club, having a child with a disability that not anyone can join. I think ... I would have to say that the biggest thing got me through anything were friends in similar situations. Absolutely. Without a doubt, I would be lost without them. I3: L439–442 (Caitlin)

Eli (I5) mentioned that he had met amazing people because of his son with disability. He was astonished by the number of people that came to the campsite to help with finding their son with autism when he went missing on a holiday. Many of these people were parents of CWD that they had never met or known, and some were past parents from the parent support groups. It was a remarkable and positive experience for them to see this support from their past friends and from other parents.

Last Easter it was amazing how many of those families went to help to find James. They didn't need to ... knowing them it's like being on a journey with them as well. Even though their kids are all different, there are times where you help each other out with it. I5: L342–345 (Eli)

When they heard that James went missing, it was that group that really pulled it together and it was amazing what they pulled together through phone calls and texts... I don't even know them, but they say they have a kid on the spectrum like they do it tough but yet here they are wanting to help, they don't have to but they felt... I5: L359–372 (Eli)

Code 2: Sharing good times as a family is important for FQOL. Most participants reported that their FQOL felt good when the family members had good experiences together, did the things that they all liked doing, and shared good times. Most parents enjoyed family activities together and reported that spending time together was important for their FQOL. Some families spent time with the siblings while their CWD engaged in respite care and reported that this time was valuable for their family. Some parents reported that when their CWD had more opportunities to engage in recreational and fun activities they felt good; however, they reported that there were not many activities that they could do with their CWD due to a lack of recreational facilities. There were two subcodes under this code namely, “Family time is important for FQOL” and “Recreation for the CWD is an important aspect of caregiving but is difficult for parents due to lack of time and resources”.

Subcode 2.1: Family time is important for FQOL. For Gary (I7) FQOL meant enjoying the company of family members without feeling stressed or burdened. For Eli (I5), a good FQOL was when the family members shared good times together, like going out on holidays, or for dinner. Sharing quality family experiences and being able to do what each member, including parents, was interested in was important for Eli. He reported that as a family, their children were able to participate in a few interests but not as desired.

Family quality of life, I think it means uhh, being able to enjoy, the company of family members, find time for each other, do fun things together ... um, without feeling overly stressed and burdened. I7: L9–13 (Gary)

Family quality of life it would be, I suppose, sharing good times together like camping or going on a day trip or visiting ... or even going out for a dinner or an ice cream. That's sharing family experiences. I suppose in amongst that, that is, for family quality time, there is an element of them having their own outlets and things they're interested in. There has to be an outlet of also following what you enjoy as well. I5: L10–14 (Eli)

Caitlin (I3) reported that when the family was spending time together and feeling happy, their FQOL was good. Bianca (I2) referred to FQOL as a quality time with her children and family members and felt sad that she could not spend enough time with her children.

I think what helps is trying to look on the positive side especially when something fantastic happens ... and the good times and the fun times that we do have with all of them [family], with everyone. I3: L74–76 (Caitlin)

“Mum, we haven't finished watching Mary Poppins yet” [her daughter wanted to watch the movie with her mum] and I said, “Well, you can go and watch it,” and she said “No, I want to do it as a family!” I2: L30 (Bianca)

For David (I4), FQOL was also about having fun with his family, meeting with friends for a meal, going out on holidays, and doing things together. It was also about going out with his wife occasionally. It was important for him to have enough money to be able to enjoy fun times with his family and go on vacations. The family had bought a caravan to be able to include their son with disability, Mick, on the holidays. However, they also planned holidays without Mick, like going on a cruise. David felt guilty about not including Mick but reported that it was important for the other siblings to have a break from constantly supervising their brother on the holiday. He would have liked time to get to know what all his family members would like and help each one with their needs. Fiona (I6) felt that to be a family they wanted to be, they needed opportunities to do things together as a family.

Over the past couple of holidays that we've had and having Mick [CWD] with us ... we're not having a holiday. So we've decided that we're going to put Mick in respite

home and go on a holiday ... It makes me feel guilty. But we know, we need a break from work; we need a break from our normal lives so we can't have that when we have Mick all the time. I4: L420–426 (David)

Oh, Family Quality of Life. I suppose it's about opportunities to do things as a family and to do things that you all enjoy and that you all get some satisfaction out of. And, yeah, just being allowed to be the family you want to be. I6: L4–6 (Fiona)

Jemima (I10) reminisced about her childhood and how it was important that the family was a cohesive unit and did family activities together and had friends visiting all the time. She said that socialising with family members and friends was important to having a good family life. Kate (I11) said that their FQOL was hard to maintain; however, they liked spending time together as a family and that helped their FQOL.

... we had a really cohesive family unit and we were able to undertake activities together we went on holidays together we went on picnics together we went to the movies together we had people around to our house ... we had lots of friends and it was never just the nuclear family for dinner we were always thinking about how many extra potatoes to put on so that we could accommodate the friends who came after school ... it was just one of those crazy houses but I liked that ... I found that very nourishing ... I really enjoyed that as a child growing up I had good relations with both my brothers and that was really um yeah a very happy childhood for me which I haven't been able to reproduce at all for my own children ... I10: L6–19 (Jemima)

It's it's what you make of it quality of life, and it is extremely hard to maintain it with the other kids as well. I mean it depends on what your expectations of quality of life are. Ours could be just going out to the park, all of us together umm ... Yeah like spending time together umm with the kids and my husband and enjoying each other's company with no stress. It's what you make of it you can say 'oh my life is crap and boring or whatever, it's too hard' and stay home and be isolated or you can go out and enjoy life no matter what your obstacles are. I11: L6–12 (Kate)

Most parents reported that their FQOL was positive when the siblings without disability were accepting of their sibling with disability and adapted to the family needs. Caitlin (I3) and David (I4) admired the siblings for supporting their brother Mick and did not think that having a CWD impacted on the siblings' quality of life

but was good for their family. Caitlin enjoyed watching them play together with their brother and valued and appreciated them for spending time doing things with Mick. David said the brothers had accepted Mick and his inappropriate social behaviours like snorting and running away did not embarrass them. Even though these behaviours seemed to make them a bit uncomfortable, they continued to bring friends home and do things like other children their age and this was a good experience for both parents.

They just crack me up doing stuff with Mick. They do things with him that ... like I don't ask them to. We went away for Christmas and ... and we went to the beach ... surf beach and it had like massive dunes and ... they just take Mick off me and take him up the top of the sand dune and he won't go too happily so he needs a bit of coercing, but they put him on the board and they all come down and they have so much fun doing that so they do... they make their own fun with Mick ... and they ... It melts my heart just to see that. They get grossed out with some of his behaviours but they do... they understand that he's a little bit different. I3: L247–258 (Caitlin)

... the stage of embarrassment, having their friends over and Mick doing what Mick does like snorting all over the place or ripping his jocks off ... you know, running to the loo or after being to the toilet, running out without jocks on ... they're feeling a little uncomfortable around their friends but they ... I don't think they have an issue with it they have accepted Mick how he is. I4: L217–221 (David)

Bianca reported that they were fortunate to have well-natured children who loved their brother with autism. When siblings got along with each other and shared good times together most parents felt happy.

... we're fortunate to have such good-natured kids and um the way they relate to him is beautiful. I2: L224 (Bianca)

Harry (I8) felt happy when his son without disability would approach him at the end of the day and talk to him about his day, because he thought it was important for children to talk to their parents about their day and how their life was going. He wanted his sons to look back at good times and have treasured memories of things they did as a family. Harry (I8) felt frustrated that he was unable to take his boys one

at a time for recreational activities like spearfishing or surfing because of lack of time and because his wife was involved in volunteering for the school or caregiving. He would have liked to take his sons one at a time to engage in fun activities with their Dad but this was not always possible.

... like in the evenings, he-he'll [son without disability], still be on his computer but he'll come out to me and he'll talk to me about what he's been doing. And he'll tell, tell me and ... I get an idea about what he's talking about. I'm sure my eyes glaze over... I enjoy the fact that he comes out and talks with me. I8: L566–588, 590 (Harry)

Because a day spearfishing is a day when I'm not, not with the other two ... They've gotta be doing something. I8: L445–447 (Harry)

Subcode 2.2: Recreation for the CWD is important but is difficult for parents due to lack of time and resources. Most of the parents wanted their CWD to have fun activities to engage in. However, they said that their CWD was not able to engage in recreational activities because they did not get time or did not have the resources for such activities. There were very few places equipped with activities for children with challenging behaviours. Eli (I5) wanted his son with ASD to participate in activities such as swimming, kayaking, and bike riding because he liked doing these. However, many of these activities needed vigilant supervision and they were constantly looking for support to provide him access to these activities. Fiona (I6) reported that her son with ASD loved recreational activities such as going on a train ride, or going to the park, however she was unable to do these activities with him. She said that children with high support needs and behaviours of concern like her son, needed to have access to recreational programs and be able to participate in activities that they enjoyed. She had some respite care available, and she looked forward to them taking her son to things he liked doing, but it was not regular. Her son also enjoyed jumping on trampolines and intense sensory experiences; however, there were very few places

set up for children of his size and age (he is 15-years-old and very tall) and she was very pleased when she found one.

We know he likes things like kayaking and canoeing but even though he can't properly do it himself if there was something there or someone other than me. I like to be involved but if there is someone there ... and take him for an hour and bring him back. It's kind of like an outlet because he's getting into the teenage years **I5: L294–299** (Eli)

Oh he loved it [respite care time]. He loves going on um, train trips and drives, and hanging out at the park and all those types of things. So he would really enjoy that, and very happily go. **I6: L362–364, L365–372** (Fiona)

... they had a, a bouncing castle, and there's all these big lumping boys – like Samuel, bouncing up and down on a jumping castle ... And it was completely fine. There were no little three-year-old girls on there, you know, that you'd get in trouble because those big lumping, bouncing boys would've knocked them over... this is what you need ... but there's just a lack of yeah, just-just places and those types of recreation activities. **I6: L1039–1065** (Fiona)

I think one of the issues impacting quality of life is lack of services and what Samuel has needed just isn't available. He's, he's needed some type with the respite but he needs some type of recreation program – something that he can go to, a day centre, a something, where there are things that he likes to do. So recreation activities, and also holiday and camp ... kind of stuff ... I think those things could make a difference **I6: L1016–1029, L1080–1082** (Fiona)

Code 3: Caregiving for the CWD is an ongoing and long-term challenge and impacts all family activities and family members. Most participants said that caregiving for their CWD was for the long-term. In the early years most participants had not expected that the caregiving would continue for the extended amount of time, but had now accepted that caregiving was a long-term issue for them. This code about the impact of long-term caregiving for the CWD has been divided into five subcodes:

- 3.1. Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings;
- 3.2. Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being;

3.3. Caregiving for a CWD impacts parent occupations; parents are unable to return to paid work, with lack of time for self-care or meaningful occupations.

Most parents become advocates and researchers;

3.4. Caregiving for a CWD impacts socialisation with friends/family, and most family activities are adapted to suit the needs of the CWD. Siblings miss out and parents feel guilty.

3.5. Parents worry about the future caregiving needs of their CWD, especially residential care. Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future.

Subcode 3.1: Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings. Some participants were constantly dealing with challenging behaviours including violent and aggressive, destructive, or escapist behaviours that needed supervision. Even though their son was 17-years-old and independent in all skills, Amanda (I1) said that they could not trust him to be safe or leave him unsupervised at home due to his behaviours. He frequently escaped or destroyed things at home. He had lit a fire, caused a flood at home, and emptied containers of flour on the floor. There had also been incidents of bullying when someone took a video of him and posted it on YouTube, and this was a devastating experience for the family.

I opened the bathroom door and there was water everywhere. He'd plug the sink and decided to see what it would be like to flood the house ... he also set fire to the house one time you know. Well twice he did ... if he gets an idea and says he wants to go and busk down the road, he'll climb out the window if the screen door is locked ... we had to call the police and it was like four hours later they said that someone had rung in and they had found him. So that whole afternoon, what we had planned went out the door, you know because we were all looking for Eddie. I1: L52–53, 62–64, 107–110, 140–142 (Amanda)

Some of them were filming and putting him on YouTube coz they thought he was silly and um ... Yeah it's really horrible. It really is horrible. So you're forever guarding him. I1: L72–74 (Amanda)

For Fiona (I6) and Gary (I7), the constant caregiving and visual surveillance for their 15-year-old son, Samuel with autism spectrum disorder (ASD), was mainly due to his violent and aggressive behaviours. Samuel had a tendency to escape from home, destroy things around the home, and was aggressive towards other members of the family. Fiona was constantly looking for activities that helped him calm down, so he wouldn't attack the family members and she and Gary took turns to supervise him. Due to the high caregiving needs, Fiona found restricted time for important household activities such as paying bills and making official phone calls. The caregiving also impacted on their sleep, as one parent had to stay up at night, because their son did not sleep at night. They had to keep their house bare as he would break objects, pull picture frames off walls and even rip their valuable clothes if they were not locked in cupboards. Fiona felt frustrated, calling her home a prison because she felt locked in.

Someone's got to be near him all the time. Because you don't know what he's going to do he might pick something up and throw it and you know you got to be around him ... just to have your ... corner of your eye looking out for him. I7: L50–53 (Gary)

Got up and there was a poo throw ... here was an incident with poo, requiring cleaning up, there was a broken window, and Jane [sister] had been attacked ... this is our lives at the moment. I6: L639–647 (Fiona)

He loved going for drives and never attacked the driver. So I used to go for you know, really, really long drives and know that that was actually a safe ... safe time for both of us. I6: L175–177, 183–194 (Fiona – calming activity)

... Because you'd have this very brief time that you could do something. Make a phone call, pay some bill or whatever it might be ... and the other thing with Samuel was he just didn't sleep. There was nothing that we could do to get him to sleep. So we'd take it in turns, but basically one of us had to be up until 2 or 3 or 4 o'clock in the morning, until he went to sleep, and because otherwise you know he'd do things – he'd cook, he'd smash things, he'd search cupboards. I6: L219–232 (Fiona)

We were all, Gary and Jane [sibling] and I had bruises and bumps and, remember going to work one day ... with this big lump on the back of my head, and you know big lump on the back of your head is a reminder, that he pushed me over really hard and I banged my head on the wall. I6: L131–139 (Fiona)

You know, we had to have everything locked ... constant vigilance, we described it as. You could not turn your back on him. And if you did, he'd throw something at the back of your head. You know, there was this constant – In the last two years, yeah. Lots of violence and aggression. I6: L120–129 (Fiona)

Harry (I8) was also tired of the constant supervision and vigilance required for his 17-year-old son, Eddie, because he had a tendency to escape from home or destroy things around the house occasionally. Harry mentioned feeling despair and hated it when he found his son still engaging in behaviours that were destructive or childlike, such as emptying the sauce bottle. He said that he walked away from these behaviours rather than address them and discipline his son.

We used to have a lot of stress because Eddie would disappear. You know we would ... finding him with the neighbours, or losing him, you know, he'd just run off – that was really stressful. I8: L357–390 (Harry)

He's, he'll still drink half the sauce bottle. But ... what happens with me when he does that sort of stuff, I kind of just, I despair. I just hate it. I walk away. And it doesn't help the situation ... Rather than you know, disciplining him, dealing with the situation, telling him that it's not right to do that, and taking half the sauce off him. I8: L1193–1197, 1213, 1214 (Harry)

Isla (I9) said that her son (with ASD) required supervision due to his tendency to wander off from home if the door was left open. Isla had to use a stroller and a strap to keep him restrained even though he was 8-years-old, when they went shopping or outdoors.

... he wanders off, he's gone, that sort of thing, so, Yeah. So I have to really be at home as well, if the door's open, being in front of a main road it's pretty scary ... he either sits in his ... he's got a special stroller. So if I'm going somewhere really busy, I'll put him in that or I'll put his strap on him because he will, if I just turn my head

for a second ... as soon as he gets the opportunity and he knows no-one's watching him, he will wander. I9: L198–221 (Isla)

Jemima (I10) reported that her 12-year-old son with ASD had to be placed in residential care at the age of 10 due to his violent and aggressive behaviours. She was constantly under threat of attacks with her son hurling objects at her or assaulting her and she often had to call for help from the police to rescue her. Her older son of 17 had ASD along with mental health issues and was suicidal, so he would often run away from home. Jemima reported that the caregiving needs were so high that she did not have time to look after her own health needs or her daughter's needs. Her daughter (12-years-old) was fearful for her mother's life due to the attacks by her brother, and often helped Jemima in caregiving for her brothers or ringing up the police if needed.

My younger son ... has had 45 triple zero call outs mainly for aggressive behaviour um about 6 or 7 for absconding in the last 3 years. So he has 25 call outs before I said I couldn't cope anymore and I put him in the care of the Department of Human Services under a voluntary care agreement. I10: L162–167 (Jemima)

On a couple of occasions he has threatened me [older son with ASD] with a knife once, and he's physically assaulted me only a couple of times whereas my younger son assaulted me on a daily basis... and I would wake up and find him. He was there with a knife in my bedroom or you know if you're cooking dinner he would hurl a tin of cat food at my head or a tin of canned tomatoes and if you know there were roadworks and we had to take a detour he would come home and smash a window... I10: L220–227 (Jemima)

Lisa (I12) compared her two children (one with cerebral palsy and the other with intellectual disability and mainly anxiety issues) and felt that the challenges of her daughter with the intellectual disability were more difficult to manage than the physical challenges of cerebral palsy.

For Cassie (child with cerebral palsy) I do everything, but I'm constantly fighting with Kara (child with intellectual disability). She's answering me back and she's starting to get aggressive umm she's starting to get frustrated so she will scream ...

Cassie, she's calm ... More physical like that's hard when I'm really sick and I'm tired cause I have, I can't fit a hoist in here, that's another thing. I12: L764–773 (Lisa)

In terms of challenging behaviours impacting siblings, Amanda (I1) reported on times when the siblings had felt disgusted and embarrassed with Eddie's behaviours. She was concerned that the siblings were aware of their brother's challenging behaviours and would resent him further if they were responsible for his caregiving.

Tom [sibling] might come up sometimes because he's really disgusted and embarrassed at what Eddie might be doing and what ... He would get embarrassed when Eddie does something silly ... mucking around you know. I1: L78–81 (Amanda)

Both Fiona (I6) and Gary (I7) reported that having a child with autism, Samuel, had a huge negative impact on their daughter. Jane [sister] struggled with his violent and aggressive attacks towards her for several years. Gary said that even though their daughter was supportive of her brother, she was unable to invite her friends over and was constantly being attacked. She would occasionally voice her discontent and wanted him to leave the home. They were also concerned for Jane's safety because their son was getting bigger, and his attacks could hurt her. Fiona said that she felt helpless as a mother in not being able to protect her daughter. Because one of the parents always had to be with Samuel, Gary said that having a child with significant caregiving needs had a significant impact on his daughter.

It was devastating for her [sibling] ... he's quite big and she's relatively petite. You know, he would grab her hair and pull her along the floor. Pull her off her feet and along the floor by her head, hair, and the idea that you know, you can't protect your child is just, is just terrible. And it wouldn't be that she was doing anything. She wasn't you know –... in his space or in his face. Just by existing –... he would go out of his way, um, and so she got used to ducking and blocking and defending so it's just horrible ... We've got a car with um, three rows of seats, and, so that you know, he could be in the back and she could be in the front or vice versa. But he would still reach over across the middle row and attack her. I6: L147–163 (Fiona)

Our daughter who's very gregarious and who could often go and visit friends, but she couldn't have friends over either, or very rarely because of that. So it was very, very isolating and very, very restricting on all of us. Oh yes. I mean I think our daughter who's um, uh, just turned 12, umm, very supportive of, of her brother, but at times when he would destroy her things or attack her physically. She would um, complain very loudly about the injustice of that and, express her desire that he could leave so that she could live in peace. I7: L50–58 (Gary)

Subcode 3.2: Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being. Many parents had CWD who needed assistance with everyday self-care-related caregiving activities such as showering, toileting, and feeding. Bianca (I2) mentioned that their CWD was nearly 13-years-old but needed constant supervision for most self-care occupations such as dressing, toileting, showering, and managing his belongings. Bianca compared his caregiving needs with other children who were developing typically and felt the difference was huge with regards to the time and extent of caregiving.

If you take the average family with kids of the equivalent ages, the parents aren't looking after spilt milk and you know, dressing their oldest child who's 12 and a half and addressing their toilet needs and making sure their shirt is on the right way around and um ... standing on the little stool so you can reach your son's mouth because he doesn't want to brush his teeth. I2: L66–70 (Bianca)

David (I4) mentioned that their son who was now 15-years-old and reaching puberty was dependent for most of his self-care skills, and needed assistance for showering, toileting, feeding, and dressing skills. David reported that he hadn't slept well since the birth of his son Mick. Mick's care was a full-time job between the parents, and he had high supervision needs even now. Till a few years back Mick needed assistance for feeding through a percutaneous endoscopic gastrostomy device (PEG). He had recently, however, started to eat orally but needed supervision, as he would throw food.

I was getting up at 2am in the morning just feeding or not feeding ... or I was out at the shops, I would be lucky to get couple of hours sleep at night, still hasn't really changed ... Mick is with us 24/7, it can be demanding especially with his eating ... he's ... yeah time consuming. I4: L177, 43 (David)

Eli's (I5) son, James, was 12-years-old with a diagnosis of autism. He needed supervision for most self-care and everyday activities when compared to his younger siblings.

I guess you have to do a few extra things ... he's not going to organise his own lunch or his own clothes. It's usually a few intricate things you need for planning for him like a spare change of clothes for the odd occasion he might need or there's medication if he's going for a respite program. I5: L45–47 (Eli)

Isla (I9) reported that caregiving for her son took up most of her time in the evenings and when he was at home. He required assistance with most of his self-care tasks such as dressing, brushing teeth, toileting, and washing self.

It's the attention in the evenings, you know because of how much I need to do to get him ready for bed, and help him and stuff. Well, yeah. He can't, he can't basically do ... He's eight, but he's still completely non-verbal. So, and he can't dress himself, he can't brush his teeth, he can't wash his hands, he can't wash himself, so I have to do all of that. We're still in nappies, so, you know, trying to toilet-train at the same time. It's all, I help him with everything. The only thing he basically does on his own, is eat and drink ... he still needs help with a fork. You know, so finger-size food he'll eat on his own, anything-anything with a spoon he'll eat on his own. He can't drink out of a cup, but he can drink out of sippy cups and bottles. He hasn't quite figured out how to open and close them and fill them up yet though. I9: L166–190 (Isla)

Subcode 3.3: Caregiving for a CWD impacts parent occupations; parents are unable to return to paid work, with lack of time for self-care or meaningful occupations. Most parents become advocates and researchers. Many participants said that they had not expected to be involved in caregiving of their CWD to the extent that they were. Even though their CWD had improved in skills, most caregivers were involved in many hours of caregiving or supervision of their CWD and had not been able to return to their previous work or lifestyle or occupations, as they had expected.

Some occupations that parents engage in include necessary occupations aimed at meeting the basic self-maintenance needs, such as eating, sleeping, sex, and personal care; committed occupations that are typically not remunerated such as housework, childcare, home and vehicle maintenance; contracted occupations that involve paid productivity or formal education; and free-time occupations that occur in the time that is left over, such as going out with friends, or joining a book club (Harvey & Pentland, 2004). Many of these parent occupations were impacted due to the caregiving needs of a CWD.

With regard to returning to paid work, 11 out of 12 participants were working part-time in paid employment. Four participants were fathers and eight were mothers. The majority of these participants, including the fathers, had expected to return to full-time work after the birth of their child or children, but were unable to do so due to the increased caregiving needs of their CWD. All mothers were the main caregivers, and 10 out of 12 fathers within this sample helped the mothers in caregiving whenever possible. Two mothers were single (separated). The majority of participants had flexible work hours or had employers who were understanding of their need to be flexible due to the caregiving and medical appointments of their CWD.

Before her children were born, Amanda (I1) worked in project management in computer consultancy and led teams of workers. She loved her work and thought she would return to at least part-time work after her son went to school; however, due to her son's medical appointments she could not resume work. She tried to go back to her previous work when her son with Down syndrome went to mainstream school. However, the frequent calls from school at odd hours due to her son's behavioural challenges meant that she had to give up work. She also expressed a desire to return to study but this was not possible due to the high demands of her family. Even though

Amanda said that she had more time now than when Eddie was little, she still did not get time to do things that would matter to her.

So I did miss it [work], but that's all I could do ... never go back to that work ... We made the decision to mainstream Eddie but they would ring me up and I would get calls to say that he's done this, can you come and sort it out or we can't get him out from under the table. I1: L259–260, 290–292 (Amanda)

Okay for a few years I wanted to go to university and do teaching in psychology because I would love to do a PhD ... Yes, but the problem with that is that I've always juggled ... is that if I was to do that I would then have to cut out the amount of time that I put into settling things at home you know. I1: L1056–1058, 1065–1067 (Amanda)

Bianca (I2) worked part-time and Eli (I5) her husband worked full-time.

Before her child was born Bianca worked full-time as a schoolteacher and would have liked to continue. However, she was never able to go back to full-time work due to the nature of care for her son and then having a young family of three children. She had started working a little but ended up working late hours after the children's bedtime and said that she often got exhausted and this impacted her physical well-being. She also reported that it was only possible to work because her employer was flexible.

I sort of wanted to [return to work] but it became, well one, it wasn't very possible because someone needed to care for James. When he went to school it was sort of possible but then it wasn't really possible because I still had issues of school pickups and a lot of James's school time was punctuated by appointments and things like that anyway ... I end up staying up late and then that affects my health and well-being ... but the reality is it's not a good way to be. I2: L462–465, 473–475 (Bianca)

David (I4) was able to return to his contracted/paid occupation but not in the same capacity as before having his CWD. He needed his job to be flexible so he could respond to any sudden medical emergencies with his CWD. Even though he was satisfied with his work situation, there were many instances when he mentioned lack of finances and that he would have liked to earn more.

... but the only reason I start at 5 [am] is so I can be home or leave at 3 or quarter to at times so I can see Mick at the bus, if I'm late so it ties in with in a sense with my job at the minute. I4: L64 (David)

... And it suits our lifestyle at the minute because, especially with kids at three different schools, I can get home ... And the boss is, the owner is being really good in that sense and they know my situation. I4: L610 (David)

... you know, we make do and money isn't everything but it's bloody nice to have a bit more. Yeah, we're sick of it, refinancing the house actually. I4: L240, 242 (David)

Both Fiona (I6) and Gary (I7) also reported that the impact of having a child with ASD on their paid work. They were both health professionals, but working part-time due to the high support needs of their son. Fiona described that most of her time revolved around looking for her son when he had escaped and maintaining good relationships with the police who helped search for him. She mentioned that she was lucky because her employers were understanding of her situation, and she was allowed flexible hours. She would have liked to do more for her professional career; however, this was not possible as she was unable to do extra hours. She was also not sure what her work life would be if she did not have to support her son, but she preferred not to think about that.

I've been with the police, we've been walking up and down looking for him. Anyway, so, yeah, we just call the police and we, we've really good relationships ... with the police for Samuel's escape antics. I6: L459–462 (Fiona)

I've been very lucky that I've had work and colleagues who are very understanding and um, I've worked part-time ... so financially we made a decision that we couldn't both work full-time so we both work part-time ... yep so that we could just manage it that way. So yeah maybe, maybe I would've fallen back into private practice. Not sure. I6: L984–989 (Fiona)

Gary (I7) mentioned that he would have worked more hours if the caregiving needs were not as high. He reported that having a child with autism had impacted on his decision-making regarding changing jobs and had reduced his career development. He

said that the stress and burden associated with his child's needs meant that opportunities for career progress such as changing employers, or working privately, were on hold. He acknowledged that if he and his wife worked full-time, it would significantly improve their financial income; however, this was not a possibility for their family due to the caregiving needs.

Changing workplace arrangements ... there is also a mental cost to that. It requires a degree of flexibility and ability to focus on your own needs and your work environment to do that, and so because of the additional major stress and burden associated with Samuel's behaviours and needs, I felt ... less inclined to make major changes to other areas of life ... you know any thought of perhaps completely leaving you know, changing employers or working privately, really I'd put on hold. I7: L248–267 (Gary)

In saying that both of us [wife], but more so myself, have had to restrict our working hours. So, from a purely financial perspective our family finances would be much better if I could work full-time. Um, there was absolutely no way I could work full-time, ah, while we were dealing with Samuel given the limited amount of, well zero amount of after school respite we were able to access after he was excluded from the after-school program. I suppose we could have paid for it privately but that would have been a burden. I7: L186–199 (Gary)

Isla (I9) had to give up working as an accounts manager after her son was diagnosed because she had to understand his condition and provide the caregiving. She had decided to start work when he started school but was unable to return to her work. She worked part-time with her husband in his business but was not getting paid. Her husband started his own business because he wanted flexible hours to be able to get to the appointments for their son. She had not expected to be a stay-at-home mum but she had to change. She did not feel regret but said that it impacted on their family financially. Jemima (I10) was struggling financially due to poor income. She used to be a lawyer and earned well; however, due to the caregiving needs and being single, she was not able to hold on to a job and said that she was unable to earn a decent income and had to live with her parents after her separation.

I was an accounts manager ... The plan was to go back to work pretty much straight away. But after the diagnosis, ... we realised obviously it's not going to happen. He needed more time, more care, I needed to learn and understand about his condition 'cause I knew nothing about it. So, we decided that ... I'd stay home with him until he was in school ... however the year he started school, I had her... So that didn't happen either ... There's just, there's too much: he demands too much of my time and attention. I9: L335–360 (Isla)

Because of the situation we're in, he ... he, we have to start our own business ... We thought it would be easier, we thought 'Oh, he can work around his own hours ... and spend more time at home, but it just so happened that to be able to pay our bills and the mortgage and everything, he's having to work ... the work's there ... so he's taking it, which means he's working more ... and less help at home ... so now I do all the books and everything for our business. So I don't get paid for it obviously. Unfortunately. Comes under housework. I9: L296–314, 364–369 (Isla)

I didn't think that I would be a stay-at-home mum. Nup, I was going places. But that changed. I don't – I'm used to it, you know ... You know, it did mean we struggled a lot financially. I9: L375–385 (Isla)

obviously too the care of those boys has impacted on my ability to earn income. I just found I couldn't hold a job you know I just never knew when I was going to be called out ... So what I make is pretty pathetic really but I'm just hoping that, you know, the clouds might pass and the sun might shine and I might actually be able to earn a reasonable living cause I'm currently functionally a homeless living with my parents out of suitcase for over a year. I10: L358–361 (Jemima)

In terms of lack of time for self-care and meaningful occupations, Bianca (I2) said that there was very limited time for her to do things for herself or with her husband. The couple planned to give each other one night (freebie) when they could do whatever they wanted, while the other spouse looked after the home and children. However, this hadn't worked out due to the unpredictability of their son, James' needs. Both Bianca (I2) and Eli (I5) had to sacrifice their personal hobbies, and Eli was unable to engage in things such as sport, or Bianca was not able to engage in her hobbies. When he tried to have some time with her, they were too exhausted to be able to do things like watch television or go to a movie together. David (I4) said that he was unable to find time for meaningful occupations such as home maintenance that seemed important to him.

We try to give each other [couple] freebie days. Um, but that's really hard ... it falls by the wayside very quickly. And that's our struggle and I don't use that word lightly, that's our struggle to try and give each other some time ... and we're talking ... if it works, and often it doesn't, we're talking maybe at best an hour and hour a half. I2: L683, L692–694 (Bianca)

I think Bianca and I have sacrificed a lot of things we like to do. Like Bianca has a lot of hobbies in photo scrapbooking and sewing and she's never been able to finish it. Once you organise everyone, it's like nine o'clock at night and you almost fall asleep ... sometimes we just fall asleep on the couch and you don't really feel like doing what you want to do. I5: L531–534 (Eli)

Oh just your normal maintenance, like mowing the lawn, house maintenance and things like ... yeah and just prepare the backyard and so forth, get that finished ... yeah more time to do that yeah ... It's very hard to get outside to do whatever you need to do ... I have to be here and I have to look after the other kids so that can be hard. I4: L53, 60 (David)

In terms of becoming advocates and researchers, most participants concurred that they had to advocate for their CWD to be able to understand the service system and avail themselves of services for their child. They had to spend significant amounts of time researching for services and entitlements with very little support from the schools or health professionals. Amanda (I1) reported that throughout her past 17 years of having her son with disability, she had to advocate for services and supports, and had to be there for him. She had constantly been researching especially when they had to transition him from one school to the other. This was time consuming and impacted her QoL.

Pillar to post [running around looking for a good school]. And this is the other thing when you're talking about quality of life. Every time you have to make a decision, you have to research everything, you have to put a lot of time into it and whereas with the boys [without disability]; yes you do research the school they go to, but it doesn't get down to that level. I1: L443–446 (Amanda)

Bianca (I2) reported that there was no time for her to look after her own needs and she spoke of how her life revolved around her son's disability and all her free-time was spent researching services and supports for him or for respite care.

I guess people spend a lot of time talking about looking after yourself, but what I found was my life still revolved around disability. It just changed, as I said, in proportions of time spent doing bits and pieces, but most of those things just still revolved around disability either becoming more informed or going to workshops. I2: L448–452 (Bianca)

Caitlin (I3), through her work of providing parent support groups, had become an advocate for parents of a CWD, and was enjoying this role. She was constantly researching and advocating for services available for CWD. She helped other parents by providing information around navigating services via the support groups. She thought that it was wrong that parents did not know enough about the services that could be tapped into for their CWD due to the current system. She expressed that parents needed to advocate for services and for disability. She had been persistent in advocacy and said that if parents were persistent and well informed, then they could get a lot more services than they are availing themselves of. She was currently researching NDIS to be able to plan her son's needs.

Oh absolutely well informed and I feel like I'm well informed um because the position that I'm in ... my workplace probably. Just ... I don't know I'm just always seeking information and ... the whole disability thing ... the whole ... the whole network of support and lots available is such a ... it's like a secret code it's hidden away. You need to search for it, which is so wrong, I think. Um and I think that's why so many families are missing out. I3: L414–421 (Caitlin)

I don't think I've ever really tired from it ... he's without an iPad at the moment. I will find funding, I will find funding to get another one. I will keep funding. I know I will. I just will. I just fight for that. And I have all these visions and plans for him when the NDIS comes. I3: L405–410 (Caitlin)

Isla (I9) said that any spare time she had was spent on researching and finding services and support for her son rather than her own needs. Jemima (I10) was a lawyer and was advocating for services all the time for her two sons and her family as she had very poor experiences from professionals helping her to acquire services.

Well at the end of the day, if I do have spare time, it's spent on the research and advocacy side of things ... rather than a haircut or something ... rather than on myself, yep. I9: L914–917 (Isla)

and my experience I mean I'm an advocate on behalf of other people, that's what I've done my whole life ... and now I'm advocating for my sons but it has been enormously difficult ... You have to advocate ... And you know, sometimes you have to do it at your own expense. You know, it's just really really difficult to constantly come up against public servants who don't care ... and yeah whatever fill in this form, nup it's the wrong form come back another time, you know, nope, you're no longer eligible we've changed our eligibility criteria, no we didn't write to you, we don't have to you know, it just, it's so exhausting. I10: L1226–1250 (Jemima)

Subcode 3.4: Caregiving for a CWD impacts socialisation with friends/family, and most family activities are adapted to suit the needs of the CWD. Siblings miss out and parents feel guilty. Most participants expressed that having a CWD impacted on family activities and family occupations such as vacations and family get-togethers due to the caregiving or supervision needs of the CWD, and the siblings often missed out.

Amanda (I1) was aware of how their family trips and generally all home activities were impacted by her son, Eddie's (17-year-old with Down syndrome) challenging behaviours. She indicated feelings of guilt towards siblings and not being able to do things like a family, especially taking holidays, because of the high supervision needs of Eddie. She said that when the family was on holidays, the constant need for supervision was prominent because very often Eddie would run away for hours and the police would be involved in searching for him. Family

holidays were difficult and not enjoyable for the siblings as they spent time looking for their brother.

I don't think Tim [sibling] would have reacted ... he wouldn't have exploded as much because he kept all this stuff inside him. I think it has affected him a lot. Yeah, because often we would be doing things and then we would have to stop because I would have to deal [with the behaviours] ... For instance we would be out in the street and Eddie would run off and I'd have to go and chase him um you know when it got too hard we would have to go home without finishing what we were ... like we would be out somewhere and his behaviour was just so bad I couldn't, we couldn't stay where we all were so we'd have to go home early and things. So I think a bit by bit that built up, the guilt the guilt of it all. I1: L644–652 (Amanda)

Bianca (I3) said that she spent most of her time caregiving for her son with ASD and felt guilty not being able to spend equal amounts of time with her other children.

She reported that simple family activities such as watching television together at home often got disrupted because of her son James' (ASD) needs and behaviours.

Even though she thought that family members need to care for each other, she felt annoyed when she had to ask for help from siblings to manage their brother with ASD, for his daily needs.

If you could do a graph of time ... and get a visual representation like if you did a pie chart of how much time we spend with each kid, naturally, there would be a section of that pie chart that would be James's [child with autism] devoted time. The bigger segment of that chart would be thoughts that are thinking or planning or organising or making appointments or phone calls or whatever all centered on James. Um, yeah, and you know what do you do? You can't change it. I2: L262–264 (Bianca)

Even if the four of us are sitting down and watching a movie together and have chips in front of the TV and chocolate and whatever and do that sort of bonding as a family time, it's not really quality time, because at the very least, Eli and I have half an ear out as to what James's doing and generally speaking his needs prevail that time so for Joel and Carla [siblings], quality time with mum and dad or as a family is very much punctuated with just a "can you put the DVD on pause because someone needs to go and help James because he's gone to the loo?" or "oh we can hear James is raiding the pantry" or "uh oh, James's poured himself a drink which probably means we need to go wipe up the spillage" I2: L623–628 (Bianca)

It annoys me because I don't like it being like that but um I don't really have a choice. I'm all about all of the family members contributing to family life and whatever, but I

don't feel like an 8-year-old and a 10-and-a-half-year-old should be having to chase around after their older brother's bits and pieces or packing the car on behalf of the parent ... I2: L86, L90–91 (Bianca)

Eli (I5) reported that the family holidays were carefully planned to suit the needs of their child with autism, James, more so than the siblings. He mentioned that the siblings never complained; however, they wished that they could spend more time with friends or do things they liked more often. He did not think that having a brother with autism impacted them hugely, but it did impact on the activities that they got involved in.

I think we pick a place that obviously all of them will like and just adapt. And like if you're going to the beach, who is going to go in with James ... looking at what beaches to go to ... are we going to go to a safe beach or are you going to a surf beach? So you have to pick a beach that is child friendly ... You got to take all of that into account, I suppose, a bit more. What's going to keep, not only the other kids, but James occupied during a holiday break or going out somewhere. I5: L144–155 (Eli)

Oh there are times when they miss out ... they don't ever complain that's the thing. But they have times when they wish they were doing this or doing that. Going to visit a friend: "why can't I visit a friend now?" You can't at the moment ... They're in the friend-building stage so we were aware that at times they would ask that they want to play with a friend or a friend comes over. It doesn't seem to faze them too much. They're pretty good kids. I5: L101–113 (Eli)

Harry (I8) reported that both siblings Tom and Clint had to constantly make changes to their social life due to the needs of Eddie (CWD). The family had moved house because of the special school and both brothers had to leave their school and friends, and move to a new area. They resented the loss of attention from the parents. He said that as parents they were not always able to manage challenging situations and Harry mentioned that he usually bottled up the anger.

And so we moved there, and the boys ... so in their mind they're there because of Eddie. They loved their previous school but of course they couldn't stay there ... they would have only had you know, at most one or two of their friends in whichever school they went to. I8: L95–99, 103–108 (Harry)

I think they [siblings] resent the fact that he took away from the attention they could get. I8: L85–86 (Harry)

I tend not to get angry until it's, you know I tend to bottle it up and then it all comes out at once ... I8: L242–243, 245 (Harry)

Isla (I9) was concerned about her 4-year-old daughter missing out on her time. She often wanted her mum to do the therapy strategies with her, and Isla included her as much as she could. She reported that her daughter felt jealous of the one-on-one time that her brother with autism, Alex, received, and as a mother she found it hard to balance both their needs because of the age gap between them. She hoped that once she was older she would understand her brother's needs. Isla expressed guilt about neglecting her daughter's needs. She mentioned that when she was pregnant with her daughter two health professionals advised her that she would have to continue to give attention to Alex, implying that his needs should come first. Isla had since then felt guilt related to neglecting her daughter and reported that her daughter's strong and bubbly personality and her attention seeking behaviour was because she neglected her when she was a baby. Isla also mentioned that it was difficult to get her daughter's friends home and the only socialisation for her was in the playgroups.

The attention side of things for the kids. Now, he obviously demands a lot of my attention, which means that she's constantly craving it. I9: L83–86 (Isla)

And um, she wants to do everything with us that we do with him. So that makes it a little bit hard ... for example, if I'm, even if I'm just doing basic therapy stuff with him, it's 'Mum, how about me?', 'Mum, it's my turn'. You know, sensory play, anything. Like we do include her as much as we can. It is hard. It's hard to balance it. I9: L93–119 (Isla)

She's pretty switched on. Umm, but yeah she does crave a lot of attention. She, and she has said to me in the past 'Oh Mum, I've got no one to play with, I've got no one to talk to'. Because she doesn't get to socialise as much as we'd like her to. I9: L137–144 (Isla)

One of our ... my paediatrician and my psychologist both told me when I was pregnant with her, and it's stuck with me, I don't know if it's a good thing or a bad

thing ... they said to me 'Okay, you're having another baby, and usually the baby is obviously the most important thing at the time, they need all your attention but, your situation's a little bit different ... and his needs need to come first'. That's what I was told by two professionals, and it's stuck with me, and now that I'm thinking back, I probably shouldn't have, like not taken too much notice of that ... **I9:** L528–539 (Isla)

Friends coming home's a bit hard. But she does, we've put her into three-year-old kinder once a week. Umm, I've just started into ... one of my friends started a family day-care ... **I9:** L588–593 (Isla)

According to Gary (**I7**), their family holidays rotated around Samuel's (son with ASD) preferences and the family could only go to one site for holidays. Fiona (**I6**) said that all home renovations had to be done with consideration of their son's challenging behaviours and the family members did not get to decorate their home as they would have liked to, impacting on family activities.

Now when the house was renovated one of the reasons for this [a little open area within the home] was that it brings the outside to the inside of the house ... that was you know, part of the design when we renovated was so that we could, you know, still be in the prison, with being locked in ... but still have the opportunity for a bit of daylight. **I6:** L88–93, 105–106 (Fiona)

If Samuel had been more typically developing ... more like his sister, we probably would have done more um, trips together as a family ... been a bit more adventurous ... umm, whereas you know, we got pretty stuck in the XX beachfront caravan park 'cause Samuel liked it there. **I6:** L958–967 (Fiona)

In terms of socialising with friends and family, most participants had adapted to the needs of their CWD and mentioned that their social circle of friends and family members changed over the past years. Amanda (**I1**) and Harry (**I8**) reported that they lost many family members and friends due to Eddie's (Down syndrome) challenging behaviours over the years. They did not trust their family to understand their son's behaviours and felt isolated.

... there was a lot of family issues so I didn't have my brother and his wife or my sister. I had mum and dad but that was it, but they were kind of older and plus they weren't like yeah ... they weren't ... I couldn't trust Ethan with them because my

father had bit of a bad temper and Ethan would easily get on his ... I couldn't leave him with them. I1: L26–30 (Amanda)

My family, he's just kind of irksome ... Although he's improving. Like my dad will actually talk to him now ... They did, you know, they could only tolerate him in small doses. He's pretty full-on. I8: L729–733, 758–761 (Harry)

Gary (I7) said that his son Samuel would physically attack his sister and visitors or demonstrate obnoxious behaviour, depriving the family of having a social life. His son's behaviours also had a profound effect on their circle of friends and restricted their friends from visiting their home. Gary reported feeling emotionally burdened having to explain things related to his son's behaviours to people over and over again, so he tended to just give up and confined his social relationships.

We had not been able to have people over or not for very long because he was so, umm, obnoxious in his behaviour towards them, and he would physically attack visitors who came to the house who stayed more than a few minutes, which really deprived us of social company and given that he, essentially uh, needed constant visual surveillance ... uh, both to you know, prevent umm, property damage and escaping it, meant that our um, family social life and social life was a – had become very restricted. I7: L40–48 (Gary)

... there's a burden, an emotional burden associated with constantly explaining to people, beyond those nearest and dearest ... about what it's like. And so I think I tended to sort of just give up ... on that and after a while stopped trying to explain things to people and just confined my social interactions to people who actually did know. I7: L401–416 (Gary)

Isla (I9) said that planning social activities with family or friends was difficult for her because of her son's needs and she preferred not to attend occasions that required planning.

Look, family life is different now. Obviously we don't get to go out much, um, we don't do a lot of family dinners, we don't get to go to all ... we miss a lot of birthdays ... things like that, family-wise because it takes planning you know, or if something's last minute usually we have to miss out – so that makes things a bit hard. The sort of going out/socialising side of things has dropped off completely. Now we sort of put his [son with Autism] needs before anything else. I9: L9–23 (Isla)

Jemima (I10) said that her friends did not understand disability nor tried to, and she did not have time for keeping friendships because of her two sons with challenging behaviours and her own health issues (she was recently diagnosed with breast cancer). Lisa (I12) said that she was unable to socialise with her friends or because of her daughter's anxiety, and apprehension, she could not take the children out on holidays or to meet friends. She mentioned feeling guilty for the two siblings who did not have any disability because they missed out on events such as sports or holidays.

Friends don't get it. I mean I am alienated from all of my friends really except one ... but everybody else, you know, live in XX [a wealthy suburb], generally married, not sick, got kids in mainstream school on that mainstream highway ticking off all those milestones, and they don't understand family violence ... they don't understand disability, they don't understand breast cancer, they don't understand any of that. So they really work to trivialise my position, they go 'oh it can't be that bad' ... I10: L863–875 (Jemima)

I have got friends umm I see them, catch up for coffees and stuff, but it's hard when you're busy and like I find with Cassie [child with cerebral palsy], she doesn't like change, she doesn't like, and Kara [child with intellectual disability] was at a point where she'd go to a party, and she'd vomit [because of anxiety]. I couldn't go anywhere, anywhere I went she'd make the ... big scene like it was, and I felt bad for her sisters. The older one would start freaking out, it was going from one child to another ... I12: L308–316 (Lisa)

I feel, I feel like the worst mother because I can't give them what they want, what they need and I know I should be pushing my oldest to go play netball but I can't be there, it's hard. Cause she wants me there at drop off and pick up and to watch them. I12: L359–362 (Lisa)

Subcode 3.5: Parents worry about the future caregiving needs of their CWD, especially residential care. Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future.

Nearly all participants were concerned about the future caregiving needs for their CWD. They thought about residential care as a future solution and were aware that

this would be an issue in the future. They did not want the siblings to be responsible for the caregiving of their CWD; however, they were worried about what would happen to their CWD once they were not living. Even though they thought that the siblings had a good relationship with their CWD, they were concerned that the siblings would reject or resent their sibling with a disability in the future due to the caregiving needs.

Amanda (I1) did not want the siblings to take responsibility for her son's care in the future. She worried about his care needs in the future, when the parents were not around to care.

I try my hardest because I don't want them [siblings] to feel it's a burden. I1: L23
(Amanda)

That's what I would want for his future. I don't want him to go and sit in the day centre all day ... if they decide to take him out for the day. I mean that's fine because you ... he doesn't need that, and it's not going to help him. I1: L1029–1033
(Amanda)

Bianca (I2) wanted the siblings to be a part of her son's life in the future but she also wanted her son with ASD to be independent of them, lead an independent life and get the care that he needed. She wondered if the siblings would reject their brother in the future even though they seemed caring and understanding in the present.

I do wonder about the future. I wonder, you know, like, for example, our preferred option would be that James leads an independent life with the care that he needs. I would always want our kids to still have a part to play in James's life. I just hope that they don't grow up going ... I really got to do 'whatever' today for my older brother. I2: L234–239 (Bianca)

I don't think they'll ever reject James totally. They're not in that way inclined and in that sense. I2: L223–225 (Bianca)

Caitlin (I3) worried about the future management of her son's needs as he had high support needs and challenging behaviours and was not independent in his daily activities. She worried that his behavioural challenges would deteriorate the

relationship between the siblings. She felt certain that she would be organising support and care for him in the future. Both Caitlin (I3) and her husband David (I4) were sure that they had no expectations from the siblings to look after their brother in the future. They wanted the brothers to have a loving relationship with Mick, but no expectations regarding his care. Caitlin was aware of relationships between siblings deteriorating and did not want that to happen to her children due to caregiving needs. David expressed concern that he and his wife were getting older, and that future long-term caregiving would require placing their son in residential care, or giving him up to the state, for their own quality of life. However, he also felt terrible about having such thoughts. They were saving for the future to be able to afford a good place for their CWD.

I can see in the future that Kyle and Cam [siblings] may really have to have their own space for things and Mick um ... needs his own space too ... the relationship they all have together I don't want it to deteriorate so I think we have to do a few adjustments within our family to support that ... to carry on with this ... they would be a part of his life but it would be out of their hands. I3: L449–455 (Caitlin)

I just didn't think it was fair on them to have to ... do with it the daily monotonous things with him that any other kids had to deal ... and I have heard of many relationships between siblings deteriorate. I3: L233–236 (Caitlin)

They know we do not expect them to take over our role with Mick. That is just not fair to the other two boys. It's not their responsibility to look after Mick. I4: L432–434 (David)

There's no, you know, 15, 16, 17, 18 leaving home ... it's just not going to happen. I mean we even spoke about if he gets really bad we're going to give him up to the state and things like that. God, it's horrible. Even putting him in a home full time feels horrible but we've got ... even though we've got to think about him, we've got to think about ourselves as well ... I mean we're touching on 50 well you know, 48 nearing 50. We need to have some sort of quality of life and things for ourselves. I4: L279–285 (David)

It does make you feel guilty thinking that way ... I mean that's why we're trying to ... we've got an investment property and that um ... for simple fact, we're trying to get some money behind us to put Mick somewhere nice rather than you know, some of the government departments ... I4: L290–293 (David)

Gary (I7) said that they would never expect their daughter to care for their son with ASD in the future. He was upset and felt guilt that their relationship with her had diminished due to the increased caregiving needs of her brother.

Of course we never handed over his [CWD] care to our daughter, but it meant that really our relationship with her was diminished as well because ... we very rarely could do things together just with her because one of us was always involved with him, almost all of the time. So and I think that uh, had a significant impact on, on her.
I7: L339–350 (Gary)

Harry (I8), Amanda's husband, was particularly concerned about the future caregiving needs and residential care for his son with disability. Their son, Eddie, was independent and capable of looking after his self-care needs. He travelled independently but his habit of escapism and some of his destructive behaviours led Harry to believe that he would need supervision in the future. Not knowing how Eddie would be managed in the future was a huge concern for Harry. He wanted Eddie to live in residential care, but independently. He mentioned that his wife had saved up money for such future needs; however, he was not trustful of the system of care and mentioned that he was worried that if there was money for their son, then it might impact on his safety. Harry seemed concerned about Eddie's future needs, safety, and well-being. He also mentioned that he did not expect the siblings to look after Eddie, as it was not fair on them.

She's [wife] always putting money away to make sure that Eddie has enough. But unless, I can see why, my thought is, it doesn't matter how much money you save up, just means there'll be more vultures. I reckon he's safer without money. Cause then there, you get all the people who want to look after him because he's destitute ... you know what I mean. The more money you have, the more vultures there are. Cause everybody wants, wants your money then. I mean you see it with these kids that murder their parents for the inheritance. I8: L1267–1272, 1276–1289 (Harry)

Harry also expressed concern that the siblings resented their brother Eddie (Down syndrome), more so as they were getting older. He was sad about the breakdown in relationships between the brothers, and that they ignored Eddie. He reported feeling frustrated that he could not do anything to help the situation and was looking for strategies or solutions to help them.

You know every family, the dynamic between brothers is always ... you know you're either great mates or you're fighting ... Yeah, yeah. They don't touch him, they don't fight him, they ignore him. I8: L159–161, 173, 174 (Harry)

And now he's started saying things like 'I wish it, I wish you wasn't my brother' which is what Tom's been saying for a long time ... well I don't want them to hate him, so I tend to react when he makes those sort of statements, and I react when Eddie makes statements in the same vein. I really don't know how to handle it any different ... I8: L199–214 (Harry)

Isla (I9) was worried about their son's care in the future, especially if something were to happen to her. She was worried regarding where he would reside and anticipated that he might be living with them even when he grew older. The family had decided to have a unit built in their backyard for the future needs of their son. She was worried that if he lived alone in the future in a respite home, that it would be unsafe for him. Lisa (I12) was worried that her eldest sibling felt very responsible for her sister with cerebral palsy and wanted to care for her in the future. She felt guilt about her feeling that way.

That's the biggest thing ... not even just if he gets older like, touch wood, if anything ever happens to me, no-one else out there knows everything about him, even my husband. Like he doesn't know where I keep all his records ... and all his reports, and, you know, everything about where, where I take him ... I9: L393–402 (Isla)

And I do, I do worry a lot. We want to stay in this house ... and I think about all of that for his future. He needs to stay somewhere where he's stable so, we're even hoping to later on put a unit up at the back. For him to stay, so that way he's got his own independence. I9: L412–415, 418–420 (Isla)

I'm still thinking about what can I do in case he is living with me for the rest of his life. I don't want him to have to lean on me and I don't want to have to be doing everything for him, I still want for him to have his independence, but I hear stories about people that are in respite homes and things like that: some good, some not so good, and you just, you don't know ... Like it's always ... Okay, well what's going to happen when, if something happens to me? Even if I have to go into hospital for surgery, or something, you know, like who's going to care for him? I9: L438–449 (Isla)

That's what I worry about. That's why I don't like she [eldest sibling] said to me one day Mum I'm going to buy me a house with an extra bedroom, and I said why and she said, oh so Cassie [CWD] can stay with me sometimes, you can have some time out. I'm like, oh my gosh. Like she loves her to death but I think she carries too much. I12: L405–410 (Lisa)

Code 4: Having a CWD impacts financial/material well-being due to extra costs and reduced income. There are no subcodes in Code 4. Most participants reported that even if they were doing well financially, the impact of having a CWD added extra costs to their finances. These extra costs included therapy, aids, home modifications, and other such costs. The fathers were more impacted with finances than the mothers and said that a lack of finances meant that they were not able to do things they would have liked to do as a family, and this impacted their FQOL. Most parents were unable to work full-time which impacted their income. The extra cost for a CWD was impacting their finances, as expressed by most parents. Most participants particularly the fathers said that they were constantly balancing and juggling finances.

Eli (I5) reported that there were added costs of having a CWD due to the extra needs associated with his diagnosis. He experienced financial pressure and compared managing the finances to juggling or a balancing act and said that even though he was working full-time, and his wife was working part-time, it was still difficult financially. He mentioned that if his wife stopped working part-time then they would find it difficult to manage their son's expenses related to his diagnosis. They were

paying for their son's therapy and any other activities that he engaged in outside of school.

... Needless to say, if James didn't have all those needs, Bianca [wife] could probably work longer hours, but she also probably wouldn't need to do those extra ... just because she wouldn't have to outweigh all the extra money. We might have a better house or whatever. So it's a juggling act, one, she can't really do full-time but by the same token she has to work. It's money we put into extra therapy and the extra things James needs over everything... It's kind of been a different balancing act in terms of work versus whether we can afford ... there's times when our budget starts going backwards. I5: L240–245, 253 (Eli)

Like speech therapy and um ... some of the occupational therapy which he needed to help him ... Like one, we need the extra money for... we don't have all the luxuries even though ... I work full time, it's a balancing act because if ... because of the type of schools and everything. I5: L219–221, 235–237 (Eli)

David (I4) seemed to be bogged down by financial difficulties and mentioned how hard it was to manage activities for the family, due to financial restrictions. Most of the financial needs for their CWD were managed by the work that his wife did in finding resources; however, for David doing things as a family and having fun was restricted due to finances. Harry (I8) reported that financial pressures were increasing as the children were getting older and he worried about the impact of the financial stress on his wife.

I guess is being able to get out, you know, of the household and go to the movies ... or we take the kids out for a meal or something like that with other friends. And that's good um ... but of course that comes down to money and you need money behind you to get ... to do these things so we don't do it that often. I4: L26, 29–31 (David)

And we just keep getting bills, and um, so she's anxious about that and she's staying up all hours of the night um, 'cause when she gets anxious she just doesn't sleep too well. I8: L323–326 (Harry)

Gary (I7) said that the family was doing well financially; however, he was unable to work full-time, affecting his income, and added to that their son's destructive behaviours meant constantly spending money on repairs and reconstruction of

property. He said that having a CWD added a huge cost to their living expenses due to his son's behaviours related to destroying property and valuables.

There was restriction of my incapacity [to work full-time] but also his destruction of property cost us many, many thousands of dollars per year. From things like breaking windows, and we'd renovated our house and when we moved back in he broke six windows ... smashing plates, damaging the floor, breaking holes in the plaster walls. That kind of thing. I7: L206–214 (Gary)

So he ripped up I think in the end ten jackets or suit jackets of mine and other items of clothing. There's a cost associated with that. I mean it's not a crippling financial cost but it is a cost as well as the annoyance of losing things and basically progressively, anything of any fragility and value that we owned he either broke or we had to um, wrap up and hide or get rid of. I7: L218–240 (Gary)

Amanda (I1) said that the family had to sell property and deal with the loss of a high wage as she was earning well prior to having children. Support from her extended family helped with financial issues occasionally.

My job paid really well. So we had savings, we owned another block of land, which we ended up having to sell because we needed the extra income ... Yeah our savings went to nothing. We sold that block of land to keep us going and um but we were always lucky because my father was quite wealthy so if we knew that we needed support, I could ask him ... at one stage we had to because you know when Eddie [CWD] got older you know our income was quite low because of other issues and that ... So we're not ... were not completely broke but we don't have ... And yeah I would have been working. I1: L870–872, 888–889, 913 (Amanda)

Bianca (I2) said that the family had to spend for the medical and therapy needs of their CWD as a priority. They got some support from their extended family and from church. However, they believed it was not a choice they had and they had to bear the extra costs for their CWD.

If there's an expense attached to meeting James' needs that takes priority. Um, but it is a big commitment financially, and you know, if we sit down and do the maths of it and ... you sort of add up the expenses ... I don't know, it takes your breath away about how much you've actually spent. I2: L770–774 (Bianca)

David (I4) said that the finances always got to him. He mentioned that he did not want to be rich, but that he was tired of re-financing and meeting the financial needs of the family.

Finance is the thing that gets to me. I want everything done, I don't want to be extremely rich ... I just want to be a little bit comfortable so we don't have to worry about money all the time. I mean you know, our credit cards have almost maxed out again and we probably refinanced a couple of years ago. I4: L328–331 (David)

And financially I'm struggling. Yeah financially, I admit, I'm struggling. No because I need to be here at the times that they need me and I find when Cassie comes home off the bus she's screaming the house down if food's not ready. So if I don't have her dinner ready it sets off the whole house. Umm I find financially it's harder this year because I'm travelling to their school further, and back and I need to pay for after school care for the other girls. It's only 15 minutes that I'm needing after care but I'm paying ... all this money ... but I have to think of their safety. I could have them walk home but it's on the back of my mind, I can't ... and I can't go back to work. I12: L64 82 (Lisa).

Code 5: Services and supports are valued and help FQOL. When asked about services and supports that helped their FQOL, most participants reported that special schools provided them with services for their CWD and with some respite. Most participants also mentioned that respite care services were most valuable. Some participants reported that their extended families were helpful, but that they felt reluctant to ask for support. There was a mixed response to the value of parent support groups and siblings groups, with some participants feeling that these support groups were helpful. However, not all participants reported the same. This code was subdivided into four subcodes, namely:

5.1. Special schools provide support for therapy needs and are a respite for parents due to long hours;

5.2. Respite care is hugely valuable because it provides parents with time away from caregiving and the CWD enjoys the time in respite too;

5.3. Friends/family help but parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older, and;

5.4. Support groups are valued because they provide information, research, and friendships.

Subcode 5.1: Special schools provide support for therapy needs and are a respite for parents due to long hours. All participants had their CWD attending a special school. Two children (interviewees 6, 7, and 10) were recently moved to an interim residential care facility due to behaviours of concern. Amanda (I1) was not happy to move her son, Eddie, to a specialist school. He had changed several schools since leaving ECIS from mainstream to special schools. The mainstream schools helped, but according to Amanda they were not equipped to manage students with challenging behaviours. However, she said that the special schools had specialist staff and were able to manage his behaviour. She was not called from school to help with his challenging behaviours so it gave her more time. The downside was that the special school did not provide the right challenge for her son's learning and she has been saddened by their input and their low expectations from him.

We made the decision to mainstream Eddie so he was at mainstream school. We found that even though he was learning, the schools were really not set up to cope with some of the issues ... You know, if he went out, he ran outside in the playground during the day, he'd spend the rest of the day outside, you know. It was totally useless as far as learning was going. I1: L290–292, 304–305 (Amanda)

and I thought that if I put him in another mainstream school ... we just won't succeed at anything ... and they [special school] assured me that they would challenge him and all the rest of it ... and to their credit they did a really good job because they were consistent and they ... his behaviour did really improve at the school. I said to them, "look can you start challenging him now". This was in second term, I said, "can you start giving him books", because the books they had been giving him to read, he had been reading in grade one, and he was now in grade 4. I1: L410–418 (Amanda)

Bianca (I2) and Eli (I5) wanted their son to attend mainstream school and tried it for a few years; however, his high needs and autism meant that they had to dual school him at a special autism school and mainstream school. Finally, he was moved into a specialist autism school, as he was not gaining much from attending a mainstream school. Eli commented that he liked the inclusive environment of a mainstream kinder, but was happier with the services at the special school.

We went [to mainstream school] because we wanted him to get a social element and get him challenged a bit. But at the same time [it was not working] ... I5: L178–179 (Eli)

I suppose then looking at primary school scenario and first, not being able to get full funding for a full time and at school we had to juggle and choose what's the best option and we chose a dual school approach so we had a full time day ... So that was where he started off schooling and then he started back at dual school. I5: L168–171 (Eli)

For Fiona (I6) and Gary (I7) special school was their preferred choice for their son with autism. They were grateful for the support from Samuel's special school. Fiona expressed that the push towards inclusive school was not for her son because she wanted smaller class sizes and did not want him to be babysat at school or have an aide following him. Mainstream school was never a consideration for Samuel according to Gary or Fiona, because both parents expressed that they were more comfortable when they visited the special school, given his highly specific behavioural needs and his severe speech and communication issues.

Oh school's [special school] been fantastic. It was the school who in fact who got us some support from DHS [for respite] because they, we just kept being knocked back and told that it wasn't serious and it wasn't important ... I6: L501, 510–511 (Fiona)

... but if he'd gone to mainstream school he would've been babysat ... he would've had an integration aide who would've just followed him around. Whereas in this environment where they had small classrooms with four or five kids in the classroom, a teacher and an assistant, and in the area where the little ones are. I6: L851–853, 868–871 (Fiona)

It was never a consideration [mainstream school] ... they said they'd be quite happy to accommodate him though they hadn't actually assessed him themselves. And finally we looked at the autism specialist special school and when we walked in there we just knew straight away it would be the only place that could possibly manage him and ... but also um, escapology and he really needed to be schooled in an environment, which had extremely tight security. I7: L118–140 (Gary)

The school bus from the special school was a long drive from home, and in some ways was a support for the family as it gave them a few extra hours of respite.

he was going there on the bus, and coming home on the bus most afternoons, that's about an hour-and-a-half trip each way. Umm, and that in itself was a form of respite because it meant that because he had to get on the bus so early and his arrival home on the bus was so relatively late compared with regular school hours that we had a bit of time to get ourselves ready to go to work. I7: L92–104 (Gary)

Kate (I11) reported that special school was the best option for her daughter with cerebral palsy as they were well equipped with access and therapy and she did not get this at mainstream school. She was not sure of the support her child would receive for her disability at mainstream school and was happier with the special school.

Yeah, yeah they you know they look after everything she needs and all the therapists there they're all under one roof sort of thing umm I'd looked into alternatives, mainstream, and like down here where her sister was going but ... there was only a couple of entry points that had ramps, all the portable classrooms had stairs, she would have been just restricted to one building pretty much and and they just had all dollar signs, you know, \$50,000 came along with her. They couldn't offer me full time aid, I said she needs someone with her all the time ... She got the level 5 funding but they said we would need to use some of that to modify the school grounds and this and that. I11: L1242–1269 (Kate)

Subcode 5.2: Respite care is hugely valuable because it provides parents time away from caregiving and the CWD enjoys the time in respite too. Most participants reported that respite care was one of the most valued supports for the family and helped their FQOL. Respite care gave them some valued time to spend with their

other children or do household chores or gain some time for themselves. They valued consistent and experienced respite care workers and the activities during the respite times that brought enjoyment for their CWD. However, most participants considered gaining access to respite a tedious and difficult process.

Well respite is probably one of the biggest things that help quality of life. I mean we know that Mick is getting looked after, we don't have to fuss over him, and we can do what we need to do. We can do things. Sometimes we go out with the other two kids and go out to the movies. I4: L373–376 (David)

Bianca (I2) and Eli (I5) valued respite care services the most out of all services and they waited for respite, as it gave them some time together, even if they rarely planned to do things together. They valued the activities offered by respite care for their son James, who had autism. They reported that it gave them some time to be with the other children without worrying about James's caregiving.

So ... we hang out for that [respite care] sort of once a month, once every six weeks night when it's like "oh great so and so is coming, what do we do?" ... And this the honest truth, we rarely plan ahead often it comes to, the person walks through the door, we're like okay let's go then we look at each other and go what are we gonna do? But we walk out and we go and we do whatever and it's a breather. I2: L546–554 (Bianca)

Having like carers coming in every week and taking James out to the park and stuff like that. That helps out even if it's an hour or two, I mean it's helping James but it's also giving either Bianca or myself to either discuss something, to eat together, or to do some chores around the house or get things done around the house or even give one of the other kids a bit of attention during that time. Even getting the 4-hour type respite once a month that helps. Because then we can go out, either plan something, go out together for tea and just talk. Sometimes we go out and we're too exhausted to talk. We just sit there. I5: L80–88 (Eli)

Respite care provided some holiday camps for their CWD, and Eli said that this was a good opportunity for the siblings to have some free-time at home with them. He appreciated respite carers who were welcoming, reliable, and ready to take on the challenge of caregiving.

There's now more of an opportunity [for their CWD] to go on some camps for 2 or 3 days, that helps out. It also gives the kids a bit of free-time as well with us; Bianca and I get a bit more free-time at nighttime. I5: L94–96 (Eli)

Picking a carer ... you could get a carer that says ... they don't like walking around because they have a bad ankle and we had a carer like that ... so you ... ask if they don't mind. The one we've got she sometimes comes on a Saturday and she's prepared, she comes with jogger pants on and she's got a water bottle like "I'm ready!... I'm ready, what do you want James?" I5: L320–324 (Eli)

Similar to Bianca and Eli, both Caitlin (I3) and her husband David (I4) valued respite care very highly and reported that it was important for having a good FQOL. Their CWD, Mick, enjoyed the activities that he attended with the respite carers. Respite care workers also helped with Mick's self-care activities such as feeding, bathing, and getting him ready for bed each week. Caitlin reported that they would not have been able to manage without respite. The respite care on weekends helped both Caitlin and David to spend time with their other two children and the holidays were important for their family.

One of them [respite carer] is actually taking him to his gym class on a Monday after school, whereas I was doing that and I found that a real rush um ... But mostly the carers come to the house in the evening to look after school, give him food, bathe him, get him ready for bed so I can concentrate on the other two kids ... Without a doubt that helps. So we're still home and the carer is here but that's ... for that person to look after him, makes a huge difference and it makes a happier household. I3: L112–117 (Caitlin)

We had a lot of support with Mick I had respite coming out of my ears ... that was vital, if I didn't have that I don't think we would be here today managing as well as what we are I suppose. I3: L145–147 (Caitlin)

If he goes away for the weekend or at home respite, I'll do something special for the kids ... and every now and again we have holidays without him. I3: L206–207 (Caitlin)

Caitlin was worried about losing this respite care due to her son's recent unacceptable social behaviours. Losing weekend respite would make it difficult for the family as they planned activities together on weekends without Mick and these activities were

helpful for their family. David said that he felt happy that because their CWD enjoyed the respite activities and loved going with the respite carers, it helped with his feelings of guilt.

... yep and we're frightened that he might be told not to come to the respite house until it [behaviour] improves and then there goes our ... our sanity if ... we don't get a break from him. I3: L33, 37–41 (Caitlin)

You know, he loves going there [respite] and I would've felt uncomfortable for him to go to these places and him not enjoying it, it would make me feel guilty. But because he enjoys it so much ... just driving to the place, he knows where he's going and he's so excited and so forth. I4: L297–300 (David)

Respite care services were also very highly valued by both Fiona (I6) and Gary (I7) and they reported that access to respite helped their quality of life. They received limited respite care funding and paid out of pocket for respite because they had significant difficulties in accessing full funding for respite care.

Well the main thing that helped our quality of life ... was the provision of some in-home respite services umm, after we received a funding package ... but at the end were still only providing about six hours of in-home care a week, and that meant basically, we could spend some time on weekends and particular Saturdays or Sundays, just relaxing at home or going out and doing things. I7: L62–72 (Gary)

Um, I suppose we could have paid for it privately ... because skilled um, respite care is, is not cheap and most um, standard respite care workers don't have sufficient training or skills to care for someone who's severely autistic. I7: L197–202 (Gary)

These hours of regular respite were greatly valued by the family as they acquired time for doing household tasks or spent some time with their daughter, or went out with friends, or just sat together as a family. The family enjoyed time sitting together and doing nothing, as that was difficult because their son with ASD had high supervision needs.

Yes, so the thing that made a difference um, was when we started getting regular respite ... for Samuel, and so before we had many, many years with nothing, and so

then we started getting regular respite and he started going for overnight respite to the place where he's now staying, and, we started using that just to do nothing. And we went to that rooftop bar [with friends], and Samuel had gone off that night for overnight. And so, you know, Jane [sibling] and I have organised Peking Duck, and we're gonna watch the Footy. I6: L276–280, 284–287 (Fiona)

Then once we started getting more regular respite, um, and then, when it was funded, you know we were being funded for regular respite, we went okay, we don't have to party every time ... We can actually just chill together at home and ... that's, that switch really made a difference, so it was the regularity of it ... I6: L295–305 (Fiona)

Fiona expressed that her son enjoyed going out with the respite care workers because he seemed happy, enjoyed the activities, and this was important for the family. The parents said that they felt happy and relieved because their son enjoyed recreational activities during the respite care times and wished that there would be more activities available for children with similar needs like their son.

And getting the same carers, carers that could cope, carers that knew what Samuel liked doing. Because he, he doesn't like other people. He's very clear about who belongs in what spaces. I6: L317–319, 324 (Fiona)

Similar to Eli, both Fiona and Gary mentioned that respite care workers needed to have specific qualities so they could trust the workers with their child. They needed to be aware of the interests and needs of the child they were working with and needed to have coping skills. Fiona also mentioned that it helped if the respite workers were open to accepting strategies from parents related to the safety of the child, because her son had a tendency to run away.

... and so, and he would just, he had his favourites but he was quite happy with them. In the previous year when we'd been trying to get some regular respite ... there was difficulty getting regular people. And so, you know, there'd be someone who'd be fine and they'd come for a couple of months and then [we] wouldn't see them again. I6: L376–383 (Fiona)

Both Fiona and Gary reported that gaining access to respite care was a difficult process and because they were competent and resilient parents they were able to shoulder the burden of care.

And I felt in some ways that because we were sort of both health professionals. We're both sort of reasonably uh, competent and resilient people, that we probably ended up shouldering a greater burden of care and stress than we would have if we hadn't been able to cope. I7: L785–793 (Gary)

Fiona mentioned that the family had to pay out of pocket for respite and were told that they could only get respite if their situation changed for worse.

So that sort of lasted for a period of time and then I you know, few months got some respite and then we just continued paying for it ... Out-of-pocket, yeah. About 40 dollars an hour, um, so for us, so we're, you know, we're saying \$200 or whatever it might have been to have a regular Saturday afternoon ... and then (DHS) every year I'd get this letter, and it would say 'Let us know if your needs are urgent'. I6: L586–599 (Fiona)

Fiona mentioned that they did not qualify for respite services despite her husband being diagnosed with a serious medical condition and the family needed respite for the hospitalization; however, they were placed on waiting lists.

And then when Gary got sick, um, with cancer and chemo and I'd get the letter saying 'Let us know if anything's changed', and I went yes, you know ... my husband's actually really sick. So I call them up again and say 'Well yes, look something has changed'. I6: L601–605 (Fiona)

Similar to Gary and Fiona, Isla (I9) reported that respite care was difficult to access.

She had very little respite support and would have liked more as it helped her to get some time off. She received respite once a month when the workers took her son out, and on school holidays she received respite for a couple of days. But she would have liked home help and had to ask her friends for respite care occasionally.

I get a bit of respite from the council. So he's in a music and movement program once a week. Once a month they take him um, on a Saturday or a Sunday for an activity, for ... six hours. School holidays I get a couple of days. It's not a lot. I don't have any

in current in-home help. I don't have any respite at home. I've got a friend that comes and helps me sometimes. I9: L224–243 (Isla)

However, similar to other parents, she also expressed that the respite workers needed to be consistent especially if children have a diagnosis of autism as their son would not be familiar with new people and would refuse to go out with them. She reported how the recreation activities that the respite carers took her son to, such as gymnastics, were helpful when she had her second baby.

I had him enrolled in gymnastics. And they organised carers to come and do the gymnastics with him ... 'Cause I couldn't be there with her at the same time. She was a baby ... cause I was busy with her. But at the same time, it was someone different every time. So it didn't work because he didn't know them, he wasn't used to them, he wouldn't let them touch him, and he wouldn't let them near him. Sometimes he didn't even want to get into the car with them. So it made it really hard. And to find funding to get a carer that's you know, used to your child or who knows your child or to get the same carer every time. I9: L1021–1046 (Isla)

Isla said that parents had to be at breaking down point for being eligible for respite.

The paperwork attached to securing respite was also an area of concern for Isla as it was slow and poorly funded. She felt strongly that accessing respite care needed to be accessible in the new environment of the National Disability Insurance Scheme (NDIS).

In the end I said look, I-I'm, I said I'm not going to be able to look after him without some help. And it took me really, really breaking down for them to actually turn around and say 'Okay look, we'll send you some paperwork out, fill it in and get back to us. But the, the process is so slow... And I don't blame the people working at DHS ... because they probably get who knows how many calls a day. And there's only so much funding to go around. I9: L1064–1074, 1090–1098 (Isla)

I'm trying to get funding for respite but I'm not getting anywhere, we're on waiting lists for everything. Which is hard, and a lot of the respite... A lot of the respite funding now, it's either really, really hard to get or it's starting to drop off because NDIS is coming in ... they're already cutting funding. I9: L971–986 (Isla)

The biggest support for Fiona's family in the past few months was that their son was accepted into interim in-home care, a residential facility. They had come to terms with not having their son at home, and it had reduced the burden of care for the family. They were still concerned and visited him regularly; however, having the support of interim residential care was a respite and relief for the family members and significantly helped their FQOL.

Now that he's actually moved out into out of home care, we feel enormously relieved and we're still obviously very concerned for his well-being and, and future, but it's taken a huge burden off us. I7: L31–33 (Gary)

And since he has moved out, his behaviour has improved because the out-of-home residential facility he is in is able to provide the kind of highly structured, predictable environment that we simply couldn't replicate in an ordinary family home. I7: L170–174 (Gary)

Subcode 5.3: Help is available from family and some others, and is valued, but parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older. Partners and spouses are the main support. Most participants were not receiving support from extended family. Ten out of 12 participants reported that they were supported in caregiving by their spouse. Two participants were single. A few participants said that they had received some support from the extended family when their children were younger; however, they felt reluctant to ask for support now. Many participants had lost old friends, but had made new friends with other parents of CWD, who were part of their support system.

Amanda (I1) was the main caregiver and had support from her husband Harry (I8). However, sometimes she reported that she had to manage his personality as well because he would become defensive and this could impact their relationship.

I had to be really careful with Harry [husband] because he's ... he's that personality where if you start talking about things, he'll go on the defensive because he thinks you're attacking him even though you're not. I1: L632–635 (Amanda)

She was also finding it difficult to manage her son's challenging behaviours as well as her other two boys, who were exhibiting behaviours related to growing up and reaching puberty. She reported on the pressure of being the only one who had to follow through with all the difficult behaviour management strategies and referred to herself as the disciplinarian.

Because I was the dragon, I was the disciplinarian across the board regardless of where we were it was always me that, you know had to tell him "no" not to do that or explain that he was doing the wrong thing or whatever, and that's what they saw me as, the disciplinarian. I1: L380–383 (Amanda)

Amanda did not get much support from her extended family, although she had received some financial support from her father in times of need. She said that her parents were not able to provide appropriate support for her children when they were growing up, so never asked for help.

I had mum and dad but that was it, but they were kind of older and plus they weren't like yeah ... they weren't ... I couldn't trust Eddie with them because my father had bit of a bad temper. I1: L464–468 (Amanda)

She also lost a lot of friends mainly because she found that their attitudes to disability were not what she expected. She felt hurt with how they viewed disability and preferred to not have their friendships. However, she missed her friends.

I lived with her [friend] for many years before I got married. Shared a house with her, so she was one of my closet friends and I said to her... and she's a schoolteacher, so I said to her ... Oh we're thinking of mainstream school for Eddie [CWD]. And she said, "oh well if you ask me, my opinion, integration has never worked". ... and um so we don't have that circle anymore. No they never came back, no ... And I still miss them all. I1: L511–515, 534–537 (Amanda)

Harry (I8), Amanda's husband, reported that support from their family was scarce, because of the distance and because they were busy with their own families. Harry

also reported that most of his family members barely tolerated their son with disability and he found it awkward so they rarely got together. Harry's parents had to look after his brother's children, and Harry said that having them involved in the caregiving of his children would increase the burden on them and they would not cope with his son with disability. He said that he did not like to ask for support because most people, even though they were good people and were empathetic, felt sympathy and he did not want sympathy for his family.

Oh, we've got family ... they, mmm, they all, they tolerate him I think, and at times, at times they'll laugh with him or ... but yeah, it's awkward. My family, he's just kind of irksome ... I think too my parents were a bit over being the grandparents. Looking after children ... and also I don't think they would have coped with Eddie – They did, you know, they could only tolerate him in small doses. He's pretty full-on. I8: L666, 690–704, 733, 758 (Harry)

there's a lot of goodie, anyway, good, nice people who come up and start uh, what empathising or something. I mean, he's my son, I don't, I don't need sympathy. I8: L983–987 (Harry)

The main support for Bianca (I2) and Eli (I5) were each other. They stood by each other and helped each other with managing the caregiving of the children. Eli worked full time but was involved with the family, and assisted Bianca with all tasks and activities to his best, and she acknowledged this. They also received some help from Bianca's parents who helped with school pickups and occasional childcare for the other siblings if needed. However, both Bianca and Eli expressed some guilt asking for help as the grandparents lived about 40 minutes from her home. The grandparents also spent holidays with them to help with looking after the children.

I couldn't do it without Eli [husband]. Um yeah, he helps a lot, I guess ... you can sort of humour it and go, he comes home from a full day at work and as soon as he gets a chance to stop and have a breather, I go "why are you putting the kettle on? You know, there's things to do!" I2: L505–508 (Bianca)

Bianca's parents actually live a fair distance away and it takes them over half an hour to get here and my parents aren't around anymore so that side of its ... So it kind of puts a bit of strain ... we don't want to keep constantly asking the same people to do this and you can't do it all ... So it's kind of knowing that we can't constantly rely on it, we're trying find another outlet. It's a difficulty. I5: L269–273 (Eli)

I don't think they [grandparents] mind but I guess there is a limit. They have other family as well and you don't want to be a burden when they might want to see other family at the same time. I5: L283–284 (Eli)

The family also valued the support they received from their church group. The church group helped with fundraisers and even if they could not offer practical support, they always called on the family to check on their well-being, and empathised with their needs. This was highly valued by the family.

Church have been really good and continue to be really good in that sense of recognising us as a family and that our family life is a bit different and James' [CWD] needs are there and need to be met. They're not always ... happy to offer practical support but sometimes they do sometimes when we're just ... when particular things happen in terms of James' situation, like when he had surgery, they were there for us just to go ... they rang in and they sort of found out how he's going and they've sort of continued to follow up to see how he's been post-surgery. When other things happen, I guess they sort of just ... they're certainly emphatic to our situation, they don't always understand, but they're there. Sometimes when they've been particular events or situations that have caused us to struggle financially sometimes they've helped, churches helped out which is good. I2: L355–365 (Bianca)

Eli also mentioned that when they had lost their son on a holiday trip, he was astonished by the number of people that came to the campsite to help with finding their son. Many of these were parents of CWD that they had never met or known, and some were past parents from the parent support groups. It was an amazing experience for them to see this support from their past friends and from other parents.

Last Easter it was amazing how many of those families went to help to find James. They didn't need to. Knowing them it's like being on a journey with them as well. Even though their kids are all different, there are times where you help each other out with it ... When they heard that James went missing, it was that group that really pulled it together and it was amazing what they pulled together through phone calls

and texts ... I don't even know them, but they say they have a kid on the spectrum like they do it tough but yet here they are wanting to help, they don't have to but they felt... I5: L342–345, 359–372 (Eli)

Caitlin (I3) and her husband David (I4) were the main support for each other. Even though Caitlin was the main caregiver, David was always there to help when needed. They also said that they had developed friendships with other parents of CWD, and they were a huge support to them. Caitlin had a group of friends that were her support system. Most of these friends were other mothers of CWD and she said that the support from her friends helped her feel normal and she would be lost without her friends.

Obviously I do most of the organising... but if I get sick he [husband] takes over completely ... absolutely completely so he's very capable and to be quite honest right from the word go, when Mick [CWD] was a baby he was the more capable parent so he's got quite a bond with Mick. I3: L285–289 (Caitlin)

We feel that our friends are our biggest support, – 99% [99% of her friends have a CWD] without a doubt. I3: L174–177 (Caitlin)

It normalises things [having friends] and you just ... I would have to say that the biggest thing got me through anything was friends in similar situations ... Without a doubt, I would be lost without them. I3: L440–442 (Caitlin)

Caitlin also expressed that it was important for parents to accept help and support from outside (such as respite care). She said that accepting their son's disability and accepting the support from others helped their family feel like any other family. It helped her feel that her son with disability was just like all other children, and their family could function better with support for his needs.

I've met so many parents that don't do that and won't accept outside help. I think we function really well as a family with a disability ... with having Mick. It doesn't mean there isn't stress there or anything like that but I think we function pretty well because um it's not all about disability it's about being a family and we often see that Mick is just Mick. The disability is just added on to it. I3: L382–384 (Caitlin)

David said that talking to other parents helped even though it did not take away the issue of living with disability. He acknowledged that the first few years of having a CWD were hard and that the feedback from other parents was one of the best things for him.

I suppose the best thing was talking to other mums and dads. Getting their feedback on things and giving feedback. I mean it's tough the first few years, real tough. But it progressively gets better once you learn about your child and you know sort of ... their personality and then you can work them out. But it's still an everyday ... I wouldn't say a battle ... but it's an everyday thing. I4: L257–263 (David)

Fiona (I6) did not talk much about support from her family or friends. Gary (I7), Fiona's husband, reported that when their son with autism was younger they received some support from the grandparents and that was helpful. They valued the grandparents' support and were thankful that they lived close to their home. However, they never considered leaving him with their friends.

Well for many years it helped enormously being able to have him looked after for short periods by, by-by grandparents ...and um, and other relatives. We'd never left him in the care of friends, we thought that uh ... even when he was at his best at home that was, that would have not been feasible. But the fact that um, uh, both Fiona and I have, have parents and other family members who live in Melbourne, was, very valuable. It would have been much more difficult for many years, if we had not had family nearby who could uh, support us and help look after him on occasions. I7: L303–320 (Gary)

Gary did not find his friends helpful. He mentioned that he had several friends who would suggest places they should visit or movies they should watch; however, he did not call upon them for support because he thought that they did not understand how difficult it was to live with a child such as their son.

I almost got annoyed on occasions with um, colleagues and friends and others telling me about all the wonderful places we should go and the films you would see, because they weren't actually witnesses to what our domestic lives had become. They had no understanding that we couldn't do that because of Samuel. I7: L380–390 (Gary)

Isla (I9) mentioned that her husband supported her with home care and caregiving as far as possible; however, he worked long hours because of financial needs.

He [husband] does when he can ... Look he's good at ... you know he'll change him, he'll feed him, you know, all that sort of stuff, he can do all that. Umm, it's just the time; he's not around enough anymore. Hopefully that will change once the business is a little bit established. I9: L455–462 (Isla)

Subcode 5.4: Support groups are valued because they provide information, research, and friendships. Six participants reported that parent groups were valuable for them. They valued the shared experiences and friendships that they had made with other parents. The information sharing was also helpful because they did not have to do all the research on their own. Amanda (I1) remembered times when parents got together and shared their experiences, understood each other, and shared their stories. She missed these groups.

We got to know each other really well, and in the end it used to be like, we would sit there and we were all so close we would talk about things that we were going through. We would cry together. We would laugh together... Yeah you didn't have to be guarded ... And we'd of course tell them the stories and we'd all laugh together or if it was something quite tragic, really sad, you know everyone really felt for you. And it wasn't pity, it was understanding. I1: L556–570 (Amanda)

However, for her husband Harry (I8), it was not the same. Harry was involved in some parent support groups and his children had been involved in sibling groups. His children enjoyed the sibling groups, but Harry said that the groups did not help them and just added to their pressure. He said that being with other families of CWD increased his grief and he would prefer to do something else than be with them. He would also prefer to know what to do about the grief, rather than discuss with others who were going through the same grief as him. He said that he couldn't do anything about the grief and talking with others did not help him.

What, it's just another group [sibling groups] of friends. And they all have similar issues. It doesn't necessarily help them just to be all-together. I mean, they enjoyed it, I know they enjoyed being with those kids. And you can keep dragging them to those things but they've got, we put our kids under so much pressure now. I8: L1336–1345 (Harry)

[About parent support groups] And getting together with other families of kids with disabilities ... it, for my part I, I find it really, heavy weather. It just struck me we're, we're kind of united in grief rather than ... I'd rather, I'd rather do anything else. ... Well I know for me I, the grief's always there. And um, sometimes I just get buried. Ah ... I don't know how you could, yeah, well, you talk about it, you're just bringing up stuff that you can do nothing about really. So we just, well, for my part I just go and do what I, what I got to do. You know, talking about it doesn't help. Doesn't change anything. I8: L846–847, 860–861, 1024–1028 (Harry)

He did not find the parent groups valuable and found fathers' groups irksome and irritating. He thought that men did not like to sit and talk abstractly to each other or laugh and talk about their children because it did not achieve anything for him. He would rather be in support groups that would help parents meet other adults with a disability similar to his son, so that he could understand the future better and prepare for the future.

I think the thing that would help us, would be, if us dads can get together with um, with young adults and men who have Down, had Down Syndrome ... and talk to them. Like sitting around and, and talking abstractly is not what guys do. It's kind of irksome and irritating and I'd rather be doing something else. Cause it's not, it doesn't achieve anything. We don't bring up that sort of stuff, unless it's you know, just to laugh about something that the kids had done. I8: L1055–1069, 1082 (Harry)

For Caitlin (I3), parent support groups were instrumental in providing her with support and information. She changed her career to become a facilitator of parent support groups. Caitlin through her work of providing parent support groups, researched and advocated for services available for CWD. She became an advocate for parents and helped other parents by providing information around navigating services via the support groups. She reported that accessing disability services was difficult and compared the network of support to a secret code that was hidden away

from families. She said that families missed out on services and was happy that she could help other families through parent support groups.

Oh absolutely well informed and I feel like I'm well informed um because the position that I'm in [parent support group facilitator] ... my workplace probably. Just ... I don't know I'm just always seeking information and ... the whole disability thing ... the whole ... the whole network of support and lots available is such a ... it's like a secret code it's hidden away. You need to search for it, which is so wrong, I think. Um and I think that's why so many families are missing out. I3: L414–421 (Caitlin)

Fiona (I6) and Gary (I7) did not feel that the parent support groups were helpful for them; however, Fiona mentioned that talking to other parents was somewhat helpful.

Look I thought they were all good [parent support groups in early years], I mean I, it's a bit hard to know, what sort of support you want but it was always, it was really good talking to other parents and you know, that, I think there was a bit more of that. I6: L897–899 (Fiona)

Gary was not convinced about the benefit of such support groups, because most parents had children with varying diagnoses. He also reported that socialising with other parents of children with autism similar to Samuel would increase the caregiving when they got together, so it was not worth the trouble.

we never really got into any kind of social scene [parent groups] through his school ... the other um, other families came from all over the place ... so if we'd taken Samuel around to their place [parents from support group] and they were similarly having to maintain, constant vigil surveillance it would just sort of double the trouble, so there didn't seem to be any, any point. I7: L421–425, 434–438 (Gary)

Even though the sessions on information related to autism seemed helpful to Gary, the parents that they met at these groups did not live close to their home or did not associate with Samuel's school, so they did not feel a desire to catch up.

I went to some classes with an organisation providing applied behavioural analysis uh, a number of years back and got talking with some of the other parents there but none of them were associated with Samuel's school or lived anywhere nearby and we didn't actually um, any of us uh, feel the need or desire to catch up. I7: L440–448 (Gary)

Isla (I9) attended a parent support group and said that these groups were important for parents; however, she found it hard to get to them on a regular basis.

I do go to My Time [parent support group] once a fortnight when I can. I don't always get to ... it's once a fortnight. Last fortnight I missed it because Alex was home sick from school. I9: L745–748 (Isla)

She valued meeting other parents in a similar situation as her and had formed a close bond with a few of them. She was reliant on the support of these parents and trusted that they would be there for her in times of need. She recognised that parents in support groups faced similar challenges as she did and that they all support each other. Isla also valued the facilitator's input and the information sharing and researching at parent support groups.

Um, the good thing is, the great thing out of that is I've met a lot of people who are in the same situation, and I've formed a really close bond with a couple of them ... and we're there, it's-it's good support to have and good to get others' ideas and experiences as well. There are two really good people that I've met through the support groups, which I know that if I click my fingers they'd be there for me. Even though they have their own challenges, and their own, they're in the same situation, probably worse. I9: L762–768, 777–786 (Isla)

And the facilitator as well, she's good, like she's got a lot of experience, she gives us advice ... she passes on information. I fell back on the, the seminar side of things, you know getting information, going to groups, that sort of thing [after her second child was born], researching, that stopped completely. So now that I've started My Time again ... I've-I've started to get back into that. You know, learning more about the NDIS and how it works and trying to be ready for it and you know. I9: L825–842 (Isla)

Code 6: Families miss the ECIS family-centred support and the keyworkers, the financial support, and fun and engaging activities for their CWD, but the early years were raw and hard. Parents adapt and become advocates for their CWD. This code had six subcodes:

- 6.1. Parents miss the ECIS services and family interaction.
- 6.2. Funding for services after ECIS is difficult. Disability support services are difficult to access. NDIS is helpful.
- 6.3. Inclusion of CWD into mainstream school is difficult and challenging for parents due to lack of supports in schools and lack of ECIS-like support.
- 6.4. Dads need support in the early years, but the support they seek is different to mothers.
- 6.5. Early years are raw and hard and more focused on the here and now and on child's therapy rather than parent well-being.
- 6.6. Parents become advocates for their CWD and for other families.

Subcode 6.1: Parents miss the ECIS services and family interaction. The majority of the participants valued their ECIS services from the early days and expressed that the difference between services at school and ECIS was huge. They missed the staff interaction, the keyworker type of case manager, and the interaction with other families. They missed the family involvement in school and the family-centred approach of ECIS. Amanda (I1) said that the biggest difference between ECIS and school was the lack of interaction between staff and parents. She missed the support and interaction with other parents and would have liked opportunities to help out in the classrooms. She also commented that at school, parents had to drop off their children without involvement in their child's activities or programs. This was different to ECIS and the family-centred practice approach.

Ok there wasn't as much interaction [with parents after school]. Like there was no support as far as like if you got stuck you could ring a parent and say, "I'm going to be late, can you just make sure Eddie's ok", or whatever. Or even the school, you know. There was none of that support there. I had nobody that I could do that with, you know. I1: L816–819 (Amanda)

There was no support whatsoever [at school] and plus the whole relationship was different too, because at early intervention ... we were really involved with his educators, you know, teachers, support staff, and when it came to school you basically dropped him off and the door was shut and that was it. I1: L797–800 (Amanda)

Bianca (I2) also missed the support and assistance the family received in ECIS. She had to research their entitlements and depended on their parent support group for receiving information and support for services, and funding for their son, as he was growing older. Compared to ECIS there was no support for family activities, recreation activities, or respite care. Overall, she found school not as supportive as ECIS, especially as it was not family-centred but more child-centred.

When he was in early intervention, there were ... people who were in that early intervention role who were able to inform us on what we were entitled to and they would source grants on our behalf or extra funds for this or the other. Now, there's no one to do that for you ... it's much harder and it's harder in the sense that you have to go looking for it yourself and harder because there's less of it. I2: L779–781, 809–810 (Bianca)

It sort of hits home that school is school and whilst the staff there is doing their very best by your child, once school finished for the day, they don't, they're not there to offer you support especially in that "whole family" sense. I2: L401–404 (Bianca)

Caitlin (I3) reported that the early intervention support for her CWD, and for her and her husband as a couple, was very helpful. The counselling she received about the importance of parent well-being helped her understand that it was important to look after her own needs and was instrumental for her well-being. Kate (I11) missed the family-centred support and the support groups for siblings from ECIS. Lisa (I12) missed the support at home and home visits to help her child with equipment needs. Being a single parent and managing four children (two with a disability) was difficult and compounded by a lack of support from the special school for equipment and the medical needs of her child with cerebral palsy.

I don't think we would be here today managing as well as what we are I suppose without a doubt ... the support we got through early intervention and all the wonderful people we met so that really helped ... without a doubt. I3: L146–149 (Caitlin)

Yooralla was more family centred with a lot of the things you know Siblings group, all of those, the sibs camps. I11: L1216–1218 (Kate)

I feel like I've got no support from the school ... When I was, went through Yooralla [ECIS], it was more settled. Like you could work with things, with now, for now, I've got no, no one coming into the home like how ... Yeah there's nothing. She's needing things I ..., yeah. I feel like I've got, like I go to... like have her foot operation once she got the new manual wheelchair because there's no way they would do the operation without her new chair. They couldn't operate because she, that chair was terrible for her ... so we waited 2 years, once we got the chair, we went in there and they said we can't operate. I12: L191–195, 207–216 (Lisa)

Compared to the other participants Fiona (I6) and Gary (I7) had a different experience of ECIS, and they did not feel that ECIS was as helpful. Their son's ECIS service was not based on a keyworker model and they attended a specialised centre-based program where services were offered in groups on a fortnightly basis, and he said that it was not enough. Fiona compared the support they received in the early years to now and said that talking to other parents helped her. However, she found that the push towards inclusive school was not for her son. Gary did not think that they received adequate support from their centre-based service. They tried private therapy to help with their son's behavioural concerns, and had a worker carrying out a home-based therapy program. However, they reported that the worker coming home was used more as a respite rather than to assist with managing his behaviour.

No I thought the system for early intervention services was useless. It [ECIS] was located a long way away, and it was only available about two hours a fortnight, and had very strict rules that if you didn't um, arrive within certain time parameters more than two sessions in a row you're expelled. And we just looked at where we were both working, and what value we thought we might get from it and decided it wasn't worth it. If there had been a specialist autism early intervention service closer and with more hours of availability, we would have taken it up of course. I7: L479, 485–495 (Gary)

Look I thought they were all good [parent support groups in early years], I mean I, it's a bit hard to know, what sort of support you want but early intervention, it was really good talking to other parents. I6: L897–899 (Fiona)

And so before he went to school we ended up, um, paying a private clinical psychologist with uh, expertise and experience in the area to develop a home-based ABA program, and then paid for, one principal worker to come and do some work with Samuel. In retrospect I don't know how much it helped, if at all. Um, but at least while he was doing the ABA work with the worker we had a bit of, a bit of time on our hands. I7: L504–516 (Gary)

Subcode 6.2: Funding for services after ECIS is difficult. Disability support services are difficult to access after ECIS. NDIS has been helpful. Most participants reported that they had to source funding and do advocacy and research on their own with no assistance from their current services. They had to pay for nearly all services that they used for their CWD outside of the special school such as therapy, respite care or counselling services. Amanda (I1) reported that there was a lack of funding for any therapy or services.

He had a speech therapist at the school that I paid for privately because we couldn't get any services through the school because ... Well early intervention is one thing but once they go to school there's no, or well there wasn't any funding then. I believe that there is funding now but not in those days. I1: L337–341 (Amanda)

Funding at school was also a huge issue for Eli (I5) when compared to ECIS. He was not happy about the deficit-based funding at school. His son was entitled to three days a week of support at school that was not sufficient according to Eli, because even though his son was able to walk independently, he needed assistance with self-care tasks such as toileting, and with communication. He mentioned that funding for mainstream was like winning a lottery and parents did not know what their entitlement would be based on. Consequently, the family had to organise two school settings for him; he attended three days of mainstream and two days of special school.

Bianca (I2) reported that compared to ECIS there was very limited funding for supporting the family for quality family activities like going out for movies.

Funding wise ... Therapy wise, there's less out there in terms of supporting. Same with quality time. I remember when James was little there'd be early intervention funding that ... and they would say "we'll give you this money and there can be a certain amount spent on James but ... you keep 100 dollars to buy a booklet of movie vouchers so you and Eli can go... I2: L799–803 (Bianca)

I suppose because he was able or more able ... Yet, they still didn't classify him as in the category like someone who was on a wheelchair or crutches like that. So ... He wasn't qualifying for a fulltime aid. Yeah ... it's like a lottery. Like you pulled out five days, one day ... Oh! You got two days! Yeah well you need assistance going to the toilet and in the early days it was a regular like ... prompting every hour and hour and a half. I5: L193–207 (Eli)

In terms of disability support, Gary said that he felt resentment with the process of applying for support and with the time it took them to receive any support for their son with autism at home. He expressed that assessments for respite care support needed to be done based on the need and burden of care for families.

Quite frequently and you know with a degree of at times of resentment, particularly when we started the process of um, application for uh, disability support, and had received nothing three years down the track. I7: L28–30 (Gary)

I think, maybe if there were some form of routine objective assessment of need, based on burden of care, that was applied routinely ... and I hate to, um ... argue that you have to become the squeaky wheel to get uh to get some services but I, I think it was very much like that. Basically services should be matched to needs, umm, that aren't dependent on, on complaint or having to make phone calls. I7: L746–756, 770–775, 781–783 (Gary)

In terms of future support from services, Gary felt strongly that to achieve a better FQOL, for caregivers of children such as his son, there needed to be coordinated care, a caseworker model of care within the public system or within the local child and youth mental health clinics, from the early days, because families struggle through navigating the maze of services.

What would have helped in retrospect would, was if we had gone directly and wholly to a public mental health clinic. Rather than, private, 'cause I think in retrospect we would have been better off if we had coordinated care within our local child and youth mental health service. Because one of the problems facing us and facing a lot of families with children with autism is negotiating the, the maze of services and just knowing what you don't know. I7: L568–587 (Gary)

Fiona (I6) reported that the family was always on waiting lists for gaining access to any support services for their son, and when they received the behaviour support and interim residential care she thought that it was really helpful. However, the visiting support workers were convinced of the family's high support needs for residential care only when they saw their son assaulting his mother. This was very frustrating for the family and impacted their well-being and QoL.

All the behavioural support staff which we've been getting, I think it was all a bit too late, but that's actually been quite good ... they've actually been quite helpful with working with the people in the um, in the house where Samuel's living now. I6: L474–479 (Fiona)

So, you know, Samuel [CWD] actually had to assault me and I had to be admitted to hospital, which in fact did end up happening in order to you know ... I6: L554–562 (Fiona)

Isla (I9) asserted that the new NDIS needed to support families and provide funding for respite care services and for case managers. Kate (I11) was the only participant who had received NDIS funding and she seemed happy with the package that she could use for her daughter. It helped her with equipment needs and she was looking forward to getting some funding for respite care as well. She liked the choice that she was able to exercise with NDIS.

but I'm thinking when NDIS comes along, if they don't have really, really, really good case managers, they're going to be in a lot of trouble. I9: L884–886 (Isla)

so I'm with NDIS now so I employ them directly ... So I can choose anybody I want that I feel is appropriate and suitable to look after her [CWD] ... and umm we pay

them under an ABN pretty much ... Yep, they don't call it respite now, they call it umm community participation ... Umm yeah so I actually have quite a lot of money for that, like over \$100,000 which is really really good. I11: L608– 634 (Kate)

Subcode 6.3: Inclusion of the CWD into mainstream school is difficult and challenging due to lack of supports in schools, and lack of ECIS-like support. Many participants reported that special schools supported their needs better due to the specialised services. Seven out of 10 participants had trialed mainstream schools and reported that being in mainstream schools was helpful for their child's socialising; however, the schools were not set up for supporting the challenges of CWD long-term, especially behavioural concerns, and they had to move their children into special schools.

Eli's son had to move to a special school from mainstream due to lack of supports at the mainstream school. The special school was a long drive on the school bus and it got hard for their son with problems of incontinence, so they had to change schools again. Their son currently attended full-time special school. Eli particularly remembered and valued that inclusion of their child with autism as a focus of the ECIS programs. He mostly missed the inclusive environments of ECIS for his son when comparing early years with now, because he wanted his son to have social interactions with his peers like all children.

We went [to mainstream school] because we wanted him to get a social element and get him challenged a bit. I5: L178–179 (Eli)

we had to juggle and choose what's the best option and we chose a dual school approach [mainstream and special school] so we had a full time day; two days a week, and then we had a period there where he was on a bus going to some autistic school ... that was good but that was, um ... because we had toileting issues he struggled with the long ... one and a half hour bus trips were too long. I5: L167–173 (Eli)

They [ECIS] were trying to make everyone inclusive and giving you tips on how to make kids inclusive and that was great ... it was just a traditional kinder [ECIS] but behind that was the programs of the mother supports groups and also the papa bear [father support groups] which was like an outlet talking about our experiences and how to get around things. I5: L333–337 (Eli)

Amanda (I1) said that the mainstream schools helped, but were not equipped to manage students with challenging behaviours. Bianca (I2) also missed the support and assistance the family received in ECIS. She had to research their entitlements and depended on their parent support group for receiving information and support for services, and funding for their son as he was growing older. Compared to ECIS there was no support for family activities, recreation activities, or respite care. Overall, she found school not as supportive as ECIS especially as it was not family-centred but more child-centred.

Subcode 6.4: Dads need support in the early years, but the support they seek is different to mothers. Some of the dads reported that fathers needed support as well, not necessarily via parent support groups, but via other ways. David (I4) felt strongly about working with dads as an essential part of services. He said that even though dads were quieter, they needed support. However, he acknowledged that it was more difficult to engage with fathers because they did not like to talk about their issues with other dads. They were quiet and appreciated ideas to help their child and family and do things together as a family. According to him, dads liked to watch their children having fun and felt good when they were able to provide fun times for their family. Harry (I8) expressed that to be able to meet other adults with disability and understand what lies ahead was very important for dads, because they did not like to sit and talk or participate in support groups.

I think it's harder for guys to just go out and just meet up at a place with a bunch of strange blokes. I don't think they'd talk at all. Where girls, you know, whether it is the colour of their sheets or the colour of their blooming eyes or their toner ... it's something to break the ice and away they go. Whereas, boys have it a little more difficult. I mean suppose if you go to a sporting event or something like that. But do you talk at a sporting event? I don't think so. I4: L615–620 (David)

I think the thing that would help us, would be, if us dads can get together with um, with young adults and men who have Down, had Down Syndrome ... and talk to them. Like sitting around and, and talking abstractly is not what guys do. It's kind of irksome and irritating and I'd rather be doing something else. Cause it's not, it doesn't achieve anything. We don't bring up that sort of stuff, unless it's you know, just to laugh about something that the kids had done. I8: L1055–1069, 1082 (Harry)

Subcode 6.5: Early years are raw and hard and more focused on the here and now and on child's therapy rather than parent well-being ... but it is still stressful.

Most participants said that the early years was a time when parents were still coming to terms with the disability and were dealing with things one step at a time. Most participants reported that the early years were very different to now, because during the early years the disability experiences were raw and difficult. They acknowledged that as parents of children in ECIS, they were more focused on improving their child's skills rather than looking after their own needs. However, they also expressed that parents in ECIS should look at respite care options early and find time to look after their own needs as well.

Bianca (I2) said that the early years were raw and hard. She commented that life was a bit easier now than before due to the constant adjustments the family made; however, the grief was still there. She mentioned that when her son was in ECIS she was more focused on the 'here and now' and developing his skills. However, she also added that he still required a lot of support and supervision and she had not anticipated this in the early years.

when you allow your thoughts to run away with you, you dip into the future a little bit, but you're so focused on the here and now [when in ECIS] you're just getting that critical stuff happening. I2: L461–446 (Bianca)

I get inwardly upset, I don't generally say anything, but I get inwardly upset when people say to us "Oh that's okay one day when your kids all grow up and leave home, you'll have lots of time," and I sort of just look at them ... because they sort of say that because that's what most families look forward to, one day your kids grow up and leave home. And yet that may never happen for us. I2: L490–495 (Bianca)

You just make adjustments as you go ... if I think about the now and think about the early intervention years, you know, is life okay? It was hard in those early days, really hard because it was all new and raw, and you just didn't want to have to be okay with it, but you sort of learn to be okay with it. And I look at now, and it's sort of easier because you've made some adjustments along the way ... but it's still just as hard, you never get over the grief of what you're having to deal with and the fact that if only it had been different but you change your perspective and you look at things and you learn to appreciate things differently ... And you know your child with needs, you know you still love them. I2: L733–750 (Bianca)

On reflecting back to the early years, Caitlin (I3) reflected and said that the impact of having a CWD was huge in the early years. She referred to the early years as a time when parents focus on their child's therapy and forget about their own well-being or their relationship with their spouse. She said that it was important for parents to look after their needs and accept help, especially respite care. Caitlin also reported that it was difficult in the early years to move away from normality into a world of disability; however, as the child gets older, the parents adjust and get to know their child's needs related to the disability better. She said that now they had accepted their son's disability and she knew his needs related to the disability better.

I think it's easy for a parent when they have a child with a disability and all the stresses and strains and all the appointments and all the extra bills the therapy ... everything ... to really concentrate on their child and forget about their own well-being or their partner's well-being or other children's well-being ... I suppose speaking to therapists and psychologists and whatnot I learnt that you can't actually help ... unless I helped myself first so really need to be in a good state of mind I need to be eating well before I could even think about helping him and I think ... and I tell

parents all the time because I've met so many parents that don't do that and won't accept outside help. I3: L375– 382 (Caitlin)

I remember in the early days that there were so much new equipment being introduced into our lives, like a walker, and pair of glasses, a pump to feed him at night ... I dealt with that very, very, very hard ... because it was moving me away from normality ... those pieces of equipment. Once I got used to pieces of equipment, they were awesome because they made my life better easier. I3: L314–319 (Caitlin)

Eli (I5) struggled during the time of diagnosis in the early years. He valued the support provided from ECIS for the family as well as their child.

we struggled when he was around the 2-year mark when he got ... 18 months, 2 years when he got diagnosed. I5: L163 (Eli)

Subcode 6.6: Parents become advocates for their CWD and for other families.

Most participants concurred that they had to advocate for their CWD to be able to understand the service system and avail themselves of services for their child. They had to spend significant amounts of time researching for services and entitlements with very little support from the schools or health professionals. Some participants reported that the parent support groups helped them gain information about services and supports. Amanda (I1) reported that throughout her past 17 years of having her son with disability, she had to advocate for services and supports and had to be there for him. She had constantly been researching especially when they had to transition him from one school to the other. This according to her was time-consuming and impacted her quality of life. Bianca (I2) reported that there was no time for her to look after her own needs and she spoke of how her life revolved around her son's disability and all her free-time was spent researching services and supports for him or for respite care.

Caitlin (I3), through her work of providing parent support groups, had become an advocate for parents of a CWD, and was enjoying this role. She was constantly

researching and advocating for services available for CWD. She helped other parents by providing information around navigating services via the support groups. She thought that it was wrong that parents did not know enough about the services that could be tapped into for their CWD due to the current system. She affirmed that parents needed to advocate for services and for disability. She had been persistent in advocacy and said that if parents were persistent and well informed, then they could get a lot more services than they are availing themselves of. She was currently researching NDIS to be able to plan her son's needs. David (I4), Caitlin's husband, was not able to be an advocate; however, he was very proud and grateful for the hard work and research that his wife had done to be able to get the services and support for their CWD. Isla (I9) said that any spare time that she had was spent on researching and finding services and support for her son rather than her own needs. Kate (I11) reported that she spent hours on research about equipment, respite, and how to avail herself of services to improve her quality of life.

Pillar to post [running around looking for a good school]. And this is the other thing when you're talking about quality of life. Every time you have to make a decision, you have to research everything, you have to put a lot of time into it and whereas with the boys [without disability]; yes you do research the school they go to, but it doesn't get down to that level. I1: L443–446 (Amanda)

I guess people spend a lot of time talking about looking after yourself, but what I found was my life still revolved around disability. It just changed, as I said, in proportions of time spent doing bits and pieces but most of those things just still revolved around disability either becoming more informed or going to workshops. I2: L448–452 (Bianca)

Oh absolutely well informed and I feel like I'm well informed um because the position that I'm in ... my workplace probably. Just ... I don't know I'm just always seeking information and ... the whole disability thing ... the whole ... the whole network of support and lots available is such a ... it's like a secret code it's hidden away. You need to search for it, which is so wrong, I think. Um and I think that's why so many families are missing out. I3: L414–421 (Caitlin)

Hats off to Caitlin because she just researched the hell out of everything well that's now where she's positioned now. Caitlin tackled that whole side of things [finding out about services]. She was working sort of part time at that stage, it wasn't full time plus she was doing part time after work as well. So she was able to find some hours in the day to do some research and find out bits and pieces and so forth you know, googling the syndrome and finding out what it was. I4: L122, 143–146 (David)

Well at the end of the day, if I do have spare time, it's spent on the research and advocacy side of things ... rather than a haircut or something ... rather than on myself, yep. I9: L914–917 (Isla)

Oh yeah, hours and hours and hours [spent on researching]. Ahh not so much about CP [cerebral palsy] umm cause there's only so much you can know about CP, you learn as you go umm more on funding. More on how to maintain her life and sustain the quality of life I suppose. I11: L904–911 (Kate)

Step 4: Themes. Themes were derived from the aims and research questions as well as from constant comparison of codes thus far. As presented in the methods section, the first theme was labeled based on the aim about gathering and exploring perspectives of FQOL from parents of school-aged CWD (see Table A3.4 in Appendix 3.2). This theme was titled *Parent perspectives of FQOL*. The first subtheme under this theme included all codes related to the perspectives of FQOL as per the parents and represented Subtheme 1.1. In order to answer the research questions, it was important within this theme to capture the codes pertinent to parent perspectives in relation to things that helped their FQOL, challenged their FQOL, and consequences of having a CWD on their FQOL. These topics were labeled as the other subthemes under theme 1. The four subthemes under theme 1 were:

Subtheme 1.1: *Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting; however, there are positives about having a CWD* – all codes related to parent perspectives about their FQOL were grouped together here.

Subtheme 1.2: *FQOL is better when we feel supported* – all codes and subcodes that were related to supports were grouped together, for example, disability-related supports.

Subtheme 1.3: *FQOL is challenged during difficult times and when we think about the future* – all codes and subcodes that presented challenges were grouped together, for example, challenging behaviours.

Subtheme 1.4: *Having a CWD has consequences for families and FQOL* – all codes and subcodes pertinent to consequences of having a CWD including consequences on parent occupations were grouped here.

The last research question was about comparing the FQOL from the times in ECIS to now, as per the perspectives of parents in study 2. All the codes and subcodes pertinent to the parent perspectives about how their FQOL was different now as compared to when they were in ECIS were grouped under theme 2: *Comparing early years to now*. Under theme 2, codes and subcodes that were pertinent to the differences were included, and were placed under four subthemes:

Subtheme 2.1: *About FQOL then and now ... It was harder in the early years, but it is still challenging, stressful, and difficult*

Subtheme 2.2: *Caregiving then and now ... did not expect caregiving to be long-term in the early years*

Subtheme 2.3: *Services and supports then and now ... less support and funding now*

Subtheme 2.4: *Parent occupations then and now ... have been able to go back to a few previous occupations, but many occupations have changed as the years have gone by ...*

Within Appendix 3.2, Tables A3.6, A3.7, A3.8, A3.9, A3.10, A3.11, and A3.12 present these themes, subthemes, codes, and quotes for further clarification of the process of analysis. These themes, subthemes, and codes were checked against each individual participant and then across participants. A table was created in Word to chart these four themes across the rows and the participant pseudonyms along the columns as seen in Table 3.8. An 'X' across the participants' column denotes their contribution to this theme.

Table 3.8 *Codes and Themes in Relation to the Participants*

Themes	1 Amanda	2 Bianca	3 Caitlin	4 David	5 Eli	6 Fiona	7 Gary	8 Harry	9 Isla	10 Jemima	11 Kate	12 Lisa
Theme 1: Parent perspectives of FQOL												
Subtheme 1.1 Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting, however there are positives about having a CWD	X	X	X	X	X	X	X	X	X	X	X	X
Subtheme 1.2 FQOL is better when we feel supported	X	X	X	X	X	X	X	X	X	X	X	X
Subtheme 1.3 FQOL is challenged during difficult times and when we think about the future	X	X	X	X	X	X	X	X	X	X	X	X
Subtheme 1.4 Having a CWD has consequences for families and FQOL	X	X	X	X	X	X	X	X	X	X	X	X
Theme 2: Comparing early years to now												

Subtheme 2.1 About FQOL then and now ... It was harder in the early years, but it is still challenging, stressful, and difficult	X	X	X		X	X	X	X	X	X	X	X
Subtheme 2.2 Caregiving then and now ... did not expect caregiving to be long-term in the early years	X	X	X	X	X	X	X	X	X	X		X
Subtheme 2.3 Services and supports then and now ... less support and funding now	X	X	X	X		X	X	X	X	X	X	X
Subtheme 2.4 Parent occupations then and now ... have been able to go back to a few previous occupations, but many occupations have changed as the years have gone by ...	X	X	X	X	X	X	X	X	X	X	X	X
Codes												
Code 1: Our FQOL is fluctuating, adapting, hard, different, limited	X	X	X	X	X	X	X	X	X	X	X	X
Code 2: Sharing good times as a family is important for FQOL	X	X	X	X	X	X	X	X	X	X	X	X

2.1: Family time is important for FQOL	X	X	X	X	X	X	X	X	X	X	X	X
2.2: Recreation for the CWD is important but is difficult for parents due to lack of time and resources	X	X	X	X	X	X	X	X		X	X	X
Code 3: Caregiving for the CWD is an ongoing and long-term challenge, and impacts all family activities and family members	X	X	X	X	X	X	X	X	X	X	X	X
3.1: Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings	X	X	X	X	X	X	X	X	X	X		X
3.2: Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being		X	X	X	X	X	X	X		X	X	X
3.3: Caregiving for a CWD impacts parent occupations; parents are unable to return to paid work, with lack of time for self-care or meaningful occupations. Most parents become advocates and researchers	X	X	X	X	X	X	X	X	X	X	X	X

3.4: Caregiving for a CWD impacts socialisation with friends/family, and most family activities are adapted to suit the needs of the CWD. Siblings miss out and parents feel guilty	X	X	X	X	X	X	X	X	X	X		X
3.5: Parents worry about the future caregiving needs of their CWD, especially residential care. Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future	X	X	X	X			X	X	X	X	X	X
Code 4: Having a CWD impacts financial/material well-being due to extra costs and reduced income	X	X	X	X	X	X	X	X	X	X	X	X
Code 5: Services and supports are valued and help FQOL	X	X	X	X	X	X	X	X	X	X	X	X
5.1: Special schools provide support for therapy needs and are a respite for parents due to long hours		X	X	X	X	X	X	X	X		X	X
5.2: Respite care is valuable because it provides parents with time away from caregiving and the CWD enjoys the time in respite too		X	X	X	X	X	X			X	X	X

5.3: Help is available from family and some others, and is valued, but parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older. Partners and spouses are the main support	X	X	X	X	X	X	X	X	X	X	X	X
5.4: Support groups are valued because they provide information, research, and friendships	X	X	X	X	X				X		X	X
Code 6: Families miss the ECIS family-centred support and the keyworkers, the financial support, and fun and engaging activities for their CWD, but the early years were raw and hard. Parents adapt and become advocates for their CWD	X	X	X	X	X				X	X	X	X
6.1: Parents miss the ECIS services and family interaction	X	X	X	X	X				X		X	X
6.2: Funding for services after ECIS is difficult. Disability support services are difficult to access. NDIS is helpful	X	X	X	X	X	X	X	X	X	X	X	X
6.3: Inclusion of CWD into mainstream school is difficult and challenging for parents due to lack	X	X	X	X	X			X	X		X	X

of supports in schools and lack of ECIS-like support

6.4: Dads need support in the early years, but the support they seek is different to mothers				X	X		X				
6.5: Early years are raw and hard and more focused on the here and now and on child's therapy rather than parent well-being	X	X	X	X	X			X		X	X
6.6: Parents become advocates for their CWD and for other families	X	X	X	X	X			X	X	X	X

Theme 1: Parent perspectives of FQOL. This theme comprised parent experiences of their FQOL. The following paragraphs present the subthemes and the codes that were grouped together to form each subtheme. Tables A3.5 through to Table A3.12 within Appendix 3.2 present the relationships between the codes, and quotes related to all subthemes below.

Subtheme 1.1: Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting; however, there are positives about having a CWD. This subtheme was derived from code 1: *Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting ... however, there are positives about having a CWD*; code 2: *Sharing good times as a family is important for FQOL*, mainly subcode 2.1: *Family time is important for FQOL*.

Most participants reported that their FQOL was hard and fluctuated as needs arose. However, as life moved on they mentioned that dealing with the ups and downs and adapting to ongoing changes and challenges was a part of their life. Some parents wished that it could be different but most said that they had learnt to accept it.

... [FQOL] it was dreadful, because it was totally dominated by his care needs, taking time away from us personally. I7: L17–21 (Gary)

I think that it fluctuates [FQOL]. It depends if he's [CWD] having a good day or a bad day. I3: L25–29 (Caitlin)

Some participants mentioned that their FQOL was challenging because of the challenges of a growing family. Along with the CWD, the siblings were growing older too and brought their own challenges and the parents had to balance these challenges.

However, despite the challenges and difficulties, many parents mentioned that having a CWD was a positive experience for them and their family members. Some

parents commented that they had established many friendships with other parents of CWD, and they valued these friendships immensely. Many parents acknowledged that they met amazing people because of having a CWD, mainly other parents who were helpful and generous. Some parents said that having a CWD brought joy for their family and changed their perspective so that they understood the value of family and were not pursuing wealth and money but wanted to have a good life with their family.

I mean it just changes your perspective. You know, your values change, your way of thinking changes, the way you want to progress with your lives changes. But having a child with special needs is like ... It makes you strong as a person and you find out about yourself ... a little truer I guess. I4: L482–488 (David)

Many parents expressed that sharing good times with their family was important for a good FQOL (code 2). Within subcode 2.1, parents mentioned that having family time with all members of the family was important for their FQOL.

Family quality of life, I think it means uhh, being able to enjoy, the company of family members, find time for each other, do fun things together ... um, without feeling overly stressed and burdened. I7: L9–13 (Gary)

They expressed that whenever they had opportunities to share good times with family members, such as going on holidays together and doing things that interested each family member, it helped their FQOL.

Subtheme 1.2: FQOL is better when we feel supported. This subtheme comprised code 5: *Services and supports are valued and help FQOL* and its four subcodes: *Special schools provide support for therapy needs and are a respite for parents due to long hours* (subcode 5.1); *Respite care is valuable because it provides parents time away from caregiving and the CWD enjoys the time in respite too* (subcode 5.2); *Help is available from family and some others, and is valued, but*

parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older. Partners and spouses are the main support (subcode 5.3); and Support groups are valued because they provide information, research and friendships (subcode 5.4).

These codes and subcodes are mentioned in detail in the earlier section on codes.

Well respite is probably one of the biggest things that help quality of life. I mean we know that Mick is getting looked after, we don't have to fuss over him, and we can do what we need to do. We can do things. Sometimes we go out with the other two kids and go out to the movies. I4: L373–376 (David)

Most parents agreed that when they had adequate supports and services for their CWD, they felt better about their FQOL. Most parents had their children attending special schools and also received respite care services, albeit not all received the same amount of respite.

he was going there on the bus, and coming home on the bus most afternoons, that's about an hour-and-a-half trip each way. Umm, and that in itself was a form of respite. I7: L92–104 (Gary)

Some parents expressed that their extended families were helpful, even though they felt reluctant to ask for support, as the children were growing older.

I don't think they [grandparents] mind but I guess there is a limit. They have other family as well and you don't want to be a burden when they might want to see other family at the same time. I5: L283–284 (Eli)

There was a mixed response to the value of parent support groups and siblings groups, with some participants feeling that these support groups were helpful, but not all participants felt the same way. When families received supports and adequate services they said that it helped their FQOL.

Subtheme 1.3: FQOL is challenged during difficult times and when we think about the future. This subtheme presents all the codes and subcodes that help in

understanding the challenges that the parents reported, and these challenges had a negative influence on their FQOL. This subtheme comprised one subcode from code 2: *Recreation for CWD is important but is difficult for parents due to lack of time and resources* (subcode 2.2) and three subcodes from code 3: *Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings* (subcode 3.1); *Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being* (subcode 3.2); and *Parents worry about the future caregiving needs of their CWD, especially residential care. Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future* (subcode 3.5).

Most of the codes and subcodes within this subtheme were related to the increased amount of caregiving for, or challenges faced, due to having a CWD. Many parents said that they experienced a sense of guilt that they were not able to help with the time or the money required for recreation for their CWD. They said that there were restricted opportunities for their CWD to enjoy and have fun. There were also very few places that offered recreational activities to suit their child. When parents compared these opportunities to other children without disability or to their siblings, they reported that their CWD missed out on going out with friends or doing things that their siblings did with their peers, and often this influenced their FQOL in a negative way.

I think one of the issues impacting quality of life is lack of services ... he needs some type of recreation program – something that he can go to, a day centre, a something, where there are things that he likes to do ... There just needs to be places and spaces, where kids like Samuel can do their thing and just be themselves, umm, doing things that they enjoy. But there's just a lack of yeah, ... just places and those types of recreation activities. I6: L1016–1029, 1054–1064 (Fiona)

Parents of children who had behavioural challenges expressed that when their child demonstrated behaviours of concern, the challenge of caregiving became more apparent and impacted their FQOL and also impacted the siblings (subcode 3.1).

Some of the behaviours of concern included destruction of property, having meltdowns, displaying violence and aggression towards family members, escaping from home or from holiday sites, or displaying embarrassing behaviours in public places.

Got up and ... he might've just smeared it ... here was an incident with poo, requiring cleaning up, there was a broken window, and Jane [sister] had been attacked ... this is our lives at the moment. I6: L639–647 (Fiona)

Some parents had children with high physical caregiving needs such as children with a diagnosis of cerebral palsy or congenital conditions, and this had an impact on their own well-being and their FQOL (subcode 3.2).

These children needed assistance with everyday self-care-related caregiving activities such as showering, toileting, and feeding, and most parents reported that they were not prepared for this long-term caregiving when their children were at preschool age. When compared to typically developing children and siblings, the physical caregiving demands were very high with regards to the time and extent of caregiving, and parents felt exhausted. Lastly, most parents were worried about the future caregiving needs of their CWD, mainly residential care as they did not want to burden the siblings (subcode 3.5).

Most parents were worried that the relationship between the siblings would diminish due to the increased caregiving needs of the sibling with disability and that the siblings would resent their brother or sister with disability.

I just didn't think it was fair on them [siblings] to have to ... and I have heard of many relationships between siblings deteriorate. I3: L233–236 (Caitlin)

All these subcodes clarify the challenges that parents face when they have a CWD and these challenges influence their FQOL in a negative way.

Subtheme 1.4: Having a CWD has consequences for families and on FQOL.

This subtheme presents all the codes and subcodes that help in understanding the consequences that having a CWD can have on family members and parents. The parents expressed that these challenges had a negative influence on their FQOL. This subtheme comprised two subcodes from code 3: *Caregiving for the CWD is an ongoing and long-term challenge and impacts all family activities and family members*. The two subcodes were: *Caregiving for a CWD impacts parent occupations; parents are unable to return to paid work, with lack of time for self-care or meaningful occupations. Most parents become advocates and researchers* (subcode 3.3); and *Caregiving for a CWD impacts socialisation with friends/family, and most family activities are adapted to suit the needs of the CWD. Siblings miss out and parents feel guilty* (subcode 3.4). The subtheme was also supported by code 4: *Having a CWD impacts financial/material well-being due to extra costs and reduced income*. Details of these codes and subcodes were described in an earlier section and all help with an understanding of the consequences of having a CWD on FQOL.

Most parents reported that their previous occupations were affected due to having a CWD. Parent occupations included necessary occupations aimed at meeting the basic self-maintenance needs, such as eating and sleeping; committed occupations that are typically not remunerated such as housework and childcare; contracted occupations that involve paid productivity or formal education; and free-time occupations that occur in the time that is left over, such as going out with friends (Harvey & Pentland, 2004). Nearly all parents were unable to return to their previous

paid work or contracted occupations, and this impacted on their finances as well as their career development. Some parents seemed more upset than others about not being able to return to their previous work; however, most of the parents had accepted that this was the only way possible for them, due to the caregiving needs of their CWD.

In saying that both of us [wife], but more so myself, have had to restrict our working hours. So, from a purely financial perspective our family finances would be much better if I could work full-time. I7: L186–199 (Gary)

Most parents did not get time to look after their own health (self-care) or engage in any leisure activities (free-time). Many parents said that they had lost their old friends as they were caught up with their busy lives, especially the caregiving. They managed to occasionally get together with friends or other parents of CWD. They also became advocates for and were involved in researching their CWD's needs and helping other parents of CWD with this information. This advocacy role was taken on as a new occupation and most parents reported that it was necessary for gaining resources and services for their CWD.

Many parents also mentioned that having a CWD meant that they were unable to socialise as before with their friends or extended families. Most activities that they did as a family were planned to suit the CWD, such as going to the same campsite for holidays for safety reasons, or missing out on family get-togethers because of loud environments, and this sometimes meant that the siblings missed out.

Look, family life is different now. Obviously we don't get to go out much, um, we don't do a lot of family dinners ... we miss a lot of birthdays ... because it takes planning you know, or if something's last minute usually we have to miss out – so that makes things a bit hard. The sort of going out/socialising side of things has dropped off completely. I9: L9–23 (Isla)

Lastly, having a CWD also influenced the family income due to loss of wages and due to the extra costs attached to the needs of the CWD. These costs included aids and equipment, home modifications, therapy, respite care, or getting modified vehicles to suit the child. Even though most families had some cost covered for these needs, they had to pay for a portion of these costs.

And financially I'm struggling. I find financially it's harder this year because I'm travelling to Frankston and back and I need to pay for after care for the girls. I12: L64–74 (Lisa)

Some parents of children with challenging behaviours mentioned the extra costs attached when their child destroyed property and valuables and added to their costs. This influenced their physical/material well-being, as the parents were exhausted of providing this extra cost of living over a period of time. Many parents felt a sense of reduced well-being and exhaustion because they were always looking for resources or funding to support their child's added needs.

Theme 2: Comparing early years to now. This theme was drawn from parent perspectives in study 2 and is a collection of codes and subcodes that highlight their experiences of comparing the times when their child was in ECIS to now. This theme was grouped into four subthemes based on the codes and subcodes, and also on the qualitative comparative analysis method. The following paragraphs present the subthemes and the codes that were grouped together to form each subtheme.

Subtheme 2.1: About FQOL then and now... It was harder in the early years, but it is still challenging, stressful, and difficult. When the families were asked to reflect on their FQOL now and compare it to their FQOL when their CWD was in

preschool, most of the parents reported that their lives were harder in the early years as the experience of disability was raw and hit them hard. Even though they had accepted living with disability now, they added that it was still a challenging and stressful life with times that were difficult. Although all the subcodes from code 6 seemed pertinent to this theme, the main subcode that guided this theme was *Early years are raw and hard and more focused on the here and now, and on child's therapy rather than parent well-being* (subcode 6.6). Most parents reported that during the early years they were still coming to terms with the disability, and the early years were very different to now, because during the early years, the disability experiences were raw and difficult.

I think about the now and think about the early intervention years, you know, is life okay? It was hard in those early days, really hard because it was all new and raw, and you just didn't want to have to be okay with it, but you sort of learn to be okay with it ... I2: L733–750 (Bianca)

It was particularly difficult to move away from normality into a world of disability. However, most parents reported that as the child got older, the parents adjusted and were able to know their child's needs related to the disability better. In the early years they were more focused on improving their child's skills rather than looking after their own needs.

I think it's easy for a parent when they have a child with a disability and all the stresses and strains ... to really concentrate on their child and forget about their own well-being or their partner's well-being or other children's well-being ... I suppose speaking to therapists and psychologists and whatnot I learnt that you can't actually help ... unless I helped myself first so really need to be in a good state of mind I need to be eating well before I could even think about helping him and I think ... and I tell parents all the time because I've met so many parents that don't do that and won't accept outside help. I3: L375–382 (Caitlin)

However, they also added that parents in ECIS should look at respite care options early and find time to look after their own needs as well.

Subtheme 2.2: Caregiving then and now ... did not expect caregiving to be long-term in the early years. One of the common experiences of most parents was related to the amount of caregiving they were still engaged in. During the early years they had expected their child to develop skills and be independent in the future. However, they were still involved in caregiving and many parents were still helping their child with basic self-care skills such as dressing, toileting, and feeding.

So, and he can't dress himself, he can't brush his teeth, he can't wash his hands, he can't wash himself, so I have to do all of that. We're still in nappies, so, you know, trying to toilet-train at the same time. It's all, I help him with everything ... He can't drink out of a cup ... He hasn't quite figured out how to open and close them and fill them up yet though. I9: L166–190 (Isla)

Many parents had children with behavioural challenges and found caregiving particularly difficult due to the constant supervision required. When their children were in ECIS, they had not expected the caregiving to continue for this long, and they had expected the CWD to learn many more skills and be independent. However, they particularly compared their caregiving now, and reflected on the increased challenges of caregiving related to behavioural challenges (subcode 3.1: *Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings*), the physical challenges associated with children who had high physical needs such as those associated with diagnoses of CP, congenital conditions (subcode 3.2: *Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being*) and most of these were not expected in the early years.

On a couple of occasions he has threatened me [older son with ASD] with a knife once, and he's physically assaulted me only a couple of times whereas my younger son assaulted me on a daily basis ... and I would wake up and find him. He was there with a knife in my bedroom or you know if you're cooking dinner he would hurl a tin of cat food at my head or a tin of canned tomatoes ... I10: L220–227 (Jemima)

Most parents also reported that they were more worried about their child's future and residential care, and this was a major cause of concern for them now, when compared to the early years. They had not thought about the future of their CWD in the early years but it was a reality now, and it was a constant cause for worry for the parents. They did not want the siblings to feel responsible for the caregiving needs of their CWD and they worried that the relationships may be effected or the siblings may reject their sister or brother if they had the responsibility of caregiving in the future (subcode 3.5: *Parents worry about the future caregiving needs of their CWD, especially residential care. Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future*).

Subtheme 2.3: Services and supports then and now ... less support and funding now. This subtheme concerned comparing the supports and services from the early years to now. Many parent responses from a number of subcodes were included in this subtheme. When asked about comparing services and supports from the early years to now, most parents reported that they had less support and services now as compared to their time in early intervention. Most of their children were attending special schools and the main reason for choosing special schools was because they would be able to get therapy support, and specialised attention for their child's requirements related to disability. Most parents reported that special schools provided them with the support and respite (subcode 5.1: *Special schools provide support for therapy needs and are a respite for parents due to long hours*) and this was a big help for them. Many parents were also able to get some hours of respite care each week.

Even though this was difficult to access and required a lot of paperwork and waiting time, most parents appreciated it. When compared to the early years, most

parents commented that they did not feel the need for respite care services in the early years, or that they were unaware of respite services when their child was in the ECIS programs. Respite care was the most valued support and most parents expressed that the time with the carers was most enjoyable for their CWD (subcode 5.2: *Respite care is valuable because it provides parents time away from caregiving and the CWD enjoys the time in respite too*).

Well respite is probably one of the biggest things that help quality of life ... We can do things. Sometimes we go out with the other two kids and go out to the movies. I4: L373–376 (David)

When compared to the early years, many families reported that they still received offers of help from their extended families; however, as their children were getting older, it was difficult for family members to help with caregiving, so they felt reluctant to ask for help. Some of their friends were helpful, and the support from family and friends was still valued whenever received. Most parents were getting their main support from their spouses or partners and most of the dads were involved in caregiving, which was different to the early years, where the mother was the main caregiver for the majority of the time (subcode 5.3: *Help is available from family and some others, and is valued, but parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older. Partners and spouses are the main support.*)

Oh, we've got family ... they, mmm, they all, they tolerate him I think, and at times, at times they'll laugh with him or ... but yeah, it's awkward. My family, he's just kind of irksome ... I think too my parents ... I don't think they would have coped with Eddie – They did, you know, they could only tolerate him in small doses. He's pretty full-on. I8: L666, 690–704, 733, 758 (Harry)

Some parents also mentioned that they were part of parent support groups, and that these groups were a huge support for them. In the early years most of these parents were not involved in parent support groups; however, they valued these groups now.

As part of these groups many parents had established friendships and were able to gain information about disability, policy, and funding from other parents and this was helpful (subcode 5.4: *Support groups are valued because they provide information, research, and friendships*). Most parents missed the support and the keyworker from the ECIS. They missed the family interaction with other families and the coordinated care that was offered by ECIS, and they had to become advocates because they did not have a keyworker to help with advocacy and information (subcode 6.1: *Parents miss the ECIS services and family interaction*). Many parents also commented on the funding system at school and the lack of funds for services and supports.

When he was in early intervention, there were ... people who were in that early intervention role who were able to inform us on what we were entitled to and they would source grants on our behalf or extra funds for this or the other. Now, there's no one to do that for you... it's much harder ... you have to go looking for it yourself and ... there's less of it. I2: L779–781, 809–810 (Bianca)

Funding wise ... Therapy wise, there's less out there in terms of supporting. Same with quality time. I remember when James was little there'd be early intervention funding that ... and they would say "we'll give you this money and there can be a certain amount spent on James but ... you keep 100 dollars to buy a booklet of movie vouchers. I2: L799–803 (Bianca)

They had significant difficulties accessing disability-related services for equipment, respite, therapy, and any other needs for their CWD due to the waiting periods and navigating the complex systems. The new National Disability Insurance Scheme (NDIS) was rolling over in some areas and parents were feeling positive about this funding. Some parents had accessed services through NDIS and were pleased and hopeful (subcode 6.2: *Funding for services after ECIS is difficult. Disability support services are difficult to access. NDIS is helpful*).

Most of the CWD in study 2 were attending special schools. Even though most of the parents wanted their children to attend mainstream schools and valued the

mainstream and inclusive approaches in ECIS, they found it was difficult for mainstream schools to deal with their child's needs. They missed the inclusive environments of ECIS but they reported that the mainstream schools were not equipped for their child and after trialing mainstream schools most of the families reverted to special schools. This was disappointing for some of the parents as it was not what they had expected in the early years (subcode 6.3: *Inclusion of CWD into mainstream school is difficult and challenging for parents due to lack of supports in schools and lack of ECIS-like support*).

They [ECIS] were trying to make everyone inclusive and giving you tips on how to make kids inclusive and that was great ... it was just a traditional kinder [ECIS] but behind that was the programs of the mother supports groups and also the papa bear [father support groups] which was like an outlet talking about our experiences and how to get around things. I5: L333–337 (Eli)

A few of the fathers who were interviewed reported that in the early years they felt isolated and in grief; however, they did not find the parent groups supportive of the fathers' needs. They reported that there should be some form of support for fathers in the early years and it would help them if such supports existed (subcode 6.4: *Dads need support in the early years, but the support they seek is different to mothers*).

I think the thing that would help us, would be, if us dads can get together with um, with young adults and men who have Down, had Down Syndrome ... and talk to them. Like sitting around and, and talking abstractly is not what guys do. It's kind of irksome and irritating and I'd rather be doing something else. Cause it's not, it doesn't achieve anything. We don't bring up that sort of stuff, unless it's you know, just to laugh about something that the kids had done. I8: L1055–1069, 1082 (Harry)

Subtheme 2.4: Parent occupations then and now ... have been able to go back to a few previous occupations, but many occupations have changed as the years have gone by. This subtheme was important for the research question related to the

relationship between having a CWD, their FQOL, and parent occupations. Many parents in study 1 (ECIS age) reported that when their CWD grew older and attended school they would be able to return to their previous occupations. So the parents in study 2 (school age) were asked to reflect on their occupations from then to now and share their experiences. Subthemes 3.3, 6.6, and code 4 were used to understand this subtheme in detail.

Most parents in study 2 reported that they had not expected caregiving to continue for this long and caregiving for their child had an impact on their occupations. Most of the parents were not able to return to their previous paid work in a full-time capacity. They were working part-time or not at all. They said that when their child was in ECIS they knew that they had to take a break from work and were happy to do that; however, they had not expected that they would not be able to return to their work or would have to continue with reduced hours of work. It was difficult for them to return to work mainly due to the caregiving, the medical appointments, follow up, and assisting their child with everyday activities. It left very little time for looking after their own self-care or engaging in meaningful occupations such as gardening or hobbies.

I was an accounts manager... The plan was to go back to work pretty much straight away. But after the diagnosis, ...we realised obviously it's not going to happen. He needed more time, more care, I needed to learn and understand about his condition 'cause I knew nothing about it. So, we decided that ... I'd stay home with him until he was in school ... There's just, there's too much: he demands too much of my time and attention. I didn't think that I would be a stay-at-home mum. Nup, I was going places. But that changed. I don't – I'm used to it, you know ... You know, it did mean we struggled a lot financially.
I9: L335–360, 375–385 (Isla)

Many parents spent their free-time researching for supports, services, and doing advocacy for their CWD and this was a new occupation for most of them (subcode 3.3: *Caregiving for a CWD impacts parent occupations; parents are unable*

to return to paid work, with lack of time for self-care or meaningful occupations.

Most parents become advocates and researchers). Many parents had started advocacy groups and participated in parent support groups to help other parents with advocacy and information. Some parents had taken up paid work in this area of practice as a new occupation, something they had never expected in the early years (subcode 6.6:

Parents become advocates for their CWD and for other families).

Every time you have to make a decision, you have to research everything, you have to put a lot of time into it and whereas with the boys [without disability]; yes you do research the school they go to, but it doesn't get down to that level.

I1: L443–446 (Amanda)

I guess people spend a lot of time talking about looking after yourself, but what I found was my life still revolved around disability. It just changed, as I said, in proportions of time spent doing bits and pieces but most of those things just still revolved around disability either becoming more informed or going to workshops. **I2:** L448–452 (Bianca)

Due to loss of income and added costs they continued to face financial difficulties. They had not anticipated the financial impact of having a CWD in the early years; however, it was ongoing, because primarily they were not able to take up full-time jobs or follow career opportunities (Code 4: *Having a CWD impacts financial/material well-being due to extra costs and reduced income*).

... Needless to say, if James didn't have all those needs, Bianca [wife] could probably work longer hours, ... We might have a better house or whatever. So it's a juggling act, one, she can't really do full-time but by the same token she has to work. It's money we put into extra therapy and the extra things James needs over everything ... **I5:** L240–245, 253 (Eli)

3.4 Discussion: Study 2

This sub-chapter will present a discussion of findings and results from the qualitative and quantitative aspects of the current study. The quantitative findings are based on the results from the BC-FQOLS survey, and the demographic questionnaire from the participants (N = 50). The qualitative findings are reported as themes from the 12 participant interviews. Within each subsequent section the discussion compares and triangulates the quantitative results with the qualitative findings. The findings are also compared with other studies and, lastly, limitations and the conclusion to study 2 will be presented. The implications from this doctoral research study are presented in Chapter 5, based on the combined findings of the two completed studies.

The research question 3 (Are there any differences between perspectives of school-aged parents of CWD when compared to parents in ECIS in relation to their FQOL, parent occupations, and disability-related supports?) applies to the aim of the total doctoral study, and will be discussed in Chapters 4 and 5.

3.4.1 Discussion: study 2. The discussion compares and triangulates the quantitative results with the qualitative findings. The quantitative findings presented the perspectives from parents in study 2 in relation to their FQOL and used the BC-FQOLS and a demographic questionnaire to yield scores. From the qualitative findings, the first theme (Parent perspectives of their FQOL) captured the rich experiences of the participants in study 2 that helped with understanding their perspectives on FQOL in detail and things that support and challenge their FQOL. Within this discussion these quantitative and qualitative results and findings will be interpreted. The findings will also be compared with other studies. Theme 2 will not

be discussed in this chapter, but in the next two chapters that are related to comparing parent perspectives from early years to now.

3.4.1a Perspectives of FQOL of parents of school-aged CWD. The high scores from the quantitative results in this study indicated that the majority of respondents were satisfied with their total FQOL ($M = 90.96$ $SD = 16.90$). However, when a subset of these participants was interviewed for the qualitative interviews, the emergent themes threw more light on the level of satisfaction. Surprisingly, contrary to the high satisfaction ratings on FQOL, the first section of theme 1.1 was related to families feeling that their FQOL was hard, limited, dreadful, and challenging. Subtheme 1.3 and codes 3.1, 3.2, and 3.5 help with understanding that despite the positives, there were challenges associated with caregiving for their CWD that families faced, and their FQOL felt challenged. See Table 3.9 for these subthemes and codes.

Table 3.9 *Theme 1 with the Subthemes and Codes*

Theme	Subtheme	Codes and subcodes
Perspectives of FQOL	1.1: Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting ... however, there are positives about having a CWD	3.1: Behaviours of concern of a CWD add to the challenges of caregiving ... 3.2: Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being
	1.3: FQOL feels challenged during difficult times and when thinking about the future	3.5: Parents worry about the future caregiving needs of their CWD especially residential care and siblings feeling the burden of caregiving ...

1.2: FQOL is better when we feel supported	5.1: Special schools provide support for therapy needs and are a respite for parents due to long hours 5.2: Respite care is valuable 5.3: Help is available from family and some others and is valued 5.4: Support groups are valued
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Similar to these findings, a study by Caples and Sweeney (2010) investigated the quality of life of 49 parents of children with intellectual disability using the Family Quality of Life Survey (I. Brown, Brown, et al., 2006). Similar to this study, most parents in their study described their quality of life as ‘good’ and ‘excellent’ despite their qualitative comments reflecting that they were feeling burdened and experiencing a reduced QoL. Some of their comments reflected hardships and challenges they faced as a family due to lack of transport for their child in a wheelchair that restricted family outings and influenced their QoL (Caples & Sweeney, 2010). However, similar to this study, these parents had high scores on their total FQOL, and added that the personality of their child made them feel happy, and they felt positive about their QoL (Caples & Sweeney, 2010). In another Israeli study by Neikrug and colleagues, 103 parents of CWD completed the FQOL-S (2006) and reported similar results to the current study. The findings from their study suggested that although the respondents were strongly challenged to meet the needs of their CWD, they also felt a sense of resilience and an ability to manage family challenges to achieve a reasonably high FQOL (Neikrug, Roth, & Judes, 2011).

The codes and subthemes also reported on challenges such as behaviours of concern that added to the challenges of caregiving. Aggressive and violent behaviours, as well as escapist behaviours, were mostly highlighted as particularly challenging and were more prevalent in children with a diagnosis of autism spectrum disorder followed by Down syndrome. Such behaviours had an impact on the relationships with their siblings, and many parents worried about the future of their CWD, and the possibility of marred relationships between siblings in the future due to the caregiving burden. Although in the current study there were no significant associations between diagnoses of children and their FQOL, many parents in the qualitative interviews reported on challenges associated with caregiving and managing disruptive behaviours.

Severity of disability was reported as a significant predictor of FQOL in a study with 364 participants (mothers and fathers of CWD) where the authors explored the associations between severity of disability and satisfaction with FQOL using the BC-FQOLS (Wang et al., 2004). The results from this study also concur with a previous study where comparisons of FQOL of parents of children with Down syndrome, autism and no disability were conducted with 69 participants (N = 33 children with Down syndrome; N = 18 with autism; N = 18 with no disability) using the FQOL-S survey (R. Brown, MacAdam-Crisp, Wang, & Iarocci, 2006). The results reported that families without a disability had statistically significant higher levels of satisfaction with their FQOL, followed by children with Down syndrome, and lastly by parents of children with autism, similar to the findings of this study (R. Brown, MacAdam-Crisp, et al., 2006). The Brown et al. (2006) study further concurs with the findings from the current study wherein the results and comments from parents relate to the disturbing and disruptive behaviours shown by children in the autism group.

There were higher counts of negative quotes from the autism group reporting on difficulties with coping with behaviours that were extremely difficult to accept (R. Brown, MacAdam-Crisp, et al., 2006).

Similar to this study, a meta-synthesis of qualitative research from 17 qualitative studies reported that caregiving for a family member with challenging behaviour is described as a 'fine balancing act' with immediate daily care needs, challenging behaviour episodes, and issues with support services (Griffith & Hastings, 2014, p. 405). The themes from the metasynthesis by Griffith and Hastings reflected that there was an underpinning deep care about the well-being of the family member with disability; however, the consuming caregiving led to many carers lamenting their loss of self-identity, battling with crisis management, and resorting to physical restraint and emergency ward admissions. A few participants within the current study reported that they had to involve the police on many occasions in attempts to manage crisis, such as their CWD escaping from home, attempting suicide, or engaging in highly violent attacks on the caregiver. Overall, the above discussion confirms that families feel that their FQOL is influenced in a detrimental way due to challenging and disruptive behaviours of their CWD.

Another finding within subtheme 1.2 was around their FQOL being better when they felt supported. Some of the subcodes under code 5 clarified that services and supports were valued and helped their FQOL. Families valued special schools and the support, therapy, and respite they provide. Families who were receiving respite care talked highly about the positive impact of respite care on their caregiving, as it allowed them time to look after their own needs or other family members' needs. These findings concur with a study that investigated the FQOL of parents of CWD availing themselves of respite care (Caples & Sweeney, 2010). The majority of the 49

parents in that study reported that access to regular respite care would improve their FQOL and agreed that their main support was from respite care services. The support from extended family and friends, although not consistent, was also valued by participants within this study. Many parents reported that support groups, and other parents of CWD were important supports that helped their FQOL. These findings are similar to a mixed-methods study by Solomon, Pistrang and Barker (2001) that examined 56 parents of CWD who participated in six parent support groups. The quantitative data from that study reported that parents found the groups helpful and supportive. The grounded theory analysis of the qualitative data reported that the parent support groups were helpful in developing a sense of control, a sense of belonging to a community, and helped parents to change at an individual level to accept the disability (Solomon, Pistrang, & Barker, 2001).

In further explanation for the high scores on total FQOL, many participants reported that despite the hardships, there were positives related to having a CWD. They reported that having a CWD brought joy and happiness to the family members. Many parents changed their perspectives about happiness related to wealth and money, and instead were able to appreciate the joys of being a family and spending time with family members. Some parents reported that they became stronger and became advocates for disability and met some other amazing families. They became more helpful, empathic, and expressed that they adapted in a positive way. Some of these experiences can be explained using literature that was drawn from positive psychology where researchers focus on positive development, strengths, and positive coping strategies, and have highlighted positive outcomes (such as FQOL) experienced by families in having a CWD (Chiu et al., 2013; Turnbull, Turbiville, & Turnbull, 2000). Families use specific positive strategies such as problem solving,

family sense of coherence, positive coping, and find ways to stay positive, manage everyday life, and remain resilient (R. Brown, Kyrkou, & Samuel, 2016). According to Chiu et al. (2013) there is an increasing capacity for positive adaptation in families who have CWD, and recognising this adaptation helps their FQOL. Most of the families in study 2 recognised this positive adaptation and talked about how the siblings had a positive attitude towards disability, how they (parents) had acquired new strengths especially around advocacy and compassion, and how these strengths helped them feel a sense of control over their lives on good days.

Finally, in understanding parent perspectives on FQOL, the subscales of the BC-FQOLS were also considered. On the subscales of the BC-FQOLS, the strongest association with total FQOL was with the subscale of ‘family interaction’, followed by ‘parenting’, ‘emotional well-being’, ‘physical/material well-being’ and, lastly, ‘disability-related supports’. The lowest association on disability-related support can be related to the results from the demographic questionnaire about affordability of services for their CWD. Only 8% of the families were able to fully afford the services and supports for their CWD, 42% were able to afford services to some extent but reported that this was not acceptable, and 6% were not able to afford services.

Low scores on disability-related support are inconsistent in past literature. In a recent publication on FQOL research, low satisfaction with services was reported as a challenge by families in almost all countries, particularly when family needs are not assessed appropriately (R. Brown et al., 2016). In a book chapter on FQOL, the authors presented results from a number of studies that were conducted in various countries including Australia, Canada, South Korea, and Taiwan and reported on disability-related support amongst many other factors (I. Brown, Hong, Shearer, Wang, & Wang, 2010). In the Australian study with 55 families, the parents in the

older age group reported low satisfaction with support from disability services, similar to this study. This was similar to the Taiwanese study with 83 parents of children with autism and the study in South Korea with 81 families where both reported low satisfaction with disability-related support (I. Brown et al., 2010; Chou & Schalock, 2009). It is interesting to note that in both Taiwan and South Korea, CWD were attending programs that included interventions specifically for the children, and involving families was overlooked (I. Brown et al., 2010). Contrary to these studies, in Belgium, the FQOLS-2006 was completed by the main caregivers of 25 families and semi-structured interviews with one or both parents were conducted within the same families (Steel, Poppe, Vandeveld, Van Hove, & Claes, 2011). Results from the Belgian study reported that parents were satisfied with the professional support they received. Another South African study including 180 families of children with autism spectrum disorder that used the BC-FQOLS, reported that families were most satisfied with their disability-related support (Schlebusch, Dada, & Samuels, 2017). The author's explanation for the South African study was that families in South Africa experience multiple disadvantages, and are more likely to be excluded from disability-related services, so perhaps the sample included in their study felt grateful for receiving services (Schlebusch et al., 2017).

Although 76% of the families were satisfied with their relationships with their service provider, in this study, satisfaction with their service provider was not significantly related to disability-related support ($\rho = -.125, p = .390$). It is possible that parents felt unsupported in helping their CWD to make friends and accomplish goals at home because 76% of the children were attending special schools, and no family support was provided. Some of the findings from the qualitative data help in understanding this result. During the interviews some parents mentioned difficulties

in accessing disability-related support services and funding for services as their child grew older (code 6.2). Even though most parents were happy with the support and therapy provided via the special schools (code 5.1), they wanted their CWD to be able to enjoy recreational activities; however, they reported that this was difficult due to a lack of time and resources, and limited opportunities and choices for their CWD to enjoy these activities (code 2.2). This concurs with findings reported in a book chapter that illustrates the developments and challenges in FQOL research (R. Brown et al., 2016). The authors of the book chapter summarise that opportunities and choices are identified as essential for a good quality of life, and recreation is identified as an important way to improve health in a family, in addition to medical and allied interventions (I. Brown et al., 2010). In another Korean study, a family support program was carried out for 21 primary caregivers of CWD where the experimental group A (N = 7) was provided with respite care services only, whereas the experimental group B (N = 7) was provided with a multifaceted family support program including recreational programs, counselling, and social support coordination in addition to respite care services (Sung & Park, 2012). No support was provided to the control group (N = 7). The results showed a significant difference in the change of FQOL scores in experimental group B compared to the other groups, confirming that recreation activities along with respite care help FQOL (Sung & Park, 2012).

The highest association of 'family interaction' with FQOL within this study can be further supported by findings from code 2 about sharing good times as a family being important to the participants within this study. Most participants reported that family time was important for their FQOL and tried to spend time with their family members and siblings as a priority. It was difficult for some families to spend this

time due to the high caregiving needs of their CWD, or due to lack of resources; however, when opportunities arose such as when their CWD was in respite care, they prioritised spending time with other family members. All four of the fathers who were interviewed in this study particularly recognised the need for spending time with other family members and tried to make time for planning holidays and events as well as planned times when they could talk to everyone as a family (at the dinner table). Most of the fathers seemed disappointed that they were unable to give enough time to the siblings or to family events, and family interactions seemed very important to them. Brown and his colleagues (2016) in a recent book chapter reported family relationships as being important to families across cultures and that most parents value spending time with their family members. They further mentioned that fathers have strong feelings and frequently seek ways to support the rest of the family (similar to the findings from this study); however, there is a paucity of research on fathers' involvement in FQOL, due to limited participation in interviews and completion of surveys (R. Brown et al., 2016) .

In summary, the results and findings from study 2 align with past findings on FQOL and add to the body of knowledge on FQOL by reporting that most families use positive adaptations to experience a good sense of FQOL. Family relationships and interactions between family members are considered important to family members. This research also adds to the literature on FQOL and emphasises the difficulties faced by parents around managing challenging behaviours, and the negative impact that the lack of supports to manage these challenges has on their FQOL. Other aspects that have a negative impact on FQOL included the long-term caregiving that leads to exhaustion and the poor health of caregivers, worries about the future for their CWD, and worries about the burden of caregiving on siblings.

3.4.1b Relationships among parent occupations, their family quality of life, and disability-related supports as per parent perspectives. In terms of committed parent occupations there were strong positive correlations between the subscale “disability-related support” and items on the BC-FQOLS, indicating an association among committed occupations (spending time-together, taking care of individual needs of every child) and the support the families were receiving from their disability-related services. This finding could be a result of the families having time for such activities, because the majority of the CWD attended special schools (76%), and the majority of the families had some access to respite care. Children attending special school were away from home for almost 6–8 hours (school-bus drive) on weekdays, and if families had respite care, then they could avail themselves of 4–6 hours of respite on weekends. This allowed parents time to plan activities with their other children and can explain this strong association.

There were also strong positive correlations among free-time occupations (time to pursue own interests) and “disability related support”. This was surprising given 42% of the main caregivers were not working, 36% were working part-time, and 24% were homemakers. One possible explanation is that 84% of the surveys were filled out by mothers, and because majority of them were not working, it is possible that they said that they were able to find time for their own interests.

The qualitative findings can further illuminate some of these results. Within code 3.3 many parents reported that even though they did not have time for paid work (contracted occupations), and self-care (necessary occupations), most of them had become advocates and researchers, looking for supports and services for their CWD. This was their new free-time occupation, as some of them spent most of their free-time looking for services or funding. Many participants also attended parent support

groups during this time and said that this was to their interest. It is possible that they felt privileged that they had time to pursue these things, as they were not working, and led to the high scores on satisfaction with time to pursue own interests.

There were no significant correlations between necessary occupations (taking care of expenses) and contracted occupations (work status) and disability-related support. It was interesting to note that 52% of this sample was earning between middle and high annual incomes and 52% of the sample also reported that they were able to afford fully, or to some extent, the services and supports for their CWD. However, 48% of the sample was unable to afford or reported that it was not reasonable for them to afford the cost of services and supports for their child; however, this is not reflected in the results. The qualitative findings, however, were important in understanding that parents were feeling the impact of loss of income, and many of them missed their work and careers. Within code 4 the parents reported that having a CWD impacted their financial income due to the added costs and reduced family income. They also added that reduced income led to them keeping their own health on standby and some participants (I10, I12) talked about not undertaking treatment for health conditions such as cancer and chronic problems such as back pain or depression. Many participants reported that they were unable to continue in their previous jobs in a full-time capacity and had to work reduced hours or not at all. These findings are similar to the few studies that have reported on career, family income, and financial status having a correlation with FQOL. A South Australian study with 42 participants conducted using the FQOL-S assessed the FQOL domains, and concluded that parents reported that financial well-being was an important domain when compared to other domains such as support from others (Rillotta, Kirby, Shearer, & Nettelbeck, 2012). In an Irish study with 49 participants, overall financial

status had a strong relationship with FQOL (Caples & Sweeney, 2010). In a Slovenian study (N = 20), many caregivers had to give up their careers to provide caregiving, and career was reported as being an important influence on FQOL (Čagran, Schmidt, & Brown, 2011). In another Malaysian study, the FQOL-S was used with 50 parents/caregivers of people with intellectual disability or autism, who reported that financial well-being and careers were considered important (Clark, Brown, & Karapaya, 2012).

In previously published literature, employment status was an important individual member variable that is linked with FQOL (Chiu et al., 2013; Zuna et al., 2010). Even though the employment status was not significantly correlated to FQOL in this study ($r = -.05$, $p = .73$), the qualitative data highlighted that their commitment to their CWD was strong and the value of being a committed parent helped them adapt positively, and they felt better about their FQOL. Most of the mothers who were advocates for their CWD expressed that they were happy with this new transformation of being able to advocate and help other parents of CWD.

Scorgie and Sobsey (2000) and Chiu et al. (2013) identified such changes in parent roles as “transformations” (personal and relational), or life-changing experiences of parents of CWD. As a part of personal transformation, family members gain new roles in their family, community, and in their careers that lead to newly acquired traits such as an ability to advocate for the CWD. This explanation about transformations fits with the findings from the current study as well.

In terms of commitment towards siblings (committed occupations), within code 2.1 spending time with their family, including siblings, was very important (committed occupation) to most of the participants in the qualitative study and they liked going out with their family members. Within code 3.4 most parents reported that

they had adapted their social events to suit the CWD. Siblings had also adapted and the parents reported that the siblings did not complain about missing out on social events, as they were considerate of their sibling with disability. Siblings adjust to disability and sometimes are even strengthened by it; however, they need appropriate opportunities for their own development and if their sibling has high caregiving needs they can become negatively affected (R. Brown et al., 2016). This study did not explore siblings' quality of life, and according to parent perspectives it seemed that parents were trying hard to balance their commitments to the siblings as well. Nearly 58% of the participants reported that they were satisfied or very satisfied with how they were able to take care of the individual needs of every child ($M = 3.34$, $SD = 1.15$). The strong association between this item and 'disability-related supports indicates that families were feeling that the supports they receive help them to find time for the siblings and to engage in activities with them.

In summary, the relationships between parent occupations and FQOL add to the FQOL literature, particularly as using parent occupations as a lens has not been previously reported within the literature on FQOL. Important findings from study 2 that add to the FQOL literature include the impact of having a CWD on their occupations and their FQOL. Most parents were not able to return to work as they had earlier expected; however, most parents had transformed their occupations and were involved in new occupations such as advocacy and supporting other parents. Caregiving was the most time-consuming occupation for parents, and most parents were unable to return to work due to the caregiving needs of their child.

All families mentioned loss of income and its impact on their FQOL; however, most parents had accepted that they would be unable to return to work in a capacity that they worked before having their CWD. Looking after their own needs was not

possible for most parents and many parents had poor health conditions but had put their health on hold. Having a CWD impacted necessary occupations (self-care), contracted occupations (work), and to some extent committed occupations (commitments increased due to caregiving). It also impacted free-time occupations, as most parents were not involved in leisure activities; however, they considered parent groups and advocacy as a good use of their free-time. Leisure and recreation for parents/caregivers is an important factor that influences FQOL in the FQOL-S (2006). Caples and Sweeney (2010) have reported in their study that level of opportunity for leisure and enjoyment correlated strongly with FQOL. Similar to this study, Steel et al. (2011) in their Belgian study, as well as Clark et al. (2012) in their Malaysian study, found strong correlations between caregivers' participation in leisure and recreation and FQOL.

In terms of the relationship between their disability-related support, services from the service provider, supports from friends and families, and respite care support will be considered as the disability-related support for the qualitative aspect of the study. Disability-related supports within the BC-FQOLS include supports at home and in the child's environments rather than services alone. The quantitative results indicated that 76% of the participants were satisfied with the relationship they had with their service provider, however there was no significant correlation between satisfaction with adequacy of services received and total FQOL satisfaction on the BC-FQOLS ($\rho = -.061, p = .68$).

Nearly 68% of the participants reported that they were getting less services than in the earlier years. Within the demographic questionnaire some participants commented on the lack of finances for looking after their family needs, and the added pressure of their CWD, as they were not able to afford private therapy, or other

recreation activities for them. Some participants also commented on the lack of coordinated services or a case manager type of support from service providers. The qualitative data indicated that most parents reported that help is available from extended family members or friends and is valued; however, most parents reported that they were reluctant to ask for help due to the high caregiving needs of their child (code 5.3). A scoping review of 18 studies on FQOL indicated similar findings reporting that parents asked for help from friends and family only as a last resort even if they were sure of receiving it (Bhopti et al., 2016). In another study 23 parents of children with multiple diagnoses of intellectual disability were interviewed to determine the supports that helped them with a better FQOL (R. Brown, Geider, Primrose, & Jokinen, 2011). Many families reported that they felt excluded within their home communities and expressed stress and frustration with service and community support.

Respite care is an important disability-related support; however, the quantitative data was not able to capture the value of respite care services with relation to total FQOL. The qualitative findings clearly reported on the value of respite care for families. Parents reported that they were able to find some time for their home chores and for other family members because of respite care, and this helped their FQOL. They also commented that their CWD enjoyed the respite activities with the respite carers and this was also a positive influence on their FQOL (code 5.2). Many parents expressed the value of a trusted relationship with the respite carer.

Parents worried about changes to their respite worker especially if their child had difficulties with building rapport. Respite workers who were confident and happy to engage with children in their activities of choice were welcomed by parents;

however, when respite workers were unable to manage challenging behaviours, parents lost their trust. Consistency of staff and respite placement are identified as important elements in making the experience a positive one for everyone and previous research reports that families need to first establish trusted relationships with respite caregivers and feel at ease before they can allow their child to be cared for by another person (R. Brown et al., 2016).

A metasynthesis of 17 qualitative studies also reiterated that relationships with support care services such as respite carers was paramount, and that even though respite services are valued they were either unavailable or very difficult to obtain, and most service systems were reported as complex and cumbersome (Griffith & Hastings, 2014). Some parents within this study also reported the bureaucracy involved and the numerous hours that they had to spend convincing service providers of their need for respite, and this was detrimental to their FQOL. Overall, most participants who received respite looked forward to this time away from caregiving and valued it; however, most parents commented on a lack of these services.

Another important disability-related support for families as their CWD was getting older was residential care and subsequent worry about how their child would be able to live independently in the future (code 3.5). Worrying about the future residential needs and caregiving for their CWD was a major finding of the qualitative study. Many participants were considering residential homes or worrying about how their child would be able to live independently without being a burden to the siblings. This is reported in past studies and most parents fear that their family member would not be loved or cared for like they are in a family home, or would not have a close relationship with anyone, or would not be treated like an individual (Griffith & Hastings, 2014).

Moving out of home and living independently is considered an important right for persons with disability (AIDD, 2000). It is advised in past literature that families need to be supported in making such decisions because gradually phasing the person with disability into accommodation improves outcomes allowing the family to become comfortable (R. Brown et al., 2016). Another finding in the qualitative study was that some children with violent and disruptive behaviours were placed in interim residential care in order to allow the family to have some respite and build relationships with other family members at home. Parents (I6, I7, I8) felt guilty about the removal of their child, but had no other choice (code 3.5). Their lives had changed dramatically for better once their child was placed in residential care away from home. The parents missed their child, but said that the removal helped stabilise their home unit and relationships with siblings. In past studies on FQOL, it has been indicated that there are times when such removal is necessary to avoid family breakdown and exclusion of the family from the community.

Removal of the CWD had a significant positive influence on everyone's quality of life, and such residential supports need to be considered rather than frowned upon (R. Brown et al., 2016). Even though the future residential care, or interim residential care, was identified as a concern for parents and an important disability-related support in the qualitative study, it was not evident in the quantitative results.

Lastly, another important disability-related support identified by parents in the qualitative study was parent support groups because parents expressed that these groups provided them with information, research, and friendships (code 5.4). Some parents also mentioned sibling support groups as being helpful. There are several studies reporting the impact of having a CWD on siblings; however, that was not a

focus of this study. Siblings play an important role in the family, and parents worried about the burden of care on siblings, and the fear of resentment of their sibling with disability. Some mentioned that parent and sibling support groups helped them with understanding the importance of looking after siblings' needs. Parent support groups were also instrumental in providing friends for most parents, thereby helping their FQOL. Parent support groups are considered as one of the most supportive practices in assisting families to meet their emotional and informational needs (Brown et al., 2016).

In summary, similar to previous studies this research adds to the literature on the importance of disability-related supports to FQOL. The qualitative findings explained that the disability-related supports most valued by families were respite care, support from special school, interim residential care, and parent support groups. Such supports may contribute towards a high total FQOL score, explaining a clear relationship between disability-related supports and FQOL within this study. The qualitative subthemes assisted in understanding that when parents felt supported they experienced a better FQOL.

3.4.2 Limitations: study 2. A limitation of this study was the smaller sample size in the quantitative study as compared to study 1. Due to the restricted timeframe and ethics it was difficult to contact families in larger organisations, and most recruitment was achieved via snowballing. This led to a slow dribble of responses of returned data and was a time-consuming exercise.

Another potential limitation was the Likert style of responding as used in BC-FQOLS. This style sometimes fails to measure the true attitudes of respondents and does not force them to select an extreme choice because of negative implications

involved with extremes. This may explain the high scores on their total FQOL. However, triangulating data with the interviews was critical for this limitation and in understanding parent perspectives.

No clear outcome measure for parent occupations was another limitation; however, this was similar to study 1 and mitigated by using data from the surveys, demographic questionnaire, and interviews.

3.5 Conclusion: Study 2

In terms of perspectives of parents of school-aged CWD, regarding their FQOL, they demonstrated high scores on total FQOL. There were some associations between their occupations, disability-related supports, and their FQOL. Since the majority of the children within this study seemed to be well supported in their special schools, and many families were availing themselves of respite care services, these systemic factors (level of supports) had a positive influence on their overall FQOL. These findings concur with the model of FQOL within the unified theory of FQOL by Zuna et al. (2010). It is affirmed within this study that systemic factors directly impact individual and family-level supports, services, and practices (Zuna et al., 2010). Individual member concepts such as their characteristics, demographics, and beliefs about family values also directly predict FQOL, as was evident in this study. The demographics suggest that some important family characteristics such as 74% of the families having both parents living at home, with 52% of the population earning between middle and high annual incomes, had a positive influence on their FQOL. There were strong relationships between parent occupations and their disability-related support indicating that families felt supported to be able to participate in some of their necessary and committed occupations. However, this study also concludes

that caregivers were unable to return to work in the same capacity despite the supports. Some hardships such as worrying about the future, long-term caregiving, and dealing with behaviours of concern, challenged their FQOL; however, they constantly dealt with consequences that arose and expressed that the positives of having a CWD outweighed the stresses.

For research question 3 regarding, “Are there any differences between perspectives of school-aged parents of CWD, when compared to parents in ECIS in relation to their FQOL, parent occupations and disability-related supports?”, studies 1 and 2 will be considered and compared. The first study helps with understanding the parent perspectives of ECIS families and the second study was about parents of school-aged children. Theme 2 will also be discussed and presented in the next chapter, as a synthesis of the findings from both studies.

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Chapter 4: Synthesis and Integration of Results from Completed Studies

Within this chapter, the results and findings from study 1 and study 2 will be compared, interpreted, and synthesised to answer the final research question that is, “Are there any differences between the perspectives of parents of school-aged children with disability (CWD), when compared to parents with children receiving ECIS, in relation to their FQOL, parent occupations and disability-related supports?” This chapter does not include external literature. The next chapter uses the integrated findings from this chapter (including both completed studies) and compares and discusses these findings with the external literature.

This chapter is indexed as follows:

- 4.1 Summary of Aims and Research Questions from Study 1 and 2
- 4.2 Methods of Analysis used for Synthesis of Quantitative and Qualitative Data from Study 1 and Study 2
- 4.3 Results and Findings from Study 1 and Study 2

4.1 Summary of Aims and Research Questions from Study 1 and 2

Study 1: Summary. The aim of study 1 was to explore parents' perspectives of FQOL when they have a child with disability (CWD) and to look for relationships between early childhood intervention services (ECIS), their occupations, and FQOL. The results from study 1 concluded that, overall, parents of children in ECIS have positive perceptions about their FQOL. The parent perspectives of "normalisation" (comparing their life with families of children developing typically) and "stability" (feeling hopeful that positive changes will continue in the future), and their positive outlook were helpful. Their ability to constantly adapt to the needs of their CWD assisted them to manage the challenges of having a CWD and had a positive influence on their FQOL. Parents were resourceful and managed their family needs; however, they needed support with their child's specific needs. The quantitative results indicated a relationship between disability-related support and FQOL, and some associations between parent occupations and FQOL.

The qualitative findings in study 1 brought new knowledge about the impact of having a CWD on parent occupations. Loss of previous occupations for the main caregiver (such as careers and time for self-care) appeared to have a detrimental impact on their financial and emotional well-being. However, family support, information about their child's disability, and getting help for looking after their child reduced their caregiving burden, and in turn improved their FQOL. Most parents in the ECIS group anticipated that their lifestyle and previous occupations would return to previous times when their child became of school age.

Study 2: Summary. It was important to consider whether the FQOL of parents of school-aged children was different to parents of children within ECIS,

whether they were able to return to their previous lifestyle and occupations when their child went to school and whether they experienced a similar sense of good FQOL. Hence study 2 was designed with parents of school-aged CWD. The main aim of study 2 was to investigate the FQOL of parents of school-aged CWD and to explore the relationships between parent occupations, disability-related supports, and FQOL. Another intention was to compare parents' perspectives of FQOL and to look for any similarities or differences in their FQOL experience from early childhood to school, with the aim of informing policy and practice for families within ECIS and school.

The results and findings from study 2 concluded that parents of school-aged CWD reported that their FQOL was hard and challenging. However, parents adapted using positive strategies to manage their daily lives and this helped them gain a good sense of FQOL. They were unable to return to their previous occupations, but had transformed their roles (see findings section in Chapter 2), and despite being exhausted from caregiving, they were feeling a sense of control over the disability needs of their child. Many of them were advocates for disability and supported other parents. Their main concerns were around the residential care for their CWD in the future.

The next section synthesises and integrates the findings from both studies with the aim of answering the research question above.

4.2 Methods of Analysis for the Synthesis: Study 1 and Study 2

Quantitative analysis. The last research question compared perspectives of parents from ECIS to school-age and investigated whether there were any differences between the two groups. Two questions from the demographic questionnaire were used for descriptive analysis. The first question compared the amount of services their CWD received now compared to ECIS and asked “What describes the services and supports you receive for your child’s needs best” with choices from, “I get more services and support for my child now compared to when they were in preschool (Early Intervention)” to “I get less service and support for my child now compared to when they were in preschool (Early Intervention)”.

The second question on the demographic questionnaire was about whether they were able to manage the expenses for their CWD and how they felt about the expenses related to disability, now that their child was at school. The question was “Are you able to afford services and supports for your CWD?” with choices from, “Yes fully”, “To some extent but that’s OK”, “To some extent but that is not OK”, to “No I am unable to”. Both questions had room for adding comments.

The next analysis compared the mean scores from study 1 (ECIS) to study 2. The ‘between-groups’ analysis of variance (ANOVA) was used with the age of the child as the independent (grouping) variable, and TFQOL (total family quality of life) as the dependent continuous variable. A one-way between groups analysis of variance was conducted to explore the impact of age on the level of satisfaction with total FQOL. The other continuous variables used were the subscales of FQOL, namely “family interaction” (TFaminteraction), “parenting” (TParenting), “emotional well-being” (TEmoWB), “physical/material well-being” (TPhymatWB), and “disability-related support” (TDisreldsupp).

Firstly, the age of the child was recorded, and the total participants were divided into four groups (0-2 years, 3-6 years, 7-10 years, 11-18 years). The participants in 0-2 years and 3-6 years were parents of children in ECIS (study 1) and the others were caregivers of school-aged CWD (study 2). The ANOVA compares the variance between the different groups with the variability within each of the groups (Pallant, 2013).

An F-ratio was also calculated that represents the variance between the groups divided by the variance within the group. A large F-ratio indicates that there is more variability between the groups (caused by the independent variable, i.e. age), than there is within each group (Pallant, 2013). To understand which groups differ, post-hoc tests were also conducted to protect against the likelihood of Type 1 error.

Bootstrapping was conducted to allow for estimation of the sampling distribution because of uneven numbers between the group sizes. The major assumption behind bootstrapping is that the sample distribution is a good approximation to the population distribution, i.e. that the sample is representative of the population (Ong, 2014).

Study 1 had 72 participants and study 2 had 50 participants. Group 1 was allocated to children between 0-2 years and had 63 participants; group 2 was between 3-6 years and had nine participants; group 3 was between 7-10 years and had 19 participants; and group 4 was between 11-18 years and had 31 participants. Three sets of ANOVA analyses were conducted, comparing FQOL and its subscales between groups, comparing parent occupations between groups, and comparing services and supports between groups.

Qualitative analyses. Two questions were added to the interview guide in study 2 to obtain the perspectives of parents on the differences between their FQOL from now, with school-aged CWD, to when their child was younger and receiving ECIS. These questions were, “Do you recall if receiving ECIS had any influence on you or your family? Could you tell me a bit more about that? Could you comment on the differences between your FQOL now when your child is at school compared to when in ECIS?”

For this analysis, firstly, theme 2 from study 2 was used. This theme was about the parent perspectives in study 2 where they compared their FQOL when their CWD was in ECIS to now when their CWD was school-aged (see Table 4.1).

Table 4.1 *Theme 2 from Study 2*

Theme 2: Comparing early years to now
<p>Subtheme 2.1 About FQOL then and now ... It was harder in the early years, but it is still challenging, stressful, and difficult</p> <p>Subtheme 2.2 Caregiving then and now ... did not expect caregiving to be long-term in the early years</p> <p>Subtheme 2.3 Services and supports then and now ... less support and funding now</p> <p>Subtheme 2.4 Parent occupations then and now ... have been able to go back to a few previous occupations, but many occupations have changed as the years have gone by</p>

Next, the qualitative comparative approach (Bradley, Curry, & Devers, 2007; Ragin, 1999) was used to compare the findings concerning the perspectives between the

parents in study 1 and study 2 of FQOL, parent occupations. and disability-related supports.

According to Ragin (1999), qualitative comparative analysis usually involves a condition shared by all participants (in this research it is having a CWD) with an eye to understanding a common outcome (in this research it is FQOL). When conducting a comparative analysis, themes can be generated by analysing concepts coded in different participant groups (ECIS and school-aged) if these groups need to be compared. Such comparisons can assess whether certain concepts and perspectives are more apparent or are experienced differently in one group than in another (Bradley et al., 2007). In both studies 1 and 2, the codes and themes reflected parent perspectives about FQOL, parent occupations, disability-related supports, and the consequences of having a CWD on FQOL and were comparable. In study 1 and study 2, tables were created to map all participants' responses alongside the codes and themes (see Tables 4.2 and 4.3). An 'X' is placed under the participant's name in Tables 4.2 and 4.3 indicating the participant's contribution to that code and theme. For the synthesis, the codes and themes that included parent perspectives of FQOL, their occupations, challenges to FQOL, things that support FQOL, and consequences of having a CWD on FQOL were highlighted in the table (Marx, Rihoux, & Ragin, 2014; Ragin, 1999). Colour-coding was used to group common findings, for example in Tables 4.2 and 4.3 and Appendix 4.1, perspectives of parents that support their FQOL are colour-coded green, parent occupations are coded red, parent perspectives of FQOL are coded orange, challenges to FQOL are coded purple, and consequences of having a CWD are coded brown.

Table 4.2 *Study 1 – Codes and Themes in Relation to Participants*

Themes	1 Alice	2 Bob	3 Cassie	4 Dee	5 Ellie	6 Fran	7 Grace	8 Hannah	9 Irene	10 Jenny	11 Kerry	12 Liam
Theme 1 My FQOL is okay, but ... different, hard, with constant ups and downs	X	X	X	X	X	X	X	X	X	X	X	X
Theme 2 FQOL is better when we feel hopeful and supported												
Code 2: Financial support for accessing services helps reduce the financial burden and helps FQOL	X	X	X	X	X	X	X	X	X	X	X	X
Code 4: Early years are similar to having a typically developing child	X		X	X	X		X		X		X	
Code 8: Progress and development of child is energising and uplifts parents and helps FQOL		X	X	X		X	X		X	X	X	
Code 9: Support from partner, family, and friends varies but is valued; however, reluctant to ask for support	X	X	X	X	X	X	X	X	X		X	

Code 10: Support from services is important and valued	X	X	X	X	X	X	X	X	X	X	
Code 12: Positive attitudes, beliefs, religion, faith, and family values help families	X	X	X	X	X	X	X	X	X	X	
Theme 3 FQOL is challenged during difficult times											
Code 7: Waiting for the diagnosis leads to stress, but knowing the diagnosis is also stressful, sad, and devastating	X		X	X			X	X			X
Code 11: Support after exiting ECIS is scarce						X		X		X	
Code 13: Having multiple children and family members with a diagnosis/illness impacts FQOL		X	X			X				X	X
Code 14: Severity of disability especially challenging behaviours impact FQOL	X	X		X		X				X	X
Code 16: Triggers/events in life can impact FQOL				X				X		X	X

Theme 4

Having a CWD has consequences for family and for FQOL

Code 3: Physical well-being of parent/caregiver is not a priority due to the child's needs and financial responsibility		X	X	X		X	X	X		X		
Code 5: Ownership and adoption of parenting role comes about after having a child	X		X	X	X		X	X		X	X	X
Code 6: Adaptations are made/previous parent occupations change	X	X	X	X	X	X	X	X	X	X	X	X
Code 15: Siblings/family relationships are impacted	X	X	X			X			X			X

Table 4.3 *Study 2 – Codes and Themes in Relation to Participants*

Themes	1 Amanda	2 Bianca	3 Caitlin	4 David	5 Eli	6 Fiona	7 Gary	8 Harry	9 Isla	10 Jemima	11 Kate	12 Lisa
Theme 1 Parent perspectives of FQOL												
Subtheme 1.1 Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting; however, there are positives about having a CWD	X	X	X	X	X	X	X	X	X	X	X	X
Subtheme 1.2 FQOL is better when we feel supported	X	X	X	X	X	X	X	X	X	X	X	X
Subtheme 1.3 FQOL is challenged during difficult times and when we think about the future	X	X	X	X	X	X	X	X	X	X	X	X
Subtheme 1.4 Having a CWD has consequences for families and FQOL	X	X	X	X	X	X	X	X	X	X	X	X

Theme 2

Comparing early years to now

Subtheme 2.1 About FQOL then and now ... It was harder in the early years, but it is still challenging, stressful, and difficult	X	X	X		X	X	X	X	X	X	X	X
Subtheme 2.2 Caregiving then and now ... did not expect caregiving to be long-term in the early years	X	X	X	X	X	X	X	X	X	X		X
Subtheme 2.3 Services and supports then and now ... less support and funding now	X	X	X	X		X	X	X	X	X	X	X
Subtheme 2.4 Parent occupations then and now ... have been able to go back to a few previous occupations, but many occupations have changed as the years have gone by ...	X	X	X	X	X	X	X	X	X	X	X	X

Codes and Subcodes

Code 1: Our FQOL is fluctuating, adapting, hard, different, limited	X	X	X	X	X	X	X	X	X	X	X	X
Code 2: Sharing good times as a family is important for FQOL	X	X	X	X	X	X	X	X	X	X	X	X
2.1: Family time is important for FQOL	X	X	X	X	X	X	X	X	X	X	X	X
2.2: Recreation for the CWD is important but is difficult for parents due to lack of time and resources	X	X	X	X	X	X	X	X		X	X	X
Code 3: Caregiving for the CWD is an ongoing and long-term challenge, and impacts all family activities and family members	X	X	X	X	X	X	X	X	X	X	X	X
3.1: Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings	X	X	X	X	X	X	X	X	X	X		X
3.2: Caregiving for self-care/physical needs of a CWD is exhausting and impacts on parents' well-being		X	X	X	X	X	X	X		X	X	X

3.3: Caregiving for a CWD impacts parent occupations; parents are unable to return to paid work, with lack of time for self-care or meaningful occupations. Most parents become advocates and researchers	X	X	X	X	X	X	X	X	X	X	X	X
3.4: Caregiving for a CWD impacts socialisation with friends/family, and most family activities are adapted to suit the needs of the CWD. Siblings miss out and parents feel guilty	X	X	X	X	X	X	X	X	X	X		X
3.5: Parents worry about the future caregiving needs of their CWD, especially residential care. Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future	X	X	X	X			X	X	X	X	X	X
Code 4: Having a CWD impacts financial/material well-being due to extra costs and reduced income	X	X	X	X	X	X	X	X	X	X	X	X
Code 5: Services and supports are valued and help FQOL	X	X	X	X	X	X	X	X	X	X	X	X

5.1: Special schools provide support for therapy needs and are a respite for parents due to long hours		X	X	X	X	X	X	X	X		X	X
5.2: Respite care is valuable because it provides parents time away from caregiving and the CWD enjoys the time in respite too		X	X	X	X	X	X			X	X	X
5.3: Help is available from family and some others, and is valued, but parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older. Partners and spouses are the main support	X	X	X	X	X	X	X	X	X	X	X	X
5.4: Support groups are valued because they provide information, research, and friendships	X	X	X	X	X				X		X	X
Code 6: Families miss the ECIS family-centred support and the keyworkers, the financial support, and fun and engaging activities for their CWD, but the early years were raw and hard. Parents adapt and become advocates for their CWD	X	X	X	X	X				X	X	X	X

6.1: Parents miss the ECIS services and family interaction	X	X	X	X	X					X		X	X
6.2: Funding for services after ECIS is difficult. Disability-support services are difficult to access. NDIS is helpful	X	X	X	X	X	X	X	X	X	X	X	X	X
6.3: Inclusion of CWD into mainstream school is difficult and challenging for parents due to lack of supports in schools and lack of ECIS-like support	X	X	X	X	X				X	X		X	X
6.4: Dads need support in the early years, but the support they seek is different to mothers				X	X			X					
6.5: Early years are raw and hard and more focused on the here and now and on child's therapy rather than parent well-being	X	X	X	X	X					X		X	X
6.6: Parents become advocates for their CWD and for other families	X	X	X	X	X					X	X	X	X

Parent perspectives of FQOL = Orange; Support to FQOL = Green; Parent Occupations = Red; Challenges to FQOL = Purple; Consequences of having a CWD = Brown

The last step at the end of this comparative analysis included the synthesis and integration of data from the colour-coded findings with the aim of answering the last research question. Three final categories were created in response to the research question about comparing the two studies: comparing FQOL between groups, comparing parent occupations between groups, and comparing disability-related supports between groups. The colour-coded findings were placed under the category they represented. A table comparing these analysed findings was created on a large whiteboard, with the three categories in one column, the colour-coded themes and subthemes from both studies in two columns (from the previous step), and the key points of the analyses in the last column depicting the similarities and differences. The process of this analysis is presented in Table A4.1 (Comparative analysis of qualitative studies) within Appendix 4.1. Detailed findings from each study are available in Chapters 2 and 3 and synthesised findings from the comparative analysis are presented in the findings section of this chapter. This method of comparative analysis was adhered to throughout the process.

Trustworthiness. Records of data and analysis processes using tables and flow diagrams linking the codes, themes, and participants from both studies to the final categories were maintained in a large scrapbook (reflective notebook) and the colour-coding process that was used to help with categorisation was photographed and added to the thesis in Appendix 4.2 (Bradley et al., 2007; Lincoln & Guba, 1985; Ragin, 1999). Constructing tables (such as Tables 4.2 and 4.3) adds credibility, and the data was constantly cross-checked and linked with observations and the interview transcripts (Lincoln & Guba, 1985). An example of this cross-checking is attached as a photo in Appendix 4.2, depicting the cross-checking of participants from study 1

and study 2 with the code and theme. The details presented within the comparative table, along with thick descriptions of the data in the findings section and a step-by-step explanation of the comparative analysis method, ensures transferability and dependability, and allows the readers to share the experiences, and make judgements about, the similarities and differences between the two study groups and thus apply them elsewhere (Lincoln & Guba, 1985; Minichiello, Sullivan, Greenwood, & Axford, 2004). Trustworthiness was thus maintained throughout the process of qualitative analysis.

4.3 Results and Findings from Study 1 and Study 2

Quantitative findings. The first question on the demographic questionnaire for study 2 compared the amount of services their CWD received now as compared to when in ECIS. Nearly 62% of the participants reported that they received less services now that their child was at school, as compared to when their child was in ECIS, while 14% said that they received more (see Table 4.4). The participants added several comments to the questionnaire. Some of these comments indicated their difficulties due to the lack of coordinated care for their child's needs, not knowing the staff at their child's school, and the lack of resources and funding for therapy, equipment, and any further developmental needs of their CWD. Participants also commented about being unable to follow through medical appointments for their CWD as compared to early years due to a lack of time and money.

Table 4.4 *Comparing Services from ECIS to Now*

What describes the services and supports you receive for your child's needs best (N = 50)	Frequency	Percent
I get more services now than ECIS	14	28.0
I get less services now than ECIS	31	62.0
Other	5	10.0
Total	50	100.0
Service provision: Are you able to afford services and supports for your CWD?	Frequency	Percent
Yes fully	4	8.0
To some extent but that's OK	22	44.0
To some extent but that's not OK	21	42.0
No I am unable to	3	6.0
Total	50	100.0

ECIS = Early childhood intervention services

Only 4% were able to afford the services and supports for their CWD fully. Around 22% participants reported that they were able to afford the services to some extent but that was acceptable for them, while 21% indicated that they were able to afford services to some extent, however it was not acceptable to them (see Table 4.4). Participants who did not find the services acceptable and affordable commented on the lack of money for looking after their family needs and the added pressure of their CWD, as they were not able to afford private therapy or other recreation activities. For further investigating the differences and comparing the FQOL, occupations, and disability-related supports of the two groups of participants, a comparative analysis between the two groups from study 1 and study 2 was conducted.

Comparing family quality of life and its subscales between groups. A one-way between-groups analysis of variance (ANOVA) was conducted to explore the impact of age (comparing ECIS to school-aged children) on the level of satisfaction with total FQOL, as measured by the BC-FQOLS (see Table 4.5). There was a statistically significant difference in the BC-FQOLS scores for TFQOL for the groups: $F(3, 118) = 6.5, p < .01$. The effect size calculated using eta squared was 0.141 and is considered a large effect size (Cohen, 1988). Post hoc comparisons using the Tukey HSD test indicated the mean score for Group 1 ($M = 102.11, SD = 14.12$) was significantly different from Group 4 ($M = 88.61, SD = 18.54$). Group 2 ($M = 89.66, SD = 8.88$) and Group 3 ($M = 94.78, SD = 13.38$) did not differ significantly from any other groups.

There was a statistically significant difference in the scores for the BC-FQOLS subscale “Total Family Interaction” for the groups: $F(3, 118) = 2.842, p = 0.04$. The effect size calculated using eta squared was 0.06 and is considered a moderate effect size (Cohen, 1988). Post hoc comparisons using the Tukey HSD test

indicated the mean score for Group 1 ($M = 24.63$, $SD = 4.78$) was significantly different from Group 4 ($M = 21.77$, $SD = 5.30$). Group 2 ($M = 21.67$, $SD = 4.97$) and Group 3 ($M = 23.05$, $SD = 4.76$) did not differ significantly on any variable.

There was a statistically significant difference in the scores for the BC-FQOLS “Total Parenting” subscale for the groups: $F(3, 118) = 4.36$, $p < .01$. Post hoc comparisons using the Tukey HSD test indicated the mean score for Group 1 ($M = 24.56$, $SD = 3.6$) was significantly different from Group 4 ($M = 21.48$, $SD = 4.98$). Group 2 ($M = 22.55$, $SD = 2.92$) and Group 3 ($M = 22.52$, $SD = 4.36$) did not differ significantly from any other groups.

There was a statistically significant difference on the scores for the BC-FQOLS subscale “Total Emotional Well-being” for the groups: $F(3, 118) = 4.19$, $p < .01$. The effect size calculated using eta squared was 0.09 and is considered a moderate effect size (Cohen, 1988). Post hoc comparisons using the Tukey HSD test indicated the mean score for Group 1 ($M = 14.70$, $SD = 3.63$) was significantly different from Group 4 ($M = 12.32$, $SD = 3.57$). Group 2 ($M = 12.11$, $SD = 2.71$) and Group 3 ($M = 12.68$, $SD = 3.86$) did not differ significantly from any other groups.

Table 4.5 *Analysis of Variance (ANOVA) Scores between Groups – ECIS and School Age – Study 1 and Study 2; N = 122*

ANOVA – Total FQOL and Subscales of BC-FQOLS					
		Sum of Squares	Df	Mean Square	F Sig.
TFQOL	Between Groups	4385.921	3	1461.97	6.500 .00*
	Within Groups	26540.735	118	224.92	
	Total	30926.656	121		

TParenting	Between Groups	217.907	3	72.64	4.363	.00*
	Within Groups	1964.257	118	16.65		
	Total	2182.164	121			
TPhysmaterialWB	Between Groups	122.511	3	40.84	6.117	.00*
	Within Groups	787.784	118	6.68		
	Total	910.295	121			
TEmotionalWB	Between Groups	162.470	3	54.16	4.190	.00*
	Within Groups	1525.038	118	12.92		
	Total	1687.508	121			
TDisabSupport	Between Groups	144.025	3	48.00	6.926	.00*
	Within Groups	817.876	118	6.93		
	Total	961.902	121			
TFamInteraction	Between Groups	207.128	3	69.04	2.842	.041*
	Within Groups	2866.970	118	24.29		
	Total	3074.098	121			

Note. * $p < .01$; TFQOL = Total Family Quality of Life; T = Total; Physmaterial WB = Physical Material Well-being; WB = Well-being; DisabSupport = Disability-related support; Fam = Family

There was a statistically significant difference in the scores for the BC-FQOLS subscale “Total Physical/Material Well-being” for the groups: $F(3, 118) = 6.11, p < 0.01$. The effect size calculated using eta squared was 0.13 and is considered a large effect size (Cohen, 1988). Post hoc comparisons indicated the mean score for Group 1 ($M = 17.12, SD = 2.50$) was significantly different from Group 2 ($M = 14.44, SD = 1.42$) and Group 4 ($M = 15.22, SD = 3.19$). Group 3 ($M = 17.21, SD = 2.07$) did not differ significantly from any other groups.

There was a statistically significant difference in the BC-FQOLS scores for subscale “Total Disability-Related Support” for the groups: $F(3, 118) = 6.93, p < .01$. The effect size calculated using eta squared was 0.15 and is considered a large effect size (Cohen, 1988). Post hoc comparisons using the Tukey HSD test indicated the mean score for Group 1 ($M = 17.11, SD = 2.07$) was significantly different from Group 4 ($M = 14.55, SD = 3.40$). Group 2 ($M = 15.78, SD = 2.77$) and Group 3 ($M = 15.63, SD = 2.81$) did not differ significantly from any other groups.

Comparing parent occupations between groups. A one-way between-groups analysis of variance (ANOVA) was conducted to explore the impact of age (comparing ECIS to school-aged children) on the level of satisfaction with parent occupations such as for committed occupations (the time spent together with family, being able to take care of the individual needs of every child), for necessary occupation (whether the family has a way to take care of expenses), and for free-time occupations (whether they had time to pursue their own interests).

There was no statistically significant difference in the BC-FQOLS scores for the item “the amount of time the families get to pursue own interests” for the groups: $F(3, 118) = 1.78, p = .15$. However, there was a statistically significant difference in the BC-FQOLS scores for the item “time they get to spend together as a family” for the groups: $F(3, 118) = 2.97, p = .03$. The effect size calculated using eta squared was 0.07 and is considered a moderate effect size (Cohen, 1988). Post hoc comparisons using the Tukey HSD test indicated the mean score for Group 1 ($M = 4.35, SD = .97$) was significantly different from Group 4 ($M = 3.65, SD = 1.38$). Group 2 ($M = 4.22, SD = .97$) and Group 3 ($M = 4.16, SD = .90$) did not differ significantly from any other groups.

There was a statistically significant difference in the BC-FQOLS item scores for “being able to take care of the individual needs of every child in the family” for the groups: $F(3, 118) = 3.91, p = .01$. The effect size calculated using eta squared was 0.09 and is considered a moderate effect size (Cohen, 1988). Post hoc comparisons using the Tukey HSD test indicated the mean score for Group 1 ($M = 3.97, SD = .98$) was significantly different from Group 4 ($M = 3.19, SD = 1.19$). Group 2 ($M = 3.56, SD = .88$) and Group 3 ($M = 3.58, SD = 1.07$) did not differ significantly from any other groups.

There was a statistically significant difference in the BC-FQOLS item scores for “being able to take care of their expenses” for the groups: $F(3, 118) = 4.92, p < .01$. The effect size calculated using eta squared was 0.11 and is considered a large effect size (Cohen, 1988). Post hoc comparisons using the Tukey HSD test indicated the mean score for Group 1 ($M = 3.98, SD = .89$) was significantly different from Group 4 ($M = 3.26, SD = 1.12$). Group 2 ($M = 3.11, SD = 1.27$) and Group 3 ($M = 3.68, SD = .89$) did not differ significantly from any other groups.

Comparing services and supports between groups. A one-way between-groups analysis of variance was conducted to explore the impact of age (comparing ECIS to school-aged children) on the level of satisfaction with the relationships the parents had with their service provider and the total disability-related support.

There was a statistically significant difference in the BC-FQOLS scores for the item “the relationship they had with their service providers” for the groups: $F(3, 118) = 7.07, p < .01$. The effect size calculated using eta squared was 0.15 and is considered a large effect size (Cohen, 1988). Post hoc comparisons using the Tukey HSD test indicated the mean score for Group 1 ($M = 4.46, SD = .59$) was significantly different from Group 3 ($M = 3.89, SD = .99$) and Group 4 ($M = 3.81, SD = .91$).

Group 2 ($M = 4.56$, $SD = .527$) did not differ significantly from the other groups. The scores for the subscale “Disability Related Support” have already been mentioned above under FQOL scores and indicated a statistically significant difference between two groups: $F(3, 118) = 6.93$, $p < .01$.

Qualitative findings. The method for qualitative comparative analysis was used as described above. Three final categories drawn from the research question were used for this comparison, namely comparing FQOL between groups, comparing parent occupations between groups, and comparing disability-related supports between groups. Please refer to Appendix 4.1, Table A4.1 where the analyses and pertinent codes and themes from both studies are displayed for the reader.

Comparing FQOL between groups. In terms of FQOL, both groups reported that they were making constant adjustments to manage their daily lives. However, contrary to parents of school-aged children, parents within ECIS reported better FQOL and used words such as “okay” and “different” to describe their FQOL. However in contrast school-aged parents used words such as “limited”, “dreadful”, “terrible”, and “challenging”. Parents of school-aged children reminisced about the early years as being raw and hard. The new diagnosis and the grief attached to the diagnosis was hard and they remembered it as being a difficult time for them and their family. They reported that with the passing years, it got easier as they adapted to the needs of their CWD, and they were constantly learning how to manage and live with the disability, despite the grief. However, they reported that overall their FQOL was hard and challenging and it fluctuated with some days better than others. The parents in ECIS confirmed what the parents in group 2 reported about the time of diagnosis being hard. They said that the unknown journey ahead with their child and the disability was stressful and devastating, and this time was reported as particularly hard for families in ECIS, impacting their FQOL in a negative way. Contrary to parents within ECIS, spending time together with their family was important to parents of school-aged children, and had a positive impact on their FQOL. Parents

within ECIS did not mention this as important and were too busy adapting to their parenting roles, and settling into their new lives of living with childhood disability.

However, both groups of parents said that despite the hard times and challenges, their overall FQOL was good, or “reasonable”, and that there were many positives that helped their FQOL. Some of their beliefs and values were adding to this positive feeling about their FQOL. Parents in the ECIS group expressed that their inherent values about being a parent, and doing the parent role well, were helping them to feel good about their FQOL. Many parents talked about their faith and their positive outlook that helped their FQOL. Some parents also used *normalisation* (that their life is similar to a family with a typically developing child) and *stability* (that their child will continue to progress and develop skills into the future) to stay positive, and this helped their FQOL. To summarise, in the early years most parents stayed positive, used their values of being a parent, and used *normalisation* and *stability*, and their faith, to help their FQOL.

Contrary to the parents in ECIS, parents in the later years from study 2 did not talk about *normalisation* and did not compare their lives to parents of children without disability. They said that as the years went by they acknowledged and accepted the disability as being long-term and tried to find positives in the transformation of their role as a parent of a CWD, within their family, and within their community. They were still hopeful that their CWD would continue to develop and learn skills (*stability*). However, they also accepted the fact that their life was different to others who did not have a CWD. Many of them reported that they felt courageous and stronger and were able to advocate for their CWD better. Some of the parents moved towards helping and nurturing other parents, and some also took up roles of educating the community (advocates). This transformation and acceptance helped their FQOL.

These qualities around transformation were developed as time went by, and were different to parents in the early years, but helped their FQOL in a positive way.

Comparing parent occupations between the two parent groups. One important finding was that caregiving for the CWD was an accepted parent occupation in both groups, due to their commitment to the parent role (committed occupation). Even though the parents in the ECIS group were not expecting the caregiving to be long-term, they had taken this role on and given up many occupations such as working in a paid job or going out with friends. Caregiving was also the most time-consuming occupation within both groups. Parents in both groups particularly commented that behaviours of concern/challenging behaviours, and children with high support needs, required large amounts of time in caregiving (see Table A4.1 in Appendix 4.1).

The impact of the caregiving occupation was apparent on the physical health and well-being (necessary occupation) of parents in both groups. Parents within ECIS said that they felt that they would be able to find time for their own health needs and be able to look after their health in the future; however, according to parents of school-aged children this did not happen. They reported that they continued to neglect their own needs and were exhausted and unwell. Many parents in both groups had been diagnosed with chronic health conditions since the early years that were left untreated. Some conditions included breast cancer, cardio-vascular problems, depression, chronic back pain, and high levels of stress that were left untreated due to lack of time or finances.

Parents in both groups did not spend time in leisure activities or pursuing hobbies (free-time occupations). Parents in ECIS thought that they would have time for these activities in the future, whereas parents of school-aged children reported that

all their free-time was dedicated to researching their child's needs or doing household chores.

In terms of contracted occupations, both groups of parents were unable to return to work in the same capacity as before having a CWD. Parents in ECIS were adapting and accepting their role of becoming a parent, so were not focused or concerned about returning to work. They were expecting to return to work in the future when their child went to school. However, when the parents of school-aged children were interviewed, it was confirmed that they were unable to return to full-time work even though some of their children were almost reaching adulthood.

Most of the parents missed their jobs and careers. Some of the fathers reported that they were not able to pursue career choices because of the caregiving needs at home. Most of the mothers, including the mothers who were working part-time, also expressed that they missed their paid work and the income. However, most of the parents had accepted that they would not be able to work in a full-time capacity, or would not be career people again. Both groups reported that the loss of income impacted their financial well-being and increased their financial burdens.

Surprisingly, they did not seem disappointed by not being able to work as before, but seemed to have moved on into different directions. Parents in ECIS reported that they felt privileged that they were able to care for their child, and did not have to return to work, and this attitude helped their FQOL. Parents of school-aged children reported that they had become advocates and researchers for disability, and were happy with this change of occupation and this helped their FQOL.

Comparing disability-related supports between groups. Parents in both groups reported that services and supports helped their FQOL. However, most parents of school-aged children expressed that they missed the ECIS support, the coordinated

care of services, and the funding. Some parents also said that inclusion of their child into mainstream schools was difficult, and they missed the inclusive settings from the early days.

Contrary to parents of school-aged children, parents in ECIS did not expect their services such as ECIS to look after their family needs or to receive help for caregiving. They were more focused on child-specific outcomes. Funding for services, particularly therapy needs, was more important to them than family outcomes or their own needs. They did not seek respite care or support groups.

In contrast, parents of school-aged children mentioned the importance of self-care and parent well-being in early years. On looking back, they said that they were child-focused because it was difficult for them to see the future, and they just wanted their CWD to progress to the best of his or her ability, so they put all their efforts into therapy. However, on reflection, most of the parents of school-aged children emphasised the importance of parents looking after their own needs during the early years for long-term well-being.

There were some similarities within both groups in terms of supports. Both groups felt reluctant to ask for support from extended families and friends; however, most parents in both groups said that their main support was from their spouse followed by their extended family, especially grandparents. Both groups valued respectful and trusting workers, and preferred consistency in the workers (therapist, keyworkers, or respite care workers) who were involved in caregiving for their CWD. Contrary to parents within ECIS, parents of school-aged children used more respite care and parent support groups, and found these two supports helpful.

One of the biggest supports that parents in both groups were seeking was related to managing the needs and future caregiving of their CWD. Parents within

ECIS were not so worried about the far future of their CWD, but seemed to be concerned about the supports and services that their child would receive when they transitioned to school. They were concerned about the lack of funding and resources at school for therapy support. Most parents in ECIS were expecting their child to attend mainstream school with a few exceptions being families who had previous experiences of having a CWD in a mainstream school.

Many parents in the school-aged group had unpleasant experiences of mainstream schools, and the lack of resources to manage their child's needs. They reported that lack of appropriate support and services for their child at mainstream schools was the main reason they chose special schools. Contrary to parents in ECIS, the main worry for parents of school-aged children was related to future supports and residential care for their child. They were also worried about siblings having to bear the burden of care, and this led to a fear of resentment by siblings. Even though some parents in ECIS mentioned that they were worried about the caregiving burden for siblings in the future, this was not a core thought for most families in the early years. They had not thought about the far future and the caregiving needs of their child as a long-term issue.

In summary, there were some similarities but many differences in factors that impacted FQOL between the two groups.

Conclusion – Chapter 4

This chapter presented results and findings from the completed studies. To finalise the study it was important to compare the perspectives of parents of school-aged children with parents in ECIS, answer all the research questions, and in conclusion be able to inform policy and practice related to children and families in ECIS. The next chapter is the final chapter in this thesis and will present an integrative and synthesised discussion from completed studies and external literature, as well as limitations, implications, and conclusions from the completed studies.

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Chapter 5: Integrative Discussion and Conclusion of Research

In the previous chapter, the findings from the quantitative and qualitative data from both studies were synthesised and integrated. This chapter discusses the integrated findings from study 1 and study 2 and the external literature, regarding the differences in the FQOL, parent occupations, and disability-related supports of participants. This chapter is the final chapter in this doctoral research and is indexed thus:

- 5.1 Comparing Parent Perspectives
- 5.2 Comparing Parent Occupations
- 5.3 Comparing Disability-related Support
- 5.4 Limitations of this Research
- 5.5 Future Research Directions
- 5.6 Implications for Families
- 5.7 Implications for Practice
- 5.8 Implications for Policy
- 5.9 Conclusion of Thesis

5.1 Comparing Parent Perspectives

The results from the quantitative studies and the ANOVA scores demonstrated a significant difference in the total scores of FQOL between the two parent groups and suggests that FQOL satisfaction was higher in the parent group from the early childhood intervention services (ECIS). In terms of the FQOL subscales, there was a significant difference in all five FQOL subscales, namely family interaction, parenting, emotional well-being, physical material well-being, and disability-related support. These quantitative results indicated that parents of younger children within ECIS were experiencing a better sense of overall FQOL, as well as the designated components of FQOL, as compared to parents of school-aged children with disability (CWD). This result is consistent with the qualitative findings where parents in study 1 used terms such as “okay”, “different, and “reasonable” to describe their FQOL compared to parents of school-aged children who used terms such as “hard”, “limited,” “dreadful”, and “challenging”.

The high scores from the quantitative results on the total FQOL in both groups also concur with the qualitative findings, where both groups of parents talked about the positives around having a CWD and how they adapted along the way. This positive attitude and adaptation helped them feel better about their FQOL. However, there were some differences in the qualitative data in both groups in terms of how parents were adapting. Parents in the ECIS group used terms consistent with “normalisation” (that their life is similar to parents of a typically developing child) and “stability” (that their child will continue to progress and develop skills into the future) as hopeful beliefs, to help them feel a good sense about their FQOL. The findings related to “normalisation” are reported in previous literature as having a positive influence on FQOL (Deatrick, Knafl, & Murphy-Moore, 1999; Knafl,

Darney, Gallo, & Angst, 2010). Deatrick and colleagues conducted a review of 33 articles using a normalisation construct and concluded that parents/caregivers use unique manifestations of normalisation to adapt and accommodate to the needs of their child with chronic conditions (Deatrick et al., 1999). In another study, 48 parents of children with a genetic condition participated in a study related to normalisation (Knafl et al., 2010). The participants reflected two groups, normalisation present (NP) and normalisation absent (NA). Similar to this study, Knafl et al.'s (2010) research demonstrated that participants in the NP group adapted successfully to the challenges of having a child with a chronic genetic condition and were competent in their parenting style. However, the parents in the NA group talked about the difficult and atypical nature of their lives and pointed to the negative impact of their child's condition on their lives.

In terms of "stability", Brown and Wang (2009) wrote a framework of FQOL for policy and social service provision referring to stability as the degree to which circumstances are likely to improve, decline, or stay the same. They reported that families tend to seek stability in economic, psychological, and social terms, and if they feel that improvements are likely to continue, their FQOL is influenced in a positive way (Brown & Wang, 2009). The findings from study 1 related to stability, where parents reported that their life would get better as the child continues to improve in their developmental skills in the future, concur with this aspect of stability mentioned in FQOL research, and was influencing their FQOL in a positive way.

In contrast, parents of school-aged children acknowledged that they did not talk about normalisation but accepted the disability as being long-term. These parents had seen more challenges with the consequences of living with disability, and were feeling that their FQOL was hard, challenging, and limited. This also explains why

their total FQOL scores were lower than the total FQOL scores of the families in ECIS. However, they had also found positives in the transformation of their role as a parent of a CWD within their family and in their community. Although past studies have not compared FQOL of parents in two age groups such as in this research, or have not conducted longitudinal studies on FQOL, the findings from this research demonstrate how families continue to adapt and stay positive, and how this adaptation continues to have an influence on their FQOL as the years progress. These results are similar to a recent study by Jess, Hastings and Totsika (2017) of 135 mothers of children with intellectual disability (ID), where maternal positivity and the positive perceptions of mothers were investigated. Similar to this research, the authors concluded that despite the elevated levels of stress and depression reported by mothers of children with ID, they also experienced a sense of positive well-being that helped with their satisfaction of life and family, and led to positive perceptions about their child with ID (Jess et al., 2017). In another study, about positive coping, 30 parents of children with acquired brain injury completed questionnaires investigating coping, social support, and perceptions of family environment (Benn & McColl, 2004). The research concluded that the parents used positive strategies to help their coping styles and that recognising parental coping styles, and enhancing the development of positive strategies, assists parents to cope positively with their child's acquired brain injury.

The early work of Turnbull, Summers, Lee and Kyzar (2007), in the conceptualisation of FQOL, also focused on positives seen in families of CWD. Their FQOL conceptualisation was chiefly drawn from literature within positive psychology where researchers focus on strengths and positive coping strategies, and report that these coping strategies lead to positive family outcomes such as FQOL (Chiu et al.,

2013; Turnbull et al., 2007; Turnbull, Turbiville, & Turnbull, 2000). Studies on positive psychology and FQOL (similar to this research) indicate that parents try and stay positive, and use specific positive strategies such as problem solving, positive coping, their belief systems, values of being a parent, and faith to help their FQOL (Brown, Kyrkou, & Samuel, 2016; Chiu et al., 2013; Seligman & Csikszentmihalyi, 2000).

In a special issue on positive psychology, Seligman and Csikszentmihalyi (2000) summarised 15 articles on positive psychology and one of their findings was that optimism and hope affect health and positive traits improve quality of life for individuals. This finding concurs with the positive transformation and adaptation that were seen in the current research. In another metasynthesis of 17 studies, experiences of carers of a family member with ID and challenging behaviours were reported (Griffith & Hastings, 2014). The combined experiences of the carers in the metasynthesis demonstrated that despite the stress and challenging behaviours associated with caregiving, the love they felt for the family member with disability helped them cope and the majority of the caregivers found their caregiving role fulfilling, similar to this research.

These positive qualities were evident in both study 1 and study 2 and explain the high scores on FQOL. However, the qualitative data also suggest that families feel challenged, and many individual stories of families (refer to quotes from the two studies) demonstrate that families of CWD were experiencing high levels of stress and loss of occupation, and many parents were living with poor health, or were at risk of health problems. Poor maternal health and high risk of health-related problems of caregivers are a common finding in past studies. In a mixed-methods Australian study, the mental health of 152 mothers of children with high care disability needs

reported that the subjective mental health of mothers was two standard deviations below that of other Australian women, with higher rates of depression and anxiety (Bourke-Taylor, Howie, Law, & Pallant, 2012). The mothers in the Bourke-Taylor et al. (2012) study attributed their poor health to caregiving for their CWD, and poor interrupted sleep due to caregiving.

In summary, there was a definite difference in FQOL between the two groups, with families in the early years experiencing a better sense of FQOL, and the findings from the completed studies confirm that despite challenges and hardships, using positive coping strategies and positive adaptation led to positive FQOL outcomes.

5.2 Comparing Parent Occupations

The results from the quantitative studies and the ANOVA scores suggest a significant difference in the total scores between the two groups of the committed occupation (spending time together as a family, and time to take care of individual needs of every child). This suggests that the satisfaction with these occupations was higher in the youngest age group. Similarly, there were significant differences for necessary occupation (able to take care of expenses) between the two groups. There was no difference between the groups for the free-time occupation (time to pursue own interests). These results indicate satisfaction with parent occupations in the current research, was better in the early years, and reduced as the children got older and were at school. The qualitative findings concur with the differences between the two groups to some extent.

Committed occupations are described as occupations that occur during committed time and even though they have a productivity or work character, they are typically not remunerated and the duration of work is diffuse and unspecified such as

housework, childcare, meal preparation, home and vehicle maintenance, or shopping (Harvey & Pentland, 2004). Caregiving for their CWD was a committed parent occupation in both groups. However, parents in the ECIS group were not expecting the caregiving to be long-term. Spending time with other family members was not mentioned as important during the interviews for the ECIS parents' group and could be because they felt that they would be able to do this at a later stage. However, many parents in the school-aged group reported on the lack of time for committed occupations such as looking after the siblings' needs and spending time with family members. These qualitative findings mirror the quantitative scores between the two groups on committed occupations. Findings on the importance of spending time with family members and having good family relationships is reported as having a strong association with FQOL in the external literature. In an Australian study, the International Family Quality of Life Survey (FQOL-S) and interviews were completed by 42 caregivers of people with ID, to investigate the FQOL of these families (Rillotta, Kirby, Shearer, & Nettelbeck, 2012). The study concluded that family relationships were considered very important by the caregivers, similar to the findings in this research. In a Slovenian study on FQOL, 20 parents of school-aged CWD used the FQOL-S and reported that family relationships contributed most to their FQOL (Čagran, Schmidt, & Brown, 2011). In another study, of siblings of CWD, 50 siblings were interviewed or participated in focus groups to gain an understanding of what defines their quality of life as a sibling (Moyson & Roeyers, 2012). Despite feeling the need for private time for themselves, the siblings in the study identified participation in joint activities as a family as an important aspect that enhanced quality of life for them. Other studies on caregiver burden have reported similar results as this research, where caregivers/parents of CWD have to spend more

hours in caregiving compared to parents of children who are developing typically (Crowe & Florez, 2006; Crowe & Michael, 2011).

Necessary occupations comprise necessary time and are aimed at meeting the basic physiological and self-maintenance needs such as eating, sleeping, resting, sex, and personal care activities related to health and hygiene (Harvey & Pentland, 2004). Both groups felt that caregiving impacted parental sleep, health, and self-care. Both groups continued to neglect their own needs and were exhausted, and unwell, with many of them experiencing poor health and chronic health conditions that were left untreated due to lack of time or finances. The main difference between the groups was that ECIS families felt that they would be able to find time for their own needs in the future; however, according to parents of school-aged children this did not happen. This can explain the difference in quantitative scores for necessary occupations between the two groups. In a study including 152 mothers of school-aged children with high care needs and developmental disabilities, maternal, child, and environmental factors were correlated to maternal mental health (Bourke-Taylor et al., 2012). The results indicated that participation in healthy activities and empowerment were strong predictors of maternal mental health (Bourke-Taylor et al., 2012). Similar to this research, interrupted sleep due to caregiving led to poor maternal health, and the majority of these mothers reported that they were unable to look after their health or participate in health activities due to high daytime and nighttime care responsibilities (Bourke-Taylor, Pallant, Law, & Howie, 2013).

Contracted occupations typically involve paid productivity or formal education (Harvey & Pentland, 2004). Both groups of parents were unable to return to work in the same capacity as before having a CWD in the qualitative studies and this was also evident in their work status on the quantitative scores. This finding is

reflected in a recent national public dashboard released by the National Disability Insurance Scheme (NDIS) in September 2017, that presents figures on the uptake of supports by family carers of participants in the NDIS scheme (NDIS, 2017). There were 14,000 participants in the 0–6 years age group and nearly 20,000 participants in the 15–24 age group. The report indicated that only 45% of family/carers were working in paid jobs in both age groups (0–6 years age and 15–24-year-olds), demonstrating that the employment rate remained the same when the child attended school.

Surprisingly, there was no association between loss of work and FQOL within both groups, even though both felt that losing one wage impacted their financial well-being and increased their financial burdens. Similar results in an Irish study on FQOL reported that 29 of the 49 families of CWD were satisfied with their financial well-being, despite an average income (Caples & Sweeney, 2010). Caples and Sweeney, similar to this research, reported that many parents gave up their careers, study, or work due to the increased amount of caregiving, impacting their financial well-being. Family income was also a significant predictor of FQOL in a Chinese study that was conducted with 442 caregivers (mothers = 284; fathers = 139; grandparents = 15) (Hu, Wang, & Fei, 2012). The Chinese study used the BC-FQOLS (Chinese version) and the results indicated that financial well-being, and more interestingly means of transportation for the family, was a predictor of physical well-being and FQOL. A Malaysian study with 52 parents of CWD also reported similar results to this research in terms of financial well-being and its relationship to FQOL (Clark, Brown, & Karrapaya, 2012). Parents in Malaysia reported that financial well-being was considered important for FQOL and, similar to this research, they reported limited opportunities to pursue careers due to caregiving.

Lastly, free-time occupations that include activities that take place in the time that is left over after necessary, contracted, and committed occupations are accomplished were also compared with external literature findings (Harvey & Pentland, 2004). Parents in both groups within this research had restricted opportunities for free-time occupations or to engage in leisure activities, primarily due to caregiving. Participating in leisure and recreation activities and community interaction were identified as important indicators of FQOL in a Malaysian study that investigated the FQOL of Malaysian families of CWD and aimed to guide policy on National Welfare in Malaysia (Clark et al., 2012). Similar to this research, Clark et al. (2012) reported that families felt that opportunities for leisure were limited. Reduced opportunities for participating in leisure and community interaction activities was also identified as detracting from a good FQOL in a mixed-methods study by Steel and colleagues from Belgium. The study was conducted with 25 participants, where parents of children with disability reported that a lack of help and support during weekends and vacations impacted their FQOL as they were not able to have any free-time during the school holidays (Steel, Poppe, Vandeveld, Van Hove, & Claes, 2011).

The findings from both completed studies concur with those from past studies about limited opportunities for parents of a CWD to engage in career, study, or leisure activities due to caregiving responsibilities. This research adds new knowledge to FQOL studies in terms of the consequences of having a CWD on parent occupations, and its relationship with FQOL. It concludes that the loss of previous parent occupations has an impact on financial stability and caregiver health, and this impact increases as the child gets older. It does not seem to have a direct impact, but has an indirect mediating or moderating effect on total FQOL.

5.3 Comparing Disability-related Support

The results from the quantitative studies and the ANOVA scores suggest a significant difference in the total scores between the two groups for satisfaction with service provider, and for disability-related support. These results indicated that parents of children in ECIS felt more satisfied with their service providers and felt better supported as compared to the school-aged group. The qualitative findings provided data to illuminate the results.

In terms of support from the service providers, despite both groups feeling that services and supports helped their FQOL, parents of school-aged children missed the ECIS support, the coordinated care of service provision, the inclusive settings, and the funding. Lack of specialist services and resources for meaningful participation and for meeting their child's needs at mainstream schools was the main reason they chose special schools. Special schools not only provided long hours away from home, but also provided programs suited to their CWD, including therapy, education, and recreation, so the parents felt more supported and less stressed.

Similar results in previous studies have reported that students who attend inclusive schools and have complex needs need to be increasingly supported by parents, as they are unable to provide the extra support due to staffing issues (Brown et al., 2016). Parents are usually contacted to take the child home, or keep them at home during difficult times. This adversely affects the parents' employment and consequently family income and FQOL. In another small sample study from England, eight classroom teachers (seven females and one male) from mainstream secondary schools across four regions in England were interviewed about their views on policy changes and barriers to successful inclusion in mainstream schools (Goodman &

Burton, 2010). Similar to the parents within study 2, the teachers in the English study spoke of the challenges to effective inclusion centring on lack of resources and level of teacher expertise. Another study, also conducted in England, interviewed 24 parents to find out their perspectives on mainstream and special schooling for their CWD (Runswick-Cole, 2008). The findings from Runswick-Cole's (2008) research were similar to the current study and revealed that when parents found that their children were being excluded, they looked for a welcoming environment, and most of the parents found this environment in a special school. The mainstream schools also lacked resources to look after the special needs of their child (Runswick-Cole, 2008). These findings concur with the current research as most participants in study 2 had to change their child's school from inclusive mainstream to special school as they felt unwelcome due to lack of support at the inclusive schools.

In terms of support from extended family and friends, parents in both groups valued this support even though they felt reluctant to ask for support. This finding adds to previous studies which show that families consider such support from informal sources as a favour, and refrain from asking for help as they feel guilty or feel that it is an imposition (Steel et al., 2011). In terms of support from parent support groups, many parents in study 2 reported that such groups were very helpful. Solomon, Pistrang and Barker (2001) examined 56 parents of CWD who participated in parent support groups and reported that such groups were helpful in developing a sense of control, a sense of belonging to a community, and helped parents to change at an individual level to accept the disability (Solomon et al., 2001). In another American study, a survey was administered to 1005 caregivers of children with autism to identify factors associated with participation in parent support groups (Mandell & Salzer, 2007). Two-thirds of the respondents participated in support

groups on referral from clinicians. Similar to this study, parents of older children attended the groups more frequently than the younger age group, and the authors reported that this could be due to the additional time it takes to establish routines and resources in the early years. Conclusions from the study commented on the perceived benefits of attending such groups, given the competing time and resource demands of caring for a child with autism (Mandell & Salzer, 2007).

In terms of support from respite care services, parents of school-aged children considered this a main support, more so than the ECIS families. Even though they valued respite care, they were unable to access respite as needed and spent hours in caregiving. According to a recent report by Access Economics for Carers Australia (CarersAustralia, 2017) informal carers such as parents provide 1.32 billion hours of care each year. The report further states that the valuable contribution of Australia's carers comes at a cost to themselves with carer-related conditions including depression, stress-related illness, and sleep deprivation. These facts from the report are similar to findings in this research and need to be carefully considered as an influence on FQOL.

Compared to the school-aged group, the families in ECIS were more focused on child-specific outcomes, particularly therapy needs, and funding for services for their child was more important to them than family outcomes or their own needs. They did not seek respite care or support groups for their own needs. This finding is reflected in the NDIS dashboard in Victoria, where the annualised committed support for participants in the 0–6 years age group was reported, and the amount spent on capacity building for health and well-being of the caregiver was an alarming 0% compared to 79.2% spent on capacity building for daily activities (NDIS, 2017). This

clearly demonstrates that parents of this age group are not seeking help for their own health and well-being.

A possible explanation is that parents in the ECIS group do not express a need for such supports because they feel supported in their capacity building due to the family-centred practice philosophy of ECIS. Most parents in the ECIS group (0–6 years) in this research felt supported at home and in the child’s early childhood settings and received support for funding and family supports if needed. This explains the high level of satisfaction with their service providers. The parents of school-aged children missed this support, and even though they were not dissatisfied with the disability-related supports, they felt the need for more coordinated care, support for their child at school, and family-centred support.

Within Australia, family-centred practice (FCP) is the overarching model of service provision in ECIS, and families are partners in the care of their CWD. Early Childhood Intervention Australia (ECIA) recently recognised FCP as the preferred model of practice in their national publication on best practice guidelines (ECIA, 2016). Even though the school system does not follow the FCP model, the Department of Education and Training (DET) encourages schools to follow the “Family-School Partnership” framework. This framework supports positive parent engagement and brings together family and community resources to enrich student learning and well-being (DET, 2017). The DET encourages parents of children in government or state schools to participate in school life both formally and informally, through school councils, parent clubs, and volunteering (DET, 2017).

Within volunteer programs parents can directly participate in school activities like helping in the school canteen, helping with school excursions and school events, assistance with reading and maths programs, and participation in environment

committees and cultural groups (DET, 2017). However, there is no research to indicate whether parents of CWD use such programs due to their added caregiving responsibilities. Special schools encourage families to work in collaboration with the staff to support the child's learning. However, individualised family-centred care and working with families as partners in the care provision of their CWD, and provision of coordinated care for the child and family, is not evident in the "Family-School Partnership" framework (DET, 2017), and is reflected in the findings from this research.

In terms of support for future needs, families of school-aged children were worried about residential care and transition to adulthood, compared to ECIS families who were worried about transition to school for their CWD. Crotty (2016) published a report on transitions to adulthood that discussed the importance of providing services and supports to people with intellectual disability who aspire to further education and employment. Similar to the findings from this research, the report concluded that transition from childhood to adulthood for people with intellectual disabilities, and for their family carers is fraught with isolation, confusion, disruption and stress in terms of their aspirations, needs, supports and services (Crotty, 2016).

In another study by Heller and Caldwell (2006), 29 families participated in an intervention to support aging caregivers of people with disabilities in planning for the future. The intervention consisted of a legal/training session and workshops that helped caregivers take action on residential planning, and developing a special needs trust. One of the conclusions from the study was that caregiver burden significantly decreased for families when they were supported in their future decision-making (Heller & Caldwell, 2006). This concurs with the results of the current research, where families of school-aged children felt unsupported for future planning for their

CWD. In an Australian study, 218 parents of a young adult with disability who had recently completed school were surveyed to investigate the outcomes for their child following a recent transition from school (Davies & Beamish, 2009). The majority of the parents in that study reported that most young adults lived at home with their parents, and that considerable family adjustment had taken place since transition from school due to the caregiving needs of their family member with disability. A number of parents reported giving up employment in order to look after their son or daughter, and this arrangement resulted in substantial financial hardship and major changes to daily routines. The study indicated a lack of options for the young adult with disability, resulting in poorer quality of life outcomes that were also a future cause of worry for parents in this research (Davies & Beamish, 2009). Based on past studies and the findings from this research, it is evident that lack of supports during transition periods, such as entering school or residential care, leads to apprehension and stress for parents and can have a negative influence on FQOL.

In terms of disability-related supports and FQOL, in a recent book chapter by Chiu et al. (2013), 11 studies promoting FQOL as an outcome of support or researching the relationship of support to FQOL were reviewed, and a need for more studies that measure the impact of support on FQOL was indicated. The findings from this research definitely show a relationship between supports and FQOL, and also demonstrate that provision of quality supports has a positive influence on FQOL. In the ECIS group, supports such as family-centred care, supports provided within a variety of natural environments for the child (in ECIS), and access to funding for therapy contributed to a better FQOL. In the school-aged group, respite care, support from special school, and parent support groups led to a good sense of FQOL.

To conclude the final discussion, the findings from both studies are linked with the unified theory of FQOL (Zuna, Summers, Turnbull, Hu, & Xu, 2010). A few related linkages drawn from this proposed theory include that family characteristics and dynamics interact with individual characteristics to influence FQOL outcomes, and individual factors like supports and services act as mediating or moderating variables to predict FQOL (Zuna et al., 2010). Similar findings were evident in both the completed studies, where supports and services were important mediating and moderating factors that impacted the FQOL of both groups. In study 1, the parents felt supported by their ECIS, their partners, and their extended families, and in study 2, the parents felt supported by their partners, special schools, friends, and respite care services, and this had a positive impact on their FQOL.

According to Zuna et al. (2010) the unified theory states that systems, policies, and programs indirectly impact individual- and family-level supports, services, and practices; individual demographics, characteristics, and beliefs, and family-unit dynamics, characteristics, and beliefs are direct predictors of FQOL. In terms of individual demographics, the majority of families in both studies were from an average income group, married, and English speaking, and these demographics were important determinants of their FQOL. Their characteristics and beliefs included feeling positive about having a CWD, and most mothers believed that parenting their child was their main role. This belief helped them accept the caregiving role and had a positive influence on their FQOL.

The unified theory also suggests that program quality predicts implementation of best practice, which in turn impacts individual factors and in turn FQOL. In terms of program quality having an influence on FQOL, most participants in study 1 experienced high-quality family-centred ECIS programs that are considered best

practice, and this could have influenced the high scores on their FQOL. In terms of participants in study 2, the majority were well-supported in special schools and had access to some respite care, so this could have influenced the high scores on their FQOL in concurrence with the theory of FQOL.

The theory of FQOL also states that if one of the system factors changes, it disrupts the smooth running of the cogs leading to changes in FQOL until adaptation or homeostasis occurs within the individual or family (Zuna et al., 2010). The findings from the qualitative studies showed that many families went through hard times such as transitions, marriage separation, and unforeseen events and these were a setback to them. However, they bounced back and used positive adaptation to continue with their everyday lives, and experienced fluctuating FQOL.

Lastly, the unified theory of FQOL emphasises that singly or combined the predictors result in a FQOL outcome that produces new family strengths, needs, and priorities that re-enter the model as new input, resulting in a continuous feedback loop throughout the life course (Zuna et al., 2010). These new strengths were seen in both groups of families in the qualitative studies. Parents in study 1 reported how they were adapting to the parent role, and parents in study 2 reported on how they had adapted their occupations to become advocates and researchers, and these new strengths helped their FQOL. The relationships of the findings from this research to the unified theory model of FQOL are depicted in Figure 5.1, where the dotted text boxes contain findings from this research.

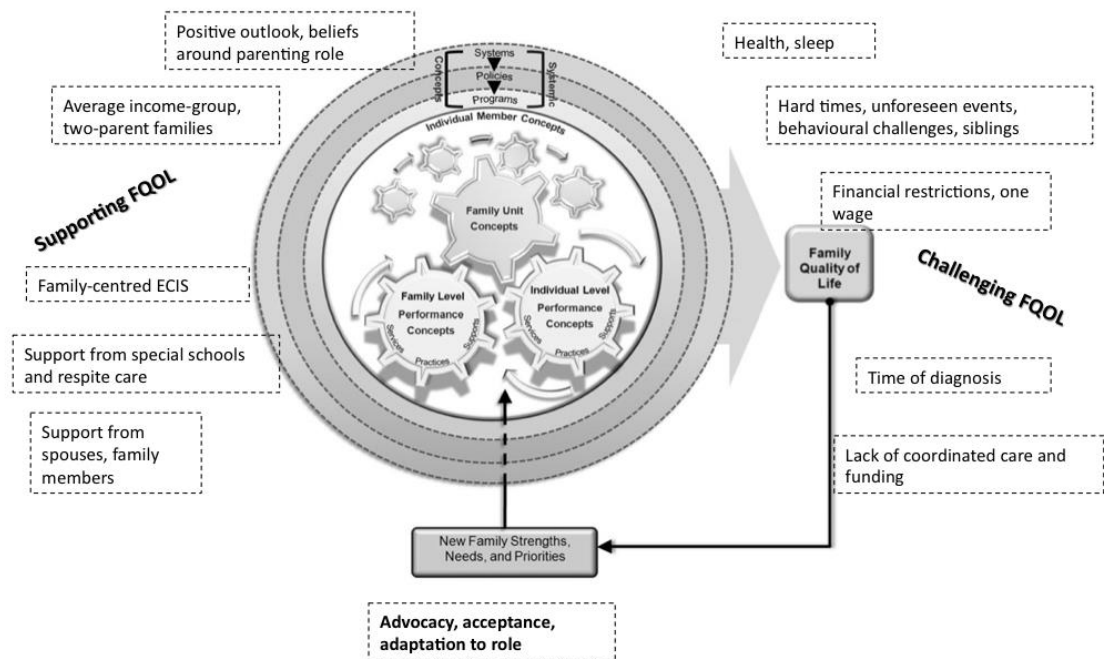


Figure 5.1. Research Findings in Relation to the Unified Model of FQOL (Zuna et al. (2010).

5.4 Limitations of this Research

All the research questions presented at the start of this research were answered; however, there are several limitations identified at the end of this research.

Sampling methods. Convenience sampling used in the quantitative part of this research resulted in participants from similar socio-economic backgrounds and locations, with English speaking abilities. This is acknowledged as a limitation that may have impacted the quantitative results within the completed studies. Convenience sampling also led to participants being recruited from similar service providers in both studies. In study 1, all participants were recruited from one single large ECIS agency wherein the service providers were family-centred and followed a transdisciplinary approach, and the children received services at home and in their early childhood settings. The families were well-supported. Comparing the FQOL of families in the early years who are not receiving this model of coordinated care, and a family-centred approach, would add more breadth to this research, as would capturing a more culturally and economically diverse sample.

In study 2, the majority of participants had children attending special schools where services such as transport, therapy, and education were tailored for their CWD. This could have led to a higher score on their FQOL given the relationship between services and FQOL. Having an equal number of participants who had a CWD attending mainstream schools would provide greater breadth for studying FQOL in the school-aged group.

Data collection. This research collected FQOL data at a single point in time and given that FQOL is cyclical in nature, collecting the FQOL data at multiple time points would have presented a better understanding of their FQOL; however, this was not possible due to time restraints and research fatigue in families.

Research methods. A lack of studies within the area of parent occupations and a lack of measuring tools for parent occupations made it difficult to design the best research method for this study. Measuring parent occupations was reliant on qualitative data. Having a tool to measure parent occupations would help in conducting relationship studies between FQOL and parent occupations.

Participants. Another limitation was including perspectives from siblings. There was an emerging need to study the perspectives of siblings during the data collection phases of both studies; however, this was not possible due to time and ethical restraints. Adding data from siblings would enrich the FQOL data of families.

Sample size. Although this research had a good sample size, there was a difference in the sample sizes between the two comparative quantitative groups. This was addressed by recoding age groups and using bootstrapping techniques. Also, matching the number of participants and the types of disability in the two qualitative samples assisted with keeping the samples in the two studies similar; however, this can be considered a limitation to the research.

5.5 Future Research Directions

This doctoral research presents evidence in support of family-centred and coordinated care approaches, and its positive relationship with FQOL. This is the second study of this nature in Australia (Davis & Gavidia-Payne, 2009) and both studies have reported similar results. The body of research supporting family-centred care and coordinated care for families of CWD needs to keep growing within Australia and it is recommended that future research continues to investigate the uptake of family-centred care within ECIS. Future research also needs to include ECIS programs that are based on similar, as well as different, models of practice to continue to understand the relationships of a good FQOL to the varying models of service provision. Such studies will inform service delivery and also guide policy, especially in the light of the National Disability Insurance Scheme (NDIS) roll out in Australia.

Current statistics from the NDIS dashboard (NDIS, 2017) report poor uptake of supports by caregivers in the 0–6 years age group for capacity building in the area of support and coordination (1.9%) and health and well-being (0.0%). There is a risk that families will not be well-informed about the positives of family-centred care and coordinated care and will continue to neglect their own health and well-being within the new NDIS environment. This is an alarming finding and future research needs to monitor the uptake of such supports, the health and well-being of caregivers, and its relationship with FQOL. It is known from this research and various external studies discussed within this thesis, that lack of such family-centred care, and poor health and well-being of caregivers, can lead to reduced FQOL outcomes and this needs to be monitored closely and be a focus of future research.

Another finding from this research is the impact of loss of parents' occupations and its relationship with FQOL. Parents in the school-aged group demonstrated a significant difference from parents in the early years in terms of their relationship between loss of occupations and their FQOL. The NDIS dashboard (NDIS, 2017) also shows that there is no change in employment rates of parents/caregivers of a CWD, indicating that they are unable to return to work even when their children are at school. There are no past studies within Australia that have considered the relationships between FQOL and parent occupations; however, having a CWD has an impact on parent occupations as is evidenced from this research. Past studies have reported on poor health outcomes (necessary occupations) and prolonged amounts of caregiving (committed occupations) of mothers of CWD.

There is a huge risk of poor health outcomes due to untreated conditions such as cardio-vascular problems, cancer, and stress and depression in parents, especially mothers of a CWD. Future research needs to combine such studies and grow a body of knowledge around parent occupations as classified by this research, namely necessary, committed, contracted, and free-time occupations. Feedback from most participants within the completed studies encouraged the researchers to continue to explore parent occupations using this classification system. Many participants commented that they felt that using the four headings for occupations helped them reflect on their occupations, and encouraged them to consider re-engaging in these occupations in the future.

Alongside studying the negative outcomes in caregivers, such as stress and depression, this research added to the body of knowledge that parents use positive adaptation, and this has a positive impact on FQOL. However, there are no studies within Australia reporting on the positive adaptation by families when they have a

CWD, and its impact on their FQOL. Conducting such studies would extend this doctoral research further and add to the understanding of positive coping and how families continue to stay positive despite having a CWD.

Many families within study 1 used the concept of “normalisation” (caregiving needs of their CWD are similar to a typical child in the early years) as a way to cope with disability; however, whether most families feel this way in the early years needs further exploration with larger study samples, and will further add to an understanding of why families feel a sense of good FQOL in the early years.

This research indicated that parents were concerned about relationships between siblings, and the burden of caregiving for their sibling in the future. Studies related to siblings of CWD and mental illness is a growing body of research in Australia but requires robust and longitudinal studies to understand the impact of having a sibling with disability on FQOL.

Lastly, the school-aged group of parents reported that supports such as respite care were extremely helpful and had a positive impact on their FQOL. Some families of children with extremely violent and aggressive behaviours reported on the benefits of removal of their CWD by placing them in interim residential care. Such opportunities helped the family in re-bonding with family members and reconnecting with their family and had a positive impact on their FQOL. While such parent experiences are not reported vastly in the literature, they have a role in improving family outcomes. Studies on the relationships of respite care, interim residential care, and FQOL are few and conducting larger studies in this area will guide future service provision for families.

5.6 Implications for Families

These implications are for families who have a young child with disability/developmental delay and are based on the collective perspectives of parents of CWD from this research. The findings from this research suggest that the families of young children need to look for supportive family-centred services that work in partnership with them, and build their capacity in the caregiving of their child.

Parents of CWD neglect their own health and well-being, and their occupations. Poor caregiver health is associated with poorer functional outcomes for CWD. It is strongly recommended that parents are informed about poor health outcomes, and that they invest time in their own health to be able to provide better support and care for all members of their family and enjoy a healthier life. Parents also need to look for supports at the time of diagnosis, as this is acknowledged as the most unexpected and difficult time for families and impacts negatively on FQOL.

Parents and caregivers need to recognise their loss of occupations upon having a CWD, and aim to return to previous occupations that are meaningful for them, including work and leisure activities like going out with friends, or necessary occupations such as looking after their self-care needs like sleep and healthcare, to enable a healthier future and a better FQOL.

In terms of parents of school-aged children, the findings from this research highlighted that parents in this group are more adapted to living with disability at home. Implications for the school-aged parent group include looking for supports to transition their CWD into residential care services, or living independently, as a future goal. They also need to continue to use respite care services as a priority to enable safe caregiving for their CWD away from home, and to assist with keeping family relationships intact. Many school-aged parents were living with children who

exhibited violent and aggressive behaviours, and it was challenging for family members to live together at home during such times. Short-term removal at such times to allow the family to become stabilised for when the child returns can be a positive influence on their FQOL, and parents need to be supported in their decision-making around interim residential care options for such times.

Lastly, parents need to advocate for their own rights as carers and for the rights of their CWD, and seek out maximum supports to enable high-quality caregiving and a better quality of life for themselves and for their family. The National Carers Recognition Act (NCRA) bill was passed in 2010 and lists a range of rights for carers; for example, that parents/caregivers need to be remunerated for their time and need support and training in caregiving. A list of these rights can be found at the link below:

<http://www.carersact.org.au/advice/advocacy-rights-change/national-carer-initiatives#Section1>

5.7 Implications for Practice

There are several implications for service providers and practitioners who work with families and CWD. Measuring family outcomes such as FQOL on a regular basis is strongly recommended, as FQOL changes based on circumstances and events. Families experience periods of low and high and constantly adapt to be able to move on with their lives. Even if they show positive adaptation and a sense of good FQOL, they need supportive and respectful service providers who understand this cyclical nature of FQOL and who care for the entire family's well-being and FQOL.

Service providers in the early years need to be aware and respectful of the parents' need for "normalisation" (the need to be treated as parents of typically developing children). Parents in ECIS seek child-focused outcomes, more so than family outcomes; however, service providers know the impact of family-centred care on FQOL. They need to provide parents with information about the evidence for family-centred care as the gold standard for service delivery in the early years. Practitioners and service providers need to take responsibility for providing information around the caregiver's health and well-being rather than just provide home-based programs that are targeted towards child-focused outcomes. Changes to service provision are recommended to identify parents in need of supports to assist with their health and well-being to ensure better FQOL.

Many families in the school-aged group missed the inclusive environments from the early years and found it difficult to retain their CWD in mainstream schools, mainly due to lack of supports and resources for inclusion and participation at schools. This is alarming given that the Disability Discrimination Act (Australian Human Rights Commission, 1992) covers every child's right to education. Within this research many children with challenging behaviours or with complex medical needs

were not able to access the same school as their siblings, due to lack of resources at the schools. Currently, schools rely on parents to provide the extra support when needed, for example during a meltdown, during an excursion, or a medical emergency, and parents are always on call. Special schools provide such specialised supports and are therefore chosen by most parents and are also recommended by health practitioners and schoolteachers; however, at a human rights level this is discriminatory and needs urgent attention. Service providers need to help parents in advocating for better supports and resources at mainstream schools to enable better inclusion and participation, thereby working towards a just and equitable society for people with disability.

In terms of supports for transition to school, or to residential care or independent living, service providers need to help families access these services. Many parents in the school-aged group found parent support groups helpful for accessing such supports. Many parents also discussed the impact of disability on siblings, and support for siblings needs to be considered. It is recommended that service providers link families with support groups and encourage families to access supports for siblings and family members if needed.

Lastly, this research recognises that caregiving is long-term, and many parents are not able to re-engage in their previous occupations even though they use positive adaptation and positive coping. Necessary, contracted, and free-time occupations are severely impacted when parents have a CWD and continued caregiving results in poor health outcomes for the caregiver, loss of well-being, and a decrease in their individual QoL. Service providers should consider re-engagement of parents in necessary and desired occupations for better FQOL outcomes.

5.8 Implications for Policy

Within Australia, the National Disability Insurance Scheme (NDIS) was established to provide services and support to people with disability nationwide (NDIS, 2013, 2016) and will roll out nationwide in 2018. The results from this research strongly recommend that the NDIS promotes ECIS providers to provide supports to children and families using a family-centred approach, and within a range of mainstream early childhood settings to ensure a good FQOL.

This research also highlights the importance of respite care services and a lack of recreational facilities for CWD as they grow older. Access to respite care needs to be urgently reviewed and parents/caregivers need to be able to access respite care as needed for a better FQOL. Sufficient public and private funding for such services is recommended.

There is currently a lack of facilities providing recreational activities for school-aged CWD, leading to a risk of isolation and poor health outcomes. Building and designing safe and accessible recreational facilities such as indoor gyms, sports centres, bike paths, and other hobbies for including adolescents with disability within the community is strongly recommended. Investing in such facilities will support equity and access for people with disability, improve FQOL outcomes for their families and create equitable and better communities.

Policy makers responsible for service evaluation need to consider family-focused outcomes such as FQOL, caregiver health, and caregiver capacity building, alongside child-focused goals. Policy needs to shape service delivery by seeking such outcomes to ensure better health outcomes for caregivers, and for building capacity of caregivers. Lastly, opportunities for returning to work or engaging in leisure activities

for parents/carers are important and currently not apparent in supports identified by policy makers for service delivery and need to be considered to ensure a better FQOL.

5.9 Conclusion

This thesis presented a series of completed mixed methods studies focusing on family quality of life when there is a child with disability. Results and findings from the studies were compared, integrated, and synthesised to answer the questions relating to perspectives of parents about their FQOL, and the relationships between parent occupations, early childhood intervention services (ECIS), and FQOL. This research found associations between parent occupations, ECIS/disability-related support, and FQOL in both study groups (ECIS and school-age). The significant differences in the ANOVA scores on total FQOL between the two groups in this research strongly suggest that FQOL scores reduce as children get older.

This research concludes that even though families feel satisfaction with their FQOL, the hardships and challenges of caregiving increase as the child gets older. Positive adaptations, positive beliefs and values, and positive transformations occur as parents/caregivers continue to live with disability, and this helps their FQOL. Family-centred and coordinated care, and supportive practitioners and workers, have a positive influence on FQOL and are highly recommended.

The consequences of caregiving for a CWD impact parent occupations and most parents/caregivers are unable to return to their previous occupations, especially work and necessary occupations such as sleep and healthcare for themselves. Supports such as respite care, periods of short-term residential care, and spending small amounts of time away from caregiving for the CWD are crucial for parents to be able to return to some of their previous occupations and are strongly advocated. Being able to participate and re-engage in meaningful occupations contributes to parent well-being, leads to better individual quality of life, and in turn improves FQOL.

Families in ECIS need to be informed about the importance of supportive family-centred care, re-engagement in previous occupations, and using supports such as respite care as early as possible, to help improve functional outcomes not only for their CWD, but to improve family outcomes such as FQOL for all family members.

This doctoral research endeavours to acquaint the families and service providers within ECIS with perspectives of parents living with disability related to their FQOL. It concurs with the unified theory of FQOL and concludes that provision of supports such as family-centred ECIS, respite care, and individualised support for CWD in schools can result in better FQOL. It further adds to the body of knowledge in FQOL research by demonstrating relationships between parent occupations and FQOL, and concludes that even though parents are happy to adopt the caregiver role, loss of occupations such as work and looking after their own health (self-care) can have detrimental impacts on their long-term well-being, and consequently on their FQOL.

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Viewpoint

Promoting the occupations of parents of children with disability in early childhood intervention services – Building stronger families and communities

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KEY WORDS *child, caregiver, early intervention, family practice, occupations, parents, quality of life.*

Introduction

This article presents a viewpoint to promote occupations of parents as an important outcome, when working with a child with disability in early childhood intervention services (ECIS). Having a child with disability is an unexpected event for most parents. The time of diagnosis is often experienced as a crisis point and is usually followed by a period of grieving, making the journey for parents of a child with disability cumbersome and lifelong (Marvin & Pianta, 1996). Maternal resolution of a child's diagnosis relates to sensitive caregiving and healthy attachment. Failure to resolve may lead to maternal distress, high caregiving burden and reduced quality of marital and social support (Kearney, Britner, Farrell & Robinson, 2011). This burden of care can cause increased stress and reduced wellbeing for carers (Chaffey & Fossey, 2004), leading to consequences such as the loss of engagement in occupations that previously provided meaning and purpose to life. Parents may provide up to 24 hours a day of care giving, associated mainly with the child's disability, in addition to the usual childcare practices (Bourke-Taylor, Howie & Law, 2010) and often describe their life as 'on hold' because of the child's needs (DeGrace, 2004). Undertaking the carer role can impact parents' immediate and long-term aspirations, occupations and pose a financial burden on the entire household with many carers giving up employment. Reduced income has a huge impact on the family quality of life and on the

productivity of the community. Almost 51% of American caregivers of children with either autism spectrum disorder (ASD) or intellectual disability had to cease working or reduce work hours, increasing their financial and employment burden (Saunders *et al.*, 2015). When parents are doing well financially, they are more able to nurture to their child, foster their child's needs and promote their development (Shonkoff & Phillips, 2000). Time for a parent/caregiver of a child with disability needs to be managed to achieve satisfaction in their occupations. However, in practice, the focus on the occupation of parents is limited. It is argued that parent occupations be considered an important aspect of service delivery in ECIS, to enable parents to pursue their life goals and improve outcomes for children and families.

Occupations of parents

The roles of parenting and caregiving are considered important occupations for all parents, especially in the early years of parenting. A classification of occupations proposed by Harvey and Pentland (2004) using four categories is used here, to gain an understanding of how parents allocate their time for occupations. These four categories are (i) necessary occupations, (ii) contracted occupations, (iii) committed occupations and (iv) free-time occupations. *Necessary* occupations comprise necessary time, aimed at meeting the basic self-maintenance needs, such as eating, sleeping, sex and personal care activities. *Contracted* occupations occur in contracted time and involve paid productivity or formal education. *Committed* occupations have a productivity or work character. However, they are typically not remunerated, and the duration of work is diffuse and unspecified, such as housework, childcare, home and vehicle maintenance or shopping. Time for *committed* occupations can be obtained by paying others to do these occupations to gain time for *free-time* or *contracted* occupations. *Free-time* occupations occur in the time that is left over after *necessary*, *contracted* and *committed* occupations are accomplished. Free-time occupations can be increased by reducing some contracted or committed occupations for

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those such as attending a book club with friends, instead of cooking a meal at home.

Caregiving impacts parents' ability to participate in *contracted* and *free-time* occupations particularly in the child's early years. This can affect productivity, increasing financial burden, causing family-life imbalance, health and psycho-social problems and impacting on the parents' sense of wellbeing and becoming (Saunders *et al.*, 2015; Sawyer *et al.*, 2011). The child's needs, multiple appointments with health professionals and lack of childcare can impact on a parent's ability to work (Kennedy, McLoughlin, Moore, Gavidia-Payne & Forster, 2010). The time mothers spend in the committed occupation of caring for children with cerebral palsy (6 hours per day on weekdays, 8.3 hours per day on the weekends) is two to three times the number that parents spend caring for children without disability (Sawyer *et al.*). Having a child with challenging behaviours frequently associated with ASD can also have an impact on free-time occupations such as family activities, resulting in families experiencing reduced positive family occupations such as birthday parties and holidays (DeGrace, 2004). These findings raise critical issues regarding the amount of *contracted* and *free-time* parents of children with disability have, to pursue their careers or maintain their own wellbeing.

Service providers, specifically in ECIS, are increasingly aware of the impact of having a child with disability on family routines and on the quality of life of all the family members. Service delivery models used in ECIS need to include family-centred practices and a transdisciplinary approach (Kennedy *et al.*, 2010). These approaches promote working closely with the family members alongside direct therapy provision to improve overall family outcomes.

Family-centred practice (FCP) and parent occupations

It is proposed that understanding parent occupations and incorporating them into ECIS service provision are well within the scope of family-centred practice because they enable parents/carers to pursue their own occupational choices in addition to their caring responsibilities (Chaffey & Fossey, 2004; Kennedy *et al.*, 2010). Part of the FCP approach is to partner with families and communities to support a child with disability to learn, grow and thrive. The family-centred practice approach views the family as a unit, coaching families to manage the ongoing care of their child, attending to the skills and resources needed by all family members and matching their goals and resources (Graham, Rodger & Ziviani, 2009; Kennedy *et al.*). This approach aligns closely with occupational therapy practice concepts, highlighting that learning occurs in the context of relationships like parents, siblings, extended family and neighbours (Pilkington, 2006). Emphasis is on using occupational interventions, such as occupational

participation, rather than short-term remediation of presenting symptoms. However, studies demonstrate that majority of the interventions used by Australian occupational therapists pay little attention to the occupational needs of the child and their family units and attempt to remediate skills of the child, without consideration of contextual issues or current state of evidence (Ashburner, Rodger, Ziviani & Jones, 2014; Rodger, Ashburner, Cartmill & Bourke-Taylor, 2010). Making a shift continues to challenge many practitioners, in spite of evidence supporting FCP and occupational-based approaches. Findings from a study involving mothers of sons with a mental illness indicated that occupational therapists could make a distinct contribution to enhancing carer's wellbeing by considering their occupations because it appears important that carers sustain satisfying lives (Chaffey & Fossey, 2004). When designing support plans with children and families, it is strongly recommended to include parent occupations within the occupational-based-approach element of FCP to improve parent satisfaction.

Transdisciplinary approach and parent occupations

It is proposed that parent occupations be included within a transdisciplinary approach (TDA) as a way of addressing and improving family outcomes. The TDA is defined as the sharing of roles across disciplinary limits for maximum communication, interaction and cooperation, with the family considered a key member of the team (King *et al.*, 2009, p. 213). Occupational therapists are members of the TDA team and can bring their knowledge and expertise around occupational issues faced by parents in a carer role, to practice. The TDA involves sharing of expertise across the team; valuing the perspectives, knowledge and skills of those from other disciplines; and trusting each other to carry out the role. The challenges of this approach may include the loss of professional identity, liability implications and inadequate sharing of knowledge. The presumed benefits include less interference, less confusion to parents, more coherent intervention plans and holistic service delivery. Working within a TDA provides opportunities for occupational therapists to use enabling principles, such as coaching and shared learning, that are at the core of their practice (Pilkington, 2006). Shared learning partnerships between occupational therapists and other team members and parents can facilitate discussions regarding inclusion of parent occupations as an important component in a support plan. Occupational therapists, with their expertise in coaching and guiding, rather than directing and doing, are well placed to explore occupational issues with team members and carers. Within a TDA, team members can then assist parents to identify ways to become or remain involved in occupations that have personal meaning and provide time away from the caring role.

This can lead to stronger partnerships between team members and also with families.

Future challenges – Are we moving towards building stronger families, stronger communities?

Families of a child with disability are faced with many challenges that place them at risk of poor outcomes for themselves and their children. Working within family-centred approaches, not just using short-term rehabilitation interventions focussed primarily on the child with disability (Raina *et al.*, 2005), can present challenges for occupational therapists working within ECIS to balance the child and family's needs. Working on family goals and as a transdisciplinary worker leaves little time for individual consultations specific to occupational therapy interventions that target child-focussed goals. However, the recommended practices for ECIS highlight that parents prefer and work more effectively with a single case worker using the TDA model (Moore, 2013). Shifting from a discipline-specific focus to a family-centred generalist approach can be challenging, especially for new practitioners.

Lack of time is another barrier for therapists having to achieve holistic family goals, within a variety of environments. In the ECIS sector, allocated funding is based on outputs (number of children serviced) and not outcomes; therefore, measuring outcomes is not a current focus when allocating services. Many therapists report that this focus deters looking after the entire family's goals and aspirations because parents/carers feel duty-bound to provide the allocated service towards their child with disability rather than within the family context (Bundy, Hemsley, Brentnall, & Marshall, 2008). Novice practitioners or recent graduates may feel overwhelmed and need ongoing mentoring or supervision. Considering occupational frameworks to assist with exploring parental occupational issues could further add to the challenge of limited time available.

Another future challenge for service providers is the implementation of the National Disability Insurance Scheme (NDIS). Most ECIS are moving towards a 'fee-for service', individualised support model in preparation for the implementation of the NDIS across Australia in 2018. The NDIS is a new way of providing community linking and individualised support for people with permanent and significant disability, their families and carers (NDIS, 2013). The NDIS website indicates that services available for families would include family support, counselling, capacity and skill building related to a family member's disability. Parent occupations, such as returning to work or engaging in leisure activities, are not apparent in supports identified and require advocacy and validation.

Another challenge is lack of research evidence supporting inclusion of parent occupations as an important outcome of service delivery. There is some research

conducted on burden of care and loss of occupations in carers of adults with acquired disability or mental illness; however, there is a paucity of research relating to the impact of having a child with disability on parent occupations.

Recommendations

Within the framework of family support, re-engaging in previous occupations is an important area of capacity/skill building for parents/carers because it provides them with personal meaning and time away from the caring role. To enable parent/carer engagement in previous occupations, ECIS team members will need to lead this advocacy and commitment. Measuring family outcomes such as parent wellbeing, and family quality of life along with child outcomes, is recommended as a key component in the rollout with NDIS. Future research focusing on the impact of loss of occupations on wellbeing of parents in ECIS is also recommended.

Key messages

In ECIS, many families are adjusting to their child's diagnoses and coming to terms with having a child with disability. Connecting with friends and with communities, though important, is challenging, due to the level of commitment required by their caregiving roles (Bourke-Taylor *et al.*, 2010; DeGrace, 2004). Reduced participation and productivity are detrimental to FQOL and for building healthier families and stronger communities (Saunders *et al.*, 2015; Zuna, Brown & Brown, 2014). Strong communities are built when community members feel happy, are healthy, are productive and have sustainable finances and a life balance (ABS, 2012; Zuna *et al.*). Occupational therapists have expertise in occupational consequences for the individual, as well as health consequences for societies. It is proposed that in ECIS, parent occupations be promoted and considered as an important part of the FCP and the TDA frameworks. Despite the challenges, it is still righteous for occupational therapists in their teams to lead and advocate for including occupations of parents into ECIS, for better family outcomes and stronger and sustainable communities.

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Appendix 2.1 - Demographic Questionnaire for Family Quality of Life Study

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Office Use Only

What is your relationship to the child?	<ul style="list-style-type: none"><input type="radio"/> Father<input type="radio"/> Mother<input type="radio"/> Grandfather<input type="radio"/> Grandmother<input type="radio"/> Foster carer<input type="radio"/> Other, please specify:
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What is the main language spoken at home?

Are any other languages spoken?	<ul style="list-style-type: none"><input type="radio"/> Yes<input type="radio"/> No
If the answer is yes, please write the languages:	

How old is your child?

- ☐ 0 – 2 years
- ☐ 2 years – 4 years
- ☐ 4 years – 6 years

What is the primary diagnosis or developmental concern?
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Who lives at home with your child?

- ☐ Father
- ☐ Mother
- ☐ Brother/s
- ☐ Sister/s
- ☐ Grandfather
- ☐ Grandmother
- ☐ Foster carer
- ☐ Other, please specify:
.....

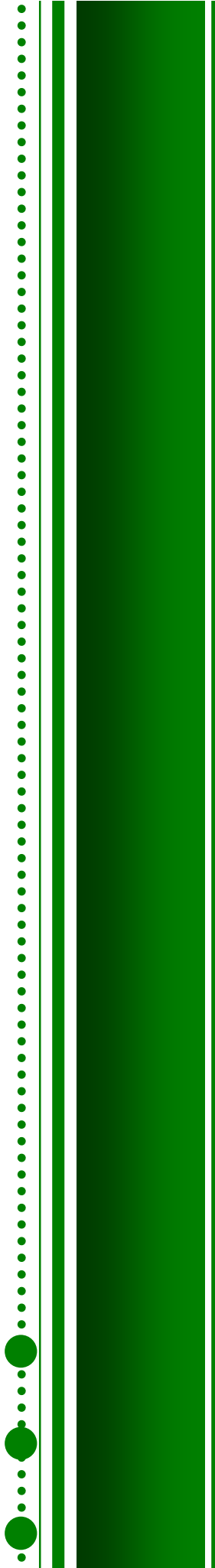
Are you of Australian Aboriginal or Torres Strait Islander origin?	<ul style="list-style-type: none"><input type="radio"/> Yes, Aboriginal<input type="radio"/> Yes, Torres Strait Islander<input type="radio"/> Yes, both Aboriginal and Torres Strait Islander<input type="radio"/> No, neither
--	---

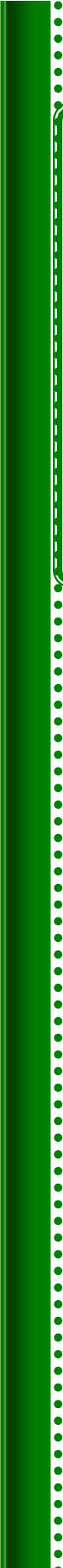
Are you the primary carer of the child	<input type="radio"/> Yes <input type="radio"/> No
Which of the following best describes your current work status?	<input type="radio"/> Not working due to my child's health <input type="radio"/> Not working due to my health <input type="radio"/> Looking for work outside the home <input type="radio"/> Working full time <input type="radio"/> Working part time <input type="radio"/> Full time homemaker <input type="radio"/> Student <input type="radio"/> Other, please specify:
Which of the following best describes your partner's current work status (if applicable)?	<input type="radio"/> Not working due to my child's health <input type="radio"/> Not working due to my/ partner's health <input type="radio"/> Looking for work outside the home <input type="radio"/> Working full time <input type="radio"/> Working part time <input type="radio"/> Full time homemaker <input type="radio"/> Student <input type="radio"/> Other, please specify:
What is the highest level of schooling you have completed?	<input type="radio"/> Some high school <input type="radio"/> Completed Year 12 <input type="radio"/> Vocational school (e.g., TAFE) <input type="radio"/> University <input type="radio"/> None of the above
What is the highest level of schooling your partner has completed (if applicable)?	<input type="radio"/> Some high school <input type="radio"/> Completed Year 12 <input type="radio"/> Vocational school (e.g., TAFE) <input type="radio"/> University
What is your annual family income	<input type="radio"/> Not working <input type="radio"/> \$30000 - \$50000 <input type="radio"/> \$50000-\$70000 <input type="radio"/> >\$71000
When did you join this ECIS service	<input type="radio"/> Less than 0 - 6 months <input type="radio"/> 7 months – 12 months <input type="radio"/> 13 months – 2 years <input type="radio"/> >2 years ago <input type="radio"/> >5 years ago
Would you be willing to participate in further interviews for this study (your identity will only be known to the researcher)	<div> <div>Yes</div> <div>Name/ Contact phone or email:</div> <div>_____</div> </div> <div> <div>No</div> </div>

What is your postcode?

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APPENDIX 2.2 - BC-FQOLS





FAMILY QUALITY OF LIFE SURVEY

*Developed by the Beach Center on Disability
The University of Kansas
in partnership with families, service providers and researchers.*



SURVEY INFORMATION AND INSTRUCTIONS

All the information you give us is confidential. Your name will not be attached to any of the information you give us. It is important that you answer as many questions as you can, but please feel free to skip those questions that make you feel uncomfortable. There are two parts to this survey. Please answer the questions in both sections.

Thank you so much for sharing your opinion with us!

FAMILY QUALITY OF LIFE

This survey is about how you feel about your life together as a family. We will use what we learn from families to help us provide better services and to advocate for children and families. .

Your “family” may include many people – mother, father, partners, children, aunts, uncles, grandparents, etc.

For this survey, please consider your family as those people

- ✓ Who think of themselves as part of your family (even though they may or may not be related by blood or marriage), and
- ✓ Who support and care for each other **on a regular basis.**

For this survey, please DO NOT think about relatives (extended family) who are only involved with your family every once in a while. Please think about your family life over the past 12 months.

The items below are things that hundreds of families have said are important for a good family quality of life. We want to know how **satisfied** you are with these things in your family. Please check the boxes on the following pages that reflect your level of satisfaction with each item.

- ✓ Ticking the **first** square means you are **very dissatisfied.**
- ✓ Ticking the **fifth** square means you are **very satisfied.**

Thank you so much for sharing your opinion with us!

PART 2 - FAMILY QUALITY OF LIFE

How satisfied am I that....

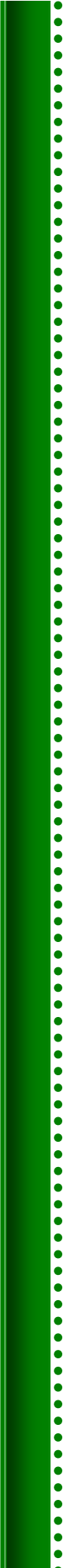
*Very
Dissatisfied* *Dissatisfied* *Neither* *Satisfied* *Very
Satisfied*

1. My family enjoys spending time together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. My family members help the children learn to be independent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My family has the support we need to relieve stress.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My family members have friends or others who provide support.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My family members help the children with schoolwork and activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My family members have transportation to get to the places they need to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My family members talk openly with each other.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My family members teach the children how to get along with others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. My family members have some time to pursue our own interests.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Our family solves problems together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My family members support each other to accomplish goals.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. My family members show that they love and care for each other.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. My family has outside help available to us to take care of special needs of all family members.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Adults in our family teach the children to make good decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

FAMILY QUALITY OF LIFE (cont.)

How <u>satisfied</u> am I that...	<i>Very Dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither</i>	<i>Satisfied</i>	<i>Very Satisfied</i>
15. My family gets medical care when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. My family has a way to take care of our expenses.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Adults in my family know other people in the children's lives (friends, teachers, etc.).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. My family is able to handle life's ups and downs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Adults in my family have time to take care of the individual needs of every child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. My family gets dental care when needed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. My family feels safe at home, work, school, and in our neighborhood.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. My family member with a disability has support to accomplish goals at childcare/ kinder.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. My family member with a disability has support to accomplish goals at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. My family member with a disability has support to make friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. My family has good relationships with the service providers who provide services and support to our family member with a disability.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you! You have finished completing this survey. If you would like to add comments please use the back of this page.



Comments

Appendix 2.3 Sample of Codebook for SPSS

Codebook

Table 1

Variable	SPSS variable name	Coding instructions
Relation to child	relationship	1=father 2=mother 3=grandfather 4=grandmother 5=foster carer 6=other
Language spoken	mainlanguage	1=English 2=other
Other languages	otherlang	1=Italian 2=Greek 3=Hindi 4=Vietnamese 5=Mandarin 6=Cantonese 7=Arabic 8=Turkish 9=Dari 10=Serbian 11=Tamil 12=Other Indian 13=Other 14=Multiple 15=None 16=Spanish 17=Phillipino
Age of child	ageofchild	1=0-2years 2=2-4years 3=4-6years
Primary Diagnosis	diagnosis	1 = "Developmental delay" 2 = "Cerebral Palsy" 3 = "Down Syndrome" 4 = "Autism ASD" 5 = "Congenital issues" 6 = "No clear diagnosis" 7 = "Behavioural concerns" 8 = "Speech and language delay" 10 = "other"
Father at home	livfather	1=yes 2=no
Mother at home	livmother	1=yes 2=no
brother at home	livbrother	1=yes 2=no
sister at home	livsister	1=yes 2=no
grandpa at home	livgrandpa	1=yes 2=no

grandma at home	livgrandma	1=yes 2=no
fostercareat home	livfoster	1=yes 2=no
Other at home	other	1=yes 2=no
Aboriginal/ TSI	Origin	1=Aboriginal 2=Torres strait 3=Both A and TSI 4=neither
primary carer	Primcarer	1=yes 2=no
Work status	Workstatus	1 = "Not working due to my child's health" 2 = "not working due to my health" 3 = "looking for work outside howm" 4 = "working full time" 5 = "working partime" 6 = "full time home maker" 7 = "student" 8 = "other"
partner work	partnerwork	1 = "Not working due to my child's health" 2 = "not working due to my health" 3 = "looking for work outside howm" 4 = "working full time" 5 = "working partime" 6 = "full time home maker" 7 = "student" 8 = "other" 9 = "single"
education	education	1 = "completed some high school" 2 = "completed year 12" 3 = "Vocational school (tafe)" 4 = "University" 5 = "None of the above" 6 = "not given"
education partner	educatpartner	1 = "completed some high school" 2 = "completed year 12" 3 = "Vocational school (tafe)" 4 = "University" 5 = "None of the above" 6 = "not given" 7 = "not applicable"
annual income	Income	1 = "not working"

		2 = "\$30000 - \$ 50000" 3 = "\$50000 - \$70000" 4 = ">71000" 5 = "not stated"
Joined ECIS	Durationecs	1 = "less than 0 - 6 months" 2 = "7 months-12 months" 3 = "13 months - 2 years" 4 = ">2 years ago" 5 = ">5 years ago"
enjoy time together	timetog	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
help children learn	childindepend	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
support for stress	supportstress	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
friends provide support	friendsother	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
help school work	schoolwork	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
transport available	transport	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
talk openly	talkopenly	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
teach getting along	teachgetalong	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither"

		4 = "satisfied" 5 = "very satisfied"
time for own interest	owninterests	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
Solve problems tog	problemsolv	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
support goals	accompgoals	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
show love/care	lovecare	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
outside help sp needs	outsidehelp	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
adults help decision	gooddecisions	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
Medical care available	medicalcare	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
Expenses taken care	expenses	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
adults know others	otherpeople	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"

handle ups/downs	upsdwns	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
individual child needs	indivchildneeds	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
dental care available	dentalcare	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
safe at home/school	safety	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
CWD has support at kinder	CWDsupoutside	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
CWD has support at home	CWDsuphome	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
CWD has support make friends	CWDsupfriends	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
Good relationship with SP	RelationSP	1 = "very dissatisfied" 2 = "dissatisfied" 3 = "neither" 4 = "satisfied" 5 = "very satisfied"
ECS site	ECSSite	1 = "Inner East" 2 = "Outer South" 3 = "West" 4 = "Inner South" 5 = "North" 6 = "Outer east"

Total FQOL	TFQOL	Total of 25 items on BCFQOLS
Family Interaction	TFamilyInteraction	Total of 6 items (1+7+10+11+12+18) TFamilyInteraction=timetog + talkopenly + problemsolv + accompgoals + lovecare + upsdowns.
Parenting	TParenting	Total of 6 items (2+5+8+14+17+19) TParenting=childindepend + schoolwork + teachgetalong + gooddecisions + otherpeople + indivchildneeds.
PhysicalmaterWB	TPhysMaterialWB	Total of 5 items (6+16+21+15+20) TPhysMaterialWB=transport + expenses + safety + medicalcare + dentalcare.
Emotional Wellbeing	TEmotionalWB	Total of 4 items (3+4+9+13) TEmotionalWB=supportstress + friendsother + owninterests + outsidehelp.
Disability-related support	TDisabSupport	Total of 4 items (22+23+24+25) TDisabSupport=CWDsupoutside + CWDsuphome + CWDsupfriends + RelationSP.

Appendix 2.4 - Simple Language FQOL definition

Research Project – Family quality of Life when there is a Child with Disability

About FQOL Interview – Definition and guide

Thank you for consenting to participate in an interview for the above research project. Through this interview we would like to gain an understanding of your individual experience of what family quality of life means for you and what factors have had an impact on your FQOL.

Family quality of life (FQOL) is a term we use to define your quality of life within your family. FQOL can be explained as a joint sense of well-being of your family collectively. It is the experience of what you think, and depends on all the members within your family. All members of the family have an impact on FQOL and it depends on the needs of every member and what happens in each one's life.

For example if one of your children is sick then someone has to take time off their usual duties and care for that child, take them to the doctor and maybe even buy some expensive medications. This can disrupt what you do usually in your everyday routine and you may end up feeling stressed, tired or annoyed at the end of such a day and this will affect how you feel about your quality of life on that day. However when your child is better the next day you go back to what you were doing and it doesn't affect your overall FQOL.

However some events in life affect family quality of life drastically more than others and you may find that you have had to make many changes to your life for a longer period following such events. Some things help to make family quality of life better for example having a friend who is supportive or people who help you to keep going.

For this interview, we would like you to think about things that have changed or caused changes to your family quality of life and factors that have impacted your quality of life for better or worse.

If you get a chance to think about this before the interview it would assist the interview. However if you don't get a chance to, I would still like to continue with the interview, as your input is valuable to the research.

Many thanks,


Ms Anoo Bhopti

Student Researcher, PhD Candidate

Department of Occupational therapy

Faculty of Medicine, Nursing and Allied Health

Monash University, Frankston



Appendix 2.5 - Interview guide

Research Project – Family quality of Life when there is a Child with Disability

Interview guide

(Upon receiving consent and before the interview, the family will be given the above simple language definition of family quality of life.)

1. How would you describe your family quality of life as of present? Could you tell me a bit more about this ?

2. What are some of the things that you think have impacted on your current family quality of life? Can you explain why?

(This is a prompt for the interviewer to find out about positive and negative factors)

3. Do you think that your family quality of life was different before having your Child (name of child with disability)? Can you give me some examples?

4. Can you tell me what has helped to improve your family quality of life? Why/how have they helped?

5. Has receiving ECIS had any influence on you or your family? Could you tell me a bit more about that?

6. Would you like to add anything to this discussion about how you experience your family quality of life? Or about your own quality of life?

Appendix 2.6: Chapter 2 Tables demonstrating the processes of data coding for the qualitative study aspect

Table A2.1 *Codes in Numerical Order with Quotes*

Codes	Description	Quotes
Code 1	My FQOL is okay... different, reasonable, however is hard and difficult at times. It is constant adaptation, ups and downs	<i>...I mean it definitely has its moments ... You know what I mean? Like we do have a couple moments where its higher stress times or demanding kinda times but overall I still think, family life's pretty good</i> (Grace)
Code 2	Financial support for accessing services helps reduce the financial burden and helps FQOL	<i>...But I've got the "Better Start" [funding] for 8 months. So we didn't feel the pressure [for extra speech therapy]</i> (Kerry)
Code 3	Physical well-being of parent/caregiver is not a priority, due to the child's needs and financial responsibility	<i>...I kind of should have a mastectomy, but I am going to delay that a little bit longer, cos I will be out of action for a little while... If it's health issues for myself, then I'm in trouble, or even Tim [husband], cos then we would have a wage reduction</i> (Cassie)
Code 4	Early years are similar to having a typically developing child	<i>... Well I think, I suppose diagnosis or no diagnosis; life prior to a child and after a child is very different... most part of it was caring for her like, for want of a better word, a normal child. So in that period, there's not too much to my day that was different to the next mum</i> (Grace)
Code 5	Ownership and adoption of parenting role comes about after having a child	<i>... But we've already done all the partying, we are quite happy to stay at home and do the 'kid' thing</i> (Cassie)
Code 6	Adaptations are made/previous parent occupations change	<i>We agreed that one of us would need to stay home, we would</i>

		<i>want to stay home, to raise him. Because we didn't see the point of putting him in childcare 5 days a week... that was something that I was happy to do (Irene)</i>
Code 7	Waiting for the diagnosis leads to stress, but knowing the diagnosis is also stressful, sad and devastating	<i>... but you know hearing the diagnosis was obviously a bit stressful and sad... just cause neither of us [parents] wanted to really say the effects that it had had on us (Grace)</i>
Code 8	Progress and development of child is energising and uplifts parents and helps FQOL	<i>But he's getting there and I'm beginning to find silver linings for things like that (Irene)</i>
Code 9	Support from partner, family, and friends varies but is valued, however reluctant to ask for support	<i>...even though there's a lot of people that are ...are willing to lend support; not just immediate family... As much as I need it, I was always one to say no (Grace)</i>
Code 10	Support from services is important and valued	<i>[keyworker] she does really good practical things like that and she sorts out funding and things like that (Irene)</i>
Code 11	Support after exiting ECIS is scarce	<i>...but next year as in November when it [ECIS] all finishes, ... every change is going to be hard and she will need support and it's going to be ongoing (Dee)</i>
Code 12	Positive attitudes, beliefs, religion, faith, and family values help families	<i>...I'm a very positive person so ... I mean he's just got a physical disability rather than intellectual, they said to us that if he survives he will be severely handicapped ...but hey look what we have got... a spunk! (Cassie)</i>
Code 13	Having multiple children and family members with a diagnosis/illness impacts FQOL	<i>You've got three with additional needs, um it is really really hard, like you know B swells himself up when he gets all upset, emotional and all the rest of it (Jenny)</i>

Code 14	Severity of disability especially challenging behaviours impact FQOL	<i>M self-harmed and like did everything. I mean like she was two and half, ram her dummy down her throat, put her hand down there and strangle herself, she didn't want to be here... do you know what I mean (Dee)</i>
Code 15	Siblings/family relationships are impacted	<i>We always know that if C [brother with autism] wants to watch this movie ... She's had to adjust cause it's not worth the tantrum from C. She will get upset, she'll cry, she will run to her room, but then 10 minutes later she will come out again and forget (Alice)</i>
Code 16	Triggers/events in life can impact FQOL	<i>...But I suppose after the separation, just the costs of running 2 households and of course I've gone down financially... The financial concern is that I may go back to having a mortgage, which we don't have at the moment (Liam)</i>

Table A2.2 *Themes in Relation to Codes – Study 1*

Codes	Themes	Theme Description	Quotes
Code 1: My family quality of life is okay... different, reasonable, however is hard and difficult at times. It is constant adaptation, ups and downs	Theme 1	My family quality of life is okay, but ... different, difficult at times, with constant ups and downs	<i>Okay. I think our quality of life is reasonable. You know, not 100% but not terrible ... I suppose that some days are more stressful than others. But overall [FQOL] hmmm (Kerry)</i>
Code 2: Financial support for accessing services helps reduce the financial burden and helps FQOL (s) Code 4: Early years are similar to having a typically developing child (h) Code 8: Progress and development of child is energising and uplifts parents and helps FQOL(h) Code 9: Support from partner, family, and friends varies but is valued, however reluctant to ask for support (s) Code 10: Support from services is important and valued (s) Code 12: Positive attitudes, beliefs, religion, faith, and family values help families (h)	Theme 2	Family quality of life is better when we feel hopeful (h) and supported (s)	<i>...Having Berta [keyworker] provides not just practical support, but she provides different ways to think about problem solving ... she does really good practical things like that and she sorts out funding and things like that (Irene)</i>
Code 7: Waiting for the diagnosis leads to stress, but knowing the diagnosis is also stressful, sad, and devastating Code 11: Support after exiting early childhood	Theme 3	Family quality of life is challenged during difficult times	<i>When we found out about her condition I suppose there was no [reaction] ... numb... because it was so early, it was only 2 weeks ... they</i>

intervention services is scarce

Code 14: Severity of disability, especially challenging behaviours impact FQOL

Code 16: Triggers and life events can impact FQOL

Code 3: Physical well-being of parent/caregiver is not a priority, due to the child's needs and financial responsibility

Code 5: Ownership and adoption of parenting role comes about after having a child

Code 6: Adaptations are made/previous parent occupations change

Code 13: Having multiple children and family members with a diagnosis/illness impacts FQOL

Code 15: Siblings/family relationships are impacted

Theme 4

Having a CWD has consequences for the family and for family quality of life

knew it was CP. They knew it was probably gonna be just kind of lower limbs. And I suppose that those days were probably much harder not knowing ... (Grace)

... I would probably be at work ... and ... I feel like Jim [son with disability] is my work and I kind of resent that a bit... pre-Jim, I had a great job and I loved work and I haven't worked since he was born um ... we've got to do some things first (Ellie)

FQOL = Family quality of life; (s) = supported; (h) = hopeful

Table A2.3 *Triangulated Quantitative and Qualitative Data – Parent Perspectives on FQOL*

Parent Perspectives on their FQOL	
Quantitative Results	Qualitative Findings
<ul style="list-style-type: none"> – Majority of respondents were satisfied with their total FQOL – High scores on satisfaction with parenting, emotional well-being, disability-related support 	<p>Theme 1: My family quality of life is okay, but...different, difficult at times, with constant ups and downs</p> <p>Theme 2: Family quality of life is better when we feel hopeful and supported (emotional well-being, disability-related support) Code 4 (normalisation), Code 8 (stability and hope) and Code 12 (inherent positive qualities) help parents feel hopeful and supported</p> <p>Theme 3: Family quality of life is challenged during difficult times (parents feel down and sad sometimes such as at time of diagnosis – Code 7)</p> <p>Theme 4: Having a CWD has consequences for the family and for FQOL (Parents adapt and change –Parenting is owned and accepted – Codes 5 and 6)</p>

Table A2.4 *Relationships Between Quantitative and Qualitative Data – Relationships Between ECIS, Parent Occupations, and Their FQOL*

Quantitative Results	Qualitative Findings
<p>Parent Occupations (Positive association between disability-related support)</p> <p>Item 19 – Taking care of needs of every child Item 16 – Taking care of expenses Item 9 – Time to pursue own interests Item 1 – Spending time together as a family</p> <p>Consequence of having a CWD – Loss of occupations</p> <ul style="list-style-type: none"> - Only 4% working in paid jobs - 54% not working in paid jobs - 60% satisfied with time to pursue interests and 40% not satisfied 	<p>Theme 2 Mothers wanted to be the main caregiver and felt reluctant to ask for support (Code 9)</p> <p>Theme 4 Mothers often neglected their own well-being and necessary occupations due to caregiving (code 3)</p> <p>Theme 4 Parenting was seen as an important transition, so parents were ready to adopt this role (code 5).</p> <p>Theme 4 Loss of work led to consequences (financially) but commitment to parent role helped FQOL (Codes 5 and 6)</p>

ECIS

Negative association between duration of ECIS and relationship with service provider (frequency of services received is related to relationship with ECIS)

Positive association between disability-related support (ECIS) and items 1, 9, 16, and 19 (see above)

Theme 2

Parents valued visits from the keyworker to the childcare/kinder, respectful and honest keyworkers, and the support and guidance from ECIS for their CWD and their family (Code 10)

Theme 2

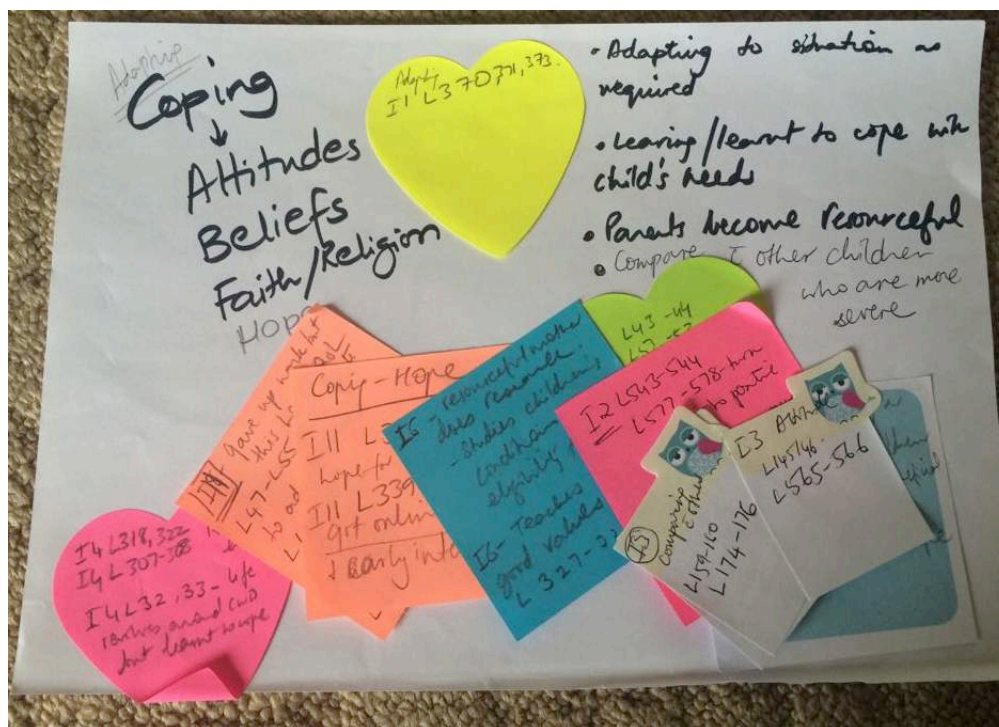
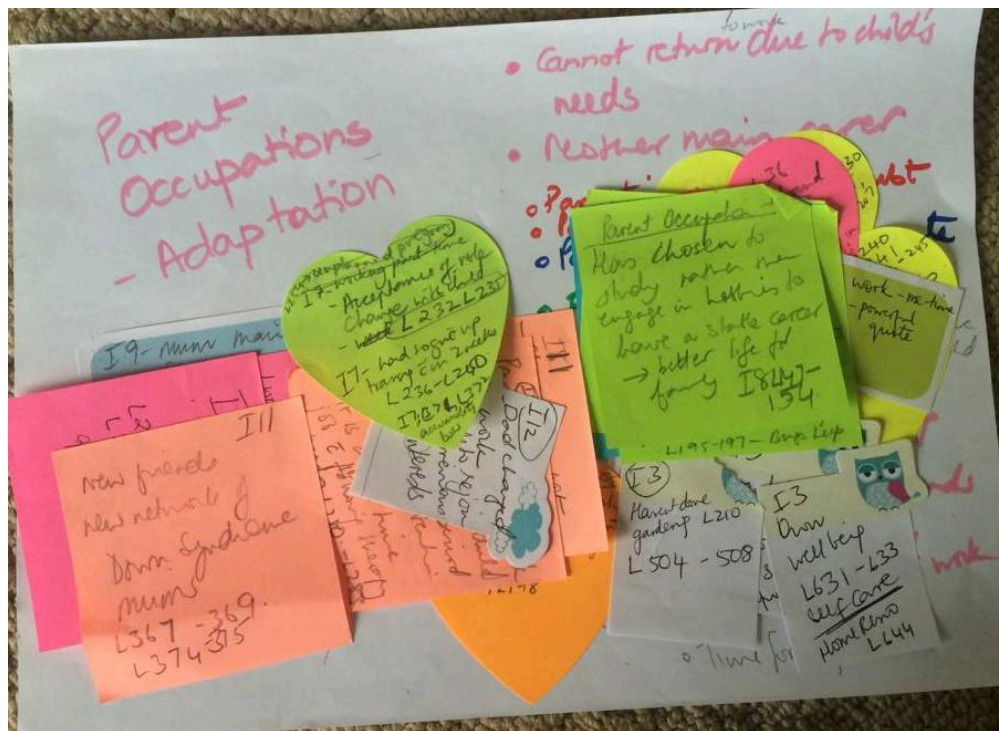
When their CWD made progress developmentally, parents felt happy and supported (Code 8)

Theme 3

Support after exiting ECIS is scarce (Code11)

CWD = Child with disability

Appendix 2.7 Sticky Notes – Study 1



My FOOL
is
OK ; Reasonable

FOOL is rushed (18)
exhausted 18/18, 22, 24
lived

17L15-
17L578522

- We are happy
- Demanding times but overall OK
- If they think that the future will be better, child will improve → FOOL is OK & only temporarily difficult

I#1 FOOL - reasonable

I#1 L13-L15 not

I#1 L13-L15 not

I#1 L13-L15 not

I#1 L13-L15 not

I#1 L13-L15 not

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Family Quality of Life: A Key Outcome in Early Childhood Intervention Services—A Scoping Review

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Abstract

A scoping review was conducted to identify factors influencing the quality of life of families of children with disability. The review also explored the scales used to measure family quality of life (FQOL) as an outcome in early childhood intervention services (ECIS). Multiple databases were searched from 2000 to 2013 to include studies pertinent to ECIS. Results were charted and summarized based on scoping methodology. Eighteen articles were chosen for the review based on the selection criteria. Results were summarized as five factors that affect FQOL, namely, (a) disability-related support, (b) family interactions/family relationships, (c) overall well-being, (d) support from services, and (e) severity and type of disability. The review also identified two FQOL scales that were used most frequently within ECIS: (a) the *Beach Center Family Quality of Life Survey*, and (b) *Family Quality of Life Survey: Main Caregivers of People With Intellectual or Developmental Disabilities*. It is recommended that those responsible for evaluation decisions within ECIS programs should consider using a FQOL scale to measure family outcomes. Furthermore, professionals working with families within ECIS should consider the factors affecting FQOL to further enhance their service provision.

Keywords

family quality of life, family, early childhood intervention, child with disability, scoping review, ECIS, FQOL

Introduction

The quality of life of family members of individuals with disability has a tendency to be neglected in practice and in research. It is important to work closely with family members when there is a child with disability (Dunst, Trivette, & Hamby, 2007). Caring for a child with disability, in addition to the usual child care practices, can add to the challenge of raising a young child (Bourke-Taylor, Howie, & Law, 2010). This additional caregiving can affect the quality of life of all family members. Improving the quality of life of families can have a positive effect on child and family outcomes (Bailey et al., 2006; Turnbull & Turnbull, 2002). Measuring positive family

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outcomes that consider all members of the family is an important aspect of service delivery in early childhood intervention services (ECIS). Family quality of life (FQOL) is one such family outcome (Poston et al., 2003; Rillotta, Kirby, Shearer, & Nettelbeck, 2012).

Understanding and measuring FQOL enables ECIS providers to enhance the quality of life and well-being of all family members (Zuna, Brown, & Brown, 2014). A meta-analysis of 47 ECIS studies concluded that the effectiveness of services for families is determined by all family members demonstrating improved outcomes in their quality of life (Dunst et al., 2007). The present review focused on FQOL as an outcome measure and will discuss factors that have an impact.

Background and Purpose

FQOL is defined as “a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact” (Zuna, Summers, Turnbull, Hu, & Xu, 2010, p. 262). FQOL is collective because it is concerned with how the family members feel about their family’s quality of life, as a group. It is dynamic because it can change in response to significant events such as moving homes, loss of a family member, or having a child with disability. The theories foundational to FQOL have been addressed in previously published literature (Kober, 2010; Zuna et al., 2014). According to the unified theory of FQOL, families adapt to events as they arise and continue to adjust until they reach a state of homeostasis or balance (Zuna et al., 2010). This adaptation process can be assisted by family members, friends, and support services.

Most children’s support services, including ECIS, follow a family-centered practice (FCP) approach and are required to demonstrate positive family outcomes annually. According to the Early Childhood Technical Assistance Center (2014), American states are required to report that ECIS programs have helped the family to know their rights, effectively communicate their children’s needs, and help their children develop and learn. The Division for Early Childhood (2014) recommends that ECIS programs be individualized, flexible, and responsive to each family member’s unique circumstances. The Office of Special Education Programs (2015) at the U.S. Department of Education requires individual states to report outcome data for children and families served through Part C and Part B Preschool of the Individuals With Disabilities Education Act (IDEA) as part of their annual performance report. In Australia, an ECIS reform document states that two outcomes for families are critical: (a) That families and caregivers access quality services that support community participation choices, and (b) that families and caregivers are well supported and confident in their ability to support their children’s learning and development, as well as their capacity to live independently (Kennedy, McLoughlin, Moore, Gavidia-Payne, & Forster, 2010).

The FCP approach is central to the general philosophy and framework of ECIS and is the recommended approach for service delivery (Kennedy et al., 2010; McWilliam, 2010, 2012; Powell & Dunlap, 2010). A recently published report by Early Childhood Intervention Australia (2016) endorses the FCP approach as a best practice approach within their guidelines for best practice in ECIS. This approach considers the skills, resources, and needs of all family members in managing the ongoing care of their child with disability. FCP emphasizes family well-being and family–professional partnerships. Family–professional partnerships are defined as “mutually supportive interactions between families and professionals, focused on meeting the needs of children and families and characterized by a sense of competence, commitment, equality, positive communication, respect, and trust” (Summers, Poston, Turnbull, & Marquis, 2005, p. 3). Effective evaluation of family-centered services should include, in addition to child outcome assessments, an evaluation of both family–professional partnerships and family well-being, or FQOL (Summers et al., 2007). Unfortunately, FQOL is not being utilized consistently as a measure of positive family outcomes when using a FCP approach within ECIS.

The present review aims to present literature findings, supporting the need to use FQOL as a family outcome measure within ECIS. The purpose of this review is twofold: to recommend appropriate scales and methods to measure FQOL within ECIS, and to summarize the factors from the literature that affect the quality of life of families. Within this review, ECIS refers to a set of service providers and not a single professional. This review also presents implications for ECIS providers, future research, and policy.

Method

A scoping study methodology was chosen for this review. It is a relatively new type of literature review that aims to map the key concepts, main sources, and types of evidence within a research area without critiquing the studies (Arksey & O'Malley, 2005). Scoping studies assist with examining the extent, range, and nature of research, with a view that the summary of findings would be disseminated to policy makers and practitioners, and provide an indication for future research. Whereas a systematic review typically focuses on a well-defined question, where suitable study designs are identified in advance, a scoping review addresses broader topics, with many different study designs. In a scoping study, however, several characteristics of the systematic review are adopted: being systematic, rigorous, transparent, and replicable (Grant & Booth, 2009). A results table is created, categorizing all the selected studies, and data are summarized and charted across this table. The five steps in scoping methodology by Arksey and O'Malley (2005) were followed, namely, (a) identifying the research question, (b) identifying relevant studies, (c) selecting studies, (d) charting the data, and (e) collating, summarizing, and reporting the results.

Step 1 of Scoping Review: Identifying the Research Question(s)

Two research questions guided the review process:

Research Question 1 (RQ1): What FQOL scales have been used to measure family outcomes in ECIS?

Research Question 2 (RQ2): What factors affect the FQOL of parents/caregivers of young children with disability/developmental delay?

Step 2 of Scoping Review: Identifying Relevant Studies

Keyword searches were conducted using the following electronic databases: ProQuest, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase (Ovid), PsycInfo, Education Resources Information Center (ERIC), and A+ education, representing the categories of health, social sciences, and education. The keywords used were *family*, *disability*, *FQOL*, *quality of family life and disability* (included *disabled*, *disabling*, or *disabilities*), *children with disability*, *developmental disability*, *family well-being and disability*, *family-centered practice*, *service provision*, and *early childhood intervention services*. This search was limited to the keywords in the title and abstract, English language, and period between years 2000 and 2013, and included peer-reviewed journal articles, literature reviews, book chapters, and conference papers. Article searches were also done using Google Scholar, citation tracking of key articles, key organizational website searches, key textbooks (Kober, 2010; Phillips, 2006; Seed & Lloyd, 1997), correspondence with key authors, and linking in with existing networks and organizations. It is beyond the scope of this review to address parental stress and depression specifically, although it is important to acknowledge the critical role these factors often play in FQOL. Interested readers are guided to a summary of these factors in a publication by Zuna et al. (2014).

Step 3 of Scoping Review: Selecting Studies

A total of 249 results that included four conference papers and 13 book chapters were located using the search terms. Limits were placed for the subsequent tiers of selection, and only articles that used distinct FQOL scales, or articles that studied factors affecting FQOL of family members, were included. This selection consisted of 32 articles and one key conference presentation (I. Brown, 2012). Articles that studied the scale development of FQOL scales, or measured psychometric properties of the FQOL scales, were then excluded. Articles that included parents of adults with disability were also excluded. Six articles that included a large range of age groups from 0 to adult were included, as the mean age of the children was either unclear or was less than 8 years. This narrowed the final selection to 18 articles. All the selected articles were research-based studies from peer-reviewed journals. The next two steps of the scoping review are as follows: Step 4—charting the data, and Step 5—collating and summarizing the results, and are presented next.

Results

Overall, 18 articles published between 2005 and 2013 met the criteria and are presented in Tables 1 and 2 in chronological order. Ten articles included studies done within ECIS, using FQOL outcome measures, to answer RQ1, and 15 articles were pertinent to RQ2.

Step 4 of Scoping Review: Charting the Studies

Charting is a technique within a scoping review, for synthesizing, interpreting, and sorting data based on key topics and themes, and applying a common analytical framework to all studies (McKinstry, Brown, & Gustafsson, 2014). Headings were created for charting the data from the 18 studies. The headings included information on the authors, publication date, country in which the study was conducted, participant details, research aim and design, the outcome measures used, and the results/findings. Two tables were created to display the data collected from the studies (Tables 1 and 2). Table 1 reports information about the authors, country, participants, design, and scales used, whereas Table 2 presents study aims and the results from each study.

Author details/date/country. Details about the authors and the year of publication are available in Table 1. The studies in this selection were conducted across a number of countries. Of the 18 studies selected, five were from the United States, followed by two from Canada (one with the United States), two from Australia, two from Belgium, and one each from Columbia, Ireland, Israel, Nigeria, Slovenia, China, and Malaysia. This information assists with an understanding of the breadth of studies done using FQOL as an outcome measure, specifically in young children with disability. It is pertinent to RQ1.

Participants. All participants were parents/caregivers of young children with disability with a mean age of the child between 0 and 8 years. Only a few studies mentioned the diagnosis, namely, developmental delay (one), autism (two), deafness (one), and intellectual disability (one). One study included siblings of a child with disability and was pertinent to RQ1 regarding the factors affecting FQOL. Six studies used a sample size of less than 60 participants, six studies had between 61 and 200 participants, four studies had between 201 and 400 participants, and two studies included more than 401 participants. The majority of the participants reported were mothers.

Design. Of the 18 studies, nine were quantitative that used a survey design, seven were mixed methods that involved surveys and interviews, and two were qualitative, including interviews

Table 1. Scoping Review Results: Author Details, Demographics, Design, and Outcomes Used.

Author/date/country (chronological order)	Participants	Design	Outcome measures used (scales)
Wang, Turnbull, Summers, Little, Poston, and Mannan (2004) The United States	<i>n</i> = 364 130 fathers and 234 mothers of families in early childhood programs.	Quantitative (Survey)	BC-FQOLS
Verdugo, Córdoba, and Gómez (2005) Columbia	<i>n</i> = 385 families Children aged between 0 and 18 years (average age 8 years)	Quantitative (Survey)	BC-FQOLS
R. Brown, MacAdam- Crisp, Wang, and Iarocci (2006) The United States and Canada	<i>n</i> = 69 <i>n</i> = 33 children with Down syndrome (<i>M</i> = 7.5 years of age) <i>n</i> = 18 with autism (<i>M</i> = 7.78 years of age) <i>n</i> = 18 no disability (<i>M</i> = 6.81 years of age)	Mixed methods Qualitative and quantitative (interviews)	FQOL-S
Wang, Summers, Little, Turnbull, Poston, and Mannan (2006) The United States	<i>n</i> = 214 107 fathers and 107 mothers Children aged birth to 5 years of age	Quantitative (Survey)	BC-FQOLS
Summers, Marquis, Mannan, Turnbull, Fleming, and Poston (2007) The United States	<i>n</i> = 180 All children aged birth to age 5 years	Quantitative (Survey)	BC-FQOLS Services Inventory; Family/Professional Partnership Scale
Davis and Gavidia-Payne (2009) Australia	<i>n</i> = 64 Parents of children aged 3 to 5 years with disability or developmental delay 95.3% = mothers	Quantitative	BC-FQOLS MPOC-56 Child Behavior/Needs subscale of the Parenting Hassles Scale
Zuna, Selig, Summers, and Turnbull (2009) The United States	<i>n</i> = 566 Parents of children without disabilities attending kindergarten	Quantitative (Survey)	BC-FQOLS
Caples and Sweeney (2010) Ireland	<i>n</i> = 49 Parents of children and adults with disability living at home and availing respite care	Quantitative (Survey)	FQOL-S
Jackson, Wegner, and Turnbull (2010) The United States	<i>n</i> = 207 Children who were deaf, <6 years of age with no other significant disability	Quantitative (survey) and one qualitative question	BC-FQOLS and one qualitative question
Čagran, Schmidt, and Brown (2011) Slovenia	<i>n</i> = 20 Children with intellectual disability, Grades 2 to 8	Mixed methods	FQOL-S Survey translated into Slovenian

(continued)

Table 1. (continued)

Author/date/country (chronological order)	Participants	Design	Outcome measures used (scales)
Epley, Summers, and Turnbull (2011) The United States	<i>n</i> = 77 Families of children <3 years of age with disabilities. Mothers = 96%	Quantitative (Multiple surveys)	Family Outcomes Survey BC-FQOLS Early Childhood Services Survey
Neikrug, Roth, and Judes (2011) Israel	<i>n</i> = 103 Age of children = 1 to 31 years 81% = mothers; 4% = fathers; 15% = missing data	Quantitative (Survey) Two general questions placed at the end of the FQOL-S	FQOL-S Hebrew version
Steel, Poppe, Vandeveld, Van Hove, and Claes (2011) Belgium	<i>n</i> = 25 Mothers = 24; fathers = 1 Child with disability aged between 4 and 21 years	Mixed methods; Quantitative (Survey) and qualitative (Semi-structured interviews)	FQOL-S Semi-structured interviews
Ajuwon and Brown (2012) Nigeria	<i>n</i> = 80 97.5% were biological mothers, and the rest were stepmothers of children with intellectual disability	Quantitative (Survey)	FQOL-S
Clark, Brown, and Karrapaya (2012) Malaysia	<i>n</i> = 52 Mothers = 43; father = 1 Child with disability between 2 and 18 years of age	Quantitative (Survey)	FQOL-S (short version translated in Bahasa-Malaysian)
Hu, Wang, and Fei (2012) China	<i>n</i> = 442 Mothers = 284; fathers = 139 Grandparents = 15; Other = 4 Children with disability 0 to 18 years of age	Quantitative (survey and factor analysis for Chinese version)	BC-FQOLS
Moyson and Roeyers (2012) Belgium	<i>n</i> = 50 Siblings of children with intellectual disability 6 to 14 years	Qualitative in-depth interviews	In-depth phenomenological interviews Focus groups conducted as well
Rillotta, Kirby, Shearer, and Nettelbeck (2012) Australia	<i>n</i> = 42 Caregivers of people with intellectual disability or autism spectrum disorder (2 to 46 years of age)	Quantitative (survey) and qualitative (interviews)	FQOL-S (adaptation of words to suit Australian language) Interview questions

Note. BC-FQOLS = Beach Center Family Quality of Life Survey; FQOL-S = Family Quality of Life Survey; MPOC-56 = Measure of Processes of Care.

Table 2. Scoping Review Results: Summary of Results Based on RQ1 and RQ2.

Author/date/country (chronological order)	Aim	Results (Q1 = Results about the use of FQOL as a measure Q2 = Results regarding factors of FQOL)
Wang, Turnbull, Summers, Little, Poston, and Mannan (2004) The United States	To explore the associations between family income and severity of disability, and fathers' and mothers' satisfaction with their FQOL	(Q2) Severity of disability is a significant predictor of mothers' and fathers' satisfaction with their FQOL. Family income is not as significant for fathers' satisfaction ratings of FQOL but is for mothers.
Verdugo, Córdoba, and Gómez (2005) Columbia	To examine the reliability and validity of the BC-FQOLS on a Spanish sample	(Q1) The BC-FQOLS is a valid instrument for Spanish-speaking community. FQOL can be used as an outcome for families of children between 0 and 18 years of age to measure satisfaction and importance of services.
R. Brown, MacAdam- Crisp, Wang, and Iarocci (2006) The United States and Canada	To examine comparative FQOL in three types of families: those with a child who has Down syndrome, those with a child with autism, and those of similar household composition but without a child with a disability.	(Q2) The families without a child with a disability showed statistically significantly higher levels of satisfaction across all domains. Significant differences reported in terms of quality of life satisfaction between the Down group (higher) and autism groups on careers and preparations for careers and leisure and enjoyment of life.
Wang, Summers, Little, Turnbull, Poston, and Mannan (2006) The United States	To test whether mothers and fathers similarly view the model of FQOL embodied in one measure.	(Q1 and Q2) There were no significant differences between fathers' and mothers' assessments regarding their overall FQOL. Both mothers and fathers reported that FQOL was very important to them, thus pointing toward using FQOL as a key outcome for both fathers and mothers in the early years.
Summers, Marquis, Mannan, Turnbull, Fleming, and Poston (2007) The United States	To determine whether parents' ratings of the adequacy of service they received are related to their quality of life, and whether the quality of their partnerships with professionals mediate the effect of services on their FQOL.	(Q2) Service adequacy is a significant predictor of FQOL. The adequacy of service provision was a significant predictor of partnership between service providers and families. Partnership with service providers was a partial mediator of the effects of service adequacy on FQOL.
Davis and Gavidia-Payne (2009) Australia	To examine the contribution of child, family, and support characteristics to the quality of life in families of young children with disabilities.	(Q2) Family-centered professional support was one of the strongest predictors of FQOL. 8 of the 10 comparisons were statistically significant. Disability-related support and family interaction were considered important. Parenting and emotional well-being were found to be less important contributors to FQOL.

(continued)

Table 2. (continued)

Author/date/country (chronological order)	Aim	Results	
		(Q1 = Results about the use of FQOL as a measure Q2 = Results regarding factors of FQOL)	
Zuna, Selig, Summers, and Turnbull (2009) The United States	To test the measurement properties of the BC-FQOLS for families of kindergarten children without disabilities.	(Q1) Results from this study indicate that the overall scale produces an excellent fit for families of children without disabilities, and each of the four subscales falls within an acceptable fit range of .77 to .85. FQOL as an outcome can be used successfully to compare satisfaction with FQOL of families with children with and without disabilities, in the early years.	
Caples and Sweeney (2010) Ireland	To investigate the quality of life of parents of children and adults with an intellectual disability who are availing respite care.	(Q2) Overall family health, financial status, family values, and family relationships had a strong correlation with FQOL. Level of career and educational opportunities was not correlated significantly with the level of satisfaction. Level of opportunity for leisure and enjoyment of life correlated strongly with level of satisfaction with FQOL	
Jackson, Wegner, and Turnbull (2010) The United States	To examine family members' perceptions of their quality of life following early identification of deafness in children 0 to 6 years of age.	(Q2) Method of communication had a significant effect on parents' satisfaction with their child's communication outcomes. The type of sensory device used did not have a significant effect on families' perceptions of the impact of deafness on their physical well-being, emotional well-being, family interaction, or parenting.	
Čagran, Schmidt, and Brown (2011) Slovenia	To test the efficacy of the translated FQOL-S with Slovenian families, and provide initial data for the study of FQOL in Slovenia.	(Q1 and Q2) FQOL as an outcome measure for Slovenian families was reported to be useful in gaining an understanding of parent perspectives about services and supports. Eight out of 9 domains showed statistically significant differences across health; finances; family relationships; support from others; support from services; and influence of values, careers, and community interaction. Family relationships contributed the most to FQOL.	
Epley, Summers, and Turnbull (2011) The United States	To examine the relationships between parent ratings of early intervention services and family outcomes for families of young children with disabilities.	(Q1) FQOL can be used as an appropriate outcome of early intervention services for families of young children with disabilities. Statistically significant 3-month test-retest reliability correlations across all subscales for the BC-FQOLS were reported making it an appropriate outcome measure for use in ECIS.	

(continued)

Table 2. (continued)

Author/date/country (chronological order)	Aim	Results (Q1 = Results about the use of FQOL as a measure Q2 = Results regarding factors of FQOL)
Neikrug, Roth, and Judes (2011) Israel	To describe and analyze the quality of life of Israeli families raising a child with a disability while challenged with all the usual demands of family life.	(Q1 and Q2) FQOL-S was reported as a viable survey instrument that addresses and measures important issues in family life for Israeli families. Overall, a high level of satisfaction with FQOL was reported in all participants. Respondents reportedly manage more responsibility than they would like in carrying out the day-to-day affairs of the family, and this is an important factor affecting FQOL.
Steel, Poppe, Vandevelde, Van Hove, and Claes (2011) Belgium	To find out parent perspectives of the measures contained in the nine domains of the FQOL-S and to understand two important domains of the FQOL-S: support from others and support from services.	(Q1 and Q2) FQOL as an outcome measure for Belgian families was reported to be useful in gaining an understanding of parent perspectives about services and supports. Relatively high mean attainment and satisfaction scores were found for the domains health, family relationships, and support from services. Support from others, and leisure and community interaction were factors detracting from a good FQOL with almost all parents reporting a lack of practical help and support during weekends, vacations, or other busy times.
Ajuwon and Brown (2012) Nigeria	To describe the FQOL of Nigerian families that have a child with intellectual disability and to provide initial ideas about the relationship between the families' life experiences and government policy and provision of services.	(Q2) All nine domains of the FQOL-S were rated <i>important</i> . Family relationships, influence of values, and health were sources of quality for families, but support from services, support from others, and leisure detracted from FQOL. From the data there was a strong need for the development of government policy and services, and for education and training.
Clark, Brown, and Karrapaya (2012) Malaysia	To establish an initial appreciation of the quality of life of families that include children with disabilities within the context of National Welfare policy in Malaysia.	(Q2) Health, financial well-being, family, values, and careers were considered important and opportunities for service supports, community careers, health, and leisure were limited. Participation in leisure and recreation and community interaction were important.

(continued)

Table 2. (continued)

Author/date/country (chronological order)	Aim	Results (Q1 = Results about the use of FQOL as a measure Q2 = Results regarding factors of FQOL)
Hu, Wang, and Fei (2012) China	To explore the perception of Chinese families who have a child with an intellectual disability regarding FQOL as well as examining the factor structure of FQOL concept for Chinese families.	(Q1 and Q2) The BC-FQOLS is a valid instrument for measuring FQOL in the Chinese community and appears to be reasonable for families of children with intellectual disability in the early years. Family income and severity of disability are significant predictors of satisfaction ratings of FQOL. Socioeconomic status is a key indicator of well-being and happiness. Transportation is an influencing factor of FQOL.
Moyson and Roeyers (2012) Belgium	To investigate how young siblings of children with intellectual disability define their quality of life as a sibling.	(Q2) Siblings described nine domains as domains of sibling quality of life: joint activities, mutual understanding, private time, acceptance, forbearance, trust in well-being, exchanging experiences, social support, and dealing with the outside world. Siblings can define their quality of life, and this definition of sibling quality of life differs from the FQOL concept; however, it is important to consider when working with children with disabilities.
Rillotta, Kirby, Shearer, and Nettelbeck (2012) Australia	To investigate the FQOL of Australian families who have a member with an intellectual/developmental disability, using the FQOL-S.	(Q1 and Q2) FQOL-S is a comprehensive, relevant, valid, and reliable measure of FQOL for Australian families having a member with an intellectual/developmental disability and can be recommended for use in this age group. All domains were considered to be quite or very important, with health of the family and family relationships very important. Practical and emotional support from other people was rated <i>quite important</i> .

Note. FQOL = Family Quality of Life; BC-FQOLS = Beach Center Family Quality of Life Survey; FQOL-S = Family Quality of Life Survey.

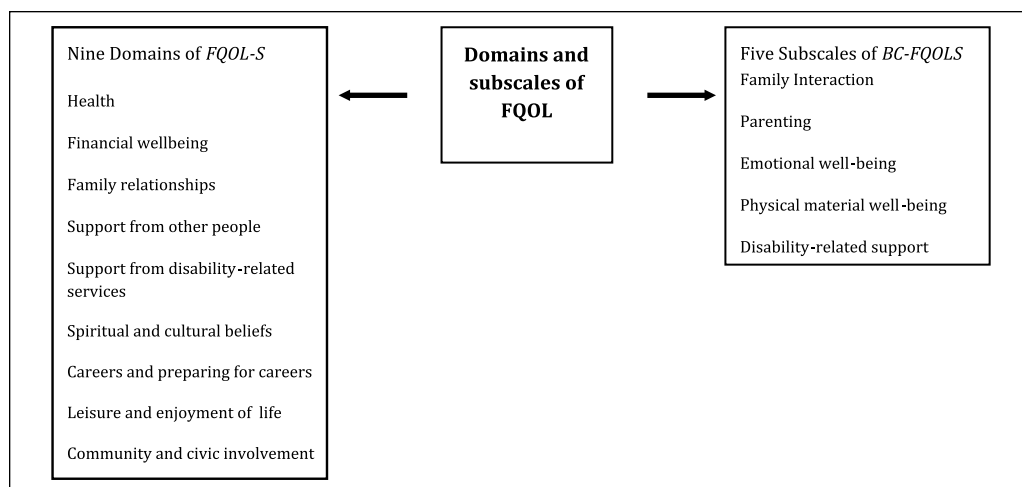


Figure 1. Domains and subscales of FQOL scales.

Source. Adapted from Brown, Brown, Baum, et al. (2006) and Summers, Poston, Turnbull, and Marquis (2005).

Note. FQOL = family quality of life; FQOL-S = Family Quality of Life Survey; BC-FQOLS = Beach Center Family Quality of Life Survey.

and a narrative (see Table 1). Five of the 18 studies used stratified sampling for sample selection (Hu, Wang, & Fei, 2012; Jackson, Wegner, & Turnbull, 2010; Summers et al., 2007; Wang et al., 2006; Wang et al., 2004), two studies used random sampling (Rillotta et al., 2012; Verdugo, Córdoba, & Gómez, 2005), six used convenience sampling (Clark, Brown, & Karrapaya, 2012; Davis & Gavidia-Payne, 2009; Neikrug, Roth, & Judes, 2011; Zuna, Selig, Summers, & Turnbull, 2009), two used purposive sampling (Çagran, Schmidt, & Brown, 2011; Steel, Poppe, Vandeveld, Van Hove, & Claes, 2011), and one study used variation sampling (Moyson & Roeyers, 2012). Three studies did not mention their sample-selection method clearly.

Step 5 of Scoping Review: Collating, Summarizing, and Reporting Results

Summary of results for RQ1. The first question was, What FQOL scales have been used to measure family outcomes in ECIS? Two FQOL scales were used in all studies: the *Family Quality of Life Survey: Main Caregivers of People with Intellectual or Developmental Disabilities* (FQOL-S, 2006) and the *Beach Center Family Quality of Life Survey* (BC-FQOLS, 2002). (I. Brown, Brown, Baum, et al., 2006; Beach Center for Disability, 2002). The BC-FQOLS takes a minimum of 20 min to complete, and the FQOL-S takes a minimum of 45 min to fill out. Details about the development of these two scales are presented in the publications on the development of FQOL concepts and measures (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Samuel, Rillotta, & Brown, 2011). The FQOL-S was developed as an international scale, to be used mainly with intellectual disability and across the life span, and the BC-FQOLS was developed primarily for young families of children with disabilities (Samuel et al., 2011). There are nine domains in the FQOL-S and five subscales in the BC-FQOLS that are used to categorize FQOL using the family's perspective (Beach Center for Disability, 2002; I. Brown, Brown, Baum, et al., 2006; Samuel et al., 2011; see Figure 1 for details).

Psychometric properties for reliability and construct validity have been published (Summers et al., 2005), and concurrent validity for both scales has been briefly reported (Samuel et al., 2011). Analysis of international data indicated high reliability and validity of the first version of the FQOL-S, and the nine domains were deemed feasible subscales for measuring different

Table 3. Six Concepts for Reporting on the FQOL-S.

Brown's six key concepts	Meaning
Importance	The degree of value the family places on that particular element
Opportunities	The option available to families
Attainment	The degree to which the family is able to accomplish or obtain what it needs
Initiative	The degree to which the families take advantage of available opportunities
Stability	The degree to which circumstances are likely to improve, decline, or stay the same
Satisfaction	Overall perception about important aspects of family life

Note. FQOL-S = Family Quality of Life Survey: Main Caregivers of People With Intellectual or Developmental Disabilities (Rillotta, Kirby, Shearer, & Nettelbeck, 2012).

aspects of FQOL (Isaacs et al., 2007). These FQOL scales were translated into Spanish, Slovenian, Hebrew, Nigerian, Malaysian, and Chinese. Most of the studies that used the translated versions reported that the translations used comparisons, discussions, and back translations by people fluent in both languages, and on an item-by-item basis. However, the exact procedures for translation were not clear.

Ten studies reported that FQOL could be used as a suitable outcome measure to evaluate service provision within ECIS. Epley, Summers, and Turnbull (2011) used the BC-FQOLS in their study with 77 parents of children with disability and concluded that FQOL could be used as an appropriate family outcome to measure the impact of ECIS programs. The FQOL-S was reported as a comprehensive, relevant, valid, and reliable measure of quality of life for families having a member with an intellectual/developmental disability or autism (Rillotta et al., 2012). It also informed service providers on how to enhance the quality of life of families of children with these diagnoses. The BC-FQOLS was used for measuring service effectiveness with 64 families attending ECIS, and family-centered service provision emerged as a strong predictor of positive FQOL (Davis & Gavidia-Payne, 2009).

Five studies done in non-English-speaking countries confirmed that the FQOL-S was an appropriate and reliable scale to measure service effectiveness and parent perceptions of their FQOL in the early years (Ajuwon & Brown, 2012; Čagran et al., 2011; Hu et al., 2012; Neikrug et al., 2011; Verdugo et al., 2005). In summary, the BC-FQOLS and the FQOL-S have been translated into several languages and used broadly as an outcome measure in ECIS, in a number of countries. Both scales have reported sound psychometric properties and good clinical utility for use in practice.

Summary of results for RQ2. The second question was, What factors affect the FQOL of parents/caregivers of young children with disability/developmental delay? Fifteen studies reported results that informed RQ2 about the links between attainment of FQOL and factors influencing FQOL (see Table 2, Q2). It was challenging to present the results due to variability in terminology used. Studies that used the FQOL-S used the nine domains to mention results and reported on the six key concepts, namely, *importance*, *opportunities*, *attainment*, *initiative*, *stability*, and *satisfaction* (Rillotta, Kirby, & Shearer, 2010). Table 3 describes these six concepts.

The BC-FQOLS reported results using the five subscales, namely, *Family Interaction*, *Parenting*, *Emotional Well-Being*, *Physical/material Well-Being*, and *Disability-Related Support*. The anchors of the items are rated on a 5-point Likert-type satisfaction scale, where 1 = *very dissatisfied*, 3 = *neither satisfied nor dissatisfied*, and 5 = *very satisfied*. Participants have to indicate how satisfied they feel with the item, for example, "My family member with disability has

Table 4. Scoping Review—Summary of Factors Influencing FQOL.

Factor	Summary
1. Disability-related support	The support received from friends and family for their child with disability
2. Family interactions/family relationships	The relationships between family members and how they support each other
3. Overall well-being	Health, emotional, physical, and material well-being
4. Service provision	Support received from service providers, ECIS, and adequacy of services
5. Severity and type of disability	The level of disability and diagnosis

Note. FQOL = Family Quality of Life; ECIS = Early Childhood Intervention Services.

support to accomplish goals at home.” There is scope to include “importance” in the current version of the BC-FQOLS, but it needs to be added on separately.

The variation of terms used in the selected papers led to a diverse spread of findings. Results relating to the factors of FQOL from the 15 studies were mapped and summarized based on common themes. All factors or domains that reported well-being such as health and physical/emotional/financial/material well-being were summarized under “overall well-being,” and included results relating to that factor. Factors including careers, preparing for careers, leisure and enjoyment, and involvement with the community were also included in “overall well-being,” because they have an effect on emotional/physical or financial well-being. “Disability-related support” included supports from others (family members, friends, and community) and excluded support from services. “Service provision” included support from services such as ECIS. “Severity of disability” was not listed as a factor within the two FQOL domains and subscales but was mentioned as a strong influencing factor in a few studies. The type of disability was mentioned in a few studies, and these emphasized the differences in FQOL related to the diagnoses. Hence, “severity and type of disability” was listed as a factor influencing FQOL in this scoping review. This process of summarizing led to five main areas (factors) emerging that were inclusive of the most significant factors affecting FQOL (see Table 4, for these five headings). These five headings will be used to summarize the factors of FQOL for reporting results regarding RQ2.

Disability-related support. Seven out of the 18 studies reported that the support from extended family and friends was very important to parents in relation to their FQOL (see Table 2). Some parents indicated that they asked for help from friends and family members only as a last resort, even if they were sure of receiving it. Employed parents indicated that they valued the social aspects of work and support from colleagues; however, they made less effort to obtain practical support as they did not want to burden other people (Rillotta et al., 2012). A Malaysian study reported that the overall satisfaction from the support received from family members and friends was low (Clark et al., 2012). Weekends, vacations, and other busy times were reported as particularly difficult, and many families experienced a lack of practical help and support for these times. Several parents in a Belgian study expressed their dissatisfaction regarding support from physicians and hospitals, commenting on ignoring the rest of the family (Steel et al., 2011). In summary, most families across countries expressed that they got little emotional support from relatives, neighbors, and friends.

Family interactions/family relationships. Family interactions involve interactions between all family members including parents, caregivers, siblings, and others involved, and a harmony within the family unit based on support, trust, and companionship. The thesaurus defines family relationships as relatedness or connection by blood or marriage or adoption; however, in FQOL literature,

family is defined as those people who consider themselves a family (whether or not they are related by blood or marriage) and support and care for each other on a regular basis (Turnbull, 2011).

Strong interactions between family members included knowing the interests of other family members, spending time together, and doing things together, and were strong predictors of increased FQOL (Davis & Gavidia-Payne, 2009). Value and priority were placed on the immediate family to uphold strong relationships, and parents had to have a strong relationship to keep a close-knit family (Rillotta et al., 2012). Mothers were recognized as primary caregivers across the studies and undertook a huge burden of keeping family relationships healthy.

Some siblings reported that they felt they took second place to their sibling with a disability, whereas some siblings associated this with positive reactions, such as feeling enriched and learning important lessons (Moyson & Roeyers, 2012; Rillotta et al., 2012). Family members of a child with disability often reported reduced opportunities for family events and, in some instances, complete breakdown of families due to having a child with disability. In summary, maintaining family relationships and interactions between family members was reported as challenging when there is a child with disability.

Overall well-being. Well-being was reported in terms of health, emotional, physical, material, and financial well-being and included family income, how families used resources to improve their lifestyle, and FQOL. Parents reported that they felt that material and physical well-being were very important, and that financial burdens had a negative impact on their FQOL (Davis & Gavidia-Payne, 2009). In an Irish study, 29 of 49 families reported that they were satisfied with their financial well-being despite an average income. Means of transportation was a predictor of physical well-being in China, with families who had better access to transport (walking, bike, public transport, and own car) reporting higher levels of satisfaction on physical well-being (Hu et al., 2012).

Factors including parent careers, engagement in leisure activities, and opportunities to be involved in the community and civic activities had a positive impact on FQOL (I. Brown, Brown, Baum, et al., 2006; Čagran et al., 2011; Neikrug et al., 2011; Steel et al., 2011). Families enjoyed opportunities for leisure and recreation activities. Respite care relieved parent burdens and improved their FQOL. In an Israeli study by Neikrug et al. (2011), parents reported that they managed more responsibility than they would like in undertaking the day-to-day affairs of the family, and in turn, this reduced the time they could spend pursuing their own interests or their occupations. Many families also reported insufficient sleep and lack of time for self-care, and not being able to provide equal attention to siblings or go on family vacations. Many parents gave up their careers and study due to the increased amount of caregiving, affecting their financial well-being, and this detracted from their FQOL (Caples & Sweeney, 2010). Families were least satisfied with emotional support. In summary, there were strong correlations between overall health, financial well-being, and FQOL of family members across countries, and many caregivers had to change their careers and occupations to enable care for their child with disability.

Service provision. Service provision includes services provided by members of the ECIS team at home, or within the child's natural environments such as child care, kindergarten, or anywhere within the community. Adequacy of service provision and positive relationships with service providers were reported as significant predictors of a good FQOL. Parents felt that receiving timely and adequate services led to stronger partnerships between them and service-provider staff (Summers et al., 2007). Parents valued experiences of family-centered support from service providers, and this contributed to their FQOL (Davis & Gavidia-Payne, 2009). In a Belgian study, parents suggested that a coach, who could show them navigation of services and regulations and help them make the best decisions, would be helpful (Steel et al., 2011). Support from

services was lowest in the areas of psychiatric help for children, counseling and therapy, rehabilitation services, and help with behavioral problems (Čagran et al., 2011).

According to 207 parents of children with deafness, positive ECIS experiences and increased informational support, additional support for family life, and additional parent support groups assisted in improving FQOL (Jackson et al., 2010). Most families across countries were not satisfied with service adequacy, information provision, and support for managing challenging behaviors. In summary, family-centered support, positive partnerships with service providers, and adequacy of services were strong predictors of FQOL, with families valuing information and support to help them manage the overall needs of their child with disability.

Severity and type of disability. Severity of disability was reported to be a significant predictor of FQOL, rating lower satisfaction with FQOL with higher severity of disability (Wang et al., 2004). Comparisons of the FQOL of parents of children with Down syndrome, autism, and no disability ($n = 69$) reported that the families without a child with disability had statistically significant higher levels of satisfaction with their FQOL, followed by children with Down syndrome, and last, by parents of children with autism (R. Brown, MacAdam-Crisp, Wang, & Iarocci, 2006). The perceptions regarding FQOL in a sample of 442 Chinese caregivers who had a child with intellectual disability reported that the severity of a child's disability had a strong correlation to FQOL (Hu et al., 2012). In summary, severity of disability and type of disability are significant predictors of FQOL satisfaction, rating lower satisfaction with higher severity of disability, and lower FQOL with challenging behaviors such as those seen in autism.

Discussion

Disability-related support from family, friends, and the community is scarce, and caregivers feel reluctant to ask for support although it is beneficial for their FQOL. In this scoping review, a lack of services and supports for all family members was a common finding across countries, and negatively affected FQOL (Davis & Gavidia-Payne, 2009; Summers et al., 2007). These results are supported by findings from a literature review conducted in Australia (Kennedy et al., 2010). The review reported that the quality of life of families of children with disability in ECIS benefited from a range of supports and services, such as emotional support, counseling, social support, information provision, strength building, parent-child relationship support, and help with additional demands and resources. The lack of consistent use of terminology of what "support" means for families in early childhood intervention, however, is a challenge for professionals to operationalize the results, and for researchers to make comparisons across studies (Kyzar, Turnbull, Summers, & Gómez, 2012). Family support has been defined as a set of strategies directed to the family unit, but that ultimately benefit the individual with disability (Kyzar et al., 2012). Although this definition was written for individuals with intellectual disability/developmental delay, it can serve as a starting point to gain a common understanding of "family support" when working within ECIS. Clearly defining supports needed by families to improve their quality of life is essential for providing enhanced services in ECIS.

In terms of family relationships and interactions, the needs of family members, particularly siblings, often get compromised due to the high financial demand for these families (Ajuwon & Brown, 2012; Moyson & Roeyers, 2012). This affects family relationships between couples and other family members. Chronic illness or disability in children can have a damaging effect on the psychosocial health of well siblings. In a study relating to mothers of sons with a mental illness, it was strongly recommended that the stresses associated with caring and managing everyday household duties need to be managed to enable families to achieve a balance between caring for each other and each family member having a fulfilling life (Chaffey & Fossey, 2004). A systematic review of studies with siblings of children with chronic illness and disability highlighted the

need for enhancing emotional and behavioral outcomes in healthy siblings (Hartling et al., 2010) to maintain strong family relationships. Maintaining strong family interactions and relationships between family members is critical to a good FQOL.

In terms of overall well-being, many family members in this review reported that restrictions on their employment opportunities, further study, and professional growth led to a reduction in family income and affected their financial and emotional well-being (Caples & Sweeney, 2010; Clark et al., 2012; Hu et al., 2012; Neikrug et al., 2011). These findings raise critical issues about challenges that families face in their everyday functioning or daily occupations. There are significant differences in the mean hours spent per week for mothers of children with disability, in occupations such as child care activities and recreational activities, when compared with mothers of children with no disability (Crowe & Florez, 2006). Similar findings are reported in the literature on human occupation and quality of life. Interviews with mothers of sons with a mental illness report on how the women's life trajectories and occupations are altered to incorporate caregiving (Chaffey & Fossey, 2004). The occupational perspective on health highlights that coping is associated with involvement in meaningful occupations away from home, and caregivers need to take care of their own occupational needs for a better quality of life (Wilcock, 1998).

This review also found that severity and type of disability are factors that affect FQOL and can be detrimental to FQOL (R. Brown, MacAdam-Crisp, et al., 2006; Wang et al., 2004). Although such comparative studies were sparse, this is a significant consideration when working with children and families. Comparing the findings of this review with studies that have focused on caregivers of children with autism spectrum disorders (ASDs) concludes that challenging behaviors are particularly difficult to manage and affect the quality of life of all members of the family (DeGrace, 2004). Research and public policy efforts for children with ASD have focused on early identification of young children with ASD. However, parents/caregivers have been confronted with the issue of how best to access the service delivery system for young children with ASD (Boyd, Odom, Humphreys, & Sam, 2010).

In the United States, many caregivers and professionals have found other means to fund services for children with ASD, such as Medicaid waivers and private insurance (Boyd et al., 2010). The Australian Government Department of Health (AGDH) also provides funding for early identification and intervention for children with ASD via the Helping Children With Autism Program (2014). Sourcing these funding opportunities helps with the financial burden; however, it can further affect the FQOL of these families due to the constant emotional drain of navigating the maze of services.

In terms of service provision, family-centered support and positive partnerships were associated with a positive FQOL. Parents value respectful relationships with their service providers and appreciate practical supports (Čagran et al., 2011; Summers et al., 2007). This is similar to findings from a research synthesis of 14 studies on the relationship of family support to family outcomes (Kyzar et al., 2012). Findings showed that, across studies, family support was significantly related to family outcomes, although there was a wide variability in the types and sources of support assessed.

The Administration on Intellectual and Developmental Disabilities (2000) expresses family goals that include enabling families to nurture and enjoy their children at home, maintain family unity, and preserve, strengthen, and maintain the family. It authorizes family support programs to implement family goals, including access to child care services, respite care, training and leadership, self-advocacy, and self-determination (Kyzar et al., 2012). It is evident from this review that including family goals and supports during service provision will enhance service delivery in ECIS and positively affect FQOL. The above five factors need consideration when planning services for families and present several implications for practice, policy, and future research.

Implications for Practice

The findings from this review have several implications for practice specifically in ECIS and suggest that ECIS providers need to consider FQOL as a key outcome when evaluating family outcomes. The two FQOL scales, namely, the BC-FQOLS and FQOL-S, presented in this review have good clinical utility for ECIS. These scales are suitable for diverse populations, as they have been validated in several languages. They can be used within ECIS teams for assessment of family needs and designing individual support plans. It is also necessary to accommodate the complex needs of all family members and provide the entire family with support. The socioeconomic status of families needs consideration for provision of intervention programs to ensure affordability and follow-up (Wang et al., 2004). Lastly, caregivers of children with disability are unable to pursue their interests although this is recognized as critical for them to sustain satisfying lives. Professional working within ECIS should not ignore changes to the occupations of parents/caregivers such as careers, leisure, and study, as these changes have an impact on their well-being and FQOL. It is recommended that for effective evaluation of family-centered services, in addition to child-focused assessments, an evaluation of family well-being can be determined by including FQOL as an outcome.

Implications for Policy

There are some implications for policy that are evident from this scoping review. The IDEA Part C policy supports nurturing relationships and family-centered care and gathers evaluative data from families for their annual performance report (Early Childhood Technical Assistance Center, 2014; Office of Special Education Programs, 2015). These data, however, do not report on the quality of life of these families. The findings from this scoping review confirm that including FQOL as one of the family outcomes will assist in providing valuable data related to quality of life and strengthen accountability of ECIS.

Federal policy in the United States has recognized the need for support to families. Although implementation of a policy for family support is in its infancy, it appears that this need has been on the rise, especially after a decline in institutionalization of individuals with disabilities. Families have been increasingly providing caregiving within their homes and communities for their child with disability. Provision of supports such as adapted equipment, aides to support inclusion, and respite care within the home and community settings needs to be included at a policy level to improve family outcomes. It is also evident from this review that FQOL is related to receiving adequate ECIS. A needs-based, outcomes-focused system is recommended to support the families of children with severe disability, and low financial income, due to their high support needs.

Implications for Future Research

There are several implications for further research following this review. More rigorous studies are recommended highlighting the relationship between elements of ECIS provision that affect FQOL of family members. Given the social complexity and diversity of families, qualitative feedback from families to measure FQOL is also recommended. The majority of the participants from the studies in this review were mothers of children with disability, and involving multiple family members such as fathers and siblings needs to be considered.

Further studies also need to determine stronger links between the positive and negative influences of having a child with disability on FQOL, as many families report on positive and joyful experiences, despite the disability. This review also indicated that parents spend more time on caregiving, and this may have an impact on their daily occupations. Future research needs to

examine the links between the caregivers' participation in meaningful occupations and their individual and FQOL. Research also needs to study the impact of implementation of policies that improve family outcomes. This will guide further policy development to enhance the quality of life of families.

Limitations

There were some limitations associated with this scoping review. As scoping reviews do not include a process of quality assessment, all the studies included in the review have different levels of rigor (Grant & Booth, 2009). This review did not include literature from family studies on disabilities and primarily focused on the studies including younger children with disability to keep the focus on the questions. This led to excluding some key articles that relate to FQOL, specifically of aging families, of families living with adults with intellectual disabilities, and issues such as family functioning, resilience, and stress. The reader is guided to the International Association for Scientific Studies of Intellectual and Developmental Disabilities (IASSIDD) website for an understanding of research in family studies when there is a person with disability (<https://iassid.org/sirgs/families>).

Conclusion

Scoping reviews are a knowledge-synthesis method used to describe the breadth of literature available in a specific area and to identify implications for practice and policy, and research gaps (Grant & Booth, 2009). In this review, we have provided a small number of available studies that have used FQOL as an outcome in the early years and recommended two outcome measures, the BC-FQOLS and the FQOL-S, for use within ECIS. We have also categorized factors from the selected studies that influence the FQOL of parents, such as disability-related support, family interactions, overall well-being, service provision, and severity and type of disability. In this review, we found an interesting link between parent occupations and FQOL, that parents make changes to their careers and have less time to engage in self-care, leisure, and civic activities although they enjoy these activities. This relationship of parent occupations with FQOL needs further exploration. It was evident that the quality of life of all family members is important to families, and measuring FQOL in ECIS will provide valuable data to enhance service provision.

Authors' Note

Ethics committee(s) approval is not required for this scoping review; however, it was sought for the proceeding study from Monash University Human Research and Ethics Committee and the Ethics Committee of the Department of Education and Early Childhood Education.

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Relationships between Early Childhood Intervention Services, Family Quality of Life and Parent Occupations – An Australian Study

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Title: Relationships between Early Childhood Intervention Services, Family Quality of Life and Parent Occupations – An Australian Study

Abstract:

This Australian study explored parents’ perspectives of family quality of life (FQOL) when they have a child with disability, the relationships between early childhood intervention services (ECIS), FQOL, and parent occupations. The study used a mixed-methods design following concurrent triangulation. The Beach Center FQOL survey (N=72), and 12 semi-structured interviews were used. Quantitative results indicated the strongest correlation between “parenting” and FQOL, and associations between ECIS, FQOL, and parent occupations. Thematic analysis highlighted that FQOL was constantly fluctuating, with many challenges. When families were hopeful and supported, FQOL was better. Parenting was an important occupation. Receiving family-centred ECIS supported FQOL.

Keywords: early childhood intervention, family quality of life, children with disability, families, parents, early intervention, occupation, mixed methods, children

Having a child with or without disability, leads to constant family adaptations, influencing the family-unit dynamic, and the everyday occupations of families (DeGrace, 2004; Zuna, Turnbull, & Summers, 2009). Compared to parents of typically developing children, it takes longer for parents of children with disability to re-engage in their previous lifestyle, and occupations, due to the caregiving needs (Crowe & Michael, 2011; DeGrace, 2004; Gevir, Goldstand, & Weintraub, 2006). The long-term caregiving for a child with disability can have an influence on the entire family's quality of life (I. Brown & Brown, 2009; Turnbull & Turnbull, 2002).

Family quality of life (FQOL) is the overall well-being of the family members as a group, and as individuals within the group (I. Brown, 2006; Zuna, Summers, Turnbull, Hu, & Xu, 2010). FQOL is dynamic, and is described by the unified theory of FQOL, wherein several factors act as predictors or mediators of FQOL. According to this theory, individual family member factors such as demographics (age, employment status), characteristics (behaviour, mental health status), beliefs (expectations of self as a parent) and family-unit dynamics are direct predictors of FQOL (Zuna et al. 2010). Performance concepts or something that is delivered or acted upon, such as services (early childhood intervention services), supports (emotional support through a group), and practices (family-centred practices) are indirect mediators of FQOL. Systemic concepts such as systems, policies and programs have an indirect mediatory influence on FQOL (Zuna et al., 2010).

According to the unified theory of FQOL, families constantly adapt to the changes that occur following having a child with disability, and these adaptations help or detract from their FQOL (Zuna et al. 2010). Some studies on adaptations to family life, have reported that parents of children with chronic illnesses or developmental disabilities want to feel "normal" and this "normalization" helps them feel better

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about their family life (Deatrick, Knafl, & Murphy-Moore, 1999; Deatrick, Knafl, & Walsh, 1988, p. 17). In a study related to normalization, 48 parents of children with a genetic condition were divided into two groups normalization present (NP) and normalization absent (NA) (Knafl, Darney, Gallo, & Angst, 2010). The parents in the NP group adapted successfully to the challenges of having a child with a chronic genetic condition, and were competent in their parenting style. However, the parents in the NA group talked about the difficult and atypical nature of their lives, and pointed to the negative impact of their child’s condition on their lives. An Israeli study by Neikrug et al. (2011) reported that when parents of children with disability can manage challenges and can see a constant progression in their circumstances (with their child or their family life), it helps their FQOL. This term is referred to as “stability” in FQOL research and is achieved when parents of children with disability feel hopeful that circumstances are likely to improve in the future (Neikrug, Roth, & Judes, 2011).

Over the last decade several studies have been conducted with a focus on the FQOL of caregivers of people with intellectual disability (I. Brown, 2010; Jokinen & Brown, 2005; Rillotta, Kirby, Shearer, & Nettelbeck, 2012; Turnbull, Brown, & Turnbull, 2004). Majority of the past studies have been quantitative (Bhoiti, Brown, & Lentin, 2016; Davis & Gavidia-Payne, 2009; Rillotta et al., 2012) with limited reports of parent perspectives. Despite disability-related support being identified as an important factor that influences FQOL, there remains a lack of research investigating the influence of services such as ECIS on family outcomes like FQOL (Zuna et al., 2010). There is only one study in Australia that has reported that the family-centred style of service delivery within ECIS has a positive relationship with FQOL (Davis &

Gavidia-Payne, 2009). It is unclear whether the supports provided via ECIS within Australia are indirect mediators of FQOL.

Many parents of children with disability report that the long-term caregiving influences their everyday occupations, and their careers (DeGrace, 2004; Gevir et al., 2006). Some studies on FQOL have reported on the importance of career and leisure opportunities for caregivers of people with disability in attaining a good FQOL (Caples & Sweeney, 2010; Clark, Brown, & Karrapaya, 2012). However, it is unclear whether changes to the previous occupations (career, leisure) after having a child with disability have any influence on the FQOL of parents/caregivers.

This paper presents parent perspectives on family quality of life (FQOL) when there is a child with disability, within an Australian context. The aim of this study was to explore parents' perspectives of FQOL when there is a child with disability, and to look for relationships between ECIS, their occupations, and their FQOL. The research questions that guided this study were:

- 1) What are the perspectives of family quality of life, of parents of children with disability, receiving early childhood intervention services?
- 2) What are the relationships among early childhood intervention services, family quality of life, and parent occupations, as per parent perspectives?

Background

This section presents a brief overview of how ECIS are provided within XXX in Australia. It also presents a section on what comprises parent occupations, for this study.

Early Childhood Intervention Services (ECIS) in Australia

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Within Australia, ECIS support children with a disability/developmental delay from birth to school entry (0-6 years) and provide therapy, education, service planning and coordination, and support to access services such as kindergarten and childcare (ECIA, 2012). Parents are provided with knowledge, skills, and support to optimize the child’s development, and ability to participate in family and community life. Most ECIS within XXX, Australia (including this current study) use a family-centred and transdisciplinary model of practice wherein every family is assigned a keyworker as part of a transdisciplinary team of allied health professionals, and specialist educators (Alexander & Forster, 2012). The keyworkers work closely with the family, and with other staff. They provide strategies to encourage participation via home visits and visits to the kindergarten or childcare. Parents are not usually present at the child’s kindergarten or childcare and most of the strategies are presented to the educators at these sites.

Since 2016 within Australia, the National Disability Insurance Scheme (NDIS) has been rolling out and is intended to be fully operational by 2019. The NDIS is a way of supporting people with disability, and is currently supporting 100,000 Australians with disability. Within the NDIS, the early childhood early intervention (ECEI) approach has been identified as the recommended service delivery approach for ECIS. The ECEI approach strongly recommends the use of family-centred practice to support every family and child individually, and enhance community participation. For further details about the NDIS and the ECEI approach the readers are directed to their website <https://www.ndis.gov.au/ecei>

Parent Occupations

According to the World Federation of Occupational Therapy (WFOT), occupations include things that people want to do, need to do and are expected to do, and bring meaning and purpose to life (WFOT, 2016). Engaging in meaningful occupations enables parents to look after their physical, material and emotional well-being, and are important determinants of quality of life (Bhopti, 2016). Some occupations that parents engage in include necessary occupations, aimed at meeting the basic self-maintenance needs (eating, sleeping, and personal care); committed occupations, that are typically not remunerated (housework, childcare, car maintenance), contracted occupations (paid productivity or formal education); and free-time occupations (going out with friends for coffee), that occur in the time that is left over (Harvey & Pentland, 2004). These occupations will be considered as parent occupations in this paper.

Methods

The mixed methods approach was selected for this study to enable the combining of elements from quantitative and qualitative research approaches. A qualitative component was added to gain a better understanding of the participants' experience (Creswell, 2009). Because of agency time constraints, the concurrent triangulation approach was most suited to this study, as both sets of data were collected within the same time period. Mixing occurred at the time of reporting results and findings, where both sets of data were triangulated, and compared to enhance and strengthen the conclusions as seen in Figure 1 (Creswell, 2009; Greene, 2006; Johnson, Onwuegbuzie, & Turner, 2007). The results and findings from the quantitative and qualitative study will be presented separately first, and then will be triangulated and integrated in the discussion section to answer the research questions.

<Insert Figure 1 here>

Quantitative Study Procedure

A demographic questionnaire, and the Beach Centre Family Quality of Life Survey (BC-FQOLS) were used for the quantitative component, and semi-structured interviews were used for the qualitative component. Ethics approval was granted from XXX University and the Department of Education and Early Childhood Development (DEECD).

The Agency

The agency selected for this study was a single large ECIS agency with six outlets across metropolitan XXX within XXX, Australia. The agency used a family-centred, transdisciplinary approach as mentioned in earlier section (Alexander & Forster, 2012). The number of visits provided by the keyworkers was frequent at the onset (weekly) of the ECIS program, and then tapered (fortnightly and monthly) to manage the workload and funding. When the family and staff were equipped with strategies, and demonstrated confidence at follow-up, the visits were reduced. The data collection for this study was done prior to 2016 before the onset of NDIS funding.

Participant recruitment and selection. A convenience sampling method was used for recruitment from within the ECIS agency. Participants included people that considered themselves a family (whether or not related by blood or marriage), and who supported and cared for each other on a regular basis (Turnbull, 2011). The inclusion criteria required all participants to be parents/caregivers of children with disability/developmental delay, and enrolled in the ECIS, to provide informed

consent, and to have a working knowledge of English for questionnaires and interviews (if selected). Parents/caregivers who did not fit within the definition of “family” as defined in the study were excluded (e.g., a birth father with no custody of the child). Three hundred and fifty surveys were supplied across six sites and the authors estimate that between 150 - 200 surveys were distributed to families.

Instrumentation. Demographic data recorded from participants included age, gender, relationship to the child, other family member details, work status of both parents, and annual income. The BC-FQOLS was used to collect data about FQOL. The BC-FQOLS (2002) is a 25-item survey composed of five subscales: i) family interaction, ii) parenting, iii) emotional well-being, iv) physical-material well-being, and v) disability-related support. Evidence of the BC-FQOLS’ convergent validity, and internal consistency have been reported (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). See Table 1 for item description and subscales of the BC-FQOLS.

<Insert Table 1 here>

Quantitative data analysis. The Statistical Package of Social Sciences (SPSS) was used for the data inputting and analysis (IBM, 2013). Descriptive analyses were calculated for items from the BC-FQOLS, and the demographic questionnaire. The Spearman’s Rho correlation was chosen as the statistic to look for associations between FQOL, parent occupations, and ECIS service provision. For research question 1, regarding parent perspectives on FQOL, the total FQOL (TFQOL) score and the total subscale scores were calculated using descriptive analysis (Table 4). The five subscales are validated as factors for FQOL by the authors of the BC-FQOLS (Summers, Poston, Turnbull, & Marquis, 2005; Zuna et al., 2010).

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For research question 2, regarding the relationships between ECIS and FQOL, the item from the demographic questionnaire ‘duration of ECIS’ was correlated to BC-FQOLS item 25 (My family has good relationships with the service providers). This item was chosen because families within the ECIS received a higher frequency of service (weekly or fortnightly visits) at the onset of services and then reduced. (A question asking parents about their perspectives on the relationship between ECIS and FQOL was included during the interviews to triangulate with these results).

Regarding relationships between parent occupations, ECIS and FQOL there were no available assessment tools relevant to parent occupations. Some items from the BC-FQOLS deemed fit to the authors, to represent parent occupations, and for inter-item correlations. Before selecting items for correlations from the BC-FQOLS, a face validity and agreement exercise was carried out with seven occupational therapists. All seven therapists were working as practitioners for 7-15 years. The four types of parent occupations (Table 2) were defined in a handout namely necessary occupations, committed occupations, contracted occupations and free-time occupations (Harvey & Pentland, 2004). The 25 items from the BC-FQOLS were also listed in random order and presented to the therapists to allocate to any of the 4 categories of parent occupations. There was 90% agreement within the item allocation from BC-FQOLS items to parent occupations as in Table 2 (Fawcett, 2007). Four items with maximum agreement were selected for correlations (In bold in Table 2). These four items were then selected for correlating with the subscale “disability-related support” (representing ECIS) on the BC-FQOLS. These four items are not included in the “disability-related support” subscale. For committed occupations, item 1 (My family enjoys spending time together) and item 19 (Adults in my family have time to take care of the individual needs of every child) were correlated with the

subscale “disability-related support”. For necessary occupations, item 16 (My family has a way to take care of our expenses) was correlated with “disability related support” and for free-time occupations item 9 (My family members have time to pursue own interests) was correlated with “disability-related support”. For contracted occupations, the work status of carer (from demographic questionnaire) was correlated with subscales and total scores from the BC-FQOLS subscales. (Parents participating in the qualitative interviews were interviewed about their perspectives on parent occupations, ECIS and FQOL to triangulate the findings for this question).

<Insert Table 2 here>

Lastly, results from all correlations were considered and triangulated with the qualitative findings to investigate whether there were any associations between the three variables in the question.

Quantitative results. Seventy-two participants completed and returned the demographic questionnaires and surveys with a response rate of 36-48%.

Demographic information. The majority of the participants were mothers (80%) followed by fathers (16%) and two grandmothers. Other details of participants are reported in Table 3.

<Insert Table 3 here>

Descriptive and correlational analysis. Regarding parents’ perspectives of their FQOL, the descriptive analysis scores indicated that the distribution of scores on the continuous variable, ‘satisfaction with total FQOL’ (TFQOL) had a range of 61 ($M = 100.56$, $SD = 14.15$). The scores on the four subscales are presented in Table 4. The scores from the BC-FQOLS indicated strongest association for total FQOL

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(TFQOL) with the subscale of ‘parenting’ ($\rho = .86, p = .01$), followed by ‘emotional wellbeing’ ($\rho = .85, p = .01$), ‘family interaction’ ($\rho = 0.85, p < .01$), disability-related support ($\rho = .70, p = .01$) and lastly ‘physical material wellbeing’ ($\rho = .61, p = .01$).

<Insert Table 4 here>

Regarding the relationship between ECIS and FQOL, the quantitative results indicated that there was no significant correlation between duration of ECIS and total FQOL satisfaction ($\rho = -.14, p = .24$). However, there was strong negative correlation between duration of ECIS, and relationship with ECIS provider (Item 25) ($\rho = -.33, p < .01$) indicating that the relationships with ECIS providers maybe associated with the frequency of visits from the keyworker. The descriptive scores indicated 96% of the participants were satisfied with the relationship they had with their service provider.

There were strong positive correlations between the selected items for committed, necessary, and free-time occupations, and the subscale “disability-related support” as detailed in Table 5. There was no significant correlation between the work status (contracted occupation) of the main carer and disability-related support ($\rho = .11, p = .35$) and with total FQOL ($r = .18, p = .12$). The descriptive scores from the demographic questionnaire indicated that over half (54%) of the participants were not working and 31% of this group were not working due to their child’s health needs, 4% were working in full-time jobs, and 35% were working in some part-time capacity. For free-time occupations, 59% of the participants were either satisfied or very satisfied with the time they could spend on pursuing their interests, and 41% were either not sure or not satisfied. The committed occupation of “parenting”

(subscale) had the strongest correlation with TFQOL ($\rho = .86, p = .01$) on the BC-FQOL scores.

<Insert Table 5 here>

Qualitative study procedure

Semi-structured interviews were conducted with purposefully-selected participants from the quantitative participant sample, who consented to be interviewed. The same inclusion and exclusion criteria, and ethics approval as the above quantitative study applied.

Participant selection. To gain a diverse sample, the selection of participants for the interviews included mothers, and fathers, from different geographical areas, and varying socio-economic status. The annual household income (Table 6), was considered based on the Australian Bureau of Statistics (ABS) figures, indicating high average income as approximately \$96,000 and low average income as \$20,800 or less (ABS, 2015). The diagnosis of the children included varying diagnoses such as cerebral palsy, Down syndrome, and autism.

Qualitative data collection. This section presents an overview of the methods used for qualitative data collection, the researchers, and about participant recruitment.

The interviews. All semi-structured interviews took place in the family home, and lasted between 45–90 minutes. Six broad questions were used as a guide to prompt participants, such as “How would you describe your family quality of life at present?”; “What are some of the things that you think have impacted or influenced

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your current family quality of life? Can you explain why?"; "Do you think that your family quality of life was different before having your child? Did you work? Or are you able to do things you did before? Can you give me some examples?"; "Has receiving ECIS had any influence on you or your family? Could you tell me a bit more about that?"

The researchers. The first author conducted all the interviews. She had over 20 years of experience working in the area of ECIS with children and families and was conscious of the cultural and ideological origins of the families within ECIS. The second author was experienced in qualitative research and met regularly for debriefing throughout the research process to maintain trustworthiness.

Participant recruitment and data collection. Qualitative data was collected over a period of 10-12 months alongside the quantitative data collection. A brief definition of FQOL was emailed or presented to the participants before the interview. The data collection process, interview content, and sample selection were discussed between the first two authors after every two to three interviews, and emerging codes were constantly compared to check for effective saturation (Liamputtong, 2013). Through this process of participant selection in relation to the developing codes, no new data seemed to be emerging at the end of ten interviews. Two more interviews were conducted to attain data saturation.

Qualitative data analysis. Data collected from the interviews were transcribed and analysed using Creswell's (2009) six steps of qualitative analysis. Step one involved reading through the data, and step two was organising and preparing the data for analysis. Step three involved the first and second authors

independently reading the transcripts, and coding the data through clustering and categorisation of topics into codes. Codes were then compared between the first two authors and then against all participants' responses for coding reliability. Quotes from the participants' responses that related to codes were selected, and then notes were compared. For step 4, similar codes were merged together. Sixteen codes were created, and numbered in no particular order. In step five, four themes were generated from the codes. Step six involved relating the themes to the research questions, and developing further recommendations (Refer to Table 7 and Table 8). As these two steps are the beginning of a discussion, they will be elaborated within the discussion section of this paper.

Methodological rigour. The level of trustworthiness of this study was evaluated using the criteria set out by Lincoln and Guba (1985). A qualitative codebook was maintained throughout the analysis process, and all methodological decisions for coding were recorded to maintain reflexivity throughout the analysis process (Barry, Britten, Barber, Bradley, & Stevenson, 1999). Triangulation and constant comparison methods between the first and second authors were used to generate and confirm codes and themes (Lincoln & Guba, 1985). A summary of transcripts, and themes were sent to all participants for member-checking before finalising the themes for credibility.

To assist transferability, descriptions of the participants have been provided in Table 6 (Liamputtong, 2013; Lincoln & Guba, 1985). Dependability was achieved by providing details about the research process. All interviews were recorded and transcribed verbatim by the researcher. For confirmability, the researcher was aware of subjectivity and bias issues associated with her experience of working in the area

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of ECIS, and therefore used the pre-written questions diligently, used self-reflection, took detailed field notes and recorded written reflections in a journal after each interview (Barry et al., 1999; Cumming-Potvin, 2013). A consistent peer debriefing occurred with the second author throughout the process of data collection and finalizing transcripts and codes for the analysis.

Qualitative findings. Ten mothers and 2 fathers (pseudonyms used) participated in the interviews (see Table 6).

<Insert Table 6 here>

The steps in the qualitative analysis led to sixteen codes that are presented in Table 7 alongside the relevant quotes.

<Insert Table 7 here>

These 16 codes were then grouped under four themes after coding reliability was carried out between the two authors as per the steps of analysis. The codes and their relation to the corresponding four themes are presented in Table 8 along with quotes.

<Insert Table 8 here>

Theme 1: My family quality of life is okay, but...different, difficult at times, with constant ups and downs. This theme emerged from code 1 that was about participants’ perspectives of their FQOL. Most of the participants said that their FQOL was reasonable, however life was demanding, there were difficulties, and struggles, and ups and downs. Some participants expressed that they felt rushed and exhausted, running around to access medical appointments, and this influenced their FQOL. Having a child with disability was different to what they had expected, their

life had taken a different path, however they were constantly adjusting and moving on. See Table 7 and 8 for relevant codes and quotes.

Theme 2: Family quality of life is better when we feel hopeful and

supported. This theme was generated from six codes (codes 2, 4, 8, 9, 10, 12) that helped in understanding what gave participants hope, and supported their FQOL (See Table 8). All twelve families valued the support they received from their keyworkers from ECIS. The keyworkers helped them access funding for services, therapy and supports for their child with disability and for their family, and helped their FQOL (Code 2). Many parents associated their experiences during the early years of having a child with disability to experiences of most families when they have a new baby (Code 4). Comparing the extent of their caregiving to a typically developing child's caregiving made them feel "normal" and less different to families without a child with disability and supported their FQOL. Most parents felt that the early years were a time to focus on the developmental skills of their child, and not on their own needs. Watching their child with disability progress and achieve developmental goals supported their FQOL, and they felt hopeful towards the future (Code 8).

Most of the mothers reported that their partners were their main support and assisted in sporadic caregiving with children. Some grandparents and friends also helped with occasional caregiving. These supports from family members and friends, even though infrequent, helped their FQOL (Code 9). However, many mothers were reluctant to ask for support because they wanted to be the main caregiver. Most of the mothers had taken ownership of the caregiving role, and felt that it was their role to help with their child's therapy and daily needs, and not the father's role. Some parents were reluctant to ask for support from their friends for fear of interfering in their lives.

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Participants valued the support and visits provided by the key worker and the visits built their confidence around sending their child to kinder or childcare (Code 10). They appreciated when the key workers were honest, treated them with respect, and guided them towards the next steps for their child and their family. They found this supportive for their FQOL.

Code 12 was about inherent qualities of parents that supported their FQOL. These qualities were their positive attitudes, their religious beliefs, and their values. Most parents focused on the positive qualities in their child, rather than their disability and this supported their FQOL. The mothers had strong family values about raising children and being the main caregiver. Some parents said that their religious beliefs helped them cope. (See Table 7 and 8).

Theme 3: Family quality of life is challenged during difficult times. This theme consisted of four codes (Codes 7, 11, 14, 16) that contributed towards the challenges that the parents talked about (Table 8). Several parents reported negative and stressful experiences around the time of diagnosis, adding that it was a time filled with sadness, devastation, and not knowing what to expect (Code 7). Delayed diagnosis was a leading cause of anxiety, anger, frustration, and self-doubt, for many families. A few participants expressed resentment with the attitude of the health professionals, and lack of support at this time and this was detrimental to their FQOL at the time.

Code 11 was about lack of support after exiting ECIS. Lack of services and supports at school, and the lack of financial and emotional support from ECIS, and from the key workers were mentioned as challenges for the future by a few parents

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3 who had older children with disability in the school system. Funding therapy services
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5 was another concern. This transition time was seen as challenging for their FQOL.
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7 Parents of children with challenging behaviours seemed to be more exhausted,
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9 and struggled with everyday activities, and balancing their family needs (Code 14).
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11 Participants who had children with high medical needs (high severity) felt that it
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13 impacted their social life, and their FQOL, and they felt isolated. A few participants
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15 were coming to terms with recent separations and relationship breakdowns. One
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17 participant had recently had an accident at their new home. This had left the family
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19 shaken and she felt that the accident triggered a series of unfavourable and
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21 unexpected events and added to their finances and emotional stress (Code 16). These
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23 events were challenging and detrimentally impacted FQOL.
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29 ***Theme 4: Having a child with disability has consequences for the family and***
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31 ***for family quality of life.*** Five codes (Codes 3, 5, 6, 13, and 15) contributed to this
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33 theme and the understanding of the consequences and the impact of having a child
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35 with disability on parent occupations (Table 8). Majority of the parents commented
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37 that their own health and well-being did not take precedence, as they were too busy
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39 looking after the care needs of their family, and their child with disability (Code 3).
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41 Participants reported being exhausted and bogged down, but continued to provide the
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43 caregiving, as it was necessary for their child. Caregiving had a significant influence
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45 on their other occupations.
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48 Code 5 was about ownership and adoption of the parenting role and code 6
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50 was about the adaptations that parents make and about how their previous occupations
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52 change following a child with disability. Most participants (mainly mothers) were
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54 committed to the occupation of being a parent. They were ready for starting a family,
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and were adapting to the parenting role, and added responsibilities. Most of the mothers had taken ownership of their role as the main caregiver, and fathers were the income earners for the majority of the families.

Parents missed time for their necessary occupations such as meeting their basic self-maintenance needs, and free-time occupations such as doing things for themselves, due to the commitments of caring for their child with disability. Majority of the mothers had given up their full-time paid work, two were working part-time, and one of the fathers had dropped work hours due to the caregiving needs of their children. Most participants recognised that staying off work or going part-time reduced career prospects for them, and impacted family income. They missed the working environments and their colleagues. However, most participants agreed that it was necessary to take this break from paid work due to the increased caregiving needs, and going back to work would be stressful. Most participants had accepted that they would have to wait for a longer time before resuming work. Caregiving had a significant influence on their contracted occupations.

A few participants had more than one child with a diagnosis, and other family members with health conditions (refer Table 6). They felt that the caregiving needs of multiple family members impacted their physical and financial well-being, compounded their challenges of living with disability, and detracted from a good FQOL (Code 13). Most parents mentioned that the siblings had to adjust to living with disability (Code 15). One parent worried about sacrifices that the sibling was making, like being unable to invite friends for a “sleepover”. Another parent was concerned that the child with disability would be a burden on the sibling in the future. Some parents mentioned being unable to engage in previous family outings due to having a child with disability and felt frustrated.

Discussion

The discussion interrelates and interprets the themes (Step 5) and compares and triangulates the qualitative and quantitative results. The findings are also compared with external literature, and implications for future practice, research and policy are presented. Figure 2 explains the four qualitative themes in relation to the research questions.

<Insert Figure 2 here>

Parent Perspectives of their FQOL

The high scores from the quantitative results in this study indicated that majority of the respondents were satisfied with their total FQOL. The qualitative codes explained that parents were using positive attitudes despite the challenges of having a child with disability. Within FQOL literature, high scores on FQOL, and positive attitudes related to having a child with disability are common. The early work of Turnbull, Summers, Lee and Kyzar (2007), in the conceptualization of FQOL focused on positives seen in families of children with disability. These positives include inherent qualities of parents, and positive coping strategies that lead to positive family outcomes such as FQOL, and concur with the qualitative findings within this study, (Chiu et al., 2013; Turnbull, Summers, Lee, & Kyzar, 2007; Turnbull, Turbiville, & Turnbull, 2000).

A positive strategy that families were using in this study was comparing their experiences to other families with typically developing young children. This strategy helped normalize their family experiences. This phenomenon of “normalization” in parents of children with medically fragile conditions, and developmental disabilities is considered a useful coping strategy (Deatrick et al., 1988; Rehm & Bradley, 2005).

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Rehm and Bradley (2005) analysed data from two ethnographic studies including parents of children who were medically fragile or had developmental disability (MF/DD) to understand normalization. Similar to this study, they concluded that families acknowledge their child’s disability, however attempt to engage in parenting behaviours, and family routines that are consistent with a normalcy lens. Parents identify ways in which their children and families are like others, and engage in activities to enhance those similarities, even though they do not minimize their differences (Rehm & Bradley, 2005). The authors concluded that parents of children who are MF/DD stay positive, and emphasize that it is still possible to lead a worthwhile life (Rehm & Bradley, 2005). Many parents in this qualitative study used a similar positive coping strategy around normalization, emphasizing that their life was not very different to a family with a typically developing child at a young age.

Another positive strategy in this study that supported FQOL was the parents’ hope into the future. This hopeful perspective is termed as “stability” and is achieved when parents of children with disability feel that circumstances are likely to improve in the future (Neikrug et al., 2011). Parents in this study were hopeful, were managing everyday challenges, and assumed that their child would follow the trajectory of attending a mainstream school in the future. These results concur with an Israeli study that included 103 main caregivers of children with disability (Neikrug et al., 2011). The authors concluded that parents were able to manage family challenges, see opportunities, and initiate actions for the future (stability), leading to higher scores on FQOL.

Lastly, an important positive strategy that supported FQOL in this study was related to the inherent qualities that parents possess. These qualities included their positive attitudes, beliefs and values (such as their duty of being a parent and provide

caregiving), and their religious views. Several parents mentioned that they used a positive outlook, focusing on the positives in their child rather than the impairments. This is similar to another study, where parents of children with a developmental disability sometimes reframed the changes in lifestyle necessitated by their child's condition, as positives in their life (Rehm & Bradley, 2005). The current findings about using positive attitudes are also similar to Breen's (2009) paper about children with disability. Breen highlighted that parents of a child with disability felt joyful, optimistic and resourceful more so than feeling grief, depression or stress (Breen, 2009) confirming positive attitudes are a coping strategy, similar to this study.

In terms of the subscales of the BC-FQOLS, parents were most satisfied with their parenting, followed by emotional well-being, family interaction, and disability-related support, and lastly physical/material well-being. Parenting was also identified as an important occupation by most parents in the qualitative interviews, suggesting a strong relationship between parent occupations and FQOL. These findings are consistent with an Australian study, that had similar results when the BC-FQOLS was used to measure satisfaction in 62 parents of children with disability attending ECIS (Davis & Gavidia-Payne, 2009). This is also consistent with the findings in a book chapter that reviewed the literature on FQOL, and concluded that family relationships and values were considered very important to families, and high scores on parenting and family interactions are common, as seen in this study (R. Brown, Kyrkou, & Samuel, 2016). Physical/material well-being rated lowest in this study, similar to the ratings from another Australian study, where parents felt that physical/material well-being were very important for FQOL (Davis & Gavidia-Payne, 2009).

However contrary to this study, where the results demonstrated high satisfaction with disability-related supports, results from a scoping review of 18

studies on FQOL by Bhojti et al. (2016) and from a literature review by Brown et al. (2016) have indicated low satisfaction with disability-related support. It is possible that families in this study felt well supported, as they were getting family-centred services. They were also receiving support from their extended family, and their spouses, leading to a higher satisfaction with supports, and a higher score on their total FQOL. Table 9 illustrates the triangulation between quantitative and qualitative data. The triangulated findings combined with findings from the external literature confirm that despite the challenges of caregiving, parents experience a good FQOL by using positive coping strategies, support from services and others, and explains the high scores on FQOL in this study.

<Insert Table 9 here>

Relationships between parent occupations, FQOL, and receiving early childhood intervention services

There were strong positive correlations between items representing committed occupations, necessary occupations, and free-time occupations with the subscale “disability related support” (on the BC-FQOLS), confirming an association between support provided from ECIS, and these parent occupations. It can be argued that these items were not clear representations of parent occupations, so the qualitative findings were considered in depth to understand the relationship between parent occupations, disability related supports, and FQOL. The qualitative findings were in concurrence with the quantitative results. Please see Table 10.

<Insert Table 10 here>

Becoming a parent and parenting their child, was seen as an important committed occupation. Most mothers reported that they believed that it was their role

to be the main caregiver, and preferred the father to be the income-earner. This qualitative finding is supported by findings presented in a gender report by the Australian Institute of Family Studies (AIFS) from a survey of Australian households completed in 2005. In this report 41% of the men and 36% of the women agreed that it is better for the family if the husband is the principal breadwinner outside the home, and the wife has primary responsibility for the home and children (Baxter, 2014). However the qualitative findings also report that the time spent on caregiving impacted parent physical well-being. Many participants reported that increased caregiving led them to suspend their own health needs, and health-related procedures, due to lack of time and money. A study on time-use of mothers reported that the time spent caregiving for a child with cerebral palsy is two to three times the number that parents spend on caring for children without disability (Sawyer et al., 2011). This confirms that the committed occupation of caregiving impacts physical well-being.

For contracted occupations, 54% of parents in the quantitative sample were not working, and 31% of these were not working due to their child's health needs. There was no significant correlation between the work status of the main carer, and disability-related support, or total FQOL on the BC-FQOLS. However the qualitative data made it clear that inability to maintain paid work (parent occupation) had a detrimental impact on parent well-being, and on their FQOL. Many participants said that being on a single wage impacted their family income, and financial well-being. These findings can be compared to a study by Caples and Sweeney (2010), where 49 parents of children with disability were surveyed using the FQOL-S, 2006 and the results indicated positive correlations between financial status and FQOL. In another Malaysian study with 52 parents of children with disability (age between 2 – 18 years), financial well-being and careers were considered important for a better FQOL

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(Clark et al., 2012). These findings concur with the current study and confirm the association of contracted occupations, financial well-being and FQOL.

In terms of free-time occupations, 59% of the participants were either satisfied or very satisfied with the time they could spend on pursuing their interests. This was surprising because it meant that most family members were able to pursue their interests. The qualitative findings illuminated these results. Majority of the mothers felt that being able to stay at home and look after the family needs was important for their FQOL, and having free-time for pursuing their interests was not important to them. While most parents missed their previous lifestyle, they added that they would be able to return to their previous occupations in a few years. They indicated that they were currently unable to find time for desired activities like going to the gym, or dancing, due to caregiving. A study on occupations of mothers by Crowe and Florez (2006) compared the time use of 30 mothers of children with disability to 30 mothers of children without disability. Mothers of children with disabilities spent significantly more time in child-care activities and significantly less time in recreational activities, (Crowe & Florez, 2006) similar to this study. This confirms the association between free-time occupations, caregiving (committed occupation), and FQOL.

In terms of ECIS and FQOL, majority of the participants were satisfied with the ECIS service provision and reported that they valued the visits and family-centred support provided by the key worker. The quantitative study showed 96% satisfaction with ECIS services. These results concur with past studies on satisfaction with family-centred ECIS. In an American national early intervention longitudinal study, 3,338 parents were asked to rate their satisfaction (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004). Results indicated that 75% of the respondents were receiving the “right amount” of services, 61% rated the quality of their child’s therapies as

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3 “excellent”, and 99% had “good feelings” about the professionals serving them,
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5 similar to this study. An Australian study about family’s perceptions of family-
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7 centred practice also reported high overall satisfaction with their ECIS, concluding
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9 significant positive relationships between parent perceptions of coordinated and
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11 comprehensive care (Ziviani, Feeney, & Khan, 2011). Similar to this study, Raspa et
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13 al. (2010) reported on data from a large-scale assessment with families participating
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15 in early intervention, concluding that the time spent in early intervention was related
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17 to positive family outcomes, like FQOL.
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20 Within this study, there was also a strong negative correlation between
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22 duration of ECIS, and relationship with the service provider. This can be attributed to
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24 the reduced frequency of visits by the keyworker in the latter years of service
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26 delivery. It is possible that families who were new to the service felt a greater
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28 satisfaction with their ECIS provider, as they had more frequent visits, and hence a
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30 stronger relationship with their key workers. Similar results in a past study reported a
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32 strong association among adequacy of services and family-professional partnerships,
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34 and with FQOL (Summers et al., 2007). Similarly in another study on first
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36 experiences of early intervention, it was concluded that early intervention services are
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38 usually highly successful during initial days (Bailey et al., 2004).
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41 Since the early nineties studies have reported similar findings about ECIS,
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43 highlighting that families ascribe most of their positive experiences to the supportive
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45 behaviors of professionals, and bad experiences are related to difficulties in finding
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47 out about and monitoring services (McWilliam et al., 1995). However it is unclear in
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49 most studies whether the family ratings of service satisfaction or adequacy are related
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51 to family outcomes, such as family quality of life. This study found correlations
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53 between FQOL, and disability-related support, confirming a relationship between
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FQOL and family-centred ECIS, and the qualitative findings further supported this result.

When looking for associations between parent occupations, ECIS and FQOL, the qualitative findings explained that parents valued the support and childcare/kinder visits from ECIS providers because it freed up some of their time to do things for themselves, and helped their FQOL. Most parents in the qualitative study did not expect ECIS to help them get back to their previous occupations. Helping their child’s developmental progress was seen as the main role for ECIS. However they also added that they could look after their own needs better if their child was well-supported by ECIS. Similar findings were reported in an Israeli study by Gevir et al. (2006) comparing occupations of mothers of children with and without disabilities. Mothers’ satisfaction with their daily occupations seemed enhanced when clinicians considered the developmental needs of their children, and this positively influenced their family well-being (Gevir et al., 2006).

Lastly the findings from this study are in agreement with the unified theory of FQOL. This study demonstrated that the direct predictors such as individual family member factors (43% families were of average or above average income), beliefs (most parents believed that parenting and caregiving was an important role) and family-unit dynamics (80% of families were two parent families, most spouses were reported to be supportive) were contributing to FQOL (Zuna et al. 2010). Performance concepts (ECIS), supports (from partners and grandparents) and practices (family-centred practices), the indirect mediators, were also contributing to their FQOL (Zuna et al., 2010). According to the unified theory of FQOL, families constantly adapt to the changes following having a child with disability, and these adaptations help or detract from their FQOL (Zuna et al., 2010). The constant

adaptation emerged as a strong theme in this study. Parents were adapting to the needs of their family and child with disability, and this was helpful for their FQOL on some days, and challenged their FQOL on other days.

Limitations

A limitation of this study was the lack of multiple ECIS agencies where different models of practice are used. The majority of the participants (97%) were mothers and capturing perspectives of fathers as well would have illuminated the results further. Another limitation was the lack of a suited outcome measure for parent occupations. This study mainly drew conclusions about parent occupations and relationships to FQOL, from the qualitative data. Lastly, the Likert style of responding used in the BC-FQOLS sometimes fails to measure the true attitudes of respondents, and the high scores on total FQOL maybe attributed to this. However, the interview data contributed to in-depth understanding of parent perspectives.

Implications for Early Childhood Intervention Service Providers

There are several implications for ECIS service providers and practitioners, including occupational therapists. Certain attributes of a key worker/family service coordinator were identified as important and supportive of their FQOL. These attributes included using a family-centred approach, establishing positive partnerships with the parents, and providing information and support to the family, and the early childhood staff. The coping strategy whereby families feel that the burden of caregiving for their child with disability is similar to a typical child in the early years (normalization) also needs to be considered. Most parents in ECIS are not ready for looking at the disability as a long-term issue. ECIS providers need to be mindful of

the parents' journey, while continuing to present information to families related to better family outcomes. The findings also highlight that parental involvement in meaningful occupations helps their overall well-being, and can contribute to a better quality of life. ECIS providers need to include re-engagement in meaningful occupations, and suggest this to parents as a part of their individual goal plan. Lastly, the satisfaction with relationships with their ECIS provider was higher in the early days. Keyworkers need to be mindful of maintaining this relationship despite reduction in visits, if needed.

Implications for Research

Many parents felt that health professionals (mainly doctors and psychologists) were not honest about the diagnosis and the future, and this impacted their trust with health professionals. Future research needs to examine and evaluate perspectives from other health professionals, to gain an understanding of their views on FCP, and to further support and advocate for working in a family-centred model of care. Most families in this study had young children, and reported that their FQOL would get better as their child got older and progressed into school. Further studies need to be conducted to investigate whether parents of children with disability attending school, report on FQOL outcomes similar to the current study.

Implications for Policy

It is evident from this study that FQOL is related to receiving family-centred ECIS. The evaluative data from families for the annual performance report within the Individuals with Disability Act (IDEA), Part C policy needs to consider FQOL as an outcome for accountability of ECIS programs. The results from this study strongly

recommend that within Australia, the National Disability Insurance Scheme (NDIS) should promote ECIS providers to offer family-centred support to children and families within a range of mainstream early childhood settings to ensure a good FQOL for parents. Policy makers need to consider family support, counselling, capacity and skill building related to the disability, and need to consider FQOL as a family outcome. Lastly opportunities for returning to work or engaging in leisure activities for parents/carers are important, and currently not apparent in supports identified by IDEA Part C, or NDIS and need to be considered to ensure a better FQOL.

Conclusion

This study concludes that positive attitudes, family values, hope, and beliefs, along with support from family, friends, and ECIS providers, help families of a child with disability experience a good FQOL. Parents in this study were constantly adapting to the ups and downs consequent to having a child with disability. Their previous occupations were impacted, however parents accepted giving up their work, or their own needs, and owned the occupations of parenting and caregiving. Being able to continue successfully in their occupation of caregiving, and looking after their child's needs was an important parent occupation for them. This study adds to the body of knowledge of past studies and confirms that receiving family-centred ECIS has a positive influence on families, and their FQOL.

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Please Note:

Tables and Figures attached as a separate document

This article does not contain any appendices.

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Table 1: Item Description and Subscales from The BC-FQOLS

Beach Centre Family Quality of Life Survey – (BC-FQOLS) - Detail	
Subscale 1- Family Interaction – Items 1,7,10,11,12,18	
Item description	
1-My family enjoys spending time together	
7- My family members talk openly to each other	
10 – Our family solves problems together	
11 – My family members support each other to accomplish goals	
12 – My family members show that they love and care for each other	
18 – My family is able to handle ups and downs	
Subscale 2 - Parenting – Items 2,5,8,14,7,19	
Item description	
2-My family members help children to be independent	
5-My family members help children with schoolwork and activities	
8-My family members help children how to get along with others	
14-Adults in our family teach children to make good decisions	
17-Adults in my family know other people in the children’s lives	
19-Adults in my family have time to take care of the individual needs of every child	
Subscale 3 - Physical Material Wellbeing – Items 6,16,21,15,20	
Item description	
6-My family members have transportation to get to places	
16-My family has a way to take care of our expenses	
21-My family feels safe at home, work, school, and in our neighborhood	
15-My family has medical care when needed	
20-My family gets dental care when needed	
Subscale 4 - Emotional Well-Being – Items 3,4,9,13	
Item description	
3-My family has support we need to relieve stress	
4-My family members have friends or others who provide support	
9-My family members have time to pursue own interests	
13- My family has outside help available to us to take care of special needs of all family members	
Subscale 5 - Disability–Related Support – Items 22,23,24,25	
Item description	
22-My FMWD has support to accomplish goals at home	
23- My FMWD has support to accomplish goals at home	
24-My FMWD has support to make friends	
25-My family has good relationships with the service provide services and support to our FMWD	
BC-FQOLS = Beach Center family quality of life survey; FMWD = Family member with disability	

Table 2: Parent Occupations Represented by Items from The BC-FQOLS

Parent Occupations - Adapted from Harvey & Pentland (2004)**Necessary Occupations** - aimed at meeting the basic self-maintenance needs

Items 3,6,12,15, 16, 20,21

3-My family has support we need to relieve stress

6-My family members have transportation to get to places

12 – My family members show that they love and care for each other

15-My family has medical care when needed

16-My family has a way to take care of our expenses

20-My family gets dental care when needed

21-My family feels safe at home, work, school, and in our neighborhood

Committed Occupations - typically not remunerated such as housework, childcare, home maintenance

Items 1,2,5,7,8,10,11,14,19,17

1-My family enjoys spending time together

2-My family members help children to be independent

5-My family members help children with schoolwork and activities

7- My family members talk openly to each other

8-My family members help children how to get along with others

10 – Our family solves problems together

11 – My family members support each other to accomplish goals

14-Adults in our family teach children to make good decisions

19-Adults in my family have time to take care of the individual needs of every child

17-Adults in my family know other people in the children's lives

Contracted Occupations - paid productivity or formal education

Not related to any item on the BC-FQOLS

Within demographic questionnaire – related to work status of carer (working or non working)

Annual income of household (< 50000 or > 50000)

Free-Time occupations - occur in the time that is left over, such as going out with friends or doing things of interest for self

Items 3,4,9,13

3-My family has support we need to relieve stress

4-My family members have friends or others who provide support

9-My family members have time to pursue own interests

13- My family has outside help available to us to take care of special needs of all family members

BC-FQOLS = Beach Center family quality of life survey. Occupations from - Harvey, A., & Pentland, W. (2004). What do people do? In C. Christiansen & E. Townsend (Eds.), *Introduction to occupation: The art and science of living* (pp. 63-90). Old Tappan, NJ: Pearson Education.

Table 3: Demographic Questionnaire Results

DEMOGRAPHICS OF QUANTITATIVE SAMPLE			
		Frequency	Percent
Relationship	Father	12	16.7
	Mother	58	80.6
	Grandmother	2	2.8
Age of child	0- 2.1years	9	12.5
	2.2- 4.1years	34	47.2
	4.2- 6+years	29	40.3
Father living at home	Father lives at home	58	80.6
Languages spoken	English	63	93.1
	Other	5	6.9
Diagnosis of child	Developmental delay	11	15.3
	Cerebral Palsy	10	13.9
	Down Syndrome	5	6.9
	Autism spectrum disorder	19	26.4
	Congenital issues	8	11.1
	No clear diagnosis	8	11.1
	Speech and language delay	5	6.9
	Other	6	8.3
Annual Income	Not working (nil income)	13	18.1
	\$30000 - \$ 50000	16	22.2
	\$50001 - \$70000	11	15.3
	>70001	31	43
	Not stated	1	1.4
Work Status	Not working due to my child's health	22	30.6
	Not working due to my health	1	1.4
	Looking for work outside home	2	2.8
	Working full time	3	4.2
	Working part-time	25	34.7
	Full time home maker	14	19.4
	Student	3	4.2
	Other	2	2.8
	Not stated	1	1.4
	Total	72	100

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Table 4: Descriptive Scores for Total Subscale Items on BC-FQOLS

	Total FQOL (MS = 125)	Total Family Interaction (MS = 30)	Total Parenting (MS = 30)	Total Physical Material WB (MS = 25)	Total Emotional WB (MS = 20)	Disability- Related support (MS = 20)
Mean	100.56	24.26	24.31	20.67	14.38	16.94
Median	99.50	25.00	24.00	21.00	15.00	16.50
Mode	94	24	23	25	16	16
Std. Deviation	14.153	4.87	3.57	3.29	3.61	2.19
Range	64	20	15	13	16	9

N=72; BC-FQOLS = Beach Center family quality of life survey; FQOL = Family Quality of life; WB = Well being; MS = Maximum score;

Table 5: Parent Occupations and Disability-Related support (ECIS)

Parent Occupations	Disability-Related Support (ECIS)
Committed Occupations	
Item 1: Spending time together	
Correlation Coefficient	.383**
Item 19: Taking care of individual needs of every child	
Correlation Coefficient	.545**
Necessary Occupations	
Item 16: Taking care of expenses	
Correlation Coefficient	.330**
Free-Time Occupations	
Item 9 – Time to pursue own interests	
Correlation Coefficient	.463**
Contracted Occupations	
Work Status (from demographic questionnaire)	
Correlation Coefficient	.111
N=72	
Spearman's Rho Correlation; ** $p < 0.01$ and ** $p < 0.05$	

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Table 6: Demographic Data – Qualitative Sample

Participant Pseudonyms	Diagnosis of child/ Severity (as per parents)	Age of child	Siblings	Marital status	Other child has disability or delay or undiagnosed	Family income	Main carer working
I1 – Alice (M)	Autism - (Mild)	4 years	2	Married	No	High average	No
I2 – Bob (F)	Cerebral Palsy – (Severe)	4 years	1	Married	No	Low average	No
I3 – Cassie (M)	Cerebral Palsy - (Moderate)	3 years	1	Married	Unsure - may have Autism	Average	No
I4 – Dee (M)	Autism - (Mild with behaviour challenges)	7 years	None	Married	N/A	Average	No
I5 – Ellie (M)	Down syndrome - (Moderate)	4 years	1	Married	No	High average	No
I6 – Fran (M)	Autism - (Mild with behaviour challenges)	5 years	3	Married	Yes – Two have Autism, one visual condition	Low average	No
I7 – Grace (M)	Cerebral Palsy - (Moderate)	4 years	None	Married	N/A	Average	No
I8 – Hannah (M)	Autism - (Moderate with behaviour challenges)	6 years	1	Separated	Yes – has autism	Low average	No
I9 – Irene (M)	Global developmental Delay (Mild)	3 years	None	Married	N/A	Average	Part time
I10 – Jenny (M)	Autism - (Moderate with behaviour challenges)	5 years	3	Single	Yes - One with Autism and other unclear diagnosis	Low average	No
I11 – Kerry (M)	Down syndrome - (mild)	2 years	None	Separated	N/A	Average	No
I12 – Liam (F)	Autism - (Mild - moderate)	4 years	1	Separated	Yes - Autism	Average	Part-time

I = Interview; (Ages have been rounded up); M=Mother; F=-Father

Table 7: Codes in Numerical Order with Quotes

Codes	Description	Quotes
Code 1	My FQOL is okay... different, reasonable, however is hard and difficult at times. It is constant adaptation, ups and downs	<i>...I mean it definitely has its moments... Like we do have a couple moments where its higher stress times or demanding kinda times but overall I still think, family life's pretty good (Grace)</i>
Code 2	Financial support for accessing services helps reduce the financial burden and helps FQOL	<i>...But I've got the funding for 8 months. So we didn't feel the pressure [for extra speech therapy] (Kerry)</i>
Code 3	Physical well-being of parent/caregiver is not a priority, due to the child's needs and financial responsibility	<i>...I kind of should have a mastectomy, but I am going to delay that a little bit longer, cos I will be out of action for a little while...If its health issues for myself, then I'm in trouble, or even Tim [husband], cos then we would have a wage reduction (Cassie)</i>
Code 4	Early years are similar to having a typically developing child	<i>...Well I think, I suppose diagnosis or no diagnosis; life prior to a child and after a child is very different... most part of it was caring for her like, for want of a better word, a normal child. So in that period, there's not too much to my day that was different to the next mum (Grace)</i>
Code 5	Ownership and adoption of parenting role comes about after having a child	<i>...But we've already done all the partying, we are quite happy to stay at home and do the 'kid' thing (Cassie)</i>
Code 6	Adaptations are made/ previous parent occupations change	<i>We agreed that one of us would need to stay home, we would want to stay home, to raise him. Because we didn't see the point of putting him in childcare 5 days a week... that was something that I was happy to do. (Irene)</i>

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		<i>...I would probably be at work...and...I feel like Jim [son with disability] is my work and I kind of resent that a bit...pre-Jim, I had a great job and I loved work and I haven't worked since he was born um... we've got to do some things first (Ellie)</i>
Code 7	Waiting for the diagnosis leads to stress, but knowing the diagnosis is also stressful, sad and devastating	<i>... but you know hearing the diagnosis was obviously a bit stressful and sad... just cause neither of us [parents] wanted to really say the effects that it had had on us (Grace)</i> <i>...because no matter what the diagnosis, it's always gonna be devastating for the parents no matter what...some psychologists and pediatricians who were especially oblivious to... the sort of mental health of parents. And so it degraded her [wife] quality of life." (Liam)</i> <i>...He [paediatrician] said that there was nothing wrong with him and I remember saying 'Autism' and he said – na na na – he is doing fine - I sort of said to my mum – that if the doctor says he is fine – he must be fine...I was still concerned ...[and he was diagnosed with autism later] (Alice)</i>
Code 8	Progress and development of child is energising and uplifts parents and helps FQOL	<i>But he's getting there and I'm beginning to find silver linings for things like that. (Irene)</i>
Code 9	Support from partner, family and friends varies but is valued, however reluctant to ask for support	<i>...even though there's a lot of people that are ...are willing to lend support; not just immediate family... As much as I need it, I was always one to say no (Grace)</i>
Code 10	Support from services is important and valued	<i>[key worker] she does really good practical things like that and she sorts out funding and things like that (Irene)</i>

Code 11 Support after exiting ECIS is scarce

...but next year as in November when it [ECIS] all finishes, ... every change is going to be hard and she will need support and it's going to be ongoing (Dee)

...but I know as soon as she starts school that's it. Y's [ECIS] gone and what their school system offers, that's disappointing (Fran)

Code 12 Positive attitudes, beliefs, religion, faith, and family values help families

...I'm a very positive person... I mean he's just got a physical disability rather than intellectual, they said to us that if he survives he will be severely handicapped ...but hey look what we have got... a spunk! (Cassie)

Code 13 Having multiple children and family members with a diagnosis/illness impacts FQOL

You've got three with additional needs, um it is really really hard, like you know B swells himself up when he gets all upset, emotional and all the rest of it. (Jenny)

Code 14 Severity of disability especially challenging behaviours impact FQOL

M self-harmed and like did everything. I mean like she was two and half, ram her dummy down her throat, put her hand down there and strangle herself, she didn't want to be here... do you know what I mean (Dee)

...we do oral feeding, takes 20 minutes to 2.5 hours...So if really we want to go out we can but...he has to... sacrifice something. Normally my life was... Saturday night we go and spend time with friends and now, isolated...our world is inside the house...whatever we had, the joyful life, turned in a different way (Bob)

Code 15 Siblings/family relationships are impacted

We always know that if C [brother with autism] wants to watch this movie ... She's had to adjust cause it's not worth the tantrum from C. She will get upset, she'll cry, she will run to her room, but then 10 minutes later she will come out again

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and forget (Alice)

...Few things have been hard for example for every Christmas we go to a Christmas party at the RSL, there's a few little rides and Santa comes and that, in the past he has had big hissy fits ...and we kinda think why did we come (Alice – family outing)

Code 16 Triggers/ events in life can impact FQOL

...But I suppose after the separation, just the costs of running 2 households and of course I've gone down financially... The financial concern is that I may go back to having a mortgage, which we don't have at the moment (Liam)

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Table 8: Coding in Relation to Themes with Quotes

Codes	Themes	Theme description	Quotes
Code 1: My Family quality of life is okay... different, reasonable, however is hard and difficult at times. It is constant adaptation, ups and downs	Theme 1	My family quality of life is okay, but...different, difficult at times, with constant ups and downs	<i>Okay. I think our quality of life is reasonable. You know, not 100% but not terrible...I suppose that some days are more stressful than others (Kerry)</i> <i>...Because sometimes the expectations are not going our way but in an alternate situation [following a different path] ...so, it's like galvanizing us...We are not going to have a quality of life that we expected all the time ... (Bob)</i>
Code 2: Financial support for accessing services helps reduce the financial burden and helps FQOL (s) Code 4: Early years are similar to having a typically developing child (h) Code 8: Progress and development of child is energising and uplifts parents and helps FQOL(h) Code 9: Support from partner, family and friends varies but is valued, however reluctant to ask for support (s) Code 10: Support from services is important and valued (s) Code12: Positive attitudes, beliefs, religion, faith, and family values help families (h)	Theme 2	Family quality of life is better when we feel hopeful (h) and supported (s)	<i>Going to private speech therapy has really helped his behaviour, and I've used that \$12000 from the government (Ellie)</i> <i>We have to see his developments in a positive way and we are able to see positive signshe is going in the right direction...We know that one day K is going to walk (Bob)</i> <i>"You know...any child you've got to, you basically have to stop for 12 months you know and get nothing done. It's just with him it's a little bit longer." (Cassie)</i> <i>I knew that if I wanted to have a child,</i>

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Codes 7: Waiting for the diagnosis leads to stress, but knowing the diagnosis is also stressful, sad, and devastating
Code 11: Support after exiting early childhood intervention services is scarce
Code 14: Severity of disability especially challenging behaviours impact FQOL
Code16: Triggers and life events can impact FQOL

Theme 3 Family quality of life is challenged during difficult times

then I'd have to be around to raise him...I didn't wanna put my child in full time child care and let somebody else be instrumental in raising him because he's my child and I wanted to make a difference. (Irene)

I am Christian and I wouldn't be here if it wasn't for my beliefs... I believe that God doesn't give you anything that you can't handle...(Dee)

When we found out about her condition I suppose there was no [reaction] ...numb... because it was so early, it was only 2 weeks...they knew it was CP... And I suppose that those days were probably much harder not knowing... (Grace)

Codes 3: Physical well-being of parent/caregiver is not a priority, due to the child's needs and financial responsibility
Code 5: Ownership and adoption of parenting role comes about after having a child
Code 6: Adaptations are made/ previous parent occupations change
Code 13: Having multiple children and family members with a diagnosis/illness

Theme 4 Having a child with disability has consequences for the family and for family quality of life

...when I got to the point of exhaustion, I spoke to carers Victoria [respite care service] and this was after the separation (Kerry)

I just don't have the money now and I don't have the resources or the time or the energy. I've got no energy left (Hannah)

"I used to dance on Friday nights. I don't

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3 impacts FQOL
4 Code 15: Siblings/family relationships are
5 impacted
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*do that because they (her children) don't
like it when I'm out of the house. (Hannah)*

*...I would probably be at work...and...I
feel like Jim [son with disability] is my
work and I kind of resent that a bit...pre-
Jim, I had a great job and I loved work
and I haven't worked since he was born
um... we've got to do some things first
(Ellie)*

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15 FQOL = Family quality of life
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Table 9: Triangulating Data – Parent Perspectives on FQOL

Parent Perspectives on their FQOL	
Quantitative Results	Qualitative Findings
- Majority of respondents were satisfied with their total FQOL	Theme 1: My FQOL is okay, but...different, difficult at times, with constant ups and downs
- High scores on satisfaction with Parenting, Emotional well-being, Disability-related support	Theme 2: FQOL is better when we feel hopeful and supported (emotional well-being, disability-related support) Code 4 (normalization), code 8 (stability and hope) and code 12 (inherent positive qualities) help parents feel hopeful and supported. Theme 3: FQOL is challenged during difficult times (At time of diagnosis– code 7) Theme 4: Having a child with disability has consequences for the family and for FQOL (Parents adapt and change –Parenting is owned and accepted –codes 5 and 6)
FQOL=Family quality of life	

Table 10: Triangulating Data – Relationships between ECIS, Parent Occupations, and FQOL

Quantitative Results	Qualitative Findings
PARENT OCUPATIONS	
Item19 – Taking care of needs of every child	Theme 2 Mothers wanted to be the main caregiver and felt reluctant to ask for support (Code 9)
Item 16 – Taking care of expenses	
Item 9 – Time to pursue own interests	
Item 1 – Spending time together as a family	Theme 4 Mothers often neglected their own well-being and necessary occupations due to caregiving (code 3)
Consequence of having a child with disability - Loss of occupations	Theme 4 Parents did not expect ECIS to help them with their own occupations. Parenting
- Only 4% working in paid jobs	
- 54% not working in paid jobs	

was seen as an important transition, so
parents were ready to adopt this role
(code 5).

Theme 4

Loss of work led to consequences
(financially) but commitment to parent
role helped FQOL (Codes 5 and 6)

ECIS

Negative association between duration
of ECIS and relationship with service
provider (adequacy/frequency of
services received is related to
relationship with ECIS)

Theme 2

Parents valued visits from the key worker
to the childcare/kinder, respectful and
honest key workers and the support and
guidance from ECIS for their CWD and
their family (Code 10)

Positive association between
disability-related support (ECIS) and
items 1, 9, 16 and 19 (see above)

Theme 2

When their CWD made progress
developmentally, parents felt happy and
supported (code 8)

Theme 3

Support after exiting early childhood
intervention services is scarce (code 11)

CWD=Child with disability; ECIS = Early Childhood Intervention Services;
FQOL = Family quality of life

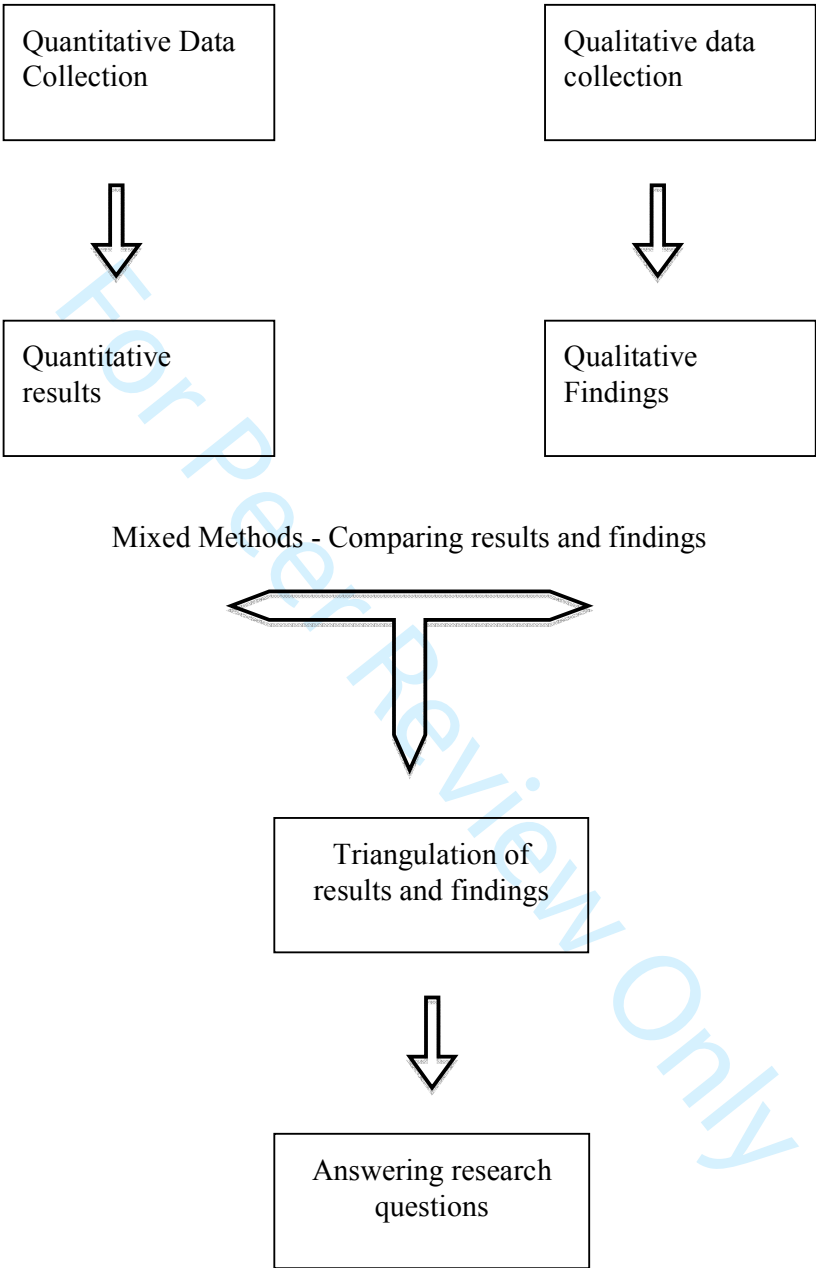


Figure 1: Mixed Methods Used in This Study

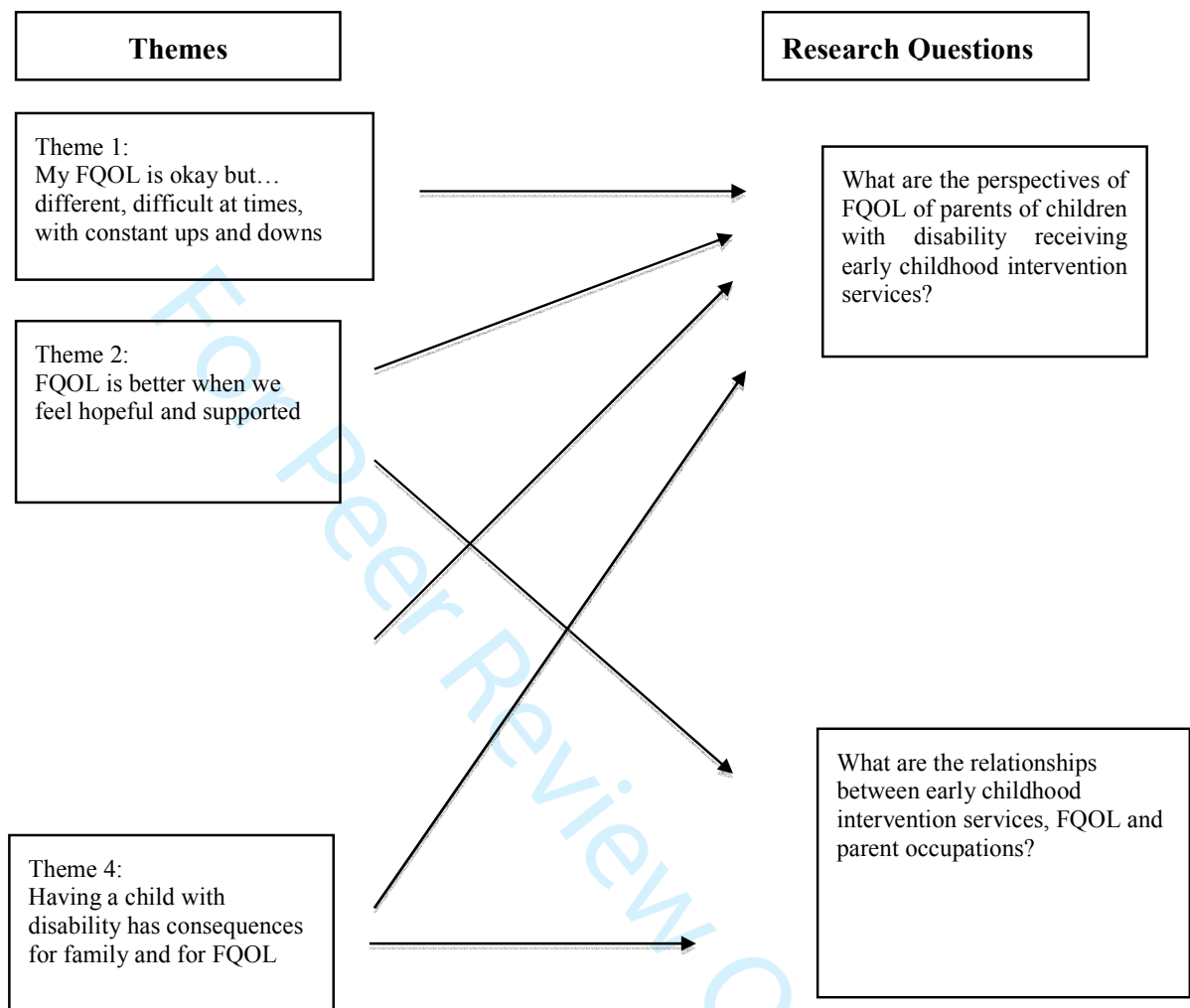


Figure 2: Step 5 - Relating Themes to Research Questions;
FQOL=Family quality of life

Appendix 3.1 - Demographic Questionnaire for Family Quality of Life Study -2

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What is your relationship to the child?	<ul style="list-style-type: none"><input type="radio"/> Father<input type="radio"/> Mother<input type="radio"/> Grandfather<input type="radio"/> Grandmother<input type="radio"/> Foster carer<input type="radio"/> Other, please specify:
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What is the main language spoken at home?

Are any other languages spoken?	<ul style="list-style-type: none"><input type="radio"/> Yes<input type="radio"/> No
If the answer is yes, please write the languages:	

How old is your child?

- ☐ 7 – 10 years
- ☐ 11 – 15 years
- ☐ 16 – 18 years

What is the primary diagnosis or developmental concern?
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Who lives at home with your child?

- ☐ Father
- ☐ Mother
- ☐ Brother/s
- ☐ Sister/s
- ☐ Grandfather
- ☐ Grandmother
- ☐ Foster carer
- ☐ Other, please specify:
.....

Are you of Australian Aboriginal or Torres Strait Islander origin?	<ul style="list-style-type: none"><input type="radio"/> Yes, Aboriginal<input type="radio"/> Yes, Torres Strait Islander<input type="radio"/> Yes, both Aboriginal and Torres Strait Islander<input type="radio"/> No, neither
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Are you the primary carer of the child	<input type="radio"/> Yes <input type="radio"/> No
Which of the following best describes your current work status?	<input type="radio"/> Not working due to my child's health <input type="radio"/> Not working due to my health <input type="radio"/> Looking for work outside the home <input type="radio"/> Working full time <input type="radio"/> Working part time <input type="radio"/> Full time homemaker <input type="radio"/> Student <input type="radio"/> Other, please specify:
Which of the following best describes your partner's current work status (if applicable)?	<input type="radio"/> Not working due to my child's health <input type="radio"/> Not working due to my/ partner's health <input type="radio"/> Looking for work outside the home <input type="radio"/> Working full time <input type="radio"/> Working part time <input type="radio"/> Full time homemaker <input type="radio"/> Student <input type="radio"/> Other, please specify:
What is the highest level of schooling you have completed?	<input type="radio"/> Some high school <input type="radio"/> Completed Year 12 <input type="radio"/> Vocational school (e.g., TAFE) <input type="radio"/> University <input type="radio"/> None of the above
What is the highest level of schooling your partner has completed (if applicable)?	<input type="radio"/> Some high school <input type="radio"/> Completed Year 12 <input type="radio"/> Vocational school (e.g., TAFE) <input type="radio"/> University
What is your annual family income	<input type="radio"/> Not working <input type="radio"/> \$30000 - \$50000 <input type="radio"/> \$50000-\$70000 <input type="radio"/> >\$71000
What type of school does your child attend	<input type="radio"/> Mainstream school <input type="radio"/> Special School <input type="radio"/> Combination of mainstream and special school <input type="radio"/> Other _____
Are you able to afford services and supports for your child with disability	<input type="radio"/> Yes fully <input type="radio"/> To some extent but that's OK <input type="radio"/> To some extent but that is not OK <input type="radio"/> No I am unable to <input type="radio"/> Other
What describes the services and supports	<input type="radio"/> I get more services and support for my child now compared to when they were in preschool (early

you receive for your
child's needs best

- Intervention)
- I get less service and support for my child now compared to in when they were in preschool (early Intervention)
 - Any other comment

Would you be willing
to participate in further
interviews for this
study (your identity
will only be known to
the researcher)

Yes Name/ Contact phone or email:

No

What is your postcode?

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Appendix 3.2 - Chapter 3 Tables

Table A3.1 *Code 3 and Subcodes – Study 2*

Code 3	Subcodes
Caregiving for the CWD is an ongoing and long-term challenge and impacts all family activities and family members	<p>3.1 – Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings</p> <p>3.2 – Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being</p> <p>3.3 – Caregiving for a CWD impacts parent occupations; parents are unable to return to paid work, with lack of time for self-care or meaningful occupations. Most parents become advocates and researchers</p> <p>3.4 – Caregiving for a CWD impacts socialisation with friends/family, and most family activities are adapted to suit the needs of the CWD. Siblings miss out and parents feel guilty</p> <p>3.5 – Parents worry about the future caregiving needs of their CWD, especially residential care. Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future</p>

Table A3.2 *Code 5 and Subcodes – Study 2*

Code 5	Subcodes
Services and supports are valued and help	<p>5.1 – Special schools provide support for therapy needs and are a respite for parents due to long hours</p> <p>5.2 – Respite care is valuable because it provides parents time away from caregiving and the CWD enjoys the time in respite too</p>

FQOL	<p>5.3 – Help is available from family and some others, and is valued, but parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older. Partners and spouses are the main support</p> <p>5.4 – Support groups are valued because they provide information, research, and friendships</p>
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Table A3.3 *Code 6 and Subcodes – Study 2*

Code 6	Subcodes
Families miss the ECIS family-centred support and the keyworkers, the financial support, and fun and engaging activities for their CWD, but the early years were raw and hard. Parents adapt and become advocates for their CWD	<p>6.1 – Parents miss the ECIS services and family interaction</p> <p>6.2 – Funding for services after ECIS is difficult. Disability support services are difficult to access. NDIS is helpful</p> <p>6.3 – Inclusion of CWD into mainstream school is difficult and challenging for parents due to lack of supports in schools and lack of ECIS-like support</p> <p>6.4 – Dads need support in the early years, but the support they seek is different to mothers</p> <p>6.5 – Early years are raw and hard and more focused on the here and now and on child's therapy rather than parent well-being</p> <p>6.6 – Parents become advocates for their CWD and for other families</p>

Table A3.4 *Themes and Subthemes from Study 2*

Theme 1: Parent Perspectives of FQOL	Theme 2: Comparing Early Years to Now
Subtheme 1.1: Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting; however, there are positives about having a CWD	Subtheme 2.1: About FQOL then and now ... It was harder in the early years, but it is still challenging, stressful, and difficult
Subtheme 1.2: FQOL is better when we feel supported	Subtheme 2.2: Caregiving then and now ... did not expect caregiving to be long-term in the early years
Subtheme 1.3: FQOL is challenged during difficult times and when we think about the future	Subtheme 2.3: Services and supports then and now ... less support and funding now
Subtheme 1.4: Having a CWD has consequences for families and FQOL	Subtheme 2.4: Parent occupations then and now ... have been able to go back to a few previous occupations, but many occupations have changed as the years have gone by ...

Table A3.5 *Subtheme 1.1 in Relation to Codes with Quotes*

Theme 1: Parent Perspectives of FQOL		
Subtheme 1.1	Codes and Subcodes	Quotes
Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting; however, there are positives about having a CWD	Code 1: Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting[FQOL] <i>it was dreadful, because it was totally dominated by his care needs, taking time away from us personally.</i> I7: L17–21 (Gary)
		<i>You just make adjustments as you go. You know, inwardly you wish it would never be like this, but you just learn to be okay with it because that's just how it is.</i> I2: L733–750 (Bianca)
		<i>At the end of the day, yeah, it's got its challenges, it's hard. But you know what, you just keep going.</i> I9: L1179–1186 (Isla)
	... however, there are positives about having a CWD	<i>I think that it fluctuates [FQOL]. It depends if he's [CWD] having a good day or a bad day.</i> I3: L25–29 (Caitlin)
		<i>I mean it just changes your perspective. You</i>

know, your values change, your way of thinking changes, the way you want to progress with your lives changes. But having a child with special needs is like ... It makes you strong as a person and you find out about yourself ... a little truer I guess. I4: L482–488 (David)

Code 2: Sharing good times as a family is important for FQOL

Subcode 2.1: Family time is important for FQOL

Family quality of life, I think it means uhh, being able to enjoy, the company of family members, find time for each other, do fun things together ... um, without feeling overly stressed and burdened. I7: L9–13 (Gary)

Table A3.6 *Subtheme 1.2 in Relation to Codes and Quotes*

Theme 1: Parent Perspectives of FQOL		
Subtheme 1.2:	Codes and Subcodes	Quotes
FQOL is better when we feel supported	Code 5: Services and supports are valued and help FQOL	<i>he was going there on the bus, and coming home on the bus most afternoons, that's about an hour-and-a-half trip each way. Umm, and that in itself was a form of respite. I7: L9–104 (Gary)</i>
	Subcode 5.1: Special schools provide support for therapy needs and are a respite for parents due to long hours	<i>So when ... we went around looking at schools, we looked at local primary school and we looked at a private special school ... it's an autism school ... in this environment they had small classrooms with four or five kids in the classroom, a teacher and an assistant, and in the area where the little ones are. I6: L851–853, 868–871 (Fiona)</i>
	Subcode 5.2: Respite care is valuable because it provides parents time away from caregiving and the CWD enjoys the time in	<i>Well respite is probably one of the biggest things that help quality of life. I mean we know that Mick is getting looked after, we don't have to fuss over him, and we can do what we need to do. We can do things. Sometimes we go out with the other two kids and go out to the movies. I4: L373–376 (David)</i>

respite too

I don't think they [grandparents] mind but I guess there is a limit. They have other family as well and you don't want to be a burden when they might want to see other family at the same time. I5: L283–284 (Eli)

Subcode 5.3: Help is available from family and some others, and is valued, but parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older. Partners and spouses are the main support

I would have to say that the biggest thing got me through anything was friends in similar situations ... Without a doubt, I would be lost without them. I3: L440–442 (Caitlin)

Um, the good thing is, the great thing out of that is I've met a lot of people who are in the same situation, and I've formed a really close bond with a couple of them ... and we're there, it's-it's good support to have and good to get others' ideas and experiences as well. I9: L762–768, 777–786 (Isla)

Subcode 5.4: Support groups are valued because they provide information, research, and friendships

Table A3.7 *Subtheme 1.3 in Relation to Codes and Quotes*

Theme 1: Parent Perspectives of FQOL		
Subtheme 1.3:	Codes and Subcodes	Quotes
FQOL is challenged during difficult times and when we think about the future	Subcode 2.2: Recreation for CWD is important but is difficult for parents due to lack of time and resources	<i>I think one of the issues impacting quality of life is lack of services ... he needs some type of recreation program – something that he can go to, a day centre, a something, where there are things that he likes to do ... There just needs to be places and spaces, where kids like Samuel can do their thing and just be themselves, umm, doing things that they enjoy. But there's just a lack of yeah, ... just places and those types of recreation activities. I6: L1016–1029, 1054–1064 (Fiona)</i>
	Subcode 3.1: Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings	<i>I opened the bathroom door and there was water everywhere. He'd plug the sink and decided to see what it would be like to flood the house ... he also set fire to the house one time you know. I1: L52–L53, 62–64 (Amanda)</i> <i>Got up and ... he might've just smeared it ... here was an incident with poo, requiring cleaning up, there was a broken window, and</i>

Jane [sister] had been attacked ... this is our lives at the moment. I6: L639–647 (Fiona)

Subcode 3.2: Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being

I was getting up at 2am in the morning just feeding or not feeding ... or I was out at the shops, I would be lucky to get couple of hours sleep at night, still hasn't really changed ... Mick is with us 24/7, it can be demanding especially with his eating ... he's ... yeah time consuming. I4: L177, L43 (David)

Subcode 3.5: Parents worry about the future caregiving needs of their CWD, especially residential care ... Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future

It does make you feel guilty thinking that way ... I mean that's why we're trying to ... we've got an investment property and that um ... for simple fact, we're trying to get some money behind us to put Mick somewhere nice rather than you know... I4: L290–293 (David)

I just didn't think it was fair on them [siblings] to have to ... and I have heard of many relationships between siblings deteriorate. I3: L233–236 (Caitlin)

Table A3.8 *Subtheme 1.4 in Relation to Codes and Quotes*

Theme 1: Parent Perspectives of FQOL		
Subtheme 1.4:	Codes and Subcodes	Quotes
Having a CWD has consequences for families and FQOL	Code 3: Caregiving for the CWD is an ongoing and long-term challenge, and impacts all family activities and family members	
	Subcode 3.3: Caregiving for a CWD impacts parent occupations; parents are unable to return to paid work, with lack of time for self-care or meaningful occupations.	<i>In saying that both of us [wife], but more so myself, have had to restrict our working hours. So, from a purely financial perspective our family finances would be much better if I could work full-time. I7: L186–199 (Gary)</i>
	Most parents become advocates and researchers	<i>Well at the end of the day, if I do have spare time, it's spent on the research and advocacy side of things... rather than a haircut or something ... rather than on myself, yep. I9: L914–917 (Isla)</i>
	Subcode 3.4: Caregiving for a CWD impacts socialisation with friends/family, and most family activities are adapted to suit the needs of the CWD	<i>If Samuel had been more typically developing ... we probably would have done more um, trips together as a family ... been a bit more adventurous ... umm, whereas you know, we got pretty stuck in the Anglesea beachfront caravan park 'cause Samuel liked it there. I6: L958–967 (Fiona)</i>

Siblings miss out and parents feel guilty

Look, family life is different now. Obviously, we don't get to go out much, um, we don't do a lot of family dinners ... we miss a lot of birthdays ... because it takes planning you know, or if something's last minute usually we have to miss out – so that makes things a bit hard. The sort of going out/socialising side of things has dropped off completely. I9: L9–23 (Isla)

Code 4: Having a CWD impacts financial/material well-being due to extra costs and reduced income

There was restriction of my incapacity [to work full-time] but also his destruction of property cost us many, many thousands of dollars per year. From things like breaking windows, and we'd renovated our house and when we moved back in he broke six windows ... smashing plates, damaging the floor, breaking holes in the plaster walls. That kind of thing. I7: L206–214 (Gary)

And financially I'm struggling. I find financially it's harder this year because I'm travelling to Frankston and back and I need to pay for after care for the girls. I12: L64–74 (Lisa)

Table A3.9 *Subtheme 2.1 in Relation to Codes and Quotes*

Theme 2: Comparing Early Years to Now		
Subtheme 2.1:	Codes and Subcodes	Quotes
About FQOL then and now ... It was harder in the early years, but it is still challenging, stressful, and difficult	Subcode 6.5: Early years are raw and hard and more focused on the here and now, and on child's therapy rather than parent well-being	<p><i>I think about the now and think about the early intervention years, you know, is life okay? It was hard in those early days, really hard because it was all new and raw, and you just didn't want to have to be okay with it, but you sort of learn to be okay with it. And I look at now, and its sort of easier because you've made some adjustments along the way ... but it's still just as hard, you never get over the grief ... but you change your perspective and you look at things and you learn to appreciate things differently ... And you know your child with needs, you know you still love them. I2: L733–750 (Bianca)</i></p> <p><i>I think it's easy for a parent when they have a child with a disability and all the stresses and strains and all the appointments and all the extra bills the therapy ... everything ... to really concentrate on their child and forget about their own wellbeing or their partner's wellbeing or other children's wellbeing ... I suppose speaking to therapists and psychologists and whatnot I</i></p>

learnt that you can't actually help ... unless I helped myself first so really need to be in a good state of mind I need to be eating well before I could even think about helping him and I think ... and I tell parents all the time because I've met so many parents that don't do that and won't accept outside help. I3: L375–382
(Caitlin)

Table A3.10 *Subtheme 2.2 in Relation to Codes and Quotes*

Theme 2: Comparing Early Years to Now		
Subtheme 2.2:	Codes and Subcodes	Quote
Caregiving then and now ... did not expect caregiving to be long-term in the early years	Subcode 3.1: Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings	<p><i>On a couple of occasions, he has threatened me [older son with ASD] with a knife once, and he's physically assaulted me only a couple of times whereas my younger son assaulted me on a daily basis ... and I would wake up and find him. He was there with a knife in my bedroom or you know if you're cooking dinner he would hurl a tin of cat food at my head or a tin of canned tomatoes ... I10: L220–227 (Jemima)</i></p> <p><i>I mean I think our daughter who's um, uh, just turned 12, umm, very supportive of, of her brother, but at times when he would destroy her things or attack her physically. She would um, complain very loudly about the injustice of that and, express her desire that he could leave so that she could live in peace. I7: L50–58 (Gary)</i></p> <p><i>So, and he can't dress himself, he can't brush his teeth, he can't wash his hands, he can't wash himself, so I have to do all of that. We're still in nappies, so, you know, trying to toilet-train at the same time. It's all, I help him with everything ... He can't drink out of a cup ... He hasn't quite figured out how to open and close them and fill them up yet though. I9: L166–190 (Isla)</i></p>

Subcode 3.2: Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being

There's no, you know, 15, 16, 17, 18 leaving home ... it's just not going to happen. I mean we even spoke about if he gets really bad we're going to give him up to the state and things like that. God, it's horrible. Even putting him in a home full time feels horrible but we've got ... even though we've got to think about him, we've got to think about ourselves as well ... I mean we're touching on 50 well you know, 48 nearing 50. We need to have some sort of quality of life and things for ourselves. I4: L279–285 (David)

Subcode 3.5: Parents worry about the future caregiving needs of their CWD, especially residential care

I just didn't think it was fair on them to have to ... do with it the daily monotonous things with him that any other kids had to deal ... and I have heard of many relationships between siblings deteriorate. I3: L233–236 (Caitlin)

Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future

Table A3.11 *Subtheme 2.3 in Relation to Codes and Quotes*

Theme 2: Comparing Early Years to Now		
Subtheme 2.3:	Codes and Subcodes	Quotes
Services and supports then and now ... less support and funding now	Subcode 5.1: Special schools provide support for therapy needs and are a respite for parents due to long hours	<p><i>I suppose then looking at primary school scenario and first, not being able to get full funding for a full time and at school we had to juggle and choose what's the best option and we chose a dual school approach, so we had a full-time day I5: L168–171 (Eli)</i></p> <p><i>... he was going there on the bus, and coming home on the bus most afternoons, that's about an hour-and-a-half trip each way. Umm, and that in itself was a form of respite ... we had a bit of time to get ourselves ready to go to work. I7: L92–104 (Gary)</i></p>
	Subcode 5.2: Respite care is valuable because it provides parents time away from caregiving and the CWD enjoys the time in respite too	<p><i>Well respite is probably one of the biggest things that help quality of life ... We can do things. Sometimes we go out with the other two kids and go out to the movies. I4: L373–376 (David)</i></p> <p><i>You know, he loves going there [respite] and I would've felt uncomfortable for him to go to these places and him not enjoying it, it would make me feel guilty. But because he enjoys it so much ...</i></p>

just driving to the place, he knows where he's going and he's so excited and so forth. I4: L297–300 (David)

Subcode 5.3: Help is available from family and some others, and is valued, but parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older. Partners and spouses are the main support

Oh, we've got family ... they, mmm, they all, they tolerate him I think, and at times, at times they'll laugh with him or ... but yeah, it's awkward. My family, he's just kind of irksome ... I think too my parents ... I don't think they would have coped with Eddie – They did, you know, they could only tolerate him in small doses. He's pretty full-on. I8: L666, L690–704, 733, 758 (Harry)

Subcode 5.4: Support groups are valued because they provide information, research, and friendships

Oh, absolutely well informed and I feel like I'm well informed um because the position that I'm in [parent support group facilitator] the whole disability thing ... the whole ... the whole network of support and lots available is such a ... it's like a secret code it's hidden away. You need to search for it, which is so wrong, I think. Um and I think that's why so many families are missing out. I3: L414–421 (Caitlin)

Subcode 6.1: Parents miss the ECIS services and family interaction

When he was in early intervention, there were ... people who were in that early intervention role who were able to inform us on what we were entitled to and they would source grants on our behalf or extra funds for this or the other. Now,

there's no one to do that for you ... it's much harder ... you have to go looking for it yourself and ... there's less of it. I2: L779–781, 809–810 (Bianca)

Subcode 6.2: Funding for services after ECIS is difficult. Disability-support services are difficult to access. NDIS is helpful

Funding wise ... Therapy wise, there's less out there in terms of supporting. Same with quality time. I remember when James was little there'd be early intervention funding that ... and they would say "we'll give you this money and there can be a certain amount spent on James" but ... you keep \$100 to buy a booklet of movie vouchers. I2: L799–803 (Bianca)

Subcode 6.3: Inclusion of CWD into mainstream school is difficult and challenging for parents due to lack of supports in schools and lack of ECIS-like support

Quite frequently and you know with a degree of at times of resentment, particularly when we started the process of um, application for uh, disability support, and had received nothing three years down the track. I7: L28–30 (Gary)

They [ECIS] were trying to make everyone inclusive and giving you tips on how to make kids inclusive and that was great ... it was just a traditional kinder [ECIS] but behind that was the program of the mother supports groups and also the papa bear [father support groups] which was like an outlet talking about our experiences and how to get around things. I5: L333–337 (Eli)

Subcode 6.4: Dads need support in the early years, but the support they seek is different to mothers

I think the thing that would help us, would be, if us dads can get together with um, with young adults and men who have Down, had Down Syndrome ... and talk to them. Like sitting around and, and talking abstractly is not what guys do. It's kind of irksome and irritating and I'd rather be doing something else. Cause it's not, it doesn't achieve anything. We don't bring up that sort of stuff, unless it's you know, just to laugh about something that the kids had done. I8: L1055–1069, 1082 (Harry)

Table A3.12 *Subtheme 2.4 in Relation to Codes and Quotes*

Theme 2: Comparing Early Years to Now		
Subtheme 2.4:	Codes and Subcodes	Quotes
Parent occupations then and now ... have been able to go back to a few previous occupations, but many occupations have changed as the years have gone by	Subcode 3.3: Caregiving for a CWD impacts parent occupations; parents are unable to return to paid work, with lack of time for self-care or meaningful occupations. Most parents become advocates and researchers	<i>I was an accounts manager... The plan was to go back to work pretty much straight away. But after the diagnosis, ... we realised obviously it's not going to happen. He needed more time, more care, I needed to learn and understand about his condition 'cause I knew nothing about it. So, we decided that ... I'd stay home with him until he was in school ... There's just, there's too much: he demands too much of my time and attention. I didn't think that I would be a stay-at-home mum. Nup, I was going places. But that changed. I don't – I'm used to it, you know ... You know, it did mean we struggled a lot financially. I9: L335–360, 375–385 (Isla)</i>
	Subcode 6.6: Parents become advocates for their CWD and for other families	<i>And this is the other thing when you're talking about quality of life. Every time you have to make a decision, you have to research everything, you have to put a lot of time into it and whereas with the boys [without disability]; yes, you do research the school they go to, but it doesn't get down to that level. I1: L443–446 (Amanda)</i>
		<i>I guess people spend a lot of time talking about looking after yourself, but what I found was my life still revolved</i>

around disability. It just changed, as I said, in proportions of time spent doing bits and pieces but most of those things just still revolved around disability either becoming more informed or going to workshops. I2: L448–452 (Bianca)

Code 4: Having a CWD impacts financial/material well-being due to extra costs and reduced income

... Needless to say, if James didn't have all those needs, Bianca [wife] could probably work longer hours, ... We might have a better house or whatever. So, it's a juggling act, one, she can't really do fulltime but by the same token she has to work. It's money we put into extra therapy and the extra things James needs over everything ... I5: L240–245, 253 (Eli)

I never planned to go back full time as such, until probably the boys were settled in school, but I figured I might be able to you know fit in sometime afterwards ... I thought I would. At one stage I kind of had hoped that ... well ... But you know the behaviour issues that Eddie had and often they wouldn't know how to deal with him, yeah. So, they would ring me up and I would get calls to say that he's done this, can you come and sort it out or we can't get him out from under the table ... I1: L245–247, 264–265, 292–295 (Amanda)

Appendix 3.2 – Photographs of Coding and Sub Coding Process

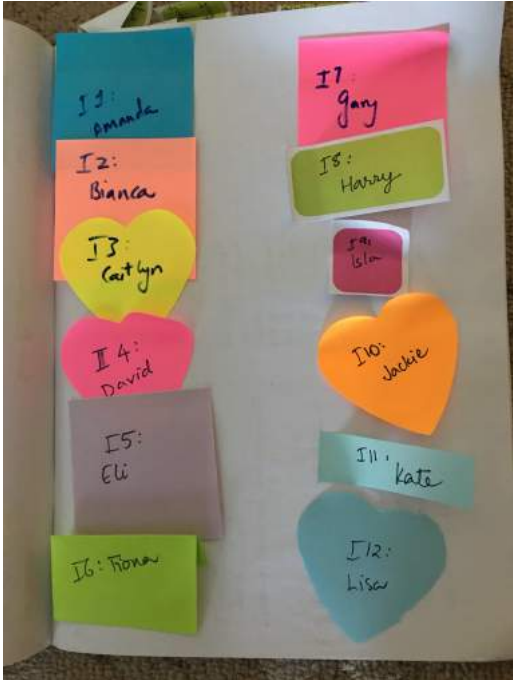


Figure 1: Pseudonyms and Sticky notes – Study 2

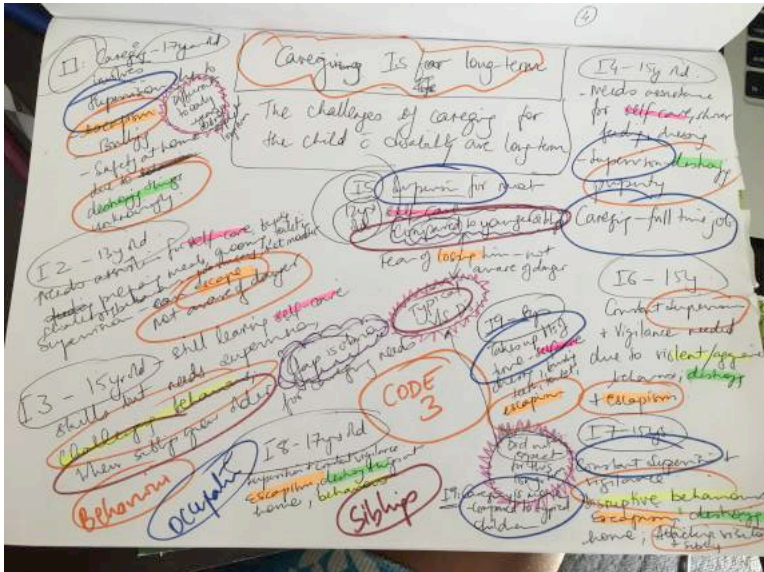


Figure 2: Code 3 and Emerging Subcodes

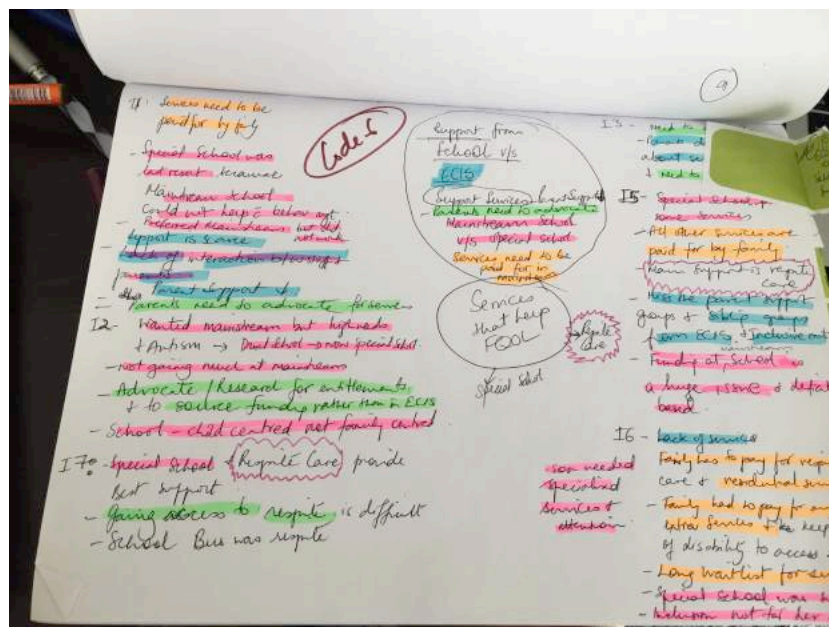


Figure 3: Code 6 and Emerging Subcodes

Appendix 4.1 Chapter 4 Tables

Table A4.1 *Comparative Analysis of Qualitative Studies 1 and 2*

Comparisons Final Categories	Study 1	Study 2	Analyses
Comparing family quality of life (FQOL) between groups	<p>Code 1: My family quality of life is okay ... different, reasonable, however is hard and difficult at times. It is constant adaptation, ups and downs</p>	<p>Code 1: Our FQOL is hard, limited, dreadful, terrible, challenging, difficult, fluctuating, adjusting, however there are positives about having a CWD</p> <p>2.1 Family time is important for FQOL</p>	<p>Both groups reported that they were making constant adjustments.</p> <p>In ECIS, families reported that their FQOL was more reasonable than in school-aged parents.</p> <p>Spending time together with family was important to parents of school-aged children but parents in ECIS did not seem to feel that this was important for their FQOL as they were too busy adapting to their parenting roles.</p> <p>Both groups looked at the positives of having a CWD and this helped their FQOL.</p>
	<p>Code 7: Waiting for the diagnosis leads to stress, but knowing the diagnosis is also stressful, sad, and devastating</p>	<p>Theme 2.1: Comparing ECIS and now ... about FQOL then and now</p> <p>... It was harder in the early years, but it is still challenging, stressful and difficult</p>	<p>The parents of school-aged children reminisced about the early years as being raw and hard and that later they adapt to the needs of their CWD and it gets</p>

	<p>Code 1: Early years are raw and hard but now families have adapted to living with disability, so it is easier than before</p> <p>6.5: Early years are raw and hard and more focused on the here and now and on child's therapy rather than parent well-being</p>	<p>slightly easier to manage the disability despite the grief.</p> <p>The parents in ECIS confirmed that the time of diagnosis and the unknown journey ahead was stressful and devastating.</p>
Beliefs and Values	Beliefs and Values	
<p>Code 4: Early years are similar to having a typically developing child</p> <p>Code 8: Progress and development of child is energising and uplifts parents and helps FQOL</p> <p>Code 12: Positive attitudes, beliefs, religion, faith, and family values help families</p>	<p>Code 1: There are positives about having a CWD</p>	<p>Difference in thinking that helps FQOL. In early years <i>normalisation</i> (that their life is similar to a typically developing child) and <i>stability</i> (that their child will continue to progress and develop skills into the future) helps FQOL. Parents try and stay positive and use their belief systems, values of being a parent, and faith to help their FQOL.</p> <p>In later years parents acknowledge and accept the disability as long-term and find positives in the transformation of their role as a parent of a CWD within their family and in their community.</p>

		Theme 2.2: Caregiving, then and now ... did not expect caregiving to be long-term in the early years	
Comparing parent occupations between groups	Caregiving: Committed Occupation Code 14: Severity of disability especially challenging behaviours impact FQOL	Caregiving: Committed Occupation 3.1: Behaviours of concern of a CWD add to the challenges of caregiving and impact siblings	Caregiving was an important parent occupation in both groups due to their commitment to their CWD. Parents in the ECIS group were not expecting the caregiving to be long-term. Both groups reported that behaviours of concern/challenging behaviours and children with high support needs required high amounts of time in caregiving.
	Physical Well-being: Necessary Occupation Code 3: Physical well-being of parent/caregiver is not a priority, due to the child's needs and financial responsibility	Physical Well-being: Necessary Occupation 3.2: Caregiving for self-care/physical needs for a CWD is exhausting and impacts on parents' well-being	Both groups reported that caregiving impacts parental physical well-being. ECIS families reported that they would be able to find time for their own needs in the future; however, according to parents of school-aged children this does not happen. They continued to neglect their own needs and were exhausted and unwell. Parents of school-aged children commented on their poor health and neglecting their health care due to caregiving.

Return to Work: Contracted occupation

Code 5: Ownership and adoption of parenting role comes about after having a child

Code 6: Adaptations are made/**previous parent occupations change**

Code 3: Physical well-being of parent/caregiver is not a priority, due to the child's needs and financial responsibility

Return to Work: Contracted Occupation

3.3: Caregiving for a CWD impacts parent occupations. Parents are unable to return to paid work, with lack of time for self-care or meaningful occupations

Code 4: Having a CWD impacts financial/material well-being due to extra costs and reduced income

6.6: Parents become advocates for their CWD and for other families

Many parents in both groups had been diagnosed with chronic health conditions since the early years that were left untreated. Some conditions included breast cancer, cardio-vascular problems, depression, chronic back pain, and high levels of stress that were left untreated due to lack of time or finances.

Both groups of parents were unable to return to work in the same capacity as before having a CWD. Parents in ECIS were adapting and accepting their role of becoming a parent. They were not concerned about returning to work. They were expecting to return to work in the future when their child went to school. However, the school-aged parents confirmed that they were unable to return to full-time work even now. Both groups reported that loss of income impacted their financial well-being and increased their financial burdens. Parents in ECIS said that they felt privileged that they were able to care for their child and did not have to return to work and this attitude helped their FQOL. Parents of school-aged children said that they had become advocates and researchers for disability and were happy

			with this change of occupation and this helped their FQOL.
Comparing disability-related supports between groups	<p>Code 10: Support from services is important and valued</p> <p>Codes 2: Financial support for accessing services helps reduce the financial burden and helps FQOL</p> <p>Code 9: Support from partner, family, and friends varies but is valued; however, reluctant to ask for support</p>	<p>Code 5: Services and supports are valued and help FQOL</p> <p>5.1: Special schools provide support for therapy needs and are a respite for parents due to long hours</p> <p>5.2: Respite care is valuable because it provides parents time away from caregiving and the CWD enjoys the time in respite too</p> <p>5.3: Help is available from family and some others, and is valued, but parents reluctant to ask for help due to increasing caregiving needs as the CWD gets older. Partners and spouses are the main support.</p> <p>5.4: Support groups are valued because they provide information, research, and friendships</p> <p>Code 6: Families miss the ECIS family-centred support and the keyworkers, the financial support, and fun and engaging</p>	<p>Both groups reported that services and supports helped their FQOL. However, parents of school-aged children missed the ECIS support, the coordinated care of services, and the funding. They also said that inclusion of their child into mainstream schools was difficult and they missed the inclusive settings from the early days.</p> <p>Families in ECIS were more focused on child-specific outcomes and funding for services, particularly therapy needs, was important to them rather than family outcomes or their own needs. They did not seek respite care or support groups.</p> <p>Parents of school-aged children mentioned the importance of self-care and parent well-being in early years and that they were child-focused because it was difficult for them to see the future.</p> <p>Both groups said that they were reluctant to ask for support from extended families and friends. Both groups reported that their main support was from their spouse.</p>

	activities for their CWD, but the early years were raw and hard. Parents adapt and become advocates for their CWD	
	6.1: Parents miss the ECIS services and family interaction	Both groups valued respectful and trusting workers and preferred consistency in the workers (therapist, keyworkers, or respite care workers) who were involved in caregiving for their CWD.
	6.2: Funding for services after ECIS is difficult. Disability support services are difficult to access. NDIS is helpful	Families of school-aged children found the supports from special school, respite care, and parent groups helpful.
	6.3: Inclusion of CWD into mainstream schools is difficult and challenging for parents due to lack of supports in schools and lack of ECIS-like support	
Future Caregiving Worries	Future Caregiving worries	Future Caregiving Worries
Code 11: Support after exiting ECIS is scarce	3.5: Parents worry about the future caregiving needs of their CWD, especially residential care. Parents worry about the siblings feeling the burden of future caregiving, and fear that siblings will resent or reject the CWD in the future	Parents in ECIS were worried about transition to school and concerned that there would be lack of funding and resources for their CWD. Most parents were expecting their child to attend mainstream school with a few exceptions being families who had previous experience of having a CWD in a mainstream school. Lack of support and funding at mainstream school limited their choice and they wanted to choose special schools over mainstream schools

due to better supports and services.

Families of school-aged CWD confirmed that lack of support at mainstream schools was the main reason they chose special schools. Many parents had unpleasant experiences of mainstream schools and the lack of resources to manage their child's needs.

The main worry for parents of school-aged children was related to future supports and residential care for their child. They were also worried about siblings having to bear the burden of care and this led to a fear of resentment by siblings.

Parent perspectives of FQOL = Orange; Support to FQOL = Green; Parent Occupations = Red; Challenges to FQOL = Purple; Consequences of having a CWD = Brown

Challenge

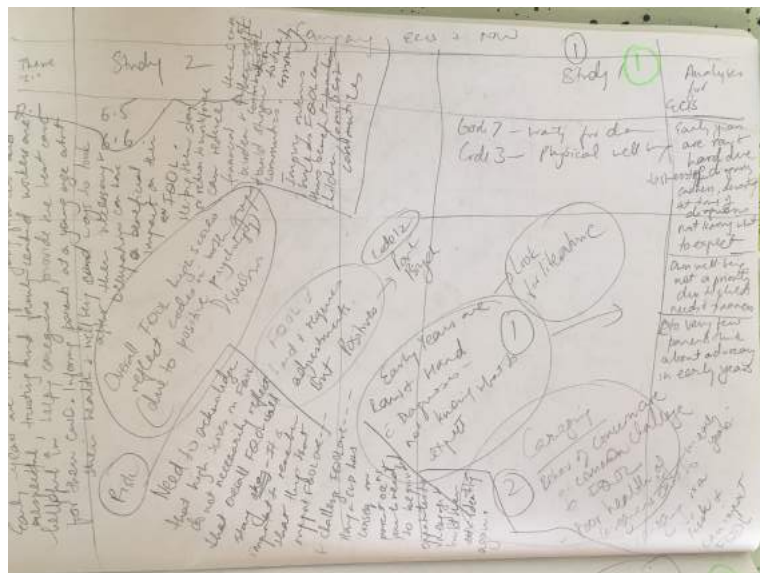
My FQOL is hard (11)
My FQOL is limited, busy (12)
Like a govt dog (13)
Parents sacrifice a lot of their time & hobbies (14)
Difficult from typical (15)
You just keep going (16)
I 2: Adapted the way (17)
Being able to enjoy the company of the family member who is bringing home something new (18)
FQOL means being allowed to be the family you need to be (19)
Do things together as a family (20)

Perspectives on FQOL

Up & Downs
Fluctuates (13)
Deal w/ Up & Down (14)
Just take everyday as it comes (15)

Make it better

Good experiences are not for FQOL (16)
FQOL is (17)
Making everything happen & fit (18)
FQOL is sharp good times together as a family (19)



- now but still not
able to work like before
- Does volunteering
 - wants to study
- 2- Able to work part time
needs flexible employer
- Life still revolves around disability
 - Still no time for own hobbies/leisure
 - ~~Research~~ analysis - time for self/leisure
- 3- Changed career path + works
disability/early childhood
- Likes helping other people
 - Likes new career
 - Family occupation
- 4- Had to work flexible hours
due to CWD needs
- Needs flexible employer
 - Cannot work in same capacity as before CWD - but its OK because flexible
 - Changed attitude towards money
- Parent Occupations
get impacted
Caring is still
a time-consuming occupation
- Now occupations
are accepted
~~not~~ Family Occupation impacted
- I7 - Work part-time + would have
worked full-time if no CWD
due to caring needs
- Couldn't make major changes
at work due to ~~stress~~ ~~stress~~ ~~stress~~
(career prospects)
 - Family occupation impacted
 - Tries as a couple
- I8 - Work full time
Family occupation get impacted
- Unable to do full time + some
one at a time
- I9 - Give up part-time + work part-time
husband - unpaid
- Don't regret but misses
the money
 - Family occupation impacted
 - No time to look at caring time
- 15 - Work was not impacted
but
Family occupations are
impacted
- Family holidays - not
enough time
needed to sacrifice hobbies
(leisure)
 - No time for parents
as a couple even now
- I6 - Work part-time
due to high support needs
- Caring occupation
- Keeping friendships is hardish
 - Family occupation deep
 - Stay at work
 - Professional career impacted
 - Parents spend time engaged
in CWD needs occupation
 - Adopted accepted - can't do
extra work

- 14 - Valued support from ECIS
parent group + friends
- From "one step at a time" to
future - living independently
 - Anticipated more progress
 - Differences b/w siblings get obvious
 - Future care options become a
priority (some guilt)
but as extended support
- 15 - Struggled to diagnosis
- Valued inclusion in ECIS
 - Valued family support in ECIS
 - Valued parent group + friends
 - School funding is deficit-based
 - Mainstream does not cater
for services/supports for world
not inclusive - social interaction
- ECIS
Versus
now
- I16 - Early years
were difficult
- Support needed to
be paid for
 - Miss interaction
- watched to do
well
- I2 - Miss support +
assistance from ECIS
related to research
& funding
- Looking into future
- Here + now in ECIS
- I3 - Early years were
difficult - ECIS was
helpful - but ECIS
was helpful
- Physical well-being was
impacted in early years

How FS FOOL that supports of challenges FOOL

Theme 1.1
Our FOOL is hard, dreadful....
however there are positives

Code 1

Theme 1.2
FOOL is better than we
feel supported

Codes 1, 5.2
5.3, 5.4

Theme 1.3
FOOL feels challenged during
difficult times & when thinking
about the future

Codes 2, 3.2
3.5

Theme 1.4
Having a child has consequences
on families & on FOOL

Code 3.3, 3.4
+ code 4

Comparing early years to now

Theme 2.1 - About FOOL then
& now
Early years are hard but not now
- families have adapted to life with
so it is easier

Codes 6.5, 6.4

Theme 2.2 - Comparing over time
Long-term -

Codes 3.1, 3.2

Theme 2.3 Services & supports
then & now
Families wish for ~~FS~~ FCP support, legal
& financial support & fun activities for
their child but NDIS is helpful

Codes 5.1, 5.2
5.4
6.1, 6.2, 6.3, 6.4

parent occupation
1.3, 3.6 (advised)
code 4

Then & now

Appendix 5

Table 4.5a: *Comparative scores with univariate data from study 1 and study 2*

Subscales of BC-FQOLS And factors for research questions	Study 1 - Total FQOL N=72	Study 2 – Total FQOL N=50
Parenting	.866**	.875**
Family Interaction	.852**	.897**
Physical Material well being	.612**	.692**
Emotional Well being	.859**	.780**
Disability-related support	.703**	.637**
Good relationship with Service provider	.399**	.410**

**. Correlation is significant at the 0.01 level (2-tailed).

EMAIL from Beach Centre notifying of the use of the BC-FQOLS scale.

From: Summers, Jean Ann [REDACTED]
Sent: Monday, 21 October 2013 12:37 AM
To: Anoo Bhopti [REDACTED]
Subject: FW: Request to use the FQOL unified theory diagram

Hello – Yes, I do remember you. I am glad you have found our FQOL measure and other publications useful. We would be happy to grant permission to use our work, since the Beach Center has a policy of open access on our publications. However, the publishers do not always follow our lead. I believe the particular publication you mention is a book chapter in a book edited by R. Kober and published by Springer Science-Business Media. Therefore, ownership – and permissions – are not in our hands. If your article is accepted for publication, you would need to approach them for permission. Sorry – I wish I could be more helpful.

Jean Ann Summers, Ph.D.
Associate Director
Beach Center on Disability
Research Professor
Life Span Institute
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

From: Beach Cntr on Families & Disab
Sent: Saturday, October 19, 2013 10:44 AM
To: Summers, Jean Ann
Subject: FW: Request to use the FQOL unified theory diagram

From: Anoo Bhopti [REDACTED]
Sent: Thursday, October 17, 2013 9:41 PM
To: Beach Cntr on Families & Disab
Subject: Request to use the FQOL unified theory diagram

Hi

I am currently doing a PhD from Monash University and my topic involves FQOL of parents of children with disability. I have made contact in the past with you and am planning to use the Beach Centre FQOL Survey. I am completing an article that I wish to submit in a journal based on a scoping review that I have undertaken on FQOL. For this I would like to mention the unified theory of FQOL by Zuna et al., 2010 and would also request permission to use the figure (with cogwheels) of the FQOL theory for the publication. I will duly acknowledge the sources and authors.

Could you please let me know the procedure for being able to do this?

Many thanks

Anoo Bhopti

Anoo Bhopti

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