“TIME TO CARE”: RELATIONSHIP BETWEEN TIME SPENT CARING FOR PRE-SCHOOL CHILDREN WITH DEVELOPMENTAL DELAYS AND PSYCHOLOGICAL, SOCIAL AND PHYSICAL WELL-BEING OF PARENTS.

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ABSTRACT

Advances in medical technologies and changing philosophies of health care have led to a rapid increase in home-based care for children with disabilities. While there are cost savings for health services if children are cared for at home there are extensive additional demands on the time and resources of parents, particularly primary caregivers, who are usually mothers. Previous studies have shown that parents caring for children with disabilities experience considerable stress and increased rates of mental health problems.

The present dissertation investigated the impact of caring on the daily lives of parents and in particular, a model proposing factors contributing to parental psychological, social and health outcomes. A preliminary qualitative study found time demands to be a core theme when discussing the consequences of caring, and when describing tasks of caring. A second, larger scale quantitative study focused on assessing the time constraints facing parents of children with developmental disabilities. Participants were 95 primary caregivers (mostly mothers) and 65 secondary caregivers (mostly fathers) of children (mean age = 4½ years) with developmental disabilities who were clients of the Early Childhood Service, part of Disability Services SA. Children‟s diagnoses included global developmental delay, Down syndrome, and autism. Caring and other activities of parents were assessed using a 24 hour pre-coded time-use diary. Parents also completed questionnaires measuring characteristics of child disability; their experience of time pressure and partner support; and psychological, social and physical well-being.

Examination of time-use diaries found parents of children with disabilities spent more time in “active” rather than “passive” caring tasks, than parents of children in the general community. As well, they spent less time in personal care, and less time in recreational activities. Intensity of caring, rather than total time caring was correlated with reports of daily stress for primary caregivers. Patterns of caring and non-caring activities carried out by primary caregivers on weekdays and weekend days differed from those undertaken by secondary caregivers, reflecting gender differences in parenting roles.

Analysis of questionnaire data showed children to have high levels of emotional and behavioural problems. Parents (particularly primary caregivers) had significantly poorer psychological, social and physical health outcomes than normative samples. Feelings of time pressure had a stronger association with parental depression than actual time spent caring. Further, testing of the model showed time pressure and partner support to be potential mechanisms by which caring for a child with a disability may lead to poor parental mental health. It is suggested that professionals providing early intervention services need a greater awareness of the constraints of the caring role undertaken by parents, together with the key role played by feelings of time pressure and partner support in contributing to the mental health of parents of children with disabilities.

DECLARATION

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

I give consent to this copy of my thesis, when deposited in the University of Adelaide library, being made available in all forms of media, now of hereafter known.

Signed,

Angela D. Crettenden

Date:

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SECTION 1:

INTRODUCTION AND LITERATURE REVIEW

CHAPTER 1

Consequences of caring for a child with a disability

1.1 Overview

Concern about the impact of caring on the lives of carers has led to considerable research over the past four decades. While much of this research has focused on care of the elderly (Zarit & Edwards, 2008), there has been a growing interest in the impact on family members of caring for a child with a disability. Rising incidences of childhood disability, at least in part due to the increased survival of infants and children born prematurely or with medical problems (Carpenter, 2000), have led to many more children with moderate to severe disabilities being cared for in the family home (Blair & Shean, 1996) The Australian Institute of Health and Welfare (AIHW, 2007) estimated 317,900 children (8.3% of all children aged 0-14 years), living in Australia in 2003 had a disability, with 165,300 children (4.3% of all children aged 0-14 years) having severe or profound core activity limitations (ie “severe” disabilities). Ninety nine percent of children were receiving home-based care (AIHW, 2004).

The move towards home based care has been in part brought about by economic pressures (Bittman & Thompson, 2000a). There are substantial cost savings to health services if care is provided by parents of children with disabilities, rather than by professional health staff. The overall value of unpaid care by parents and other carers has been estimated to be greater than the total value of government expenditure on all welfare services (AIHW, 2007). In addition to economic factors, changing ideologies now consider that it is in children‟s best interest to remain with their families rather than be cared for in institutions, with the home being considered the optimal environment for children‟s social and psychological development (Wolfensberger, 1972).

Increased pressures for parents to care for children with disabilities at home have occurred at the same time as significant changes to family structures (Cummins, 2001). Modern families are generally smaller than in the past and increasingly consist of just one parent, or two parents in paid employment, or are "blended" with two adults and children from different relationships. These changes mean that there are potentially fewer adults, fewer older children and fewer available extended family members to help care for children with disabilities (Cummins, 2001).

While there are potential psychological and social benefits for children who are cared for at home, there can also be personal and financial impacts for parents, particularly mothers, who are most commonly the primary carers for children with disabilities (AIHW, 2007; Craig, 2002; Craig & Bittman, 2005; Cummins, 2001). Parents must balance their additional caring responsibilities with other family responsibilities. This may add to the emotional distress experienced as a consequence of having a child with a disability (Bruce & Schultz, 2001).

Changes within the service sector, including an emphasis on early intervention (Ramey & Ramey, 1998) and the family-centred service model (Dunst, 2002; Rosenbaum, King, Law, King, & Evans, 1998) have also impacted on parental resources. It has been long recognized that early intervention is critical in helping to maximize children‟s development in the preschool years in particular (Ramey & Ramey, 1998). More recently, research has highlighted the critical role of parent involvement in achieving these outcomes (Benson, Karlof, & Siperstein, 2008; Dunst, Hamby, Trivette, Raab, & Bruder, 2002). The philosophy of the family-centred service model also emphasizes parental involvement. The model suggests parents are „experts‟ in their child‟s care and should be equal partners in the early intervention process (Raghavendra, Murchland, Bentley, Wake-Dyster, & Lyons, 2007). Parents, therefore, are increasingly being asked to play a much more active role in planning, participation, and advocacy for their children‟s treatment and therapy.

The pressures facing parents who care for children with disabilities at home highlight a pressing need for research to explore the ways in which additional caring responsibilities impact on the psychological and physical well-being of parents. Potential benefits for children with disabilities, arising from receiving home-based care, will be jeopardized if parents are not sufficiently supported. There is considerable evidence of the adverse effects of maternal depression, as well as poor maternal health and mental health more generally, on children‟s development (Sohr-Preston & Scaramella, 2006). As well, lack of support may lead to family breakdown and increase the risk of children with disabilities being placed in out-of-home care (Llewellyn, Dunn, Fante, Turnball, & Grace, 1999). This places additional pressures on welfare services, with obvious economic implications. It is not sufficient, though, for studies to focus only on outcomes for parents. Well-designed, theoretically driven research must also attempt to examine the pathways by which caring may lead to poor outcomes for some parents rather than others, so that supports may be better tailored to parent needs.

The remainder of this chapter summarises results of research examining outcomes for parents caring for children with disabilities, including studies contrasting consequences for mothers and fathers. Chapter 2 reviews research identifying characteristics of children, such as type and severity of disability, which may differentially impact on parents. As well, an overview of the role of social support in contributing to parent well-being is undertaken. Chapter 3 evaluates previous research, using diary methodologies, describing the activities of caring required by parents of children with disabilities. Chapter 4 concludes the Introduction and Literature Review by summarizing theoretical models that have been developed to assist the undertaking of research into carer stress. Chapter 4 also identifies the theoretical framework used in the present dissertation.

1.2 Definitions and categories of disability

The International Classification of Functioning, Disability and Health (ICF) compiled by the World Health Organisation (WHO) is the most frequently used framework for defining disability (WHO, 2001). The ICF describes disability as a multi-dimensional concept, framed in the context of a health condition or diagnosis. The conceptual framework used by the ICF includes: body functions and structures (eg extent of physical impairment); activities and participation (eg extent of activity limitations and participation restrictions); and environmental factors (eg family supports, social attitudes). Many studies reviewed in this and following chapters use the ICF or have a similar multi-dimensional conception of disability. For example, national surveys, such as the Survey of Disability, Aging and Carers (SDAC) undertaken by the Australian Bureau of Statistics, use the ICF framework when identifying the disability status of participants (ABS, 1998, 2003). Severity of disability in the SDAC is indicated by the extent to which an individual has a severe and profound activity limitation.

Another approach to categorizing disability involves the use of disability groups based on the activity limitations and participation restrictions shared by people with different health conditions (York & Bricknell, 2004). Such groupings are commonly used in the disability literature and include the broad categories of “intellectual disability”, “developmental disability” and “physical disability”. A problem for research in this area, however, is the inconsistency with which health conditions are included within disability groupings. This is a particular concern for prevalence estimates based on population surveys such as the SDAC (ABS, 1998, 2003). For example, the broad grouping “intellectual/learning disability” in the SDAC survey includes health conditions such as autism spectrum disorders (referred to throughout the dissertation as autism for simplicity) and attention deficit hyperactivity disorder, the latter condition more commonly considered as a psychological or psychiatric disorder. Estimates based on population data may not, therefore, align with estimates from other sources (York & Bricknell, 2004).

Stoneman (2007) suggests differences in the findings of studies in the field of disability research may well be a consequence of researchers using similar terms to describe participants with different health conditions or characteristics. In studies examining outcomes for parents of children with disabilities, for example, the term “disabilities” may include children with chronic health conditions such as cystic fibrosis (Breslau, Staruch, & Mortimer, 1982; Leonard, Johnson, & Brust, 1993).

Pelchat et al. (1999) examined the adaptation of parents to their children"s different types of “disability”, including Down syndrome, congenital heart disease and cleft lip and/or palate. Other studies focusing on parents of children with mental retardation or intellectual disabilities illustrate how children may have health conditions that fit into more than one disability grouping. The “hallmark” of cerebral palsy, for example, is impaired motor function, or physical disability (Raina et al., 2005). It has been estimated, however, that 30-60% of children with cerebral palsy also experience significant cognitive impairment (Harris, 1998). Children with cerebral palsy, therefore, are frequently included in studies of children with intellectual disability (Cormack, Brown, & Hastings, 2000; V. Harris & McHale, 1989; Hoare, Harris, Jackson, & Kerley, 1998).

International differences in the use of terminology may also impact on the consistency of research findings. In the United States of America, for example, the term developmental disability is an umbrella term referring to any severe or chronic disability resulting in activity limitations that are attributable to a mental or physical impairment, and manifesting before age 22 (Stoneman, 2007). Developmental disability, therefore, may include children (and adults) with a wide range of diagnostic conditions. In Britain, the term learning disability is used to mean anyone with below average intelligence, a different meaning to that used in the United States (Stoneman, 2007). Most recently, the American Association for Intellectual Disabilities (previously the American Association for Mental Retardation) recommended the term intellectual disability be used instead of the term mental retardation (Schalock et al., 2007).

While there are difficulties involved in directly comparing results of studies because of the issues described above, the volume of research that has been undertaken in the past few decades allows some broad conclusions to be drawn about the factors that may contribute to the psychological and physical health outcomes for parents of children with disabilities. The following review of research focuses on studies of parents of children with disabilities, and more specifically on studies on children with developmental disabilities. The term developmental disability is considered to include children with mental retardation, intellectual disability and also developmental delay (for children too young to have a formal diagnosis of intellectual disability). Studies examining outcomes for parents of children with chronic illnesses, such as cystic fibrosis or diabetes, were not reviewed unless such children were included in disability groupings for a particular study, or if the research findings were particularly relevant. It is of note that the findings of the Ontario Child Health Study, a large scale epidemiological survey of children in the general community, found children with both chronic illness and associated "disability" were at much greater risk for psychiatric disorders and social adjustment problems, than children with chronic illness alone (Cadman, Boyle, Szatmari, & Offord, 1987).

1.3 Outcomes literature

Prior to the 1980s, research assessing the effects of childhood disability on families was characterised by perspectives reflecting an underlying belief that parents experience a mourning reaction after giving birth to a child with a disability (Solnit & Stark, 1961). Dykens and Hodapp (2001) suggest this belief led to a number of different perspectives towards families of children with disabilities. Chiefly, most early studies had a "pathology orientation", assuming that caring was likely to have negative impacts on parent well-being and to be likely to lead to poor individual, marital and family adjustment. The implicit assumption in this research was that "families of children with disabilities are – or are in grave danger of becoming – "disabled families"" (Dykens & Hodapp, 2001, p. 55). A second early perspective was the focus on mothers, consistent with the psychoanalytic framework behind the "mourning model" of Solnit and Stark.

In more recent times, Crnic, Friedrich, & Greenberg (1983) suggested families of children with disabilities were families under stress, rather than being inherently "pathological". Models of stress predict individuals will respond in different ways to stressful situations (Lazarus and Folkman, 1984). While some parents caring for children with disabilities will suffer negative psychological and physical health consequences for example, not all parents will be similarly affected. Research is now more likely to focus on factors which may lead some families, or family members, to experience problems but not others (McCubbin and Patterson, 1983; Pearlin, 1999). As well, a growing literature is investigating potential positive impacts from caring for children with disabilities (Blacher & Baker, 2007). To acknowledge that carers may experience rewards and satisfactions from caring, however, does not mean that carers may not also experience negative impacts at the same time (Cummins, 2001).

The large amount of research examining outcomes for parents, and mothers in particular, has led many authors to undertake reviews and to carry out meta-analyses to summarise results of studies with a particular focus. Meta-analysis is a statistical approach to synthesizing the results of a body of research, standardising differences between groups in individual studies (using effect sizes) so that results may be combined across studies (Hedges, 1982, Hedges & Olkin, 1985). The following sections examining different types of outcomes for parents caring for children with disabilities will present findings of the most recent papers reporting results of meta-analytic analyses or of other forms of review in the context of a critical analysis of research in this area.

1.31 Maternal depression

Maternal depression has significant impacts both for individuals, and for other family members, including the children for whom mothers care (Sohr-Preston & Scaramella, 2006). Cummins (2001), examining studies of the subjective well-being of carers, including those caring for children with chronic illness and disabilities, concluded that close to half of the carer population experience clinical levels of depression. More recently, Singer (2006) completed a meta-analysis of studies conducted between 1984 and 2003, addressing the question of whether mothers with children with developmental disabilities are more likely to experience depression than mothers caring for children without disabilities. Singer limited the analysis to studies published in the United States and Canada. His definition of developmental disability included developmental disabilities associated with mental retardation, or a combination of intellectual and physical impairments (including conditions such as autism, cerebral palsy and spina bifida). As well, Singer restricted studies to those that included a “non-disability” comparison group, rather than relying on population norms to compare results for mothers of children with disabilities. His final criteria related firstly to the use of published, standardized measures of depression; secondly to the inclusion of sufficient information to enable the estimation of effect sizes; and thirdly to the ability to disaggregate information for mothers and fathers. Studies determined by Singer to show extreme results ("outliers") were also excluded.

Of the 358 studies initially identified from a search of the literature, Singer (2006) identified only 18 studies, conducted between 1982 and 2003, as fitting his criteria for the meta-analysis. The final set of studies, despite the selection process, were still of variable quality. Inspection shows them to be characterised by cross-sectional research designs and small participant numbers, mostly obtained from convenience samples. One half of the studies included in the meta-analysis had sample sizes of less than 50 mothers of children with disabilities (Bristol, Gallagher, & Schopler, 1988; V. Harris & McHale, 1989). Studies with larger sample sizes, however, were more likely to use a broad definition of "disability" and to use less rigorous methods to assess psychological well-being (indicating inconsistent application of the selection criteria for the meta-analysis). One study cited in Singer"s meta-analysis for example, was that of Breslau, Starich and Thompson (1982). They investigated levels of psychological distress in a sample of 369 mothers of children, aged between three and 18 years of age, with chronic illness or physical "handicaps" compared to 456 mothers from a randomly selected sample of families. Psychological distress was measured using a brief selection of items from existing measures of depression and anxiety. Results showed mothers of children with disabilities experienced higher levels of distress which were related to the level of functional dependence of the child, rather than to type of disability. A second large scale study cited in Singer"s review used data obtained from a United Sates population health survey (Witt, Riley, & Coiro, 2003). A population sample of over 3000 included children aged between six and 17 years of age with parent identified functional impairment due to broadly defined "chronic conditions" such as mental retardation. The study relied upon maternal report of depressive symptoms with results indicating mothers of children with disabilities had significantly higher rates of distress and depression when compared to mothers of children without disabilities.

Despite problems with the quality of research surveyed for the meta-analysis, Singer (2006) found a weighted effect size of .39 calculated using means and standard deviations for depressive symptom scores. This indicated a small to moderate increased likelihood of mothers of children with developmental disabilities experiencing depressive symptoms in comparison with mothers of children without disabilities (using Cohen"s (1988) guidelines for interpreting effect sizes). On average, 29% of mothers caring for children with disabilities had elevated levels of depression, in comparison to 19% of mothers of children without disabilities, a difference in prevalence of 10%. Rates of depression were identified using the recommended cut-off scores for the Beck Depression Inventory (BDI: Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) and the Centre for Epidemiological Studies Depression scale (CES-D: Radlof, 1977). Results for mothers of children without disabilities were consistent with rates of depression found for adults in the general community, when using the BDI and the CES-D (Roberts, Lewinsohn, & Seeley, 1991).

Singer (2006) undertook a number of planned comparisons to explore variables that may help to explain differences in results between studies included in the meta-analysis. Results suggested, firstly, that parents of children in early and middle childhood had higher levels of depressive symptoms than parents of adult children. A longitudinal study carried out by Glidden and Schoolcraft (2003), not included in the meta-analysis because it lacked a control group, also found evidence that maternal distress decreased over time. Glidden and Schoolcraft used the Beck Depression Inventory to examine differences in the incidence of depression between 90 adoptive and 97 birth mothers of children (aged between 12 months and 12 years) diagnosed with intellectual disability. Mothers were assessed on three occasions, over a period of 11 years (with a retention rate of approximately 65%). Rates of depression in adoptive mothers were low when first assessed, three to five years after child diagnosis, and remained low when reassessed approximately six years later. In contrast, birth mothers had high rates of depression when first assessed but were found to have much lower levels of depression when re-assessed. A second set of planned comparisons carried out by Singer (2006) suggested mothers of children with autism experienced higher levels of depressive symptoms than mothers of children with mental retardation and children with spina bifida. This conclusion is consistent with other research examining diagnostic differences in parental outcomes, to be examined in Chapter 2 (Eisenhower, Baker, & Blacher, 2005; Head & Abbeduto, 2007).

Another recent review of research examining rates of depression in mothers of children with developmental disabilities was undertaken by Bailey, Golden, Roberts, and Ford (2007). These authors, partly in response to the meta-analysis conducted by Singer (2006), employed broader criteria for the selection of studies for analysis. In particular, they allowed studies using interview assessments of clinical depression, as well as standardized scales of depression, with the aim of distinguishing between mothers exhibiting depressive symptoms and mothers meeting clinical criteria for depressive disorder. In addition, studies which did not have a comparison group of mothers of children without disabilities were included (eg Abbeduto et al, 2004)

Bailey et al. (2007) identified 42 studies, conducted between 1980 and 2004, for inclusion in their review, only seven of which were also included in the Singer (2006) meta-analysis. Eight of the studies involved clinically diagnosed depression, the remainder used rating scales such as the Beck Depression Inventory and the Centre for Epidemiological Studies Depression Scale. In most studies the child disability status was mental retardation or developmental disability. Diagnostic groups, however, included children with autism, cerebral palsy, mental health or behavioural problems, and prematurity, again illustrating the lack of consistency in the use of the term "disability" in research in this area.

Results of analysis of the 42 studies found mothers of children with developmental disabilities to have a higher than average rate of depressive symptoms, and to be more at risk for clinical depression. The weighted average of reported rates of depression (ie the percentage of mothers with a number of symptoms above a threshold for depression as measured by standardised ratings scales such as the BDI and the CES-D) resulted in an estimated rate of 23.6 % across all studies, compared to the 29% reported in Singer"s (2006) analysis. Bailey et al. also found mothers of children with autism and/or high ratings on a measure of behaviour problems had consistently higher ratings of depressive symptoms. As well, in all cases where higher rates of depressive symptoms were reported mothers also reported high levels of stress, less effective coping styles, poorer health and low family support or cohesion.

In summary, although many of the studies investigating prevalence of psychological problems for mothers of children with disabilities are of dubious quality, evidence from the substantial literature in this area, summarized by both Singer (2007) and Bailey et al (2007), shows mothers to be at greater risk of experiencing psychological distress and particularly symptoms of depression.

1.32 Parenting stress

The presence of child disability has been typically assumed to be a factor (a "stressor") that may contribute to higher levels of parental stress (Dyson, 1993). Research examining psychological well-being for parents of children with disabilities has, therefore, in addition to investigating mental health outcomes such as depression also investigated whether stress is a consequence of caring. Studies have most commonly found this to be the case. That is, they found parents (usually mothers) generally experience higher levels of stress than parents of children without disabilities (Dyson, 1991; Dyson, 1993; Pelchat, 1995; Webster, Majnemer, Platt, & Shevell , 2008; Woolfson and Grant , 2007). Dyson (1991, 1993) for example, used the Questionnaire on Resources and Stress (Holroyd, 1987) in a longitudinal study of 55 families caring for children with "developmental handicaps" in comparison with 55 families caring for children without handicaps. Children were under seven years of age when first assessed and between five and 11 years at re-assessment four years later. Child diagnoses included mental retardation, physical and sensory handicaps, speech disorders, learning disabilities, and developmental delays. Dyson found parents of children with disabilities experienced significantly higher levels of stress than parents of comparison children on both occasions of assessment. In particular, increased parental stress related to (a) parent and family problems in the care of the child, and (b) parental pessimism over the child‟s future.

A number of more recent studies have used the Parenting Stress Index (PSI: Abidin, 1995) to investigate the well-being of parents of children with disabilities. Pelchat et al. (1999) found 144 mothers and fathers of infants with Down syndrome or congenital heart disease to have higher levels of parenting stress than parents of babies with a cleft lip/ palate, or no disability. Parents of children with Down syndrome and heart disease also reported higher stress appraisal, and more psychological distress than parents of children in the other groups. Mothers experienced more stress related to role restriction; felt more threatened and stressed by their parenting role; and reported more psychological distress than fathers in all groups (including parents of babies without disabilities). Woolfson and Grant (2007) also used the PSI to investigate the well-being of 53 parents of children with moderate to severe developmental delays (including children with a diagnosis of autism, Down syndrome and cerebral palsy) in comparison with 60 parents of typically developing children. This study is one of only a few to examine the consequences of caring for children of different ages. Woolfson and Grant found no difference in levels of parenting stress for carers of children with developmental disabilities between 3-5 years of age, compared with carers of children 9-11 years of age. When compared with parents of typically developing children, however, parents of children with developmental delays experienced significantly higher levels of parenting stress.

Finally, Webster, Majnemer, Platt, & Shevell (2008) examined levels of parenting stress in 65 parents of school aged children who had previously been identified as having global developmental delay or developmental language impairment prior to school entry. Over 95% of children continued to show developmental impairments on reassessment approximately 4 years after first diagnosis. Almost half the parents in this study were found to have clinically significant levels of total parenting stress as measured by the PSI (ie scoring at or above 85% for this scale).

1.33 Marital adjustment

Early studies assumed the birth of a child with disability was “a tragedy”, resulting in negative outcomes for parents and families (Dykens & Hodapp, 2001). A consequence of this “tragedy” model was the expectation that parents of children with disabilities would be more likely to experience marital distress and to have higher rates of divorce and separation than other parents (Risdal & Singer, 2004). The evidence for this, however, is inconclusive. Benson and Gross (1989) reported that studies investigating the impact of childhood illness or disabilities diagnosed at birth, on marital relationships showed extensive variability in outcomes for couples. This finding is reflected in the Australian Institute of Health and Welfare (2003) report, based on the 1998 Survey of Disability, Aging and Carers (ABS, 2003) which showed that 25% of carers felt their marital relationship was unaffected by their caring responsibilities, 13% experienced a greater closeness, about 26% described their relationship as strained, and another 20% reported they lacked time alone together.

A recent meta-analysis of research addressing the comparative levels of marital satisfaction or discord among parents of children with or without disabilities was undertaken by Risdal and Singer (2004). As in the meta-analysis undertaken by Singer (2006), addressing the question of maternal depression, stringent criteria were used for the selection of studies. Studies needed to have a comparison group of children without disabilities; to have used standardized measures of marital satisfaction or adjustment, or report divorce and separation rates; and to have included sufficient statistical information to enable calculation of an effect size. Of the several hundred studies found during an initial search of the literature, only13 met the criteria for inclusion in the meta-analysis. Nearly one third of these articles were also included in the later meta-analysis investigating maternal depression. The studies, conducted between 1975 and 2003, included children with a wide variety of disabilities, including autism; spina bifida; mental retardation; and cerebral palsy. Six studies reported divorce or separation rates indicating that in families of children with disabilities, the average increase in the percentage of marriages ending in divorce was approximately six percent. The remainder of studies reviewed used standardised measures to assess marital satisfaction and adjustment. Results of the meta-analysis, synthesizing the results of all studies, showed an overall weighted effect size for marital adjustment of d=.21. While this indicates an increased level of marital strain in families of children with disabilities, Cohen"s (1988) guidelines for interpreting the significance of effect sizes suggests .21 is a relatively small effect size. Risdal and Singer conclude that early assumptions of "severe strain" in families of children with disabilities are not supported by the studies included in their meta-analysis.

1.34 Physical health

Many studies have demonstrated a link between chronic stress and indices of poor health, and suggest stress may promote earlier onset of age-related diseases (Epel et al., 2004; McEwen, 1998; Segerstrom & Miller, 2004). Research examining the experience of caring for the elderly, considered in this context as a chronic stressor, has shown a greater risk of health problems for the carer, with evidence of increased stress hormones and poorer immune function (Vitaliano, Zhang, & Scanlan, 2003). There have been fewer studies investigating the physical health of parents caring for children with disabilities. A national survey of almost 1500 carers, undertaken by the Carers Association of Australia (Briggs & Fisher, 2000), found the most frequently reported negative physical health change was tiredness or exhaustion (55%). Upper body (back/ neck/ shoulder) problems were particularly common for carers of children (47%). Rates of back pain reported by 113 parents of children with physical disability attending paediatric hospital clinics were shown to be as high as 70% (Tong et al., 2003). Brehaut et al. (2004) undertook a large scale population survey of 468 parents of children with cerebral palsy. Parents in this study reported higher rates of most types of chronic physical health problems, in comparison with parents of children without disabilities. Health conditions included arthritis; back problems; migraine; heart disease and stomach ulcers. Finally, a qualitative study of 40 parents of children with a wide range of severe disabilities (including mental retardation, physical disabilities and psychiatric disorders) found more than half of parents in the study reported their physical and emotional health had been negatively impacted by the demands of caring (Murphy, Christian, Caplin, & Young, 2006). All parents reported experiencing chronic fatigue and sleep deprivation. Nearly three out of five parents reported difficulty performing their daily work because of poor physical health; slightly more than half reported experiencing moderate to severe pain in the four weeks prior to the study. Significantly, most parents ranked their own health needs as having low priority and neglected their health due to time constraints and lack of alternative care providers.

1.35 Comparison of maternal and paternal well-being

Few studies have examined the impact of caring for children with disabilities on the psychological well-being of fathers. In some cases, information collected from fathers has been combined with that collected from mothers (eg Baxter, Cummins & Yoilitis, 2000; Dyson, 1991, 1993). This is most often a consequence of the smaller numbers of fathers who are recruited to research of this kind. Studies specifically focusing on differential impacts for parents are generally characterized by small numbers of participating fathers (eg Esdaile & Greenwood, 2003; Young & Roopnarine, 1994; Hastings, 2003). This has contributed to conflicting results. A number of researchers, for example, have found fathers experience similar levels of stress to mothers. Esdaile and Greenwood (2003) used the Parenting Stress Index (PSI) to investigate levels of parenting stress in a sample of 53 mothers and 25 fathers of preschool aged children with unspecified disabilities. Results showed both mothers and fathers to experience elevated levels of parenting stress in comparison with parents of children without disabilities. Mothers, however, reported feeling more restricted by their parenting role and also had higher scores on the depression subscale of the PSI. Mothers and fathers of preschool aged children with Down syndrome (Roach, Osmond, & Barratt, 1999) and mothers and fathers of preschool aged children with developmental disabilities (Oelofsen & Richardson, 2006) were also found to have high scores on the PSI, in comparison with parents of typically developing children. In the latter study, 84% of mothers and 67% of fathers scored above clinical cutoffs, indicating clinically significant levels of parenting stress.

In contrast to these findings, other studies have failed to find differences between fathers caring for children with disabilities, and fathers of children without disabilities when using other measures of well-being. Rodrigue, Morgan and Geffken (1992) compared 20 fathers of children with autism, 20 fathers of children with Down syndrome, and 20 fathers of developmentally normal children using a range of self-report measures of individual and family functioning. Results showed fathers in all three groups reported similar levels of perceived parenting competence, marital satisfaction and social support. As well, Young and Roopnarine (1994) compared parents in 23 families of preschool aged children with disabilities, with parents in 24 families of children without disabilities. Children had a range of diagnoses including autism, Down syndrome cerebral palsy and language/speech delay; with a wide range of severity of disability. No significant differences were found between the two groups of fathers on measures of family functioning, marital stress and social support.

Pelchat, Lefebvre and Levert (2007) undertook a systematic review of ten years of research examining the different experiences of mother and fathers parenting children with health problems (a term used to describe children with chronic health problems as well as physical and intellectual "deficiencies"). While acknowledging inconsistency in the findings of different studies, Pelchat et al. conclude that there is more evidence to suggest mothers feel greater stress, are more likely to have depressive episodes, and to show more emotional distress than fathers. Olsson and Hwang (2001) illustrate this finding, in a large study which compared mothers and fathers of 65 children with autism, mothers and fathers of 151 children with intellectual disability but no autistic behaviours, and mothers and fathers of 214 children with no disabilities. They found mothers of children with autism to have the highest levels of depressive symptoms as measured by the Beck Depression Inventory (Beck, Steer, & Garbin, 1988; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), followed by mothers of children with intellectual disability, then fathers of children with autism and fathers of children with intellectual disability. Mothers and fathers of typically developing children had the lowest depression scores, all being within normal limits for the BDI.

Pelchat et al. also suggest that there is evidence fathers experience stress differently from mothers. Frey, Greenberg and Fewell (1989), for example, found fathers of children with “handicaps” (primarily Down syndrome but also including children with cerebral palsy) experienced more distress if their children with disabilities were male, had lower levels of communication (more severe disability), and if they experienced criticism within their support network. Krauss (1993) reported the well-being of fathers of 121 “toddlers” with disabilities was influenced by the child‟s temperament, the quality of their relationship with the child, and the quality of the family environment. Mothers‟ stress levels, however, were more influenced by the personal consequences of caring, and social support networks. Finally, Hastings (2003) investigated the role of behaviour problems and partner mental health in 18 couples caring for children with autism. Results showed child behaviour problems and fathers‟ mental health were associated with mothers‟ stress levels but that neither child behaviour problems nor mothers‟ mental health contributed to fathers‟ stress levels.

1.36 Longitudinal studies

Most studies reported in the previous sections have used cross-sectional methodologies. While these have generally shown parents (particularly mothers) of children with disabilities experience greater psychological distress and poorer physical health than parents of children without disabilities, it is difficult to make conclusions about longer term impacts. A small number of longitudinal studies provide some information about outcomes for parents over time.

As previously described, Dyson (1991, 1993) investigated stability and change in levels of parental stress experienced by carers of children with disabilities. Parents (mostly mothers) of 38 children with disabilities, and 36 children without disabilities completed the Questionnaire on Resources and Stress (Friedrich, Greenberg and Crnic, 1983) on two occasions, four years apart. Parents of children with disabilities (aged between 5 and 11 years at re-assessment) were found to have significantly higher levels of parent stress, which persisted over time.

A much larger scale longitudinal study, the Early Intervention Collaborative Study, is described by Hauser-Cram, Warefield, Shonkoff and Krauss (2001). This study investigated outcomes for 183 children with Down syndrome, motor impairment and developmental delay and their parents, assessed at five time points from point of entry into an early intervention programme to the child‟s 10th birthday.

Parent well-being was assessed using the Parenting Stress Index (PSI), with results described in terms of child-related stress and parent-related stress, the two components comprising the parenting stress measure. Hauser-Cram et al. found a high percentage of mothers (38%) and fathers (44%) had scores indicating clinically significant levels of child-related stress when their child reached 10 years of age. Rates of parent-related stress showed a linear increase over time for both parents, but relatively fewer mothers (11%) or fathers (11%) scored above clinical cutoffs when their child was 10 years.

An Australian longitudinal study compared information collected from parents of children with moderate/ severe disabilities, over a seven year period (Baxter, Cummins, & Yiolitis, 2000). All children in this study attended or were on the waiting list to attend a special school, and at initial assessment were between 3-5 years of age; 10-12 years of age; or 17-19 years of age. The initial sample size for this study was 131 parents from 70 households, dropping to 93 on reassessment approximately seven years later. The focus of the study was the attributions parents made about their stress levels over time (with parent stress assessed using a simple self-report scale rather than standardised measures), and changes to the specific foci of parental worry. Results showed parents attributed almost double the amount of stress to their child with a disability, in comparison with the level of stress attributed to their youngest child without a disability, on both occasions of testing. Scores on the measure of stress remained stable over time though the strength of specific worries decreased over the seven year period. Somewhat unexpectedly, the pattern of worries remained the same over this time for children of all ages. Predominant worries related to children"s behaviour and speech.

A final longitudinal study of note was undertaken by Gallimore and colleagues, focusing on the ways families create and sustain a daily routine (ie the process of “family accommodation”) in response to child disability (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996; Gallimore, Keogh, & Bernheimer, 1999; Keogh, Garnier, Bernheimer, & Gallimore, 2000). These authors found the number and range of accommodations made by families increased as children with developmental disabilities grew older. Examples of accommodations included: “mother‟s decision to stay home because child needed her”, “mother got up at 4am to do laundry, housework”, and “child‟s older sisters assisted with child care tasks”. The “intensity” of accommodations was found to remain stable between three years and seven years, but decreased significantly from seven to 11 years.

In summary, results of the longitudinal studies reviewed here, suggest the higher levels of stress experienced by parents of children with disabilities are likely to persist throughout the early to middle childhood period.

1.37 Caregiver burden (strain)

Final mention should be made of the concept of caregiver burden that has been widely used to describe the impact and/ or stress that a family member experiences when undertaking caring, particularly in research focusing on outcomes for carers of adults with physical and mental illness (Montgomery, 1989; Sales, Greeno, Shear, & Anderson, 2004). More recently the term caregiver strain has been used in preference to the more emotionally laden caregiver burden (Brannan, Heflinger, & Bickman, 1997). Brannan et al. define caregiver strain as “the demands, responsibilities, difficulties, and negative psychic consequences of caring for relatives with special needs" (Brannan et al., 1997, p. 212). They suggest caregiver strain is conceptually distinct from psychological "distress". Support for this has been found by Brannen and Heflinger (2002), using data from the Fort Bragg Evaluation Project, a large scale longitudinal evaluation of outcomes for 514 children receiving intervention for emotional and behavioural problems, and their families. Parents completed measures of caregiver strain, as measured by the Caregiver Strain Questionnaire (CGSQ: Brannan et al., 1997) and caregiver psychological distress measured by the Brief Symptom Inventory (BSI: Derogatis & Melisarartos, 1983). Results showed caregiver strain and caregiver psychological distress to be related to each other, but to have different correlates. Child symptoms, as measured by the Child Behavior Checklist (CBCL: Achenbach, 1991) were the best predictor of caregiver strain, while life stressors were the best predictor of caregiver distress.

Typically, caregiver strain is viewed as comprising two different dimensions (Montgomery, 1989). Objective strains reflect impositions that can be objectively quantified, such as impacts on finances and activities. Subjective strains reflect impositions on feelings and family relationships. This is a useful distinction, with a recent study, using an adaptation of the Burden Assessment Scale (Reinhard, Gubman, Horwitz, & Minsky, 1994) showing 81 mothers of children with disabilities (including cerebral palsy, Down syndrome, spina bifida and unspecified developmental delay) to be more likely to report being affected by indicators of objective burden (eg financial stresses and time constraints) than the emotional distress of subjective burden (Green, 2007). Green found mothers of children with a disability to be more likely to experience feelings of fatigue, than feelings of emotional distress.

The concept of caregiver strain has not been widely used in research examining outcomes for parents. The development of the CGSQ has facilitated research into the extent of caregiver strain experienced by parents of children with mental health issues. Recent studies have examined the relationship between caregiver strain and use of child health services (Brannan & Heflinger, 2005; Brannan, Heflinger, & Foster, 2003) and differences in the experience of caregiver strain in families with different types of caregivers (Taylor-Richardson, Heflinger, & Brown, 2006) and caregivers of different racial backgrounds (Kang, Brannan, & Heflinger, 2005). Investigation of caregiver burden or strain in parents of children with disabilities, however, has not been examined in detail or systematically. The terms may be used without reference to a clear conceptual framework. Maes, Broekman, Došen, & Nauts, (2003), for example, describe their goal of investigating caregiving burden in families with children and adults with intellectual disability, without clearly defining what is meant by burden or indicating how their measures operationalise the concept.

The CGSQ, as a standarised measure of caregiver strain, has potential to contribute to a more comprehensive understanding of the experiences of parents caring for children with disabilities. Caregiver strain has the advantage of being specifically related to caring, and may be a more sensitive measure of the impact of caring than measures of either psychological well-being or parenting stress (Montgomery, 1989).

1.4 Conclusion

The evidence reviewed in this chapter relates to a substantial number of studies examining outcomes for parents who are caring for children with developmental or intellectual disabilities. As illustrated during the chapter, despite the volume of research, many of the studies undertaken have been flawed by methodological problems. In particular, studies generally lack a clear definition of disability, resulting in the inclusion of children with different types of disability; studies predominantly have small sample sizes; and studies either focus on the experience of mothers or fail to differentiate between data collected from mothers and fathers. Most studies have used cross-sectional designs, though a small number of longitudinal studies have contributed important information.

Despite the variable quality of research, the large number of studies undertaken and the consistency of results obtained allow some conclusions to be made about psychological and physical health outcomes experienced by parents of children with disabilities. Firstly, in contrast to assumptions underlying much of the research undertaken prior to the 1980s, there is evidence that not all parents caring for children with disabilities have poor outcomes. Researchers are now more likely to conceptualise caring as a stressor which impacts differentially on parents (Dykens & Hodapp, 2001). Secondly, the preponderance of evidence described in the present chapter suggests parents caring for children with disabilities are more at risk of experiencing poorer psychological and physical health outcomes than other parents. Mothers in particular, exhibit higher rates of depressive symptoms, and are more at risk of clinical depression (Singer, 2006; Baily et al, 2007). As well, studies consistently show mothers and fathers of children with disabilities to have high levels of parenting stress (Dyson, 1991, 1993; Pelchat et al 1999; Woolfson & Grant, 2007), which persists over time (Hauser-Cram, Warefield, Shonkoff and Krauss, 2001). They are also more likely to experience marital strain, though rates of marital separation and divorce are only marginally higher than in families of children without disabilities (Risdall & Singer, 2004). Finally, a smaller number of studies suggest parents risk experiencing a range of physical health problems, particularly back pain (Tong, 2003; Brehaut et al, 2004).

Evidence of poorer outcomes for parents caring for children with disabilities is concerning, as the success of home based care is dependent on the well-being of parents. Chapters 2-4 will review studies exploring factors which may help to answer why it is that some families or individuals are negatively affected by caring and others are not. Rather than simply investigating the "direct effects" of caring, different methodologies, such as an increased use of within group analyses to examine moderating or mediating variables, are more frequently being used in research, accompanied by new theoretical models.

CHAPTER 2

Factors influencing psychological outcomes for carers

2.1 Overview:

A number of variables have been hypothesized to influence the relationship between caring for a child with a disability, and outcomes for parents. One set of research has examined contextual variables, such as different characteristics of the child‟s disability. Another set has investigated intervening variables, such as the interpersonal and personal resources available to parents (eg social supports or coping strategies). This chapter will review studies describing relationships between characteristics of child disability and outcomes for parents caring for children with disabilities, and will also present an overview of research examining the role of social support in contributing to parental well-being.

2.2 Characteristics of child disability

The largest group of studies examining factors that may predict psychological outcomes for parents has focused on characteristics of child disability. The following sections will firstly review studies investigating the well-being of parents caring for children with different diagnoses. Secondly, research involving variables which are typically used to assess "severity of disability" will be summarized. Unfortunately, there is no universal definition of severity, which limits the ability to compare results across studies. In some cases, severity is measured by level of adaptive behaviours (including the ability to complete activities of daily living, as well as communication and social skills) or by extent of caring tasks undertaken by parents (Breslau et al., 1982; Wallander, Pitt, & Mellins, 1990; Wiegner & Donders, 2000). In other studies, severity of disability is reflected by the presence of additional problems such as emotional or behavioural problems (eg Baker, Blacher, & Olsson, 2005; Floyd & Gallagher, 1997; Hastings, Daley, Burns, & Beck, 2006). Of note, epidemiological studies suggest about 40% of children with developmental and intellectual disabilities are also found to have significant levels of psychopathology (Dekker, Koot, Van der Ende, & Verhulst, 2002; Einfeld & Tonge, 1996; Hoare et al., 1998; Stremme & Diseth, 2000). Evidence examining the role of adaptive behaviours, and additional behavioural problems will be discussed separately.

2.21 Diagnostic group

Many children with developmental delays or intellectual disability have no identified reason for their cognitive impairment. There is evidence that a lack of diagnosis can be a source of parent distress. For example, Feldman et al. (2007) found parents of 2 year old children with no specific diagnosis explaining their developmental delays had higher levels of depressive symptoms, as measured by the Beck Depression Inventory (Beck et al., 1988; Beck et al., 1961), than parents of children with specific diagnoses. Other children, however, have an identified diagnostic reason for their developmental or intellectual disability. Disabilities of differing aetiologies vary in their profiles of typical behaviours (“behavioural phenotypes”) and in the probability of co-morbid conditions (Dykens & Hodapp, 2001). Considerable research has been conducted looking at the behavioural features of two of the most common diagnostic groups: autism and Down syndrome. Head and

Abbeduto (2007) described Down syndrome, the most common chromosomal disorder leading to cognitive impairment, to have a characteristic phenotype with both physical and behavioural features. Children with Down syndrome experience serious delays in language development. They are typically described as being sociable and having low rates of challenging behaviours. In contrast, Head & Abbeduto (2007) reported children with autism, a neuron-developmental disorder, to experience impairments in communication and social reciprocity, and display high levels of behavioural difficulties. Behaviours that are typically associated with autism include: stereotyped and repetitive motor mannerisms (ie hand or finger flapping/ twisting) and adherence to specific, nonfunctional routines. Children with autism, however, may also exhibit problem behaviours such as physical aggression, self-injury, defiance and tantrums (Horner, Carr, Strain, Todd, & Reed, 2002).

Recently, researchers have begun to examine whether behavioural phenotypes impact on parents in different ways, leading to differences in psychological outcomes (Head & Abbeduto, 2007). Eisenhower, Baker and Blacher (2005) examined the relative contribution of syndrome, cognitive level and behaviour problems (measured using the Child Behaviour Checklist, Achenbach, 2000) to the stress levels of mothers caring for 215 pre-school aged children, 79 of whom were receiving early intervention for developmental delays. Within the developmentally delayed sample, 43 children had no specified diagnosis, 12 children had a diagnosis of Down syndrome, 14 had autism spectrum disorders, and 10 had cerebral palsy. Eisenhower et al. found child behaviour problems accounted for considerable variance in maternal stress, as measured by the negative impacts of caring on the Family Impact Questionnaire (FIQ: Donenberg & Baker, 1993). Child syndrome, however, contributed to levels of parental stress after controlling for behaviour problems and cognitive level. The independent contribution of syndrome was mostly accounted for by the autistic group. That is, mothers of children with autism were more likely to experience negative impacts of parenting than mothers of children in other diagnostic groups. Eisenhower and colleagues suggest this may be because of the impact of behaviours not measured by standard behavioural checklists, such as self-injury, insistence on routine and disrupted sleep.

Blacher and McIntyre (2006) explored the well-being of mothers caring for 282 young adults (aged between 16 and 26 years of age) with moderate to severe intellectual disability of different aetiologies. Fifty nine young adults had a diagnosis of Down syndrome, 23 had a diagnosis of autism, 87 of cerebral palsy and 113 had undifferentiated intellectual disability. While they too found maternal well-being was almost entirely accounted for by the level of behavioural problems, diagnostic status was also shown to have an independent contribution to positive impact of parenting (also measured by the FIQ), in this case accounted for by children with Down syndrome. That is, mothers were more likely to experience positive impacts from parenting a young adult with Down syndrome, than parenting young adults with other diagnoses.

The comparatively small numbers of children within diagnostic groups in the above two studies reflect a problem for the research in this area more generally, and suggest caution in generalizing from results. The two studies, however, also illustrate the most frequent findings in this area. Firstly, parents of children with a diagnosis of autism are shown to experience poorer psychological outcomes than parents of children with other diagnoses (Bailey, Golden, Roberts, & Ford, 2007; Singer, 2006) As well, parents of children with Down syndrome are usually found to cope slightly better than parents of children in other diagnostic groups, a phenomenon called the "Down syndrome advantage" (Hodapp, 2007). Hodapp points out, however, that the Down syndrome advantage occurs relative to families of children with other diagnoses. Parents of children with Down syndrome generally show higher levels of stress when compared to parents of children without disabilities (Roach et al., 1999).

2.22 *Severity of disability: Adaptive behaviours*

Children with disabilities, particularly intellectual disabilities, exhibit varying degrees of impairment in adaptive behaviours (Sparrow, Balla, & Cicchetti, 1984). Adaptive behaviours are those that are needed by individuals to take care of themselves, to get along with others and to handle everyday demands in different settings. They include the ability to perform tasks of daily living, communication skills and social skills. These abilities are considered conceptually distinct from cognitive skills, as measured by intelligence tests (Luckasson et al., 2002). The terms "functional skills" or "functional abilities" or "functional independence" are also used to describe adaptive behaviours. The present dissertation considers these terms to be interchangeable, directed by the type of measure used to assess behaviours. The Vineland Adaptive Behavior Scale (Sparrow et al., 1984) has been used most frequently in intellectual disability research, while the WeeFIM® (Msall et al., 1994b), a children"s version of the Functional Independence Measure, has been principally used in the disability and rehabilitation literature.

Children with greater severity of disability as measured by their level of adaptive behaviours are more physically dependent upon their parents for assistance with everyday activities. Intuitively, it may be expected that these increased care demands will lead to greater parenting stress and poorer psychological well-being. While there is some evidence for this proposition, there are also studies which show level of adaptive behaviours to have no, or little, impact on parental outcomes. Evidence for both conclusions is summarized below.

Early studies assessed level of adaptive behaviour or functional skills by using checklists completed by parents, describing the level of help provided to children with self-care activities or mobility. Results of these studies found evidence in support of the hypothesis that children with less skill were more likely to have parents with poorer psychological adjustment. Breslau, Staruch & Mortimer (1982), for example, found levels of psychological distress reported by mothers of 369 children aged 3-18 years with chronic illness or physical disabilities, to be significantly related to the degree of help the child required with daily activities. In a smaller scale study of 31 infants with developmental delays, Beckman (1983) found parent reported caregiving demands, reflecting the degree of help required with daily living skills in areas such as feeding, mobility or medical needs, to be positively correlated with levels of maternal stress as measured by the Questionnaire on Resources and Stress (Holroyd, 1987). Leonard, Johnson and Brust (1993) also used a checklist to assess children"s ability to perform tasks of daily living such as feeding, toileting and dressing. In this study, mothers of children aged 0- 18 years who were eligible to participate in a specialized programme for children with handicaps, were categorised as being “OK” or “not OK” on the basis of their response to the question “How much longer do you feel you can provide care". Ninety five parents indicated they were managing "OK". Thirty seven parents, placed in the "not OK" group, indicated they were managing but needed help, or were not managing and looking at alternative care arrangements. Results showed mothers of children described as having more severe disabilities, and greater functional dependence, were more likely to be "not OK".

Results of studies using standarised measures of adaptive functioning, such as the Vineland Adaptive Behavior Scales (VABS: Sparrow, 1984), have been inconsistent. Some have shown no relationship between adaptive behaviour and parental well-being. Others have found parents of children with lower levels of adaptive behaviour (ie greater severity of disability) have poorer outcomes, that is, parents of children with lower levels of adaptive behaviours report more stress or depressive symptoms than parents of children with higher levels of adaptive behaviours. This situation appears unrelated to characteristics of children included in the studies (eg age of child, diagnosis, or cognitive level) or measures used to assess parent well-being. It should be noted that most studies in this area have small samples. Studies with larger sample sizes typically have a broader definition of disability, for example, including children with chronic medical conditions (Breslau et al., 1982; Wallander et al., 1990; Wiegner & Donders, 2000)

Studies finding no relationship between severity of disability, as reflected by lower levels of adaptive behaviours, and parent outcomes include research undertaken by Jan Wallander and colleagues. Wallander, Pit and Mellins (1990), found levels of child adaptive behaviours (described as functional independence), using the VABS, to be unrelated to measures of stress or psychological adaptation experienced by 131 mothers of children aged 2-18 years diagnosed with cerebral palsy, spina bifida, or hearing problems. This study replicated findings from an earlier, smaller study involving 50 mothers of children aged 6-11 years with physical disabilities which found neither severity of physical handicap (rated from observation of the child), or child intellectual functioning, was related to maternal psychological functioning (Wallander et al., 1989a). Wallander et al. (1990) concluded from both studies, that differences in maternal adaptation are better explained by mothers‟ perceptions of the strain of caring for the child, regardless of extent of disability. More recently, Wiegner and Donders (2000), also found level of adaptive behaviours as measured by the VABS, of 121 children between 3-12 years with cerebral palsy, spina bifida, and limb deficiencies, to be unrelated to parental distress. They suggested parental perception of unequal role distribution and lack of family support with day-to-day family tasks was more important in predicting parent distress than objective degree of burden as reflected by severity of child disability.

In contrast to the above research, White and Hastings (2004) examined the relationship between level of adaptive behaviours (using the VABS) of 33 adolescents with moderate-profound intellectual disabilities, and parent well-being as measured by standardized measures of anxiety and depression and the Questionnaire on Resources and Stress (Holroyd, 1987). Results showed significant negative correlations between scores on the VABS and the measures of parental well-being, suggesting children with lower levels of adaptive behaviours had parents with high levels of anxiety and stress. Finally, Plant and Sanders (2007) used the VABS to investigate factors contributing to stress of mothers of pre-school aged children with developmental disabilities (including Down syndrome, cerebral palsy, autism and unspecified developmental delay). Results showed level of child disability as reflected by scores on the VABS, to make a unique and significant contribution towards predicting higher levels of parental stress (as measured by ratings of stress associated with specific caregiving tasks).

In summary, results of studies investigating the role of adaptive behaviours in predicting parent psychological well-being have been inconsistent. Early studies using parental checklists to identify the level of help provided to children with self-care activities or mobility, were more likely to find a positive association between amount of help required and levels of parental stress or distress (Beckman, 1983; Breslau, Staruch & Mortimer, 1982; Leonard, Johnson and Brust, 1993). Some researchers, using standardized measures of adaptive functioning, have also found that parents of children with greater severity of disability (as reflected by lower levels of adaptive behaviours) experience higher levels of stress and anxiety (Plant & Sanders, 2007; White & Hastings, 2004). In contrast, others have found no relationship between parental stress and adaptive behaviours (Wallander et al., 1990; Wallander et al., 1989a). In general, however, studies in this area feature small sample sizes and/or include children with a broad mix of impairments which may contribute to the mixed results.

2.23 Severity of disability: Behavioural problems

A large body of research has highlighted the role of child behaviour problems in contributing to differences in outcomes for parents caring for children with disabilities. One group of studies has contrasted the psychological well-being of parents of children with disabilities who also have behaviour problems, with the well-being of parents of children without disabilities who also have behaviour problems. Donenberg and Baker (1993), for example, compared primary carers of 22 preschool aged children with “externalising” behaviour problems (ie children exhibiting hyperactive or aggressive behaviours), 20 children diagnosed with autism (ie having intellectual and social disability), and 22 children without disabilities. In all but two cases, primary carers were mothers. Multiple measures of parent well-being were used, including the Parenting Stress Index (Abidin, 1995), the Family Impact Questionnaire (Donenberg & Baker, 1993), and the Beck Depression Inventory (Beck et al., 1988; Beck et al., 1961). Results showed primary carers of children with behaviour problems scored similarly to parents of children with autism on measures of child related stress, and family impact. That is, carers of children with externalizing behaviour problems and carers of children with autism reported higher child-related stress, more negative impact of parenting; and less positive feelings toward parenting than parents of normally developing children.

A study undertaken by Floyd and Gallagher (1997) compared mothers and fathers of 66 school aged children (6-18 years of age) with mental retardation without behaviour problems; 46 children with mental retardation and behaviour problems; 45 children with chronic illness or physical disability without behaviour problems; 28 children with chronic illness/ physical disability and behaviour problems; and 46 children with no cognitive impairment, chronic illness or physical disabilities but who were receiving mental health services for help with emotional or behavioural problems. Behaviour problems were identified by using the clinical cut-off on the Child Behavior Checklist (Achenbach, 1991), and parent stress was assessed using the

Questionnaire on Resources and Stress (QRS: Holroyd, 1987). Floyd and Gallagher concluded that the presence of behaviour problems was more important than type of disability in predicting most forms of parent stress, as reflected by the different scales of the QRS. In particular, child behaviour problems were associated with higher levels of reported parent and family problems, more depressive symptoms and more time demands for mothers; and more stress associated with child dependency for both mothers and fathers. Results also showed greater utilization of support services, particularly mental health services, was associated with child behaviour problems, regardless of disability status.

More recently, researchers have used longitudinal designs to examine how child behaviour problems may be causally related to parent well-being. Baker and colleagues at the University of California (Baker, Blacher, Crnic, & Edelbrock, 2002; Baker, Blacher, & Olsson, 2005; Baker et al., 2003) examined the well-being of mothers and fathers of 81 pre-school aged children with developmental disabilities (excluding children with a diagnosis of autism), and 123 children without delays, over the period of a year. The Child Behavior Checklist (Achenbach, 1991) was used to assess child behaviour problems, and the Family Impact Questionnaire (Donenberg & Baker, 1993) and the Centre for Epidemiologic Studies Depression Scale (Radloff, 1977) were used to assess parental well-being. Results showed children with developmental delays to be three to four times more likely than children without disabilities to have a total behaviour problems score in the clinical range on the CBCL. As well, mothers and fathers of children with developmental delays reported greater negative impact of the child on the family. Levels of both child behaviour problems and parental stress were shown to remain stable over the course of the year.

Regression analyses found parent experience of child related stress was more strongly related to the presence of behaviour problems than to extent of developmental delay. As well, levels of child behaviour problems at three years of age, and increases in behaviour problems over the one-year period were associated with higher levels of parent stress. Baker et al. (2005) suggest this finding was consistent with a transactional model, such that behaviour problems and parent stress have a mutually escalating effect on each other.

Hastings, Daley, Burns and Beck (2006) undertook a two year longitudinal study of 75 mothers of children with intellectual disabilities (aged between 3 and 19 years of age). Child behaviour problems were measured using the Strengths and Difficulties Questionnaire (Goodman, 1997), and maternal well-being was assessed using the Parent Stress Index (Abidin, 1995) and the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). Results of this study showed externalizing behaviour problems (eg hyperactivity and aggression), rather than internalizing problems (eg anxiety) to be better predictors of maternal stress than child diagnosis. Analysis of follow-up data showed maternal stress and child externalising behaviour problems to have a bi-directional relationship over time, consistent with the findings of Baker et al. (2003). That is, maternal stress led to increases in child behaviour problems over time, and child behaviour problems led to increases in maternal stress over time.

Another group of studies has examined the influence of child behaviour problems on the well-being of parents of children with specific diagnoses. Raina et al. (2005) undertook a large multi-factorial study of 468 families of children with cerebral palsy. Child behaviour problems were measured by a short form of the Child Behavior Checklist (Achenbach, 1991) while well-being of the primary caregiver was measured using items selected from a national population survey. Results of structural equation modelling (in which the contribution of a range of variables measuring different child, caregiver and family characteristics was evaluated) showed child behavioural problems to be the single most important child characteristic predicting both psychological and physical health of carers. As well as having a direct effect on parent outcomes, child behaviour problems also indirectly impacted on parent psychological health by influencing parental self-esteem and self-concept, and family function.

Lecavalier, Leone and Wiltz (2006) examined the impact of behaviour problems on caregiver stress of 293 children and adolescents (between 3 and 18 years of age) with autism. In this study child behaviour problems were assessed using parent and teacher completed versions of the Nisonger Child Behavior Rating Form, a behavioural checklist specifically for children with developmental disabilities (Aman, Tassé, Rojahn, & Hammer, 1996). Parent stress was measured using the short form of the Parental Stress Index (Abidin, 1995). Results found both parent and teacher ratings of behaviour problems were more strongly associated with parental stress than any other parent or child characteristics (including child adaptive behaviours). Conduct problems (ie aggressive and disruptive type behaviours) had the strongest relationships with parent stress. Parent rated child behaviour problems were stable over a one year period, and regression analyses also supported a transactional model of stress, such that behaviour problems and parent stress exacerbated each other over time.

In summary, research which has investigated the well-being of parents caring for children with developmental disabilities and additional behavioural problems has consistently shown that parents of children with disabilities and additional behavioural problems are more likely to experience stress and other negative outcomes, than parents of children without additional behavioural problems. The research in this area has been, for the most part, methodologically rigorous, and includes a number of longitudinal studies which indicate interactions between behavioural problems and parent stress over time, such that maternal distress leads to increases in child behaviour problems, and child behaviour problems lead to increases in maternal stress (Baker et al., 2005; Hastings, Daley, Burns, & Beck, 2006).

2.3 Social Support

The previous sections have reviewed evidence for the influence of child characteristics, and particularly indices of severity of disability, in helping to understand variability in the psychological outcomes of parents caring for children with developmental disabilities. Another significant area of research has investigated the importance of interpersonal resources in supporting the well-being of parents. The remainder of this chapter will firstly review theoretical issues and approaches to understanding and researching the role of social support in contributing to individual outcome. Secondly, research focusing on social support and parents caring for children with disabilities will be summarized.

Cohen and Wills (1985), reviewing research examining the role of social support in contributing to health outcomes carried out in the 1980s, concluded that a substantial number of studies showed social support to be a “causal contributor to (individual) well-being” (Cohen & Wills, (1985), p.310). That is, people with partners, family and friends who provide emotional and material support have better psychological and physical health than those with fewer social supports. Differences in theoretical, methodological and statistical approaches, in studies in this area, however, make it difficult to come to firm conclusions about the mechanisms by which social support may mitigate the effects of stress on individual well-being, as shown by the following brief overview.

Social support has been typically considered to contain both structural and functional elements (Lin, Ye, & Ensel, 1999). Structural elements are reflected by variables such as the size and density of social networks, from which functional supports (eg emotional or tangible aid) are derived. While some authors argue for the primacy of structural supports in contributing to psychological outcomes such as depression (Lin, Ye & Ensel, 1999), others suggest that network size does not necessarily reflect the quality, availability or effectiveness of support received (Kazak & Marvin, 1984; Pearlin, Menaghan, Lieberman, & Mullan, 1981; Quittner, 1992). There is evidence as well, for the differential importance of support received from different members of social networks. Spousal support, for example, has been found to be of greater importance than support from others (eg extended family or friends) for parents caring for children with behavioural problems or chronic illness (Quittner, 1992; Suárez & Baker, 1997).

Functional elements of social support are typically conceptualised as varying according to a number of dimensions. The distinction between *received social* *support* and *perceived social support* is one such dimension. Haber, Cohen, Lucas and Baltes (2007) describe measures of received social support, such as the Inventory of Social Supportive Behaviors (ISSB: Barrera, Sandler, & Ramsey, 1981), to assess the frequency with which specific supportive behaviours are provided to recipients by their support networks. For example, items in the ISSB include: "(How often have your friends or relatives) pitched in to help you do something that needed to be done … was right there with you (physically) in a stressful situation" (Barrera et al., 1981). In contrast, perceived support as described by Haber et al. reflects the recipient‟s perceptions concerning the general availability of support and/or global satisfaction with support provided. Measures of perceived support are subject to individual differences in perception, judgment and memory processes (Haber, 2007). One commonly used measure of perceived support is the Social Support Questionnaire (SSQ: Sarason, Levine, Basham, & Sarason) which includes items such as "Who (do you feel) accepts you totally, including your worst and best points?" and "Who helps you feel that you have something positive to contribute to others?" Respondents indicate both the number of perceived supports, and their satisfaction with perceived available support. Previous research has shown received social support and perceived social support to be only weakly related (Barrera, 1986; Sandler & Barrera, 1984). Studies comparing the relative influence of received social support and perceived social support in predicting psychological and health outcomes, however, have been inconclusive. Some studies have found perceived support to have the strongest association with outcomes (Quittner, 1992, Sandler and Barrera, 1984; Sarason et al 1987). Others, however, have found contrary evidence (Paykel et al , 1980; Haber, 2007).

Another dimension which has been used to describe functional elements of social support is the type of support provided. For example, Cohen and Wills (1985) describe four commonly used types of support: *esteem support; instrumental support; informational support; social companionship*. The first two types of social support are particularly important for parents of children with disabilities. Esteem support, subsequently described as emotional support in this dissertation, includes supportive actions encouraging the recipient to feel esteemed, cared for and accepted. In the context of parenting, emotional support raises the parent"s self-esteem and provides confidence to undertake the parenting role (Andresen & Telleen, 1992). Instrumental support (also described as tangible, material or practical support, the latter term preferred in this dissertation) involves the provision of financial aid, material resources or needed services. Practical support provides parents with the physical resources needed to cope with the demands of parenting, including behaviours that directly assist the parent such as helping with child care or housework (Andresen & Telleen, 1992).

Several models have been proposed to help explain the ways in which social support may modify the negative consequences of stress, each having important implications for the development of interventions to help people experiencing high levels of stress. The first, a "main" or "direct" effects model suggests that social support has generic beneficial effects for psychological and physical health, regardless of the person"s level of stress. Cohen and Wills (1985), in a review of the literature, found evidence for a main effect in studies assessing the degree to which a person is integrated into their social community; such that a person who is integrated in to their community, is more likely to experience positive well-being. An alternative model, the “buffer” or “moderator” model, suggests an interaction between levels of stress and social support, in their effect on well-being. Cohen and Wills (1985) also found evidence for the buffering effect of social support when the social support measures were perceived availability and responsiveness of interpersonal resources. Thus, a person who reports high levels of stress but who perceives themselves supported by others will be protected from the negative effects of stress.

A third “mediating” model suggests social support functions as an intervening variable between the stressor and outcomes. Support for a mediating model of stress has been found by Quittner, Glueckauf & Jackson, (1990) who compared outcomes for 96 mothers of children with hearing impairments (aged between 2 and 5 years of age) with 118 mothers of normally hearing children. Multiple variables describing maternal well-being were measured, including the Parenting Stress Index (Abidin, 1995) and the Centre for Epidemiological Studies Depression Scale (Radloff, 1977). As well, multiple measures of social support were used, including standardized measures of perceived emotional support and network structure (the Norbeck Social Support Questionnaire: Norbeck, Lindsey, & Carrieri, 1983), and satisfaction and need for support (the Arizona Social Support Interview Schedule; Barrera, 1981). Results showed mothers of deaf children experienced higher levels of parenting stress, more depressive symptoms, and had significantly smaller support networks than mothers in the comparison group. The two groups of mothers, however, did not differ in terms of the level of their perceived emotional support, though mothers of deaf children relied more heavily on health care professionals than family or friends to meet their support needs. Results of regression analyses showed little evidence for the moderating, or “buffering” models for either structural aspects of social support (ie network size) or for perceived support. In contrast, support was found for a mediating model, in which maternal stressors (as measured by the PSI) were associated with lower levels of perceived support and increases in symptoms of depression and anxiety. It is of note that in this study, parental stress was considered to be an independent variable, rather than a dependent variable as in other studies, illustrating the lack of conceptual consistency in the social support literature.

Inconsistent results between studies investigating the way in which social support may lead to psychological outcomes for individuals, may be a function of the multi-dimensional nature of social support. Different types of social support may have different types of relationship with different outcome measures. Some evidence for this proposition has been found by Suárez and Baker (1997) who investigated the mechanisms by which social support related to the stress of parents caring for children with externalizing type behaviour problems (ie aggressive, acting out behaviours). In this study, parent stress (considered to be a dependent or outcome variable) was measured by the three subscales of the Family Impact Questionnaire (FIQ: Donnenberg & Baker, 1993): Social Relationships; Negative Impact (of parenting); and Positive Impact (of parenting). Measures of perceived social support included a marital adjustment scale (the Dyadic Adjustment Scale: Spanier, 1976), a purpose developed scale assessing extent of agreement about child rearing, and a semi-structured interview aimed at identifying degree of support received from others (eg family and friends).

Suárez and Baker (1997) found evidence for co-existing main, moderating and mediating effects of spousal support on measures of parental psychological outcomes, and evidence for moderating effects of marital adjustment on outcomes. In addition, the study found different results for mothers and fathers, and for different subscales of the FIQ (ie social relationships; negative impact; and positive impact). Thus, spousal support and maternal adjustment moderated the impact of child behaviour on social relationships for mothers, and negative impacts of parenting for fathers. Spousal support was also shown to mediate between child behaviour and positive impacts of parenting for both mothers and fathers. That is, parents of children with higher levels of behaviour problems also reported less spousal support, and in turn reported fewer positive impacts of parenting. A mediating relationship between child behaviour problems, spousal support and negative impact for fathers, indicated fathers of children with high levels of behaviour problems also reported less spousal support and in turn more negative impacts of parenting.

Quittner (1992) proposed another primary reason for inconsistencies in research examining the mechanisms by which social support links stressors and individual outcomes: a lack of “contextual specificity”. She gave the example of studies that use life event scales (to obtain a measure of global life “stressors”) and measures of everyday “daily hassles” instead of assessing the specific stressors (and also social supports) that are relevant to the context in which individuals live. Other authors have also argued for the importance of matching the demands of the stressor (or the needs of the recipient) with types of support (Paykel, 1980; Pearlin et al, 1981). In relation to the specific situation of caring for children with disabilities, Quittner suggested a *contextual approach* would include consideration of factors such as: the severity of child disability; the age and developmental level of the child; and specific task demands (caring responsibilities) associated with characteristics of child disability. Types of support would relate to the primary social roles affected by the caring (eg parenting and marital relationships) and the principal needs of carers (eg for emotional and practical support).

2.31 Social support and parents of children with disabilities

Social isolation and loneliness are commonly reported consequences of caring (Briggs & Fisher, 2000). Parents of children with disabilities have been found to have smaller social networks than parents of children without disabilities (Kazak, 1987; Kazak & Marvin, 1984; Seybold, Fritz & McFee,1989). Kazak & Marvin (1984) suggest this is primarily due to smaller friendship networks, rather than smaller family networks. They suggest carers are more likely to rely on family support, and to relate to friends with common interests and activities, particularly the shared experience of caring for a child with a disability. As well, they are more likely to have higher density networks, reflecting the extent to which members of the network know and interact with each other independently of the carer. While this can lead to greater closeness within families, Kazak and Marvin (1984) found evidence that greater network density can also be a source of stress for parents of children with spina bifida.

Many studies have investigated the role of social support in counteracting the demands of caring for a child with a disability. Parents caring for children with disabilities who are more satisfied with the support provided by their social network, and who have more sources of support, have been found to have better personal well-being, more positive attitudes, and a better relationship with their spouse than those without supportive networks (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Dunst

& Trivette, 1986; Horton & Wallander, 2001; White & Hastings, 2004). This in turn positively influences parent-child interactions, child behaviour and child development (Dunst & Trivette, 1986). Satisfaction with support has also been related to higher perceptions of parenting competence and the ability to juggle multiple role demands (Seybold, Fritz, & MacPhee, 1991).

Studies have also shed light on the types of support that are most helpful to parents of children with disabilities. Trute (2003), for example, examined the impact of grandmother and grandfather support on parent psychological adjustment (i.e., self-esteem and depression) and on family health indicators (i.e., parental stress and overall family well-being) in a sample of 64 families of children with a primary diagnosis of developmental delay. Average age of the children was 12 years. Results of this study highlighted gender differences in the types of support that were important to parents. Emotional support from the father‟s mother was shown to be most crucial for the adjustment of fathers, and emotional support that was available from the mother‟s mother was most crucial for the mother. Trute found practical help from grandparents was less important for parent and family well-being than emotional support.

White and Hastings (2004) also examined the role of different types of support in 33 families of adolescent children with moderate-profound intellectual disability (including children with diagnoses of autism, cerebral palsy and Down syndrome) with an average age of 16 years. Information was collected on informal and formal sources of support available to parents, as well as the amount of practical and emotional support provide by others. Measures of parent mental health and parent stress included the Questionnaire on Resources and Stress (Crnic, Friedrich, & Greenberg, 1983). Results of this study showed perceptions of the helpfulness of support provided by the spouse, family and friends had a stronger relationship with parental well-being than the number of sources of support available to parents of children with disabilities. Support provided by spouse, family and friends was more important than professional and service supports. In contrast to the findings of Trute (2003), practical support was associated with well-being, while emotional support was not. The children in this study were older than the children in the Trute (2003) study, suggesting emotional support may be of more importance to parents of younger children.

Research has also examined whether social support has a direct, moderating and/or mediating role in contributing to the well-being of parents of children with disabilities. Dunst and Trivette (1986), for example, undertook an influential early study of 137 parents of preschool aged children with intellectual, developmental and physical disabilities using the Family Support Scale (Dunst, Jenkins, & Trivette, 1984) to assess satisfaction and sources of social support, and the Questionnaire on Resources and Stress (Holroyd, 1987) to measure parental well-being. Dunst and Trivette found evidence for both main and interactive (ie moderating) effects of both satisfaction with support and number of sources of support on parental well-being.

Dunn, Burbine, Bowers, and Tantleff-Dunn (2001) investigated relationships between stressors (using a “life experience” scale), practical support (measured using the Inventory of Socially Supportive Behaviors: Barrera, Sandler, & Ramsey, 1981), and psychological outcomes (depression, social isolation, and spousal relationship problems) for 39 mothers and 19 fathers of children diagnosed with autism (using subscales of the Parenting Stress Index: Abidin, 1995). Children ranged in age from three to 15 years. Dunn et al. found practical support to moderate, or "buffer," the negative impact of general life stresses on social relationships. Thus, higher levels of support decreased the likelihood that life stressors would lead to social isolation.

Raina et al. (2005) included social support in a large multi-factorial study of 468 parents of children (mean age 10 years) with cerebral palsy. Network size, perceived social support, and parent well-being were measured using items from previous national surveys of population health. Results of structural equation modelling found social support to have an indirect role in contributing to psychological health outcomes. Thus, social support influenced carer psychological and physical health by mediating between other variables, including self-perception (carer self-concept and self-esteem) and family function.

Finally, Skok, Harvey and Reddihough (2006), examined the role of perceived social support in predicting maternal well-being in a sample of 51 Australian mothers of school-aged children with cerebral palsy. In this study, stressors were assessed using the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983) which assesses how unpredictable, uncontrollable and overloaded respondents find their lives. Perceived social support was measured using the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988) which identified level of support from partners, family, and friends. Skok et al. found perceived social support to mediate between perceived stress and maternal well-being. Thus, the effect of perceived stress on well-being was influenced by level of perceived social support from others, such that higher levels of perceived stress resulted in lower levels of well-being if mothers also perceived themselves to have lower levels of support from others.

Another set of studies has considered how social support influences the relationship between children with disabilities and additional behaviour problems, and carer outcomes. Feldman et al. (2007) investigated the well-being of 178 primary carers (96% mothers) of 2 year old children receiving or eligible to receive early intervention services for developmental delay. Child behaviour problems were measured using the Child Behavior Checklist (Achenbach, 1991), availability of social support was measured using the Interpersonal Support Evaluation List (Cohen et al., 1983), and parent well-being using the Beck Depression Inventory (Beck et al., 1961). Results of regression analyses showed social support to have a mediating as well as a small moderating role in explaining the relationship between behaviour problems and maternal depression. Thus, a lack of available social support partially explained the relationship between high levels of child behaviour problems and parent depression. As well, higher levels of support "buffered" or protected parents from the negative impact of caring for children with disabilities and additional child behaviour problems.

In an Australian study of 105 mothers of pre-school aged children with developmental disabilities, Plant and Sanders (2007) took a "contextual approach" to investigating the relationship between child disability (including measures of additional behaviour problems), social support and maternal outcomes. Social support was assessed using purpose developed scales asking for extent of practical help received from partner/ family, friends or service providers with caregiving tasks; stressors and maternal stress were also assessed in relation to caregiving tasks. Severity of child disability was measured using the Vineland Adaptive Behaviour Scales (Sparrow et al., 1984) and the Developmental Behaviour Checklist (Einfeld & Tonge, 2002). Results of this study found partner and family support to moderate, or buffer, the impact of severity of child disability on levels of caregiving task specific parenting stress. That is, parents of children with more severe disabilities, who have more help from family and friends, are less likely to experience caregiving specific stress. Help from friends, and external professional support also limited negative outcomes as a consequence of child behaviour problems.

2.32 Summary of evidence relating to social support

Research examining the role of social support in the lives of parents of children with disabilities mirrors research looking at the role of social support in contributing to the well-being of other populations. Parents caring for children with disabilities, however, are at particular risk of experiencing social isolation as a consequence of their caring responsibilities (Briggs & Fisher, 2000). In both sets of studies, there is evidence for the link between social support and psychological outcomes for individuals (Cohen & Wills, 1985; Dunst & Trivette, 1986; White & Hastings, 2004). The multi-dimensional nature of social support contributes to the variety of results from studies investigating the ways in which social support influences outcomes. Some studies have shown social support to have direct effects on outcomes for parents of children with disabilities; other studies have found evidence for moderating impacts and mediating relationships (Dunn et al., 2001; Dunst & Trivette, 1986;

Raina et al., 2005; Skok, Harvey, & Reddihough, 2006). As well, while emotional support and practical support with caring would appear to be the most relevant types of caring for parents, the value of such supports appears to change over time (eg Trute, 2003; White, & Hastings, 2004). The variability in results suggests the importance of a "contextual approach" (Quittner, 1992) to research investigating the role of social support in contributing to parental well-being, that is, matching the types of stressors specific to caring with the social resources and outcomes also most pertinent to the caring situation (Cutrona & Russell, 1990; Quittner, 1992).

2.4 Parental roles

This section reviews studies exploring aspects of spousal support that may impact on the well-being of both mothers and fathers. In particular, one area of the social support literature, relevant for the present dissertation, relates to the ways in which parents share, or divide, their parenting roles. A perception of unequal distribution of tasks has been linked to psychological distress and poorer marital quality in a large community survey of married mothers (Voydanoff & Donnelly, 1999). Milkie, Bianchi, Mattingly, and Robinson (2002) investigated perceived and actual role divisions in relation to child-rearing, in 234 married couples with children under 18 years of age, in the general community. Participants rated their stress levels in the two weeks prior to the survey, as well as perceived equity in the division of household labour. Results of the study showed both parents to have strong egalitarian ideals about father involvement in child rearing, but mothers perceived much less actual father involvement than fathers perceived. Discrepancies between ideal and actual ratings were related to parental stress levels. Parents who reported less than ideal father involvement in childcare activities and in financial support were more likely to experience higher levels of stress. Mothers“ stress levels were specifically impacted upon by less than ideal father involvement in discipline activities. As well, discrepancies in expectations of involvement in play and monitoring children led to mothers feeling that the divisions of household labour were unfair.

Few studies have examined the distribution of roles between parents caring for children with disabilities. In one of the earliest published accounts, Bristol, Gallagher and Schopler (1988) compared the psychological well-being of 31mothers and fathers caring for children with developmental disabilities (aged between 2 and 6 years of age) with 25 parents of matched children without disabilities. Spouse support (based on the discrepancy between current and perceived “appropriate” responsibility for childcare and other household labour) was assessed using the Carolina Family Responsibilities Scale (Gallagher& Bristol, 1981), while parent outcome measures included the Centre for Epidemiological Studies Depression Scale (Radloff, 1977) and the Locke-Wallace Marital Adjustment Test (Locke & Wallace, 1959). Results showed fathers of children with disabilities to spend less time in child care (particularly care of the more severely disabled child) than fathers in the comparison group. The well-being and marital adjustment of mothers and fathers of children with disabilities was dependent on the levels of perceived support, especially emotional support, from their partners. The single biggest predictor of negative adaptation of parents was the extent of disharmony between actual and perceived “appropriate” spousal support (both practical and emotional support), with disharmony over household chores being most pertinent.

Bristol et al.ʻʻs (1988) study was the first to show clear evidence for the link between the division of parenting roles in families caring for a child with a disability, and marital adjustment. Other studies have sought to replicate and extend the findings. For example, Erikson and Upshur (1989) found mothers of 202 infants with Down syndrome, motor impairment, developmental delay, or no known disabilities, experienced less caretaking burden when fathers participated in childcare tasks and provided emotional support. Role satisfaction has also been associated with higher well-being and family function in mothers of infants and preschool aged children with mental retardation, physical disabilities, or developmental delay (Trivette & Dunst, 1992), and parents of children with cerebral palsy, spina bifida, and limb deficiencies (Wiegner & Donders, 2000). More recently, Simmerman, Blacher and Baker (2004) found positive marital adjustment was related to greater satisfaction with partner involvement with childcare, in parents of 60 children with severe intellectual disability aged between 8 and 15 years.

A number of studies have suggested that the relationship between help received from partners, and negative outcomes (for mothers in particular), may relate more strongly to perceptions of required support, rather than actual support received. Simmerman, Blacher and Baker (2001), for example, found maternal satisfaction with help provided by fathers to relate more strongly to indicators of family well-being than the actual extent of help provided. Button, Pianta and Marvin (2001) found no relationship between maternal stress (as measured by the short-form of the Parenting Stress Index) and amount of partner support received from fathers when caring for preschool aged children with cerebral palsy. Counter-intuitively, in this study mothers were most stressed when children had more severe disabilities and partners provided higher levels of support. The possibility that social support may be deleterious is one that is rarely considered in the literature (Wight, Aneshensal & LeBlanc, 2003). It is possible that mothers may find assistance from fathers as interference, for example.

The results of a final study in this area are of particular relevance for the present dissertation. Quittner et al. (1998) used standardized questionnaires, a card sort procedure, and telephone diaries to give a comprehensive picture of how caring affects the daily life of parents of 33 children with cystic fibrosis in comparison to parents caring for 33 matched healthy children, aged between 2 and 6 years of age. Multiple measures of "role strain" were included in the study, to reflect the concept of role strain proposed by Pearlin and colleagues as a component part of an influential model of stress (Pearlin, 1989, 1999; Pearlin et al, 1981). More specifically, Quittner et al. included measures of four components of role strain: stressors related to parenting; frustration with role expectations; role conflict; and affective exchange. Results showed that couples caring for children with chronic illness experienced greater marital role strain than couples caring for healthy children. They undertook more childcare tasks, had fewer daily exchanges of affection with their partner, and spent less time in social and recreational activities. As well, parents of children with chronic illness experienced higher levels of conflict over child rearing, and reported more role frustration (as evidenced by a greater discrepancy between real and ideal division of roles). For women, role frustration and conflicts about child rearing were most strongly associated with marital satisfaction/ dissatisfaction, and parenting stress and role frustration to levels of depression. In contrast, for men, role conflict and positive interactions with their partner were associated with marital adjustment and parenting stress; and daily stress and role conflict were related to depression. Time spent in recreation was found to mediate the negative relationship between role strain and well-being.

2.5 Conclusion

This chapter has presented an overview of some of the most important variables that may help to explain the variability in the outcomes of parents caring for children with disabilities. Studies examining the impact of child characteristics, in particular those investigating the role of adaptive behaviours, are inconsistent in their findings. However, parents of children with autism appear at greater risk of psychological and physical health problems (Hodapp, 2007; Singer, 2006). This may be, in at least some part, a consequence of the higher rates of behavioural problems associated with this diagnosis. In general, up to 40% of children with developmental and intellectual disabilities also exhibit emotional and behavioural problems (Dekker et al., 2002; Einfeld & Tonge, 1996; Hoare et al., 1998; Stremme & Diseth, 2000). This review has shown a consistent association between child behaviour problems and parent well-being (Floyd & Gallagher, 1997; Lecavalier, Leone, & Wiltz, 2006), a finding of considerable importance when considering the impact of caring for a child with a disability.

The review of research pertaining to social supports, suggests the important role of social support in counteracting some of the stressors associated with caring for a child with disabilities. Evidence suggests social support can have a direct impact on outcomes for parents, as well as acting as a moderator and/ or a mediator variable. Different types of social support appear to act in different ways in response to different stressors, suggesting the need for a “contextual approach” (Pearlin, 1999; Quittner, 1992). For example, spousal support is an important *source* of support for parents of children with disabilities (Quittner, 1992; Suárez & Baker, 1997), while emotional and practical supports appear to be the most salient *types* of support for parents (Andresen & Telleen, 1992). Finally, the chapter concludes by highlighting the importance of considering ways in which parents of children with disabilities divide childcare and other household responsibilities. There is evidence that an unequal division of responsibilities, or a discrepancy between what is perceived to be ideal, and the reality of daily life, contributes to poor outcomes, particularly for mothers.

CHAPTER 3

Time use of parents caring for children with disabilities

3.1 Overview

This chapter reviews studies focusing on the consequences of caring on the daily lives of parents of children with disabilities, consistent with a "contextual approach" (Quittner, 1992; Quittner et al., 1998). The use of diary methodologies has been most commonly used to identify the ways that people in the general population use their time. The chapter will start by reviewing this literature, most of which has been undertaken in the field of sociology. The smaller body of work examining the ways in which caring changes time use and more specifically, how the lives of parents of children with disabilities differ from other parents, will also be reviewed. Of particular relevance for the present dissertation is research which examines the extent to which parents of children with disabilities spend more time in child care activities than parents of children without disabilities. The chapter concludes by describing results from studies that have linked time spent caring with measures of psychological outcomes for parents.

3.2 Time use in the general population

Investigators have long been interested in how people use their time. Many countries now undertake large scale surveys of time use, most often using 24 hour time use diaries to measure the wide range of activities that individuals undertake on a particular day. The Australian Bureau of Statistics has undertaken a number of wellrespected time use surveys, the most recent having been published in 2006 (ABS, 1997, 2006).

Studies using time use diaries typically distinguish between categories of time use that are considered to be fundamentally different in character. The broadest level of classification, first proposed by Aas (1982) makes distinctions between *contracted* time (including time spent in paid work and educational activities), *committed* time (including time spent in domestic work and childcare), *necessary* time (including activities such as sleeping and personal hygiene), and *free* time (including time spent in leisure and social activities). Analysis may be undertaken examining types of time use within these broad categories, as will be further outlined in Chapter 7.

The information obtained from time diaries provides a strong basis for investigations of social changes and trends (Robinson & Godbey, 1997). One of the most significant changes since the 1960s has been the dramatic increase in the number of women in the paid work force (Bittman, 1992). As well, the trends for people to get married later, to have fewer children, and to have shorter relationships, have led to fewer traditional (ie a mother, a father and children) households (Robinson & Godbey, 1997). The number of one-parent families, for example, increased by 23% in the period 1996-2006 (ABS, 2008).

While there is evidence that traditional gender roles are shifting, time use diaries also show that differences between men and women in the use of time still exist. For example, men continue to spend the most time in paid work, and this time is increasing (Bittman, 1992). Women spend substantially more time in unpaid work than men (Bittman & Wajcman, 2000c; Rogers & Amato, 2000). Having children is associated with a considerable increase in unpaid work for mothers, with the highest levels of unpaid work reported by mothers of preschool aged children (Bittman, 1992). While this work is mostly associated with childcare, time is increasingly allocated to domestic work as children get older (Craig & Bittman, 2005).

Time use surveys show women to be spending more time in paid work than they did in the past, however they are also spending more time in unpaid work. (Bianchi, Milkie, Sayer, & Robinson, 2000; Mattingly & Sayer, 2006). This has led to the concepts of "dual burden" or "second shift", reflecting how women add a second shift of paid work to existing responsibilities for housework and childcare (Bittman & Wajcman, 2000c). Surveys have also found that men are doing more unpaid work than they did in the past, though this time is mostly spent in child care rather than domestic work (Craig & Bittman, 2005; Zuzanek, 2001),

The types of work undertaken by men when engaging in the different forms of unpaid work are qualitatively different from the unpaid work done by women. For example, when considering domestic or house work, women are more likely to do routine, onerous tasks in the home (Bittman, 1992; Roxburgh, 2002). Men are more likely to do household maintenance activities, often outside of the house. When considering childcare, women are more likely to have responsibility for physical care of the child, while men are more likely to engage in passive child care and play activities (Craig, 2002). Bittman and Wajcman (2000c) found that the proportion of women"s child care devoted to play activities remains less than half that of men until the child reaches 10 years.

Further evidence for gender inequities in time use is evident when considering free time activities. Having children reduces leisure time for women (Bittman and Wajcman 2000c). As well, women are more likely to have poorer quality leisure time. Leisure time for parents, particularly those with young children, means that leisure is more likely to be family orientated, but even so, women are less likely to have “adult leisure”, that is, time away from children. Their leisure time is also more likely to be interrupted (Bittman & Wajcman, 2000c; Mattingly & Sayer, 2006).

Time use surveys often include measures of perceived time pressure, typically asking respondents to report how much they feel rushed or short of time. Results show that feelings of time pressure are increasing over time, independently of actual time use (Robinson & Godbey, 1997). Those who are most rushed are parents of pre-school aged children, and women (Mattingly and Sayer, 2006). Several reasons have been proposed for the increasing feelings of time pressure in the general population. There is evidence, for example, that being “busy” has become more socially desirable, particularly for the more affluent (Gershuny, 2005; Roxburgh, 2004). Changing ideas about parenting may also lead parents to feel that they should spend more time with their children. Milkie, Mattingly, Nonaguchi, Bianchi, and Robinson (2004) found that both mothers and fathers felt they should spend more “family” time, even though actual time spent in child care had increased, particularly for parents of pre-school aged children. Roxburgh (2006) found that fathers want to increase the amount of time they spend with their children, while women want to increase the quality of time with children.

What are the outcomes of experiencing feelings of high time pressure? Evidence suggests that in the general population those who perceive themselves to be “often” or “always rushed” are more likely to feel stressed, “burnt-out”, angry; to be less satisfied with life (particularly family life); and to have poorer subjective physical health (Robinson & Godbey, 1997; Roxburgh, 2004; Schieman, 1999; Shields, 1999). Research undertaken by Roxburgh (1999; 2002; 2004; 2006) surveying men and women in paid employment, has shown women to be more time pressured than men, and to be more likely to feel depressed as a consequence of subjective time pressure. Roxburgh found time pressure to increase linearly with more role commitments (ie worker, spouse, parent, homemaker, volunteer), but that only some roles created time pressure, and in turn higher depression for women. For example, time pressure was shown to be a significant mediator between the role of homemaker (undertaking 10 hours or more of housework a week) and depression in women (Roxburgh, 2004). Partner support, particularly when this took the form of practical help, was important in reducing feelings of time pressure for women (Roxburgh, 2002). Partner support was also found to reduce the experience of depression for both men and women, but did not moderate the impact of time pressure on depression (Roxburgh, 2004).

3.21 Summary of time use in the general population

Time use diaries have been shown to be a useful way of documenting social change. While there is evidence for a shift in traditional gender roles, there are still substantial differences in the way women and men spend their time. For example, men continue to engage in more paid work than women, while women spend much more time in unpaid work, particularly childcare and domestic work (Bianchi et al., 2000; Bittman, 1992). Women who care for a pre-school aged child report the highest levels of unpaid work (Bittman, 1992). This reflects the general finding that having a child has a considerable impact on the time use of parents. Results of recent time use surveys show that the amount of time that men spend in childcare is increasing (Craig, 2002). They are more likely, however, to spend time in passive child care and play activities with their child, while women take primary responsibility for physical care activities such as feeding, toileting and bathing (Craig, 2002). The experience of leisure time has also been shown to be affected by caring for a child, with women being less likely to have “adult” time to themselves and to be more likely to have poorer quality leisure time when available (Bittman & Wajcman, 2000c).

Time use surveys have also investigated the experience of time pressure in the general population. Women, and in particular those caring for preschool aged children, report being the most rushed or pressed for time (Mattingly & Sayer, 2006). Higher feelings of time pressure have been associated with poorer psychological and physical health outcomes (Robinson & Godbey, 1997; Roxburgh, 2004). Recent research suggests that women who take on the additional role of homemaker are more likely to feel time pressured, and in turn are more likely to feel depressed (Roxburgh, 2004).

3.3 Impact of caring on time use

Caring for a family member with a disability (ie adult or child) can lead to significant impacts for individuals. Fredrick and Fast (1999), for example, when considering data from a population survey including 1,366 Canadian carers (mostly women) of the elderly, found that caring restricted social and leisure activities, impacted on employment opportunities and finances; and also impacted on personal care and sleep. More time spent in caring was associated with greater emotional and psychological burden. Lee (1999) summarised evidence for the impact of family-based caring for a dependent adult, most of which is undertaken by women. She reported on research showing caring to be associated with high levels of psychological distress and reduced physical wellbeing, as well as having negative consequences for employment and leisure. In the Australian context, results of the Women"s Health Australia longitudinal survey showed mid aged or older women carers to be more likely than women who were not carers, to experience low levels of emotional well-being and to feel stressed, rushed and pressured (Lee, 2001; Lee & Porteous, 2002).

Bittman and colleagues have undertaken analysis of the Australian Bureau of Statistics 1997 Time Use Survey (TUS), examining results for a sample of people who identified themselves as carers (Bittman, Fast, Fisher, & Thompson, 2004; Bittman & Thompson, 2000a). They found that carers reported very low levels of time attributed to "voluntary work and care", the category of time thought to be most likely to reflect caring activities. They suggested this highlights the limitations of time diaries, in particular, their inability to capture the experience of "being on call" typical of caring or to reflect restrictions in activities especially as many caring activities are undertaken at the same time as other activities. Bittman et al. (2004) proposed the concept of "time signatures", by comparing patterns of time use of carers in comparison with non-carers, to better identify carers and describe their experiences. Using the 1997 TUS they found carers to sleep less; to have lower participation in paid employment and significantly lower incomes; and to spend more time in domestic activities and child care (particularly women). Time spent in these latter categories was substantially higher for co-residential carers of children with disabilities. Carers of children with disabilities spent double the time of all other Australians in food preparation, clean-up, laundry and housework; with even more time spent on activities such as gardening outside of the house. As well, carers of children had the lowest weekly hours of recreation and leisure time.

Bittman et al. (2004) found the time signatures, or patterns of time use reflecting the experience of carers, were robust enough to be present even after controlling for the effects of age and employment status of the carer. Further, results of analysis of comparable time use data from Canada showed the time signatures of carers to be substantially the same. Bittman et al. (2004) suggest that this points to the hidden nature of many caring activities; additional domestic work and child care being examples of "hidden" care. They argue caring increases carer burden in ways not easily distinguishable from normal household responsibilities.

3.31 Summary of time use of carers

There is consistent evidence for the significant impact of caring on the daily lives of carers, with studies showing negative consequences for psychological and physical health (Frederick & Fast, 1999; Lee, 1999). Recent work undertaken by Bittman and colleagues in the Australian context (Bittman et al., 2004; Bittman & Thompson, 2000a, 2000b) has identified a typical "time signature" reflecting the patterns of time use reported by carers, most of whom are women. In general, carers spend less time in employment; have lower incomes; have less time for their own personal care including sleep; and spend more time in child care and domestic work. Much of the time spent in caring was found to be “hidden” amongst normal household responsibilities.

3.4 Time use of parents of children with disabilities

Relatively few studies have investigated the ways in which caring for a child with a disability may affect the time use of parents. A comprehensive literature search, using both computer sources (PsychINFO and Medline databases) and manual methods (tracking citations), identified 15 studies that used diary methodologies to calculate total time spent in childcare activities by parents of children with disabilities. Table 3.1 summarises the characteristics of each of the studies, organized according to year of publication. While not included in the table, a small number of additional studies that also used time use methodologies but did not report a total time spent in child care, will be cited when discussing findings.

Table 3.1 *Details of studies using diary methodologies to calculate total time spent in childcare activities by parents of children with disabilities*

Authors	Target children age range, diagnosis/group, (N)	Measures	Characteristics of child care	Mean (SD) time spent in childcare (minutes/day)
McAndrew	Mother report			
(1976)	5-10 years	Time estimate	Helping with dressing, feeding, toileting	
	Physical disability (116)		occupation, supervising difficult behaviour	120
Dupont	Parent report			
(1980)	6-14 years	Time diary	Night, bedtime, care, clothes, food,	
	Severe mental handicap (39)		occupation	431
Lucca & Settles	Mother report			
(1981)	2-18 years	Time diary	Physical care (bathing, feeding, dressing,	
	Learning disability/ behavioural (19)		medical care)	71 (63)
	Multihandicapped (22)			62 (72)
	Normal (18)			76 (116)
Breslau	Mother report	Time estimate	Childcare (excluding therapy and escorting to	
(1983)	3-8 years		appointments)	
	Disability, including chronic illness (369):			
	Married			198 (189)[b]
	Single			213 (199)
	Conrrols (456):			
	Married			192 (163)
	Single			206 (132)
Johnson	Mother report			
& Dietz	3-5 years	Time diary	Feeding, personal care, transportation	
(1985)	Physically disabled (16)			100 (35)[b]
	Normal (21)			45 (17)

Authors	Target children age range, diagnosis/group, (N)	Measures	Characteristics of child care	Mean (SD) time spent in childcare (minutes/day)
Erikson & Upshur	Mother report			
(1989)	4-15 months	Questionnaire	Feeding, bathing, dressing, special activities	
	Down syndrome (33)			283 (168)
	Motor impaired (43)			224 (140)
	Developmental delay (41)			155 (69)
	Comparison (85)			159 (70)
Harris and McHale	Mother report			
(1989)	3-12 years	Time diary	Play, watching TV, caregiving, chores,	
	Mental retardation (30)		outings	226 (100)
	Nonretarded (N=30)			159 (61)
Brust, Leonard	Mother report			
Sielaff	0-18 years	Time estimate	(1) Personal care, medical care,	
(1992)	Disability/ chronic illness (N-133)		travel, vigilance/emotional support	606 (562)
			(2) Personal care, medical care	
			travel	216 (156)
Crowe	Mother report			
(1993)	6 months- 5 years	Time diaries	Childcare (personal care, feeding,	
	Multiple disabilities (45)		participating in school programme,	340 (92) [b]
	Down syndrome (45)		transport, play, therapy)	281 (74)
	Typically developing (45)			283 (85)

Authors	Target children age range, diagnosis/group, (N)	Measures	Characteristics of child care	Mean (SD) time spent in childcare (minutes/ day)
Cant	Mother report			
(1994)	2-15 years	Time diaries	Childcare as primary activity	
	Cerebral palsy-preschooler (29)		(Physical care, minding, teaching,	239
	Cerebral palsy-teenager (24)		playing, travel)	152
	Spina bifida (20)			180
	ABS[a] survey 0-4 years			196
	ABS survey 5-11 years			71
Barnett & Boyce	Mother and Father report	Time Diaries	Childcare	
(1995)	1-27 years			
	Down Syndrome: mothers (237)			156[b]
	University of Michigan survey: mothers (216)			78
	Down Syndrome: fathers (134)			69.43
	University of Michigan survey: fathers (174)			31.71
Padeliadu	Mother report			
(1998)	Mean age = 12.25	Time estimate	Dressing, feeding, bathing/toilet, play	
	Down‟s syndrome (41)		teaching, bedtime	259.88 (240.58)
	Non-disabled (41)			138.66 (208.08)
Crowe	Mother report of father‟s time			
(2000)	6 months -5 years	Time diaries	Childcare (personal care, feeding,	
	Multiple disability		participating in school programme,	78.86 (56.57)[bc]
	Down syndrome		transport, play, therapy)	94.29 (62.57)
	Typically developing			79.71 (48)

Authors	Target children age range, diagnosis/group, (N)	Measures	Characteristics of child care	Mean (SD) time spent in childcare (minutes/ day)
Crowe & Florez (2006)	Mother report			
	3-14 years	Time diaries	Childcare (personal care, feeding, participating in school programme, transport, play, therapy)	
	Disabilities (30)			275.14 (165.43)[b]
	Typically developing (30)			162.96 (78.86)
Gevir, Goldstand, Weintraub, &Parush (2006)	Mother report			
	2-11 years	Time diary	Activities with children	
	Mental retardation (29)			285
	Motor difficulties (30)			273
	Attention deficit hyperactivity disorder r(30)			273
	Typical development (31)			262

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[a] ABS survey = 1987 pilot time use survey of the general Sydney population (ABS,1988)

[b] Estimated from published figures (hours/week)

[c] Combined time weekdays and weekend days

Note: 1. Diagnosis/ group as described in the original articles

2. Characteristics of childcare abbreviated from original articles

Several points of note may be made on examination of the Table 3.1:

- Studies described child care for children with a wide range of different ages, in some cases spanning infancy to adolescence (and adulthood) in the one study (Barnett & Boyce, 1995; Brust et al., 1992). They also include a broad range of diagnostic/ disability groups. Several studies include children with chronic illnesses such as cystic fibrosis; together with children who have physical and intellectual impairment (Breslau, 1983; Brust et al., 1992;Geviret al. 2006);
- Mean time (minutes/day) spent in child care is reported in the table. This masks substantial individual variation in time spent in child care for children with different caring needs, reflected by the large standard deviations described for some studies (Brust et al. 1992; Lucca & Settles, 1981;Breslau, 1983; Padeliadu, 1998);
- Most studies investigated impact of caring on the lives of mothers, with one exception. Barnett and Boyce (1995), collected time use information independently from fathers with results showing fathers of children with Down syndrome increased their time spent in child care in comparison to fathers of children without disabilities, and decreased their time spent in social activities. In general, though, there is insufficient evidence of the ways in which caring may impact on the lives of fathers, as secondary carers;
- Table 3.1 illustrates the range of different ways in which time use has been measured. Some studies relied upon parent estimates of daily time spent in specified categories of activities (Breslau, 1983; Brust et al., 1992; McAndrew, 1976; Padeliadu, 1998). There is evidence that this may lead to significant overestimates of time spent, when compared to diary data (Juster & Stafford, 1991). Although many studies reported using time diaries, there were methodological differences in the ways in which diary information was collected. Barnett and Boyce (1995), for example, required parents to recall activities

- during a daily phone call (ie retrospective accounts of time use). Other studies asked them to complete a daily record of activities, sometimes in relation to pre-determined blocks of time (eg half hour, or 10 minutes), sometimes in relation to pre-coded categories of activities (Cant, 1994; Crowe, 1993; Gevir et al., 2006; Johnson & Dietz, 1985; Lucca & Settles, 1981). Different methodologies have contributed, at least in part, to variability in time use estimates;
- Most importantly, in terms of the interpretation of the reported figures in Table 3.1, the studies varied in terms of the ways in which childcare was conceptualized. The narrowest interpretations of "childcare" related to physical care only (Lucca & Settles, 1981; Johnson & Dietz, 1985) while other authors were more inclusive in their definitions of child care, including time spent in activities such as "keeping the child occupied" or "vigilance and emotional support" (Brust et al., 1992; Cant, 1993). In some cases definitions of childcare were not described, or were vague and unclear (Barnett & Boyce, 1995; Gevir et al., 2006).

Keeping in mind these issues, it is possible to make some broad conclusions from the studies represented in Table 3.1 about the impact of caring for a child with a disability on the time use of mothers, in particular. Before outlining these findings, however, it should be recognised that much child care is undertaken at the same time as other activities (Craig, 2002; Cant, 1994). Lack of information in the studies shown in Table 3.1, mean that it is not possible to know whether time estimates in these studies recorded child care as a primary activity only, or as a primary and a secondary activity. If child care was recorded as a primary activity only, studies may have underreported the actual time spent by parents when caring for their children.

3.41 Time spent caring

While most of the studies (five out of nine studies that included a “no” disability comparison group) demonstrate differences in total time spent in child care activities for parents of children with disabilities compared to parents of children without disabilities, such that parents of children with disabilities spend longer in child care, this is not a universal finding. In particular, Lucca and Settles (1981) failed to demonstrate differences in time spent in physical care by mothers of children with learning disabilities and behavioural problems, mothers of multi-handicapped children, and mothers of “normal” children. More recent research by Gevir (2006) also showed no overall differences in the amount of time spent in activities with their child by mothers of children with attention deficit hyperactivity disorder, mental retardation, multiple disabilities and typical development. Other studies show differences in time spent in child care by parents of children with different diagnoses. Erickson and Upshur (1989), for example, found differences for mothers of children with Down syndrome and motor impairments, and not for mothers of children with developmental delay. Crowe (1993) found differences for mothers of children with multiple disabilities, and not for mothers of children with Down syndrome.

One possible explanation for the inconsistent results when considering total time spent in child care by parents may relate to the different caring needs of children of different ages or disability. Results of studies that have included measures of “severity of disability” generally suggest that increasing levels of disability lead to more caring responsibilities, though this finding is not universal. For example, an early paper by Dupont (1980) showed mothers of children with higher levels of “handicap” spent longer in child care activities than mothers of children who had little need of extra help. Havemann, van Berkum, Reijnders, and Heller (1997) found time demands for parents of children with mental retardation to be higher for children with fewer adaptive skills, more behaviour problems and poorer physical health. Curran, Sharples, White, and Knapp (2001), using an event diary, also found a significant correlation between frequency of personal care and severity of impairment of functional skills. In contrast to this pattern of results, however, Lucca and Settles (1981) found no significant differences between the amount of time spent in physical care and degree of disability as measured by the Vineland Social Quotient.

Brust, Leonard, and Sielaff (1992) found younger children with “physical and mental handicaps” who needed more medical treatments, required the most time from their parents, when compared to older children with less needs. This study also reflects the more general finding that time spent in child care decreases as a child get older, although time spent by mothers of children with disabilities remains high in comparison to time spent caring for children without disabilities (Cant, 1994; Crowe & Florez, 2006; Havemann, van Berkum, Reijnders, & Heller, 1997).

In general, results from studies shown in Table 3.1 suggest that time spent caring for a child with a disability increases when additional activities are included in the definition of “child care”. Thus, the smallest amounts of time spent reflect a narrow definition of child care (ie physical care only), while time spent increases with the addition of time spent in play, therapy and teaching activities. The largest amounts of time spent are found when child care includes vigilance and “minding” activities. Brust et al. (1992) found mothers of children with disabilities and chronic illness spent twice as much time in vigilance and emotional support of the child, than in personal care and medical care. Dupont (1980) found the constant need of supervision was rated by parents as their “most heavy burden”. Other studies report on other child care activities that are associated with higher levels of stress for parents. Cant (1994), for example, found teaching activities to be most stressful for mothers of children with physical disabilities, while physical care activities such as toileting and bathing were the most disliked. Padeliadu (1998) found play and teaching activities to be the most stressful for mothers of children with Down syndrome.

3.42 Activities other than caring

When considering time spent in activities other than child care, there is more consistent evidence for the impacts of caring on the daily lives of parents caring for children with disabilities,. For example, Lucca and Settles (1981) found mothers of children with disabilities had less time for their own personal care and less time for family activities than mothers of “normal” children. As well, their children spent less time being cared for by others than children without disabilities. Mothers of children with poorer functional skills experienced the most time constraints. Erikson and Upshur (1989) also reported that mothers of infants with Down syndrome had less time to themselves than mothers of infants with no disability. Crowe (1993) found mothers of children under five years of age with disabilities spent less time socializing than mothers of children of a similar age without disabilities. In contrast, when investigating the time use of mothers of school-aged children with disabilities, they found no differences in time spent in socialising. Mothers, however, spent less time in recreational/ leisure activities than mothers of children without disabilities; reported having fewer “typical” days; and rated the quality of their days as poorer (Crowe & Florez, 2006).

Cant (1994) also found mothers of children with physical disability to spend less time in recreational and leisure activities.

Several studies have indicated that one of the most prominent consequences of caring is the impact on employment opportunities for mothers, in particular. For example, Cant (1994), Barnett and Boyce (1995), and Gordon, Rosenman, and Cuskelly (2007) all showed mothers of children with disabilities to spend substantially less time in paid work than mothers of children without disabilities, despite an equal desire to work. As well, Curran et al. (2001) found 75% of their sample of 31 mothers of children with severe disabilities (aged between 3 and 17 years of age) did not return to paid work, in comparison to 60% of mothers of children without disabilities who returned to work as their child became more independent. Lack of employment can lead to financial strains on the family. Leonard, Brust, and Sapienza (1992) found time spent caring was the best predictor of out-of-pocket expenses estimated by parents who took part in the Brust et al. (1992) study.

3.43 Time use of fathers

As noted earlier, few studies have evaluated the time use of fathers of children with disabilities. Several studies relied on mothers‟ reports of fathers‟ time spent in child care, with the potential for inaccuracy. For example, Erikson and Upshur (1989) found fathers of infants with disabilities were reported to spend the same amount of time in child care as fathers without disabilities. Similarly, mothers in the study undertaken by Crowe et al. (2000) reported fathers of young children with disabilities to spend the same amount of time in child care as fathers of children without disabilities, regardless of the disability status or age of the child. Of note, 75% of mothers of children with disabilities in the study by Crowe et al. (2000) reported themselves to be satisfied with the amount of help they received from their partner. Barnett and Boyce (1995) were the only researchers, of those included in Table 3.1, to collect information independently from fathers. They compared the time use records of a large group of fathers of children with Down syndrome with national time use data. Fathers of children with Down syndrome spent longer in child care and less time in socialization than their counterparts with normally developing children. Differences, however, were small relative to the effects of caring on mothers" time use.

3.44 Time use and well-being of parents

A final area of investigation to be reviewed in this chapter explores the relationship between time spent caring and psychological outcomes for parents of children with disabilities. Not all studies reviewed in this section are included in Table 3.1, as only a small number of studies that measured actual time use also included measures of parent well-being.

Brotherson and Goldstein (1992) undertook 4 focus groups with 21 parents of young children with disabilities (aged between 1 and 15 years) with mild to severe disabilities, and 4 focus groups with professionals working in early intervention. They found “time” to be a core theme in the lives of parents of children with disabilities, with many mothers reporting that they felt overwhelmed by their caring responsibilities. Studies including measures of time use also reflect the psychological impacts of caring. For example, Harris and McHale (1989) found the amount of time spent caring by mothers in activities with their children with mental retardation, was significantly related to the frequency and intensity of difficulties in family life. Intensity of family problems was also related to symptoms of maternal depression. Haveman et al. (1997) completed a large population based survey in the Netherlands, of 2573 families including a member with mental retardation. As part of this study, caregivers were asked to estimate the number of hours per week they spent in care of the child with mental retardation, and to also indicate the degree of impact of caring on the family‟s financial, physical, social and emotional status (considered in total to be an estimate of subjective burden). Haveman et al. found families who spent more time caring for their child, and in particular, when the child had more severe behaviour problems, poorer physical health and less adaptive skills, were more likely to report subjective burden. Papaliadu‟s (1998) study found mothers of children with Down syndrome to report spending more time caring, and to experience more stress than mothers of children without disabilities. Time spent caring, however, was correlated with stress for both groups of mothers.

Lastly, a recent Australian study undertaken by Plant and Sanders (2007) investigated the role of time spent caring on the level of parenting stress experienced by 105 mothers of pre-school aged children receiving early intervention services for developmental disabilities. In this study, time spent caring was assessed by asking parents to estimate whether they spent more or less time completing specific caring tasks with their developmentally disabled child, than they would with a child without disability. Results showed the more difficult caring tasks, and behaviour problems shown by children during tasks, had the strongest association with maternal stress. Mothers of children with lower levels of functional skills were also more likely to report higher levels of task related stress. In contrast to the studies described earlier in this section, there was no evidence for a relationship between maternal stress and the extra time spent caring for a child with a disability, or overall child behaviour problems.

3.45 Summary of time use of parents of children with disabilities

Research examining the time use of parents caring for a child with a disability is difficult to collate. Studies vary in terms of the characteristics of disability investigated, the methodologies used to measure time use, and in particular, definitions of child care used to quantify caring. As well, all studies surveyed in this review, with one exception, collected information only from mothers. Keeping these concerns in mind, it is possible to make some broad conclusions from the results of previous research.

Firstly, research shows that caring for children with disabilities is almost always undertaken primarily by mothers (Bittman et al., 2004). The small numbers of studies including fathers suggest they spend the same amount of time in childcare as fathers without children with disabilities (Crowe, VanLeit, & Berghmans, 2000; Erickson & Upshur, 1989). Studies also suggest that caring for children with disabilities takes more time than caring for same aged children without disabilities (Blaylock-Johnson & Dietz, 1985; Crowe & Florez, 2006; V. Harris & McHale, 1989; Padeliadu, 1998), though this result has not been universally found (Gevir, Goldstand, Weintraub, & Parush, 2006; Lucca & Settles, 1981) . There is evidence that time spent caring will be greater if children are younger, and have more severe impairments (Brust, Leonard, & Sielaff, 1992).

There is more consistent evidence for changes in the time use of parents of children with disabilities (mostly mothers) in areas other than child care, reflecting the time signatures of carers more generally. In particular, they spend less time in paid work and less time in personal care than parents of children without disabilities (Gordon, Rosenman, & Cuskelly, 2007; Lucca & Settles, 1981) . Some studies have also shown they spend less time in recreational and social activities (Crowe, 1993; Crowe & Florez, 2006).

Finally, only a few studies have included measures of parent psychological or emotional outcomes. They indicate that more time spent caring may result in poorer psychological well-being, and that this may be dependent on characteristics of the child"s disability (Brotherson & Goldstein, 1992; Havemann et al., 1997). A recent Australian study, however, suggests extra time taken to care for a child with disability is not related to maternal task-related stress (Plant & Sanders, 2007). None of these studies used standardised measures of parental psychological well-being, limiting the generalisability of the findings. Further research is needed to clarify how caring responsibilities; the time taken by caring; and the time pressures of caring impact on carer psychological and physical well-being.

3.5 Conclusion

Diary methodologies have contributed a great deal to our understanding of the ways in which people use their time, and the impact that caring has on the daily lives of parents. In general, women appear to be most affected by having children, and by caring for a child with a disability in particular (Barnett & Boyce, 1995; Craig, 2002). While there is evidence that caring prevents mothers of children with disabilities from returning to work, creates more housework and limits time available for recreation and socialization (Crowe & Florez, 2006; Gordon et al., 2007), the evidence regarding time spent in child care is less clear. More research is needed to explore the specific ways that caring alters or adds to the tasks required when looking after a child, and how these activities are influenced by different characteristics of child disability. Similarly, there are very few studies that have used time use methodologies together with standardized measures of psychological outcomes. Results from existing research are inconclusive, though the greater number of studies suggests time spent caring may have a role in helping to explain the higher rates of stress for parents of children with disabilities (Brotherson & Goldstein, 1992; Havemann et al., 1997). While no studies have specifically examined the concept of time pressure in parents caring for children with disabilities, the literature in this area more generally suggests this type of cognitive appraisal may have a mediating role in the link between caring and parent well-being (Robinson & Godbey, 1997). Finally, more attention could usefully be directed to exploring differences between parents, identifying the different ways that caring impacts on time use, and psychological and physical outcomes for mothers and fathers.

CHAPTER 4

Theoretical models relevant to caring

4.1 Overview

This chapter will highlight the importance of conceptual frameworks in helping to understand the ways in which the variables relevant to understanding the impacts of caring, relate to each other in meaningful, and testable, ways. Influential models in the area of stress research, and caring in particular, will be reviewed including several that allow the examination of both moderating and mediating effects. The chapter will conclude by presenting a model of carer well-being, which reflects the importance of the context of caring for a child with a disability, and attempts to draw together some of the most pertinent variables identified in the previous chapters.

4.2 Definitions of stress

The relationship between caring and well-being has typically been described in terms of “stress” (Raina et al., 2005). Definitions of “stress”, however, vary in terms of how much they emphasise the role of objective, measurable changes in an individual‟s environment (ie “life events”), or the role of subjective factors such as cognitive appraisal of changes (Grant et al., 2003). Lazarus and Folkman (1984) have been the most influential proponents of a “subjective” definition of stress. They propose a transactional model of stress and coping, in which stress is a consequence of the interaction (transaction) between an individual and their external environment. Stress is defined by Lazarus and Folkman as “a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus and Folkman, 1984, p.21). The stress and coping model explains variation in outcomes for people in similar circumstances to be a consequence of different processes of cognitive appraisal. Thus, stress may not eventuate if an individual perceives a situation as positive or challenging rather than as threatening, and if they are confident they possess adequate rather than deficient coping strategies. In the context of caring, parents who perceive their child"s disability or the tasks of caring as being beyond their coping resources are more likely to experience stress and other negative psychological outcomes.

4.3 Models of family adaptation

Stress and coping theory has been the predominant influence in research examining family adaptation to childhood chronic illness or disability. There are other theoretical frameworks that have made an impact, however, particularly the social-ecological theory of Bronfenbrenner (1979), and family systems theory (Olsen, Russell & Sprenkle, 1989). Bronfenbrenner"s theory highlights the importance of considering the individual within his/her social context, while family systems theory stresses the importance of family relationships in contributing to the psychological health of the individual. Stoneman and Gavidia-Pyne (2006) recently used a family systems framework to examine the influence of partner stress and coping on spousal marital adjustment in families of 67 children aged between one and six years of age, attending early intervention and preschool special education programmes. In this study, stressors were measured using the Hassles and Uplifts Scale (Delongis, Folkman, & Lazarus, 1988), and marital adjustment using the Dyadic Adjustment Scale (Spanier, 1976). Results showed firstly, that when daily stressors/hassles were higher, parents viewed their marriages more negatively. As well, marital adjustment reported by mothers was significantly influenced by partner use of problem-focused coping strategies, such that women reported higher marital adjustment when their husbands employed more problem focused coping strategies. Stoneman and Gavidia-Payne suggest this result confirms the systemic nature of family processes, reinforcing the role of cross-spousal influences among stressors, coping and marital adjustment.

A conceptual framework that has been commonly used in studies of children with disabilities and their families, based on stress and coping theory, is the “Double ABCX” model of family stress and coping (McCubbin and Patterson, 1983; Lavee, McCubbin & Patterson, 1985). McCubbin, Patterson and colleagues adapted an earlier model (the ABCX model) proposed by Hill (1958), by including a temporal factor. The double ABCX model hypothesises that accumulated stressors (ie a “pile-up” of stressors) arising from a child‟s disability status (A) may lead to family crisis, or alternatively to adaptation (X), dependent upon several intervening variables including family resources (B), and the meaning the family assigns to the situation(C). Bristol (1987) tested the Double ABCX model with a sample of 45 families of children with autism and communication impairments. Components of the model in this study included severity of disability and other family stresses, family resources of cohesion and social support, family definition of child problems, and adequacy of coping patterns. Bristol found the Double ABCX Model to be a useful way of conceptualizing the process of maternal and family adaptation to child disability, with all elements of the model included in the study contributing to outcome measures. The “pile-up” of family stressors was the most significant predictor of maternal depression. Ratings of family functioning were positively predicted by adequacy of social support and active coping patterns. Poorer family functioning was predicted by other family stresses, unwarranted maternal self-blame for the child‟s disability, and maternal definition of the child‟s disability as a “family catastrophe”.

More recently, Saloviita, Itälinna, and Leinonen (2003) tested the Double ABCX model with data collected from a large scale population survey of children and young adults with intellectual disability in Finland. Two hundred and fifty eight parents (116 mothers and 120 fathers) of children aged between one and ten years of age completed a short form of the Questionnaire of Resources and Stress (Holroyd, 1987); measures of family stressors including child severity of disability; measures of adaptive resources including informal and formal support and parental coping strategies; and measures of parental cognitions, including the meanings parents attributed to their situation. Results of multiple regression analyses found components of the model to account for 72% of variance in maternal stress and 78% variance in paternal stress with parental definitions of their situation as a “catastrophe” being the most important component. In mothers, this component was related to child behaviour problems, while for fathers it was associated with perceived social acceptance of the child. The most important resource for mothers was informal support, while for fathers it was spouse support.

A second conceptual model that also draws upon stress theory is the disability-stress-coping model of Wallander and colleagues (Wallander et al., 1989a). Variables associated with differences in the adaptation of children with chronic illness and/or disabilities and their parents, are organised into a “risk-and-resistance” framework. Risk factors are considered to include characteristics of the child‟s disability, and psychosocial stressors including the strain of caring for a child in activities of daily living; daily hassles; and other major life events. The impact of risk factors is hypothesized to be influenced by "socio-ecological" factors such as family environment and social supports (reflecting the influence of Bronfenbrenner); intrapersonal factors such as perceived control or impact; and coping strategies. These constitute resistance (or resilience) factors related to adaptation in both direct and indirect ways. Different aspects of the risk-resilience model have been investigated in a series of studies undertaken by Wallander and colleagues (Wallander & Noojin, 1995; Wallander et al., 1990; Wallander, Varni, Babani, Banis, & Wilcox, 1989b; Wallander et al., 1989c; Wallander et al., 1989a). For example, a study investigating different types of disability related stressors experienced by 119 mothers of children with physical or sensory disabilities found maternal physical health was related to concerns about self, including concerns about additional responsibilities and time demands of caring (Wallander & Noojin, 1995). Another study examined the relationship between socio-ecological factors and maternal outcomes for mothers of 50 physically handicapped school-aged children (Wallander et al., 1989c). Results showed family environment, marital satisfaction and size of social networks to all significantly contribute to measures of maternal mental and social well-being.

A third prominent model used in research investigating variation in carer outcome, is the stress process model proposed by sociologist Pearlin and colleagues (Pearlin et al, 1981). Pearlin, Aneshensel & LeBlanc (1989) coined the phrase "stress proliferation" to indicate the potential for primary stressors to beget additional, secondary stressors. Pearlin and colleagues considered the demands of caring, measured by the number and intensity of caring activities, to be a "core" primary stressor (Pearlin et al, 1997). The experience of role overload, or role restriction are examples of subjective primary stressors. While secondary stressors arise from primary stressors, by disrupting activities and relationships outside of caring, they may independently impact on carer well-being. Financial, social and work related restrictions; as well as marital and family strains, are proposed as examples of secondary consequences that may arise from the demands of caring. Pearlin (1999) has suggested that the concept of stress proliferation helps to explain variability in outcomes for carers. Reactions to primary stressors will differ, as will the types and consequences of secondary stressors encountered by individuals. He further hypothesises that the occurrence and extent of stress proliferation is dependent on the social and economic situation of the carer, the neighbourhood context, and the carer's access to “moderating” resources such as social support, or use of cognitive coping strategies (Pearlin, 1999). Studies investigating the stress process model have been mostly undertaken with caregivers of adults with chronic medical conditions. Aneshensel, Pearlin, and Schuler (1993), for example, investigated difficulties experienced by 555 carers of elderly relatives with Alzheimer‟s disease. They found role captivity (being an unwilling and involuntary incumbent of the caregiver role), and economic strain were the variables most directly related to the decision to place relatives in institutional care. Turner, Pearlin, and Mullan (1998) explored the determinants of social support with a sample of 642 carers of persons with AIDS, showing the importance of social networks, carer demands and time constraints experienced by carers on the perception of emotional support and the receipt of instrumental (practical) support.

The three models described above share some characteristics in common. They consider the child‟s disability as a source of stress (a stressor) for parents and they hypothesise that intervening variables (family resources, or social support) influence the relationship between the stressors related to the child‟s disability and the psychological and physical health of children and carers. The models also share a lack of specificity in identifying the mechanisms by which the intervening variables impact on outcomes. There is an assumption in the models that intervening variables act in similar ways, and an inconsistency in the language used to describe how this happens. Thus, Pearlin and colleagues suggest “people typically confront stress-provoking conditions with a variety of behaviours, perceptions, and cognitions that are often capable of altering the difficult conditions or of **meditating** their impact” (Pearlin, Menaghan, Lieberman, & Mullan, 1981, p. 340). Wallander and colleagues state: “The impact of these risk factors on adaptation is, however, hypothesized to be **moderated** by intrapersonal factors, social-ecological factors, and coping ability, which consequently constitute a set of resistance factors.” (Wallander et al. 1989, p. 25). Further, Grant et al. (2003) point out the lack of conceptual clarity, and the resultant empirical problems associated with testing a transactional model of stress as proposed by Lazarus and Folkman (1984), which emphasises the interaction between (and thus essentially “lumps together”) stressors and variables such as cognitive appraisal. Grant, Compas, Thurn, McMahon, and Gipson (2004), for example, suggest there is a divide between transactional conceptualisations of stress and the methods used to operationalise stressors in many studies in the field of child and adolescent psychology.

The lack of specificity in the three models of stress is reflective of terminological, conceptual and statistical inconsistency in studies exploring moderation and mediation effects within the paediatric field, more generally (Holmbeck, 1997). There are, however, clear conceptual differences between the two constructs. Baron and Kenny (1986) have been most influential in describing the differences between moderator and mediator variables. They identify a moderator variable as “a variable that affects the direction and/or strength of a relation between an independent or predictor variable and a dependent or a criterion variable" (Baron & Kenny, 1986, p. 1174). Grant et al. (2003) suggest moderator variables, such as age, gender or social supports, increase or decrease the likelihood that stressors will lead to negative physical, social or psychological outcomes. A moderator model, for example, would predict social support to interact with stress level to modify psychological adjustment, such that parents who report high levels of stress but who also report high levels of social support would report better psychological outcomes than parents with high stress and low support (Quittner, Glueckauf, & Jackson, 1990). This example illustrates how moderator variables have also been viewed as protective factors, or as "buffering" against the impact of stressors.

In contrast, mediator variables are considered to be "caused" by the stressor, and to conceptually and statistically account for the relationship between the stressor and outcomes (Baron and Kenny, 1986). Holmbeck (1997) suggests that while the relationships between mediators and outcomes may not necessarily be "causal", the relationship is such that the stressor influences the mediator which in turn influences outcomes. Examples of mediator variables may include coping styles, cognitive attributions, and family processes (Grant et al., 2003). Some variables can exert both a moderating and a mediating function. Chapter 3 has shown how studies investigating social support, for example, have found evidence for both moderating and mediating effects. A mediating model, therefore, would predict social support to act as an intervening variable, indirectly influencing the effects of stress on psychological adjustment, such that parents reporting high levels of stress may perceive their relationships as less supportive, which would in turn be associated with poorer psychological outcomes (Quittner et al., 1990). It may also be the case that moderating and mediating processes may change over the course of a child"s development (Grant et al., 2003). This would argue for the importance of undertaking studies of children of similar developmental stages.

More recently, new models have been proposed that specify moderating and/or mediating relationships between stressors, intervening variables and individual outcomes (Grant et al., 2003; Plant & Sanders, 2007). Plant and Sanders (2007) used the stress and coping framework to identify the mechanisms by which intervening variables (cognitive appraisal and social support) related to the psychological well-being of 105 mothers of pre-school aged children receiving services for developmental delay. The model they proposed (depicted in Figure 4.1) hypothesised cognitive appraisal (ie how mothers view their caring responsibilities) to mediate between characteristics of child disability (adaptive behaviour and behaviour problems); characteristics of caregiving tasks (difficulty of task and time taken) and maternal outcomes (stress associated with specific tasks of caring). As well the model specified that the extent of informal social support received from partners, family, friends; and formal social support from professional services, moderates the impact of child disability and caring tasks on maternal outcomes).

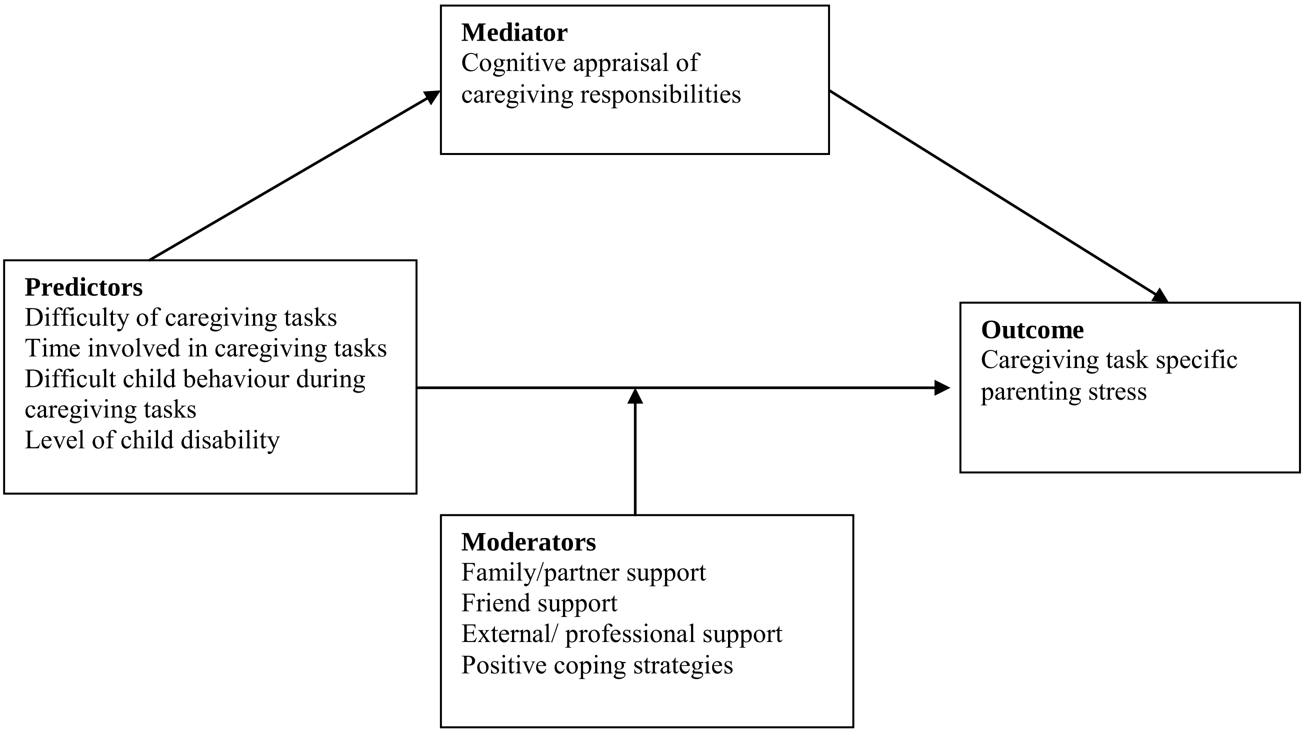


Figure 4.1. Conceptual model of caregiver stress used by Plant & Sanders (2007).

Results of Plant and Sanders‟ study partially confirmed their model of caregiver stress. Perceived difficulty of caregiving tasks, difficult child behaviour during caregiving tasks, and cognitive appraisal of caregiving responsibilities made unique contributions towards predicting mothers‟ level of caregiving stress. These variables were measured using rating scales developed for the study. There was, however, no evidence to support the proposition that cognitive appraisal mediated between difficulty of caring tasks or behaviour problems during tasks, and levels of maternal stress. Cognitive appraisal had a modest role in mediating between level of child disability (measured using the Vineland Adaptive Behavior Scales, Sparrow et al., 1984) and maternal stress. In addition to these results, partner/ family support moderated the impact of level of child disability on mothers‟ caregiving stress; support from friends moderated the impact of difficult behaviour during tasks, and external/

professional support moderated the impact of overall levels of child behaviour problems (measured using the Developmental Behaviour Checklist: Einfeld and Tonge, 1995) on maternal stress.

A recent review of studies testing for moderating or mediating variables contributing to the relationship between stressors and child and adolescent psychopathology, has suggested that particular contexts may moderate the role of mediating processes (Grant et al, 2006). When investigating risk factors for adolescents adapting to the diagnosis of cancer in a parent, for example, Grant and Compas (1995) found that adolescent girls whose mothers had been diagnosed with cancer experienced high levels of anxious-depressed symptoms. They had significantly more symptoms than girls with fathers who had been diagnosed with cancer, or boys whose mothers *or* fathers had cancer. The study showed that increased family responsibilities (ie housework and caring for siblings) of these girls mediated the relationship between parent diagnosis and symptoms of psychopathology in the adolescent. That is, girls were more likely to assume greater responsibility for housework and childcare when their mothers were diagnosed with cancer, than boys whose mothers had been diagnosed with cancer. Further, girls who had increased family responsibilities also had more symptoms of psychopathology. Thus, the mediating relationship was only evident in the context of the gender of the adolescent and the gender of the parent (a “moderated mediation” relationship).

Muller, Judd and Yzerbyt (2005) argue for the theoretical importance of both “moderated mediation”, and also “mediated moderation”, terms first coined by Baron and Kenny in 1986. Preacher, Rucker and Hayes (2007), more simply, describe such effects as conditional indirect effects, defined as: “the magnitude of an indirect effect at a particular value of a moderator (or at particular values of more than one moderator)" (Preacher, Rucker, & Hayes, 2007, p. 186). Preacher et al, suggest that conditional indirect effects may have gone unnoticed or unexamined in the past because of the lack of methods for investigating whether, and how, indirect effects vary systematically as a function of another variable. Clearly articulated analytic strategies have only recently become available, allowing for the investigation of conditional indirect effects and the inclusion of such effects in theoretical models (Muller et al, 2005; Preacher et al, 2007).

Grant et al. (2003), in response to perceived shortcomings in previous conceptual models, developed a model that specifies the ways in which both moderator and mediator variables may work together to better explain relationships between stressors and child and adolescent psychopathology. As well, they use a definition of stress that avoids the difficulties involved in measuring "transactional" stressors. Grant et al. (2003), therefore propose that: "Stressors should be defined, specifically and exclusively, as environmental events or chronic conditions that objectively threaten the physical and/ or psychological health or well-being of individuals of a particular age in a particular society" (Grant et al., 2003, p. 462). In their model, stressors are represented by major life events, minor events and "chronic" conditions. Early studies researching stress focused almost exclusively on the negative impact of "major" life events, such as divorce or unemployment (Holmes & Rahe, 1967). More recently, however, other studies have found "minor" daily stressors (ie the everyday demands of daily life), termed "daily hassles", to be strong predictors of psychological well-being (Crnic & Greenberg, 1990; DeLongis, Folkman & Lazarus, 1988). Crnic and Greenberg, (1990), for example, showed minor parenting "hassles" among typically developing children predicted less positive family well-being. The inclusion of “chronic conditions”, such as chronic illness or poverty, is consistent with Quittner‟s (1992) suggestion that stress research use measures of stress which are relevant to the context in which individuals live.

Grant et al.‟s general conceptual model of the role of stressors in the aetiology of child and adolescent psychopathology, and underlying propositions, is shown in Figure 4.2.

NOTE:
This figure is included on page 99 of the print copy of
the thesis held in the University of Adelaide Library.

Figure 4.2. General conceptual model of stress (Grant et al., 2003).

Grant et al. (2003) tested the basic elements of the conceptual model by undertaking a meta-analytic path analysis on results from studies investigating the relationship between poverty and the psychological health of children and adolescents. They found evidence for the mediating effects of negative parenting and additionally, for the moderating role of child gender. Thus, the association between poverty and negative parenting was stronger for boys than for girls. As well, the association between negative parenting and internalizing type symptoms was stronger for girls than for boys. Grant et al. conclude that results of the meta-analytic path analysis provided support for many of the propositions of the general conceptual model, and indicate how the model the may help in developing specific testable hypotheses.

4.4 Model of carer well-being

The conceptual model as described by Grant et al. (2003) was specific to child and adolescent psychopathology. The general conceptual framework, however, is well suited to the context of caring. The ability to explore potential interactions between intervening variables may help to better explain the complex relationships between childhood disability and parent well-being. Figure 4.3 depicts an adaptation of the Grant et al. conceptual model, including variables identified in the literature reviews outlined in previous chapters.

NOTE:
This figure is included on page 101 of the print copy of
the thesis held in the University of Adelaide Library.

Figure 4.3. Model of carer well-being.

The model of carer well-being is a simplified version of Grant et al‟s (2003) framework, omitting the pathways illustrating reciprocal and dynamic relationships between stressors, mediators, moderators and parent outcomes. *This does not mean that these relationships do not exist, but acknowledges the difficulties involved in testing for them.* The other propositions inherent in Grant et al‟s model may be specified for the model of carer well-being, such that:

1. Stressors contribute to parent outcomes;
2. Mediators explain the relationship between stressors and parent outcomes;
3. Moderators influence the relationship between stressors and parent outcomes;
4. There is specificity in the relations among stressors, moderators and mediators and parent outcomes.

In contrast to the model proposed by Plant and Sanders (2007), described earlier in this chapter, the model of carer well-being specifies objective indicators of caring responsibilities such as time spent caring, as well as subjective indicators such as perceptions of time pressure (a specific type of cognitive appraisal), to be potential mediating variables rather than stressors. For example, time spent caring, and perceptions of time pressure are assumed to be the mechanism by which child disability influences parent well-being. Characteristics of child disability (regarded as a chronic stressor) are assumed to lead to more or less time spent caring, or to increase or decrease the experience of time pressure. A key component of the carer well-being model, that also distinguishes it from the model of Plant and Sanders (2007), is the proposition that social support, including emotional and practical support, moderates the impact of caring responsibilities on the well-being of carers.

4.5 Conclusion

This chapter has described theoretical frameworks which attempt to explain relationships between key variables related to caring. The Double ABCX model (McCubbin & Patterson, 1983) and the disability-stress-coping model (Wallander et al., 1989a) both draw upon the stress and coping theory of Lazarus and Folkman (1984), and assume a transactional definition of stress. These models, together with the socio-ecological model of stress (Pearlin, 1989), however, do not specify the mechanisms by which different intervening variables influence the relationship between stressors and psychological, social and physical outcomes for individuals. Holmbeck (1997) suggests conceptual, terminological and statistical inconsistency in the use of the terms “mediating“ and “moderating” variables, is characteristic of research in the field of mental health. Baron and Kenny (1986), and other authors

(Holmbeck, 1997; James & Brett, 1984; Quittner et al., 1990) have sought to bring clarity to the distinction between moderator and mediator variables, to better explain the conditions under which individuals (or parents/ families) are most vulnerable to stress. In addition, new analytic strategies have enabled conceptual and statistical investigation of more complex interrelationships, such as those described as conditional indirect effects (Preacher & Hayes, in press; Preacher, Rucker, & Hayes, 2007).

The general conceptual model proposed by Grant and colleagues, in the area of child psychopathology, specifies potential pathways by which moderator and mediator variables can better explain the relationship between stressors and child and adolescent psychological health (Grant et al., 2003). Grant et al"s model lends itself well to being adapted for the task of investigating variables that influence parent adaptation to the long term chronic stressor of caring for a child with a disability. The model of carer well-being described in this chapter, proposes caring responsibilities to mediate the relationship between characteristics of child disability and parent well-being. Thus, the model predicts that objective and subjective indicators of caring responsibilities (such as time spent caring and feelings of time pressure) indirectly influence the relationship between stressors (reflected by characteristics of child disability and life stressors more generally) and psychological and physical well-being of parents. Further, the model specifies the influence of social support in influencing the relationship between caring responsibilities and parent outcomes.

The previous chapters have shown that parents of children with disabilities are vulnerable to psychological, social and physical health problems. There have been very few studies, however, that have examined ways in which additional caring responsibilities change the daily lives of parents. There is even less information about the mechanisms by which caring responsibilities may impact on parental outcomes. The model of carer well-being proposes potential pathways between child disability, the time constraints of caring, and the role of partner support in contributing to parental well-being. The chapter to follow will describe the first study undertaken as part of the present dissertation. Study 1, a qualitative study using focus group methodology, aimed to ask parents directly about the consequences of caring for children with disabilities, and the specific caring activities that they undertake as part of their daily routine. It was intended that the results of the study would be a preliminary investigation of the model of carer well-being.

4.6 A note about terminology

The broad aim of the present dissertation is to examine the role of caring responsibilities in contributing to the psychological, social and physical health outcomes of parents caring for children with disabilities. Data to be reported in future chapters will be structured to reflect this focus, with results being analysed and presented separately for primary caregivers (as being the person who assumes the most care of children in a family) and secondary caregivers (the person in a family who takes a secondary role in the care of children) where possible, throughout the dissertation. Traditionally, mothers are most likely to take on the role of primary caregiver of young children, while fathers take on the role of secondary caregiver. Secondary caregivers are often involved in paid employment outside of the family home. Organising data around gender status, that is presenting results for males and females or mothers and fathers, however, does not directly acknowledge the importance of the secondary role of caring. As well, a focus on gender ignores the growing number of fathers who choose, or are required by circumstance, to be the primary carer for their child.

In some instances, it was necessary to analyse caregiver data using gender categories. The terms male and father, and the terms mother and father have been used interchangeably for these analyses. It should also be noted that no distinction has been made between caregivers who are biological parents and caregivers who are not directly related to the child.

In addition to the terms “primary caregiver” (abbreviated to PCG) and “secondary caregiver” (abbreviated to SCG), the term “carer” will be used for brevity throughout the thesis. The terms “parents” and “carer” are used synonymously and the term “caring” is used to describe what it is that parents do. While it is acknowledged that all parents care for children, the model of carer well-being assumes (as has been found in research reviewed in earlier chapters) that parents of children with disabilities have *additional* caring responsibilities.

SECTION 2:

QUALITATIVE EVIDENCE FOR THE MODEL OF CARER WELL-BEING

CHAPTER 5:

Talking to parents about the consequences of caring

5.1 Overview

This chapter will describe results of the first study (Study 1) completed as part of the present dissertation. The study was undertaken as a preliminary step towards testing the model of carer well-being, shown in Figure 4.3 at the end of Chapter 4. It employed a qualitative methodology using focus groups and home interviews with parents caring for children with physical and other disabilities. In the focus groups parents were asked to describe the consequences of caring for children with disabilities, the tasks involved with caring, and the things that help support caring. Results of thematic analysis of focus group transcripts were analysed using the QSR NVivo Version 7 software package (QSR International Pty. Ltd. 1999-2007).

5.2 Specific aims

The specific aims of Study 1 were:

1. To explore with parents their experiences of caring for a child with a disability. In particular, to identify the impact of daily caring responsibilities (the different tasks of caring) and the supports that parents thought most helpful.

2. To undertake an initial investigation of the model of carer well-being. Findings from the focus group data aided the selection and development of measures used in the quantitative study which forms Section 3 of the dissertation.

5.3 Method

5.31 Focus group design

Focus groups are unstructured (or semi-structured) interviews with small groups of participants who interact with each other and with a group leader or moderator (Bowling, 2004). Krueger & Casey (2000) highlighted the role of focus groups in providing valuable information to help in the planning of larger quantitative studies. Morgan (1988) suggested that focus groups can generate hypotheses based on the insights of participants and provide information that will help in the development of interview schedules and questionnaires.

The present study utilised three focus groups, a number typically considered sufficient to achieve “saturation”, the point at which no new information is obtained from the group discussions (Krueger & Casey, 2000). The use of multiple groups also allows for comparison of themes and patterns across groups.

The focus groups comprised mothers who were caring for children with physical disabilities. Many of the participating mothers knew each other from previous attendance at a group programme run by an organisation providing services to their children. The decision to recruit participants who knew each other was made for pragmatic reasons, both to maximise the number of potential focus group participants, and to encourage the easy flow of discussion between participants. While focus groups are typically composed of people who are strangers, researchers have questioned the need and practicality of this approach for community or clinically based studies (Krueger & Casey, 2000).

The focus groups ranged in size from three to eight participants. The size of the individual focus groups was determined by the procedures used to recruit participants (see section 5.33.1). Several mothers were unable to attend the focus groups as planned due to unexpected caring commitments. In general, there are no strict guidelines about the ideal number of participants in a focus group. A smaller number of participants encourages more opportunities to share insights, but may limit the range of experiences described (Krueger & Casey, 2000). Krueger (1996) suggests that the more expertise participants have on a subject the lower should be the number in the group. As participants were discussing a subject with which they were very familiar, it was felt that relatively small groups were appropriate.

5.32 Participants

Thirteen mothers of children who were clients of the Novita Children's Services attended one of the three focus groups. Novita Children"s Services are the primary provider of therapy and family support services to children with physical or multiple disabilities living in South Australia. Two mothers, who wished to participate but were unable to attend a focus group, were interviewed at home. All participants were the primary caregivers of young children (most of pre-school age) with moderate to severe physical and other disabilities. Most mothers were also caring for non-disabled siblings.

While the original intention of the study was to involve mothers and fathers in the focus groups, insufficient numbers of fathers expressed interest in attending a group. This, in large part, is a consequence of mothers being the principal carers of children with disabilities, and the parent with the most contact with service providers such as Novita Children‟s Services. Previous experience by the researcher suggests that different approaches are needed, both to recruit fathers; and to ensure that fathers feel comfortable in discussing their experiences. Those fathers who did respond positively to the present study were reluctant to take part in a focus group primarily composed of women. Practical reasons prevented the researcher from being able to further pursue the option of a separate focus group for fathers.

5.33 Procedure

5.33.1 Recruitment of participants

Procedures for recruiting participants for the focus groups were approved by the Ethics Committee of the Women‟s and Children‟s Hospital. At the start of the study, meetings were held with the Managers of the different regional offices of Novita Children‟s Services to discuss the aims of the research and plans for the focus groups. Subsequently, Managers and staff in the regional offices identified several existing group programmes they considered to be suitable sources of participants for the study. Two of the group programmes identified were early intervention (ie therapy) playgroups, in which parents met weekly with their therapy staff. The third was a support group for mothers, facilitated by psychologists, that met in the evening approximately once per school term. Novita staff in the relevant regional offices assisted by providing parents attending the identified programmes with an

Information Sheet about the study (see Appendix A). The Information Sheet was also included in a newsletter, regularly sent to all clients of Novita services. The Information Sheet asked parents to contact the researcher directly if they were interested in taking part in the study. Contact by telephone was made with all respondents (mothers) to answer any questions about the study, and to discuss options for when and where the focus groups could be held. All respondents agreed to participate in the study.

5.33.2 Focus groups

The first focus group, comprising eight participants, was held in the evening at the South-Eastern Regional Office of Novita Children‟s Services. This had been the venue for a mothers support group, attended by most of the participants in the focus group. The second focus group was held in the daytime at the Western Regional Office of Novita Children‟s Services, the location of a regular early intervention playgroup. Four mothers, who were all regular attendees of the playgroup, met together while their children remained with therapy staff in another room. The third and last focus group was held in the evening at the Northern Regional Office of Novita Children‟s Services. The three mothers who attended were all previous participants of an early intervention programme held at the same venue. The focus groups varied in length from 90 minutes to two hours.

The groups were moderated by the author of this dissertation, who is a clinical psychologist with training and experience in group work skills. Refreshments were provided to assist the moderator in providing a relaxed and open environment. All focus groups were tape-recorded (with the written consent of participants) and notes were also taken during the sessions. Copies of the consent forms used for the study, and completed at the start of each group, are included in Appendix A.

The focus groups began with a brief overview of the process; highlighting that there were no right or wrong answers, that all comments and views were welcome, and exploring the importance of group confidentiality. The same format and series of open-ended questions were used to facilitate and direct discussion in each of the groups. Questions were structured according to the guidelines set out by Krueger & Casey (2000). Specifically, group discussions were started with an introductory question that encouraged participants to introduce themselves and their child to the group. Questions which followed were designed to move from broad issues to more specific issues of relevance to the study (Krueger & Casey, 2000). There were three key questions:

1. What have been the most important consequences to you and your family of caring for your child?
2. What are the extra tasks of caring that are involved in caring for your child?
3. What helps you and your family to fit in the extra tasks of caring?

Additional, transitional and probing questions were used as needed to clarify and encourage discussion. An ending question (ie “Of all the things we have discussed, what is the most important to you?”) was used to bring closure to the group.

Two mothers indicated that they were eager to participate in the study, but were unable to attend the planned focus groups. It was decided to proceed with home interviews to meet with these parents. The questions used in the focus groups were also used to direct conversation in the home interviews allowing the information from the interviews to be included in subsequent analyses.

The audio-tapes from the 3 focus groups were all professionally transcribed to allow formal analysis, yielding 78 pages of text. The home interviews were not audio-taped, precluding the use of transcripts. Extensive verbatim field notes were taken, however, that allowed the information from the interviews to be analysed in a similar fashion to the focus groups.

An informal summary of the main outcomes of the focus groups and interviews was sent to all participants, and to the staff of Novita Children‟s Services, at the conclusion of data collection. The summary was intended as feedback for participants and those working with mothers caring for children with disabilities. It was also a way of checking the validity of the information contained. Several positive comments were received, suggesting that the summary accurately portrayed the main issues raised by the mothers.

5.34 Analysis

Qualitative analysis of focus group data (or any other form of qualitative data) may be seen as a way of summarising, organising or reducing the data in a way that relates meaningfully to the research questions. The first step is to impose some structure onto the text. This process is commonly referred to as coding (or categorising), or as thematic analysis. These terms are often used interchangeably, but more recently Braun and Clarke (2006) described thematic analysis as “a method for identifying, analysing and reporting patterns (themes) in the data” (Braun & Clarke, 2006, p.79), and outlined a step-by-step guide to the conduct of thematic analysis which includes the process of coding. Table 5.1 presents the guidelines suggested by Braun and Clarke, and describes the processes involved.

Table 5.1
Step – by –step guide to doing thematic analysis

NOTE:
This table is included on page 117 of the print copy of the thesis held in the University of Adelaide Library.

Note: From Braun & Clarke (2006), p. 87.

The guidelines outlined by Braun & Clarke were used to analyse the data in the present study. Thematic analysis was firstly undertaken across the whole data set (that is, all focus groups and the home interviews), to obtain a detailed description of the themes important to the participants. Subsequently, a single theme (that of “time demands”) was extracted and subjected to more detailed analysis. The intention of this analysis was to explore the relationship between “time demands” and the other themes arising from the focus groups. Information from these analyses was subsequently compared with the model of carer well-being described in Chapter 4 and used in planning the quantitative study to be described in Section 3.

Coding of the data was undertaken in an inductive (“bottom up”) way, in contrast to a theoretical, or deductive (“top down”) way (Braun & Clarke, 2006). Thus, codes emerged from the data, rather than the data being fitted into a pre-existing coding framework. The data was analysed in sections (corresponding to participant comments, or quotes), at a semantic level, using QSR NVivo Version 7 software package (QSR International Pty. Ltd. 1999-2007). NVivo software is an analytical tool that is consistent with the methodologies of many theoretical approaches to qualitative analysis, including thematic analysis. NVivo facilitates the process of coding and the identification of themes, and has the advantage of allowing data to be coded to multiple categories.

Coding was undertaken according to the 3 key questions used in the focus groups (“Consequences of caring”; “Tasks of caring” and “Things that help (support caring”). Participant quotes were examined for direct or indirect references to meaningful elements that could help to accurately describe the data.

The following provides an example of codes applied to a short extract of data (participant quote).

“There‟s nothing to track it and it‟s like I have to go through the whole story every time we go to hospital. And when you‟ve got complicated children that takes a lot of time. It also means that I have to relive the whole story every time I say it. I feel all the emotions again. I should have a file at home (with medical reports etc) and take it with me every time I go to the hospital. That‟s what I should do but I don‟t have time to do it!” (Participant Focus Group 1)

This quote was coded for:

Hospital visits
Time constraints
Grief – recurrent
Difficulties with services (communication/record keeping)
Things that would help (record keeping)

As coding progressed, it became easier to identify patterns (themes) across the data, signalling phase 3 of the analysis. Theme identification was a more interpretive process than coding, involving consideration of the ways in which codes were related to each other in a meaningful fashion. Sub-themes were identified if participants made a number of references to issues within themes. Sub-themes were coded hierarchically, or nested, within relevant themes. Individual quotes could be coded for one or more themes or sub-themes, allowing for a comprehensive description of participant comments. A coding booklet, outlining the decision making rules in determining inclusion of a reference in a theme, or sub-theme, has been included in Appendix B.

The final phases of thematic analysis described by Braun and Clarke, involved an ongoing process of reviewing, refining and relating themes to each other, both at the level of the coded data extracts, and in relation to the entire data set. Thematic analysis was completed with the production of a thematic map, which was considered to provide an accurate and concise description of the data.

Analysis of the focus group data will be presented in terms of the thematic maps that were the outcome of thematic analysis. In addition, mention will also be made of the number of times that participants referred to the themes across the data set. The use of frequency data is often seen as a characteristic of content analysis (Wilkinson, 2000). For the purposes of this study, frequency data was used to help illustrate the importance of themes to the participants of the focus groups. The benefits of presenting the data in this way were thought to outweigh the difficulties inherent in the use of frequency data, in particular the fact that themes may be over-represented by a single participant. In addition to frequency counts, reference will also be made to the number of sources from which the theme was coded (ie whether it was coded from one, two or three focus groups, or included in the interviews). This was considered to provide an additional reflection of the relevance of the theme to a broader number of participants.

5.35 Reliability Testing

To ensure that coding was undertaken consistently, an associate experienced in the analysis of survey and statistical data, who had not participated in the focus groups, coded all 71 participant quotes for the theme “Time demands of caring” (for a description of this theme, see later) identified in Stage 1 of analyses. This theme was selected as being most relevant to the model of carer well-being. Agreement as to the validity of including the quote in the “Time demands of caring” theme was obtained for 61 quotes (84% agreement). Discussion about discrepancies resulted in a clarification of the decision-making rules (see Coding Booklet in Appendix B) and subsequently resolved the status of an additional 10 quotes (97% agreement). Two quotes were ultimately considered to be inappropriately placed in the “time demands” theme and were therefore omitted from analyses. All tables to follow report data after adjustments had been made in consequence of reliability testing.

Reliability checking was also undertaken for the second stage of analyses, in which participant quotes within the core theme “Time demands of caring” were re-coded (see later). Initial agreement of 86% was obtained. Further discussion resolved discrepancies in coding.

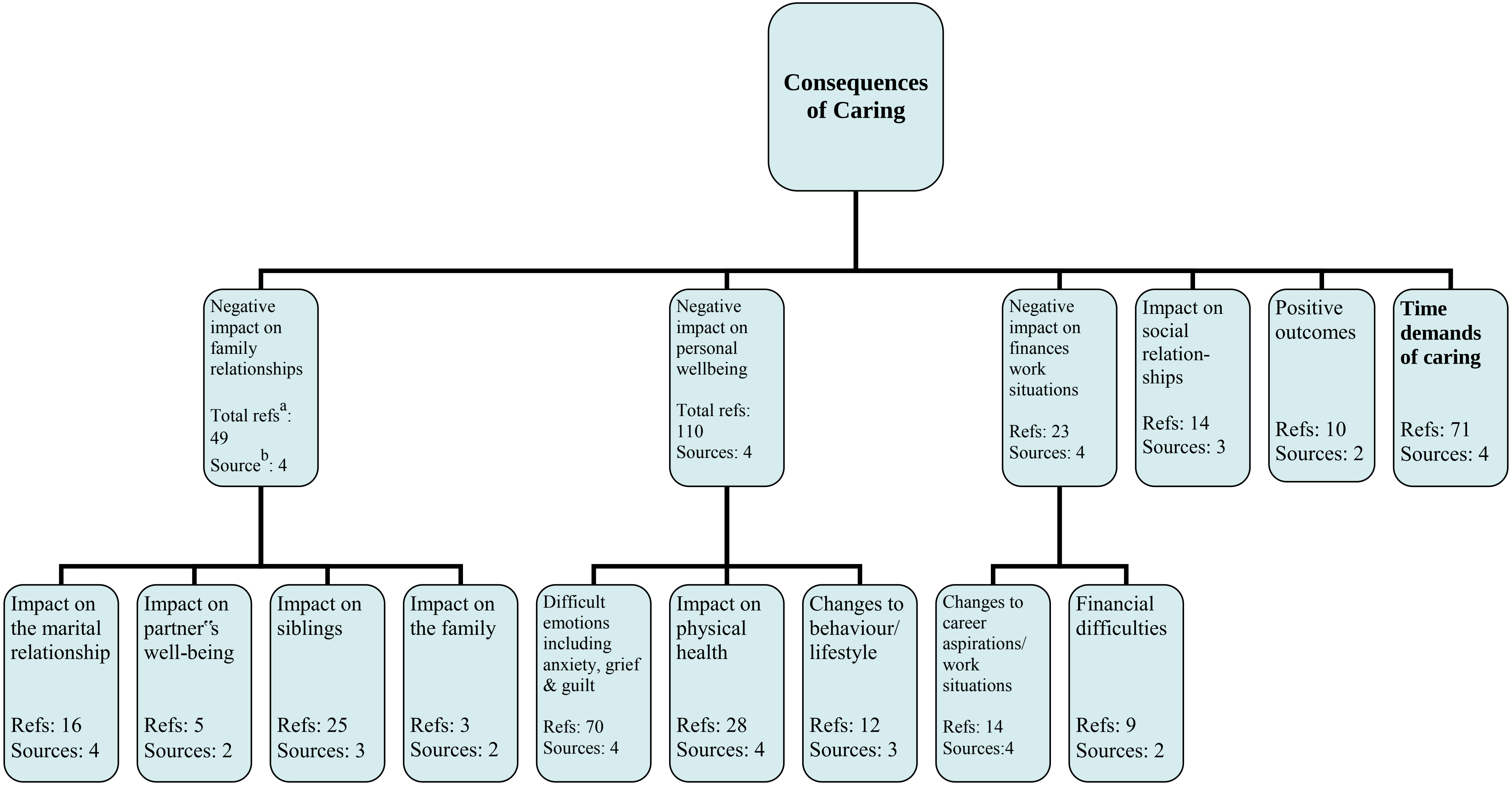
5.4 Results

5.41 Aim 1: the experience of caring

Results of thematic analysis of the focus group and home interviews data are presented in relation to the three key questions. In each case, a thematic map, the end result of analysis, is presented. Quotes will illustrate the main concerns (represented by the themes in the data) expressed by the mothers who took part in the study.

5.41.1 Consequences of caring

Figure 5.1 presents the thematic map that resulted from coding of participant comments made in relation to the first key question introduced in the focus groups and home interviews (ie "What have been the most important consequences to you and your family of caring for your child").



[a] Number of references made to this theme by the participants in the focus group s and home interviews; [b] Number of sources from which this theme was obtained (one, two, three focus groups and /or home interviews)

Figure 5.1. Thematic map from "Consequences of Caring" key question.

Figure 5.1 shows the theme with the largest number of sub-themes identified in response to the "Consequences of Caring" question related to the negative impacts of caring on family relationships. Mothers were most concerned about the impact of caring on their child‟s siblings, and on the marital relationship.

Some quotes illustrate the issues relating to family relationships expressed by the mothers in the study:

> "Yeh, it‟s the whole realization that, my goodness, our family‟s not a normal family, we are a special family, it‟s not just our special child…" (Participant Focus Group1)

> "Marriages! How they survive, I think is a credit to us, I really do and if people split up it wouldn‟t surprise me in the slightest. But to be a sole parent, bringing up a child with special needs, would be even harder than what we do."
> (Participant Focus Group 3)

> "I actually lie (to my child‟s sibling)…when she asks what I do because I don‟t want to admit to her that I took M… to the gastroenterologist and then we had the Novita therapist come around, because she gets a message that my whole day is M…. which it is. I tell her I did the washing." (Participant Focus Group 3)

> "I found his (my husband‟s) way of dealing with it is to bury himself in his work, which helps him deal with it, but it doesn‟t help me." (Participant Focus Group 3)

The largest number of references made by participants in response to the first key question related to the negative impacts on personal well-being arising from caring. Most references within this theme related to the sub-theme of emotional impacts, with grief figuring prominently (21 references were solely made to grief and the process of grieving). As well, many participants referred to the negative health impacts of caring, particularly exhaustion and the difficulties in finding time to look after oneself. Changes to personal behaviours and the family‟s lifestyle were noted by some participants. The following quotes illustrate these concerns:

> "I‟ve heard that people say that parents that lose a child go through grief, whereas parents of disabled children never actually move quite through…"
> (Participant Focus Group 3)

> "I don‟t look after myself. I mean, you don‟t get time." (Participant Focus Gropup 2)

> "I guess for me it‟s still early days and it‟s still overwhelming. It‟s (the emotions) as well as exhaustion. It‟s trying to function and remember who I am as a person as well as being K..‟s mum, carer, therapist, advocate, case manager. You know, there‟s not a lot of room left for (me) in there?" (Participant Focus Group 1)

> "I‟ve just noticed our behaviour‟s changed. We take vitamin C tablets all the time. We are just so conscious of ourselves not getting sick, not just so M… doesn‟t get sick, but we‟re also aware that if we get sick, how are we going to look after him?"
> (Participant Focus Group 2)

The next theme described by the thematic map shown in Figure 5.1, relates to the negative impacts on finances and work situations. The need to provide extensive care for a child with disabilities required a number of the mothers (and in some cases fathers too) in both the focus groups and interviews to stay at home rather than return to work after the birth of their child. For example:

> "If my husband hadn‟t done that (left work) our marriage wouldn‟t have survived – it‟s too high stress having to do it all, so some sacrifices had to be made. It‟s working out what‟s more important, your job or having a marriage and being there for your kids." (Participant Focus Group 1)

> "I‟ve had to leave work. Financially we are suffering incredibly, we live on love as my husband would say…That was the biggest thing, giving up my job."
> (Participant Focus Group 3)

Participants also referred to changes in social relationships, following the birth of their child with disabilities:

> "I‟m still finding it hard to be around my friends that have got kids W…‟s age, and them talking about how (their child) is walking or whatever… I find that really hard"
> (Participant Focus Group 1)

> "I‟m better now than I was... in a way, 50% of the time I‟m glad that this has happened to me... because we‟ve just grown from it. I look at the people I used to

> hang around with and I think I‟m so glad I‟m not there anymore, because it‟s so superficial." (Participant Focus Group 1)

The thematic map illustrates that caring most often had negative impacts for the mothers in the study, and their families. It is important to note, however, that the mothers in two of the focus groups mentioned some positive outcomes of caring. For example:

> "I think too, that these kids definitely put your life into perspective."
> (Participant Focus Group 3)

> "I think self-awareness has been the big thing I‟ve gotten out of this. It‟s made me look at who I am, who my family is, who my friends are….and got rid of all the BS, I guess." (Participant Focus Group 1)

> "I‟ve seen some fantastic positives (like new friends) but just my outlook on life, like working isn‟t the most important thing, money isn‟t the most important thing, people are and what you do with your time and your family." (Participant Focus Group 1)

The final theme displayed in Figure 5.1 refers to the "time demands" experienced by the mothers when caring for their children with disabilities. It reflects both the additional time required by caring tasks as well as the other time demands of daily living. This theme received the second largest number of references in response to the "Consequences of Caring" key question, and by far the most references to a single theme without additional sub-themes. This theme was of particular relevance to the present study as it relates directly to the day-to-day strains of caring. The following are some illustrative quotes:

> "The time…the time…you have no idea how much time you spend with (your) child. It‟s unbelievable!" (Participant Focus Group 3)

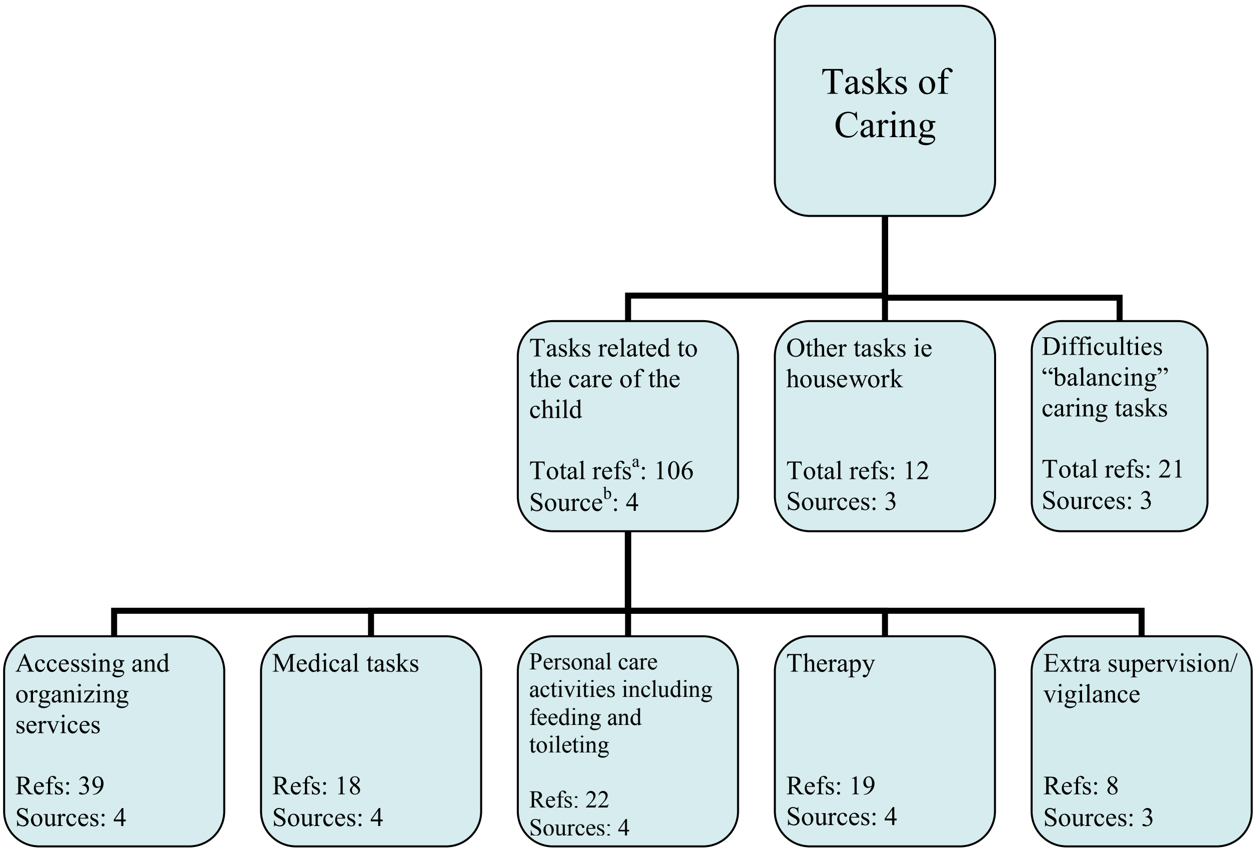
> "Time management is the most important issue for me. Just how to fit everything in…" (Participant Focus Group 2)

> "..it‟s so intense, its such an intense experience, its full on all the time without a break, its not like you can get days off." (Participant Focus Group 1)

The "time demands" theme, both because of it‟s relevance to the aims of the research outlined in the Introduction, but also because it cut across so many of the other themes identified in the thematic analysis, was identified as a core theme for further, in depth analysis. This analysis will be discussed in detail later in this chapter, and will focus on the relationships between time demands and other major themes identified by the participants of the focus groups and interviews, addressing the second aim of the study.

5.41.2 Tasks of caring

Figure 5.2 presents the thematic map that arose from analysis of participant discussion in response to the second key question (ie “What are the extra tasks that are involved in caring for your child with a disability”)



[a]Number of references made to this theme by the participants in the focus group s and home interviews; [b]Number of sources from which this theme was obtained (either one, two, three focus groups and /or home interviews)

Figure5.2. Thematic map from “Tasks of Caring” key question .

The thematic map shows that participants made most mention of the tasks that related to the direct or indirect care of the child. The most prominent concern of participants within this theme was the need to organize and access services for their child, including the need to make appointments; to liaise with doctors, therapy and school staff; and to complete paperwork. These tasks resulted in considerable stress for participants, and contributed substantially to feelings of time demands. Some examples of comments made:

> "We have people from all over the place ring us up for different things and you have to be really on the ball to try to remember what it is and what has happened."
> (Participant Focus Group 3)

> "Chasing people up drives me insane. You don‟t have time to chase people up to make appointments for therapists to do this and that, they need to chase you."
> (Participant Focus Group 2)

> "But you have to keep being the advocate all of the time. You have to grit your teeth and say I have to do this, no matter what this makes me feel like."
> (Participant Focus Group 1)

Other tasks of note included medical tasks undertaken by the mothers on their child‟s behalf. Several children in the sample had medical conditions such as epilepsy, requiring medication and the need for extra vigilance on the part of parents. Other children had medical problems requiring parents to be trained in the use of complex medical technologies at home. Both were sources of stress for parents. For example:

> "I have to medicate her and that‟s a real charm at the moment because she refuses everything that I have got that medicine in. I have tried all ways to feed, so that has been really difficult." (Participant Focus Group 3)

> "Especially feeding in public, because my husband just doesn‟t cope with that in public, so then he has to go off somewhere with L… (child‟s sibling) and I have to go and find somewhere to give M.. his gastro-feed." (Participant Focus Group 3)

> "It‟s a huge responsibility, massive, because you know if you get the dose wrong, your child is at high risk of potentially dying or having a seizure, or any of those sort of things. So I think that level of responsibility is huge…"
> (Participant Focus Group 2)

> "If he didn‟t have seizures, I‟d find it so much easier to cope with a disabled child. The seizures are so disruptive, because they are unpredictable, you don‟t know if you‟re going to have a good day or a bad day…." (Participant Focus Group 2)

Personal care tasks such as feeding and toileting were also often found to be difficult for the mothers, particularly in terms of the extra time needed by these tasks.

> "But for me, it‟s like nappy changes and struggling with mashed food and things like that, that‟s probably going to be the next…however long his life expectancy is."
> (Participant Focus Group 2)

> “She has this issue with continence, she‟s incontinent often and that‟s been a huge issue to deal with because it‟s so erratic. Trying to deal with things like that when you‟re trying to liaise with the school, to try to get them to do what they are supposed to do…” (Participant Focus Group 3)

> “There are always little extra things you have to do ….then I have to put her orthotics on and brush her hair and that all has to be done at the table. That‟s before I have got myself ready you know, if I‟m going to have a shower in the morning. Often I don‟t because I don‟t have time.” (Participant Focus Group 1)

Therapy was a prominent part of the lives of the mothers in the groups, as most children were of pre-school age and receiving early intervention services. However, therapy was often a source of ambivalence. On the one hand, therapy was regarded positively because of the benefits it gives, but on the other, creating considerable anxiety and guilt because of the difficulties in being able to find time for it in daily life. For example:

> “Because you‟re left doing this homework which half the time you feel like you're stuffing up, or, you‟re not doing it properly or “I wish (the therapist) was here because he‟s just bumped his head again…” (Participant Focus Group 2)

> “I feel guilt about…I‟ve got to work doubly hard because I‟ve got to make a difference for this child. Not only do I feel that I don‟t do my best as a mum, I‟ve got this homework coming from a whole range of therapists.”
> (Participant Focus Group 2)

> “It‟s really in the best interests of the children. I loved it (the Hannen programme). I‟ve never done a course that I have enjoyed so much in my life.”
>
> (Participant Focus Group 3)

The need for extra vigilance or supervision when caring for the child with a disability was mentioned by a number of mothers, and was a particularly emotive issue for one of the mothers in the home interviews whose child was experiencing behavioural problems..

> “Well. I‟m still on my guard, I don‟t think I sleep solidly. I know that‟s a typical mum thing but, we found H… in his cot and he was the colour of beetroot because he‟d had a seizure and he‟d held his breath…He was eight weeks old then, and still, if I can‟t hear him in his room, you know, I‟ve got to get up and go and look.”
>
> (Participant Focus Group 2)

The other themes in the “Tasks of Caring” question related to tasks that were not specifically directed towards the care of the child, such as housework. Primarily, mothers expressed the difficulties of finding time for housework,

> “You can‟t imagine what it‟s like, to see a thousand things that you need to be doing in your home and not be able to do a single thing because your child is sitting there and you feel sorry for them because they cannot play.” (Participant Focus Group 1)

> “I‟m quite lucky that we‟ve sort of got it sorted now that I‟ve got someone that comes and cleans the house once a fortnight, because I just can‟t find the time to do it.”
>
> (Participant Focus Group 2)

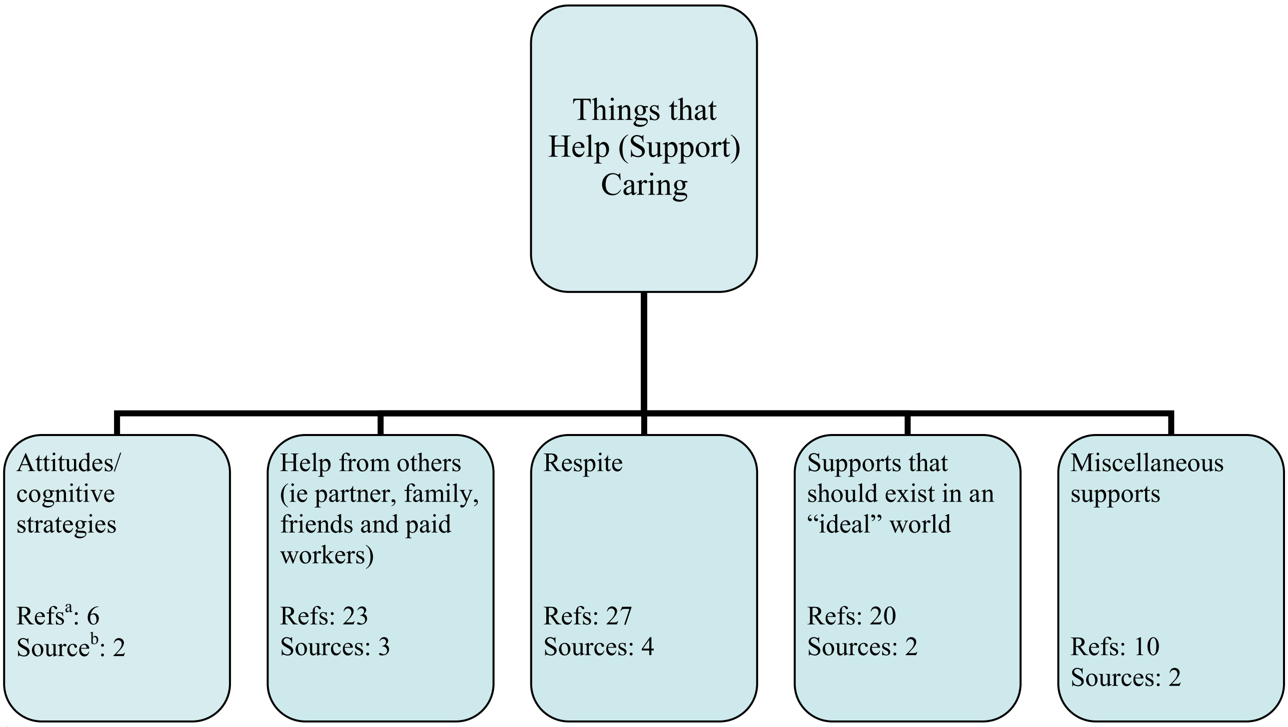
The difficulties of “balancing” caring tasks with other responsibilities were raised in a number of contexts, warranting a theme to describe the concerns of the mothers and to illustrate consequences for them.

> “I find it, the housework, has to be done outside of (my child‟s) waking hours. So if she is up for 12 hours, hey ho, guess who has to stay up and does a 14 or 15 hour day. Everyday. Seven days a week.” (Participant Focus Group 1)

> “I seem to just beat myself up. I just worry, like “why did I not manage to organize myself, to not to be able to do this? What did I do today?”
> (Participant Focus Group 2)

5.41.3 Things that Help (Support) Caring

Figure 5.3 shows the thematic map arising from analysis of the final key question used in the focus groups (ie “What helps (supports) you and your family in caring”).



[a] Number of references made to this theme by the participants in the focus group s and home interviews;
[b] Number of sources from which this theme was obtained (one, two, three focus groups and /or home interviews)

Figure 5.3. Thematic map from “Things that Help (Support) Caring:” key question.

The final key question resulted in a range of themes representing the things participants found helpful in supporting their caring role. A small number of mothers mentioned attitudinal or cognitive strategies. For example:

> “I‟m OK as long as I don‟t think too far into the future. Like I can‟t think five or ten years time, I‟m very much for the moment - the next two years I can probably cope with, but anything beyond that…” (Participant Focus Group 3)

> "So I kind of think there are negatives and there are positives. I have to focus on the positives." (Participant Focus Group 1)

More mention was made of the help received from others, mostly partners (secondary caregivers) and grandparents. The value of support groups was also highlighted.

> "My husband works full-time so he literally walks in the door and I go "here you go". He does that willingly, he‟s happy to do that. I go for a walk or go somewhere to get away for a little while." (Participant Focus Group 1)

> "My mum and mum-in-law are fantastic, I couldn‟t ask for better."
> (Participant Focus Group 2)

> "I think meeting other parents helps, especially other mothers, and knowing that you are not the only one dealing with this." (Participant Focus Group 3)

The thematic map illustrates that the most frequent support referred to by participants was represented by the theme of respite. As the children were mostly very young (pre-school or early school aged), "respite" was frequently achieved by a child‟s attendance at childcare and school. No children in the study received out-of-home care (excepting that provided by families or friends). Paid carers, if available, cared for the child in the family home. Some comments illustrate the importance of respite to participants:

> “We created our respite by putting her in childcare. I had to; I was going out of my tree. I was going to end up in a mental hospital. Just from (needing to) sit with my child all day, trying to come up with new ways to play.” (Participant Focus Group 1)

> “Yes, that‟s what I did (when he was at childcare). Today I turned up the music loudly and I did some paperwork and then I turned off the music and spoke to the Paediatrican and 2 or 3 specialists and then did some more housework.”
> (Participant Focus Group 1)

> “In the last few years my mum has been an awfully great support for me. She has offered many times to take (my child). Of course we don‟t want to take advantage of her, but that has been of great comfort to me, to know that I can pop out to the shops, I have to just ring mum and she‟ll come over and I can go to the shops for a few hours if I have to, that type of scenario.” (Participant Focus Group 3)

A final theme in this group reflected the supports that were not available to participants at the present time, but that they thought would be helpful if they existed “in an ideal world”. References to this theme were made by the mothers in two of the focus groups,

> “I think what would have made my life easier from the beginning is to have had an advocate. Someone who would have gone in and fought wars for me. Who would have pointed me in the right direction and told me what I needed, when I didn‟t know what I needed.” (Participant Focus Group 1)

> “Just being able to get more house helpers coming in, I think….help with ironing and cleaning and things like that….” (Participant Focus Group 2)

5.41.4 Additional emergent themes

While the principal organization of the themes was directed by the questions asked in the focus groups, several themes emerged from the transcripts that were felt to be important enough to be coded independently. Firstly participant comments made frequent, often indirect, reference to the differences made by the severity of a child‟s disability (27 references in total). Severity of disability was coded if there was evidence of severe developmental delay (ie if a child was unable to play independently, or was nonverbal); or if a child was reported to have additional behaviour problems (including sleep disturbance); or medical complications. The presence of additional behavioural problems received the most references within this theme (15 references). Examples of quotes coded for this theme include:

> “He can be very strong willed, so when he gets something in his mind that he wants, and he can‟t communicate with me, it‟s frustrating.”(Participant Focus Group 3)

> “With typical kids with sleep problems, you‟re dealing with just that, we are dealing with no sleep plus all the other stuff that comes with caring for a child with a disability.”(Participant Focus Group 1)

> "She has been a baby all her life, she‟s 3½ but she‟s still a baby – of a mental age, but if they‟re mobile they have no concept of danger, like toddlers."
> (Participant Focus Group 3)

> "I sincerely spend 90% of my day sitting with my child or playing for her."
> (Participant Focus Group 1)

Secondly, participants referred to the changes in the demands of caring that come about because of changes in a child‟s age (10 references in total). Attendance at school was a factor that seemed to reflect a significant transition point for parents, with both positive and negative consequences. For example:

> "Now she‟s getting bigger and she doesn‟t walk, I can‟t lift her now. I‟m only short and she‟s getting bigger and I can‟t lift her." (Participant Focus Group 1)

> "School is a sense of relief in one way, because someone else is responsible, however, you still have to be there checking up. So you never actually are able to hand it over completely because you know that if there‟s a relief teacher or whatever, so many different things…" (Participant Focus Group 1)

5.41.5 Summary

The focus group and interviews were a rich source of information identifying issues of importance for mothers caring for children with disabilities. The responses from mothers suggest that caring has a significant impact, particularly on their emotions, with feelings of grief predominating. The consequences of non-finite, or chronic, grief for parents of children with intellectual disability have been described by Bruce & Schulz, 2001. Of the tasks of caring, the work undertaken to ensure their children are properly managed and appropriately access professional services (including the phone-calls and paperwork associated with this), was a principal source of stress for mothers. The strain of fitting in daily personal care activities for their child, such as feeding and toileting was also stressful. Finally, respite ("time out"), and practical help provided by others were the forms of support most valued by the participants in the study.

The extent to which participants in the study were concerned about the time taken by caring is reflected by the fact that references to the "time demands" theme made up 26% of the total number of references coded across all focus groups for the Consequences of Caring question, more than any other individual theme identified for this question (excluding those with sub-themes). Though coded for the "Consequences of Caring" key question, the concept of time (and the stress of time demands) permeated many of the comments of participants, whether they were discussing the consequences of caring, the tasks of caring, or supports that help with caring. A further stage of thematic analysis was therefore undertaken, with the aim of examining in detail the concerns of participants that were related to the time demands of caring. This next stage of analysis, involving the process of relating all other themes to the "time demands" core theme, will be described in detail in the following sections.

5.42 Aim 2: Time demands of caring

To undertake this stage of thematic analysis, each of the 71 quotes from the focus groups and home interviews, which had been earlier coded in the "Time demands of caring" core theme in the first stage of analysis, were re-examined to identify relevance for other themes (ie additional to the time demands of caring). To illustrate this process, the following quotes are shown with the results of coding for additional themes:

> "We tag team at home, we have no couple time, and that‟s awful."
> (Participant Focus Group 1)

This was coded for: Consequences of Caring –Impact on marriage
Changes made to fit in the tasks of caring

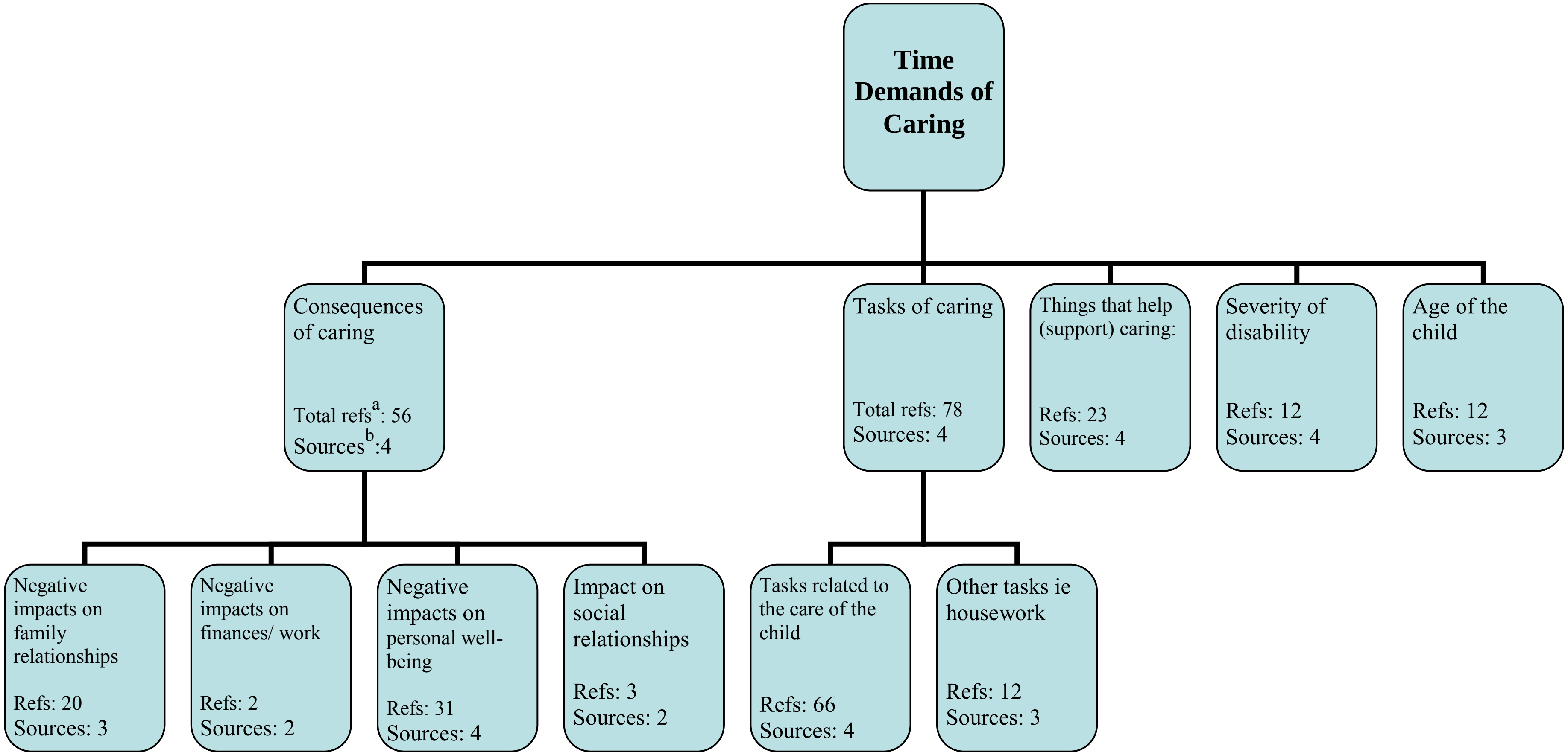
> "A lot of my time when (my child) isn‟t with me is making phone calls. My husband says "You look absolutely shot, go have a break. "I don‟t think "Yippee, I‟m having a break" I think "great, what can I get done". So, I‟ll quickly make some formula or I‟ll wash out the feeding line, or I‟ll start making these 3 billion phone calls I have to make." (Participant Focus Group 1)

This was coded for: Daily Tasks - Accessing/ organising services
Changes made to fit in the tasks of caring

Things that Help – Partner support

> “I‟m at the WCH at least once if not twice every week … I was there today and I‟ll be there again in Friday, so for me it‟s the waiting time actually for me for doctors.” (Participant Focus Group 3)
>
> This was coded for: Daily Tasks of Caring – Accessing/ organising services
>
> “And I think too, that when you are at home you are always distracted. There is always something that needs to be done, like housework is never ending (cleaning, cooking or washing) or organising stuff and paperwork. I go through paperwork and I look at an invitation or something and I think, no that‟s already been and gone, didn‟t even read that.”
> (Participant Focus Group 3)
>
> This was coded for: Consequences of Caring - Social
> Daily Tasks of Caring
> - Housework
> - Accessing/ organising services

When re-coding was finished, the themes and sub-themes were grouped together. Figure 5.4 shows the results of this process in the form of a thematic map, portraying the ways in which the different themes and sub-themes related to time demands experienced by parents caring for children with disabilities.



[a] Number of references made to this theme by the participants in the focus group s and home interviews; [b] Number of sources from which this theme was obtained (one, two, three focus groups and /or home interviews)

Figure 5.4. Thematic map of the core theme “Time demands”.

The thematic map portrayed in Figure 5.4, represents most, but not all, of the themes and sub-themes shown in the earlier thematic maps produced in the first stage of analysis. When considering the "Consequences of caring", time demands were linked to a range of negative consequences for the health and well-being of mothers and their families. Time demands were also described as negatively impacting on marital and sibling relationships, for example limiting time available to mothers to spend with partners or with other children in the family. There were fewer references to impacts on financial and work situations, and social relationships more generally. As well, the sub-theme reflecting positive consequences of caring and the sub-theme reflecting impact on partner‟s well-being were not represented in the quotes included in the "Time demands of caring" core theme .

When examining the "Tasks of caring", mothers made particular mention of difficulties associated with finding time to access and organise services for their child, to complete daily caring activities, and to undertake therapy "homework". Time constraints also impacted on the ability to complete other tasks, particularly housework. As in the first stage of analysis, the principal supports related to the time demands of caring were the support of others, and various forms of respite. Benefits were described in terms of providing more "free" time, commonly used by the mothers to "fit in" other activities rather than to achieve any rest or relaxation. Finally, the extra time required by a child with more severe disabilities (especially the presence of additional behavioural problems) was reflected by quotes included in the "Time demands of caring" core theme, as well as the changes resulting from a child‟s increasing age.

5.5 Conclusions

Results from focus group and interview data suggested caring has a significant impact on parent and family well-being. The time demands of caring were central to understanding these impacts. Parents described how caring responsibilities limited time available for other activities and contributed to them feeling time pressured. Children with more severe disabilities, and in particular those who had behavioural problems, required more care, adding to the time pressures experienced by parents. Finally, supports identified by parents as being most helpful, for the most part, related to receiving practical help to lessen the caring load or to having “time out” from caring. The model shown in Figure 5.5 was developed to describe these results.

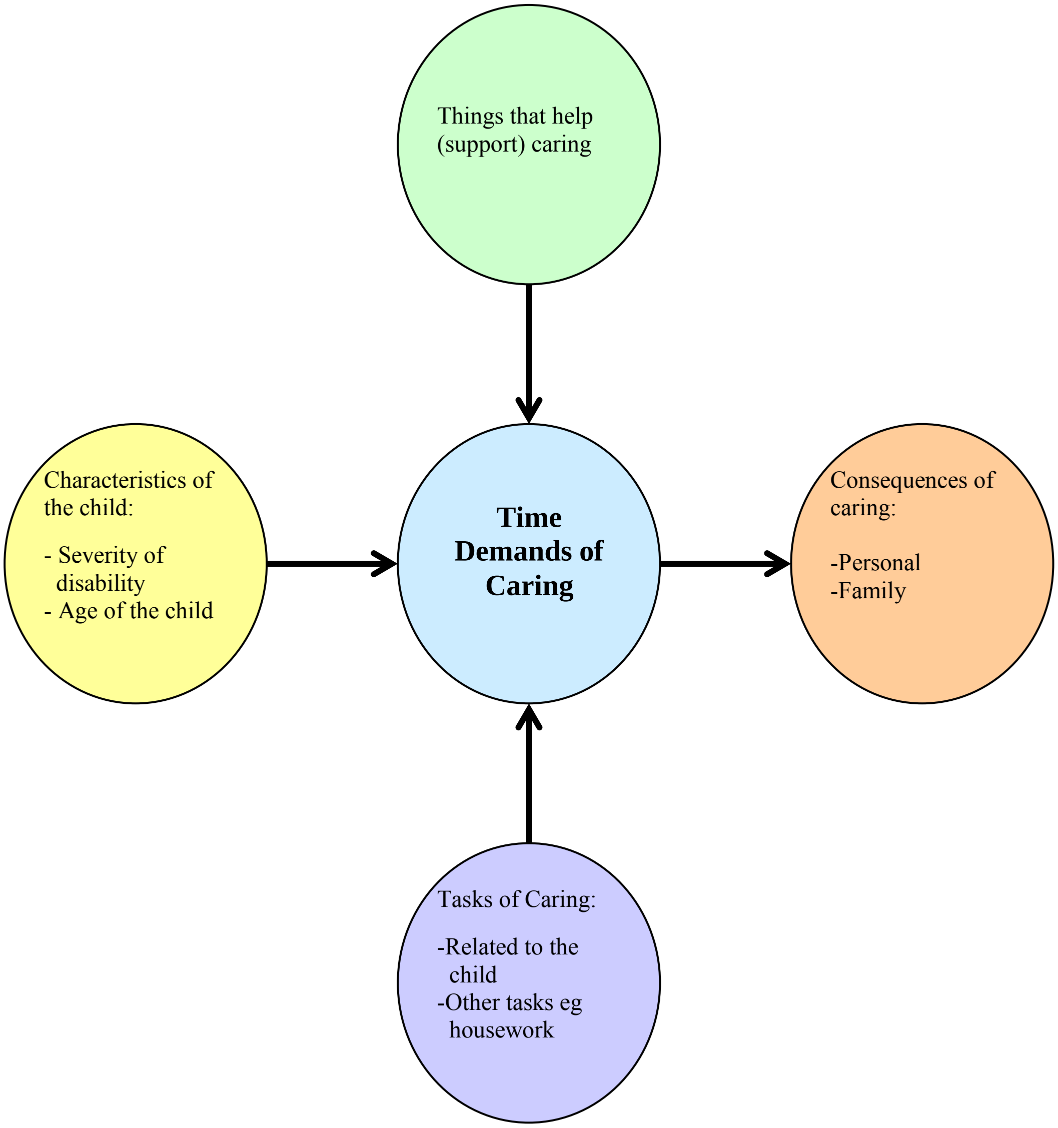


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Figure 5.5. Model showing potential relationships between themes arising from "time demands of caring".

Evidence for relationships shown in the model described in Figure 5.5 is found in the focus group and interview data. For example, the following quote illustrates links between characteristics of the child‟s disability, the impact of time demands resulting from the tasks of caring and the consequences of caring (or outcomes) for mothers:

> "He can be very strong willed, so when he gets something in his mind that he wants, and he can‟t communicate with me, it‟s frustrating… Yeh, it‟s very draining when I realise I have only got two minutes to get up to the school to pick G…(child‟s sibling) up and he‟s made himself that upset that he‟s vomiting. It‟s those sort of dramas that I find are hard to deal with." (Participant Focus Group 3)

The role of social supports ("Things that help (support) caring") in counteracting the impact of time demands is illustrated by the following quote:

> "In the last three years my mum has been an awfully great support for me, and she has offered many times to have S… Of course we don‟t want to take advantage of her, but that has been of great comfort to me, to know that I can pop out to the shops, I just have to ring mum and she‟ll come over and I can go to the shops for a couple of hours if I have to, that type of scenario." (Participant Focus Group 3)

The model described in Figure 5.5, representing results of qualitative analysis of the data from Study 1, is similar to the model of carer well-being derived from the research literature and described in Chapter 4. The model of carer well-being is reproduced in Figure 5.6.

NOTE:
This figure is included on page 148 of the print copy of
the thesis held in the University of Adelaide Library.

Adapted from Grant, Compas et al (2005).

Figure 5.6 Model of carer well-being

The central role of "Time demands of caring" in the model shown in Figure 5.5 is represented by the mediator variables described as "Caring responsibilities" in the carer model of well-being. As well, "Things that help support caring" in the model shown in Figure 5.5 are represented by the moderator variable "social support" in the model of carer well-being.

Results of thematic analysis of the focus groups and home interviews were considered, therefore, to provide support for the model of carer well-being and justify further research exploring the role of caring responsibilities, and particularly time demands, in contributing to parent outcomes. The rich source of information about the impacts of caring on parents in Study 1 provided useful background for the development of Study 2, a larger scale quantitative study undertaken as part of the present dissertation to further test the model of carer well-being.

SECTION 3:

QUANTITATIVE EVIDENCE FOR THE MODEL OF CARER WELL-BEING

CHAPTER 6:

Hypotheses, methods and measures

6.1 Overview

The present chapter outlines the methodological framework for Study 2. This study was undertaken in association with Disability Services SA, and in particular the Early Childhood Services (ECS) of this organisation. The ECS provides early intervention services for pre-school aged children with significant global developmental delays. Participants in the study were parents of children aged between the ages of three and six years. Children within this age range are in a period of transition, moving into kindergarten and school. Parents typically report this to be a particularly stressful time. Children are often required to undertake assessments to establish suitable educational placements. This can be emotionally confronting for parents, who may also be challenged by seeing their child interact with non-disabled children, thereby highlighting differences between them.

Measures were chosen to reflect the context of caring, that is, were directly related to the experiences of parents caring for children with developmental disabilities. An important component of the study was the inclusion of a time use diary which enabled a detailed picture of the daily routine of parents. The diary, using pre-coded categories identified partly from information collected in Study 1, was developed to enable comparison with normative data from a national survey of time use (ABS, 1997). Another distinctive characteristic of Study 2 was the emphasis on collecting information from both parents, enabling comparisons of the caring responsibilities, as reflected by data from the time use diary, of both primary and secondary carers. In addition to the diary, parents also completed a number of standardized questionnaires including measures assessing their psychological, social and physical wellbeing. Information was also collected on several characteristics of disability including the extent of child functional abilities and levels of child emotional and behaviour problems. Finally, caregivers were asked to report on the practical and emotional support provided by their partners (ie secondary caregivers). Partner support was identified as being the most relevant form of social support to parents of children with disabilities.

The aims of Study 2, and the hypotheses derived from the model of carer well-being will be described in the following section. The remainder of the present chapter will report on the characteristics of parents, children and families who participated in Study 2 and the procedure by which the study was undertaken. Finally, the chapter will conclude with a description of the Caregiver Diary used to collect detailed information about the time use of parents, and the questionnaires used to reflect the different components of the model of carer well-being.

6.2 Aims and hypotheses

A. To obtain a detailed account of the time use of parents caring for young children with developmental disabilities.

This aim was exploratory, though previous research and the results from Study 1, suggest parents in Study 2 will spend more time caring for their child with a disability than parents of young children without disabilities. As well, it is anticipated that they will engage in different types of caring activities and will have a different balance of caring activities than parents of young children without disabilities.

B. To test relationships between variables included in the model of carer well-being.

The model of carer well-being, described in Chapter 4, assumes parents of children with disabilities are more likely to experience poorer psychological, social and physical health outcomes than parents of children without disabilities. This is consistent with previous research (eg Briggs & Fisher, 2000; Pelchat et al., 1999; Sales, Greeno, Shear, & Anderson, 2004; Singer, 2006). The model proposes, in addition, a number of intervening variables to help explain why some parents experience poorer outcomes than others. In particular, the extent of caring responsibilities undertaken by parents (reflected by time spent caring and carer perceptions time pressure) is suggested to mediate between child disability and parental outcomes. Parents who spend more time caring (ie primary caregivers) are therefore expected to experience poorer outcomes than parents who spend less time caring (ie secondary carers). Further, characteristics of child disability that may result in the need for more care are also expected to be associated with poorer outcomes for parents. This may explain why parents of children with autism, for example, have been found to do less well on indices of well-being than parents of children with different diagnoses (Bailey, Golden, Roberts, & Ford, 2007; Singer, 2006) and conversely, why parents of children with Down syndrome have been found to score better on indices of well-being than parents of children with other diagnoses (Hodapp, 2007). The model would also anticipate that parents of children with lower levels of functional skills or adaptive behaviours (i.e. requiring more help from carers) would score less well on measures of psychological, social and physical health than parents of children with higher levels of functional skills, as has been found in some earlier studies (eg Skok, Harvey & Reddihough; White & Hastings, 2004). As well, parents of children with disabilities who also exhibit emotional and behavioural problems (assuming this adds to caring responsibilities) would also be expected to show poorer outcomes than children with lower levels of emotional and behavioural problems as has also been found in previous research (Floyd & Gallagher, 1997; Hastings, Daley, Burns & Beck, 2006). In addition to caring responsibilities, the model of carer well-being proposes the extent of social support experienced by parents of children with developmental disabilities influences the relationship between child disability and parental outcomes. The model further suggests that social support has its greatest influence by decreasing the impact of caring responsibilities.

Chapter 2 shows the concept of social support is very broad, encompassing structural and functional elements. As well, different types of social support (eg emotional and practical support) can be received from a number of sources (eg partners, families, friends, or formal services). As it was not possible to measure all forms of social support, Study 2 will focus upon emotional and practical support received from partners.

The underlying assumptions of the model of carer well-being, as outlined above, lead to the specification of a number of hypotheses that will be tested in Study 2. The first five hypotheses relate to expectations that being a parent of a child with a disability is a risk factor for poorer psychological, social and physical well-being; and additionally, that characteristics of child disability make it more or less likely that poorer outcomes will eventuate for parents:

Hypothesis 1: Carers of young children with developmental disabilities will have poorer psychological, social and physical well-being than carers of children without disabilities;

Hypothesis 2: Primary carers of young children with developmental disabilities will have poorer psychological, social and physical well-being than secondary carers;

Hypothesis 3: Carers of children with different diagnoses will show different patterns of psychological, social and physical well-being. In particular, parents of children with autism are expected to have poorer outcomes than parents of children with Down syndrome;

Hypothesis 4: Carers of children with greater functional impairment will have poorer psychological, social and physical well-being than carers of children with less functional impairment;

Hypothesis 5: Carers of children with disabilities who also exhibit higher levels of emotional and behavioural problems will have poorer psychological, social and physical well-being than carers of children with disabilities who have lower levels of emotional or behavioural problems.

The final two hypotheses tested in Study 2 describe the more complex relationships between variables represented in the model of carer well-being:

Hypothesis 6: Caring responsibilities (reflected by time spent caring and carer perceptions of time pressure), mediate the effects of child disability on carer psychological and physical well-being. Higher levels of caring responsibilities (ie more time spent caring or more perceived time pressure) are expected to lead to poorer outcomes;

Hypothesis 7: Partner support moderates the impact of caring responsibilities (total time spent caring and carer experience of time pressure), on carer psychological and physical well-being. Higher levels of partner support are expected to lead to better outcomes.

It should be noted that hypothesis 7 reflects one form of moderated mediation, such that the moderator exerts its effect through the mediated relationship (ie social support impacts on maternal outcomes through its role in moderating the impact of time pressure). This was considered to be the most plausible interpretation based on both previous research and parent report. It is acknowledged, however, that the model of carer well-being may also allow for the specification of other forms of moderated mediation (for more information about different forms of moderated mediation, refer to Preacher, Rucker and Hayes, 2007).

6.3 Methods

6.31 Participants

Participants in the study were 160 parents (95 primary caregivers and 65 secondary caregivers) of children who were clients of the Early Childhood Service (ECS), part of Disability Services SA (previously Intellectual Disability Services Council of South Australia). There was an overall response rate of 63% (ie of households in which one or both parents agreed to take part in the study). Twenty percent of primary caregivers in Study 2 were single parents, with 80% of families being two parent households. These percentages compared well to the proportion of single parent families in the general population at the time Study 2 was conducted (ie 22% of all households including children under 15 years of age (ABS, 2007)). Of the two parent households represented in Study 2, 88% of primary caregivers were mothers (*N*= 84) and 12% were fathers (*N* = 11).

The ages of children whose parents participated in the study ranged from 2 years, 9 months to 6 years, 7 months (*M*= 4 years, 6 months, *SD*= 11 months). Thirty six percent (*N* =34) received a diagnosis of global developmental delay (GDD), 24% (*N* = 23) had Down syndrome (DS), 25% (*N* =24) had a formal diagnosis of autism, and 15% (*N* = 14) of children had a range of other diagnoses (including cerebral palsy & Fragile X). Seventy eight percent of children in the study had one or more siblings, from infancy to 18 years of age. Twenty two percent of the siblings were reported by their parents to have a disability of their own. The range of diagnostic categories for siblings included learning problems/ intellectual disability (44%), autism (12%), DS (4%), and “other” disabilities (36%) including speech/ language disorder and behavioural problems.

Table 6.1 shows information about the level of schooling, occupational prestige, and employment status for both primary caregivers and secondary caregivers.

Table 6.1

Selected demographic characteristics of primary and secondary caregivers (percentage of carers in different categories)

	% Primary caregiver	% Secondary caregiver
Highest level of schooling:		
Primary School	--	1
Some years of high school	24	20
Year 12	19	17
Trade/TAFE Certificate	35	31
University Qualifications	22	31
	(100%)	*(100%)*
Category of occupational prestige:		
Low	34	45
Medium	35	46
High	2	5
Other (ie home duties, unemployed or student)	29	4
	(100%)	*(100%)*
Employment Status:		
In paid employment	37	73
Employed full-time:	20	88
Employed part-time:	80	12
	(100%)	*(100%)*

Family in receipt of a pension (other than the carers allowance): 33%

Note. Occupational group identified using Daniel"s Prestige Scale (Daniel, 1983)

Primary caregivers were mostly not in paid employment, and of those that were in paid employment, 80% worked part-time. In contrast, 73% of secondary caregivers were in paid employment, and of these 80% were working full-time. The Daniel Prestige Scale (Daniel, 1983), which provides a rating of Australian occupational prestige (1 = high prestige to 7 = low prestige) was used to categorise the occupations of primary and secondary carers. The mean score for secondary carers (excluding those who indicated they were unemployed or students) was 4.6 (SD=1.1), and for those primary carers who reported an occupation (rather than "home duties") was 4.4 (1.2). Rounded scores were also grouped according to whether an occupation was of high prestige (1-2), medium prestige (3-4), or low prestige (5-7). Table 6.1 shows an equal distribution of primary and secondary carers who were working in occupations of low or medium prestige. The low numbers of carers in high prestige occupations is of note and may reflect the difficulty of sustaining a career in addition to caring for children with disabilities, or may also reflect characteristics of clients receiving services from Disability Services SA.

6.32 *Early Childhood Services* (ECS) *of Disability Services SA*

Children whose parents participated in Study 2 were all clients of the ECS, a major provider of early intervention services to children in South Australia. To be eligible for ECS services, children need to have significant developmental delays in the majority of areas of development (for example, speech and language delays as well as gross or fine motor problems), or have a medically diagnosed condition that has a substantial probability of intellectual disability. Parents of children with a diagnosis of autism have the option of seeking services from the ECS. Most children who are registered with the ECS continue to receive services from Disability Services SA when turning five years of age or commencing school, following a process of formal assessment to identify intellectual disability at this time.

The decision to recruit participants for Study 2 from clients of Disability Services SA, rather than Novita Children‟s Services, as in Study 1, was prompted by practical reasons (access to a larger participant population). The characteristics of the samples included in Study 1 and Study 2 therefore, differed in ways reflecting the characteristics of the populations serviced by the two agencies. More specifically, children who are clients of Novita Children‟s Services principally have a physical disability, although many also exhibit more global developmental delays. Many also have chronic health conditions requiring regular medical treatment. In contrast, children who are clients of Disability Services SA have a primary presentation of global developmental delay, though some may also have physical impairments. Most of the children in Study 2 did not have chronic medical conditions, with only 19% of children requiring regular medical treatment (eg medication for epilepsy, asthma, anxiety).

The ECS is comprised a number of multi-disciplinary teams that are based at one of five regional offices in the Adelaide metropolitan area. Teams include speech pathologists, occupational therapists, physiotherapists and family support workers. The teams work with children & families within a community based, family-centered approach. Parents were recruited from four of the five regional offices of the ECS. A fifth office was not included in the study due to time constraints. This was considered unlikely to have influenced the results, as the socio-economic characteristics of families who attended the fifth office were comparable to those families who attended other offices. Response rates ranged from 53 -71% for households across the four regional offices.

Sixty two percent of children whose parents participated in Study 2 were receiving one or more therapy services from ECS staff (76% speech pathology, 45% physiotherapy, 71% occupational therapy & 56% family support). Children who were not receiving services were on the waiting list for therapy to commence, in the process of transferring to school-aged services, or were receiving therapy services from another agency (ie Autism Association of South Australia). In addition to services provided by Disability Services SA, 23% of children were receiving private therapy services. Children with a diagnosis of autism were most likely to be receiving private therapy (39% of children with autism), followed by children with "other" diagnoses (27% of children with "other" diagnoses) and children with DS (26%). Only 9% of children with GDD were receiving private therapy services. Fifty percent of children were registered with an agency other than Disability Services SA (eg Autism Association of South Australia or the Down Syndrome Society of South Australia).

6.33 Procedure

Approval was obtained from the Human Research Ethics Committee of the Women"s and Children"s Hospital (WCH) prior to the start of Study 2. Recruitment was undertaken with the assistance of the managers of each of the ECS regional offices, and a "key" liaison person within the regions (a social worker, psychologist or family support worker). Recruitment occurred from one ECS regional office at a time. The process involved initial meetings with the key person, and then subsequently with all members of the regional office team, to inform staff of the aims of the study and to outline how recruitment would occur. Following the meetings, the key person and manager of the region identified a list of children between three years and six years of age, whose parents would be eligible for the study. Parents with children who were newly referred to the ECS or children who had received a recent diagnosis were excluded, as it was assumed that these families would be experiencing higher levels of acute stress which would impact on caring responsibilities and parent well-being. As well, parents who were identified by ECS staff as being in crisis were also excluded from the study. The numbers of parents for which this was an issue were small. Other exclusion criteria were identified for pragmatic reasons. Thus, parents who were primarily non-English speakers, or who had an identified intellectual disability were also not included in Study 2.

A covering letter from the ECS manager and an Information Sheet about the study were sent to all parents on the eligibility list (see Appendix C). Subsequently a staff member from the ECS contacted parents by telephone to obtain permission for the researcher (the author of the present dissertation) to call them. During this telephone call, the researcher provided further information about the study and asked for consent to participate. If parents were agreeable, an appointment time was made for the researcher to visit. In 97% of cases assessments were completed in the family home, a small number of parents arranged the visit at their place of work, or met the researcher at her office in the Women‟s and Children‟s Hospital. Many appointments took place in the evening, enabling both parents to attend. Copies of the “permission to contact” form and the consent form used in Study 2 are included in Appendix C.

During the home visit, a structured interview was completed and primary caregivers and secondary caregivers also independently completed questionnaires. Parents were then invited to complete the Caregiver Diary (see page 169) describing their caring activities over two days in the following week. Diary days were chosen to cover both weekdays and weekends, and were chosen non-randomly to ensure an even selection of days across the sample. The home visits took between one and two hours, on average, to complete.

Following the home visit, a telephone call was made to parents on the first diary day. The purpose of the call was to ensure that parents were able to complete the diary successfully, and to answer any questions about the diary method. Further phone calls were made as needed, or if requested by parents to assist with the completion of the diaries on the second diary day. Parents were also encouraged to contact the researcher directly if encountering problems.

6.34 Measures

All measures used in Study 2 are described in Table 6.2. Copies of the questionnaires and the Caregiver Diary are included in Appendices D to L. Table 6.2 is organised to reflect the different components of the model of carer well-being, described in Chapter 4.

Table 6.2
Measures used in Study 2

1. **Stressors**
    a. Child disability
        i. Functional independence (WeeFIM® Version 4.0: Uniform Data Set for Medical Rehabilitation, 1993)
        ii. Emotional and behavioural problems (Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997)
    b. Life stress
        i Life Stress subscale (Parent Stress Index PSI: Abidin, 1995)
2. **Parent Outcomes**
    Psychological and physical well-being
    a. Centre for Epidemiological Studies Depression Scale (CES-D: Radloff, 1997)
    b. Role Restriction, Social Isolation, and Physical Health subscales (PSI)
    c. Caregiver Strain Questionnaire (CGSQ: Brannan, Heflinger, & Bickman, 1997)
3. **Mediator variables**
    Caring responsibilities
    a. Objective indicators
        i. Time spent caring & caring activities (Caregiver diary)
    b. Subjective indicators
        i. Time pressure ("Rushed/ pressed for time" item
        ii. Time Crunch scale: Robinson, 1991)
4. **Moderator variables**
    Partner support
    a. Spouse support subscale (PSI)
    b. Carer Support Scale

6. 34.1 Child disability: The Functional Independence Measure for Children: WeeFIM® (Version 4.0)

The WeeFIM® (Version 4.0: Uniform Data System for Medical Rehabilitation, 1993) was utilised to measure children‟s functional abilities (ie adaptive behaviours) and "need for assistance" from their parents. The WeeFIM® (Version 4.0) was completed through structured interview with parents, during the home visit in which other questionnaires were administered. Specific guidelines provided in the manual accompanying Version 4.0 assisted in the scoring of responses. A copy of the guidelines adapted for use in Study 2 is included in Appendix D.

The WeeFIM® is an adaptation of the Functional Independence Measure (FIM) used with adults. The FIM is widely used to measure severity of disability and is based on the definition of disability put forward by the World Health Organisation (WHO, 2001). It consists of 18 items, comprising six domains. Items are scored according to a seven level scale, representing gradations from total dependence to complete independence. The Wee FIM (Version 4.0) manual combines four domains (self-care, sphincter control, transfers and locomotion) to form a "Motor" subscale. A further two domains (communication and social cognition) are combined to form a "Cognitive" subscale. A total functional independence score can also be obtained by summing scores for all items, across all domains.

Table 6.3 shows the domains of the WeeFIM® (Version 4.0), the items that constitute the domains, and the seven level rating system. Total scores for the WeeFIM® (Version 4.0) range from 18-126, though it is recommended to convert raw scores to developmental quotients using normative data (ie obtained score/expected score x 100). Lower scores indicate higher levels of disability, with quotients between 50 and 75 suggestive of moderate disability, while quotients < 50 indicate severe disability (Lowen, Msall, Jenny, & et al, 2000).

Development of the WeeFIM® was undertaken in 1987, with normative data for children between 6 months and seven years of age being collected a few years later (Msall et al., 1994a; Msall et al., 1994b; Ottenbacher et al., 1999; Uniform Data System for Medical Rehabilitation, 1993). The normative data showed that children of 7 years and above, without disabilities, tend to achieve full functional independence on all items of the WeeFIM®. Children with functional impairments, however, typically score at significantly lower levels across the age ranges. Validity and inter-rater reliability of the WeeFIM® have been examined in a number of studies and found to be adequate (Msall et al., 1994a; Msall et al., 1994b; Ottenbacher et al., 1999; Ottenbacher et al., 1997; Ottenbacher, Taylor, Msall, & et al, 1996).

Table 6.3
Rating scale, domains and items of the WeeFIM$^{®}$ (Version 4.0)

Rating scale:

7 = Complete independence
6 = Modified independence (ie use of aids)

5 = Supervision
4 = Minimal assistance (child completes 75% of task)
3 = Moderate assistance (child completes 50% of task)
2 = maximal assistance (child completes 25% of task)
1 = total assistance

Subscales:

Motor Subscale:

- Self-care
  - Eating
  - Grooming
  - Bathing
  - Dressing- Upper Body
  - Dressing – Lower Body
  - Toileting
- Sphincter Control
  - Bladder Management
  - Bowel Management
- Transfers
  - Chair, Wheelchair
  - Toilet
  - Bathtub, Shower
- Locomotion
  - Walk/ Crawl/ Wheelchair
  - Stairs

*Cognitive Subscale***:**

- Communication
  - Comprehension
  - Expression
- Social Cognition
  - Social Interaction
  - Problem Solving
  - Memory

6.34.2 Child disability: The Strengths & Difficulties Questionnaire

The Strengths and Difficulties Questionnaire is a brief screening measure used to identify emotional and behavioural problems in children and adolescents (Goodman, 1997). Parent and teacher completed versions of the SDQ are available for children aged between 3 and 16 years. A version of the SDQ for completion by carers of very young children (3-4 years) was used in this study. A copy of this questionnaire is shown in Appendix E.

The SDQ comprises 25 items asking about positive and negative attributes of a child. Items are scored on a 3 point scale, with respondents reporting whether the item is “true”, “somewhat true” or “certainly true” of the child. The items are divided between 5 subscales: emotional problems, conduct problems, hyperactivity, peer relationship problems and prosocial behaviour. A “total difficulties” scale is calculated by totaling the four negatively focused subscales (ie all subscales with the exception of prosocial behaviour). Clinical cut-offs for the SDQ, indicating the likelihood of clinically significant problems, have also been identified from normative data by Goodman (2001). The SDQ has been extensively used in many different countries, including Australia, showing evidence for reliability and validity (Goodman, 1997, 2001; Goodman & Scott, 1999; Mathai, Anderson, & Bourne, 2002, 2004).

6.34.3 Life stress: Life Stress subscale (Parenting Stress Index)

The Life Stress scale of the Parenting Stress Index (PSI: Abidin, 1995) provided a general index of stressors experienced by carers outside of the parent-child relationship. A copy of the scale is shown in Appendix F. The Parenting Stress Index (PSI: Abidin, 1995) is a widely used measure of parenting stress for use with parents of children between 3 months and 10 years. Further details of the PSI will be provided later in this chapter. It was anticipated that high scores on the Life Stress scale would intensify the total stress experienced by parents.

6.34.4 Psychological and physical well-being: Centre for Epidemiological Studies Depression Scale

The Centre for Epidemiological Studies Depression Scale (CES-D: Radloff, 1977) was used to assess the level of depressive symptoms in carers. Twenty items are rated on a 4 point scale, with respondents recording how often they felt or behaved that way, during the week prior to assessment. Four items are reverse scored, with the sum of all items providing a total score. Higher scores indicate the presence of more depressive symptoms. Radloff and Locke (1986) recommend a cut-off of 16 to indicate respondents are at risk of clinical depression. A score of 22 or greater indicates a major depressive episode. The CES-D has been widely used in studies of adolescent and adult depression, including studies of parents of children with disabilities (Bristol et al., 1988; Quittner et al., 1990; Roberts et al., 1991). Early studies established both reliability and validity

(Radloff, 1977; Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977). A copy of the CES-D, as used in Study 2, is shown in Appendix G.

6.34.5 Psychological and physical well-being: Role Restriction, Isolation, and Health subscales (Parenting Stress Index)

The Parenting Stress Index (PSI: Abidin, 1995) contains 13 subscales, organized under two domains; the child domain and the parent domain. For the purposes of the present study, three subscales from the parent domain were chosen to reflect areas of parent stress that were most relevant for the population of carers. The three subscales were; Role Restriction (7 items); Isolation (6 items); and Health (5 items). Copies of the subscales are shown in Appendix H. Responses for items comprising the subscales were scored by use of a five point scale (1 = strongly agree to 5 = strongly disagree). Results from all subscales are scored such that higher scores indicate higher levels of stress.

High scores on the Role Restriction subscale indicate that the parent experiences their parenting role as being restricting, and as limiting their ability to maintain their own identity independent of their child. These issues were apparent in the comments of parents who participated in the focus groups. Parents who obtain high scores on the Isolation subscale are likely to be socially isolated from peers, relatives and other emotional support systems. Parents who score highly on the Health subscale are likely to be experiencing poor physical health.

The PSI has extensive research establishing reliability and validity (Abidin, 1995) and has been found to discriminate between parents of children with disabilities and parents of children without disabilities (Pelchat et al., 1999; Webster, Majnemer, Platt, & Shevell, 2008; Woolfson & Grant, 2007).

6.34.6 Psychological and physical well-being: Caregiver Strain Questionnaire

The Caregiver Strain Questionnaire (CGSQ: Brannan, Heflinger, & Bickman, 1997) was developed as part of the Fort Bragg Evaluation Project, a large-scale study of the effectiveness of mental health services for children. The scale assesses the impact on parents of caring for children with emotional or behavioural problems. Although the CGSQ has been used almost exclusively with families caring for children with mental health problems, the items which comprise the questionnaire are generally applicable to other populations in which parents are caring for children with special needs. Many items assess issues raised in the focus groups in Study 1. A copy of the questionnaire is shown in Appendix I.

The CGSQ measures objective and subjective dimensions of caregiver strain. Objective strain refers to the negative, observable consequences of caring (eg financial strain, disruption of family/ social relationships, changes to work situations). Two unique aspects of subjective strain are measured by the CGSQ (Brannan et al., 1997). The internalised subjective strain dimension involves negative feelings that are directed inwardly, such as worry, guilt, and sadness. The externalised subjective strain dimension refers to negative feelings that are directed outwards, towards the child (such as anger, resentment or embarrassment).

The CGSQ consists of 21 items that are rated on a 5 point scale ranging from 1 = “not at all” a problem to 5 = “very much” a problem. Eleven items measure the objective strain dimension, five items measure internalised subjective strain and five items measure externalised subjective strain. Higher scores on all three dimensions indicate higher levels of caregiver strain. Several studies have shown the CGSQ to have good reliability and validity (Brannan & Heflinger, 2001, 2005; Brannan et al., 1997; Sales et al., 2004).

6.34.7 Caring responsibilities (time spent caring): Caregiver Diary

Time-use diaries are used to measure how individuals spend time in various daily activities. Activities are commonly recorded in five-minute periods over a 24 hour time period. Time-use diaries have been extensively used in international and national surveys, including surveys undertaken by the Australian Bureau of Statistics (ABS, 1997, 2006), and have well-established reliability and validity (Niemi, 1993; Robinson, 1985; Robinson & Godbey, 1997). Though providing the ability to report on the broadest range of activities, traditional “full” time-use diaries in which respondents provide own word descriptions of their behaviour, can be time consuming to complete and require significant resources to code and interpret the results. An alternative is a “light” time-use diary, which requires respondents to record how much time they spend in pre-coded activities. A pre-coded light diary enables a greater focus on a restricted range of activities of interest, such as caring for a child with a disability. The Caregiver Diary employed in the present study was modelled on the light diary used in the “Growing Up in Australia” Longitudinal Study of Australian Children (Sanson et al., 2002).

The Caregiver Diary (shown in Appendix J) collected detailed reports from carers about their caring and other activities, pre-coded into 32 categories in quarter hour blocks, for a 24-hour period. Primary and secondary caregivers were asked to independently complete diaries on the same days, one a weekday and one a weekend day. Collection and analysis of two days of data is common in the time-use literature, and previous research confirms the intuitive expectation that time-use patterns for a weekday are very different from time-use patterns characterising weekends (ABS, 1978 TUS). Diary days were allocated to parents at the conclusion of the home interview, ensuring a spread of days was obtained across the whole sample. Parents were asked to complete the diaries during the week following the home visit.

The Caregiver Diary was structured into three sections. The first section recorded caring activities. Seventeen pre-coded items describing individual caring activities were identified from the focus group discussions, from previous research, and from the personal experience of the researcher in working with families caring for children with disabilities. Physical care activities include helping with feeding; helping with toileting; and helping with other aspects of personal care. Socialisation activities included time spent playing/ talking to the child or time spent cuddling/ comforting them. Other items asked parents to record time spent teaching their child (communication skills/ therapy activities). Several items assessed time spent monitoring/ supervising a child‟s behaviour. Items also allowed for periods of time when the child was away from the carer (eg sleeping, watching TV), or being cared for by someone else). Explanatory notes describing caring activities were provided for parents when completing the diaries (the explanatory notes are also included in Appendix J).

The second section of the diary recorded “other activities”, and included 10 items that were not related to the care of the child with a disability. Items included employment, sleeping, personal care activities, recreational activities and socialisation. Also included was an item asking parents to indicate any caring undertaken specifically for other children in the family (ie children other than the child identified as participating in the study). The third section of the Caregiver Diary titled “Who was with me” was intended to provide a measure of the social context of the carer‟s activities. Pilot testing of the diary was undertaken with a small number of mothers, to ensure the final pre-coded activities were meaningful, relevant and comprehensive.

Coding of the diary will be described in greater detail in Chapter 7. In brief, coding was undertaken in several steps. Firstly, an overall estimate of total time caring for the child with a disability was identified by calculating the number of quarter hour blocks recorded by the parent in the “caregiver activities” section, over the 24 hour period. This enabled comparisons with other studies that have provided estimates of total time spent caring and also provided a figure that could be used in subsequent analyses of the hypotheses testing the theoretical model. Secondly, a number of sub-groupings of the items within the two sections recording caring activities and other activities allowed for a more detailed exploration of the data.

A short questionnaire at the end of the Caregiver Diary asked respondents information about the day for which the diary was collected. Items asked the carer to describe how stressful was their day (ie a measure of daily stress), and if so, what were the main stressors that contributed to this. Four sections offered a range of stressors, each completed with a 5 point scale showing how much the stressor contributed to feelings of stress (ranging from 1 = not at all to 5 = very much). The first two sections included the caring and other activities included in the diary. The last two sections offered a range of social stressors (eg conflict with others) and intrapsychic stressors (eg worries). Information from the questionnaire was intended to supplement the diary data, providing estimates of the frequency of different stressors for the parents participating in the study.

6.34.8 Caring responsibilities (time pressure): "Rushed/ pressed for Time" item

A number of large time use data sets from several different countries have included information about perceived time stress. Typically, respondents are asked, "How often do you feel rushed or pressed for time", with answers coded on a 3 or 5 point scale (from 1= always to 5=never). The "rushed/ pressed for time" item has been used in several national surveys undertaken in Australia, including the Time Use Survey (TUS: ABS, 1997, 2006). The TUS also asks respondents to indicate reasons why they feel rushed, including: (1) trying to balance work and family responsibilities; (2) pressure of work/ study; (3) demands of family; (4) take too much on/ not good at managing time; (5) too much to do/ too many demands.

The rushed/pressed for time item was included as a measure of perceived time pressure in Study 2, enabling a comparison with data from the 1997 TUS. A copy of the item and the question asking for reasons why parents feel stressed is included in Appendix K.

6.34.9 Caring responsibilities (time pressure): Time Crunch Scale

The concept of “time crunch”, the result of feeling rushed all the time, was first measured in the 1991 Hilton Time Values Project (Robinson, 1991). The ten questions included in the Time Crunch scale to assess attitudes to time related stressful situations, are shown in Table 6.4, and are also included in Appendix L.

Table 6.4
Items in the Time Crunch scale

1. I often feel under stress when I don‟t have enough time
2. When I need more time, I tend to cut back on sleep
3. At the end of the day, I often feel that I haven‟t accomplished what I set out to do
4. I worry that I don‟t spend enough time with my family and friends
5. I feel that I am constantly under stress – trying to accomplish more than I can handle
6. I feel trapped in a daily routine
7. When I‟m working long hours, I often feel guilty that I‟m not at home
8. I consider myself a workaholic
9. I just don‟t have time for fun anymore
10. Sometimes I feel my spouse doesn‟t know who I am anymore

Note: From Robinson, 1991; Hilton Time Use Survey

The Time Crunch scale was included in Study 2 as an additional measure of perceived time pressure. Parents were asked to answer each of the 10 items of the scale according to a 5 point scale (1 = strongly agree to 5 = strongly disagree). Results for the “strongly agree” and “agree” answers were combined to obtain an estimate of how many respondents agreed with each item, enabling comparisons to be made with the data from the Hilton Time Values Project.

6.34.10 Partner Support: Spouse subscale (PSI: Abidin, 1995)

Two measures of partner support were included in Study 2. The first was the Spouse subscale of the PSI, comprising 6 items all scored on a 5 point scale ranging from 1 = strongly disagree to 5 = strongly agree (see Appendix H). High scores on the subscale indicated respondents perceive themselves to be lacking in the emotional and active support of their partner in the area of child management (Abidin, 1995). The Spouse subscale was used as a moderating variable in the context of the present study, reflecting perceptions of social support provide by the partner.

6.34.11 Partner Support: Carer Support Scale (CSS)

The second measure of partner support, the Carer Support Scale (CSS) was developed specifically for Study 2 and is shown in Appendix M. The CSS provided measures of practical support received by the primary caregiver from their partner, and levels of satisfaction with the support received.

As previously outlined in Chapter 2, social support is considered to consist of both received support, and perceived support. Measures of received support assess the specific supportive behaviours that are provided to the respondent by others (Haber, Cohen, Lucas, & Baltes, 2007). Measures of perceived support assess the perceptions of respondents as to the availability of support, and/or their general satisfaction with support provided (eg Sarason, Saranson, Shearin, & Pierce, 1987b).The two scales most commonly used to assess received support are the Inventory of Supportive Social Behaviours (Barrera, Sandler, & Ramsey, 1981b) and the Social Support Behaviours Scale (Vaux, Riedel, & Stewart, 1987). Both scales ask respondents to indicate the frequency with which they receive supportive behaviours from others (for example: "would look after my belongings for a while" or "loaned you over $25 dollars"). While generally applicable, the items in the two scales do not reflect the supportive behaviours considered important by carers of children with disabilities. The importance of context in the link between social support and outcomes has been suggested by a number of authors (Cutrona & Russell, 1990; Quittner, 1992) and led to the development of a caregiver specific measure of social support for the purposes of the present study.

The results of the focus groups, previous research describing the extra care needs of children with disabilities, and the personal experience acquired by the researcher in interviewing carers of children with disabilities, provided background for the development of items for the CSS scales. The final scale included six items reflecting areas of practical support, and one item measuring emotional support.

Primary caregivers were asked to rate how much help they received from their partner (*"How much has your partner helped with the care of your child in the past month?*") in the areas of:

(1) practical care tasks;

(2) attending appointments for the child;

(3) caring for other children in the family;

(4) household chores/ food preparation;

(5) caring for the child with a disability; and

(6) attending to the child with a disability at night;

(7) talking about feelings (emotional support).

Primary caregivers rated degree of support on a 5 point scale, ranging from 1 = not at all to 5 = very much. They were then asked to rate how much more help they would ideally like (ie "*How much more you would ideally like your partner to help with the care of your child*"), for each of the same items. The 5 point rating scale for this section of the questionnaire ranged from 1 = no more help wanted to 5 = a lot more help wanted. Scoring of the CSS was undertaken by summing the scores for each item to create a "Received Support" subscale and an "Ideal Support" subscale, each with a range of 5-35. The Ideal Support scale was considered to be a measure of perceived satisfaction with support received from secondary caregivers.

6.34.12 Demographic Information

A structured interview was developed for the study that collected a range of demographic information thought to be relevant to an understanding of the circumstances of the children and families who took part. Information was also collected to provide estimates of socio-economic status, using a series of brief questions that have been regularly used by the Research and Evaluation Unit of the Women‟s and Children‟s Hospital. A copy of the interview is shown in Appendix N.

6.4 Statistical analyses

It was anticipated in the present dissertation that analyses exploring the potential role of time use and time pressures on parent psychological and physical well-being would involve the use of multiple statistical analyses. The more statistical tests performed, however, the greater the risk that Type I errors will occur (ie rejecting the null hypothesis when it is true). In consequence of this risk, correction procedures such as the "Bonferroni adjustment" are typically applied. Problems have been raised with the use of correction procedures when used in studies with small sample sizes as is common in the behavioural sciences (Perneger, 1998; Rothman, 1986). In particular, the practise of lowering the critical value of p means that there is an increased risk of making Type II errors (ie accepting the null hypothesis when there is an effect to be found). In consequence of these concerns, Bonferrroni corrections will not be carried out in the statistical analyses in this thesis as recommended by Perneger and Rothman, who also suggest the importance of reporting the number of comparisons made and both negative and positive (that is, nonsignificant as well as significant) results. For multiple comparisons, the strength of association (as reflected by effect size statistics) will be reported in addition to traditional p values. This will enable a discussion of both the statistical significance of a finding (whether a results exceeds a critical p value or not), as well as an understanding of the magnitude of the effect.

Statistical analyses undertaken for Study 2 will be described at the beginning of each chapter in the “Methods and Measures” sections. In all cases, preliminary analyses were carried out to establish the statistical characteristics (ie extent of skew and kurtosis) of the data.

6.5 Structure of results chapters

The following chapters, describing the outcomes of analysis of the data collected for Study 2, are organised so to address the primary aims of the study. Thus, Chapter 7 and Chapter 8 report the results from the Caregiver Diary in relation to the first aim, providing a comprehensive description of the caring undertaken by both primary and secondary caregivers. Chapter 7 compares the time use of the carers in the study with the time use of different subgroups of parents identified from an Australian Bureau of Statistics national survey of time use (the 1997 Time Use Survey). Chapter 8 gives a more detailed comparison of the time use of primary caregivers in the study, when compared to the time use of secondary caregivers. Chapter 8 also describes the results of a measure of daily stress and links this to the proposed mediating variables; total time spent caring and time spent in different caring tasks. Results will again contrast primary and secondary caregivers.

Chapters 9 and 10 focus on the second aim of the study, and the specific hypotheses arising from the model of carer well-being. Chapter 9 addresses hypotheses 1 to 4, providing a detailed account of the characteristics of the children and carers who participated in the study using the results of the questionnaire data obtained during the home interview. Chapter 10 is directed towards hypotheses 5 and 6, using regression procedures to test the proposed role of time spent caring and time pressure as mediating variables explaining the relationship between child disability and carer well-being; and the proposed role of partner support in moderating the impact of time variables on carer well-being.

CHAPTER 7:

Patterns in the time use of parents caring for young children with developmental disabilities: Comparisons with 1997 Time Use Survey (ABS, 1997)

7.1 Overview

This chapter provides a detailed account of the time use of parents caring for young children with developmental disabilities. Data obtained from the Caregiver Diaries completed by parents is used to provide information about caring and other activities, and to estimate total time spent caring. Results from the present study are compared with results from the 1997 Time Use Survey (TUS), a national survey of time use undertaken by the Australian Bureau of Statistics (ABS, 1997).

7.2 Materials and Method

7.21 Caregiver Diary

The Caregiver Diary collected detailed reports from the parents who participated in Study 2, about their caring and other activities. The Caregiver Diaries, as previously described in Chapter 6, required parents to record their activities for a 24 hour period, using 32 pre-defined categories. Parents were each asked to complete two diaries; one diary to be filled out on a weekday and one diary to be filled out on a weekend day. Diaries were completed by both parents in the family on the same days. It was not possible to identify carer status in the 1997 Time Use Survey (TUS: ABS, 1997). In consequence, results of comparisons between the Caregiver Diaries and the TUS diaries are reported for gender groups (ie male and female carers), rather than for primary and secondary carers as occurs in other results chapters.

A total of 278 Caregiver Diaries (representing 278 diary days) were collected from 119 male study participants (ie fathers) and 159 female study participants (ie mothers). This represents a response rate of 91% for all participants in the study. Five male and seven female participants completed only one Caregiver Diary, describing a single day, instead of two Caregiver Diaries, describing two days. Weekdays accounted for 52% of all diary days, and weekend days accounted for 48% of total diary days. Figure 7.1 shows the distribution of completed diaries.

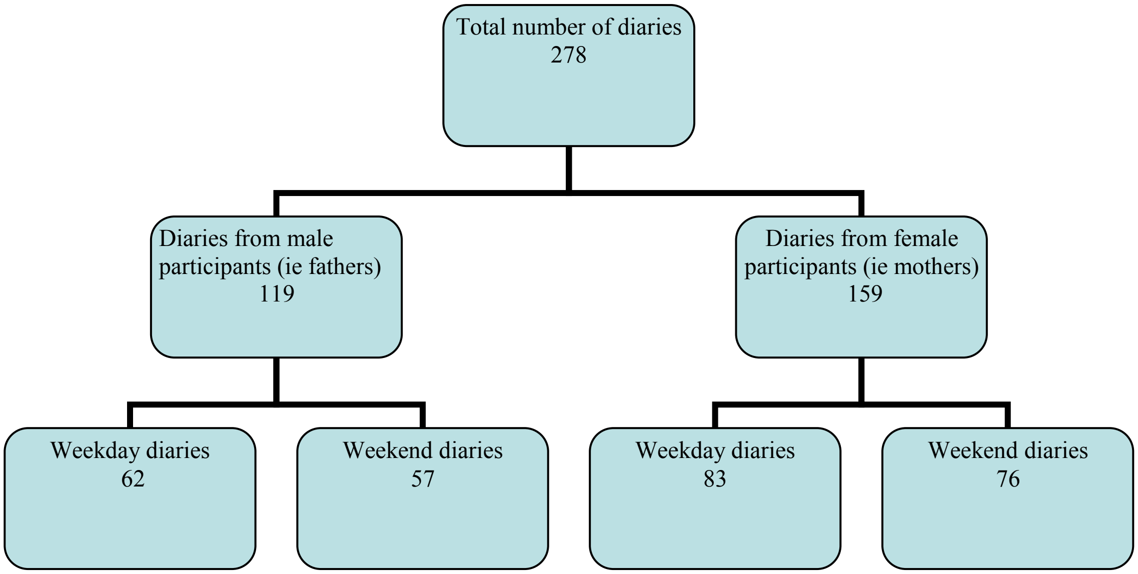


Figure 7.1. Number of Caregiver Diaries completed by mothers and fathers in Study 2, on weekdays and weekend days.

7.22 The 1997 Time Use Survey (ABS, 1997)

Data from the Australian Bureau of Statistics (ABS) 1997 Time Use Survey (TUS: ABS, 1997) was used to provide “normative” data which could be compared to the results of the Caregiver Diary. The TUS is the primary source of official Australian statistics describing how much time the adult Australian population devotes to different daily activities. The TUS collects data from all persons over 15 years living in randomly selected households throughout Australia. In the 1997 TUS each participant completed two 24 hour diaries. The diaries were traditional “full” diaries requiring respondents to keep a detailed hand written record of all activities in the day. In addition to the diary, structured interviews were completed with one adult member of each household. The interview provided detailed information about family and individual characteristics. The final data set from the 1997 TUS included 14,315 diaries from 7260 individuals in 3757 households. Analysis for the present study was undertaken using Confidentialised Unit Records Files (CURFS). A CURF is a de-identified unit record file made available for public use by the ABS.

For the purposes of the present study, data from the TUS was limited to:

1. Family households in which there was either a married/defacto couple caring for children 0-15 years;
2. Family households in which there was a single parent caring for children 0-15 years.
3. Family households in which the youngest two children were between 0-9 years, the third youngest child between 0-12 years and the fourth youngest child between 0-14 years (96% of families in the present study had children who fitted within these age ranges).

In summary, the subgroup identified from selected TUS data intended to provide the closest comparison to the data set represented by participants in Study 2 (the “STUDY” group), were parents caring for children in the general community – subsequently referred to as the community “COMM” group. A small number of parents (*N* = 71: 5% of the total number of parents) in the COMM group were caring for children with severe-profound disabilities, the category of disability most comparable to children in Study 2. This was not considered, however, to have made a substantial impact on the data obtained from the TUS.

Table 7.1 compares the sample sizes and number of diaries in the STUDY and COMM groups, for weekdays and weekend days. The sample size for participants in the STUDY group includes only those who completed Caregiver Diaries (rather than all participants in Study 2).

Table 7.1

Distribution of diaries: Study 2 sample and 1997 Time Use Survey "community" group

Group	Carer gender	Sample size	*Number of Diaries:* Total	Weekday	Weekend
COMM	Male	699	1376	988 (72%)	388 (28%)
	Female	856	1688	1228 (73%)	460 (27%)
STUDY	Male	62	119	62 (52%)	57 (48%)
	Female	83	159	83 (52%)	76 (48%)

Note. COMM = Parents of children in the general community, who participated in the 1997 TUS
STUDY= Participants in Study 2

7.23 Coding of Activities

The pre-coded categories for the Caregiver Diary used in the current study were designed to be consistent with the categories that were used in coding of the free-form TUS diary. This enabled comparison of time spent on activities in the present study with time spent by participants in the 1997 TUS. The TUS uses a standard four level classification of time use activities (Aas, 1982). Table 7.2 shows the broadest level of the classification used in the TUS, together with the nine activities that make up the second level. A further level of analysis (Level 3) used in the TUS allows division of activities into 64 groups, the most pertinent of which (in relation to the present study) are also shown Table 7.2. Comparisons between the Caregiver Diary and the TUS diaries were made at the second and third levels of the classification. Table 7.3 shows the groupings of the pre-coded categories used in the Caregiver Diary and the ways in which the categories were used to establish concordance with the TUS categories. The Caregiver Diary emphasised child care activities (being of most relevance to the aims of the present research) so the greatest detail is reported in relation to these activities. A list of coding rules used to collate data from the Caregiver Diary is included in Appendix O.

Table 7.2
Classification of time use activities used in the 1997 Time Use Survey

Level 1	Level 2	Level 3
Necessary time	Personal care activities	Activities of personal hygiene, sleeping, eating & drinking
Contracted time	Employment	
	Education activities	
Committed time	Domestic activities	Housework and home maintenance activities; Food preparation
	Child care activities	Care of children; teaching/ helping/ reprimanding children; playing/reading/ talking to children; minding children
	Purchasing goods and services	
	Voluntary work and care activities (adults)	
Free time	Social and community interaction	
	Recreation & leisure	

Table 7.3

Comparison between diary coding categories: 1997 Time Use Survey (TUS) and Caregiver Diary

TUS categories (Levels 2 & 3)	Caregiver Diary (pre-coded categories)
Personal care activities	
Sleeping	Sleeping
Personal hygiene	Personal hygiene
Eating/drinking	Eating/drinking
Employment	
Education activities	Employment/ study
Domestic activities	
Food preparation & cleanup	Food preparation
Laundry "Other" housework Grounds/animal care Home maintenance Household management	Household chores/ household maintenance
Childcare activities	
Care of children	
Physical care of child	Toileting Feeding Personal care activities
Emotional care of child	Holding, cuddling, comforting or soothing my child
Teaching/ helping/ reprimanding	Helping with communication Teaching, doing therapy activities Managing behaviour
Playing/ reading/ talking	Playing, reading, singing, talking with my child
Minding children	General monitoring/ checking my child is OK Watching my child closely, ready to step in straight away
	Attending organized lessons/ activities (watching my child)
Associated travel (with child)	Travel (with child)
	Appointments with doctors/ therapists/ and other meetings about my child[a]
	Phone calls/ paperwork/ research about my child[a]
Purchasing goods and services	Shopping
Voluntary work and care activities	OMITTED
Social and community interaction	Talking/ socializing
Recreation and leisure	Recreational activities

[a] Activities with no direct TUS equivalent

In addition to time spent in individual activities, a measure of total time caring (of those categories selected for use in the present study) was calculated from both diaries. Total time caring for the Caregiver Diary was calculated by adding the time spent in caring activities during each individual 15 minute period, regardless of the number of activities that were being undertaken at the same time (for example, if three caring activities were recorded within a 15 minute period, only 15 minutes was counted not 45 minutes). For the purposes of the present study, total time caring for the TUS diaries was calculated by summing time spent in all individual child care activities over the course of a day. The total time caring for the TUS included both time in child care recorded as a primary activity and also time in child care recorded as a secondary activity. This ensured that all child care time was included in calculations, but has meant that total time caring for the TUS is inflated by the occasions that child care activities occurred as both a primary and secondary activity during the same time period. Examination of a random sample of records from 10 female carers in the COMM group showed child care was recorded as both a primary and secondary activity on 6% of occasions, suggesting only a small impact on estimates of total time caring from the TUS data.

7.24 Differences between the Caregiver Diary and the TUS diary

Several important points of difference between the diary used in the present study and the diary used in the TUS should be noted before comparing the two sets of data:

- Firstly, the TUS collected data for up to two simultaneous activities within a five minute period. The diary used in the present study allowed parents to report multiple simultaneous activities within the one 15 minute time period. Coding of the Caregiver Diary limited whether some activities could be concurrent with others (see Appendix O for coding rules) and not all parents took the opportunity to record multiple activities, however, the results of the Caregiver Diary may not be exactly concordant with the results of the TUS diary. The differences in the diaries are most apparent when examining time spent in different caring activities, reflecting the greater emphasis of the Caregiver Diary on caring activities. The differences are less pronounced when considering activities other than caring (eg sleeping or employment/ education activities) where it was less likely multiple activities would be recorded.

- Secondly, the Caregiver Diary was primarily focused on the care of the child with a disability. Care of other children in the family was included in the "Other Activities" section of the diary, and has not been included in the analysis of times spent in different caring activities to follow. In consequence, time spent in child care activities (including the measure of total time caring) may be underestimated in comparison with the data from the TUS that does not distinguish between

> children within a family. This discrepancy, however, is likely to be small as examination of the Caregiver Diaries showed that, unless the sibling of the child with a disability was an infant, parents only infrequently recorded time caring for their other children. In most cases, child care for other children in the family was undertaken concurrently with child care for the child with a disability. The finding of less time spent with siblings is of note in itself. While this may reflect the emphasis in the study on children with a disability, parents also have less time and attention to give to siblings because of the demands of caring. This may contribute to the negative psychological and social impacts that have been found for siblings of children with disabilities (Sharpe & Rossiter, 2002).

In conclusion, the Caregiver Diary was a purpose designed instrument, intended to provide a detailed picture of a day in the life of a carer, focusing upon caring activities. The pre-coded categories reflect this focus. The information about caring activities obtained from the diary is, therefore, more detailed than the information obtained about activities other than caring. As well, the information about caring is more detailed than that obtained by the TUS diary.

7.25 Analysis

The TUS is a large scale population survey that is generally analysed using parametric statistics (ABS, 1997; 2006). Parametric methods, therefore, were chosen to undertake comparisons between the Caregiver Diary and the TUS diary. Two tailed independent t-tests were used to compare mean total time caring and mean times for individual activities (expressed as minutes/day) for male and female carers in the COMM group, and results of time use variables derived from the Caregiver Diary used in Study 2. Effect sizes were assessed using *d* coefficients (Cohen, 1988), and interpreted using Cohen‟s guidelines (.2= small effect; .5=moderate effect; .8=large effect). Due to reservations about the assumption, intrinsic to t-tests, that times were all normally distributed, caution has been exercised when interpreting the results of analyses with primary focus being placed upon large differences between mean times and patterns evident in the data.

7.3 Results

In this section results for parents in Study 2 (the “STUDY” group) and parents who participated in the TUS (the “COMM” group) will be compared with respect to:

- Total time caring
- Time spent in individual child care activities
- Time spent in activities other than child care

7.31 Total child care activities

Figure 7.2 graphically shows total time caring for the parents in the STUDY group and parents in the COMM group, for weekdays and weekend days. Table 7.4 reports the actual mean times spent caring (minutes/day) by male and female carers in the two groups and the results of analyses using independent sample t-tests.

Figure 7.2 illustrates that female carers in both groups spend more time in caring activities than males. For example females in the STUDY group spent 9 hours caring each weekday, on average, rising to approximately 9¾ hours on weekend days. Females in the COMM group spent 9¼ hours caring on weekdays, on average, rising to nearly 10 hours on weekend days. In contrast, males in the STUDY group spent, on average, 3¾ hours caring on weekdays, rising to approximately 6¼ hours on weekend days. Males in the COMM group spent nearly 5 hours caring on weekdays, on average, rising to 6½ hours on weekend days.

The difference between mean time spent caring for males and females was highly significant for both weekdays (*t*=-9.20 (143), *p*<.001, *d*=-1.56) and weekend days (*t*=-6.11 (131), *p*<.001, *d*=-1.08). It is of note that, while male carers in both groups increased their total time caring on weekend days, female carers also increased their caring commitment. Males in the STUDY group showed the biggest increase in total time caring from weekdays to weekend days (an extra 2 hours 23 minutes/day: *t*=-4.08 (117), *p*<.001, *d*=-.76), followed by males in the COMM group (an extra 1 hour 48 minutes: *t*=-5.83 (1374), *p*<.001, *d*=-.35). The increase in total time caring on weekend days was much smaller for females in both groups (approximately an extra ½ hour/day). The increases in time spent caring on weekends, however, were not statistically significant for females in the STUDY group (*t*=-1.14 (157), *p*=.26, *d*=-.18) or for females in the COMM group (*t*=-1.56 (1686), *p*<.12, *d*=-.09).

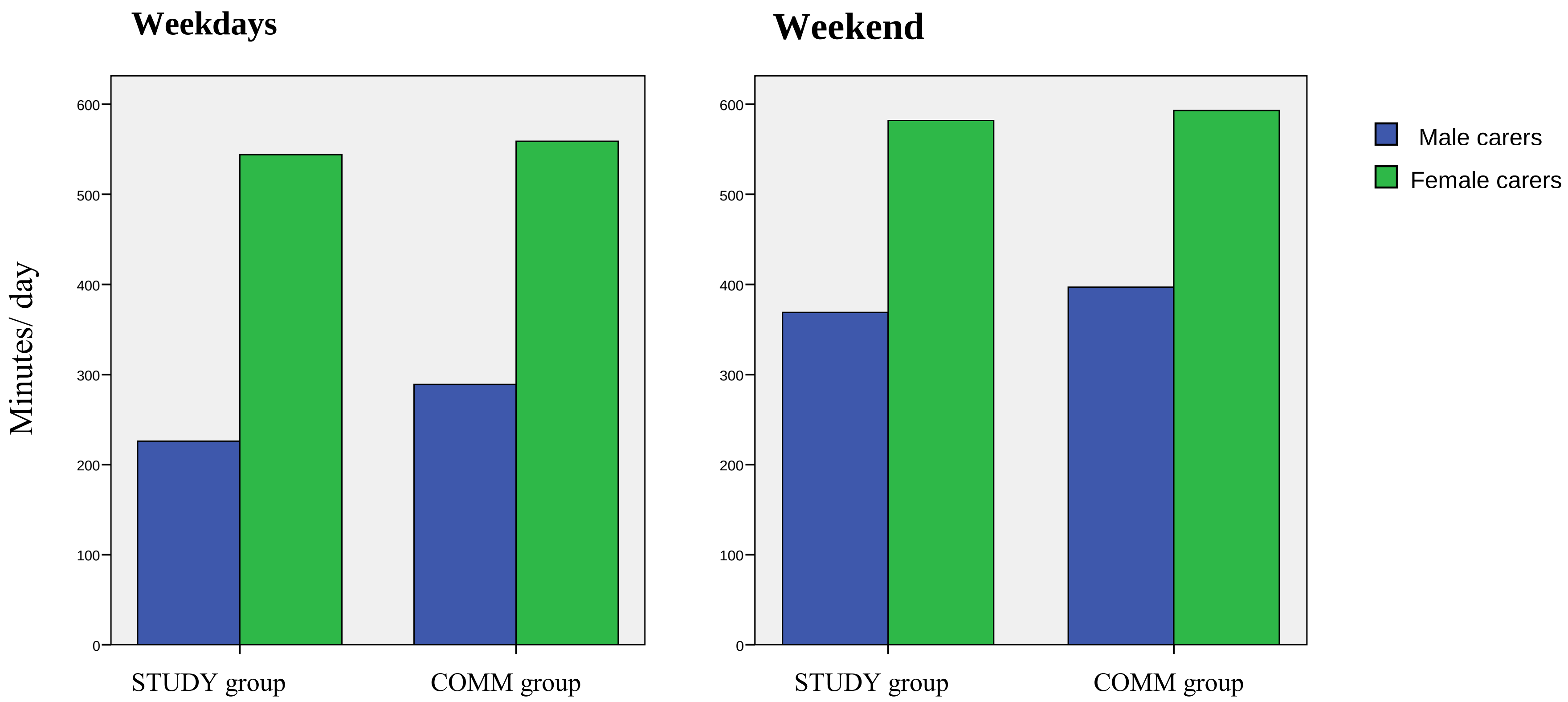


Figure 7.2. Mean total time caring (minutes/day): Male and female carers in Study 2 (STUDY) and the 1997 Time Use Survey “community”(COMM) group on weekdays and weekend days.

Table 7.4

Mean minutes/day (SD) total time spent caring and results of analyses using independent sample t-tests: Male and female carers in the Study 2 and the 1997 Time Use Survey "community" group on weekdays and weekend days

	STUDY		**COMM**				
Total time caring (minutes/ day)	*N*	*Mean (SD)*	*N*	*Mean (SD)*	*t*	*p*	*d*
Weekdays							
Males	62	226 (182)	988	289 (289)	-1.70	.09	-.22
Females	83	544 (222)	1228	559 (389)	-.35	.73	-.04
Weekend days							
Males	57	368 (200)	388	397 (355)	-.58	.56	-.08
Females	76	582 (198)	460	593 (424)	-.22	.82	-.03

Note. STUDY= Participants in Study 2
COMM = Parents of children in the general community who participated in the 1997 TUS

Figure 7.2 shows male carers in the COMM group spend approximately one more hour a day caring on weekdays, than male carers in the STUDY group. While this appears to be a relatively large difference in time, Table 7.4 shows the difference was not statistically significant (*p* = .09). Males in the COMM group also spent an extra 20 minutes in caring activities on weekend days, though the difference was also not statistically significant. A similar pattern was also found for females, though differences in caring time were less marked. Thus, females in the COMM group spent an additional 15 minutes caring on weekdays, and approximately 10 minutes more on weekend days. Table 7.4 shows differences in total time caring between females in the STUDY and COMM groups, were not statistically significant.

7.32 Individual child care activities

Tables 7.5 to 7.8 compare time spent in individual child care activities by male and female carers in the STUDY and COMM groups, for weekdays and weekend days. Parents in the STUDY group spent significantly more time in most child care activities than parents in the COMM group. Thus, male and female carers in the STUDY group spent significantly more time in physical care activities, as well as more time teaching/ helping/ reprimanding their child than male and female carers in the COMM group, on weekdays and weekend days. Female carers in the STUDY group also spent significantly more time in emotional care (comforting/ soothing their child) and in travel with their child, than female carers in the COMM group. Male carers in the STUDY group spent significantly more time in emotional care than male carers in the COMM group on weekend days only, and travelling with their child on weekdays. Parents in the STUDY group also recorded more time spent in more "qualitative" child care activities, such as play, reading or talking to their child. The difference between time spent by parents in both groups for qualitative activities, however, was much less marked than the differences found for other child care activities, and none achieved statistical significance.

The principal exception to the pattern of results found above was for the child care activity "minding" (general supervision). Male and female carers in the COMM group spent substantially more time minding their children, rather than engaging in activities involving more "active" care, than male and female carers in the study sample. Given the differences in "active caring" detailed above it is this large difference in "minding" which accounts for the observation that *total time* caring is similar for both groups

Table 7.5

Mean minutes/day (SD) spent in different child care activities and results of analyses using independent sample t-tests: ***Male carers*** *in Study 2 and the 1997 Time Use Survey "community" group on* ***weekdays***

		MALE CARERS: STUDY (*N*=62)		**COMM (*N*=988)**			
Purpose of activity	*n*	Mean (*SD*)	*n*	Mean (*SD*)	*t*	*p*	*d*
Care of Child							
Physical care	48	87 (58)	422	42 (43)	6.60	<.001	1.01
Emotional care	36	53 (51)	49	34 (72)	1.35	.18	.30
Teaching/ helping /reprimanding	38	135 (126)	83	37 (28)	6.76	<.001	1.34
Playing/reading /talking	41	76 (68)	573	65 (58)	1.16	.25	.19
Minding	42	109 (99)	474	361 (286)	-5.68	<.001	-.92
Assoc.Travel	22	56 (40)	226	32 (25)	3.87	<.001	.87

Note. STUDY= Participants in Study 2
COMM = Parents of children in the general community who participated in the 1997TUS

Table 7.6

Mean minutes/day (SD) spent in different child care activities and results of analyses using independent sample t-tests: ***Female carers*** *in Study 2 and the 1997 Time Use Survey "community" group on* ***weekdays***

		FEMALE CARERS: **STUDY (*N*=83)**		**COMM (*N*=1228)**			
Purpose of activity	*n*	Mean (*SD*)	*n*	Mean (*SD*)	*t*	*p*	*d*
Care of Child							
Physical care	83	185(90)	1048	103 (104)	6.98	<.001	.80
Emotional care	62	95 (85)	144	35 (66)	5.47	<.001	.84
Teaching/ helping /reprimanding	71	350 (322)	274	38 (29)	15.86	<.001	2.12
Playing/reading /talking	74	141 (120)	953	121(110)	1.50	.13	.18
Minding	77	207 (137)	870	517 (359)	-7.53	<.001	-.90
Assoc.Travel	61	64 (39)	653	46 (34)	3.90	<.001	.52

Note. STUDY= Participants in Study 2
COMM = Parents of children in the general community who participated in the 1997TUS

Table 7.7

Mean minutes/day (SD) spent in different child care activities and results of independent sample t-tests: ***Male carers*** *in Study 2 and the 1997 Time Use Survey "community" group on* ***weekend days***

	MALE CARERS: STUDY (*N*=57)		**COMM (*N*=388)**				
Purpose of activity	*n*	Mean (*SD*)	*n*	Mean (*SD*)	*t*	*p*	*d*
Care of Child							
Physical care	42	119 (71)	181	48 (58)	6.84	<.001	1.18
Emotional care	33	68 (71)	21	24 (25)	2.73	<.05	.78
Teaching/ helping /reprimanding	37	241(259)	26	63(71)	3.41	<.001	.89
Playing/reading /talking	47	109(79)	227	108(92)	.07	.94	.01
Minding	45	187 (124)	204	449(368)	-4.71	<.001	-.78
Assoc.Travel	26	56 (40)	58	32 (25)	1.61	.11	.38

Note. STUDY= Participants in Study 2
COMM = Parents of children in the general community who participated in the 1997TUS

Table 7.8

Mean minutes/day (SD) spent in different child care activities and results of independent sample t-tests: ***Female carers*** *in Study 2 and the 1997 Time Use Survey "community" group on* ***weekend days***

	FEMALE CARERS: STUDY (*N*=76)		**COMM (*N*=460)**				
Purpose of activity	*n*	Mean (*SD*)	*n*	Mean (*SD*)	*t*	*p*	*d*
Care of Child							
Physical care	74	176 (101)	364	95(96)	6.56	<.001	.84
Emotional care	59	89 (81)	40	36(38)	3.86	<.001	.80
Teaching/ helping /reprimanding	62	321(315)	56	42 (48)	6.56	<.001	1.22
Playing/reading /talking	70	151 (129)	341	118(101)	2.37	<.05	.31
Minding	72	237 (140)	339	578 (405)	-7.05	<.001	-.92
Assoc.Travel	43	70 (42)	108	46 (44)	3.06	<.001	.56

Note. STUDY= Participants in Study 2
COMM = Parents of children in the general community who participated in the 1997TUS

7.33 Activities other than child care

Tables 7.9 to 7.12 show the mean time spent in activities other than caring for parents in the STUDY group, and parents in the COMM group, together with results of statistical comparisons using independent sample t-tests. The tables show male and female carers in the STUDY group consistently spent *less* time in personal care activities (sleep, personal hygiene, eating/ drinking) and in recreation/leisure activities than male and female carers in the COMM group, on weekdays and weekend days. Results of analyses comparing time spent in personal care activities were significant, with small to moderate effect sizes. Differences in time spent in recreation/ leisure were highly significant for males and females, on both weekdays and weekend days.

In contrast to the above findings, the tables show parents in the STUDY group spent *more* time purchasing goods (ie shopping) and in social/community interaction than parents in the COMM group. Differences in time spent shopping between males in the STUDY and the COMM groups were significant, with moderate to large effect sizes. Females in the STUDY group spent significantly more time shopping on weekends only. Results of analyses were highly significant for both males and females, on weekdays and weekend days, for differences in time spent socialising or in community interaction. Parents in the STUDY group reported themselves to spend substantially more time socialising than parents in the COMM group.

Differences in time spent in domestic activities (food preparation; household chores) were less consistent than the differences found for other activities, and for the most part, did not achieve statistical significance. Males in the STUDY group spent slightly more time in food preparation and household chores on weekdays, but spent slightly less time in chores on weekend days. Females in the STUDY group spent less time in food preparation, particularly on weekend days, but spent slightly more time in household chores on weekdays.

Table 7.9

Mean minutes/day (SD) spent in activities other than child care and results of independent sample t-tests: ***Male carers*** *in Study 2 and the 1997 Time Use Survey "community" group on* ***weekdays***

	MALE CARERS: STUDY (*N*=62)		**COMM (*N*=988)**				
Purpose of activity	*n*	Mean (*SD*)	*n*	Mean (*SD*)	*t*	*p*	*d*
Personal care							
Sleep	62	444 (92)	988	480 (94)	-2.93	<.05	-.38
Hygiene	54	33 (16)	947	41 (26)	-2.24	<.05	-.31
Eating/drinking	61	60 (32)	964	85 (54)	-3.58	<.001	-.47
Recreation & leisure	54	138 (100)	973	343 (206)	-7.26	<.001	-1.02
Purchasing goods	14	77 (64)	281	35 (39)	3.70	<.001	1.04
Social & community interaction	37	157 (118)	354	62 (680	7.42	<.001	1.29
Domestic							
Food preparation	29	55 (38)	632	44 (41)	1.42	.16	.27
Household chores	31	102 (90)	589	92 (103)	.53	.60	.10
Employment/education	48	538 (159)	829	562 (177)	-.92	.36	-.14

Note. STUDY= Participants in Study 2
COMM = Parents of children in the general community who participated in the 1997TUS

Table 7.10

Mean minutes/day (SD) spent in activities other than child care and results of independent sample t-tests: ***Female carers*** *in Study 2 and the 1997 Time Use Survey "community" group on* ***weekdays***

		FEMALE CARERS: **STUDY (*N*=83)**		**COMM (*N*=1228)**			
Purpose of activity	*n*	Mean (*SD*)	*n*	Mean (*SD*)	*t*	*p*	*d*
Personal care							
Sleep	83	444 (119)	1227	494 (87)	-4.93	<.001	-.56
Hygiene	77	36 (19)	1185	45 (29)	-2.69	<.05	-.32
Eating/drinking	81	80 (40)	382	92 (55)	-1.93	.05	-.22
Recreation & leisure	66	124 (84)	1210	333 (181)	-9.46	<.001	-1.18
Purchasing goods	43	66 (50)	687	54 (55)	1.39	.16	.22
Social & community interaction	56	140 (122)	698	71 (78)	6.06	<.001	.84
Domestic							
Food preparation	75	88 (49)	1180	97 (59)	-1.29	.20	-.15
Household chores	76	146 (96)	1141	140 (100)	.51	.61	.06
Employment/education	30	307 (205)	500	365 (203)	-1.52	.13	-.29

Note. STUDY= Participants in Study 2
COMM = Parents of children in the general community who participated in the 1997TUS

Table 7.11

Mean minutes/day (SD) spent in activities other than child care and results of independent sample t-tests: ***Male carers*** *in Study 2 and the 1997 Time Use Survey "community" group on* ***weekend days***

		MALE CARERS: STUDY (*N*=57)		**COMM (*N*=388)**			
Purpose of activity	*n*	Mean (*SD*)	*n*	Mean (*SD*)	*t*	*p*	*d*
Personal care							
Sleep	56	493 (129)	388	528 (117)	-2.07	<.05	-.30
Hygiene	45	32 (22)	359	41 (29)	-2.01	.05	-.32
Eating/drinking	54	81 (57)	382	112 (80)	-2.75	<.05	-.40
Recreation & leisure	43	226 (130)	385	432 (213)	-6.51	<.001	-1.05
Purchasing goods	23	72 (54)	178	48 (50)	2.15	<.05	.48
Social & community interaction	47	272 (203)	213	107 (111)	7.75	<.001	1.25
Domestic							
Food preparation	32	56 (47)	254	57 (49)	-.11	.91	-.02
Household chores	31	125 (84)	293	157 (140)	-1.25	.21	-.24
Employment/education	21	299 (248)	153	397 (246)	-1.71	.09	-.40

Note. STUDY= Participants in Study 2
COMM = Parents of children in the general community who participated in the 1997TUS

Table 7.12

Mean minutes/day (SD) spent in activities other than child care and results of independent sample t-tests: ***Female*** *carers in Study 2 and the 1997 Time Use Survey "community" group on* ***weekend days***

	FEMALE CARERS: **STUDY (*N*=76)**		**COMM (N=460)**				
Purpose of activity	*n*	Mean (*SD*)	*n*	Mean (*SD*)	*t*	*p*	*d*
Personal care							
Sleep	74	497 (102)	460	523 (96)	-2.14	<.05	-.27
Hygiene	65	38 (23)	438	46 (29)	-2.13	<.05	-.28
Eating/drinking	73	86 (55)	456	104 (70)	-2.10	<.05	-.26
Recreation & leisure	58	174 (123)	457	381 (196)	-7.85	<.001	-1.10
Purchasing goods	35	81 (69)	251	58 (54)	2.28	<.05	.41
Social & community interaction	57	244 (179)	280	96 (105)	8.45	<.001	1.23
Domestic							
Food preparation	71	80 (47)	438	97 (66)	-2.09	<.05	-.27
Household chores	65	157 (101)	430	157 (104)	.00	1.0	.00
Employment/education	10	396 (307)	79	264 (198)	1.86	.07	.63

Note. STUDY= Participants in Study 2
COMM = Parents of children in the general community who participated in the 1997TUS

Tables 7.9 to 7.12 show mean times spent in employment and study activities for parents in both groups. While males in the STUDY group spent less time in employment or study than males in the COMM group, differences did not attain statistical significance. Females in the STUDY group who engaged in these activities, spent less time overall on weekdays, but more time on weekends. These differences, however, were also not statistically significant.

Table 7.13 presents the number and percentage of days on which parents in the STUDY or COMM groups recorded having participated in employment or education activities on weekdays and/ or weekend days. A chi-square analysis examining the differences between the number of days on which males in the STUDY or COMM groups worked on weekdays was not significant ($X^2 = 1.8$ (3), $p = .61$). Results for males on weekend days also showed differences were not significant ($X^2 = .14$ (3), $p =.99$). Similarly, results of analyses between females in the STUDY and COMM groups on weekdays were not significant ($X^2 = .69$ (3), $p = .88$), as were differences on weekend days ($X^2 = .75$ (3), $p = .86$)

Table 7.13

Number of days on which male and female carers in Study 2 and the 1997 Time Use Survey recorded participation in paid employment/education, on weekdays or weekend days

Group:	**STUDY**	**COMM**
Males		
Weekdays	48 (77%[a])	829 (84%)
N	62	988
Weekend days	21 (37%)	153 (39%)
N	57	388
Females		
Weekdays	30 (36%)	500 (41%)
N	83	1228
Weekend days	10 (13%)	79 (17%)
N	76	460

Note: STUDY= Participants in Study 2; COMM = Parents of children in the general community who participated in the 1997 TUS

[a] Number of days in employment/education as a percentage of total weekday or weekend diary days

7.4 Conclusions

The most striking findings from the present chapter were the differences found when comparing data from parents caring for children with disabilities, with the patterns of time use reflecting caring and other activities of parents of children in the general community. While total time caring was not significantly different between parents in the two groups, caring for a child with a disability required significantly more time in individual caring activities reflecting "active" care of the child (ie physical care; emotional care; & teaching/ helping/ reprimanding) on both weekdays and weekend days. Parents of children with disabilities spent the largest amount of caring time in teaching, helping or reprimanding their child, reflecting the specific needs of children with developmental delays, particularly those with additional behavioural problems. Parents of children in the general community who participated in the 1997 TUS survey spent substantially more time in minding their child ("passive" child care activities). Of note, there were no significant differences found between time spent by parents in both groups in the more "qualitative" caring activities such as time spent playing, reading or talking to children.

Differences in time spent in caring activities between the two groups may, in part, reflect differences in the design and coding rules in the Caregiver Diary and the TUS diary. Total time spent caring for parents in the TUS group, for example, may have been slightly inflated by inclusion of both primary and secondary activities in the TUS group. As well, total time caring was potentially underestimated in the study sample because child care activities were only recorded for the child with a disability. Results for the study group for individual child care activities were also influenced by the decision to allow carers to record multiple concurrent activities within the Caregiver Diary, rather than limiting the number of concurrent activities to two, as is the case in the TUS. These methodological differences may have minimised differences in total time caring, and maximised differences in time spent in individual child care activities.

Differences may also reflect variations in the aims of the two diaries. The Caregiver Diary was a purpose developed tool, completed in the context of research focusing on caring activities. As such it encouraged parents to be more descriptive and more comprehensive when recording their time use when caring. In contrast, the TUS was a large scale population survey aimed at reporting on the time use patterns of the general population, not just carers. The extra time spent in individual child care activities reported by the study participants may reflect the greater detail recorded by parents in the study diaries and highlights the finding that many child care activities are undertaken concurrently. It is likely that the category "minding" was used by parents in the TUS study as a general category covering a number of different activities. This is given credence by the finding that time spent in some child care activities (eg emotional care) by carers in the TUS was unrealistically low, and even in some cases non-existent. It also reflects the finding that participants in the TUS mostly recorded child care as a secondary activity; this is, undertaken at the same time as activities other than child care.

While it is important to acknowledge the potential influence of methodological differences between the diaries used in Study 2, and in the 1997 TUS, the finding that caring for a child with a disability requires more "hands on" work is consistent with the report of parents in Study 1, who emphasised the greater intensity of caring for a child with disabilities. The need to be actively involved in caring limits opportunities to engage in other, secondary tasks such as housework, and may therefore contribute to increased feelings of time pressure and parental stress.

Some notable differences between the time use of parents in the study and parents in the TUS were also apparent when considering activities other than caring:

- Firstly, carers in the study sample spent less time in personal care activities (ie sleep; personal hygiene and eating/ drinking) than carers in the TUS groups. Personal care is typically sacrificed in order to find time for the extra demands of caring (Erickson & Upshur, 1989; Lucca & Settles, 1981).

- Secondly, carers in the study sample spent significantly less time in recreational activities than carers in the TUS groups. These results may have been influenced by procedural differences in coding rules between the Caregiver Diary and the TUS diary. The results, however, are consistent with previous research in the area showing that parents caring for children with disabilities have less time to spend in recreational activities (Cant, 1994; Crowe & Florez, 2006).

- Thirdly, the present study found carers to spend more time socialising than carers in the TUS groups. This finding is in contrast to Crowe‟s (1993) study which found parents caring for pre-school children with disabilities to spend less time socialising than parents caring for pre-school children without disabilities. Results, however, are consistent with a more recent study of mothers of children with disabilities who are in paid employment, also using the 1997 TUS data (Brandon, 2007). While the present results may have been influenced by procedural differences between the Caregiver Diary and the TUS diary, the finding that carers in the study spent more time socialising than parents in the general community may also reflect the importance of social support to parents of children with disabilities (Brandon, 2007; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Dunst, Hamby, Trivette, Raab, & Bruder, 2002; White & Hastings, 2004).

- While differences between males and females in the STUDY and COMM groups in the number of days on which they participated in employment or educational activities on weekdays or weekend days were not statistically significant, patterns in the data showed males and females in the STUDY group consistently reported working on fewer days than parents in the COMM group. It should be noted that the measure used to identify rates of participation in employment was indirect, in that it relied upon the days that parents completed diaries. Parents who work part-time for example could have been underestimated using this procedure

- Finally, the present chapter also highlighted patterns of time use across the two data sets. Male carers were found to spend much less time in child care activities than female carers, reflecting the predominant role of women as primary carers of children within a family. As well, the diaries show that patterns of time use vary substantially across weekdays and weekend days. Combining data for different days of the week, as has occurred in most previous research investigating time use of parents caring for children with disabilities, masks significant differences in the patterns of activities undertaken by parents on weekdays and weekend days. These differences may reflect upon parenting roles, in particular. This chapter has illustrated how fathers spend more time in activities outside of the home on weekdays (ie employment or study), but increase their commitment to caring on weekend days when they are more likely to be spending time with the family.

CHAPTER 8:

Patterns in the time use of parents caring for children with developmental disabilities: Comparisons between primary and secondary caregivers

8.1 Overview

This chapter further explores the Caregiver Diaries, as part of the first aim of Study 2, focusing on comparisons between primary caregivers (PCGs) and secondary caregivers (SCGs) rather than male and female carers. This reflects the focus on caring in the present dissertation, and acknowledges the experiences of fathers who identified themselves as primary carers. The comparison between carers aimed to provide a clear picture of the role of the primary caregiver, and the typical tasks this person is usually required to carry out. Analyses for this chapter will investigate differences in total time caring between PCGs and SCGs. Additional information from the Caregiver Diary, however, will also enable comparisons in time spent in night-time care. Subsequent analyses will investigate differences in time spent in individual child care activities, in much greater detail than was possible when comparing with the more general TUS. The chapter will also examine differences in time spent in activities other than child care (non-caring activities). Finally, the chapter will report on other information collected by the study diary including: the experience of daily stress on each diary day; and perceptions of tasks and situations (from the pre-coded categories in the Caregiver Diary) that contributed to the experience of daily stress.

8.2 Measures and Methods

Data for analyses in this chapter was obtained from the Caregiver Diaries completed by study participants. The Caregiver Diary has been previously described in Chapter 6 Figure 8.1 shows the distribution of diaries completed by PCGs and SCGs.

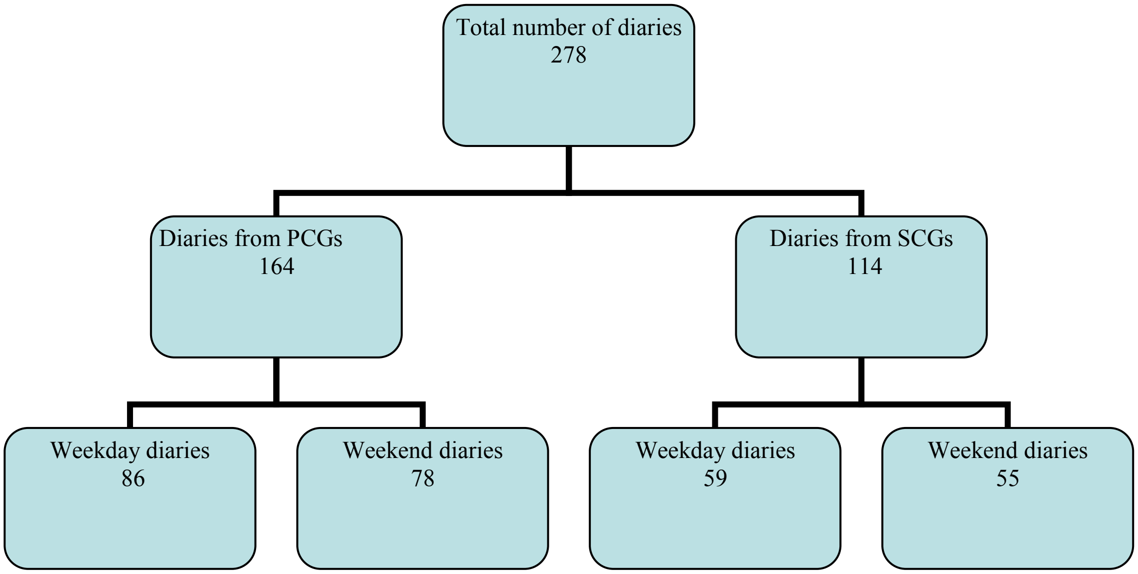


Figure 8.1. Number of Caregiver Diaries completed by primary caregivers (PCGs) and secondary caregivers (SCGs) in Study 2, on weekdays and weekend days.

As in Chapter 7, results of comparisons between the time use of carers in different activities, are principally expressed as minutes/day. Results are reported separately for PCGs and SCGs and for weekdays and weekends.

Preliminary analyses showed the distributions of many of the time use variables from the Caregiver Diaries were positively skewed and bounded at zero. Eliminating outliers and using square root and logarithmic transformations were only partially successful in changing the shape of distributions so a decision was made to use nonparametric, rather than parametric tests for all analyses in the present chapter. In consequence, median times and time ranges are reported following the advice of Olsen (2003). Statistical comparisons between time use of PCGs and SCGs were undertaken using Mann-Whitney *U* tests. Effect size was assessed using Cliff"s *d* (Cliff, 1993) and interpreted according to the guidelines used by Vargha and Delaney (2000): .11 = small effect size; .28 = medium effect size; and .43 = large effect size. Statistical analyses of the relationships between daily stress and time use variables (later in this chapter) were undertaken using Spearman"s *Rho* correlation coefficients and where appropriate, Pearson chi-square tests and Kruskal-Wallis tests.

8.3 Results

8.31 Total time caring

Figure 8.2 illustrates that PCGs, as expected, undertake most caring activities. Table 8.1 shows median time spent caring, by primary caregivers and secondary caregivers, time ranges, and results of analyses using Mann-Whitney *U* tests to examine the significance of differences in total time spent caring.

Table 8.1

Median minutes/day total time spent caring by primary caregivers (PCGs) and secondary caregivers (SCGs), and results of Mann-Whitney U test for weekdays and weekend days

Total time caring (minutes/ day)	N	Median	Range	*U*	*p*	*Cliff's d*
Weekdays						
PCGs	86	540	120-1065			
SCGs	59	150	0-660	401.0	p<.001	-.84
Weekend days						
PCGs	78	600	195-1080			
SCGs	54	368	0-690	842.5	p<.001	-.60

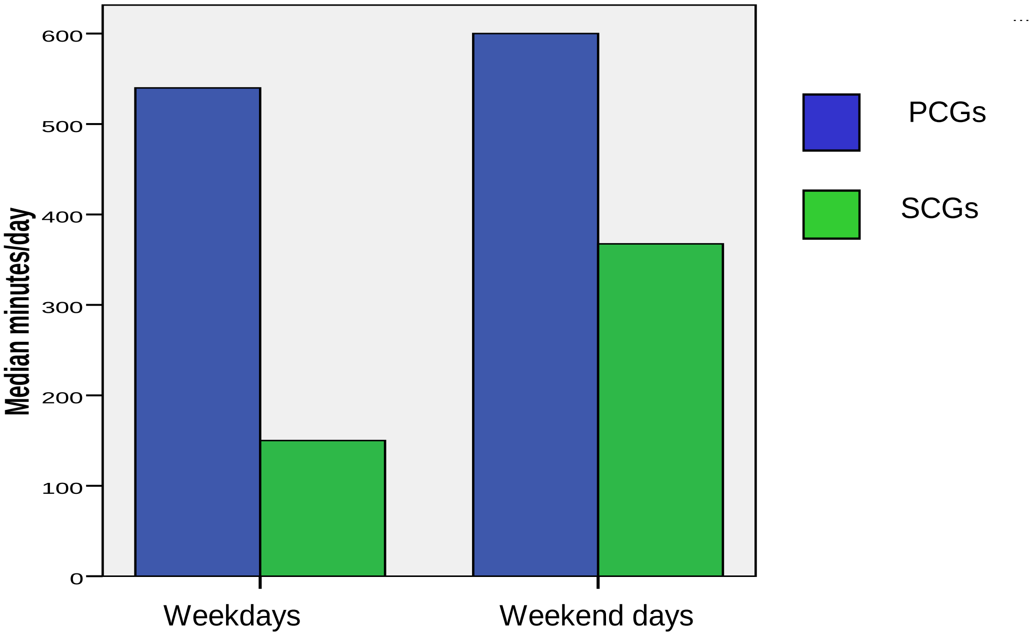


Figure 8.2 Comparisons between primary caregivers (PCGs) and secondary caregivers (SCGs) for total time caring on weekdays and weekend days.

Table 8.1 shows PCGs carried out 9 hours of caring each weekday, and 10 hours on weekend days. In contrast, most SCGs spent 2½ hours caring on weekdays, rising to 4½ hours on weekend days. The difference between total time spent caring by PCGs and total time spent caring by SCGs was highly significant on both weekdays and weekend days. Of note, while SCGs almost double their time in caring activities on weekend days, they continue to spend much less time caring than their partners.

8.32 Total night-time care

The Caregiver Diary asked parents to record their caring activities for a 24 hour period, enabling an estimate of time spent in night-care (rather than daytime) care. Night time care was judged to be any care undertaken for the child, between the hours of 10pm at night and 6am the following morning (see diary coding rules in Appendix O). Results showed 39% percent of PCGs who completed diaries were required to provide night-time care on weekdays, and 31% provided night-time care on weekend days. In contrast, 10% of SCGs who completed diaries provided night-time care on weekdays, and 11% on weekend days. The role of a primary carer, therefore, would appear to require principal responsibility for both daytime and night-time care of children. When considering total time taken during night-time care for PCGs and SCGs who recorded having been required to tend to their child at night, there was no difference between time spent by PCGs (*N*= 32, *Mdn*=52.50 (*Range* =15-195)), and time spent by SCGs (*N*=6, 52.50 (15-150); *U*= 80, *p*=.52, Cliff‟s *d*=-.17) on weekdays. Similarly, PCGs (*N*=24, 45 (15-225)) and SCGs (*N*=6, 45 (15-60); *U*=58, *p*=.46, Cliff‟s *d*=-.29) spent the same total time in night-time care on weekend days.

8.33 Individual child care activities

Tables 8.2 and Table 8.3 show the median time spent in individual child care activities by PCGs and SCGs, on weekdays and weekend days, and the results of analyses using Mann Whitney *U* tests. The tables present the broad categories of child care used in comparisons with the TUS in Chapter 7, as well as including more specific information about the types of activities within each broad grouping. For example, within the category of "physical care" are the more specific activities: helping with toileting; helping with feeding; or helping with personal care. Activities included in the broad category of "teaching/ helping/ reprimanding" included: helping with communication; therapy; and behaviour management. Lastly, within the broad category of "minding": general monitoring of my child; watching my child carefully; and attending organised activities, were included. A new broad category of care, "appointments/ phonecalls/ research about my child", which was not used in the previous chapter, has also been included in the present chapter.

Table 8.2

Median times (minutes/day) spent in different child care activities by primary caregivers (PCGs) and secondary caregivers (SCGs), on ***weekdays****, and results of Mann-Whitney U tests*

Weekdays

Activity type	**PCGs (Total diaries= 86)**		**SCGs (Total diaries =59)**				
	N[a] %[b]	Median time (range)	N[a] %[b]	Median time (range)	*U*	*p*	*Cliff's d*
Care of Child							
Physical care	86 (100%)	180 (45-495)	45 (76%)	60 (15-255)	448.0	<.001	-.77
Feeding	81 (94%)	75 (15-195)	30 (51%)	38 (15-90)	520.5	<.001	-.57
Toileting	76 (88%)	60 (15-330)	27 (46%)	15 (15-90)	483.5	<.001	-.53
Personal care	83 (97%)	60 (15-180)	41 (70%)	30 (15-75)	850.0	<.001	-.50
Emotional care	67 (78%)	60 (15-435)	31 (53%)	45 (15-225)	778.0	<.05	-.25
Teaching/ helping/ reprimanding	72 (84%)	263 (15-1350)	37 (63%)	90 (15-55)	600.5	<.001	-.55
Helping with communication	59 (69%)	150 (15-780)	24 (41%)	60 (15-345)	410.0	<.01	-.42
Behaviour management	58 (68%)	90 (15-645)	26 (44%)	53 (15-210)	477.5	<.01	-.37
Therapy	46 (54%)	75 (15-375)	11 (19%)	45 (15-135)	188.0	.19	-.26
Playing/ reading/ talking	75 (87%)	105 (15-645)	40 (68%)	53 (15-210)	788.5	<.001	-.47
Minding	81 (94%)	180 (30-675)	38 (64%)	53 (15-360)	561.0	<.001	-.64
General monitoring	77 (89%)	135 (15-675)	34 (58%)	45 (15-300)	560.0	<.001	-.57
Watching carefully	38 (44%)	60 (15-120)	11 (19%)	45 (15-120)	194.0	.72	-.07
Attending organised activities	16 (19%)	60 (15-180)	2 (3%)	38 (15-60)	8.50	.28	-.47
Travel with child	66 (77%)	60 (15-180)	17 (29%)	30 (15-105)	360.0	<.05	-.34
Appointments/ phonecalls/ research	15 (17%)	150 (60-315)	1(2%)	105 (105-105)	4.50	.51	-.40

[a] N= number of caregivers who recorded times for an individual child care activity on weekdays; [b] percentage of total number of caregivers participating in activities

Table 8.3

Median time (minutes/day) spent in different child care activities by primary caregivers (PCGs) and secondary caregivers (SCG's) on ***weekend days****, and results of Mann-Whitney U tests*

Weekend days

	PCGs (Total diaries= 78)		**SCGs (Total diaries =55)**				
Activity type	N[a] %[b]	Median time (range)	N[a] %[b]	Median time (range)	*U*	*p*	*Cliff's d*
Care of Child							
Physical care	77 (99%)	165 (15-435)	39 (71%)	90 (15-270)	909.0	<.001	-40
Feeding	68 (87%)	83 (15-210)	32 (58%)	53 (30-120)	678.5	<.01	-.38
Toileting	61 (78%)	60 (15-165)	26 (47%)	30 (15-150)	535.5	<.05	-.33
Personal care	74 (95%)	60 (15-150)	33 (60%)	30 (15-135)	867.0	<.05	-.29
Emotional care	58 (74%)	60 (15-405)	34 (62%)	53 (15-360)	787.0	.104	-.20
Teaching/ helping/ reprimanding	63 (81%)	225 (15-1410)	36 (66%)	120 (15-900)	836.5	<.05	-.26
Helping with communication	52 (67%)	143 (18-735)	27 (49%)	75 (15-675)	538.5	.09	-.23
Behaviour management	50 (64%)	83 (15-780)	22 (40%)	60 (30-450)	533.5	.84	-.03
Therapy	31 (40%)	60 (15-330)	13 (24%)	60 (15-180)	160.0	.28	-.21
Playing/reading/ talking	73 (94%)	120 (15-645)	44 (80%)	83 (15-300)	1361.0	.17	-.15
Minding	73 (94%)	210 (30-660)	44 (80%)	165 (30-450)	1130.5	<.01	-.30
General monitoring	67 (86%)	180 (15-660)	38 (69%)	150 (30-450)	980.5	.05	-.23
Watching carefully	35 (45%)	60 (15-450)	20 (36%)	60 (15-225)	326.5	.68	-.07
Attending organised activities	5 (6%)	45 (45-90)	1 (2%)	45 (45-45)	1.5	.49	-.40
Travel	40 (51%)	60 (15-180)	25 (46%)	60 (15-180)	464.5	.63	-.07
Appointments/ phonecalls/ research	2 (3%)	113 (105-120)	1(2%)	45 (45-45)	0.0	.22	-.00

[a] N= number of caregivers who recorded times for an individual child care activity on weekdays; [b] percentage of total number of caregivers participating in activities

Tables 8.2 and 8.3 confirm, as expected, PCGs are more likely to engage in child care activities than SCGs on both weekdays and weekend days. As well, they spend significantly more time in all categories of child care than secondary caregivers. Results of analyses examining differences in the times spent by PCGs and SCGs, using Mann-Whitney *U* tests, were significant for weekdays. While PCGs continue to spend more time than SCGs in all caring activities on weekend days, Tables 8.2 and 8.3 show that SCGs increased their time spent in most caring activities on weekends. This resulted in fewer significant differences between PCGs and SCGs for weekend days. The most marked difference between the activities of PCGs and SCGs on weekend days related to time spent in physical care tasks, with PCGs spending significantly more time feeding and toileting, and in personal care of their children.

Tables 8.2 and 8.3 also include information about the total number of caregivers who recorded having participated in individual child care activities on either weekdays or weekend days. This information was used to indirectly investigate whether there are differences in the types of child care activities undertaken by PCGs and SCGs. Table 8.4 presents the three categories of activities undertaken by the largest number of primary caregivers, and the three categories of activities carried out by the largest number of secondary caregivers, on weekdays and weekend days.

Table 8.4
Categories of the activities undertaken by the largest number of parents, on weekdays and weekend days

Primary caregivers

Weekdays	*Weekend days*	
1. Physical care	1. Physical care	
2. Minding	2. Play/reading/talking	equal rank
3. Playing/reading/talking	Minding	
	3. Teaching/helping/reprimanding	

Secondary caregivers

Weekdays	*Weekend days*	
1. Physical care	1 Play/reading/talking	equal rank
2. Play/reading/talking	Minding	
3. Minding	2. Physical care	
	3. Teaching/helping/reprimanding	

Table 8.4 shows PCGs were most likely to undertake physical care activities for children on both weekdays and weekend days. Physical care was also the category of activity undertaken by most SCGs on weekdays. SCGs, however, were most likely to participate in “qualitative” caring activities such as playing or reading with children, or to engage in passive care (ie general monitoring) on weekend days.

Differences in the length of time spent in activities may also reflect differences in the types of caring undertaken by primary and secondary caregivers. Table 8.5 shows the three activities in which PCGs and SCGs spent the most time on weekdays and weekend days (independently of how many caregivers engaged in these activities). Results for SCGs excluded one SCG who spent an unusually large time in appointments/phonecalls on weekdays.

Table 8.5
Categories of activities in which primary and secondary caregivers spent the most time, on weekdays and weekend days

Primary caregivers

Weekdays	*Weekend days*
1. Teaching/helping/reprimanding	1. Teaching/helping/reprimanding
2. Physical care Minding } equal rank	2. Minding
3. Appointments and phonecalls	3. Physical care

Secondary caregivers

Weekdays	*Weekend days*
1. Teaching/ helping/reprimanding	1. Minding
2. Physical care	2. Teaching/helping/reprimanding
3. Playing/reading/talking Minding } equal rank	3. Physical care

Table 8.5 indicates PCGs spent most time in the broad category of "teaching, helping or reprimanding" their children, on both weekdays and weekend days. Helping with communication was the most time consuming task within this broad category of activities. SCGs also spent the most time "teaching/ helping or reprimanding" their children on weekdays, but on weekend days SCGs spent more time in "minding" or passive childcare activities, particularly general monitoring.

8.34 Activities other than caring

Tables 8.6 and Table 8.7 show the median time spent in the activities other than child care for PCGs and SCGs on weekdays, and weekend days, together with results of analyses using Mann-Whitney *U* tests.

Table 8.6

Median time (minutes/day) spent in activities other than child care by primary caregivers (PCGs) and secondary caregivers (SCGs), and results of Mann Whitney U test, for ***weekdays***

Weekdays							
	PCGs (Total diaries= 86)		**SCGs (Total diaries =59)**				
Activity type	N[a] %[b]	Median time (range)	N[a] %[b]	Median time (range)	*U*	*p*	*Cliff's d*
Employment/ education	28 (33%)	217.50 (15-600)	50 (85%)	577.50 (60-720)	155.5	<.001	-.78
Personal Care							
Sleep	86 (100%)	442.50 (30-675)	59 (100%)	480 (165-600)	2320.0	.38	-.09
Personal hygiene	80 (93%)	30 (15-90)	51 (86%)	30 (15-105)	1893.5	.47	-.07
Eating/drinking	84 (98%)	75 (15-225)	58 (98%)	60 (15-135)	1561.5	<.001	-.36
Domestic							
Food preparation	83 (97%)	90 (15-210)	21 (36%)	45 (15-105)	457.5	.001	-.48
Household chores	81 (94%)	135 (15-465)	26 (44%)	52.50 (15-330)	508.0	<.001	-.52
Purchasing goods	49 (57%)	60 (15-285)	8 (14%)	45 (30-240)	180.5	.73	-.08
Recreation/leisure	72 (84%)	97.50 (15-360)	50 (85%)	112.50 (15-570)	1741.5	.76	-.03
Social/community interaction	8 (9%)	105 (15-480)	35 (59%)	120 (15-420)	964.0	.69	00
Care of siblings	58 (67%)	412.50 (15-1020)	29 (49%)	150 (15-735)	455.0	<.001	-.46

[a] N= number of caregivers who recorded times for an individual child care activity on weekdays; [b] percentage of total number of caregivers participating in activities

Table 8.7

Median times (minutes/day) spent in non-caring activities by primary caregivers (PCGs) and secondary caregivers (SCGs), and results for Mann Whitney U test, for ***weekend days***

Weekend days	**PCGs (Total diaries = 78)**		**SCGs (Total diaries=55)**				
Activity type	N [a] %[b]	Median time (range)	N [a] % [b]	Median time (range)	*U*	*p*	*Cliff's d*
Employment/ education	11(14%)	240 (45-1200)	20 (36%)	345 (15-780)	96.0	.56	-.13
Personal care							
Sleep	77 (99%)	480 (225-720)	53 (96%)	480 (240-1005)	2015.5	.91	-.01
Personal hygiene	67 (86%)	30 (15-120)	43 (78%)	30 (15-135)	1354.5	.58	-.06
Eating/drinking	76 (97%)	75 (15-285)	51 (92%)	60 (15-345)	1576.5	.07	-.19
Domestic							
Food preparation	74 (95%)	67.50 (15-210)	29 (53%)	30 (15-150)	577.0	<.001	-.46
Household chores	68 (87%)	135 (15-450)	28 (51%)	97.50 (30-375)	741.0	.09	-.22
Purchasing goods	36 (46%)	60 (15-300)	22 (40%)	60 (15-255)	391.0	.94	-.01
Recreation/leisure	60 (77%)	150 (30-630)	41 (75%)	195 (60-570)	942.5	.05	-.23
Social/community imteraction	23 (30%)	250 (15-870)	44 (80%)	217.50 (15-960)	1304.5	.92	00
Care of siblings	44 (56%)	240 (15-1350)	29 (53%)	240 (15-960)	515.0	.17	-.19

[a] N= number of caregivers who recorded times for an individual child care activity on weekdays; [b] percentage of total number of caregivers participating in activities

Tables 8.5 and 8.6 show patterns in the types of non-caring activities PCGs and SCGs are more, or less, likely to undertake. For example, larger percentages of PCGs participate in domestic activities (food preparation and household chores), purchase goods (ie go shopping), and care for siblings, than SCGs. This pattern is particularly evident on weekdays, though there are also more PCGs who participate in domestic activities on weekend days. In contrast, as expected, PCGs are less likely to engage in employment or educational activities on weekdays. They are also much less likely to participate in social and community interaction on all days of the week.

When considering time spent in different activities, the table reflects some expected differences between PCGs and SCGs on weekdays. Thus, PCGs spend significantly less time in employment than their partners. As well, they spend significantly more time eating/drinking; in domestic activities (food preparation and household chores); and caring for siblings of the child with a disability. Differences between PCGs and SCGs in time spent in activities were less pronounced on weekend days. PCGs, however, continued to spend more time in food preparation and also spent less time in recreation/ leisure activities than their partners on weekends.

8.35 Daily Stress

Participants were asked to assess their daily stress on a 5 point Likert type scale, from 1= “not at all” stressed to 5=”very much” stressed, for each day on which a diary was completed. Figure 8.3 presents the percentages of PCGs and SCGs who reported different daily stress scores for weekdays and weekends.

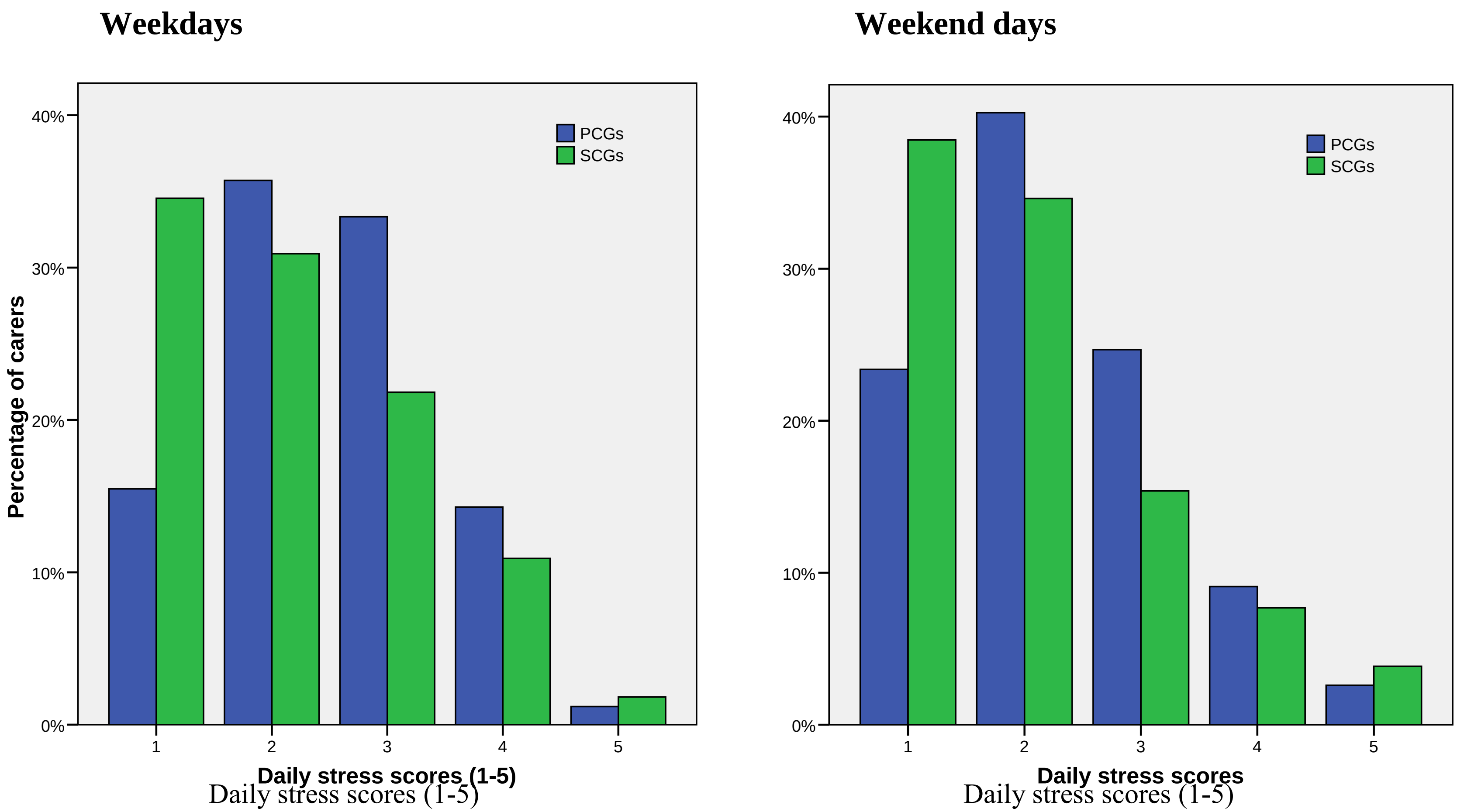


Figure 8.3 Percentages of primary caregivers (PCGs) and secondary caregivers (SCGs) with different daily stress scores, on weekdays and weekend days.

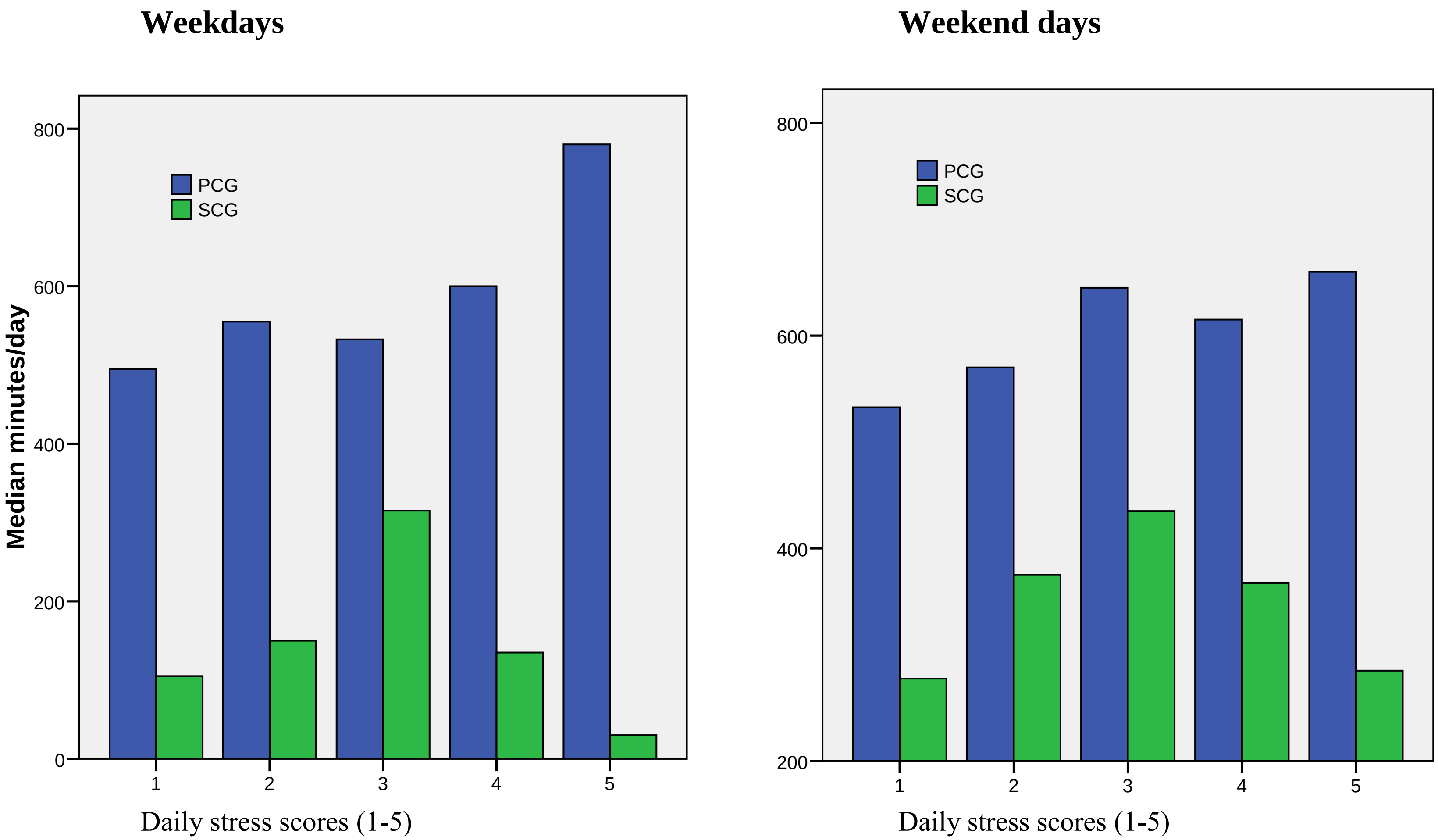
Figure 8.3 shows the largest proportion of PCGs report themselves to be “a little” or “somewhat” stressed on weekdays and weekends (daily stress scale scores = 2 & 3). In contrast, the largest proportion of SCGs report themselves to be “not at all” stressed on both weekdays and weekend days (daily stress score =1). Overall, Figure 8.3 shows PCGs to be more likely to experience some degree of stress than SCGs on all days of the week. In addition, both PCGs and SCGs experience lesser amounts of stress on weekend days than on weekdays.

The strength of the association between the daily stress scores of PCGs and SCGs was examined using chi-square analyses. Scores from the daily stress scale were collapsed to form three broad categories (levels of stress) to ensure cell sizes did not violate the assumptions of the chi-square test (at least 80% of cells to have expected frequencies above 5). The three categories were; Level 1 = responses to scale score 1 (“not at all” stressed); Level 2= responses to scale scores 2 and scale score 3 (“a little” and “somewhat” stressed); and Level 3 = responses to scale scores 4 and scale scores 5 (“quite a bit” and “very much” stressed). Differences between the daily stress scores for PCGs and SCGs on weekdays were significant (X^2 (2)= 6.84, $p<.05$, Cramers V=.22). Differences on weekend days, however, were not significant (X^2(2)= 3.57, p=.17, Cramers V=.17).

8.36 Relationship between daily stress and time use

8.36.1 Total time caring

Figure 8.4 shows the relationship between daily stress (using the 5 point scale) and total time caring for PCGs and SCGs, on weekdays and weekend days.



Weekdays

Weekend days

Figure 8.4. Relationship between median total time caring and daily stress for primary caregivers (PCGs) and secondary caregivers (SCGs), on weekdays and weekend days

Spearmans Rho correlation coefficients were used to examine the strength of the association between daily stress and total time caring. Results for PCGs on weekdays (r_s= .10, N= 84, p= .38) and weekend days (r_s= .13, N= 77, p= .24) were not significant. Figure 8.4 would suggest, however, that there may be a stress threshold for PCGs on weekdays such that total time caring above 600 minutes (10 hours) a day leads PCGs to feel “very stressed”. The same pattern is not evident for weekend days, though there is a general upward trend suggesting stress levels do increase with increasing total time caring.

The relationship between daily stress ratings and total time spent caring for SCGs was also not significant on weekdays (r_s= .25, 55, p=.06) or weekend days (r_s= .17, N= 51, p= .24). Figure 8.4, however, shows a very different stress response for SCGs from that found for PCGs. In particular, SCGs are shown to experience the highest levels of daily stress when spending the least time caring. This data would suggest that factors other than caring contribute to the daily stress of SCGs who have the least time available to participate in caring activities. It may be that the inability to help out with caring is stressful in itself, or alternatively that activities such as paid employment are sources of stress for SCGs, especially on weekdays.

The relationship between daily stress scores of PCGs and total time caring undertaken by SCGs (as a measure of partner support received by PCGs) was not significant (r_s= 13, N= 110, p=.19). Similarly, the relationship between daily stress scores of SCGs and total time caring undertaken by PCGs was also not significant (r_s= .10, N= 161, p= .22).

8.36.2 Total night-time care

Speaman‟s Rho correlation coefficients were used to examine the statistical significance of relationships between daily stress and total time spent in night-time care. Results for PCGs (r_s =.20, N=32, p=.28) were not significant. Similarly, results for SCGs (r_s =-.21, N=6, p=.69) were also not significant. Data for weekdays and weekend days was combined for these analyses due to small numbers.

Further analysis was undertaken to explore the possibility that daily stress was a consequence of having to wake up to care for a child (ie of having broken sleep), regardless of the amount of time this may have taken. A chi-square test was used to examine the relationship between daily stress (using the three levels of daily stress), and a new categorical variable which indicated whether night-time care was undertaken in the course of a diary day, or not (ie night-time care = YES/NO). Table 8.8 shows the relationship between total time in night-time care and daily stress for PCGs was not significant. Similarly, Table 8.9 shows the results for SCGs were also not significant.

Table 8.8

Percentage of ***primary caregivers*** *engaging in night-care care, experiencing different levels of daily stress*

Primary caregivers

Night-time care	Level of daily stress 1	2	3	Total
Yes	23	69	13	105
No	8	39	9	56
Total	31	108	22	161
	X^2= 1.55 (2), *p*=.46			

Note. Level 1 = responses to scale score 1 (“not at all” stressed); Level 2= responses to scale scores 2 and scale score 3 (“a little” and “somewhat” stressed); and Level 3 = responses to scale scores 4 and scale scores 5 (“quite a bit” and “very much” stressed).

Table 8.9

Percentage of ***secondary caregivers*** *engaging in night-care care, experiencing different levels of daily stress*

Secondary caregivers

Night-time care	Level of daily stress 1	2	3	Total
Yes	37	46	12	95
No	39	55	13	107
Total	76	101	25	202
	X^2= 3.08 (2), *p*=.46			

Note. Level 1 = responses to scale score 1 (“not at all” stressed); Level 2= responses to scale scores 2 and scale score 3 (“a little” and “somewhat” stressed); and Level 3 = responses to scale scores 4 and scale scores 5 (“quite a bit” and “very much” stressed).

8.36.3 Individual child care activities

The relationship between mean time spent in individual child care activities, and ratings of daily stress were examined using Spearman Rho correlation coefficients. Table 8.10 shows the results of analyses for PCGs, for weekdays and weekend days.

Table 8.10
Spearman Rho correlation coefficients (N) for daily stress and mean time spent in child care activities for ***primary caregivers****, on weekdays and weekend days*

Primary Caregivers	**Weekdays**		**Weekend days**	
Activity type	r_s (N)	P	r_s (N)	P
Care of Child				
Physical care	.10 (84)	.34	.03 (76)	.79
Feeding	.05(79)	.69	-.05 (68)	.66
Toileting	.08 (74)	.48	-.07 (60)	.63
Personal care	.11 (81)	.33	.07 (73)	.56
Emotional care	.23 (65)	.07	.21 (57)	.11
Teaching/ helping/ reprimanding	.21 (70)	.09	.29 (62)	<.05
Helping communication	.29 (57)	<.05	.25 (51)	.08
Behaviour management	.16 (57)	.23	.42 (50)	<.01
Therapy	-.07 (45)	.66	.25 (30)	.18
Playing/reading/ talking	-.15 (74)	.20	-.10 (72)	.39
Minding	-.01 (79)	.97	-.11 (72)	.37
General monitoring	-.16 (75)	.18	-.27 (66)	<.05
Watching carefully	.40 (38)	<.05	.22 (34)	.22
Organised activities	-.58 (16)	<.05	-.06 (5)	.93
Travel	.34 (64)	<.01	.15 (40)	.35
Appointments/phonecalls	-.26 (15)	.36	- (2)	-

Results displayed in Table 8.10 suggest that on weekdays PCGs experienced more stress when needing to provide help with communication, when being required to watch children carefully, and when needing to travel with children. Stress was reduced when attending organised activities with children (eg watching a swimming lesson). On weekend days, increased time spent in the category “teaching/ helping /reprimanding” was associated with greater stress for PCGs. This relationship was strongest for the individual child care activity “managing children‟s behaviour”. Stress was reduced when spending more time in passive child care (general monitoring). The decision to not correct for multiple comparisons, as recommended by Perneger, 1998 and Rothman, 1986, may mean that some of the more modest results in this set of analyses could be spurious. The general pattern of results, however, suggests time spent in “active care” tasks is more likely to result in daily stress, and conversely, less time spent in “passive care” tasks is more likely to lead to higher daily stress.

Table 8.11 shows the results of analyses using Spearman‟s Rho correlation coefficients testing the strength of association between mean time spent in child care activities and ratings of daily stress for SCGs, on weekdays and weekend days.

Table 8.11

Spearman Rho correlation coefficients (N) for daily stress and mean time spent in child care activities for ***secondary caregivers****, on weekdays and weekend days*

Secondary Caregivers	**Weekdays**		**Weekend days**	
	r_S (N)	P	r_S (N)	P
Activity type				
Care of Child				
Physical care	.19 (41)	.25	.14 (36)	.42
Feeding	-.06 (27)	.78	.04 (29)	.84
Toileting	.03 (26)	.85	.00 (23)	.99
Personal care	-.18 (37)	.30	-.15 (30)	.42
Emotional care	.08 (27)	.68	-.11 (32)	.57
Teaching/helping/reprimanding	-.06 (34)	.75	.24 (34)	.18
Helping communication	-.23 (23)	.30	.43 (25)	<.05
Behaviour management	-.16 (23)	.47	.14 (20)	.56
Therapy	-.01 (11)	.98	-.08 (13)	.80
Playing/reading/ talking	-.01 (37)	.97	-.19 (41)	.25
Minding	.00 (34)	.99	.03 (42)	.85
General monitoring	.09 (30)	.64	.06 (36)	.72
Watching carefully	.20 (10)	.58	-.10 (18)	.70
Organised activities	- (2)	-	- (1)	-
Travel	.04 (15)	.90	-.03 (24)	.88
Appointments/phonecalls	- (1)	-	- (1)	-

Table 8.11 shows correlation coefficients to be generally very small, with only one result reaching statistical significance, suggesting SCGs experienced increased stress on weekend days when needing to spend more time helping with their child"s communication. The pattern of results, however, suggests caring is not a primary source of stress for SCGs.

8.36.4 Activities other than caring

Table 8.12 shows results of analyses using Spearman‟s Rho correlation coefficients examining the strength of relationships between time spent in activities other than child care and daily stress reported by PCGs, on weekdays and weekend days.

Table 8.12

Spearman Rho correlation coefficients (N) for daily stress and non-caring activities for primary caregivers, on weekdays and weekend days

Primary caregivers	**Weekdays**		**Weekend days**	
Activity type	r_S (N)	P	r_S (N)	P
Employment	.03 (27)	.89	.18 (11)	.60
Personal Care				
Sleeping	-.03 (84)	.78	-.11 (76)	.36
Personal hygiene	-.06 (78)	.63	.04 (66)	.73
Eating/ drinking	-.13 (82)	.24	-.03 (75)	.83
Domestic				
Food preparation	-.02 (81)	.85	.08 (73)	.48
Household chores	-.26 (79)	<.05	-.04 (67)	.74
Purchasing goods	-.16 (49)	.29	.00 (36)	.99
Recreation & leisure	-.05 (70)	.68	-.10 (59)	.48
Social/ community interaction	-.15 (57)	.28	-.04 (59)	.78
Care of siblings	-.16 (56)	.24	.10 (43)	.53

Correlation coefficients were generally very small, with only one result reaching statistical significance, suggesting a negative relationship between ratings of daily stress and household chores for PCGs on weekdays. While this result may be an artefact of the large number of tests undertaken, it may also suggest that PCGs experience greater stress when they spend less time in household chores on weekdays, possibly due to feelings that housework is "building up".

Table 8.13 shows the results of Spearman Rho correlation coefficients comparing ratings of daily stress and non-caring activities for SCGs, on weekdays and weekend days.

Table 8.13
Spearman Rho correlation coefficients (N) for daily stress and non-caring activities for secondary caregivers, on weekdays and weekend days

Secondary Caregivers	**Weekdays**		**Weekend days**	
Activity type	r_s (N)	P	r_s (N)	P
Employment	.15 (47)	.32	-.11 (18)	.65
Personal Care				
Sleeping	-.04 (55)	.76	.01 (51)	.95
Personal hygiene	.00 (48)	.98	.00 (40)	.98
Eating/ drinking	-.08 (54)	.54	-.18(48)	.25
Domestic				
Food preparation	-.18 (18)	.48	-.21 (26)	.29
Household chores	.07 (23)	.75	.19 (26)	.35
Purchasing goods	.36 (6)	.48	-.03 (20)	.90
Recreation & leisure	-.28 (46)	.06	.06 (39)	.71
Social/ community interaction	-.16 (31)	.38	-.11 (42)	.49
Care of siblings	-.13 (27)	.53	.00 (28)	1.00

All correlations were mostly very small, with none reaching significance. The only result approaching significance was a negative relationship for recreation/ leisure activities on week days. This might suggest SCGs experience greater stress (or perhaps frustration) when spending less time in recreation/ leisure activities on weekdays.

8. 36.5 Intensity of caring

Previous analyses focused upon the relationships between the types of child care tasks and daily stress. A measure of "intensity" of caring was also derived from the study diaries. Intensity of caring was defined as the number of different child care activities undertaken by a carer during the course of a day, ranging from 0-14 activities. Mann-Whitney U tests were used to examine the significance of differences between Intensity scores for PCGs (*N* = 86, *Mdn* =10 (*Range* = 5-14)) and SCGs (*N =59*, 6 (0-11)) on weekdays, and also for PCGs (*N =78*, 8 (3-12)) and SCGs (*N* = *55*, 6 (0-11)) on weekend days. The large difference between Intensity scores for PCGs and SCGs on weekdays, was significant (U =711.00, p<.001, Cliff"s *d* =-.72). The difference between Intensity of caring on weekend days was also significant (U =1139.50, p<.001, Cliff"s *d* =-*.47*). Results suggest PCGs experience greater intensity of caring (as indicated by the need to undertake a greater number of different child care activities during a day), than SCGs.

Spearmans Rho correlation coefficients were used to examine the strength of the relationship between daily stress scores (using the 5 point scale), and the measure of Intensity for PCGs and SCGs. Results for PCGs on weekdays were significant (r_s=.24, *N* = 84, p<.05) and also approached conventional significance on weekend days (r_s=.22, *N* =77, *p* =.06). Correlations for SCGs were positive but not statistically significant on weekdays (r_s=.21, N =55, p =.12) or weekend days (r_s=.18, N =52, p=.19).

8.37 Subjective experiences of stress

The Caregiver Diary asked carers to nominate the activities, tasks and situations that might have contributed to their level of stress on the diary day and further, to indicate the stress level attributable to each on a 5 point Likert type scale (ranging from 1=”Not at all” to 5= “Very much”). Carers were asked to record whether they considered their level of stress was related to any specific caring activity, or to a non-caring activity represented in the diary. In addition, categories in the questionnaire queried whether carers considered their level of stress to relate to interpersonal conflicts, or worries. Responses to this item reflected subjectively identified concerns that may have been unrelated to the actual time spent in any activity. It is of note that no parent reported experiencing “very much” stress in consequence of any activity or situation, that is, the highest level of stress reported was “quite a bit”.

Table 8.14 shows the child care activities or situations that were *most frequently identified* by PCGs and SCGs as contributing to their level of daily stress. The table was collated by identifying activities or situations which were reported as contributing to <u>any level of stress</u> (ie contributing “a little”, “somewhat”, or “quite a bit” to levels of parental stress during the day). The table shows many more PCGs reported activities or situations to be stressful than SCGs. Forty four percent of PCGs identified “managing my child‟s behaviour” as being their most frequent source of stress, followed by worries about children and worries about the future. Worries about children were most frequent source of stress for SCGs, followed by worries about the future and managing children‟s behaviour.

Table 8.14
The five activities most frequently identified as stressful[a], for primary caregivers and secondary caregivers

Primary caregivers (*N* = 164)	Secondary caregivers (*N* = 114)
1. Managing behaviour (*n*=63[b])	1. Worries about my child (*n*=25)
2. Concerns about my child (*n*=44) Worries about the future (*n*=44) } equal rank	2. Worries about the future (*n*=23) Managing behaviour (*n*=23) } equal rank
3. Helping with communication (*n*=34)	3. Employment/ study (*n*=18)
4. Conflict with family (*n*=31) General monitoring (*n*=31) } equal rank	4. Helping with toileting (*n*=14)
	5. Caring for other children (*n*=12)
5. Helping with toileting (*n*=28)	

[a] Stressful activities were those that made parents feel any level of stress ie “a little, “somewhat”, “quite a bit” or “very much” stressed
[b] *n* = number of parents who reported activities or situations as being stressful

Table 8.15 shows the activities or situations that were rated as being the *most stressful* for PCGs and SCGs (ie those that were reported as contributing “quite a bit” to parental stress levels). A smaller number of activities/ situations are shown because of the fewer number of activities or situations identified by parents as contributing “quite a bit” of stress. There were more PCGs who found activities or situations to be “quite a bit” stressful, than SCGs. Worries were most likely to contribute “quite a bit” to the stress levels of PCGs, while employment/ education was more likely to contribute “quite a bit” to the stress of SCGs.

Table 8.15

The activities /situations rated as being the most stressful[a] for primary caregivers and secondary caregivers

Primary caregivers (*N* =164)	Secondary caregivers (*N* = 114)	
1. Worries about the future (*n*=21[b])	1. Employment/ study (*n*=5)	
2. Concerns about my child (*n*=14)	2. Helping with communication (*n*=3) Worries about the future (*n*=3)	} equal rank
3. Managing behaviour (*n*=8)	3. Managing behaviour (*n*=2) Worries about my child (*n*=2)	} equal rank

[a] Most stressful activities were those that made parents feel “quite a bit” stressed

[b] *n* = number of parents who reported activities or situations as being most stressful

8.4 Conclusions

Results of analyses showed PCGs spent significantly more total time caring, and more time in individual child care activities than SCGs on weekdays and weekend days. PCGs also spent approximately 3½ hours/day in employment or study on weekdays, rising to 4 hours/day on weekends suggesting many PCGs take on a "second shift" of paid work in addition to their childcare and caring responsibilities, reflecting a similar trend for women in the general community (Bittman & Wajman, 2000). As well, PCGs increase the time they spend in childcare on weekend days, even though SCGs also increase the time they spend in caring for children. This reflects the fact that children do not attend childcare, kindergarten or school on weekends, but also suggests that PCGs see caring for children as their principal responsibility regardless of the day of the week or the availability of practical support from their partner. Being a PCG is, therefore, a seven day a week commitment.

Results for night-time care showed PCGs spent the same amount of time in night-time care as SCGs, on any day of the week. This finding, however, masked the frequency with which parents were required to provide care at night, regardless of the amount of time required to settle the child. When considering frequency of night-time care, PCGs were required to attend to their child almost four times as often as SCGs on weekdays, and about three times as often on weekend nights. The role of a PCG, therefore, included primary responsibility for night-time as well as day-time care, supporting claims that caring is a "24 hour job". The frequency with which PCGs were required to attend to their child indirectly reflects the high incidence of sleep problems in children with developmental disabilities (Richdale, Francis, Gavidia-Payne, & Cotton, 2000).

An examination of the types of childcare activities carried out by parents also suggested differences between PCGs and SCGs, particularly on weekend days. Primary caregivers most frequently engaged in activities related to the physical care of their child; such as feeding, toileting and bathing. This was the case on both weekdays and weekends. The tasks requiring the longest periods of time for PCGs, however, involved teaching, helping or disciplining their child. In contrast, while SCGs also most frequently engaged in physical care and spent the most time in directive activities such as teaching, helping and discipline on weekdays, on weekends they were more likely to play with their child and spent the most time in passive, supervisory childcare. These findings are consistent with research examining gender differences in childcare tasks in the general population, showing women to be more likely to have responsibility for the physical care of the child, while men are more likely to engage in play activities (Craig, 2002).

In addition to child care, PCGs spent more time in a range of other activities, than did SCGs. In particular, they were shown to spend significantly more time in domestic activities such as food preparation and household chores, and in the care of other children in the family. These differences were most marked on weekdays, though PCGs continue to spend more time in food preparation on weekend days than SCGs, and have less time in recreation and leisure activities. Previous research has found women to do substantially more unpaid work, reflecting both childcare and general domestic activities, than men. As well, women are doing more unpaid work now than in the past (Bianchi et al., 2000; Bittman & Wajcman, 2000c; Mattingly & Sayer, 2006; Rogers & Amato, 2000). Mothers of pre-school children have the highest levels of unpaid work (Bittman, 1992). As the majority of PCGs in the present study (88%) were women, the results suggest parents of preschool children with disabilities generally exhibit patterns of time use reflecting typical gender roles found in the general community.

PCGs reported higher levels of daily stress than SCGs, particularly on weekdays. This may reflect, in some part, the perceived benefit of the extra help with childcare provided by SCGs on weekends, even if this does not reduce the time spent caring by PCGs. The lack of association between daily stress reported by PCGs and total time spent caring by SCGs may suggest help with specific tasks is more important than the total amount of help provided by partners. This is also reflected in the lack of association between ratings of daily stress and total time spent caring by the PCG on weekdays or weekends although visual inspection of the data suggests the possibility of a stress threshold for PCGs on weekdays. This indicates PCGs experience “quite a bit”, or “very much stress” only when the total time caring exceeds 600 minutes, or 10 hours a day, on weekdays.

When considering specific caring activities, levels of daily stress reported by PCGs were related to tasks requiring more active involvement with the child, such as helping with communication, managing behaviour and watching carefully. Conversely, results indicated that time spent in passive child care (general supervision) for PCGs was associated with lower ratings of daily stress. These results coincide with findings from the previous chapter showing parents in the present study engaged in significantly more active caring than parents of children who participated in the 1997 TUS. One factor contributing to the higher levels of daily stress experienced by PCGs, therefore, would appear to be the increased time spent in “active care”. PCGs also experienced higher levels of stress on days when they were engaged in a greater number of different caring activities. That is, intensity of caring as reflected by the need to undertake a range of different caring tasks was another factor contributing to the higher stress levels experienced by PCGs. An additional finding of note suggested PCGs reported higher levels of daily stress when spending less time in household chores. Mothers who took part in the focus groups in Study 1 reported feeling stress when unable to find time for household chores because of their caring responsibilities. The results of Study 2, therefore, lend support to the idea that difficulty “fitting in” chores contributes to the daily stress of PCGs of children with disabilities. Relationships between time spent in caring activities and levels of daily stress for SCGs were not strong, suggesting that for SCGs child care activities were not associated with elevated levels of daily stress. A similar pattern of very small correlations was found when considering other, non-caring activities undertaken by SCGs, further indicating that time spent in non-caring activities had little association with the daily stress of SCGs. These findings would suggest the prominence of subjective stressors in contributing to the daily stress of SCGs, in particular.

The qualitative account of activities which were related to daily stress, given by parents at the end of the Caregiver Diary, was consistent with results of quantitative analyses using the daily stress rating scale for PCGs. Tasks requiring more active caring (ie behaviour management, helping with communication and helping with toileting), for example, were among the five activities or situations most frequently reported as contributing to levels of daily stress experienced by PCGs. Results for SCGs, however, indicate that subjective experience of stress does not necessarily relate to actual time spent in activities. SCGs, for example, also reported managing their child‟s behaviour and helping with toileting were sources of daily stress, as well as “employment/ study”. Of particular note for both parents was the prominence of worries (“concerns about my child” and “worry about the future”) in contributing to daily stress.

CHAPTER 9:

Relationship between time spent caring for preschool children with developmental disabilities and psychological, social and physical well-being of parents: Hypotheses 1 to 5 of the model of carer well-being

9.1 Overview

The present chapter will present evidence to test Hypotheses 1 to 5, derived from the model of carer well-being. The hypotheses are outlined below, as previously described in Chapter 6. It should be noted that Hypotheses 6 and 7 will not be addressed in the present chapter, as these will be tested with regression analyses carried out in Chapter 10.

1. **Hypothesis 1: Carers of young children with developmental disabilities will have poorer psychological, social and physical well-being than carers of children without disabilities**

2. **Hypothesis 2: Primary caregivers (PCGs) of young children with developmental disabilities will have poorer psychological, social and physical well-being than secondary caregivers (SCGs)**

3. **Hypothesis 3: Carers of children with different diagnoses will show different patterns of psychological, social and physical well-being. In particular, parents of children with autism are expected to have poorer outcomes than parents of children with Down syndrome.**

4. **Hypothesis 4: Carers of children with greater functional impairment will have poorer psychological, social and physical well-being than carers of children with less functional impairment**

5. **Hypothesis 5: Carers of children with disabilities who also exhibit higher levels of emotional and behavioural problems will have poorer psychological, social and physical well-being than carers of children with disabilities who have lower levels of emotional or behavioural problems.**

Hypotheses will be tested using questionnaire data collected during home interviews with parents who participated in Study 2. Results for questionnaires completed by parents will be compared to normative data, including clinical cut-offs where available. Analyses will provide a comprehensive picture of the psychological, social and physical health of parents, addressing Hypothesis 1. Comparisons within the dataset, between primary caregivers and secondary caregivers, will give evidence towards Hypothesis 2. The final three hypotheses relate to characteristics of child disability. This chapter will firstly present the results of the measures used to assess severity of disability (ie functional skills and child emotional and behavioural problems).

Analyses will then be undertaken within the data-set to compare outcomes for parents of children with different levels of severity of disability.

9.2 Measures and Analyses

Table 9.1 shows the questionnaires and other indices and measures used in Study 2, each representing the different components of the model of carer well-being. Descriptions of the content and psychometric characteristics of the questionnaires are described in Chapter 6.

Table 9.1

Questionnaires and other measures used in Study 2, in relation to components of the model of carer well-being

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Stressors:

Child disability

1. Functional skills: The Functional Independence Measure for Children (WeeFIM® Version 4.0: Uniform Data Set for Medical Rehabilitation, 1993)
2. Emotional/ behavioural problems: Strengths and Difficulties questionnaire (SDQ:Goodman, 1997)

Other stressors

Life Stress subscale of the Parent Stress Index (PSI: Abidin:1995)

Parent Outcomes:

1. Depression: Centre for Epidemiological Studies Depressions Scale (CES-D:Radloff, 1977)
2. Parent stress: Role restriction, Social Isolation and Physical Health subscales of the PSI
3. Caregiver strain: Caregiver Strain Questionnaire (CGSQ: Brannan, Heflinger, & Bickman, 1997)

Proposed mediating variables:

Caring responsibilities

Objective indicators:

1. Time use: Caregiver Diary

Subjective indicators:

2. Time pressure:
    - Rushed/ pressed for time item
    - Time Crunch Scale (Robinson, 1991)

Proposed moderating variables:

Partner support

1. Spouse subscale of the PSI
2. Carer Support Scale (CSS)

Preliminary analyses were performed to assess whether there were violations of the assumptions of normality for the summary variables from all measures to be used in analyses. Scores for the CES-D showed problems with both skew and kurtosis, so results for this measure were analysed using a square root transformation. Two-tailed independent sample t-tests, one-way analyses of variance and Pearson chi-square tests were used to analyse differences between groups where appropriate. Effect size was assessed using η^2 (eta squared), Cohen"s *d,* Cohen"s *f* and Tukey"s honestly significance difference (HSD), and interpreted according to Cohen"s guidelines.

9.3 Results for Hypothesis 1: Carers of young children with developmental disabilities will have poorer psychological, social and physical well-being than carers of children without disabilities

Hypothesis 1 will be tested by comparing results for parents who participated in Study 2, with normative data for each of the questionnaires used in the study. Results of all measures used in the study to assess carer psychological, social and physical well-being will be presented, regardless of whether they are considered to reflect different components of the model of carer well-being. Results will be presented in the order in which measures are shown in Table 9.1.

9.31 Life Stress subscale: Parenting Stress Index

The Life Stress subscale of the Parenting Stress Index (PSI: Abidin, 1995) was included in Study 2 to assess the extent of stressors experienced by parents, other than those related to caring for a child with a disability. The Life Stress Index was completed only by PCGs. Mean scores (*M*=2.77, *SD*=2.09) were lower than scores obtained for the normative sample recorded in the manual for the PSI (*M*=7.8, *SD*=6.2), suggesting the PCGs in the study experienced fewer life events than parents in the general community. An independent sample t-test showed this difference to be highly significant (*t* (2,726) =-7.89, *p*<.001; *d* =-.82). This result is unexpected. It may be that parents of children in the study were focused on describing their caring tasks and therefore did not consider other stressors to be of note.

9.32 Centre for Epidemiologic Studies – Depression Scale

The Centre for Epidemiologic Studies-Depression Scale (CES-D, Radloff, 1977) was used as the principal measure of parental mental health in Study 2, focusing upon the extent of depressive symptoms. The mean score obtained for PCGs on the CES-D was 16.57 (*SD*= 10.38) and for SCGs was 14.25 (*SD*=9.52). Mean scores for the normative samples used in field testing the CES-D ranged from 7.94 (7.53) to 9.25 (8.58). Higher scores indicate more depressive symptoms.

A score of 16 or greater was used as a threshold, or cut-off, to indicate "possible" clinical depression (ie Roberts, Lewinsohn, & Seeley, 1991). The mean score for PCGs in Study 2 was above this cut-off. A total of 49% of PCGs obtained CES-D scores of 16 or higher, and a total of 33% of SCGs also obtained scores of 16 or higher. These results contrast with the percentage of people who obtained a score above 16 in the normative sample for the CES-D (Radloff, 1977), ranging between 15 and 19%.

Some authors have criticised the cut-off of 16 as producing high false positive rates, suggesting a higher cut-off should be used to ensure more accurate identification of people with “probable” (as opposed to possible) depression (Husaini et al 1980). The results of the present study, therefore, were also examined in relation to a second cut-off, a score of 23 or greater. When considering the higher cut-off, 31% of PCGs and 22% of SCGs achieved scores on the CES-D indicating *probable* clinical depression. This contrasts with the 6% rate of probable depression in the community sample reported by Husaini (1980).

9.33 Role Restriction/ Isolation/ Health subscales: Parent Stress Index

Study 2 included a number of subscales from the PSI to reflect areas of concern highlighted by the literature review. Thus, subscales measuring role restriction, social isolation and physical health were selected because previous studies indicating carers, and parents of children with disabilities in particular, were often found to experience more role restriction, more social isolation and poorer physical health, than parents of children without disabilities (eg Brehaut et al., 2004; Briggs & Fisher, 2000; Trivette & Dunst, 1992).

To enable comparison with normative data (2,633 mothers of children one to 12 years) reported in the manual for the PSI, results for the Role Restriction, Isolation and Health subscales of the PSI were calculated separately for female and male carers, rather than PCGs and SCGs. Independent sample t-tests were used to compare the scores for the subscales for female carers in the study with mothers of young children in the normative sample. Table 9.2 shows mean scores obtained from female carers in Study 2, compared to the mean scores obtained from the normative sample. In all cases, higher scores indicate poorer outcomes. The table shows female carers in the study reported more role restriction, social isolation and poorer physical health than mothers in a community sample. Results of independent sample t-tests were strongly significant for all subscales.

Table 9.2
Mean (SD) scores for the Role Restriction, Isolation and Health subscales of the Parenting Stress Index (PSI), and results of independent sample t-tests comparing female carers from Study 2 and the normative sample

PSI Subscales	Female Carers *N*=91 Mean (*SD*)	Normative Sample *N*= 2,633 Mean (*SD*)	*t* (df=2,722)	*p*	*d*
Role Restriction	24.91 (5.76)	18.9 (5.3)	10.60	<.001	1.13
Isolation	16.51 (4.51)	12.6 (3.7)	9.83	<.001	1.05
Health	14.54 (4.07)	11.7 (3.4)	7.78	<.001	.83

Table 9.3 shows the means scores for the PSI subscales for male carers in Study 2 when compared to the mean scores obtained from fathers in the general community. The table shows fathers of children in Study 2 perceived themselves to be more role restricted and socially isolated, and to have poorer physical health than fathers in the general community. Results of independent sample t-tests were also strongly significant.

Table 9.3

Mean (SD) scores for the Role Restriction, Isolation and Health subscales of the Parenting Stress Index (PSI), and results of independent sample t-tests comparing male carers from Study 2 and data from normative samples

PSI Subscales	Male Carers (*N*=69) Mean (*SD*)	Normative Sample (*N*=100) Mean (*SD*)	*t* (*df*=167)	*p*	*d*
Role Restriction	22.20 (5.90)	15.8 (4.0)	8.41	<.001	1.32
Isolation	16.44 (4.36)	13.5 (3.7)	4.72	<.001	.74
Health	13.62 (3.51)	11.7 (3.0)	3.81	<.001	.60

9.34 Caregiver Strain Questionnaire

The Caregiver Strain questionnaire (CGSQ: Brannan, Heflinger, & Bickman, 1997) was included in Study 2 to reflect the impact of caring specific stressors on parent psychological well-being. Table 9.4 reports mean CGSQ scores for PCGs and those from a clinical comparison sample (Brannan, Heflinger, & Bickman, 1997), together with results of analyses using independent sample t-tests. The comparison sample for the CGSQ comprised parents caring for children who were receiving help for emotional and behavioural problems, surveyed as part of the development of the questionnaire. Table 9.5 reports the same information for SCGs. Higher scores for the subscales and for total caregiver strain indicate poorer well-being.

Table 9.4 shows PCGs in Study 2 reported higher levels of objective strain, reflecting direct and observable consequences of caring for their child with a disability, than parents of children receiving help for emotional and behavioural problems. In contrast, PCGs had lower scores for internalized subjective strain (ie worries and feelings of distress arising from caring for their child with a disability) and also for externalized subjective strain, suggesting that parents in this study reported themselves to experience less hostility towards their child than parents of children receiving help for emotional and behavioural problem, in the normative sample. Results of independent sample t-tests for all three subscales were significant, with moderate effect sizes. Results of analysis between mean scores for the index of total caregiver strain were not significant.

Table 9.4
Mean (SD) subscale scores for primary caregivers (PCGs) on the Caregiver Strain Questionnaire (CGSQ), and results of independent sample t-tests

	PCGs Mean (*SD*) *N*=95	Normative sample Mean (*SD*) *N*=978	*t* (*df*=1071)	*p*	*d*
CGSQ Subscales:					
Objective Strain	2.51 (.93)	2.02 (.99)	4.63	<.001	.50
Subjective Strain–internalizing	3.10 (.95)	3.43 (.94)	-3.26	<.01	-.35
Subjective Strain-externalizing	1.73 (.58)	2.29 (.94)	-5.70	<.001	-.61
Total Caregiver Strain	2.45 (.69)	2.48 (.82)	-0.34	.73	-.04

Table 9.5 shows the mean scores for SCGs on the subscales of the CGSQ and the mean scores reported for the comparison sample. A pattern of results similar to that found for PCGs can be seen. SCGs reported significantly more objective strain, and significantly less subjective strain than parents of children receiving treatment for emotional and behavioural problems. Differences between groups for total caregiver strain were not significant.

Table 9.5

Mean (SD) subscale scores for secondary caregivers (SCGs) on the Caregiver Strain Questionnaire (CGSQ), and results of independent sample t-tests

	SCGs Mean (*SD*) *N*=65	Normative sample Mean (*SD*) *N*=978	*t* (*df*=1041)	*p*	*d*
CGSQ subscales:					
Objective Strain	2.34 (.80)	2.02 (.99)	2.55	<.05	.33
Subjective Strain –internalizing	3.02 (1.03)	3.43 (.94)	-3.38	<.001	-.43
Subjective Strain-externalizing	1.72 (.61)	2.29 (.94)	-4.82	<.001	-.62
Total Caregiver Strain	2.36 (.68)	2.48 (.82)	-1.15	.25	-.15

9.35 Measures of Time Pressure

Study 2 included a number of measures of caring responsibility, reflecting both objective and subjective experience. The Caregiver Diary was used to provide a comprehensive picture of daily caring responsibilities, as portrayed in Chapters 7 and 8. Two measures of perceived time pressure were chosen to represent the subjective experience of caring responsibilities; the Rushed/ pressed for time item; and the Time Crunch scale.

9.35.1 Rushed/ pressed for time” item

Participants in Study 2 rated how often they felt rushed or pressed for time on a five point scale, ranging from 1=never to 5=always rushed/ pressed for time. Previous research has combined the categories “always” rushed/ pressed for time and “often” rushed/ pressed for time, to indicate the experience of time pressure (AIHW, 2006, 2007). Results are reported for male and female carers, rather than primary caregivers and secondary caregivers, to enable comparison with data from the 2004 Household, Income and Labour Dynamics in Australia (HILDA) survey and the Longitudinal Survey of Australian Children (LSAC).

Thus, 77% of female carers in Study 2 experienced time pressure, and 77% of male carers experienced time pressure. This compares with 58% of mothers and 48% of fathers of children under 5 years in the HILDA survey, and 44% of mothers and 43% of fathers of young children in LSAC.

9.35.2 Time Crunch Scale

Participants completed the ten item Time Crunch (Robinson, 1991*)* scale using a five point scale to record responses, ranging from “strongly agree” to “strongly disagree”. To enable comparison with data from the Hilton Time Values Survey (reported in Robinson & Godbey, 1997) results for Study 2 were again separately calculated for female and male carers. The mean number of agreements with the 10 items of the Time Crunch scale was 4.9 for female carers and 5.2 for male carers. This compares with the mean number of agreements for women caring for children less than six years of age in the Hilton Time Values Study of 4.0 and 2.8 for males. These results confirm that the carers in the study experienced higher levels of time pressure than a general population of adults, as well as parents caring for pre-school aged children in a community sample. Of interest, the experience of time pressure was comparatively greater for male carers in the study when compared to male parents in the Hilton Time Values Survey, than the contrast between females in these two studies.

9.36 Partner Support

Two measures of partner support were included in the study. The first, the Spouse Support subscale from the PSI, asked the respondent to comment on their perceptions of how much emotional and active support they are given by their partner. The second measure, the Carer Support Scale, was purpose developed for Study 2 and lacks comparative data. Results for the Carer Support Scale will be discussed when considering differences between primary caregivers and secondary caregivers, following analyses testing Hypothesis 2.

9.36.1 Spouse Subscale: Parent Stress Index

To enable comparison with normative data, results for the Spouse subscale of the PSI were calculated separately for female carers and for male carers who participated in Study 2. Female carers obtained higher scores for the Spouse subscale (*M*=21.82, *SD*= 6.21) than mothers of young children in the normative sample for the PSI (*M*=16.9, *SD* =5.1), with higher scores indicating less partner support. Results of an independent sample t-test comparing the two means were significant (*t* (2716) =8.69, *p*<.001, *d*=.96) suggesting female carers in the study were significantly less satisfied with the support given by their partners than mothers in a community sample. Similarly, male carers obtained higher mean scores for the Spouse subscale (*M*=19.39, *SD*= 4.95) than fathers of children 4-6 years in a normative sample (*M*=16.9, *SD* = 4.1). Results of analyses were also significant (*t*(166), *p*<.001, *d*=.56).

9.37 Summary of evidence for Hypothesis 1

Hypothesis 1 is supported by the results of Study 2. It is particularly concerning that PCGs in the study were found to be over five times more likely to report depressive symptoms suggestive of probable clinical depression, than community samples. SCGs were over three times more likely to achieve scores suggestive of probable clinical depression. Previous research has highlighted the increased risk of depression in mothers and fathers of children with disabilities (Olsson & Hwang, 2001;.Singer, 2006). The findings of the present study suggest this increased risk may be related to the caring role.

PCGs and SCGs described themselves as feeling restricted in their parenting role, to be more socially isolated and to experience poorer physical health than parents in community samples. These results are consistent with previous research examining outcomes for parents of children with disabilities (Brehaut et al., 2004; Pelchat et al., 1999). The finding that parents perceive themselves to be more socially isolated than other parents, however, does not reflect results of analysis of the Caregiver Diary showing parents in Study 2 spent more time socialising than parents in the general community. The definition of “time spent socialising” used in the Caregiver Diary, however, was broad and included time spent in social activities with partners, as well as family and friends. The items included in the Isolation subscale of the PSI related primarily to the availability and quality of friendships. It is possible, therefore, that the parents in Study 2 spent more time with their partners and family, in comparison with time with friends. It is also probable that feelings of social isolation may have little association with actual time spent in activities. In other respects the results of the Caregiver Diary illustrated the constraints associated with caring which would be expected to contribute to feelings of role restriction and poorer health.

PCGs and SCGs also reported more "objective strain" than parents caring for children receiving treatment for emotional and behavioural problems. This may indicate the greater number of physical demands facing parents of children with disabilities, particularly pre-school children who are receiving early intervention services. It should be noted too, that many of the children in the present study were reported to be experiencing emotional and behavioural problems in addition to their developmental disability.

In contrast to the findings in relation to objective strain, parents of children in the present study reported less subjective strain than parents of children with emotional and behavioural problems. Inspection of the CGSQ suggests that items relating to feelings of anger and resentment towards the child, which are included in the subjective strain subscale, are more likely to be of relevance for parents of children in the comparison sample (ie a clinical sample including children with externalising type problems such as oppositional disorder or conduct disorder) than parents of children with disabilities.

PCGs and SCGs in the present study reported themselves to experience greater feelings of time pressure than adults in the general community and, more specifically, parents of young children in the general community. This result is anticipated by the model of carer well-being. The difficulty of juggling paid employment and caring may be reflected by the comparatively higher levels of time pressure experienced by SCGs. Finally, both PCGs and SCGs feel less satisfied with the social support provided by their partner, than parents of young children in normative populations. Results of the Caregiver Support Scale, however, would indicate that PCG dissatisfaction is more specifically related to the need for more emotional support, "time-out" from caring, and for more help with night-time care, than it is to the provision of practical support such as help with feeding and dressing.

9.4 Results for Hypothesis 2: Primary carers of young children with developmental disabilities will have poorer psychological, social and physical well-being than secondary carers

The following sections will present the results of comparisons between results for PCGs, and results for SCGs, on measures of carer well-being.

9.41 Centre for Epidemiologic Studies – Depression Scale

The mean score obtained for PCGs on the CES-D (*M*=16.57, *SD*= 10.38) was higher than that obtained by SCGs (*M*=14.25, *SD*=9.52). An independent sample t-test, using a square root transformation of the data, showed the difference between the means to be not significant (*t* (158)=1.08, *p*=.28, *d*=.18). More PCGs, however, fell above cut-offs for "possible" and "probable" clinical depression, than SCGs.

9.42 Role Restriction/ Isolation/ Health subscales: Parent Stress Index

Table 9.6 shows the mean scores achieved by PCGs and SCGs for the different subscales of the PSI, and the results of analyses using independent sample t-tests. The table shows that PCGs obtained higher scores than SCGs for each of the subscales, though differences were small. Results were significant for the Role Restriction subscale, indicating PCGs were more likely to perceive themselves to be role restricted than SCGs, with a small-moderate effect size.

Table 9.6
Mean (SD) scores for the Role Restriction, Isolation and Health subscales of the Parenting Stress Index (PSI) and results of independent sample t-tests comparing primary caregivers (PCGs) and secondary caregivers (SCGs)

PSI Subscales	PCGs (*N*=95) Mean (*SD*)	SCGs (*N*=65) Mean (*SD*)	*t* (*df* =158)	*p*	*d*
Role Restriction	24.74 (5.77)	22.29 (5.97)	2.60	<.01	.42
Isolation	16.51 (4.76)	16.43 (3.94)	.10	.92	.02
Physical Health	14.45 (4.01)	13.69 (3.60)	1.23	.22	,20

9.43 Caregiver Strain Questionnaire

Table 9.7 compares the mean scores for PCGs and SCGs, for the different subscales of the CGSQ, together with the results of analyses using independent sample t-tests. PCGs obtained higher mean scores than SCGs for all subscales and for total caregiver strain, but differences were small and not statistically significant.

Table 9.7
Mean (SD) subscale scores of the Caregiver Strain Questionnaire (CGSQ), and results of independent sample t-tests comparing primary caregivers (PCGs) and secondary caregivers (SCGs)

	PCGs Mean (*SD*) *N*=95	SCGs Mean (*SD*) *N*=65	*t* (*df*=158)	*p*	*d*
CGSQ subscales:					
Objective Strain	2.51 (.93)	2.34 (.80)	1.17	.24	.19
Subjective Strain –internalizing	3.10 (.95)	3.02 (1.03)	0.47	.64	.08
Subjective Strain-externalizing	1.73 (.58)	1.72 (.61)	0.09	.93	.02
Total Caregiver Strain	2.45 (.69)	2.36 (.68)	0.77	.46	.13

9.44 Time Pressure

9.44.1 Rushed/ Pressed for Time item

As previously described, participants in Study 2 rated how often they felt rushed or pressed for time on a five point scale, ranging from 1=never to 5=always rushed/ pressed for time. Thirty six percent of PCGs and 20% of SCGs indicated “always” feeling rushed/ pressed for time. However, combining the “often” and “always” categories to indicate the overall experience of time pressure (AIHW, 2006, 2007) revealed that many more SCGs were “often” stressed so that in total 76% of PCGs felt time pressured as compared to 79% of SCGs.

Table 9.8 shows the percentage of PCGs and SCGs who recorded an affirmative response to items describing different reasons for time pressure. “Demands of family” was the most frequent item selected by PCGs as the reason for feeling rushed/ pressed for time, while "trying to balance work and family responsibilities" was the item most often selected by SCGs.

Table 9.8
Percentage of primary caregivers (PCGs) and secondary caregivers (SCGs) agreeing with different reasons for feeling "rushed/ pressed for time"

Reasons	PCGs %	SCGs %
1. Trying to balance work and family responsibilities	53	86
2. Pressure of work/ family	22	60
3. Demands of family	76	68
4. Take too much on/ not good at managing time	38	29
5. Too much to do/ too many demands placed on you	64	49

9.44.2 Time Crunch Scale

The ten items of the Time Crunch Scale were rated by participants in Study 2 according to a five point scale, ranging from "strongly agree" to "strongly disagree". Total scores for the scale could range from 0-50. The means score obtained for PCGs (*M=37.12, SD=7.51)* was higher than the mean score for SCGs (*M=33.72, SD=6.95),* with the results of an independent sample t-test indicating this was a significant difference (*t(158)= 2.8, p<.01, d=.47).* The Cohen"s *d* statistic indicates a moderate effect.

All items comprising the Time Crunch Scale are shown in Table 9.9. The table indicates the percentage of PCGs and SCGs who either agreed or strongly agreed with each item. Item 7 shows the greatest contrast between parents, and reflects the higher number of SCGs in paid employment.

Table 9.9
Percentage of primary caregivers (PCGs) and secondary caregivers (SCGs) agreeing with items on the Time Crunch Scale

Items	PCG %	SCG %
1. I often feel under stress when I don‟t have enough time	92	80
2. When I need more time, I tend to cut back on sleep	57	55
3. At the end of the day, I often feel that I haven‟t accomplished what I set out to do	62	63
4. I worry that I don‟t spend enough time with my family or friends	51	66
5. I feel that I‟m constantly under stress-trying to accomplish more than I can handle	58	48
6. I feel trapped in a daily routine	45	55
7. When I‟m working long hours, I often feel guilty that I‟m not home	23	74
8. I consider myself a workaholic	25	20
9. I just don‟t have time for fun any more	44	34
10. Sometimes I feel that my spouse doesn‟t know who I am anymore	32	32

Note: Percent included responses indicating both “agree” and “strongly agree” to each of the items

9.45 Partner Support

9.45.1 Spouse Subscale: Parent Stress Index

Mean scores of PCGs (*M*=21.66, *SD*=6.20) on the Spouse subscale of the Parenting Stress Index were significantly higher than scores for SCGs (*M*=19.49, *SD*=4.98; *t* (151)=2.32, p<.05, *d*=.09), suggesting PCGs perceived themselves to be receiving less partner support than SCGs. The Cohen‟s *d*, however, indicates a small effect.

9.45.2 Carer Support Scale

The Carer Support Scale (CSS), completed by PCGs, provided an assessment of support received from SCGs with caring tasks, and perceptions of satisfaction with this support. The information from this measure, while not directly addressing Hypothesis 2, provides an interesting insight into the division of caring responsibilities between primary and secondary caregivers, and the impact of such divisions on the psychological well-being of primary caregivers.

Table 9.10 shows the percentage of PCGs who indicated that their partner helped them “not at all” through to “very much”, for each of the items of the CSS: Received Support subscale of the CSS.

Table 9.10

Percentage of primary caregivers responding to the Carer Support Scale (CSS): Received Support subscale

Items	Not at all	A little	Sometimes	Quite a bit	Very much
How much does your partner help with:					
1. Practical care (eg toileting, bathing)	5	22	23	30	20
2. Attending appointments (eg doctors, therapists)	31	24	13	19	13
3. Caring for other children	12	13	10	45	20
4. Chores/ food preparation	13	26	27	21	13
5. Caring for your child so you can have a break	8	26	36	19	11
6. Comforting child at night	25	14	27	20	14
7. Talk about feelings	8	22	16	25	29

Note. Items abbreviated for inclusion in the table

When considering the combined categories “quite a bit” and “very much” help received, Table 9.10 suggests that partners provided the most support in the areas of:

- helping to care for other children in the family;
- talking about feelings; and
- practical care.

In contrast, when considering the category “not at all”, Table 9.10 shows partners to provide the least amount of practical support in the areas of:

- attending appointments for the child with a disability; and
- comforting or attending to the child with a disability at night .

Table 9.11 shows how much more help PCGs would ideally like from their partner, from “no more” through to “a lot more”, for each of the items of the CSS: Ideal Support subscale. The table reports the percentage of PCGs indicating the amount of help they would like for each item of the scale.

Table 9.11

Percentage of primary caregivers responding to the items of the Carer Support Scale (CSS): Ideal Support subscale

Items	No more	A little more	Somewhat more	Quite a bit more	Very much more
How much more help would you ideally like from your partner with:					
1. Practical care (eg toileting, bathing)	53	23	9	8	7
2. Attending appointments (eg doctors, therapists)	45	27	11	8	9
3. Caring for other children	63	20	9	4	4
4. Chores/ food preparation	43	20	22	4	11
5. Caring for your child so you can have a break	26	37	13	11	13
6. Comforting child at night	50	20	12	8	10
7. Talk about feelings	38	24	11	12	15

Note. Items abbreviated for inclusion in the table

In general, the majority of PCGs would seem to be happy with the amount of practical support received from their partner. That is, in all areas of care, with the exception of “caring for my child so I can have a break” the largest percentage of PCGs considered that they ideally needed no more help from their partner than was already being received. When considering the combined categories “quite a bit more” and “a lot more”, the three areas in which PCGs would ideally like more help were:

1. talking about feelings;
2. caring for the child with a disability so the PCG can have a break ; and
3. comforting/ attending to the child with a disability at night.

These results indicate that PCGs continue to feel the need for more emotional support from their partner, even though most partners are already providing “quite a bit” or ”very much” emotional support. As well, while 62% of partners provide respite for the PCG by caring for the child with a disability “a little” or “sometimes”, 74% of PCGs would like at least “a little” more help in this area and of these PCGs, 25% would like “quite a bit” or “very much” more. Finally, providing care at night would appear to be part of the role of the PCG, though “in an ideal world” 25% of PCGs would like this to be different.

9.46 Summary of evidence for Hypothesis 2

Evidence for Hypothesis 2 is inconclusive. While results of analyses comparing outcomes for PCGs and outcomes for SCGs showed PCGs to consistently obtain mean scores indicating poorer functioning on all measures, differences were small with only three statistically significant results. Thus, PCGs reported feeling significantly more role restricted, to experience more time pressure on the Time Crunch scale and to have less partner support than SCGs. Effect sizes were mostly small.

Examination of results from the Carer Support Scale adds to knowledge about the division of caring roles between PCGs and SCGs, and supplements information obtained from the

Caregiver Diary. Results indicated that most PCGs were happy with amount of support received from their partner, but also highlighted a number of areas in which they would ideally like more support. PCGS particularly wanted more opportunities to talk about feelings.

9.5 Hypothesis 3: Carers of children with different diagnoses will show different patterns of psychological, social and physical well-being. In particular, parents of children with autism are expected to have poorer outcomes than parents of children with Down syndrome.

One way analyses of variance were used to compare the results obtained for carers of children with different diagnoses, for each of the measures used in Study 2. Effect size was calculated using η^2 (eta squared), interpreted according to Cohen"s guidelines. Cohen classifies .01 as a small effect, .06 as a medium effect and .14 as a large effect.

Thirty six percent (*N* = 34) of children whose parents participated in Study 2 had a diagnosis of global developmental delay, 24% (*N* = 23) had a diagnosis of Down syndrome, 25% (*N* = 24) had a formal diagnosis of autism, and 15% (*N* = 14) of children had a range of other diagnoses (including cerebral palsy & Fragile X).

9.51 Centre for Epidemiologic Studies – Depression Scale

Table 9.12 presents mean scores for the CES-D scale, for parents of children in each of the three diagnostic groups outlined above. The table shows parents of children with global developmental delay had the highest depression scores and parents of children with Down syndrome had the lowest scores on this measure. Primary caregivers of children with global developmental delay and children with autism obtained mean scores on the CES-D above the recommended cut-off indicating possible clinical depression (Radloff and Locke, 1986). Results of one-way analysis of variance, using the square root transformation of CES-D scores, showed the difference between the groups for PCGs was not significant ($F(3,91)=.54$, $p=.65$, $\eta^2=.02$). Similarly, differences between the groups for SCGs were also not significant ($F(3,61)=.19$, $p=.90$, $\eta^2=.01$). The η^2 values for both analyses were small.

Table 9.12
Mean (SD) total scores on the CES-D: primary caregivers (PCGs) and secondary caregivers (SCGs) of children with different diagnoses

	PCGs		SCGs	
Diagnostic groups	*N*	Mean (*SD*)	*N*	Mean (*SD*)
Global developmental delay	34	18.47 (11.24)	22	15.82 (10.85)
Autism	23	16.83 (10.27)	17	14.29 (7.92)
Down Syndrome	24	14.50 (8.49)	15	12.47 (7.47)
Other diagnoses	14	15.07 (11.51)	11	13.46 (11.96)

Note. CES-D = Centre for Epidemiologic Studies Depression Scale

9.52 Role Restriction/ Isolation/ Health subscales: Parent Stress Index

Table 9.13 reports the mean scores for the Role Restriction, Isolation, and Health subscales of the PSI, for PCGs of children with different diagnoses. Table 9.14 shows the same information for SCGs. Primary caregivers of children with autism are shown to have the highest scores for the PSI variables, suggesting they may experience more role restriction, more social isolation, and poorer physical health than parents of other children with disabilities. Parents of children with Down syndrome generally had the lowest scores on each of the subscales. Results of one way analyses of variance between primary caregivers and secondary caregivers of children with different diagnoses, however, were not significant with mostly small η^2 values. A moderate effect size was found for the Role Restriction subscale, for secondary carers and it is clear from Table 9.14 that this is largely due to the experience of carers of children with autism.

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Table 9.13
Mean (SD) scores for the Role Restriction, Isolation and Health subscales of the Parenting Stress Index (PSI) completed by ***primary caregivers****, and results of one-way analyses of variance*

Primary caregivers

PSI Subscales	GDD *N*=34	Autism *N*=23	DS *N*=24	Other *N*=14	*F* (df=3,91)	*p*	η^2
Role Restriction	24.62 (5.31)	25.87 (5.29)	23.21 (5.90	25.79 (7.22)	1.02	.39	.03
Isolation	16.53 (5.29)	17.70 (4.07)	15.25 (4.59)	16.64 (4.68)	1.04	.38	.03
Health	14.68 (4.27)	15.26 (3.56)	13.71 (4.56)	13.86 (3.03)	.72	.54	.02

Note. GDD =Global developmental delay; DS= Down Syndrome; Other = Other diagnoses

Table 9.14

Mean (SD) scores for the Role Restriction, Isolation and Health subscales of the Parenting Stress Index (PSI) completed by ***secondary caregivers****, and results of one-way analyses of variance*

Secondary caregivers

PSI Subscales	GDD *N*=22	Autism *N*=17	DS *N*=15	Other *N*=11	*F* (df=3,61)	*p*	η^2
Role Restriction	22.23 (6.32)	24.88 (4.27)	20.67 (7.03)	20.64 (5.22)	1.79	.16	.08
Isolation	16.77 (3.95)	16.53 (3.34)	15.47 (4.87)	16.91 (3.70)	0.40	.75	.02
Health	13.73 (3.50)	13.71 (3.22)	12.87 (3.82)	14.73 (4.22)	0.56	.65	.03

Note. GDD =Global developmental delay; DS= Down Syndrome; Other = Other diagnoses

9.53 Caregiver Strain Questionnaire

Table 9.15 shows the mean scores for total caregiver strain, for PCGs and SCGs of children with different diagnoses. Results of one-way analyses of variance between the mean scores for diagnostic groups are also shown. The table shows parents of children with autism to obtain the highest scores for total strain. Parents of children with Down syndrome again had the lowest scores on this measure. Results of analyses, however, were not significant though the η^2 value indicates a moderate effect size for secondary caregivers.

Table 9.15

Mean (SD) total strain scores from the Caregiver Strain Questionnaire for primary caregivers (PCGs) and secondary caregivers (SCGs) of children in different diagnostic groups, and results of one-way analyses of variance

	GDD	Autism	DS	Other	*F(df)*	*p*	η^2
PCGs	2.44 (.67)	2.60 (.69)	2.27 (.60)	2.53 (.88)	1.00	.40	.03
N	34	23	24	14	(3, 91)		
SCGs	2.37 (.69)	2.64 (.69)	2.09 (.72)	2.28 (.48)	1.85	.15	.09
N	22	16	15	11	(3, 60)		

Note. GDD =Global developmental delay; DS= Down Syndrome; Other = Other diagnoses

9.54 Time Pressure

9.54.1 Rushed/ Pressed for Time item

Table 9.16 shows the percentage of PCGs and SCGs of children in the different diagnostic groups, who reported being “often” or “always” rushed/ pressed for time (reflecting the overall experience of time pressure). Small numbers prevented the use of chi-square analyses however, inspection of the data would suggest differences between the diagnostic groups were small. PCGs of children with autism and Down syndrome, and SCGs of children with autism were most likely to report feeling often or always rushed or pressed for time.

Table 9.16

Percentage of primary caregivers (PCGs) and secondary caregivers (SCGs) of children in different diagnostic groups, reporting themselves to be often or always rushed or pressed for time

	GDD	Autism	DS	Other
PCGs % *N*	23 (68%) *34*	19 (83%) *23*	20 (83%) *24*	10 (71%) *14*
SCGs % *N*	16 (73%) *22*	15 (88%) *17*	12 (80%) *15*	8 (73%) *11*

Note. GDD =Global developmental delay; DS= Down Syndrome; Other = Other diagnoses

9.54.2 Time Crunch Scale

Means scores for PCGs and SCGs of children in the different diagnostic groups are presented in Table 9.17. Results indicate PCGs of children with autism and SCGs of children with global developmental delay experienced the highest levels of time pressure, and PCGs and SCGs of children with Down syndrome and “Other” diagnosis experienced the lowest levels of time pressure. Results of independent sample t-tests, however, were both not significant, and had small effect sizes.

Table 9.17
Mean (SD) scores for the Time Crunch Scale, for primary caregivers (PCGs) and secondary caregivers (SCGs), and results of one-way analyses of variance

	GDD	Autism	DS	Other	*F* (df)	*p*	η^2
PCGs	37.65 (8.08)	38.52 (7.31)	35.79 (7.33)	35.79 (6.88)	.71	.55	.02
N	*34*	*23*	*24*	*14*	(3,91)		
SCGs	35.09 (8.16)	33.94 (5.12)	31.53 (6.82)	33.64 (7.15)	.78	.51	.04
N	22	17	15	11	(3,61)		

Note: GDD =Global developmental delay; DS= Down Syndrome; Other = Other diagnoses

9.55 Partner Support

9.55.1 Spouse Subscale: Parent Stress Index

Table 9.18 shows the mean scores for the Spouse subscale of the PSI, for PCGs and SCGs of children with different diagnoses. PCGs and SCGs of children with autism had the highest scores on this measure, indicating they perceived themselves to receive less support from their partner than other parents. Parents of children with Down syndrome obtained the lowest scores on this subscale. Results of independent sample t-tests, however, found these differences to be not significant.

Table 9.18
Mean (SD) scores for the Spouse Support subscale of the Parenting Stress Index for primary caregivers (PCGs) and secondary caregivers (SCGs), and results of one-way analyses of variance

	GDD	Autism	DS	Other	*F* (df)	*p*	η^2
PCG	21.64 (5.46)	23.44 (5.97)	19.82 (6.77)	21.54 (7.08)	1.26	.29	.04
N	31	23	21	13	(3,84)		
SCG	20.27 (4.84)	21 (4.36)	17 (5.84)	19 (4.05)	2.09	.11	.09
N	22	17	15	11	(3,61)		

Note: GDD =Global developmental delay; DS= Down Syndrome; Other = Other diagnoses

9.56 Summary of evidence for Hypothesis 3

Results of analyses did not support Hypothesis 3. Differences between the mean scores for all measures used in Study 2, completed by parents caring for children with different diagnoses were small and none were statistically significant. There were, however, some patterns in the data that may have obtained significance if a larger sample had been used. Thus, caregivers of children with autism consistently obtained scores indicating poorer outcomes than carers of other children with disabilities. As well, parents of children with Down syndrome were consistently found to do better on the outcome measures used in Study 2, in comparison to other parents. These trends in the data reflect results of previous research (Hodapp, 2007; Singer, 2006). As noted previously, results should also be considered in the context of the poorer well-being of all parents who participated in Study 2.

Parents of children with global developmental delay reported the highest levels of depressive symptoms, in comparison to other parents in Study 2. This finding may warrant further investigation, particularly as this group of parents is not often the focus of research.

9.6 Results for Hypothesis 4: Carers of children with greater functional impairment will have poorer psychological, social and physical well-being than carers of children with less functional impairment

The children of parents who took part in the study were all clients of Early Childhood Services (ECS), part of Disability Services SA. They had, therefore, been identified prior to Study 2 as having significant developmental delays in the majority of areas of development (for example, speech and language delays as well as gross or fine motor problems), or to have a medically diagnosed condition with a substantial probability of intellectual disability. The WeeFIM® Version 4.0 (Uniform Data Set for Medical Rehabilitation, 1993) was included in Study 2 as a measure of child functional skills, reflecting the extent of developmental delays experienced by children. While it was expected that children would be shown to have poorer levels of functional skills, it was also expected that there would be variability in the skills of children whose parents participated in Study 2 and that this variation would result in differential well-being of parents. As an initial step to test this hypothesis, results of the WeeFIM® measure, describing the functional skills of children whose parents took part in Study 2, are described. In a second step, Pearson product-moment correlation coefficients are used to examine the relationships between the WeeFIM® scores and scores obtained from measures of parent psychological, social and physical well-being. It should be noted that mean values for each of the variables used have been presented earlier in this chapter, so only results of analyses will be presented here.

9.61 WeeFIM® Version 4.0: Comparison with normative data

Normative scores were obtained from the manual for the WeeFIM® Version 4.0 (Uniform Data Set for Medical Rehabilitation, 1993). The mean total WeeFIM® quotient for the children in the study was 57 (*SD*=15) with scores ranging from 18 to 92. Ninety percent of children in the study obtained quotients indicative of significant functional disability. Ten percent (n=10) of children achieved quotients above 75 (ie suggesting no functional disability), 60% (n=57) fell in the range of moderate disability and 30% (n= 28) were in the range suggesting severe levels of disability. Quotients were also calculated for the two subscales of the WeeFIM®. The mean quotient for the motor subscale obtained by the children in the study was 59 (*SD*=18), while the mean quotient for the cognitive subscale was 50 (*SD*=15). This pattern suggests that the children in the study were characterised by greater levels of disability in the areas of communication and social cognition, as compared to self-care and physical mobility. This is consistent with the clientele of the Early Childhood Service, most of who do not have significant medical or physical disabilities.

9.62 Correlations between child functional skill and parent outcomes.

Table 9.19 shows the results of Pearson product-moment correlations for the WeeFIM® total quotient and mean scores from the CES-D (using a square root transformation); the Role

Restriction, Health subscales of the PSI, and for total caregiver strain from the CGSQ, for both PCGs and SCGs. The table shows correlation coefficients to be small (according to Cohen"s (1988) suggested guidelines). None were statistically significant.

Table 9.19

Pearson product-moment correlation coefficients for the WeeFIM$^{®}$ total quotient and mean scores from outcome measures for primary caregivers (PCGs) and secondary caregivers (SCGs)

Carer	CES-D	PSI: Role restriction	PSI: Isolation	PSI: Health	CGSQ: Total caregiver Strain
PCG (*N*=95)	.06	.02	.09	.14	.03
SCG (*N*=65)	.20	.15	.01	.16	.21

Note: CES-D= Centre for Epidemiologic Studies–Depression scale; PSI=Parenting Stress Index; CGSQ= Caregiver Strain Questionnaire

Table 9.20 shows the correlation coefficients for the WeeFIM$^{®}$ total quotient and mean scores from the Time Crunch Scale and the Spouse subscale of the PSI, completed by PCGs and SCGs. All coefficients were small, and not significant.

Table 9.20

Pearson product-moment correlation coefficients for the WeeFIM® total quotient and mean scores for the Spouse subscale of the Parenting Stress Index (PSI) and the Time Crunch Scale, for primary caregivers (PCGs) and secondary caregivers (SCGs)

Carer	Time Crunch Scale	PSI: Spouse
PCG (*N*=95)	.06	.15
SCG (*N*=65)	.18	.19

A Spearman"s Rho correlation coefficient was carried out to examine the relationship between the WeeFim® Total Quotient and the ratings of time pressure using the Rushed/ pressed for time item. Results for PCGs (r_s = .09, p =*.40*), and SCGs (r_s = .19, p = .14) were not statistically significant.

9.63 Summary of evidence for Hypothesis 4

Hypothesis 4 was not supported by the results of the present study. Previous research examining the role of functional impairment on parent well-being has been equivocal. The present results are consistent with studies showing functional skills to be unrelated to maternal adaptation or parent distress (Skok, 2006; Wallender et al 1989; 1990; Wiegner & Donders, 2000). These results would suggest the level of stress perceived by carers is independent of the extent of the child"s functional skills.

9.7 Results for Hypothesis 5: Carers of children with disabilities and emotional and behavioural problems will have poorer psychological and physical well-being than carers of children with disabilities who do not have emotional or behavioural problems

The Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997) was used to assess the extent of emotional and behavioural problems experienced by the children whose parents took part in Study 2. It was strongly anticipated that the children in the study would show more emotional and behavioural problems than children in the general community, and further, that parents of children with higher levels of emotional and behavioural problems would have poorer outcomes than parents of children with fewer additional problems. As in the previous section, analyses were carried out in two steps. Firstly, results for the SDQ were compared with results from a normative sample of five to ten year old British children (Goodman, 2001). This sample was the closest match for children in the present study. Subsequently, the degree of association between child emotional and behavioural problems and parent psychological, social and physical well-being was examined using Pearson product-moment correlation coefficients. Results are concluded by comparing the scores for the SDQ completed by PCGs and scores for the SDQ completed by SCGs. The SDQ was the only measure included in Study 2 that enabled an assessment of child severity of disability by both PCGs and SCGs.

9.71 Strengths and Difficulties Questionnaire: Comparison with normative data

Table 9.21 and Table 9.22 present mean scores for the different subscales of the SDQ for the children in the study, reported independently by PCGs and SCGs, as well as mean scores reported for the normative sample. The tables show children in the study to have higher scores for the emotional problems, conduct problems, hyperactivity, and peer problems subscales, and for the index of total emotional and behavioural problems than children in the community sample (ie indicating more emotional and behavioural problems). They had lower scores for the prosocial behaviours subscale, indicating they had fewer prosocial skills than the normative sample. Independent sample t-tests were used to test for the significance of differences between the two sets of mean scores. Results are also shown in Tables 9.21 and 9.22. All were significant; with most having Cohen‟s *d* values indicating large effect sizes. Thus, the children in the study were independently reported by both their parents to have significantly more emotional and behavioural problems and significantly less prosocial behaviours than children in the normative sample.

Table 9.21

Mean (SD) scores for the subscales of the Strengths and Difficulties Questionnaire reported by **primary caregivers**, *and for the normative sample, and results of independent sample t-tests*

	Primary Caregiver Mean (*SD*)	Normative sample Mean (*SD*)	*t* (*df*=5947)	*p*	*d*
SDQ Subscales:					
Emotional problems	2.68 (2.10)	1.9 (2.0)	3.75	<.001	.39
Conduct problems	3.01 (1.93)	1.6 (1.7)	7.96	<.001	.83
Hyperactivity	7.15 (2.14)	3.6 (2.7)	12.68	<.001	1.32
Peer problems	4.17 (1.84)	1.4 (1.7)	15.65	<.001	1.63
Prosocial behaviours	4.96 (2.50)	8.6 (1.6)	-21.64	<.001	-2.28
Total emotional & behavioural problems	17.01 (5.08)	8.6 (5.7)	14.21	<.001	1.48

Table 9.22

Mean (SD) scores for the subscales of the Strengths and Difficulties Questionnaire reported by ***secondary caregivers****, and results of independent sample t-tests*

	Secondary caregiver Mean (*SD*)	Normative sample Mean (*SD*)	*t* (*df*=5917)	*p*	d
SDQ Subscales					
Emotional problems	2.84 (1.96)	1.9 (2.0)	3.74	<.001	.47
Conduct problems	3.28 (2.12)	1.6 (1.7)	7.84	<.001	.99
Hyperactivity	6.80 (2.24)	3.6 (2.7)	9.45	<.001	1.19
Peer problems	3.89 (1.90)	1.4 (1.7)	11.64	<.001	1.46
Prosocial behaviours	4.63 (2.64)	8.6 (1.6)	-19.56	<.001	-2.46
Total emotional & behavioural problems	16.81 (5.24)	8.6 (5.7)	11.47	<.001	1.44

The percentage of children scoring above clinical cut-offs, indicating the likelihood of clinically significant problems for each of the subscales of the SDQ, are shown in Table 9.23, together with the percentage of children who fell above the cut-offs (or below the cut-off for the Prosocial subscale) as reported by PCGs or SCGs. Percentages indicate the number of children in the study whose scores on the subscales of the SDQ were suggestive of clinically significant problems. Of note, over half of the children were reported by their carers to experience clinically significant problems in the areas represented by the subscales, with the exception of Emotional problems with excellent agreement between PCGs and SCGs. Rates of total emotional and behavioural problems are comparable to those found in recent studies using the SDQ with populations of children with intellectual disability, which found 60% of children to achieve scores above clinical cut-offs (Emerson, 2005; Kaptein et al, 2008).

Table 9.23

Percentage of children falling outside of clinical cut-offs for the Strengths and Difficulties Questionnaire completed by primary caregivers and secondary caregivers

	Clinical cut-off	Primary caregivers *N*=94	Secondary caregivers *N=64*
Subscales			
Emotional Problems	≥4	34	33
Conduct problems	≥3	55	64
Hyperactivity	≥7	60	59
Peer problems	≥3	77	80
Prosocial behaviour	<6	73	70
Total emotional & behavioural problems	≥16	64	58

9.72 Relationships between child emotional and behavioural problems and parent outcomes

Hypothesis 5 was tested by examining the relationships between child emotional and behavioural problems, as measured by the SDQ total emotional and behavioural problems score, and measures of carer outcomes. Table 9.24 shows the results of Pearson product-moment correlations between the total emotional and behavioural score and mean scores from the CES-D (using a square root transformation); the Role Restriction, Health subscales of the PSI, and for total caregiver strain from the CGSQ completed by PCGs. It also shows results of correlations between total emotional and behavioural problems scores and mean scores from the CES-D (using a square root transformation); the Role Restriction, Health subscales of the PSI, and the total caregiver strain scale from the CGSQ completed by SCGs. All results were significant, most with a medium effect size, with one exception. The correlation between Social Isolation and SDQ total score was not significant for SCGs, and was also the smallest result obtained for PCGs.

Table 9.24

Pearson product-moment correlation coefficients between the SDQ total emotional and behavioural problems scale and mean scores from outcome measures, for primary caregivers (PCGs) and secondary caregivers (SCGs)

Carer	CES-D	PSI; Role restriction	PSI: Isolation	PSI: Health	CGSQ: Total Caregiver Strain
PCG (*N*=94)	.37***	.36***	.23*	.32**	.49*** .
SCG (*N*=64)	.26*	.39**	.16	.28*	.47***

Note. CES-D= Centre for Epidemiologic Studies–Depression scale; PSI=Parenting Stress Index; CGSQ= Caregiver Strain Questionnaire
* = .05, ** = .01, ***= .001

Table 9.25 shows correlation coefficients for the SDQ total emotional and behavioural problems score and means scores from the Time Crunch Scale and the Spouse subscale of the PSI, completed by PCGs. The table also shows the results of correlations between the SDQ total emotional and behavioural problems score and means scores from the Time Crunch Scale and the Spouse subscale of the PSI, completed by SCGs. All correlations were significant, indicating moderately strong relationships.

Table 9.25
Pearson product-moment correlation coefficients for the SDQ total emotional and behavioural problems scale and mean scores for the Time Crunch Scale and the Spouse subscale of the Parenting Stress Index (PSI), for primary caregivers (PCGs) and secondary caregivers (SCGs)

Carer	Time Crunch Scale	PSI: Spouse
PCG	.27**	.34**
(*N*)	(94)	(87)
SCG	.31**	.41**
(*N*)	(64)	(64)

* = .05, ** = .01, ***= .001

A Spearman"s Rho correlation coefficient was used to examine the relationship between the SDQ total emotional and behavioural problems score and ratings of time pressure using the Rushed/ pressed for time item. Results for PCGs ($r_s = .37$, $p < .001$), and SCGs ($r_s = .31$, $p < .05$) were significant, indicating small to moderately strong relationships.

Further analyses were undertaken to investigate whether children with more emotional and behavioural problems were over-represented within a single diagnostic group. This would be consistent with previous research showing children with autism to be more likely to exhibit more emotional and behavioural problems than children with developmental delays due to other reasons. Table 9.26 presents mean scores for the SDQ total emotional and behavioural scale, completed independently by PCGs and SCGs, for children in different diagnostic groups. The table shows parents of children with global developmental delay to report their children to have the highest levels of emotional and behavioural problems. Results of one-way analysis of variance, however, showed the difference between the diagnostic groups for PCGs was not significant (*F* (3,93) = .90 *p* = .45). Similarly, differences between the groups for SCGs were also not significant (*F*(3,61) = 1.70, *p* =.18).

Table 9.26
Mean (SD) scores on the SDQ total emotional and behavioural problems scale, reported by primary caregivers (PCGs) and secondary caregivers (SCGs)

Diagnostic groups	PCG *N*	Mean (*SD*)	SCG *N*	Mean (*SD*)
Global developmental delay	34	18.47 (11.24)	22	15.82 (10.85)
Autism	23	16.83 (10.27)	17	14.29 (7.92)
Down Syndrome	24	14.50 (8.49)	15	12.47 (7.47)
Other diagnoses	14	15.07 (11.51)	11	13.46 (11.96)

9.73 Strengths and Difficulties Questionnaire: Comparisons between primary caregivers and secondary caregivers

Table 9.27 compares the scores obtained from the SDQ completed by PCGs, and scores from the SDQ completed by SCGs. The table shows PCGs to be less likely to report emotional and conduct problems, but more likely to report hyperactivity, peer problems and prosocial behaviours. Differences between caregivers, however, were small and not significant when examined using independent sample t-tests. A paired sample t-test for total emotional and behavioural problems, on children with both a PCG completed SDQ (*M*=17, *SD* = 4.9) and a SCG completed SDQ (*M* = 16.81, *SD* = 5.24) was also not significant (*t (63)* = .36, *p* = .72, *d* = .06).

Table 9.27

Mean (SD) scores for the subscales of the Strengths and Difficulties Questionnaire reported by primary caregivers and secondary caregivers, and results of independent sample t-tests

	Primary caregiver Mean (*SD*) *N*= 94	Secondary caregiver Mean (*SD*) *N*= 64	*t (df=156)*	*p*	*d*
SDQ subscales:					
Emotional Problems	2.68 (2.10)	2.84 (1.96)	-.48 (156)	.63	-.08
Conduct problems	3.01 (1.93)	3.28 (2.12)	-.83 (156)	.41	-.14
Hyperactivity	7.15 (2.14)	6.80 (2.24)	.99 (156)	.32	.16
Peer problems	4.17 (1.84)	3.89 (1.90)	.93 (156)	.36	.15
Prosocial behaviours	4.96 (2.50)	4.63 (2.64)	.80 (156)	.43	.13
Total emotional & behavioural problems	17.01 (5.08)	16.81 (5.24)	.24 (156)	.81	.04

9.74 Summary of evidence for Hypothesis 5

The present study provides strong support for Hypothesis 5. That is, results indicate that children with higher levels of emotional and behavioural problems had parents who reported themselves to have more depressive symptoms, to feel more role restricted; to have poorer physical health, and to experience greater caregiver strain and feelings of time pressure than parents of children with lower levels of emotional and behavioural problems. In addition, parents of children with higher levels of emotional and behavioural problems were more likely to perceive themselves to have less partner support than parents of children with fewer problems. Analyses indicate these results were not a consequence of differences in the prevalence of behavioural problems between diagnostic groups, consistent with the lack of support found for Hypothesis 3 (indicating no differences between parent outcomes for children with different diagnoses). The findings of the present study conform with the large number of studies indicating the importance of behavioural problems in contributing to the well-being of parents caring for children with cognitive and other disabilities (Baker et al, 2002; 2003; 2005; Donenberg & Baker, 1993; Floyd and Gallagher, 1997; Hastings et al., 2006; Raina et al 2005).

It is of note that the relationship between emotional and behavioural problems and parent outcomes was found for both PCGs and, to a lesser extent, SCGs. Thus, the level of a child‟s emotional and behavioural problems was more important than the amount of caring undertaken, in contributing to parent well-being. The only non-significant result to be found when examining the relationship between emotional and behavioural problems and parent outcomes, suggested the extent of children‟s problems did not impact on the degree of social isolation experienced by the SCG. Thus, while PCGs would seem to experience more social isolation as a result of their children‟s behaviour, SCGs are less impacted by this, perhaps a consequence of increased opportunities to interact with others outside of the home because of paid employment or other commitments.

9.8 Conclusions

The present chapter aimed to address Hypotheses 1 to 5, derived from the model of carer well-being. Results of analyses found:

- This study supported Hypothesis 1, that is, carers of young children with developmental disabilities who participated in Study 2 had poorer psychological, social and physical well-being than carers of children without disabilities;

- This study found inconclusive evidence for Hypothesis 2, that is, while PCGs consistently obtained scores indicating they experienced poorer well-being than SCGs, there were only a small number of statistically significant results. PCGs reported themselves to feel significantly more role restricted, to experience more time pressure and to have less partner support than SCGs. Moderate effect sizes for these analyses suggest that larger sample sizes may be needed to adequately test this hypothesis.

- This study does not support Hypothesis 3, that is, there were no significant results from comparisons of the mean scores of parents of children with different disabilities on all outcome measures. Effect sizes for PCGs were uniformly small, with only a small number of moderate results for SCGs. Consistent patterns in the data, however, suggested parents of children with autism may have poorer well-being than parents of children with Down syndrome.

- This study does not support Hypothesis 4, that is, carers of children with greater functional impairment did not have significantly poorer psychological and physical well-being than carers of children with less functional impairment;

- This study found strong support for Hypothesis 5, that is, carers of children with developmental disabilities who also had higher levels of emotional and behavioural problems were shown to have poorer psychological and physical well-being than carers of children with disabilities who had lower levels of emotional or behavioural problems.

CHAPTER 10

Relationship between time spent caring for preschool children with developmental disabilities and psychological, social and physical well-being of parents: Testing the model of carer well-being

(Hypotheses 6 & 7)

10.1 Overview

This chapter will report on the results of analyses testing the model of carer well-being. The model, first described in Chapter 4, arose from a review of research examining outcomes for parents caring for children with disabilities. Results of Study 1, a qualitative study involving focus groups and interviews with parents of children with disabilities, provided preliminary evidence for the model. Study 2 aimed to test the model using quantitative methods.

The model of carer well-being, reproduced in Figure 10.1, hypothesises a moderated, mediating relationship between stressors (characteristics of the child‟s disability) and outcomes for caregivers. That is, the impact of stressors on the psychological, social and physical well-being of parents is assumed to occur through the mediating influence of caring responsibilities. The strength of the relationship between caring responsibilities and parent well-being is further assumed to be a function of the extent of partner support.

NOTE:
This figure is included on page 306 of the print copy of
the thesis held in the University of Adelaide Library.

Adapted from Grant, Compas et al (2005).

Figure 10.1. Model of carer well-being.

The relationships portrayed in the model of carer well-being are described in several specific hypotheses:

Hypothesis 6: Caring responsibilities (reflected by time spent caring and carer perceptions of time pressure), mediate the effects of child disability on carer psychological and physical well-being. Higher levels of caring responsibilities (ie more time spent caring or more perceived time pressure) are expected to lead to poorer outcomes;

Hypothesis 7: Partner support moderates the impact of caring responsibilities (total time spent caring and carer experience of time pressure), on carer psychological and physical well-being. Higher levels of partner support are expected to reduce the impact of child disability on carers.

To help explain the methodology and approaches to analysis used in the present chapter, a brief summary of commonly used statistical approaches to testing for mediator and moderator relationships will be outlined. Firstly, a simple mediation model, from Baron and Kenny (1986), is shown in the path diagram in Figure 10.2.

NOTE:
This figure is included on page 307 of the print copy of
the thesis held in the University of Adelaide Library.

Figure 10.2. A simple mediation relationship (from Baron & Kenny, 1986).

In this model, mediation can be said to occur when the casual effect of an independent variable (X) on a dependent, or outcome, variable (Y) occurs through the operation of a third variable, or the mediator (M). That is, X affects Y because X affects M, and M in turn affects Y (Preacher & Hayes, 2007). Baron and Kenny (1986) specified a series of causal "steps" for testing a simple mediation hypothesis, using regression procedures. While there has been some debate about whether all of the steps need to be met to establish mediation (Kenny et al 1998), the procedures have been very widely utilized in psychological literature.

Preacher and Hayes (2007) have summarized the causal approach of Baron and Kenny as follows, referring to the model of simple mediation shown in Figure 10.2:

A variable M is a mediator if:

1. The independent variable X significantly accounts for variability in the dependent variable Y;
2. X significantly accounts for variability in M;
3. M significantly accounts for variability in Y when controlling for X;
4. The total effect of X should be greater than the direct effect of X when controlling for the influence of M.

Preacher and Hayes suggest that in relation to Figure 10.2, these steps require paths a, b and c to be statistically significant. Further, path c´ should be smaller than path c. Baron and Kenny considered “perfect” mediation to be present when c´-c approaches zero.

A second path diagram, shown in Figure 10.3 illustrates a simple moderation relationship.

NOTE:
This figure is included on page 308 of the print copy of
the thesis held in the University of Adelaide Library.

Figure 10.3. A simple moderation relationship (from Baron & Kenny, 1986).

Moderation can be said to occur when the operation of a variable (W) affects the direction or strength of the relationship between the independent variable (X) and the dependent, or outcome, variable (Y). Baron and Kenny considered moderation to be present when the interaction between the independent variable and the moderator (ie XxW) was statistically significant.

Baron and Kenny‟s (1986) approaches to testing for the significance of mediation and moderation have influenced others to find ways of assessing more complex theoretical models, combining both moderation and mediation (Muller et al, 2005). For example, a moderated mediation model, such as the one proposed in the model of carer well-being, suggests that a mediated relationship is contingent on the level of a moderator explaining both how and when a given effect occurs (Frone, 1999). Preacher et al (2007) have explored different methods for estimating and testing hypotheses involving moderated mediation relationships (which they prefer to call "conditional indirect effects"), based on Baron and Kenny‟s procedures. They have provided an SPSS macro (a programmed set of statistical procedures) to allow the application of their recommended methods, using both normal theory and "bootstrap" approaches to assess the presence, strength and significance of indirect effects. Bootstrapping involves the nonparametric estimation of the sampling distribution of the conditional indirect effect. Preacher argues for the superiority of bootstrapping over other methods of assessing the significance of indirect effects such as the Sobel test (Sobel, 1982) involving the use of standard errors, as bootstrapping does not require an assumption that the sampling distribution of the indirect effect is normal.

The procedure for testing the model of carer well-being used in the present chapter has been influenced by Baron and Kenny‟s recommended steps for testing mediation and moderation. Preacher et al‟s (2007) SPSS macro, using standard regression procedures consistent with Baron and Kenny‟s steps, facilitated analysis for the presence of a moderated mediated relationship, as proposed in the model of carer well-being.

10.2 Measures and methods

Figure 10.4 shows the summary variables used in Study 2 to make the different components of the model of carer well-being. All measures have been previously described in Chapter 6.

1. Stressors
Child's Disability:
- WeeFIM$^{\circledR}$ (total quotient)
- SDQ (total problems)

2. Caregiver Outcomes:
Psychological, social and physical well-being
- CES-D (total depression)
- CGSQ (total strain)
- Role Restriction (PSI)
- Social Isolation (PSI)
- Health (PSI)

3. Mediators
Time use (Caregiver diary)
- Total time caring
- Intensity of caring

Perceived time pressure:
- Rushed/ pressed for time
- Time Crunch Scale

4. Moderators
Partner support:
- Spouse support (PSI)
- Received Support (CSS)[a]
- Ideal Support (CSS)[a]

SDQ = Strengths and Difficulties Questionnaire; CES-D = Centre for Epidemiologic Studies-Depression Scale; CGSQ = Caregiver Strain Questionnaire; PSI = Parenting Stress Index; CSS = Carer Support Scale
[a] Variables available for primary caregivers only

Figure 10.4. Summary variables representing components of the model of carer well-being.

It should be noted that multiple variables, from multiple measures, were used to represent the different components of the model. The use of regression procedures, however, requires that the number of variables be limited by the size of the data set. Tabachnick & Fidell (2000), for example, suggest a formula for calculating sample size based on the number of variables: N> 50 +8m (where m= the number of independent variables). Using this formula, it was judged that the present study should (ideally) include no more than 5 independent (or predictor) variables for primary caregivers (PCGs), and fewer for analyses involving secondary caregivers (SCGs). Regression procedures are also sensitive to multicollinearity (when independent variables are highly correlated). To limit the number of variables and to ensure that variables were independent, therefore, a series of preliminary analyses were undertaken to identify the most appropriate variables for use in subsequent regression procedures:

1. Firstly, to address the problem of multicollinearity, analyses were undertaken to assess inter-relationships between the different variables used to assess stressors, caregiver outcomes, mediator and moderator variables. Pearson product-moment correlation coefficients were used to examine the extent of association between variables, using Cohen‟s guidelines (1988) to aid in the interpretation of values:

r = .10 to .29 or r = -.10 to -.29	small
r = .30 to .49 or r = -.30 to -.49	medium
r = .50 to 1.0 or r = -.50 to -1.0	large

Strongly correlated variables suggested the selection of one stressor, outcome, mediating or moderating variable over others, for use in analyses to test the theoretical model.

2. The second set of preliminary analyses, following Baron and Kenny‟s (1986) recommended first step towards establishing mediation, examined relationships between stressors, mediator variables, and caregiver outcomes. Stressors and mediating variables that did not show a relationship with variables representing carer outcomes were excluded from further analyses.

3. The last set of preliminary analyses examined the relationship between mediator variables and moderator variables (ie practical support and time pressure/ time use). Variables with the strongest relationships were chosen for use in regression procedures when testing the theoretical model.

Previous chapters have examined whether the summary variables violated assumptions of normality. Analyses in the present chapter used transformed data for the total depression score of the CES-D due to problems with skew and kurtosis. Total time caring and intensity of caring from the Caregiver Diary were normally distributed, facilitating the use of parametric methods.

10.3 Results

10.31 Preliminary analyses (1): Relationships between variables making up the different components of the theoretical model (stressors, caregiver outcomes, mediators, moderators)

Results of analyses using Pearson product-moment correlation coefficients are reported separately for the different components of the model of carer well-being depicted in Figure 10.4. Thus, correlations between variables measuring aspects of severity of child disability will be presented first; followed by results of correlations between variables measuring caregiver outcomes, correlations between variables representing caring responsibilities; and finally results of correlations between the variables measuring partner support. All analyses will be reported separately for primary caregivers (PCGs) and secondary caregivers (SCGs).

10.31.1 Stressors: Characteristics of child disability

The Pearson product-moment correlation coefficient for the two variables assessing severity of disability (ie the total WeeFIM® quotient and total emotional and behavioural problems score for the Strengths and Difficulties Scale) was not significant for PCGs (r=.05, N=94, p=.65). This suggests that children‟s functional abilities were not associated with levels of emotional and behavioural problems as reported by PCGs. In contrast, there was a small, significant relationship between these variables for SCGs (r= .27, N=64, p<.05).

10.31.2 Caregiver outcomes: Psychological, social and physical well-being

Table 10.1 shows estimates of Pearson product-moment correlations for the variables assessing psychological, social and physical measures outcomes for PCGs. Table 10.2 shows the estimates for SCGs. The tables show strong relationships between the variables measuring different outcomes for both parents.

Table 10.1

Pearson product-moment correlation coefficients between variables measuring different outcomes for ***primary caregivers*** *(N=95)*

Primary caregivers	Role Restriction	Isolation	Health	CGSQ Total strain
Total depression (CES-D)	52***	.49***	.55***	.50***
Role restriction (PSI)	---	.56***	.59***	.64***
Isolation (PSI)		---	.57***	.55***
Health (PSI)			---	.66***

Note. CES-D = Centre for Epidemiologic Studies - Depression Scale; PSI = Parenting Stress Index; CGSQ = Caregiver Strain Questionnaire
***p<.001

Table 10.2

Pearson product-moment correlation coefficients between variables measuring different outcomes for ***secondary caregivers***

Secondary caregivers	Role Restriction (*N*=65)	Isolation (*N*=65)	Health (*N*=65)	CGSQ Total strain (*N*=64)
Total depression (CES-D)	.60***	.55***	.61***	.61***
Role restriction (PSI)	---	.53***	.54***	.74***
Isolation (PSI)		---	.44***	.47***
Health (PSI)			---	.51***

Note. CES-D = Centre for Epidemiologic Studies - Depression Scale; PSI = Parenting Stress Index; CGSQ = Caregiver Strain Questionnaire
***p <.001

10.31.3 Mediator variables: Time use and time pressure

Variables measuring total time caring, and intensity of caring were taken from the Caregiver Diary as indicators of objective caring responsibilities. To limit the number of variables available for analysis, total time caring and intensity of caring were averaged across weekdays and weekend days. Pearson product-moment correlation coefficients showed a strong association between total time caring and intensity of caring for PCGs (r = .58, *N* = 86, *p*< .001). Similarly, there was a strong association between these two variables for SCGs (*r* = .77, *N* = 59, *p*< .001).

The Rushed/ pressed for time item and the Time Crunch scale were used to measure caregiver experience of time pressure, an indicator of subjective caring responsibilities. Results of analyses using Pearson product-moment correlations coefficients found the Rushed/ pressed for time item, and Time Crunch for PCGs to be highly correlated (r = .51, N = 95, p< .001). Results also showed a strong association between the two variables completed by SCGs (r = .50, N = 65, p< .001)

Correlations between variables measuring time pressure completed by PCGs, and variables from the Caregiver Diaries, also completed by PCGs, are shown in Table10.3. The table indicates that time use variables, as objective indicators of the extent of caring responsibilities were not significantly related to psychological perceptions of time pressure experienced by PCGs.

Table 10.3
Pearson product-moment correlation coefficients showing relationships between variables measuring time pressure and variables measuring time use from the Caregiver Diaries, for ***primary caregivers***

Primary caregivers	Total time caring (N = 86)	Intensity of caring (N = 86)
Rushed/ pressed for time	.07	.15
Time Crunch	.16	.07

A similar pattern of results is shown in Table 10.4, for the variables measuring time pressure completed by SCGs, and the variables taken from the Caregiver Diaries also completed by SCGs. No correlation was significant indicating that the lack of association between time pressure and measures of time use was not a function of caregiver status.

Table 10.4
Pearson product-moment correlation coefficients between variables measuring time pressure and time use from the Caregiver Diaries, for secondary caregivers

Secondary caregivers	Total time caring (N = 59)	Total intensity of caring (N = 59)
Rushed/ pressed for time	.04	-.01
Time Crunch	.05	-.14

10.31.4 Moderator variables: Partner support

The Carer Support Scale was completed by PCGs, but not SCGs. The following analyses, relating the two variables used to measure partner support in Study 2 were therefore specific to primary caregivers. Moderate correlations were found between the Spouse subscale of the PSI and the Received Support subscale of the CSS completed by PCGs (r=-.37, N=78, p<.01); and between the Spouse subscale and the Ideal Support subscale also completed by PCGs (r=.48, N=76, p<.001). A large correlation between the Received Support subscale of the CSS and the Ideal Support subscale of the CSS, both completed by PCGs (r=-.52, N=77, p<.001) indicated higher scores for received support (reflecting greater levels of practical support provided by the partner of the PCG) were associated with lower scores on the Ideal support subscale (reflecting greater satisfaction of the PCG for the practical support received from their partner).

10.31.5 Summary: Preliminary analyses (1)

The first set of preliminary analyses examined correlations between variables taken from measures making up the components of the model of carer well-being (ie stressors, outcomes, mediating and moderating variables). These analyses were undertaken to direct the selection of variables and to prevent the problem of multicollinearity in future regression procedures. When variables measuring the same construct showed high levels of association, only one of those variables was used in subsequent analyses. Variables showing low levels of association were retained for future analyses.

Stressors: Severity of child disability

The lack of association between the WeeFIM® and the SDQ, completed by PCGs, suggested subsequent analyses should include both variables as indicators of severity of disability. The small but significant association between scores for the WeeFIM® and the SDQ, completed by SCGs, suggested *either* the WeeFIM or the SDQ be used.

Caregiver outcomes:

Strong relationships between all outcome measures used in the study, for both PCGs and SCGs, suggested it was appropriate for one variable to be chosen to represent carer outcomes, for use in regression analyses. The total depression score from the CES-D was chosen for this purpose, although other outcome measures (particularly the total strain score from the CGSQ) achieved consistently larger correlations with other outcome variables. The reasons for this choice were two-fold: (1) the total depression score was considered to most directly reflect the psychological functioning of parents, and (2) the CES-D has been more commonly used in previous research examining outcomes for parents of children with disabilities (Baker et al , 2003; Breslau, Staruch, & Mortimer, 1982; Bristol, Gallagher, & Schopler, 1988).

Mediating variables: Time pressure and time use

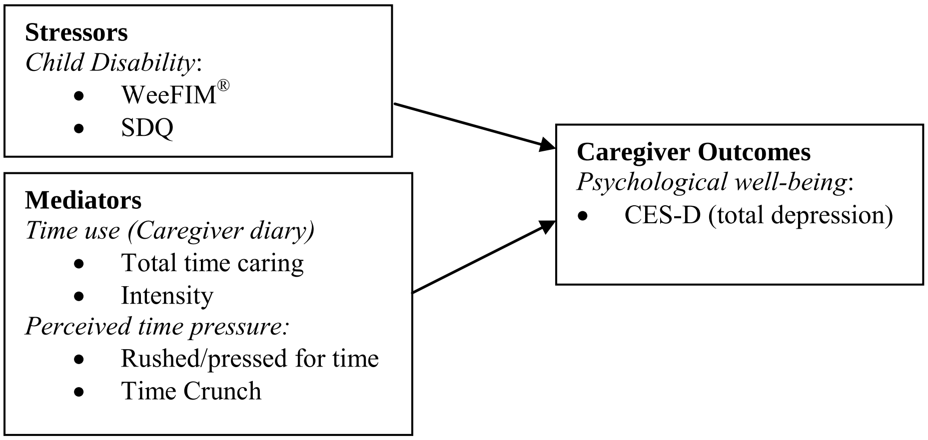
Variables assessing time spent caring, and intensity of caring were not significantly correlated with variables assessing time pressure, for either PCGs or SCGs. This would suggest that objective indicators of caring responsibilities and subjective indicators of caring responsibilities should be independently represented in regression analyses. Significant correlations between the different measures of time pressure (ie Rushed/ pressed for time and Time Crunch), and between the measures of caring time taken from the Caregiver Diary (ie total time caring and intensity of caring), suggested that only one of measure of time pressure and only one measure of caring time was required for subsequent analyses for PCGs. Similarly, results suggest only one measure of time pressure, and either total time caring or intensity of caring on weekdays or weekend days be chosen for SCGs.

Moderating variables: Partner Support

Significant correlations between the Spouse subscale, and the Received Support and Ideal Support subscales of the CSS suggest only one of these variables be used in regression analyses for PCGs. The Spouse subscale of the PSI was the only moderating variable available to SCGs.

10.32 Preliminary analyses (2): Relationships between total depression, characteristics of disability, time use and time pressure

The second set of analyses, again using Pearson product-moment correlation coefficients, aimed to identify which of the variables used to measure severity of child disability, and which of the variables used to measure time pressure and time use, demonstrated significant relationships with caregiver depression, as shown in Figure 10.5. Analyses were undertaken separately for PCGs and SCGs.



Note. SDQ=Strengths and Difficuties Questionnaire; CES-D=Centre for Epidemiologic Studies-Depression Scale

Figure 10.5. Variables included in analyses between stressors, mediators and caregiver depression.

10.32.1 Severity of child disability and caregiver depression

The relationship between the total depression scale from the CES-D and the total WeeFIM® quotient was not significant for PCGs (*r*=.06, *N*=95, *p*=.56) or SCGs (*r*=.20, *N*=65, *p*=.11), suggesting severity of the child‟s impairment in functional abilities was not related to the number of depressive symptoms reported by caregivers. In contrast, a moderate significant correlation between total emotional and behavioural problems from the SDQ and the total depression scores from the CES-D was found for PCGs (*r*=.37, *N*=94, *p*<.001) and a small significant correlation for SCGs (*r*=.26, *N*=64, *p*<.05), with higher levels of child emotional and behavioural problems was associated with higher levels of carer depression.

10.32.2 Time pressure and time use, and caregiver depression

Table 10.5 shows correlations between the measures of time pressure used in the study, the variables derived from the Caregiver diary, and the total depression scale from the CES-D completed by PCGs.

Table 10.5

Pearson product-moment correlation coefficients between total depression (CES-D) and measures of time pressure and time use for ***primary caregivers***

Primary caregivers	Total depression (CES-D)
Rushed/ pressed for time (*N* = 95)	.43***
Time Crunch (*N* = 95)	.65***
Total time caring (*N* = 86)	.02
Total intensity of caring (*N* = 86)	.02

Note. CES-D = Centre for Epidemiological Studies – Depression Scale
***p<.001

The results show moderate to strong relationships between Rushed/ pressed for time and total depression scores from the CES-D, and also between Time Crunch and total depression. In contrast, relationships between total time caring and total depression, and total intensity of caring and total depression were not significant.

Table 10.6 shows correlations between variables measuring time pressure, the time use variables from the Caregiver Diary, and the total depression scale from the CES-D, completed by SCGs.

Table 10.6

Pearson product-moment correlation coefficients between total depression (CES-D) and measures of time pressure and time use for ***secondary caregivers***

Secondary caregivers	Total depression (CES-D)
Rushed/ pressed for time (*N*=65)	.23
Time Crunch (*N*=65)	.61***
Total time caring-weekdays (*N*=59)	.17
Intensity weekdays (*N*=59)	.06

Note. CES-D = Centre for Epidemiological Studies – Depression Scale
****p*<.001

Results indicate the strongest relationship for measures obtained from SCGs, was between Time Crunch and total depression. Total time spent caring on weekdays and intensity of caring on weekdays were shown to have non significant relationships with total depression.

10.32.3 Summary: Preliminary analyses (2)

The second set of analyses examining correlations between caregiver depression and measures of stressors and mediating variables were intended to provide further evidence to help identify the best selection of variables for subsequent analyses testing the model of carer well-being. Results are considered in association with results from the first set of preliminary analyses.

Child disability:

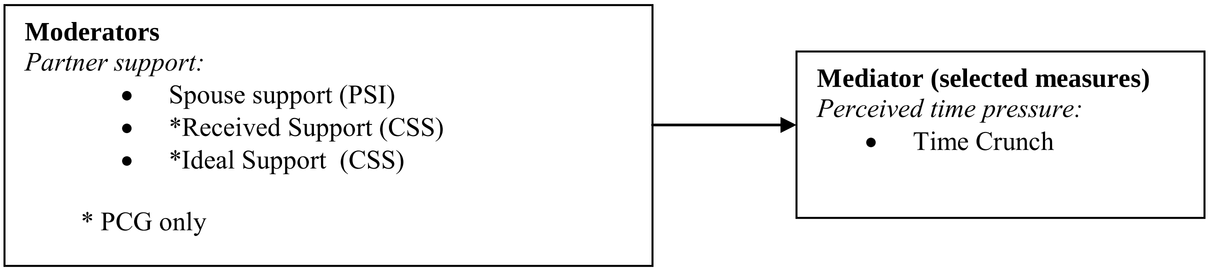
Total emotional and behavioural problems scores from the Strengths and Difficulties Questionnaire were more strongly associated with PCG and SCG total depression scores from the CES-D, than was the total WeeFIM® quotient. Total emotional and behavioural problems scores, therefore, were used to reflect severity of child disability, in preference to the total WeeFIM® quotient, in regression analyses.

Mediating variables:

Time Crunch was more strongly related to PCG and SCG total depression scores, than was the Rushed/ pressed for time item. Time Crunch was therefore chosen to be the variable measuring time pressure, a potential "mediator" of caregiver outcomes, for regression analyses. In contrast, measures of time use derived from the Caregiver diaries (being objective measures of caring responsibilities) had weak, non significant relationships with levels of total depression scores, for both PCGs and SCGs. Total time caring and total intensity of caring were therefore not included in subsequent analyses.

10.33 Preliminary analyses (3): Relationships between variables assessing time pressure (mediating variables) and partner support (moderating variables)

The third step in preliminary analyses was to examine relationships between the different measures of partner support, proposed to be a moderating variable in the present study, and variables used to assess time pressure and time use, selected in the earlier preliminary analyses as shown in Figure 10.6. The theoretical model suggests that partner support moderates the impact of time pressure and time use on caregiver outcomes. This presupposes significant relationships between the variables.



Note. PSI = Parenting Stress Index; CSS = Carer Support Scale
PCG = Primary caregiver

Figure 10.6 Variables used in analyses examining moderator and mediator constructs

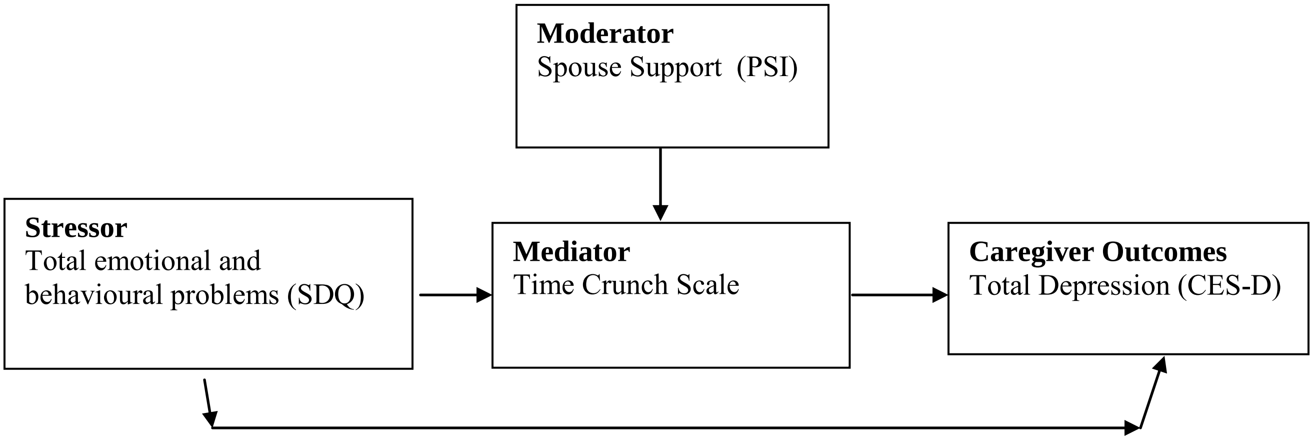
The relationship between Time Crunch and the Spouse Support subscale for PCGs was strongly significant (*r*=.58, *N*=88, *p*≤.001), with higher feelings of time pressure associated with less satisfaction with spouse support (higher scores on the Spouse Support scale indicted lower levels of perceived support). The relationship between Time Crunch and Received Support from the Carer Support scale completed by PCGs was moderately significant (*r*=-.37, *N*=79, *p*≤.01), with higher feelings of time pressure associated with less practical support received from partners. The relationship between Time Crunch and Ideal Support from the Carer Support Scale was also moderately significant (*r*= .41, *N*=77, *p*<.001), with higher time pressures associated with less satisfaction with partner support. Results for SCGs also indicated a strong, significant association between Time Crunch and Spouse Support (*r*=.60, *N*=65, *p*<.001).

10.33.1 Summary: Preliminary analyses (3)

Results of the final set of preliminary analyses showed significant correlations between all measures of partner support and Time Crunch for PCGs and SCGs. The Spouse Support subscale from the Parenting Stress Index completed by PCGs was more strongly related to Time Crunch than either of the subscales from the Carer Support Scale. The Spouse Support subscale was therefore chosen to be the variable measuring partner support, a potential moderator of time pressure, in the next set of analyses undertaken for PCGs.

10.34 Regression analyses

The results from preliminary analyses identified the most appropriate variables for inclusion in the regression analyses testing the theoretical model. The number of variables identified for PCGs (*N* = 87) complies with the formula for sample size suggested by Tabachnick and Fidell, 2000 (ie 87 > 50 + (8*4)). The sample size for SCGs (*N* = 64) is somewhat small on this criterion, however, other authors use less stringent guidelines (Stevens (1996) for example proposes 15 participants per predictor variable). The scarcity of research exploring the experience of SCGs argues for continuing with regression analyses for this group. Figure 10.7 shows the variables used to test the models for the selected outcome measure (CES-D), for both PCGs and SCGs.



Note. SDQ = Strengths and Difficulties Questionnaire; PSI = Parenting Stress Index; CES-D = Centre for Epidemiologic Studies-Depression Scale

Figure 10.7. Variables used to test the model of carer well-being predicting primary caregiver and secondary caregiver depression.

The model of carer well-being predicts parents will experience higher perceived time pressure as a consequence of caring for children with disabilities. Parents of children with higher levels of emotional and behavioural problems (as an indicator of severity of disability) are predicted to be more likely to feel time pressured and therefore more likely to have higher levels of depressive symptoms. The model also proposes that increased partner support will moderate the experience of time pressure, such that higher levels of partner support will reduce perceptions of time pressure and lower levels of partner support will increase feelings of time pressure, thereby indirectly influencing severity of psychological distress in caregivers.

10.34.1 Moderated mediation model

The hypotheses arising from the moderated mediation model in the present study were assessed with standard simultaneous regression procedures using the SPSS macro of Preacher et al (2007), described earlier in this chapter. The specific moderated mediation model tested (Model 3 in Preacher et al., 2007) proposed the independent (or predictor) variable to be total emotional and behavioural problems from the Strengths and Difficulties Questionnaire (SDQ: IV), the mediator (M) to be Time Crunch, the dependent variable to be total depressions from the Centre for Epidemiologic Studies – Depression Scale (CES-D: DV), and the moderator variable to be the Spouse Support subscale from the Parenting Stress Index (Spouse Support:W).

Results of analyses for PCGs are shown in Table 10.7. The first part of the table (mediator variable model) shows the results of a simple regression predicting Time Crunch from SDQ were significant (coefficient = .51, $p < .01$) that is, the Time Crunch score increases by one *SD* for one *SD* increase in SDQ score. The second part of the table (dependent variable model) shows the results of a multiple regression predicting CES-D from Time Crunch, Spouse Support, SDQ and the interaction between Time Crunch and Spouse Support (Time Crunch X Spouse Support). The table shows there was no interaction (interaction coefficient = .00, $p = .99$). This indicates the effect of Time Crunch in predicting CES-D scores for PCGs does not depend on Spouse Support. That is, the measure of partner support chosen for these analyses does not moderate the variable measuring perceived time pressure for PCGs, as predicted by the model of carer well-being

Table 10.7
Summary of standard regression analyses testing the moderated mediation model for ***primary caregivers*** *(N=87):*
(1)Time Crunch as a mediator (M) of the relationship between SDQ total emotional and behavioural problems (IV) and CES-D total depression (DV)
(2) Spouse Support as a moderator of the relationship between Time Crunch (IV) and CES-D total depression (DV)

	Mediator variable model: SDQ (IV) as a predictor of Time Crunch (M)			
Predictor	*B*	*SE*	*t*	*p*
SDQ	.51	.16	3.14	<.01

	Dependent variable model: Predicting CES-D (DV)			
Predictor	*B*	*SE*	*t*	*p*
SDQ	.06	.03	2.10	<.05
Time Crunch	.10	.06	1.88	.06
Spouse Support	.03	.10	.27	.79
Time Crunch by Spouse Support interaction	.00	.00	-.01	.99

Note. SDQ = Strengths and Difficulties Questionnaire; CES-D = Centre for Epidemiologic Studies-Depression Scale
$R^2 = .46, p<.001$

Results of analyses for SCGs are shown in Table 10.8. The outcome of analyses was identical to those obtained with PCGs. That is, SDQ significantly predicted Time Crunch (coefficient = .41, *p*<.05) but a nonsignificant interaction coefficient (interaction coefficient = -.00, *p* =.69) indicated Spouse Support did not influence the effect of Time Crunch in predicting

CES-D scores for SCGs. That is, partner support did not moderate time pressure for SCGs, as predicted by the model of carer well-being.

Table 10.8
Summary of standard regression analyses testing the moderated mediation model for ***secondary caregivers*** *(N=64):*
(1)Time Crunch as a mediator (M) of the relationship between SDQ total emotional and behavioural problems (IV) and CES-D total depression (DV)
(2) Spouse Support as a moderator of the relationship between Time Crunch (IV) and CES-D total depression (DV)

	Mediator variable model: SDQ (IV) as a predictor of Time Crunch (M)			
Predictor	*B*	*SE*	*t*	*p*
SDQ	.41	.16	2.58	<.05

	Dependent variable model: CES-D (DV)			
Predictor	*B*	*SE*	*t*	*p*
SDQ	-.00	.03	-.04	.97
Time Crunch	.11	.09	1.28	.21
Spouse Support	.14	.14	1 .05	.30
Time Crunch by Spouse Support interaction	-.00	.00	-.40	.69

Note. SDQ = Strengths and Difficulties Questionnaire; CES-D = Centre for Epidemiologic Studies-Depression Scale
R^2= .44, <.001

10.34.2 Moderation or mediation models

Further analysis of the data was undertaken to examine whether Spouse Support, rather than moderating the influence of Time Crunch, directly moderated the relationship between SDQ and CES-D, that is, to test the possibility that partner support influenced the impact of child emotional and behavioural problems on caregiver depression. To examine this hypothesis, two sets of multiple regression procedures were undertaken following Baron and Kenny (1986). First, the direct contribution of SDQ and Spouse Support in predicting CES-D was examined. The next step involved the introduction of an interaction variable, created between SDQ and Spouse Support (SDQ X Spouse Support). Table 10.9 shows that neither of the interaction coefficients, for PCGs or SCGs, were significant. That is, Spouse Support did not moderate the relationship between SDQ and CES-D. In contrast, significant direct (or main) effects were found for Spouse Support, for both PCGs and SCGs, indicating this variable has a mediating rather than a moderating role in contributing to caregiver well-being. Spouse Support accounted for 13% and 26% of the variance in depression scores for PCGs and SCGs respectively.

Table 10.9

Summary of standard regression analyses: Spouse Support as a moderator of the relationship between SDQ (IV) and CES-D (DV) for primary caregivers (PCGs: N=87) and secondary caregivers (SCGs: N=64)

Predictor	*B*	*SE*	*t*	*p*
Step1				
PCG				
SDQ	.08	.03	2.63	<.05
Spouse Support	.09	.02	3.83	<.001
SCG				
SDQ	.01	.03	.27	.79
Spouse Support	.15	.03	4.91	<.001
Step 2				
PCG				
SDQ	.17	.11	1.57	.12
Spouse Support	.17	.09	1.90	.06
SDQ X Spouse Support	-.00	.01	-.87	.39
SCG				
SDQ	.05	.11	.49	.63
Spouse Support	.19	.10	1.98	<.05
SDQ X Spouse Support	-.00	.01	-.43	.67

Note. SDQ = Strengths and Difficulties Questionnaire; CES-D = Centre for Epidemiologic Studies-Depression Scale
Step 1 PCG $R^2 = .23$, $p<.001$, SCG $R^2 = .33$, $p<.001$;
Step2 PCG $R^2 = .28$, $p<.001$, SCG $R^2 = .34$, $p<.001$

Further analysis using multiple regression procedures was also undertaken to identify whether, as predicted, Time Crunch also had a mediating role in contributing to caregiver depression independently of Spouse Support. Table 10.12 shows the results of analyses for PCGs and SCGs, confirming a significant direct effect for Time Crunch which accounted for 30% of the variance in caregiver depression scores in both data sets.

Table 10.10
Summary of standard regression analyses: Time Crunch as a mediator (M) of the relationship between SDQ total emotional and behavioural problems (IV) and CES-D total depression (DV) for primary caregivers (PCGs: N=87) and secondary caregivers (SCGs: N=64)

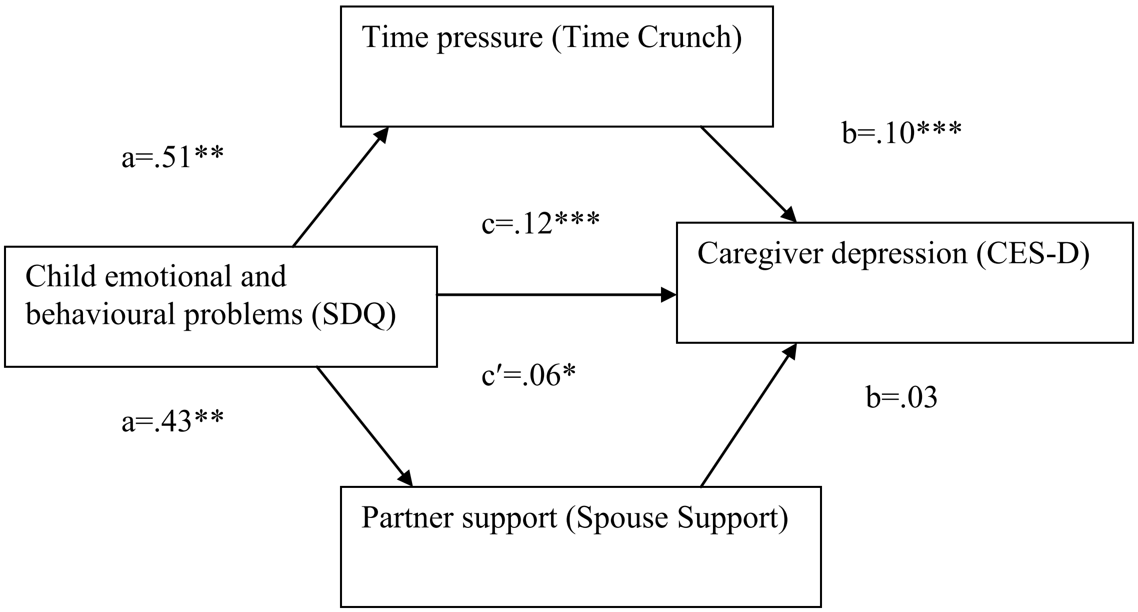
Predictor	*B*	*SE*	*t*	*p*
PCG				
SDQ	.06	.03	2.37	<.05
Time Crunch	.11	.02	6.77	<.001
SCG				
SDQ	.02	.03	.79	.43
Time Crunch	.11	.02	5.37	<.001

Note. SDQ = Strengths and Difficulties Questionnaire; CES-D = Centre for Epidemiologic Studies-Depression Scale
PCG $R^2 = .45$, $p<.001$, SCG $R^2 = .37$, $p<.001$

10.34.3 Multiple mediation models

A final stage of analyses examined the contributions of both Time Crunch and Spouse Support in mediating between SDQ and CES-D. Another SPSS macro provided by Preacher and Hayes (under review) for investigations of multiple mediation models was used for this stage of analyses. Preacher and Hayes suggest analyses should firstly address whether both mediators contribute to the effect of the independent variable (ie SDQ) on the dependent variable (ie CES-D). Secondly, they recommend an investigation of individual mediators in the context of a multiple mediator model, that is, an exploration of the comparative contribution of the indirect effects of each mediator. In the case of the present study, the second stage of investigation would examine which of Time Crunch or Spouse Support has the strongest role to play in mediating between child emotional and behavioural problems and caregiver depression.

Figure 10.8 depicts the results of regression analyses testing proposed mediator variables, Time Crunch and Spouse Support for PCGs. The results suggest that taken together, Time Crunch and Spouse Support mediate the effect of SDQ on CES-D as reported by PCGs, accounting for 41% of the variance in depression scores. The difference between the total and direct effects (the c and c′ paths) is the total indirect effect through the two mediators with a point estimate of .0632 and a 95% bias corrected and adjusted bootstrap confidence interval (CI) of .0273 to .1159 with 5000 resamples (ie this result indicates the difference between the total and the direct effect of SDQ and CES-D is significantly different from zero). This result coincides with normal theory testing using Sobel‟s (1982) test ($z = 3.02$, $p<.01$). The directions of the a and b paths are consistent with the interpretation that higher levels of child emotional and behavioural problems lead to higher feelings of time pressure and less perceived partner support, which in turn lead to more depressive symptoms experienced by PCGs. An examination of specific indirect effects indicates only Time Crunch is a mediator, as its 95% CI: (.0170, .1098) does not contain zero, that is, Spouse Support does not contribute to the indirect effect above and beyond Time Crunch. The results of normal theory testing using Sobel‟s test also show a significant result for Time Crunch (z=2.72, *p*<.01), and a nonsignificant result for Spouse Support (z=.99, *p*=.33).

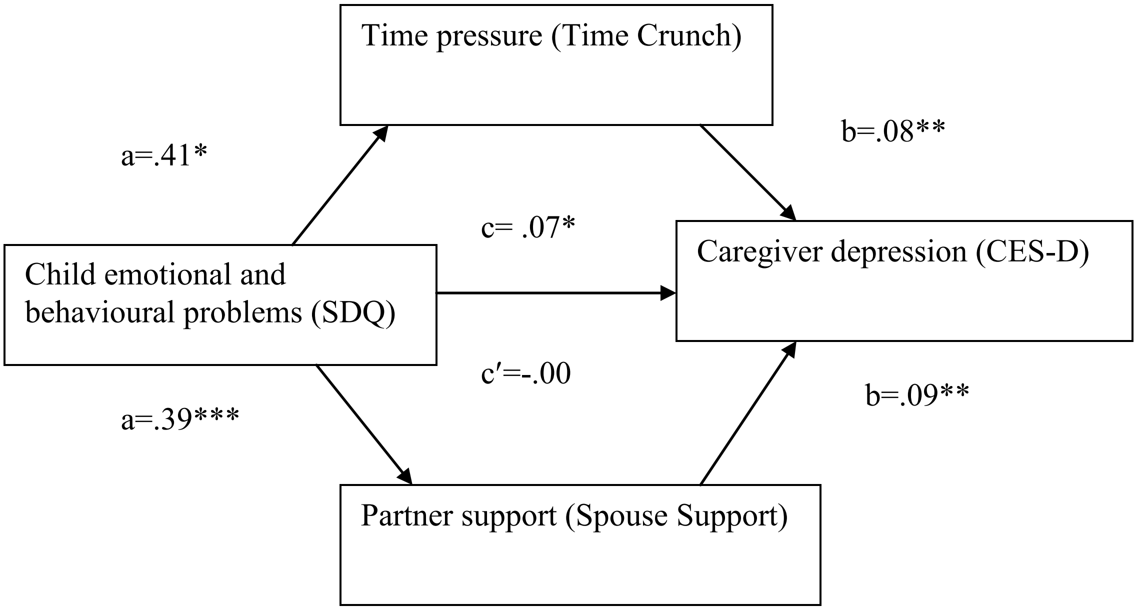


Note. SDQ = Strengths and Difficulties Questionnaire; CES-D = Centre for Epidemiologic Studies-Depression Scale
R^2= .46, *p*<.001, **p*<.05.***p*<.01,****p*,.001

Figure 10.8. Summary of standard regression analyses testing for a multiple mediator model: Time Crunch and Spouse Support as mediating the relationship between SDQ (IV) and CES-D (DV) for primary caregivers (*N*=87).

Results of analyses to examine the action of multiple mediators for SCGs are displayed in Figure 10.9. The results suggest Time Crunch and SDQ act together in mediating the effect of SDQ on CES-D, accounting for 41% of the variance in depression scores. The total indirect effect through the three mediators has a point estimate of .0674 and a 95% bootstrap CI: (.0324, .1088) indicating the difference between the total and direct effect is significantly different from zero. This result coincides with results of Sobel‟s test (z = 3.01, *p*<.01). The direction of the a and b paths in Figure 10.7, as for PCGs, are consistent with the interpretation that higher levels of child emotional and behavioural problems lead to higher feelings of time pressure and less perceived partner support, which in turn lead to more depressive symptoms experienced by SCGs.

Examination of specific indirect effects indicates that both Time Crunch [95% CI: (.0093, .0670)] and Spouse Support [95% CI: (.0142, .0723)] mediate between SDQ and CES-D. The results of normal theory testing using Sobel‟s test are also significant for Time Crunch (z =2.07, *p*<.05), and Spouse Support (z = 2.19, *p*<. 05).



Note. SDQ = Strengths and Difficulties Questionnaire; CES-D = Centre for Epidemiologic Studies-Depression Scale
R^2= .44, *p*<.001, **p*<.05, ***p*<.01,****p*.001

Figure 10.9. Summary of standard regression analyses testing for a multiple mediator model: Time Crunch and Spouse Support as mediating the relationship between SDQ (IV) and CES-D (DV) for secondary caregivers (*N*=64).

10.34.4 Summary of model testing

Results of analyses showed the moderated mediation model proposed in earlier chapters to explain the relationship between child disability and caregiver well-being was not upheld by the present data. Partner support, while initially suggested as having a moderating influence, was shown instead to have a mediating role in explaining the relationship between child problems and caregiver outcomes. When time pressure and partner support were considered together, however, only time pressure was shown to be a significant contributor to PCG levels of depression. Thus, results for PCGs indicate higher levels of child emotional and behavioural problems lead to greater feelings of time pressure, which in turn lead the caregiver to experience higher levels of depressive symptoms. The results for SCGs showed both time pressure and partner support to be significant contributors to the relationship between child disability and caregiver outcomes. Thus, higher levels of child emotional and behavioural problems lead to both greater time pressure and less perceived partner support, which in turn leads to more depressive symptoms for SCGs.

The results also show measures of time pressure to be unrelated to measures of time use reflecting actual time spent caring. Both variables were proposed as mediating variables in the theoretical model, but results of regression analyses showed only time pressure to mediate between child emotional and behavioural problems and caregiver depression for PCGs and SCGs.

10.4 Conclusions

Results of preliminary analysis, in addition to identifying the most appropriate variables to test the model of carer well-being, also provided some information worthy of independent note. Firstly, when considering the inter-correlations between the different variables measuring the component of the model, it was found that:

- The two variables used to reflect different aspects of the severity of child disability (ie the total WeeFIM quotient and the total emotional and behavioural problems score from the SDQ) were not significantly related for PCGs. Results for SCGs a small but significant likelihood that children with poorer functional skills would also experience emotional and behavioural problems.

- Results for the different variables assessing carer outcomes (ie the CES-D total depression score; the Role restriction, Social isolation and Physical health subscales of the PSI; and the total strain score from the CGSQ) showed them to be strongly related to each other. Thus, parents with higher levels of depressive symptoms were more likely to report feeling role restricted, to experience more social isolation, poorer physical health and more total caregiver strain than parents who showed lower levels of depressive symptoms.

- The strong relationships between the variables Rushed/ pressed for time and Time Crunch, for both PCGs and SCGs, confirmed they were measuring the single concept of "time pressure". Of particular interest, however, is the lack of association between the variables assessing time pressure, and the variables taken from the Caregiver Diary, measuring actual time use. Thus, the *experience* of time pressure was consistently found to be unrelated to *absolute measures* of total time caring, or *intensity of caring* for both PCGs and SCGs.

- Finally, results of comparison between the different variables assessing partner support suggested they were measuring a single concept, providing evidence of the validity of the Carer Support Scale developed specifically for the present study. Further, the negative relationship between received support and perceived support indicate PCGs to feel more supported when they receive a higher level of practical support from their partners, or alternatively, to feel less supported when they receive less practical support from their partner.

Results of the second set of preliminary analyses were aimed at assessing the extent of association between the variables measuring different aspects of severity of child disability, variables measuring time pressure and time use, and the CES=D total depression score for both PCGs and SCGs. The results indicated:

- Of the two measures of severity of child disability, functional skills and emotional and behavioural problems, emotional and behavioural problems had the strongest relationship with parent depression. This result is consistent with previous research (Floyd & Gallagher, 1997; Baker et al, 2005).

- Of the variables measuring time pressure and time use, Rushed/ pressed for time and Time Crunch had the strongest relationship with parent depression for PCGs and SCGs. Thus, the experience of time pressure was more likely to lead to poorer psychological well-being, than actual time spent caring. Time Crunch also had the strongest relationship with levels of depressive symptoms for SCGs.

The final set of preliminary analyses examined the relationship between variables assessing partner support, and variables measuring time pressure and time use. Results indicated:

- Partner support to be strongly associated with subjective reports of time pressure for both PCGs and SCGs. Thus, parents who reported receiving less practical and other support from their partners, were more likely to report experiencing higher levels of time pressure. As well, PCGs who were less satisfied with the amount of partner support provided, also experienced more time pressure.

Results of analyses provided partial support for **Hypothesis 6.** More specifically, total time spent caring and intensity of caring did not mediate the effects of child disability on the psychological and physical well-being of either primary or secondary carers. However, there was evidence to support the role of time pressure in mediating the relationship between severity of child disability (as reflected by the extent of emotional and behavioural problems) and carer depression.

Hypothesis 7 was not supported by the results of the present study. That is, partner support did not moderate the impact of total time spent caring and carer experience of time pressure to improve carer psychological and physical well-being. Instead, parent support was shown to have a mediating role in explaining the relationship between child disability and carer outcomes for both primary and secondary carers. This result is consistent with previous research undertaken by Quittner et al (1990) who found social support mediated the relationship between chronic parenting stress and depression and anxiety in caregivers of children with sensory disabilities.

In summary, the moderated mediation model of carer well-being proposed in Figure 10.1 was not supported by the results of the present study. Further exploration of the data was undertaken to identify a more accurate model representing the relationships between the variables used. Results for PCGs indicated that, while both partner support and time pressure independently mediated the relationship between severity of child disability (as reflected by the extent of emotional and behavioural problems) and carer depression, when considered together only time pressure was a significant contributor to the level of depressive symptoms accounting for 41% of the variance in depression scores. PCGs of children with developmental disabilities and additional emotional and behavioural problems were more likely to feel time pressured, and in turn more likely to experience higher levels of depressive symptoms.

Results for SCGs also highlighted the role of time pressure in explaining the level of depressive symptoms experienced by parents. In contrast to the findings for PCGs, however, a multiple mediation model in which both partner support and time pressure contributed to carer outcomes was found, also accounting for 41% of the variance in depression scores. SCGs of children with developmental disabilities and additional emotional and behavioural problems were more likely to feel time pressured, and to report themselves to have less partner support, and in turn more likely to experience higher levels of depressive symptoms.

To conclude, while failing to find support for a moderated mediated relationship, the present study found significant evidence for the importance of time pressure in contributing to the psychological well-being of primary and secondary carers of young children with developmental disabilities. Partner support was also found to have an important role in contributing to the well-being of secondary carers.

SECTION 4:

GENERAL DISCUSSION

CHAPTER 11

Summary and conclusions

The rapid increase in home based care of children with disabilities has led to extensive additional demands on the time and resources of their parents. The research described in the present dissertation aimed to shed new light on the challenges of caring for young children with developmental disabilities, specifically highlighting the impact of caring responsibilities and the time constraints of caring. The first study undertaken as part of the dissertation involved a series of focus groups held with mothers of children with disabilities. Results of qualitative analysis found “time” to be a key theme for mothers, giving evidence for a new theoretical model to explain carer well-being. The model, derived from previous research, proposed caring responsibilities to mediate between child disability and parent psychological, social and physical health outcomes. Caring responsibilities were defined as the time spent caring and intensity of caring, as well the subjective experience of time pressure. A second study was undertaken to provide quantitative data to test the model of carer well –being in a sample of parents of pre-school aged children with developmental disabilities. In doing so, it uniquely combined diary methodologies to obtain accurate measures of the impacts of caring on the time use of parents caring for children with disabilities, as well as standardised measures of parent outcomes. Consistent with a “contextual approach”, measures were specifically chosen to reflect the experience of caring. A measure of partner support was developed for the study, focusing on the level of practical help given by secondary cares to primary carers, and satisfaction with this support. The study collected information from primary caregivers and secondary caregivers, enabling a comprehensive examination of the different patterns of time use, and different outcomes for parents.

The following discussion will be organised around the aims and hypotheses derived from the model of carer well-being, that formed the basis of the research undertaken for the present dissertation.

11.1 Time use of parents caring for young children with developmental disabilities

11.11 Comparisons with parents in the general community

There have been few previous studies examining the time use of parents of children with disabilities, nearly all involving mothers only, and very few with sample sizes comparable to that obtained in Study 2. While several of studies have found no differences in overall time spent caring (Breslau, 1983; Gevir et al., 2006; Lucca & Settles, 1981), many have found parents of children with disabilities spend more total time caring than do parents of normally developing children (Barnett & Boyce, 1995; Cant, 1994; V. Harris & McHale, 1989; Johnson & Deitz, 1985; Padeliadu, 1998). Variations in research methods, however, have contributed to inconsistencies in results. In particular, discrepancies in what tasks are considered to constitute "caring" have led to substantial differences in total time reported. The present study found mothers (rather than primary carers for this analysis) of pre-school aged children with disabilities spend an average of between 9 and 10 hours caring a day ie the majority of child waking hours. This result is comparable to that of Brust, Leonard and Sielaff (1992) whose definition of caring included “vigilance” activities, similar to the “general supervision” and “watching carefully” categories used in Study 2. It is much more, however, than studies with narrow definitions of caring. Lucca and Settles (1981), for example, found mothers spent between 1 and 1½ hours a day on “caring” activities. In that case, caring activities constituted only physical care tasks such as bathing, feeding, dressing and medical care. When examining time spent in individual child care activities, parents in Study 2 spent between 2 and 3 hours in physical care activities, a figure that is closer to that found by Lucca and Settles. The hour difference may be accounted for by the younger ages of children in Study 2, as younger children can be expected to require more care, and by methodological differences related to the way in which the time use data was collected.

Analysis of data from diaries collected in the 1997 Time Use Survey (ABS, 1997) showed parents in the general community to also spend between 9 and 10 hours a day caring, suggesting that caring for young children, regardless of whether they have a developmental disability or not, is a “full-time” job. It is unlikely that small variations in time spent caring between parents of young children with disabilities and parents of young children without disabilities, if found, would have been very meaningful given the considerable overall time commitment involved. It is more useful to examine differences in the types of caring undertaken by parents of children with disabilities in Study 2, and parents in the general community who participated in the 1997 TUS. The most significant finding from such a comparison was that mothers and fathers who participated in the TUS spent most time “minding” their child while mothers and fathers in Study 2 spent most time teaching, helping and reprimanding their children. This pattern was present across weekdays and weekend days.

Differences in the types of caring tasks undertaken by parents in Study 2 and parents of children in the general community reflect the needs of children with developmental disabilities who are of pre-school age, and receiving early intervention services. All children whose parents participated in Study 2 were experiencing significant delays in all areas of development. All children, therefore, required some level of extra help with tasks of daily living, and were also receiving therapeutic support from the staff of the Early Childhood Services. Recent research highlighting the crucial role of parents in helping children to achieve developmental outcomes has led to greater involvement of parents in their children‟s treatment and therapy (Benson et al., 2008; Dunst et al., 2002; Raghavendra et al., 2007). It is not surprising, therefore that a substantial component of the caring time of parents of children with developmental disabilities is devoted to "teaching" and "helping". The higher rates of behavioural problems found in children with disabilities (Baker et al., 2003; Donenberg & Baker, 1993; Floyd & Gallagher, 1997), also help to explain extra time spent in behaviour management.

In addition to extra time spent in teaching, helping and behaviour management, parents in Study 2 also spent significantly more time in physical care of their child than parents in the 1997 TUS, suggesting that the care of children with developmental disabilities requires more active involvement of parents than does the care of children in the general community. This is consistent with the findings that most of the child care undertaken by parents of young children who participated in the 1997 TUS was categorized as "minding" (ie general supervisory activities). Further, most child care undertaken by parents who participated in the 1997 TUS was recorded as a secondary, rather than a primary activity. That is, parents in the general community were able to engage in activities other than caring at the same time as looking after their children. It is of note that time spent in qualitative activities such as playing, reading or talking to children, did not differ between parents of children in Study 2 and parents of children in the general community. This would suggest that the extra care required by children with developmental disabilities is mostly related to routine, daily care activities that may be less rewarding for parents. This may be an important factor when considering psychological outcomes for these parents as will be discussed later.

The need to spend more time actively involved with children, together with less opportunities to engage in other activities at the same time as caring, means that parents in Study 2 were required to limit time spent on other, non-caring activities. Results of comparisons with parents who took part in the 1997 TUS showed mothers and fathers in Study 2 consistently spent less time in their own personal care (ie they spent less time sleeping, in personal hygiene activities, and in eating and drinking). As well, they spent less time in recreational activities. This pattern of results is consistent with that found in other studies (Cant, 1994; Crowe & Florez, 2006; Erickson & Upshur, 1989; Lucca & Settles, 1981). Missing between ½ hour to an hour of sleep per day in addition to rushing or skipping mealtimes, may be expected to have substantial impacts for parental well-being.

In addition to other non-caring activities, parents in Study 2 participated in employment or study on fewer weekdays and weekend days than mothers and fathers in the general community (despite spending the same amount of time on days when they did engage in paid work). These results, however, were not statistically significant most likely because the measure used only indirectly assessed participation in employment. A better approach would be to ask about patterns of employment over a longer period to be more consistent with employment surveys. Previous studies have shown mothers of children with disabilities are less likely to return to work as their children get older, and also spend less time in work overall (Barnett & Boyce, 1995; Cant, 1994; Curran, Sharples, White, & Knapp, 2001; Gordon et al., 2007). Mothers in the focus groups described in Chapter 5 suggest one reason for this is that the additional needs of children with disabilities make it harder to find alternative care arrangements, significantly limiting their labour force participation.

In addition to spending less time in some activities, results of comparisons with parents who participated in the 1997 TUS showed mothers in Study 2 spent significantly *more* time shopping than their counterparts with children in the general community. As well, both mothers and fathers spent more time in social activities than parents who participated in the TUS. Another study analysing data from the 1997 TUS found mothers who engaged in paid employment as well as caring for children with disabilities also spent more time socialising than other mothers (Brandon, 2007). In contrast, studies using different data sources have found evidence indicating mothers of children with disabilities generally have *less* time available for socialising than mothers of children without disabilities (Crowe, 1993; Crowe & Florez, 2006). These conflicting results are likely a consequence of methodological differences relating to definitions of activities comprising the broad category of “socialising”. This may also explain why parents in Study 2 were found to report themselves to be more socially isolated than parents of children without disabilities. Others have found, for example, that parents of children with disabilities are *more* reliant upon their partner and extended family for support (Bristol, Gallagher & Schopler, 1988; Hastings, 1997; Kazak & Marvin, 1984). They may, therefore, be *less* reliant on friends. Alternatively, mothers who participated in the focus groups in Study 1 indicated that they chose to limit their broader social networks preferring to associate only with parents in similar circumstances. Further research is needed to clarify which are the most important sources and types of support for parents of children with disabilities, and relationships between social supports, time spent socialising and feelings of perceived social isolation.

Recent shifts towards a "family-centred" approach to service delivery in agencies providing early intervention for children with disabilities, have led to a greater involvement of parents in planning and implementing therapeutic programmes for children (Raghavendra et al., 2007). The findings of the present research, however, suggest that a broader definition of family-centredness be used, requiring an assessment of the needs of other family members. In particular, the present research suggests service providers should be aware of the time constraints confronting parents of children with disabilities, especially primary caregivers who most often implement therapy programmes in the home environment. Service providers need to avoid overloading parents with extra tasks, leading to stressful outcomes and a risk that programmes do not get implemented. Recent moves towards exploring ways with parents of integrating therapy into daily routines (rather than therapy being an additional "task" that needs to be fitted into an already crowded day) may be one answer to the dilemma of meeting both child and parent needs (Brotherson & Goldstein, 1992; Donovan, VanLeit, Crowe, & Keefe, 2005) .

A number of caveats should be made regarding comparisons using the TUS, undertaken in Study 2. Firstly, the large standard deviations for time spent in caring and non-caring tasks suggest caution in assuming that all families have the same experiences when caring for children with developmental disabilities. Characteristics of children which may impact on the time use of parents will be discussed later in this chapter. Secondly, the Caregiver Diary used in Study 2 was developed with the aim of providing time use data that was comparable to that obtained from the diaries used in the TUS. The methodology to collect data for Study 2, however, differed from the process of collecting handwritten accounts of time use used in the TUS diaries. The use of pre-coded categories was, at least in part, prompted by feedback received from parents who participated in the focus groups in Study 1, who felt that a handwritten diary would be much more onerous for them to complete. The use of a different methodology in Study 2, from that used in the TUS means that the data from the diaries may not be directly comparable. The greater ease of using a pre-coded approach led parents to provide substantially greater detail about specific tasks of caring. The focus on caring meant that there was potentially less detail provided about other, non-caring activities. The coding of data from the Caregiver Diary was undertaken to be as close as possible to that used by the Australian Bureau of Statistics when analysing the TUS but it is likely that some differences in interpretation did occur also potentially impacting the direct comparability of data. Despite these difficulties, there were sufficient similarities between the data from the different diary formats to enable meaningful comparisons to be made. Future studies however, would benefit from the inclusion of a comparison group of parents caring for children without disabilities. This would also ensure greater confidence when making conclusions about the different types of caring undertaken as a consequence of caring for children with disabilities.

11.12 Comparisons between primary caregivers and secondary caregivers

The focus of the present research was on the consequences of caring for a child with a developmental disability. It was anticipated, for example, that there would be different consequences for parents who had different caring commitments. While mothers are usually the individuals who are most often the primary carer (AIHW, 2007; Craig, 2002; Craig & Bittman, 2005; Cummins, 2001), and conversely fathers are most often the secondary carer, this is not always the case. In Study 2, 12% of fathers, through circumstance or choice, were identified as the primary carer of the child with a developmental disability. The focus on caring, rather than gender, and the small but significant number of fathers undertaking the primary caring role in families who participated in Study 2, led to the analysis of data according to caring status, rather than gender, wherever possible.

Chapter 8 in the present dissertation described results of comparisons between primary caregivers and secondary caregivers. This set of analyses was undertaken as part of the first aim of Study 2, to provide a detailed picture of the time use of parents caring for children with developmental disabilities. In particular, comparisons between carers enabled a clearer understanding of the role of the primary caregiver, and the typical tasks this person is usually required to carry out. As expected, the primary caregivers of children in Study 2 spent more time caring than did secondary caregivers on all days of the week. This was the case, even though secondary caregivers were found to almost double their total time caring on weekend days. Rather than reducing their caring load to reflect the extra help they were receiving, primary caregivers also increased their total time caring on weekend days. Analysis of the different types of caring activities helps to shed some light on this finding. Results showed the increase in total time spent caring on weekend days for secondary caregivers was largely accounted for by a tripling of time spent "minding". Thus, while secondary caregivers spend more time caring on weekend days, the caring they undertake is mostly supervisory, leaving the more routine tasks of daily care to continue to be carried out by primary caregivers. Secondary caregivers, therefore, may not provide a significant respite role for primary caregivers on weekends. Interestingly, these findings are consistent with previous research showing fathers in the general community spend proportionately more of their child care in passive care or play activities (Craig, 2002). Caring for a child with a developmental disability, therefore, does not appear to alter the types of caring tasks undertaken by secondary caregivers (who are mostly fathers).

In addition to day-time caring, results of analysis of showed primary caregivers also assumed principal responsibility for night-time care. Thus, while by definition primary caregivers would be expected to spend more time caring than secondary caregivers, the results of analysis of the Caregiver Diaries showed the role of the primary caregiver includes responsibility for caring on all days of the week, and also for all hours of the night. This again reflects the feedback from mothers who attended the focus groups in Study 1, that caring is a "24/7" commitment. The results are also consistent with previous studies examining gender differences in the types of caring undertaken by parents in the general community, with women having primary responsibility for "unpaid" work including childcare (Bittman & Wajcman, 2000c; Craig, 2002).

Results of comparisons between time spent in activities other than caring by primary caregivers and secondary caregivers provided more information about the consequences of the different caring roles. As expected, secondary caregivers were more likely to engage in paid employment or study on weekdays, than primary caregivers. Approximately ⅓ of primary caregivers, however, indicated that they undertook a “second shift” of paid employment. This percentage is slightly higher than the percentage of mothers of children with severe disabilities who engaged in paid work (25%) in the study undertaken by Curran, Sharples, White and Knapp (2001), but is still much less than the 60% of mothers of children without disabilities who participated in paid employment in the same study. In addition to caring responsibilities primary caregivers in Study 2 were more likely to undertake domestic activities than secondary caregivers, on any day of the week. While more secondary caregivers participated in household chores on weekend days, they continued to spend less time in these activities than primary caregivers. Results also showed that primary caregivers generally had the same number of occasions of recreation and leisure as secondary caregivers, but spent less time doing these activities. Primary caregivers had fewer occasions of socialising than secondary caregivers on all days of the week, but spent longer in these activities on weekend days. These findings mirror the patterns of time use to be found in the general community. Thus, there is evidence that women spend considerably more time in unpaid work (including both childcare and domestic activities such as housework) than men (Bittman, 1992; Craig & Bittman, 2005). Mothers in the general community have been found to have less time available for recreation and leisure than fathers, and to be more likely to experience interruptions when engaging in leisure activities (Bittman & Wajcman, 2000c; Mattingly & Sayer, 2006).

Thus, evidence from Study 2 suggests that caring for children with developmental disabilities does not necessarily change the time use of primary caregivers and secondary caregivers, when compared to the patterns of time use to be found amongst parents in the general community. The question as to how much the differences in time use and in the types of tasks associated with the primary caregiving role are a consequence of gender, or a consequence of caring for children (regardless of whether they have a disability or not) cannot be answered by the present research. The number of fathers who identified themselves to be primary caregivers, and conversely, the number of mothers who identified themselves to be secondary caregivers were too small to allow separate analysis for these groups. If social trends lead to a growth in numbers of males undertaking primary caring responsibilities, future studies may be able to tease out the contribution of gender or caring status to parental role divisions. It is also of note that analyses of the Carer Support Scale showed primary carers in Study 2 were generally not seeking more support from their partners with caring activities. This is consistent with previous studies that have shown women to be satisfied with the division of labour in their relationship, even where they do the bulk of childcare and housework (Baxter & Webster, 1997; Crowe et al., 2000). The Carer Support Scale indicated that primary carers reported their partners to provide the most help in caring for siblings, talking about feelings and last of all, help with personal care activities for children with developmental disabilities.

In addition to recording time use, the Caregiver Diary also asked parents to rate their levels of daily stress, and to give an indication of the sorts of activities and situations that were more likely to contribute to daily stress. This information has not been collected in previous studies and complements analyses using standardised measures of stress and other psychological outcomes. The lack of an existing literature base about the daily stress of carers does however make it difficult to situate the findings of Study 2 into a broader context as comparisons with previous findings cannot be made. It is, perhaps, closest to the concept of “daily hassles” (DeLongis, Coyne, Dakof, & Folkman, 1982). The indicator of daily stress used in the Caregiver Diary, however, while reflecting the impact of daily hassles also captured the specific impacts of the demands of caring; the influence of subjective factors such as worries, and stressors arising from other settings (eg paid employment). Future studies could be undertaken to establish the concordance between simple indicators of stress, such as the daily stress indicator used in the Caregiver Diary, and other more commonly used measures of “generic” stressors (ie life event and daily hassles).

Results of the Caregiver Diary showed primary caregivers reported significantly more daily stress than secondary carers on weekdays. Daily stress, however, was not significantly related to total time spent caring. Days rated as being more stressful, therefore, were not necessarily days in which primary caregivers or secondary caregivers were required to spend more time caring. There was, however, a suggestion of a stress threshold for primary carers, with the likelihood of being “very stressed” increasing when time spent caring exceeded ten hours per day on weekend days. There was also evidence that higher levels of daily stress for primary carers were associated with “intensity” of caring, reflected by a measure of the number of different caring activities undertaken in any one day. Days in which primary caregivers were required to engage in a greater number of different caring activities were more likely to be rated as being stressful than days in which they needed to carry out a more limited range of activities. Finally, daily stress ratings for primary caregivers were also linked to a number of caring tasks.

Of particular note, results indicated primary caregivers found activities relating to teaching, helping or behaviour management to be positively associated with daily stress, and activities related to "minding" to be negatively associated with daily stress. These activities demonstrated the biggest differences between the types of caring undertaken by parents in Study 2, when compared to parents in the general community who participated in the 1997 TUS. They also show the biggest difference between primary caregivers and secondary caregivers. Results of the present research, therefore, shows that the need to undertake more "active" care, coupled with fewer opportunities to engage in "passive" care leads to significantly higher levels of daily stress in primary caregivers. The only "non-caring" variable to show a significant (albeit small) association with daily stress for primary caregivers was time spent in household chores on weekdays. A negative relationship suggests that it is the difficulty of "fitting in" responsibilities that is more stressful for primary caregivers, as found for participants in the focus groups for Study 1.

Previous studies have found the rate of sleep problems in children with intellectual disability is much higher than in typically developing children (Berkman, 2006; Cotton & Richdale, 2006). There is also evidence that childhood sleep problems are a significant source of stress for parents of children without disabilities, and also with disabilities (Richdale et al., 2000; Stores, 1996). The lack of significant association between night-time care and daily stress found in Study 2 is therefore surprising. It is likely, however, that methodogical issues contributed to this result. The Caregiver Diary was principally focused upon day-time care. The time period for parents to record their daily activities extended from 4am on the morning of one day and extended to 4 am the following day. Ratings of daily stress, therefore, may not necessarily have related to nights in which care was required. A more accurate indication of the impact of night-time care on the daily stress of parents would be found using a diary that specifically focuses upon night-time care (ie requiring a continuous record of the night-time hours) and also has parents rate their experience of stress for the following day.

Non-significant relationships between ratings of daily stress and total time spent caring indicate factors other than caring contribute to parent psychological well-being. This is particularly the case for secondary caregivers, for whom there was very little association between daily stress and tasks undertaken during the day (either caring or non-caring activities). The Caregiver Diary also asked parents to nominate situations or events which may have caused their daily stress. Primary caregivers indicated worries about the future and about their child were more stressful than caring activities, while secondary caregivers found employment or study to be most stressful. Of note, time spent in employment was not significantly associated with the daily stress scores of secondary caregivers suggesting other aspects of the work situation were more important contributors to daily stress. These results indicate a simple model which proposes increased time spent caring (or time spent at work) will necessarily lead to increased parental stress is not in itself sufficient, that is, stress is not a simple function of the extent of demands placed on the parent (Lazarus & Folkman, 1984) . It is important that models take account of both objective and subjective indicators of caring responsibilities (as does, for example, the general conceptual model of stress proposed by Grant et al. (2003) and the carer model of well-being presented in this dissertation), and also enables examination of the contribution of different types of caring tasks.

11.2 Psychological, social and physical outcomes for parent of children with developmental disabilities

One of the most concerning findings from the present research showed parents of children with developmental disabilities who participated in Study 2 experienced significantly poorer psychological, social and physical health outcomes than the normative samples for the measures used in the study. Results for the Centre for Epidemiologic Studies- Depression Scale (CES-D) found 49% of primary caregivers and 33% of secondary caregivers obtained scores indicting levels of depressive symptoms suggestive of possible clinical depression. These percentages are much higher than the 21% of the general population who scored above clinical cut-offs in the normative sample. Even when using the more stringent cut-off suggested by Husaini (1980), 31% of primary caregivers and 22 % of secondary caregivers in Study 2 were shown to have scores on the CES-D indicating *probable* clinical depression.

The meta-analyses of Singer (2006) and Baily, Golden, Roberts and Ford (2007) obtained weighted averages of 24% and 29% for mothers of children with disabilities scoring above clinical thresholds for depression for the Beck Depression Inventory and the CES-D. Examination of the studies included in these papers, however, shows a large variation in the percentages of mothers scoring above clinical cut-offs. In the Singer (2006) paper, for example, percentages of mothers above the standard cut-off indicating possible clinical depression for the CES-D, ranged from 24% to 50%. Bristol, Gallagher, and Schopler (1988) in a sample of pre-school aged children with developmental disabilities found 44% of mothers in their sample were above the clinical cut-off, comparable to the rate found in the present research. The rates of depression found in Study 2, therefore are high, but within ranges found in previous research examining psychological outcomes for parents of children with disabilities. The similarity between rates of depression found in Study 2 , and rates found in the Bristol et al. study suggests parents of pre-school aged children may be more likely to experience higher levels of depression than parents of older children, a proposition that is supported by longitudinal research (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001).

In addition to the CES-D, Study 2 also included a number of scales from the Parenting Stress Index (PSI) measuring aspects of psychological functioning previously found to be of particular relevance for parents caring for children with disabilities. Results showed mothers and fathers who participated in the study experienced significantly more role restriction and social isolation than the normative sample of mothers of children on the general community (Abidin, 1995). As well, they reported having poorer physical health and less partner support than normative samples for the PSI. These results are consistent with previous studies using the PSI to investigate psychological outcomes for parents of children with disabilities, that have found parents feel more restricted by their parenting role, experience more social isolation and loneliness and to have poorer physical health than parents of children without disabilities (Briggs & Fisher, 2000; Esdaile & Greenwood, 2003; Murphy et al., 2006; Pelchat et al., 1999).

Lastly, Study 2 showed primary and secondary caregivers to report higher levels of time pressure than parents of young children in the general community, and to report significantly higher levels of "objective strain" on the Caregiving Strain Questionnaire (CGSQ: Brannan, Heflinger, & Bickman, 1997). Examination of the items comprising the Objective Strain scale of the CGSQ indicate parents caring for young children with developmental disabilities were more likely to report time constraints, disruption to routines and family relationships, financial problems, and social isolation as a consequences of caring. The comparison sample for the CGSQ comprised parents caring for children between five and 17 years who were receiving treatment for emotional and behavioural problems (Brannan, Heflinger, & Bickman, 1997). As many of the children whose parents took part in Study 2 also experienced high levels of emotional and behavioural problems, this result would suggest that caring for children with developmental disabilities adds to the objective strain of caring for children with psychological disorders.

In summary, results from the present research show the experience of caring for children with developmental disabilities has significant consequences for parents. The extent of psychological difficulties experienced by parents in Study 2 indicate the need for psychological or counselling supports to be readily available when children are identified as having developmental disabilities. While for the most part consequences of caring for parents were negative, it is important to stress that not all parents experienced poor outcomes. In addition, parents reported that caring could also have positive impacts for themselves and for family life more generally. Participants in the focus groups carried out in Study 1 referred to changes in personal priorities and attitudes to life, as well as opportunities to form close friendships with other parents in the same situation. Many, (but not all) parents in Study 2 could also identify one or more benefits of caring during the home interview undertaken as part of this study. Examples included:

1. Positive consequences arising from the child themselves, such as: their loving or affectionate nature; feelings of pride, reward, and satisfaction from participating in children‟s developmental progress
2. Benefits for the parent such as: acquiring new knowledge or skills (including "patience"); meeting a new range of people; learning to appreciate the "little things"
3. Benefits for the family or other family members more generally, such as: closer family bonds; siblings becoming more understanding or empathic of the needs of others

Blacher and Baker (2007) found positive feelings about caring for a child with a disability were unrelated to negative impacts when examining factors contributing to the parenting stress of parents of young adults with intellectual disabilities. This confirms, as found in the present dissertation, that parents can experience positive and negative consequences of caring at the same time.

11.21 Comparing the psychological, social and physical well-being of primary and secondary caregivers

The model of carer well-being tested in Study 2 proposed time constraints, as an indicator of caring responsibilities, to have an important role in contributing to outcomes for parents of children with developmental disabilities. Hypotheses 1 to 5 specified the implications of the model. While evidence previously summarised showed caring to have substantial negative impacts for carer well-being (confirming Hypothesis 1), findings relating to the differential impact of caring for primary and secondary caregivers was less clear-cut. Primary caregivers had scores indicating poorer functioning on all outcome measures, in comparison to secondary caregivers, but most differences were mostly not statistically significant. These results need to be considered in context, however, as both primary caregivers and secondary caregivers experienced more depressive symptoms, greater social isolation, poorer physical health, and more caregiver strain than parents of children in the general community (or parents of children receiving treatment for emotional and behavioural problems, in the case of the Caregiver Strain Questionnaire). It may be that even a minimum of time spent caring for a child with a disability has a negative impact on parent well-being. In addition, findings may reflect the impact of factors other than direct caring, for secondary caregivers in particular. Results presented earlier, for example, suggested employment or study contributed to the daily stress of secondary carers. Finally, previous research has highlighted the importance of considering ways in which psychological problems experienced by mothers may lead to and/or exacerbate the psychological problems experienced by fathers (Hastings, 2003; Roach, Osmond, & Barratt, 1999).

11.22 Relationships between parent outcomes and characteristics of child disability

The model of carer well-being described in Chapter 4 proposed that different characteristics of child disability were likely to lead to different outcomes for parents. Analyses were undertaken to examine the impact of diagnosis, functional abilities (termed adaptive behaviours in different contexts), and extent of child emotional and behavioural problems. The latter two variables were conceived as reflecting different aspects of severity of disability. Results of analyses examining outcomes for parents of children in different diagnostic groups were not statistically significant, with mostly small to moderate effect sizes. Patterns in the data, however, were consistent with trends found in previous research (Hodapp, 2007; Singer, 2006). For example, caregivers of children with autism consistently obtained scores indicating poorer outcomes than carers of children in other diagnostic groups. In addition, parents of children with Down syndrome were consistently found to do better on the outcome measures used in Study 2, in comparison to other parents. The small numbers of children in the different diagnostic groups in Study 2, though typical of previous research, may have led to the lack of significant results. Future studies should endeavour to obtain larger sample sizes, to clarify the impact of child diagnosis on parental outcomes. As noted previously, results of the present study should also be considered in the context of the poorer well-being of all parents who participated in Study 2.

When considering variables relating to severity of disability, Study 2 found clear support for the hypothesis that parents of children with higher levels of emotional and behavioural problems were more likely to report depressive symptoms, to feel more role restricted; to have poorer physical health, and to experience greater caregiver strain and feelings of time pressure than parents of children with lower levels of emotional and behavioural problems. In addition, parents of children with higher levels of emotional and behavioural problems were more likely to perceive themselves to have less partner support than parents of children with fewer problems. These findings are concerning given the high prevalence of child emotional and behavioural problems found in Study 2, and in children with intellectual disability more generally (Brereton, Tonge, & Einfeld, 2006; Dykens, 2000; Emerson, 2003). Results are consistent, however, with the large number of studies indicating the importance of behavioural problems in contributing to the well-being of parents caring for children with cognitive and other disabilities (Baker et al, 2002; 2003; 2005; Donenberg & Baker, 1993; Floyd and Gallagher, 1997; Hastings et al , 2006; Raina et al 2005). It is of note that the relationship between emotional and behavioural problems and parent outcomes was found for both primary caregivers and secondary caregivers. This suggests (as is also shown in other analyses) that the level of a child‟s emotional and behavioural problems is more important than total time spent caring, in contributing to parent well-being.

In contrast to the results for emotional and behavioural problems, there was very little evidence for the role of functional abilities in contributing to parent well-being. That is, outcomes for parents of children with developmental disabilities were shown to be independent of extent of child functional abilities. Previous research examining the role of functional abilities (or adaptive behaviours) on parent well-being has been equivocal, with no clear indication as to reasons for differences between studies. The present results are consistent with research showing functional abilities to be unrelated to maternal adaptation or parent distress (Skok, 2006; Wallender et al 1989; 1990; Wiegner & Donders, 2000). They are inconsistent, however, with studies suggesting functional abilities do contribute to parental well-being (Plant & Sanders, 2007; White & Hastings, 2004).

When considered collectively, evidence relating to the impact of different characteristics of child disability on parental outcomes suggests caring demands specific to children with psychological problems have greater impact on parental well-being than caring demands relating to children with different functional skills. The WeeFIM®, used as a measure of functional skills in Study 2 , provided a comprehensive account of the extent of help required to assist children with mobility; daily living skills; communication and problem-solving. Results suggested that the need to provide physical help with activities of daily living was not a significant source of stress for parents, whereas caring for a child with additional emotional and behavioural problems was a significant source of stress. It should be acknowledged that the cross-sectional design of Study 2 does not allow for the investigation of directional relationships. It is possible therefore, that "stressed" parents may perceive their child‟s behaviour as problematic, thereby influencing their perception of the relationship between their child‟s emotional and behavioural problems and their own psychological outcome. The problem of shared method variance (Podaskoff, MacKenzie, Lee, & Podaskoff, 2003) where one parent completes measures of both child problems and parent outcomes may have contributed to this possibility. In Study 2, however, primary and secondary caregivers independently completed the SDQ. Results of analyses showed considerable agreement between parents as to the extent of their children‟s emotional and behavioural problems reducing the likelihood of individual misperceptions. Another possibility, suggested by previous research, is that child behaviour problems and parent stress have a mutually escalating effect upon each other (Baker et al., 2005; Baker et al., 2003; Hastings et al., 2006). The present research is unable to address this hypothesis, indicating the necessity of future studies using longitudinal research designs to clarify the complex relationships between child emotional and behavioural problems, functional abilities and outcomes for parents of children with developmental disabilities.

Results of analyses in Study 2 indicated that levels of emotional and behavioural problems did not significantly differ across the different diagnostic groups. That is, children with a diagnosis of autism did not show significantly more emotional and behaviour problems than children with diagnoses of global developmental delay or Down syndrome. This was unexpected in that a diagnosis of autism in particular, assumes significant impairments in social interaction, communication and behaviour (American Psychiatric Association, 1994). It is likely, however, that the Strengths and Difficulties Questionnaire, which was developed to measure emotional and behavioural problems in children without disabilities, does not include items reflecting the specific problem behaviours demonstrated by children with autism. Future studies may be better served to use measures, such as the Developmental Behavior Checklist (Einfeld & Tonge, 1995) that has been specifically developed to assess problems behaviours in children with developmental and intellectual disability. Patterns in the data suggesting poorer outcomes for parents of children with autism, and comparatively better outcomes for parents of children with Down syndrome would seem to indicate the influence of factors other than child emotional and behavioural problems (which did not significantly distinguish between diagnostic groups). One such factor may be the influence of external supports. Donenberg and Baker (1993) suggest the importance of external supports in contributing to parental well-being. Qualitative evidence from Study 1 and Study 2 is consistent with this hypothesis. The majority of parents of children with Down syndrome were receiving support from the Down Syndrome Society of South Australia. This organisation provides services to parents from diagnosis (often a consequence of prenatal testing)), as well as a comprehensive early intervention and education support program for children with Down syndrome. The majority of parents in Study 2 were satisfied with the extent of external assistance they were receiving from both the Down Society and the Early Childhood Services of Disability SA. In contrast, the level of service provision to parents of children diagnosed with autism at the time the present research was undertaken was less comprehensive. This is partly a consequence of the greater time taken to obtain a diagnosis of autism (a stressor in its own right). A significant number of parents (39%) of children with autism had sourced private therapy for their children, often at great expense. In contrast, only 9% of children with global developmental delay were receiving therapy from private practitioners. In sum, it is highly likely that different levels of external support received (or not received) by parents of children with different diagnoses impact on parental well-being. Future research should be directed towards more accurately describing the link between external support and parental outcomes to identify the types of support that are most salient for parents, and to advocate where necessary, for additional supports and services.

The findings from Study 2, relating to the influence of child characteristics on parental well-being, suggest social skill development and child behaviour problems should be a core focus of early intervention (Baker et al., 2002). There is considerable evidence for programs teaching parenting strategies to help parents of children with intellectual disability acquire skills in behaviour management (Gavidia-Payne & Hudson, 2002). Additional programs, however, could also be offered to primary caregivers and secondary caregivers more generally, to support strategies for coping with stress (Baker et al., 2005).

11.3 The model of carer well-being

The principal aim of Study 2 was to provide quantitative evidence for the moderated mediation model of carer well-being. The model proposed that the time constraints of caring (represented by time spent caring as well as the subjective experience of time pressure) were the mechanism by which the stresses associated with child disability resulted in different psychological, social and physical health outcomes for parents. The model further proposed that partner support (practical help with caring, as well as emotional support) would moderate the impact of time constraints upon parental well-being. That is, it was expected that higher levels of partner support would lessen total time caring and the experience of time pressure, and in turn help to improve outcomes for parents caring for children with developmental disabilities.

One of the most prominent findings from analyses testing the model of carer well-being showed that total time spent caring and intensity of caring did not significantly relate to the number of depressive symptoms reported by parents. In contrast, perceptions of time pressure (found to be independent of time spent caring) were strongly related to depression in both primary caregivers and secondary caregivers. These results are consistent with earlier findings that ratings of daily stress from the Caregiver Diary were unrelated to total time spent caring, and instead were linked to “worries” and to situations other than caring. Further analysis of the model of carer well-being showed time pressure mediated between child emotional and behavioural problems and parent depression. While causality cannot be inferred because of the cross-sectional design of Study 2, results indicate child emotional and behavioural problems were associated with higher levels of time pressure and more depressive symptoms in parents of children with developmental disabilities. A mediating relationship was shown for both primary caregivers and secondary caregivers.

Results of Study 2, therefore, suggest feeling continually rushed and short of time would seem to be more important in contributing to parent mental health, than the total time commitment required when caring for children with developmental disabilities, or the intensity of such caring. Previous research examining the distribution and correlates of time pressure has shown women, and particularly mothers of pre-school aged children, experience the most "time stress" amongst adults in the general community (Mattingly & Sayer, 2006). The extra time constraints involved in caring for pre-school aged children with disabilities, therefore, add to the feelings of time pressure experienced by parents of young children with disabilities relative to parents of children without disabilities. Previous studies also indicate that people who perceive themselves to be time pressured are more likely to feel stressed, "burnt-out", angry; to be less satisfied with life (particularly family life); and to have poorer subjective physical health (Robinson & Godbey, 1997; Roxburgh, 2004; Schieman, 1999; Shields, 1999). Only one study was found, however, that directly investigated the link between time pressure and depression for adults in the general community (Roxburgh, 2004). Results of this study, as in the present research, showed time pressure to mediate the impact of stressors upon the mental health of men and women in a community sample. Roxburgh concluded "the subjective experience of time pressure can be thought of as a potentially important mechanism by which lived experience is transformed into depression" (Roxburgh, 2004, p.128)

Also arising from analyses testing the model of carer well-being, was the finding that partner support did not, as expected, influence the impact of time constraints on parental depression. That is, higher levels of partner support did not lead to less time spent caring or reduced feelings of time pressure, and conversely, lower levels of partner support did not lead to more time spent caring or higher levels of time pressure. Results of analyses showed, instead, that the Spouse subscale had a mediating rather than a moderating role in contributing to the relationship between child disability (as represented by emotional and behavioural problems) and levels of depressive symptoms showed by primary and secondary caregivers. Child emotional and behavioural problems were associated with lower levels of partner support and more depressive symptoms in parents of children with developmental disabilities. Previous research has found evidence for direct, moderating and mediating effects of social support, dependent upon the source or type of social support measured or whether generic or contextually specific stressors are assessed (Cohen & Wills, 1985; Quittner et al., 1990; Suárez & Baker, 1997). Findings from the present research are consistent with results found by Quittner et al. (1990) when considering the role of social support in parents of children with and without hearing impairments. In the Quittner et al. study perceived emotional support was found to mediate between parenting stress and symptoms of depression and anxiety, rather than acting as a moderator or "buffer" (ie protecting parents against the negative impacts of stress arising from caring role). It should be noted that in the Quittner et al. study the Parenting Stress Index was considered to indicate the extent of "stressors" encountered by parents, rather than as being a measure of parent psychological outcomes as used in Study 2. This reflects conceptual and methodological differences in research examining the role of social support more generally, which limits the ability to compare results across studies. Finally, it was not possible to determine from Study 2 whether emotional support or alternatively practical support from partners was of greater importance to parents. Results from the Carer Support Scale, however, gives some indication that primary caregivers would ideally like more emotional support from their partner, regardless of the level of support already being received, ahead of any other form of support. Future research could explore the differential importance of different types of support and different sources of support (ie whether from partners, family or friends) for primary caregivers and secondary caregivers.

Final analyses testing for the model of carer well-being examined the joint role of partner support and time pressure in predicting parent depression. Time pressure and partner support together accounted for a substantial 41% of the variance in primary caregiver depression, but only time pressure was shown to have a significantly mediating effect. Thus, the experience of time pressure was more important than the extent of emotional and active support received from partners in contributing to the well-being of primary caregivers. In contrast, results showed both time pressure and partner support (together accounting for 41% of the variance in levels of secondary caregiver depression) mediated between child emotional and behavioural problems and secondary caregiver depression. The finding that partner support is of greater importance for men, than for women, fits with evidence that men rely heavily upon their partners as a source of emotional support at times of stress (Antonucci, & Akiyama, 1987; Huston-Hoburg,, & Strange, 1986).

In summary, the model of carer wellbeing was only partially supported by analyses in the present research. The model, however, was tested using a selected range of variables and it is possible that different results would have been found if a different selection of representative variables had been chosen. Results from the Caregiver Diary indicate, for example, that tasks of caring contribute differentially to daily stress. The design of the Caregiver Diary did not allow for an accurate summation of active and passive caring which would have enabled inclusion of these summary variables in a model. Future research could overcome this limitation and further explore the relationships between tasks of caring and parental mental health. In addition, it should be acknowledged that the Time Crunch scale was an unstandardised measure that requires further research to establish its validity. Finally, the cross-sectional design of Study 2 does not allow the investigations of possible directional effects. It is possible, for example, that feelings of depression may lead parents to feel more time pressured, and to perceive their child"s disability as being more stressful. Future research could use longitudinal designs to explore these possibilities, ideally contrasting the impacts of caring for parents of children of different ages. Mothers who participated in the focus groups in Study1 highlighted the different challenges that parents encounter when caring for children of different ages. Studies comparing parents caring for children of different ages, and at different developmental transition points would provide useful information about the ways caring responsibilities change over time, and supports that may be most helpful to parents at specific time points. The utility of using diary methodologies to provide a comprehensive picture of the experience of caring have been illustrated by the present research.

11.4 Implications for practice

The findings of the present research have a number of implications for organisations and practitioners working to support parents of young children with developmental disabilities. There is a need for greater awareness of both the constraints of the caring role undertaken by parents, together with the key role played by feelings of time pressure in contributing to parental mental health. Ways of "giving back" time to parents, including respite options, may be limited but should be explored where possible. Mothers who participated in the focus groups in Study 1 pointed to the value of home help services as a way of enabling them to balance their caring and domestic responsibilities. As well, they also stressed the ways that improved communication and sharing of information both within and between organisations would reduce the need for them to spend time liaising between agencies and persons working with their child and family.

There are also a number of approaches that may be taken to better support parents in their caring role. Parents in a qualitative study undertaken by Brotherson and Goldstein (1992), for example, suggested that professionals identify ways in which therapy and educational activities can be integrated, or embedded, into the family"s daily routines and home environment. Encouraging awareness of the impacts of caring on family life and individual well-being is also important and can be undertaken in group settings such as early intervention play groups, where parents can share strategies for accommodating the demands of caring. Donovan, VanLeit, Crowe, & Keefe (2005) reported mothers in their study used multi-tasking to help "fit in" therapy tasks; "stretched" their day by getting up before other members of the family; used organised and efficient schedules and routines; and sought out family friendly work places. Therapists working with parents may also offer specific interventions aimed at increasing understanding about the impact of time pressures, and to assist individuals in learning a broader range of strategies to better manage time constraints, and stress more generally. Crowe and Florez (2006) suggest time use diaries as useful tools to assist parents to be more aware of the ways in which caring impacts on daily life and to help identify specific problems that can be targeted in interventions.

Finally, a particular challenge to practitioners working with parents is to find ways to engage secondary caregivers in interventions. Primary caregivers are typically the parent who has the most to do with early intervention services. The experience of time pressure, however, was shown to have equal consequences for primary and secondary caregivers. Paid employment, and the difficulties balancing caring with responsibilities external to the family, however, would appear to be of greater relevance to the feelings of time pressure experienced by secondary caregivers. These concerns also contribute to the challenge of involving secondary caregivers, such that interventions may need to be held at different times and in different settings to those offered to primary caregivers. Where possible, though, results from the present research suggest the need of working with both partners to foster their relationship, as this is an important source of practical and emotional support for both primary caregivers and secondary caregivers.

Research undertaken for the present dissertation has successfully used diary methodologies to provide a detailed picture of the lives of carers of young children with developmental disabilities. It has highlighted the impacts of caring on the day-to-day activities of parents, and the important role of time pressure and levels of partner support as potential mechanisms by which caring may lead to psychological problems for carers. It is hoped that the results of analyses of the Caregiver Diary and of the model of carer well-being will stimulate future studies into the complex relationships which impact on psychological, social and physical well-being of parents. Such research is necessary to identify ways in which parents can be better supported in their caring role, by the organisations and professionals who work with children with disabilities and their families.

APPENDICES

APPENDIX A
Information sheet and consent forms used in Study 1

Information Sheet

TALKING TO PARENTS: THE IMPACT OF DAY-TO-DAY TASKS OF CARING ON THE LIVES OF PARENTS CARING FOR CHILDREN WITH DISABILITIES.

We are asking for your help in a study of the effects of caring for a young child with a disability or special needs. We know that care-giving can involve frequent trips to the doctor or to the hospital and visits with therapists. It may also mean giving extra support for children who take longer to learn to look after themselves. We are interested to know how parents manage to fit these other responsibilities with existing family and work commitments (including looking after other children).

We are inviting parents (both mothers and fathers) to take part in a discussion group with a small number of other care-givers (eg 6-8 parents) in a similar situation. We will be arranging a number of groups for parents of preschool children who are clients of Novita Children's Services. The discussion groups will be an opportunity to tell us the types of issues that are important to you in caring for your child, and how you and your family have adjusted to the extra responsibilities. The groups will last an hour and half, at a time and place convenient to you. Discussions during the group will transcribed and the information gained will help us plan future research aimed at identifying the most important areas of stress for parents. Research such as this is needed to help target future services and supports for parents.

Discussions held during the group, and the information obtained from the group will be treated in the **strictest confidence**. In particular, names will not be used in the reporting of results. Your participation is completely voluntary and you can change your mind about attending at any time.

The study has been approved by the Research Ethics Committee of the Women's and Children's Hospital and has also been approved by the Research Committee of the Novita Children's Services. If you have any questions about the study please feel free to contact Angela Crettenden or Professor Michael Sawyer at the Women's and Children's Hospital (telephone: 8161 7207), or Ms. Brenda Penny of the WCH Research Ethics Committee (telephone: 8161 6521).

If you are interested in this opportunity to let us know what is important for you in caring for your child with a disability or special needs, please fill out the attached slip and accompanying consent form, and post them to us in the enclosed envelope. We will be in touch to talk to you about the groups, and to make a time for you to attend.

We look forward to hearing from you!
Yours sincerely,

Angela Crettenden	Professor Michael Sawyer
Clinical Psychologist & PhD. Student	Head, Research & Evaluation Unit
University of Adelaide	Women's & Children's Hospital

I/ We am interested in attending a group discussion YES/ NO

My/ Our names:____

My/ Our contact details:____

The best time for me/ us to attend a discussion group would be:____

Thank you for your support!

Consent form 1

<u>WOMEN’S AND CHILDREN’S HOSPITAL RESEARCH ETHICS COMMITTEE</u>

I ____

Hereby consent to my involvement in the research project titled:

TALKING TO PARENTS: THE IMPACT OF DAY-TO-DAY TASKS OF CARING ON THE LIVES OF PARENTS CARING FOR CHILDREN WITH DISABILITIES.

1. The nature and purpose of the research project described in the Information Sheet has been explained to me. I understand it, and agree to taking part.
2. I understand that I may not directly benefit by taking part in the study.
3. I acknowledge that the possible risks, discomforts and inconveniences, as outlined in the Information Sheet, have been explained to me.
4. I understand that while information gained in the study may be published, I will not be identified and information will be kept confidential.
5. I understand that I can withdraw from the study at any stage, and that this will mot affect care or any other aspects of our relationship with (agency name) or the Women’s and Children’s Hospital.
6. I understand that there will be no payment for taking part in this study.
7. I have had the opportunity to discuss taking part in this research project with a staff member from (agency name), or a family member of friend and/or have had the opportunity to have a family member or friend present whilst the research project was being explained to me by the researcher.
8. I am aware that I should retain a copy of the Consent Form, when completed, and the Information Sheet.

Signed: ………………………………………………….. Dated:…………………..

I certify that I have explained the study to the study participant, and consider that they understand what is involved.

Signed:……………………………………………………Dated:………………….
(Chief Investigator)

Consent form 2

<u>WOMEN'S AND CHILDREN'S HOSPITAL RESEARCH ETHICS COMMITTEE</u>

I____

Hereby agree to the audio-taping of discussion held during a focus group for the purposes of the research project entitled:

TALKING TO PARENTS: THE IMPACT OF DAY-TO-DAY TASKS OF CARING ON THE LIVES OF PARENTS CARING FOR CHILDREN WITH DISABILITIES.

1. I understand that information from the audio-tape will be used only for the purposes of the research study, and will only be made available to the researchers involved with this study.

2. I understand that I will not be identified in information from the audio-tape, and information will be confidential.

Signed: ………………………………………………….. Dated:…………………..

I certify that I have explained the audio-taping procedure to the study participant, and consider that they understand what is involved.

Signed:……………………………………………………Dated:………………….
(Chief Investigator)

APPENDIX B

Coding booklet used to assist quantitative analysis of transcripts from focus groups (Study 1)

1. Child Factors

Age of child:

Issues that directly relate to the age of the child, or that are a function of a child growing older (including physical changes and tasks required to accommodate these changes; and consequences of a child starting/ **attending school**).

Severity of Disability:

Relates to the different caring impacts on parents caring for children with more severe (or multiple) disabilities. Included in this category are:

- issues relating to the need to facilitate a child's interactions (eg **play**);
- problems arising from a lack of language (**communication**); and
- problems arising from difficult **behaviour**. Includes **sleeping difficulties**
- medical Problems

2. Task Factors

Personal Care Tasks:

Issues relating to the daily caring tasks that are undertaken by the parent, specifically, those tasks that relate to the personal care of the child. Included are 2 separately coded categories, being:

- **Toileting;**
- **Feeding**

Medical Tasks:

Issues that relate to the extra caring tasks required by a child's medical condition, including medical treatments or medical procedures undertaken by the parent. Includes the need to be trained in procedures. Does not include attendance at appointments with doctors (coded for accessing/ arranging services).

Therapy:

Issues that relate to the child's need of therapy. Includes being present during attending appointments with a therapist, and therapy tasks undertaken by the parent. Use of physical aids, including lifters.

Housework:

Relates to the extra housework tasks required by the need to care for a child with a disability (eg more washing, cleaning up after a child). Includes the extra time needed to undertake regular housework activities.

Vigilance:

Relates to the need for the parent to be more vigilant about their child because of their disability or medical needs. Includes the need for extra supervision for those children whose behaviour may place them at risk (ie safety concerns).

Organising/ Accessing Services;

Issues relating to the extra work required by a parent to:

- Organize services for their child. Includes:
  - **Phonecalls** to make appointments or to follow-up with medical/ therapy staff
  - **Paperwork**
- Attend **appointments** with doctors or to attend **meetings** with schools or other service providers (with the aim of facilitating services for a child). Includes **travel** to appointments or to service venues (eg school/ childcare).

Fitting in the tasks of caring:

Quotes relating to the difficulties associated with fitting in the extra caring activities with other family commitments (eg fitting in medical appointments as well as the needs of a sibling)

3. Parent Outcomes

Personal Consequences

Issues relating to the impact of caring on the personal lives of parents. Includes :

- Changes to **attitudes or outlook on life,**
- Changes to **physical health** (eg energy level, sleep) as a consequence of caring, including the difficulties in caring for self, and
- **Emotional consequences**, including
  - **Grief** (with separate reference if quote relates to **The early years** following diagnosis**);**
  - **Guilt;**
  - **Anxiety**
  - **Anger**/ frustration
  - **Stress** more generally.

Family/ Marital Consequences

Relates to the impact of caring on the family as a whole, or on individuals in the family (ie **siblings, partners**). Includes reference is made to negative impacts on the **marital relationship** (eg arguments or marital strain).

Social Consequences

Issues relating to the impacts of caring on the social lives of parents or the family. Relates to both negative and positive changes that may have resulted from the need to care for a child with a disability.

Financial Consequences

Relates to the financial changes that have come about from the need to care for a child with a disability. Includes reference to the need to make changes to a **work** situation, or impacts of caring on a **career.**

4. Things That Help (Supports)

Relates to situations or supports that help parents in their caring role. Includes:

- Various forms **respite** or time-out from caring ie
    - **care provided by a partner**, extended family member or friend for a period of time;
    - **childcare or school**;
    - assistance of a **paid carer**).
- **Practical support** provided by a family member or friend (eg help with shopping/ meals). Includes:
    - Paid services such as a cleaner or housekeeper
- **Social/ Emotional** support given by a **partner**, family member or friend
- **Cognitive strategies identified by a carer (eg changing ways of thinking)**
- **Formal Supports,** such as counseling, seeing a psychologist
- **"In an Ideal World"** supports that a parent felt <u>would be helpful</u>, if they were available.

5. "Other" Categories (are subsumed by other categories).

<u>Consequences of Caring</u>:

Positives of caring (eg social relationships made, or personal changes made.)

<u>Different caring Tasks</u>:

The Hardest Tasks of Caring (eg references to the most difficult things that a parent needs to do.)

"TIME" NODE; EXTRA TIME REQUIRED FOR CARING

Included in this node were all references (direct and indirectly related) to the extra time required by caring (see below for decision rules). Included were references to the extra tasks of caring, and the juggling (steps taken or emotional toll) required to fit in caring responsibilities.

Decision Rules (following independent rating):

a) Where a quote was indirectly, rather than directly, related to the time commitments of parents required by their caring role;
    a. The quote was coded within the "Time" node if the quote related to a caring task required by the parent (such as toileting or therapy tasks) and it was felt to be a reasonable assumption that undertaking the task would impact on time available to parents;
    b. The quote was **not** included in the "Time" node if the quote referred to a general concept (such as the need to provide help to the child) or a consequence of caring (such as physical ill health) and where it was felt to be an unreasonable assumption that these situations necessarily would lead to an impact of time available to parents.

b) Vigilance (the need to supervise or watch carefully because of safety issues) was considered a caring task, and as such assumed to impact upon time available to parents. Quotes relating to the need for vigilance were therefore coded within the "Time" node.

APPENDIX C

Information sheet, letter to parents, permission to contact form and consent form used in Study 2

Information Sheet

THE IMPACT OF THE DAY-TO-DAY TASKS OF CARING ON THE LIVES OF PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES.

We are advising parents (both mothers and fathers) of children who are clients of the IDSC Early Childhood Service (ESC) of a study that will provide new information about the impact of caring for a young child with developmental disabilities. In particular, the study will identify the extra time and tasks involved in caring for children with developmental disabilities, and the effect of these on the psychological well-being of parents. This information will help agencies like IDSC to direct existing services and supports for parents of children with developmental disabilities to where they are most needed. The information will also help in developing new services for parents, and in advocating on behalf of parents for more funds or services where this is needed.

If you agree to take part in the study we will arrange a convenient time to visit you at home. During the visit, which will last about 1 hour, you will be asked to give some background information about your child who is a client of the ECS, and your family. You will also be invited to complete a questionnaire that asks for information about your child's abilities and behaviour as well as the emotional, social and practical impact of caring on you and other family members. An important aim of our study is to document the extra time and tasks that are needed by parents caring for children with developmental disabilities. To obtain this information we will be asking you to complete a diary that will describe your caring responsibilities on two days in the week following the home visit. The diary should take approximately 30 minutes to complete in your own time. During the home visit, we will also seek your permission for the ESC therapy team to complete a brief checklist about your child's abilities.

The study has been approved by the Research Ethics Committee of the Women's and Children's Hospital and has also been approved by the Research Committee of the Intellectual Disability Services Council. If you have any questions or concerns about this, please feel free to contact Ms. Brenda Penny, WCH Research Secretariat on 8161-6521. All information from the study will be treated in the **strictest confidence**. In particular, names will not be used in the reporting of results. Your participation is completely voluntary and you can change your mind about participating at any time. There is no payment to parents for being involved in this study.

PTO

A member of IDSC staff will soon be in contact with you to seek your permission to release your telephone number to Ms. Angela Crettenden, a researcher from the University of Adelaide, so that she may advise you about the study. You will not be asked for any other contact details and your consent to be contacted does not mean that you have to take part in the study. Angela is a clinical psychologist and she will be using results obtained from the study in her PhD. thesis. You are also welcome to contact Angela directly, or Professor Michael Sawyer at the Women's and Children's Hospital (telephone: 8161-7207) if you would like further information about the study.

We would like to stress again that any information you provide will be treated in the strictest confidence. We hope you will take this opportunity to let us know how things are for you and your family, and for helping us to learn how to better support you in the future.

Angela Crettenden
Clinical Psychologist & PhD. Student
University of Adelaide

Professor Michael Sawyer
Head, Research & Evaluation Unit
Women's & Children's Hospital

Letter from ECS Manager

Dear……………………..

I am writing to inform you of a research study which will involve the parents of children who are clients of the Early Childhood Services. The study will provide information about how day-to-day caring responsibilities affect the well-being of parents who are caring for a child with developmental disabilities. The study will be undertaken in association with the Adelaide University and the Women's and Children's Hospital. It will coordinated by Ms. Angela Crettenden, a clinical psychologist who is also working towards her PhD. Degree.

An Information Sheet is attached which gives details about the study, and what would be involved if you agree to take part. All information collected in the study will be treated in the strictest confidence. Of course, you are under no obligation to take part in the study and your decision will not affect your child's services or any other aspects of your relationship with the ECS or IDSC.

A member of IDSC staff will soon be in contact with you to seek your permission to release your telephone number to Angela, so that she may advise you about the study. You will not be asked for any other contact details. Your consent to be contacted does not mean that you have to take part in the study.

If you have any questions about this letter, please feel free to call me (telephone:)

Yours sincerely

Permission to contact form

I/ We agree to be contacted about the study titled:

THE IMPACT OF THE DAY-TO-DAY TASKS OF CARING ON THE LIVES OF PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES.

My/ Our names:

____

My/ Our telephone contact details:

Home : ____

Mobile: ____

Work: ____

Best time to call?____

My/ Our address:

____

____

Thank you for your support!

Consent Form

WOMEN'S AND CHILDREN'S HOSPITAL RESEARCH ETHICS COMMITTEE

I ____

hereby consent to my involvement in the research project titled:

THE IMPACT OF THE DAY-TO-DAY TASKS OF CARING ON THE LIVES OF PARENTS OF CHILDREN WITH A DEVELOPMENTAL DISABILITY.

9. The nature and purpose of the research project described in the Information Sheet has been explained to me. I understand it, and agree to taking part.
10. I understand that I may not directly benefit by taking part in the study.
11. I acknowledge that the possible risks, discomforts and inconveniences, as outlined in the Information Sheet, have been explained to me.
12. I understand that while information gained in the study may be published, I will not be identified and information will be kept confidential.
13. I understand that I can withdraw from the study at any stage, and that this will not affect care or any other aspects of our relationship with the Early Childhood Services IDSC or the Women's and Children's Hospital.
14. I understand that there will be no payment for taking part in this study.
15. I have had the opportunity to discuss taking part in this research project a family member or friend and/or have had the opportunity to have a family member or friend present whilst the research project was being explained to me by the researcher.
16. I am aware that I should retain a copy of the Consent Form, when completed, and the Information Sheet.

Signed: ………………………………………………….. Dated:…………………..

I certify that I have explained the study to the study participant, and consider that they understand what is involved.

Signed:……………………………………………………Dated:………………….
(Chief Investigator)

APPENDIX D
Scoring guidelines for the WeeFIM Version 4.0

MOTOR SKILLS

SELF-CARE

A. **Eating**: Includes the use of suitable utensils to bring food to the mouth, sucking, biting, chewing and swallowing

eg 7 = eats all consistencies of food from a dish and use a spoon or a fork and a cup without any help

B. **Grooming**: Includes oral care, hair grooming (combing or brushing hair), washing and rinsing the hands and washing and rinsing the face

eg 7= brushes teeth, combs hair, and washes and rinses hands and face without any help

C. **Bathing**: Includes bathing (washing, rinsing and drying) the body from the neck down (excluding the back); may be either tub, shower, or sponge/bed bath

D. **Dressing – Upper Body**: Includes dressing and undressing above the waist; as well as applying and removing a prosthesis or orthosis when applicable

eg 7 = dresses self from the waist up, gets clothes from drawers and wardrobes, and manages zippers, buttons and snaps without any help. Includes putting on and taking off a prosthesis

E. **Dressing – Lower Body**: Includes dressing and undressing from the waist down as well as applying and removing a prosthesis when applicable.

eg 7 = dresses self from the waist down, gets clothes from drawers and wardrobes, and manages zippers, buttons, and snaps without any help. Includes putting on and taking off a prosthesis.

F. **Toileting**: Includes maintaining perineal hygiene and adjusting clothing before and after using toilet or bedpan

eg 7 = wipes self and adjusts clothing without any help when toileting

SPINCTER CONTROL

G. **Bladder Management (Part 1: Level of Assistance and Part 2: Frequency of Incontinence)** Includes complete intentional control of urinary bladder and, if necessary, use of equipment or agents for bladder control <u>NB: Rate Part 1 & Part 2 separately, then record the lower rating.</u>

eg **Part 1**: 7 = performs bladder management tasks without any help)

Part 2:
7 = has no accidents,
5 = accidents at night, or during the day once every 2 or 3 months,
4 = accidents once a month,
3 = accidents weekly but not every day,
2 = accidents everyday but indicates being wet,
1= accidents everyday but no indication of being wet

H. **Bowel Management (Part 1: Level of Assistance and Part 2: Frequency of Incontinence)** Includes complete intentional control of bowel movements and, if necessary, use of equipment or agents for bowel control.
See examples above (Bladder Management)
<u>NB: Rate Part 1 & Part 2 separately, then record the lower rating.</u>

TRANSFERS

I. **Transfers: Chair, Wheelchair** Includes all aspects of transferring to and from a chair, and wheelchair, or coming to a standing position if walking is the typical mode of locomotion

eg 7= transfer self to and from a chair without any help

J. **Transfers: Toilet** Includes getting on and off a toilet

eg 7 = transfer self to and from a standard toilet seat without any help

K. **Transfers: Bathtub or Shower** Includes getting into and out of a bathtub or shower stall

LOCOMOTION

L. Walk/Wheelchair/Crawl

NB: Mark the most frequent mode of locomotion, eg Walk/Wheelchair/Crawl or mark Combination if different modes are used equally.

<u>NB: If child needs an assistive device for locomotion such as a wheelchair or walker then their score can never be higher than 6. If child crawls, their score must be 5, 4, 3 or 1.</u>

Part 1: Walking Includes walking, once a standing position, on a level surface, for a minimum of 150 feet (50 metres) at one time

eg
7= walks by self for a minimum of 50 metres at one time,
6 = takes longer than others, needs assistive device or safety concerns,
5 = walks short distance (17 metres) by self on own or with a device,
4 = does most of the effort but needs help with balance (contact guarding or steadying),
3 = ½ or more of the effort with a little support,
2= gives less than ½ effort to walk 17 metres with a lot of support,
1 = gives little effort, or needs 2 people to walk

Part 2: Wheelchair Includes safe use of wheelchair(manual or powered), in a situation free of physical hazards for a minimum of 50 metres at one time, and, without help, negotiating a grade of at least 3% and maneuvering on rugs and over doorsills(indoors) or negotiating a distance of one city block in the community

eg
6 = wheels self for a minimum of 50 metres, independently turns wheelchair around, wheel on rugs and over doorsills,
5 = wheels self for short distance (17 metres) or needs hands-off supervision or instructions to wheel self 50 metres, may also be safety or time concerns,
4 = makes most of the effort to wheel 50 metres with help for the rest,
3 = ½ or more of the effort to wheel 50 metres with a little support,
2= gives less than ½ effort to wheel 17 metres with a lot of support,
1 = gives little effort to wheel 17 metres, or needs 2 people to walk

Part 3: Crawling Includes crawling or self mobility for a distance of 17 metres at one time, safely and without assistance or help in a situation free of physical hazards

<u>NB: The ONLY ratings that can be used for crawling are 5,4,3,1</u> where:
5 = crawls through 2 rooms (minimum 17 metres),
4 = crawls from one room to another (less than17 metres, but more than 9 metres),
3 = crawls to change location within a room (less than 9 metres, but more than 4.5 metres),
1 = does a little crawling

M. **Locomotion: Stairs** Goes up & down 12 to 14 stairs (one flight) indoors

eg 7= can go up and down 12 to 14 stairs without help, safely and without a handrail,
6 = 12 to 14 stairs without help but needs assistive device or takes longer, safety concerns,
5 = 4-6 stairs without help (with or without device), OR goes up and down 12 -14 stairs but needs supervision/ instructions
4 = does most of the effort to go up and down 12-14 stairs with help for the rest (eg steadying)
3 = does ½ of the effort to go up and down 12-14 stairs
2= does less than ½ effort
1 = does little of the effort, or needs the help of 2 people

COGNITIVE

COMMUNICATION

N. **Comprehension**: Includes understanding of either auditory or visual communication (eg writing, sign language, gestures, and pictures). Evaluate and check the more usual mode of comprehension (auditory or visual, or if used equally, check both)

eg 7 = understand conversations about everyday situations and follows unrelated three step
directions without an help (eg put away your toy, wash your hands and get your coat),
6 = as in 7 but takes longer than the rest of the family to understand or needs a device such as a hearing aid or glasses,
5 = understand conversations almost always (90%) and follows related three part directions eg get your coat, get your boots and get your hat),
4 = understand conversations most of the time with minimal help and follows unrelated 2 part directions (eg Put away your toy and wash your hands),
3 = follows conversations more than ½ of the time and follows related 2 part directions (eg get your shoes and get your socks),
2 = understands conversations less than ½ of the time or understand single words, brief phrases or 1 step commands,
1 = understands little of conversations or responds inconsistently/ inappropriately despite
prompting

O. **Expression**: Includes clear vocal or nonvocal expression of language. This item includes intelligible speech or clear expression of language using writing or a communication device. Check Vocal, Nonvocal or, if both are used equally, check Both.

eg 7 = expresses basic needs and ideas about everyday situations clearly and fluently without any help,
6 = takes longer or needs an assistive device (augmentative communication device),
5 = expresses needs and ideas 90% of the time with rare help,
4 = as 5 - most of the time with minimal help,
3 = as 5 – more than ½ of the time, or combines words, gestures, pictures (simple 2 word questions),
2 = as 5 – less than ½ of the time, uses single words appropriately (No, Mama, baby),
1 = expresses needs/ ideas little of the time or responds inconsistently/ inappropriately despite prompting

SOCIAL COGNITION

P. **Social Interaction**: Includes skills related to getting along and participating with others in play and social situations. It represents how one deals with one's own needs, <u>together with</u> the needs of others.

eg 7 = plays appropriately with other children without adult supervision,
6 = plays appropriately in structured/ modified environments or needs medication,
5 = understand simple rules & takes turns 90% of the time with rare help. Needs help only in stressful/ unfamiliar situations,
4 = understand rules/ takes turns most of the time. Needs help to organize play occasionally (less than 25%),
3 = as 4 – understands more than ½ of the time, needs help less than ½ of the time,
2 = as 4 – understands less than ½ of the time/ needs help more than ½ of the time,
1 = rarely plays with other children, needs help to organize play all of the time

Q. **Problem Solving**: Includes skills relating to solving problems of everyday living. This means making reasonable, safe, and timely decisions, and initiating, sequencing and self-correcting tasks and activities to solve problems.

eg 7 = can recognise and solve a problem without prompting,
6 = takes longer or has slight difficulty in unfamiliar situations,
5 = recognizes and solves problems almost always, needs help rarely or in stressful situations,
4 = as 5 - very often, needs prompting less than 25% of the time,
3 = as 5 – more than ½ of the time, needs prompting less than ½ of the time (eg cause-effect relationships, hide & seek),
2 = can recognise/ solve problems less than ½ of the time, needs prompting more than ½ of the time (eg move obstacles aside to get object or toy),
1 = recognises/solves problems little of the time, needs help all of the time

R. **Memory**: Includes skills related to recognizing and remembering while performing daily activities. It includes the ability to store and retrieve information, particularly verbal & visual. The functional evidence of memory includes recognizing people frequently encountered, remembering daily routines, and executing requests without being reminded. A deficit in memory impairs learning as well as performance of tasks.

eg 7 = learns new games without needing many repetitions of the rules, can describe rules to another child without help,
6 = needs many repetitions to learn rules in order to play with another child,
5 = recognizes/ remembers almost always, needs help rarely or under stress, tells about important aspects of holidays, birthdays etc from memory,
4 = as 5- most of the time, tells something about an activity/ story if asked a question about it (eg where did you go today),
3 = as 5 – more than ½ of the time, can sing or act out part of a rhyme or a song (eg sings or hums part of 'Twinkle Twinkle Little Star'),
2 = recognizes/ remembers less than ½ of the time, remembers where a toy or other object is after a few minutes,
1 = recognizes/ remembers little of the time or none at all, recognizes familiar people or toys

APPENDIX E
Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997)

For each item, please consider your child who is in the study and mark the box with a clear 'X' for Not True, Somewhat True, or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain. Please give your answers on the basis of your child's behaviour OVER THE PAST SIX MONTHS.

	Not True	**Somewhat True**	**Certainly True**
Considerate of other people's feelings	☐	☐	☐
Restless, overactive, cannot stay still for long	☐	☐	☐
Often complains of headaches, stomach-aches or sickness	☐	☐	☐
Shares readily with other children, for example toys, treats, pencils	☐	☐	☐
Often loses temper	☐	☐	☐
Rather solitary, prefers to play alone	☐	☐	☐
Generally well-behaved, usually does what adults request	☐	☐	☐
Many worries or often seems worried	☐	☐	☐
Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
Constantly fidgeting or squirming	☐	☐	☐
Has at least one good friend	☐	☐	☐
Often fights with other children or bullies them	☐	☐	☐
Often unhappy, depressed or fearful	☐	☐	☐
Generally liked by other children	☐	☐	☐
Easily distracted, concentration wanders	☐	☐	☐
Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
Kind to younger children	☐	☐	☐
Often argumentative with adults	☐	☐	☐
Picked on or bullied by other children	☐	☐	☐
Often volunteers to help others (parents, teachers, other children)	☐	☐	☐
Thinks things out before acting	☐	☐	☐
Can be spiteful to others	☐	☐	☐
Gets along better with adults than with children	☐	☐	☐
Many fears, easily scared	☐	☐	☐
Sees tasks through to the end, good attention span	☐	☐	☐

APPENDIX F
Life Stress subscale of the Parenting Stress Index (PSI: Abidin, 1995)

During the past 12 months, have any of the following events occurred in your immediate family? (please mark a clear 'X' in ALL boxes that apply to you or your immediate family)

	YES	NO
1. Divorce	☐	☐
2. Marital reconciliation	☐	☐
3. Marriage	☐	☐
4. Separation	☐	☐
5. Pregnancy	☐	☐
6. Other relative moved into household	☐	☐
7. Income increased substantially (20% or more)	☐	☐
8. Went deeply into debt	☐	☐
9. Moved to a new location	☐	☐
10. Promotion at work	☐	☐
11. Income decreased substantially	☐	☐
12. Alcohol or drug problem	☐	☐
13. Death of a close family friend	☐	☐
14. Began new job	☐	☐
15. Entered new school	☐	☐
16. Trouble with superiors at work	☐	☐
17. Trouble with teachers at school	☐	☐
18. Legal problems	☐	☐
19. Death of immediate family member	☐	☐
20. Major Illness	☐	☐

APPENDIX G
Centre for Epidemiological Studies Depression Scale (CES-D: Radloff, 1977)

Below is a list of the ways you might have felt or behaved in the past week. Please mark a clear 'X' in the box that shows how often you have felt or behaved this way in the past week.

	Rarely or none of the time (less than 1 day)	**Some or a little of the time**	**Occasionally or a moderate amount of time (3-4 days)**	**Most or all of the time (5-7 days)**
I was bothered by things that usually don't bother me	☐	☐	☐	☐
I did not feel like eating; my appetite was poor	☐	☐	☐	☐
I felt that I could not shake off the blues even with help from my family and friends	☐	☐	☐	☐
I felt that I was just as good as other people	☐	☐	☐	☐
I had trouble keeping my mind on what I was doing	☐	☐	☐	☐
I felt depressed	☐	☐	☐	☐
I felt that everything I did was an effort	☐	☐	☐	☐
I felt hopeful about the future	☐	☐	☐	☐
I thought my life had been a failure	☐	☐	☐	☐
I felt fearful	☐	☐	☐	☐
My sleep was restless	☐	☐	☐	☐
I was happy	☐	☐	☐	☐
I talked less than usual	☐	☐	☐	☐
I felt lonely	☐	☐	☐	☐
People were unfriendly	☐	☐	☐	☐
I enjoyed life	☐	☐	☐	☐
I had crying spells	☐	☐	☐	☐
I felt sad	☐	☐	☐	☐
I felt that people dislike me	☐	☐	☐	☐
I could not "get going"	☐	☐	☐	☐

APPENDIX H

Role Restriction, Isolation and Health subscales of the Parenting Stress Index (PSI: Abidin, 1995)

For each of the following statements, please focus on your child who is in the study, and pace a clear 'X' in the box which best represents you.

Role Restriction subscale:	**Strongly agree**	**Agree**	**Not sure**	**Disagree**	**Strongly disagree**
Most of my life is spent doing things for my child	☐	☐	☐	☐	☐
I find myself giving up more of my life to meet my children's needs than I ever expected	☐	☐	☐	☐	☐
I feel trapped by my responsibilities as a parent	☐	☐	☐	☐	☐
I often feel that my child's needs control my life	☐	☐	☐	☐	☐
Since having this child, I have been unable to do new and different things	☐	☐	☐	☐	☐
Since having this child, I feel that I am almost never able to do things that I like to do	☐	☐	☐	☐	☐
It is hard to find a place in our home where I can go to be by myself	☐	☐	☐	☐	☐
Spouse subscale:					
Since having this child, my spouse (or male/female friend) has not given me as much help and support as I expected	☐	☐	☐	☐	☐
Having this child has caused more problems than I expected in my relationship with my spouse (or male/female friend)	☐	☐	☐	☐	☐
Since having this child, my spouse (or male/female friend) and I don't do as many things together	☐	☐	☐	☐	☐
Since having this child, my spouse (or male/female friend) and I don't spend as much time together as a family as I had expected	☐	☐	☐	☐	☐
Since having this child, I have had less interest in sex	☐	☐	☐	☐	☐
Having this child seems to have increased the number of problems I/we have with in-laws and relatives	☐	☐	☐	☐	☐

Subscales of the PSI continued:

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
Having this child has been much more expensive than I expected	☐	☐	☐	☐	☐
Isolation subscale:					
I feel alone and without friends	☐	☐	☐	☐	☐
When I go to a party, I usually expect not to enjoy myself	☐	☐	☐	☐	☐
I am not as interested in people as I used to be	☐	☐	☐	☐	☐
I often have the feeling that other people my own age don't particularly like my company	☐	☐	☐	☐	☐
When I run into a problem taking care of my children, I have a lot of people to whom I can talk to get help or advice	☐	☐	☐	☐	☐
Since having children, I have a lot fewer chances to see my friends and to make new friends	☐	☐	☐	☐	☐
Health subscale:					
During the past 6 months I have been sicker than usual or have had more aches and pains than I usually do	☐	☐	☐	☐	☐
Physically, I feel good most of the time	☐	☐	☐	☐	☐
Having this child has caused changes in the way I sleep	☐	☐	☐	☐	☐
I don't enjoy things as I used to	☐	☐	☐	☐	☐

Please mark the box that best describes you (mark only one box):

Since I've had my child:

1. I have been sick a great ☐
2. I haven't felt as good ☐
3. I haven't noticed any change in my health ☐
4. I have been healthier ☐

APPENDIX I

Caregiver Strain Questionnaire
(CGSQ: Brannan, Heflinger, & Bickman, 1997)

Please look back over the past six months and try to remember how things have been for your family. We are trying to get a picture of how life has been in your household over that time.
In the past 6 months, please mark a clear 'X' in the box that shows how much of a problem were the following:

	Not at all	**A little**	**Somewhat**	**Quite a bit**	**Very much**
Interruption of personal time resulting from your child's problems?	☐	☐	☐	☐	☐
Your missing work or neglecting other duties because of your child's problems?	☐	☐	☐	☐	☐
Disruption of family routines due to your child's problems?	☐	☐	☐	☐	☐
Any family member having to do without things because of your child's problems?	☐	☐	☐	☐	☐
Any family member suffering negative mental or physical health effects as a result of if your child's problems?	☐	☐	☐	☐	☐
Your child getting into trouble with the neighbours, the community or law enforcement?	☐	☐	☐	☐	☐
Financial strain for your family as a result of your child's problems?	☐	☐	☐	☐	☐
Less attention paid to any family member because of the attention given to your child?	☐	☐	☐	☐	☐
Disruption or upset of relationships within the family due to your child's problems	☐	☐	☐	☐	☐
Disruption of your family's social activities resulting from your child's problems?	☐	☐	☐	☐	☐
How socially isolated did you feel as a result of your child's problems?	☐	☐	☐	☐	☐
How sad or unhappy did you feel as a result of your child's problems?	☐	☐	☐	☐	☐

Caregiver Strain Questionnaire continued:

	Not at all	**A little**	**Somewhat**	**Quite a bit**	**Very much**
How embarrassed did you feel about your child's problems?	☐	☐	☐	☐	☐
How well did you relate to your child?	☐	☐	☐	☐	☐
How angry did you feel toward your child?	☐	☐	☐	☐	☐
How worried did you feel about your child's future?	☐	☐	☐	☐	☐
How worried did you feel about your family's future?	☐	☐	☐	☐	☐
How guilty did you feel about your child's problems?	☐	☐	☐	☐	☐
How resentful did you feel toward your child?	☐	☐	☐	☐	☐
How tired or strained did you feel as a result of your child's problems?	☐	☐	☐	☐	☐
In general, how much of a toll has your child's problems been on your family?	☐	☐	☐	☐	☐

APPENDIX J
The Caregiver Diary

CAREGIVER DIARY

THIS WILL BE REMOVED

Name of child:………………………………

Respondent: Primary Caregiver
(please circle)
Secondary Caregiver

Date:…………………………………………

Interviewer:…………………………………..

THIS BOOKLET HAS TWO PARTS

PART A contains the diary and instructions for its completion

PART B contains a brief questionnaire for you to fill out AFTER you have completed the diary

PLEASE COMPLETE THIS DIARY ON: ☐

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
☐	☐	☐	☐	☐	☐	☐

CG ID ☐

C ID ☐

PART A

This diary covers what **you have been doing** over the 24 hours that started at 4 am today and ends at 4 am tomorrow. Each square in the diary represents 15 minutes.

Each page of the diary includes three numbered parts:

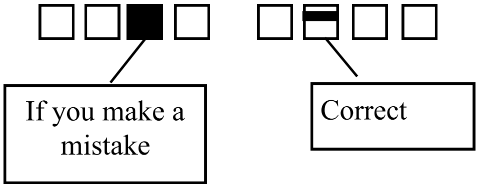
SECTION 1 describes care-giving activities you may be doing,

SECTION 2 describes other activities you may be doing,

SECTION 3 asks if there was someone else with you when you were doing various activities.

To complete the diary use a blue or black pen to mark **ALL** the activities that you were doing in each 15 minute period. Fill in at least one square in each of the three numbered sections for each 15 minute period. If you were doing more than one activity during the 15 minutes, please mark **ALL** of these activities.

PLEASE PLACE A CLEAR MARK INSIDE THE BOXES. YOU MAY DRAW A LINE BETWEEN BOXES IF YOU WERE DOING AN ACTIVITY FOR MORE THAN 15 MINUTES. IF YOU MAKE A MISTAKE, FILL THE ENTIRE BOX AS SEEN IN THE EXAMPLE.



Below is how the diary is filled in for the following example of a care-givers morning:

This mother woke up at 6.30 am to settle her pre-school aged child with a disability who was upset when waking. She changed her child's nappy and brought him into the kitchen to feed him breakfast. She also ate breakfast at this time, and then washed the dishes while her child watched TV and his older siblings finished in the kitchen. This care-giver then supervised her other children while they got ready for school, while helping her child with a disability get dressed and washed. She practised some signs with her son, who is non-verbal. The mother dropped off her older children at school and then stopped by the shops with her son on the way home. She needed to watch her son carefully while shopping as he often grabs things off the shelf when they are walking around. She needed to reprimand him once or twice, but was pleased that he did not have a tantrum at the shops, so let him look around the pet-shop as a treat before heading home.

Morning

1. Caregiving Activities	4am 0 15 30 45	5m 0 15 30 45	6am 0 15 30 45	7am 0 15 30 45	8am 0 15 30 45	9am 0 15 30 45
Helping with feeding	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Helping with toileting	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Helping with other personal care activities (eg bathing, dressing/ undressing, teeth cleaning, hair brushing)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Playing, reading, singing, talking with my child	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Holding, cuddling, comforting or soothing my child	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Helping with communication	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Teaching, doing therapy activities	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Managing behaviour	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
General monitoring/checking that my child is OK	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Watching my child closely, ready to step in straight away	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Traveling with my child (eg to/ from childcare, shopping)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Attending organised lessons/activities	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Appointments with doctors/ therapists & other meetings about my child	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Phone calls/ paperwork/research about my child	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Child by themselves (eg sleeping/ playing **without an adult** present, watching TV)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Child being cared for by another family member (eg my partner, child's sibling, grandparent) or adult friend	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Child being cared for by a paid carer or in childcare/ kindergarten/ school	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Other:	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
2. Other Activities	4am 0 15 30 45	5am 0 15 30 45	6am 0 15 30 45	7am 0 15 30 45	8am 0 15 30 45	9am 0 15 30 45
Employment/ study/ voluntary work	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Sleeping	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Hygiene activities (eg showering)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Eating/ drinking	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Food preparation	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Household chores/ household maintenance	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Shopping	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Recreational activities (sport, walking the dog, reading, watching TV)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Talking/ socialising (with my partner, family or friends)	☐☐☐☐	☐☐ ☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Caring for another child in the family	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Other:	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
3. Who was with me?	4am 0 15 30 45	5am 0 15 30 45	6am 0 15 30 45	7am 0 15 30 45	8am 0 15 30 45	9am 0 15 30 45
Alone	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
My child	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
My partner	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Other adult(s) (eg family/ friend)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Child's brother(s) / sister(s), other children	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐

10am 0 15 30 45	11am 0 15 30 45	12pm 0 15 30 45	1pm 0 15 30 45	2pm 0 15 30 45	3pm 0 15 30 45	1. Caregiving Activities
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Helping with feeding
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Helping with toileting
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Helping with other personal care activities (eg bathing, dressing/ undressing, teeth cleaning, hair brushing)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Playing, reading,singing,talking with my child
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Holding, cuddling, comforting or soothing my child
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Helping with communication
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Teaching, doing therapy activities
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Managing behaviour
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	General monitoring/checking that my child is OK
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Watching my child closely, ready to step in straight away
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Traveling with my child (eg to/ from childcare, shopping)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Attending organised lessons/ activities
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Appointments with doctors/ therapists & other meetings about my child
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Phone calls/ paperwork/research about my child
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Child by themselves (eg sleeping/ playing without an adult present, watching TV)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Child being cared for by another family member (eg my partner, child's sibling, grandparent) or adult friend
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Child being cared for by a paid carer or in childcare/ kindergarten/ school
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Other:
10am 0 15 30 45	11am 0 15 30 45	12pm 0 15 30 45	1pm 0 15 30 45	2pm 0 15 30 45	3pm 0 15 30 45	2. Other Activities
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Employment/ study/ voluntary work
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Sleeping
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Hygiene activities (eg showering)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Eating/ drinking
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Food preparation
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Household chores/ household maintenance
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Shopping
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Recreational activities (sport, walking the dog, reading, watching TV)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Talking/ socialising (with my partner, family or friends)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Caring for another child in the family
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Other:
10am 0 15 30 45	11am 0 15 30 45	12pm 0 15 30 45	1pm 0 15 30 45	2pm 0 15 30 45	3pm 0 15 30 45	3. Who was with me?
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Alone
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	My child
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	My partner
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Other adult(s) (eg family/ friend)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Child's brother(s) / sister(s), other children

		Afternoon			Evening	
1. Caregiving Activities	4pm 0 15 30 45	5pm 0 15 30 45	6pm 0 15 30 45	7pm 0 15 30 45	8pm 0 15 30 45	9pm 0 15 30 45
Helping with feeding	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Helping with toileting	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Helping with other personal care activities (eg bathing, dressing/ undressing, teeth cleaning, hair brushing)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Playing, reading, singing, talking with my child	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Holding, cuddling, comforting or soothing my child	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Helping with communication	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Teaching, doing therapy activities	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Managing behaviour	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
General monitoring/checking that my child is OK	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Watching my child closely, ready to step in straight away	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Traveling with my child (eg to/ from childcare, shopping)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Attending organised lessons/activities	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Appointments with doctors/ therapists & other meetings about my child	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Phone calls/ paperwork/research about my child	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Child by themselves (eg sleeping/ playing **without an adult present**, watching TV)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Child being cared for by another family member (eg my partner, child's sibling, grandparent) or adult friend	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Child being cared for by a paid carer or in childcare/ kindergarten/ school	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Other:	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
2. Other Activities	4pm 0 15 30 45	5pm 0 15 30 45	6pm 0 15 30 45	7pm 0 15 30 45	8pm 0 15 30 45	9pm 0 15 30 45
Employment/ study/ voluntary work	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Sleeping	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Hygiene activities (eg showering)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Eating/ drinking	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Food preparation	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Household chores/ household maintenance	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Shopping	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Recreational activities (sport, walking the dog, reading, watching TV)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Talking/ socialising (with my partner, family or friends)	☐☐☐☐	☐☐ ☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Caring for another child in the family	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Other:	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
3. Who was with me?	4pm 0 15 30 45	5pm 0 15 30 45	6pm 0 15 30 45	7pm 0 15 30 45	8pm 0 15 30 45	9pm 0 15 30 45
Alone	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
My child	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
My partner	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Other adult(s) (eg family/ friend)	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐
Child's brother(s) / sister(s), other children	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐

Evening **Night**

10pm 0 15 30 45	11pm 0 15 30 45	12am 0 15 30 45	1am 0 15 30 45	2am 0 15 30 45	3am 0 15 30 45	**1. Caregiving Activities**
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Helping with feeding
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Helping with toileting
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Helping with other personal care activities (eg bathing, dressing/ undressing, teeth cleaning, hair brushing)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Playing,reading,singing,talking with my child
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Holding, cuddling, comforting or soothing my child
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Helping with communication
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Teaching, doing therapy activities
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Managing behaviour
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	General monitoring/checking that my child is OK
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Watching my child closely, ready to step in straight away
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Traveling with my child (eg to/ from childcare, shopping)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Attending organised lessons/ activities
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Appointments with doctors/ therapists & other meetings about my child
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Phone calls/ paperwork /research about my child
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Child by themselves (eg sleeping/ playing **without an adult present**, watching TV)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Child being cared for by another family member (eg my partner, child's sibling, grandparent) or adult friend
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Child being cared for by a paid carer or in childcare/ kindergarten/ school
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Other:
10pm 0 15 30 45	11pm 0 15 30 45	12am 0 15 30 45	1am 0 15 30 45	2am 0 15 30 45	3am 0 15 30 45	**2. Other Activities**
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Employment/ study/ voluntary work
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Sleeping
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Hygiene activities (eg showering)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Eating/ drinking
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Food preparation
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Household chores/ household maintenance
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Shopping
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Recreational activities (sport, walking the dog, reading, watching TV)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Talking/ socialising (with my partner, family or friends)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Caring for another child in the family
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Other:
10pm 0 15 30 45	11pm 0 15 30 45	12am 0 15 30 45	1am 0 15 30 45	2am 0 15 30 45	3am 0 15 30 45	**3. Who was with me?**
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Alone
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	My child
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	My partner
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Other adult(s) (eg family/ friend)
☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	☐☐☐☐	Child's brother(s) / sister(s), other children

PART B

PLEASE ANSWER THE FOLLOWING QUESTIONS AFTER COMPLETING THE DIARY. USE A BLUE OR BLACK PEN, PLACE A CLEAR 'X' INSIDE THE BOX.

What kind of day is described in this diary? Tick the option that best describes your day:

☐ An ordinary day

☐ A holiday or a family

☐ A school holiday for brother/sister

☐ A parent took time off work

☐ Our family dealt with a crisis

☐ We has guests staying with us

☐ A family member was ill

☐ I was ill

☐ The child for whom I am a primary care-giver was a great deal more stressed than normal

☐ The child for whom I am a primary care-giver was ill

☐ An unusual day for another reason (please specify):

How stressful was this day?

Please place a clear “X” in the box that best describes how stressful was your day:

Not at all	A little	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐

Please go to Question 3 on the next page

Thank you.
You have finished the questionnaire!

Do care-giving activities make you feel stressed?

YES
☐ → **Continue**

NO
☐ → **Please go to Question 5 on the next page**

Please mark a clear 'X' in the box that shows how much each care-giving activity made you feel stressed:

	Not at all	**A little**	**Somewhat**	**Quite a bit**	**Very much**
Helping my child with feeding	☐	☐	☐	☐	☐
Helping my child with toileting	☐	☐	☐	☐	☐
Helping with other personal care activities (eg bathing, dressing/undressing)	☐	☐	☐	☐	☐
Playing, reading, singing, talking with my child	☐	☐	☐	☐	☐
Holding, cuddling, comforting, soothing my child	☐	☐	☐	☐	☐
Helping my child with communication	☐	☐	☐	☐	☐
Teaching or doing therapy activities with my child	☐	☐	☐	☐	☐
Managing my child's behaviour	☐	☐	☐	☐	☐
General monitoring/ supervising my child	☐	☐	☐	☐	☐
Watching my child closely	☐	☐	☐	☐	☐
Traveling with my child	☐	☐	☐	☐	☐
Attending organised lessons/activities	☐	☐	☐	☐	☐
Appointments with doctors/ therapists & other meetings about my child	☐	☐	☐	☐	☐
Phone calls/ paperwork/research about my child	☐	☐	☐	☐	☐
Other (please specify):	☐	☐	☐	☐	☐

5. Do your other activities make you feel stressed?

YES ☐ → **Continue**

NO ☐ → **Please go to Question 7 on the next page**

Please mark a clear 'X'in the box that shows how much each activity made you feel stressed:

	Not at all	**A little**	**Somewhat**	**Quite a bit**	**Very much**
Employment/ study/ voluntary work	☐	☐	☐	☐	☐
Household chores/ household maintenance	☐	☐	☐	☐	☐
Food preparation	☐	☐	☐	☐	☐
Shopping	☐	☐	☐	☐	☐
Socialising with others	☐	☐	☐	☐	☐
Caring for another child in my family	☐	☐	☐	☐	☐
Other (please specify):	☐	☐	☐	☐	☐

Please continue on the next page

7. Did interpersonal problems make you feel stressed?

YES ☐ → **Continue**

NO ☐ → **Please go to Question 9 (below)**

Please mark a clear 'X' in the box that shows how much each of the following may have made you feel stressed:

	Not at all	A little	Somewhat	Quite a bit	Very much
Conflict with partner	☐	☐	☐	☐	☐
Conflict with family	☐	☐	☐	☐	☐
Conflict with friends	☐	☐	☐	☐	☐
Other (please specify):	☐	☐	☐	☐	☐

9. Did general worries make you feel stressed?

YES ☐ → **Continue**

NO ☐ → **You have finished the questionnaire**

Please mark a clear 'X' in the box that shows how much each worry made you feel stressed:

Financial problems	☐	☐	☐	☐	☐
Concerns about my child	☐	☐	☐	☐	☐
Worry about the future	☐	☐	☐	☐	☐
Other (please specify):	☐	☐	☐	☐	☐

Explanatory Notes for the Caregiver Diary

Helping with feeding –	Includes time spent feeding your child or assisting with some part of this activity, as well as time spent supervising your child during meals if this is necessary.
Helping with toileting -	Includes time spent assisting with your child's toileting in any way (including changing nappies and cleaning up accidents), as well as time spent supervising your child during toileting if this is necessary.
Helping with hygiene Activities-	Includes time spent on all activities that relate to your child's cleanliness and grooming such as, bathing and showering, washing hair, brushing teeth as well as time spent supervising hygiene activities if needed.
Helping with dressing/ grooming -	Includes all activities that relate to getting your child dressed and ready for the day, or undressed and ready for bed. Includes time spent dressing or grooming your child, or assisting with some part of these activities, or supervising these activities if this is necessary.
Helping with treatment tasks -	Includes helping your child with any medical procedures as well as time spent organising medications, giving your child medications, or supervising this activity, if appropriate. If you engage in treatment tasks at the same time as another activity, then record both activities. For example, if you use a gastrostomy tube to feed your child, then record this time in the "helping with feeding category", as well as "helping with treatment tasks" for this period of time.
Playing, reading, singing, talking with my child-	Includes all free time spent with my child.
Holding, cuddling, comforting or soothing my child-	Includes affectionate hugging, cuddling etc, as well as time spent comforting your child if they are upset of frightened.
Managing behaviour-	Includes time spent using all behavioural management strategies (whether they work or not!) as well as time spent reprimanding your child for misbehaviour.
Teaching, doing therapy	Includes time spent teaching your child, as well time spent doing tasks set by therapists. If therapy activities are included as part of other daily activities, then record both categories. For example, if you do leg stretches while your child is on the change table, record both "helping with toileting", as well as "teaching, doing therapy activities" for this period of time.
Helping with communication-	Includes time spent helping your child to communicate their needs. Includes your use of signs or other assistive devices (eg augmentative communication device).
Helping with chores-	Includes time spent assisting child to complete a chore (eg making their bed or cleaning their room) or supervising them in doing such an activity. If you are also doing other activities at the same time, then record both activities. For example, if you are teaching your child to do a chore, or if you are managing misbehaviour as a result of asking your child complete a chore, then record "teaching, doing therapy activities", or "managing behaviour", as well as "helping with chores".

General monitoring/ checking my child is OK-	Includes time spent checking your child even if they are not in the same room with you, or playing by themselves. In this example, record time spent in "child by themselves" category, as well as "general monitoring/ checking my child is OK" category.
Watching my child closely ready to step in straight away-	Record this category even if you and/or your child are engaged in another activity. For example, if you are watching your child closely while you are both out shopping, record "shopping" in OTHER ACTIVITIES as well as "watching my child closely". Or, if you are watching your child closely while they are playing with other children, record "child by themselves" as well as "watching my child closely".
Traveling-	Includes time spent traveling <u>with your child</u>. For example, this includes time spent transporting them to appointments or childcare, as well as time spent travelling for other, more general purposes (shopping, picking up siblings).
Phone calls/ paperwork/ research/ meetings on behalf of my child-	Includes any phone calls or paperwork that you need to complete in order to meet the medical, therapy or educational needs of your child. For example, time spent filling in forms to ensure that your child is enrolled in kindergarten or school, or time spent obtaining information from doctors or therapists. Also include time spent researching your child medical condition in libraries, or on the internet.
Appointments with doctors/ Therapists-	Includes time spent attending appointments, or time spent in an individual or group therapy sessions (for example, in a special needs playgroup).
Child by themselves-	Record this category if your child was asleep in the same room, or sleeping in another room without you being present. Also record this category if your child is watching TV or playing by themselves without needing your intervention, either in the same room or in another room without you being present. If you are monitoring or watching your child whilst they are sleeping/ playing then record both activities, that is, record "child by themselves" as well as "general monitoring/ checking my child is OK", or "watching my child closely, ready to step in straight away".
Child being cared for by another family member or adult friend-	Record this category if your child was <u>not being cared for you at all.</u> For example, if a family member or friend was caring for your child in your home while you go out, or if your child is being cared for in a location other than your home.
Child being cared for by a paid carer or in childcare/kindergarten/ school-	Record this category if your child was <u>not being cared for you at all.</u> For example, if a paid carer was caring for your child in your home while you go out, or if your child is being cared for in a location other than your home.

APPENDIX K
Rushed/pressed for time item (ABS 1997, 2006)

Please mark a clear ‘X’in the box that best shows how often you feel rushed or pressed for time.

Always	**Often**	**Sometimes**	**Rarely**	**Never**
☐	☐	☐	☐	☐

What are ALL the reasons you feel rushed? (please place a clear ‘X’ in ALL the boxes that represent you)

Trying to balance work and family responsibilities	☐
Pressure of work/ study	☐
Demands of family	☐
Take too much on/ not good at managing time	☐
Too much to do/ too many demands placed on you	☐
Other (please specify): ………………………………………………………………………	☐

APPENDIX L

Time Crunch Scale (Robinson, 1981)

For each item, please place a clear 'X' in the box that best matches how you feel.

		Strongly agree	**Agree**	**Not**	**Disagree**	**Strongly disagree**
I often feel under stress when I don't have enough time		☐	☐	☐	☐	☐
When I need more time, I tend to cut back on sleep		☐	☐	☐	☐	☐
At the end of the day, I often feel that I haven't accomplished what I set out to do		☐	☐	☐	☐	☐
I worry that I don't spend enough time with my family and friends		☐	☐	☐	☐	☐
I feel that I am constantly under stress—trying to accomplish more than I can handle		☐	☐	☐	☐	☐
I feel trapped in a daily routine		☐	☐	☐	☐	☐
When I'm working long hours, I often feel guilty that I'm not at home	**N/A** ☐	☐	☐	☐	☐	☐
I consider myself a workaholic		☐	☐	☐	☐	☐
I just don't have time for fun anymore		☐	☐	☐	☐	☐
Sometimes I feel that my spouse doesn't know who I am anymore	**N/A** ☐	☐	☐	☐	☐	☐

APPENDIX M

Carer Support Scale (CSS)

N.A. ☐

The following are areas that caregivers of children with disabilities often have to deal with. For each area, please mark a clear 'X' in the box that shows how much your PARTNER has helped with the care of your child IN THE LAST MONTH:

	Not at all	**A little**	**Sometimes**	**Quite a bit**	**Very much**
1. Practical care tasks (eg toileting, bathing)	☐	☐	☐	☐	☐
2. Attending appointments (eg doctors, therapists, teachers)	☐	☐	☐	☐	☐
3. Caring for other children in the family	☐	☐	☐	☐	☐
4. Household chores/ food preparation	☐	☐	☐	☐	☐
5. Caring for your child so you can have a break, take part in a recreational activity or spend time with another family	☐	☐	☐	☐	☐
6. Comforting or attending to my child at night	☐	☐	☐	☐	☐
7. Someone to talk to about my feelings	☐	☐	☐	☐	☐
8. Other (please specify):	☐	☐	☐	☐	☐

For each area, please mark a clear 'X' in the box that shows how much <u>more</u> you would <u>ideally</u> like your PARTNER to help with the care of your child:

	No more	**A little more**	**Somewhat more**	**Quite a bit more**	**A lot more**
1. Practical care tasks (eg toileting, bathing)	☐	☐	☐	☐	☐
2. Attending appointments (eg doctors, therapists, teachers)	☐	☐	☐	☐	☐
3. Caring for other children in the family	☐	☐	☐	☐	☐
4. Household chores/ food preparation	☐	☐	☐	☐	☐
5. Caring for your child so you can have a break, take part in a recreational activity or spend time with another family member	☐	☐	☐	☐	☐
6. Comforting or attending to my child at night	☐	☐	☐	☐	☐
7. Someone to talk to about my feelings	☐	☐	☐	☐	☐
8. Other (please specify):	☐	☐	☐	☐	☐

APPENDIX N
Structured interview used to collect demographic information for Study 2

1. What is the sex of the child in this study?

   Male ☐

   Female ☐

2. What is the age of the child in this study?

   _______________years

3. What have doctors told you about your child's medical diagnosis or condition

____

4. What are the medical treatments that are required by your child on a daily basis?

____

____

5. What are the ages and sex of all other dependent children (18 years or younger) in your home

   1. sex_______________age_________________
   2. sex_______________age_________________
   3. sex_______________age_________________

6. Do any of these children have a disability or a chronic medical condition?

   No ☐

   Yes ☐

   If YES, please describe what doctors have told you about their diagnosis or condition:

   1. ____
   2. ____
   3. ____

7. Which of the following best describes your relationship to the child in this study?

   Natural mother ☐

   Natural father ☐

   Stepmother ☐

   Stepfather ☐

   Other (please describe):____

8. Who has primary responsibility for the care of the child in this study?

Natural mother ☐

Natural father ☐

Stepmother ☐

Stepfather ☐

Other (please describe):____

9. What is the mother's highest completed level of schooling?

Primary school ☐

Some years of high school ☐

Year 12, SACE, Matric. or equivalent ☐

Technical, trade or TAFE certificate, or some university ☐

Completed university qualifications ☐

10. Is the mother in the child's household currently in paid employment?

No ☐

Yes ☐

If YES, is the mother working

Full-time ☐

Part-time ☐

11. What is the father's highest completed level of schooling?

Primary school ☐

Some years of high school ☐

Year 12, SACE, Matric or equivalent ☐

Technical, trade or TAFE certificate, or some university ☐

Completed university qualifications ☐

12. Is the father the child's household currently in paid employment?

No ☐

Yes ☐

If YES, is the father working

Full-time ☐

Part-time ☐

13. Does your family receive any pension or benefit?

No ☐

Yes ☐

If YES please specify:____

14. What therapy services does your child currently receive?

1.____

2.____

3.____

15. What other services do you or your family receive to help support you in caring for your child with a disability? (eg respite, home help)

1.____

2.____

3.____

16. Does the child in this study attend child-care?

No ☐

Yes ☐

If YES, please state how often they attend:

____

17. Does the child in this study attend kindergarten?

No ☐

Yes ☐

If YES, please describe how often they attend

____

18. Is the child in this study cared for by another adult on a regular basis?

No ☐

Yes ☐

If YES, please describe your relationship with the carer, and how often the child is cared for:

____

19. Do you, or another member of your immediate family, have responsibility for the care of another person with a disability (eg an elderly relative)?

No ☐

Yes ☐

If YES, please describe:

____

20. In this study we will be exploring with you, some of the difficulties involved in caring for a child with a disability. However, we are also aware from what other parents tell us, that there can be rewards in parenting a child with a disability.

Do you agree?

No ☐

Yes ☐

If YES, please describe some of the rewards you experience in parenting your child:

____

____

APPENDIX O
Coding Rules assisting analysis of the Caregiver Diary

Diaries for both primary and secondary caregivers covered a 24 hour period. **Each diary was carefully examined to ensure that each 15 minute period was accounted for.** This was facilitated by having a pair of diaries from both the PCG and the SCG covering the same day. Reconciliation of the diaries enabled gaps within individual diaries to be completed.

For example:

- Enabling the transfer of information between diaries as to when a child was asleep in the morning and evening if this had not been recorded

- Allowing the recording of whether a child was being cared for by the other parent (or another family member, or a paid carer) OR still in the care of the PCG or SCG but therefore BY THEMSELVES (ie if no other caring activity is recorded).

- The use of the WHO WAS I WITH section was used to show whether a child was in the care of both or one parents, or to determine the time when a parent went to bed in the evening if not recorded.

If the diaries were incomplete, the following rules were applied:

1. If the PCG records themselves to be asleep (ie in the early morning) with the child showing no activity, assume that the child was also asleep if this has not been recorded (ie record CHILD BY THEMSELVES until the parent is awake and commences caregiving tasks). The child is assumed to be asleep until caring activities commence. If caring activities are undertaken by the other caregiver ie if the PCG (or SCG) sleeps in, then record CHILD CARED FOR BY ANOTHER FAMILY MEMBER from the time they are judged to have woken up.

2. If no caregiving activity was indicated, when it can be reasonably assumed that the child is still in the care of the parent ie
    - The diary does not show that the child is being cared for by another
    - The diary shows the parent to be with their child in the WHO WAS WITH ME section,

   then record that the child was CHILD BY THEMSELVES (ie without need of supervision or active care.)

3. If the child is clearly asleep/ settled for the evening and the parent has not recorded an “other” activity, record OTHER (NOC: not otherwise coded) in the Other Activity section.

The diaries allow for recording of multiple activities in the same time period. Many caregivers took advantage of this to record the different thing they may be doing in a 15 minutes time period, sometimes up to 6 different activities were recorded (in excess of this was judged to be infeasible within 15 minutes). For example, in one diary a therapist visit (therapy/ teaching) required comforting of the child, managing of the child's behaviour, help with feeding & toileting. To ensure intelligibility of the data, however, some scoring rules were established:

1. Activities that were clearly incompatible or illogical were not recorded. For example, traveling and helping with toileting, were judged to be incompatible. These decisions were established in consultation with Robyn. Active caregiving was also judged to preclude recreational activities.

2. If periods longer than 15 minutes were recorded for a number of different personal care activities (ie feeding or toileting) then one 15 minute time period was allocated for each activity.

3. General monitoring and watching were considered to be incompatible with other (inherent in the explanation provided to parents). As well, general monitoring/ watching were considered to be activities that could only be undertaken when the caregiver was not otherwise ACTIVELY engaged with the child ie helping with personal care, teaching, playing, comforting the child. Exceptions were made for helping with communication and managing behaviour (see parent quote) as it is feasible for parent to have to intervene while monitoring or watching their child carefully. As well, monitoring and watching were also allowed if a child was traveling with their parent, or outside of the home ie shopping, attending an appointment.

Total time spent caregiving was calculated by adding all 15 minute time periods over the 24 hours of a single day in which any caregiving occurred, regardless of the number of activities that were recorded within each individual 15 period.

Specifically:

1. Total time caregiving included periods of nighttime care.

2. Active and passive caregiving activities were included in total caregiving time.

3. Phone calls/ research for my child was recorded as caregiving time even if the child was not present with the parent. As well, some parents indicated attending appointment about their child when the child was not present.

Totals for specific caring tasks were calculated by adding the 15 minute periods in which the activity happened over the day.

Total for nighttime care was calculated by adding all 15 minute periods in which a parent was actively engaged with a child in the night. To be considered as nighttime care:

1. The child needed to have been previously asleep (ie CHILD BY THEMSELVES indicated with a complete cessation of caregiving activities for several hours) even if their parent was still awake, or the parent was themselves woken from sleep by their child.

2. Nighttime caregiving occurred after 10 pm at night and before 6am in the morning

In many cases, activities that were recorded in the OTHER categories (in the caregiving or other activity sections) were able to be coded within pre-existing activity groupings. For example, helping children with Xmas activities was coded as playing etc with child. Attending church was coded as socializing with others

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