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One parent's advice to another: An exploration of self-care for parents of children with high-need disabilities and the development of a psychoeducational resource

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Jana Aria Dunlop Oskam

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ABSTRACT

Currently over 95,000 children are affected by a disability in New Zealand (NZ), making up 11% of the child population (Statistics New Zealand, 2013). Receiving a childhood disability diagnosis can be a life-changing event for the entire family. As current societal structures require parents to assume unforeseen caregiving roles (that typically last the course of their child's lifetime), parents as informal caregivers make up a significant sector within NZ. Nevertheless, the dominant approach to research in the field of childhood disability has been based on the assumption that informal caregiving results in adverse outcomes for parents. Consequently, existing research has largely focused on the well-documented negative impact of caregiving for parents and their families.

Although evidence suggests that effective self-care may act as a mediator against caregiver stress, few studies have approached informal caregiving from a positive psychology and health-promotion perspective. However, it can be argued that by adopting a positive health promotion perspective, we can improve understanding on how best to promote wellbeing for parents, and consequently, their children and families as well. Through two studies, this thesis explored the experience of self-care and wellbeing for parents of children with high-need disabilities (HND). Study One achieved this by interviewing 11 parents of children with high-need cerebral palsy or autism. Thematic analysis found that participants typically experienced and enacted self-care in four key areas, including parents' *Formal Supports and Resources*, *Informal Relationships*, *Values and Goals*, and their use of *Time*.

In line with a transformative framework, Study Two developed a psychoeducational resource, aimed at enhancing parents' self-care and perceived wellbeing, by integrating findings from the first study with existing literature. Preliminary evaluation of the resource booklet was achieved by 14 participants completing a written questionnaire to obtain parents' feedback. Descriptive statistics and thematic analysis of participants' responses identified that the booklet appears to capture parents' experiences of self-care when raising a child with HND. Two key themes included participants' *Positive Remarks* and *Ideas for Change*. Overall, findings suggest that despite caregiving challenges, there are effective self-care strategies which parents use to mitigate these risks and improve wellbeing.

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GLOSSARY OF ABBREVIATIONS

CPAG	Child Poverty Action Group
HND	High-need disabilities
NHC	National Health Committee
NZ	New Zealand
UN	The United Nations
WHO	World Health Organisation
ZBI	Zarit Burden Interview (1985)

SECTION ONE

CHAPTER ONE:

Introduction

You do need to look after yourself first. I think of that safety video on Air New Zealand, when they say, "Put the oxygen mask on yourself before you put it on someone else". I actually think that it's kind of the same, because you're not going to do a good job with your child if you don't look after yourself.

(Rachael[1], full-time mother of an 18-year-old daughter with high-need autism and intellectual disability, personal communication, November 2016)

Prior to formally presenting the literature review to this thesis, I have decided to first position myself in the research by providing a brief reflection on how I chose the topic of self-care for parents of children with HND. Following this, a thesis outline has been presented to introduce the structure and layout of this research.

My main motivation for choosing a topic focused on families of children with HND stemmed from my work as a respite carer of children with intellectual and physical disabilities. In this role (2010 – present), I am able to provide a much-needed break for families and work alongside parents towards building everyday life skills for their children. Through my personal experience with families, I noticed a lack of positive support and understanding regarding parents' health and wellbeing. Although the majority of these families were able to access supports and resources for their children, the focus appeared largely restricted to the child's individual wellbeing, without much consideration for the wider family or systems in which that child lived and interacted day in, day out.

Being in a privileged position to spend time in these family's homes, I saw the toll that caregiving responsibilities can have on parents' physical health, emotional and spiritual wellbeing, and relationships with their children and partner. I was also privileged to have parents share and discuss their stories, trauma, life challenges, and concerns for the future with me. Alongside noticing the challenges parents faced when

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[1] All parents throughout this thesis have been given pseudonyms to protect their identities.

raising a child with special needs, I saw their incredible resilience, courage, creativity and inner strength to carry on every day. Further, some parents appeared to thrive (despite daily challenges) better than others, seemingly independent from their child's symptom severity or the family's access to supports and funding.

Through this work, I very quickly realised that if I had the opportunity to complete doctorate study, I would find a way to give back to the families that trusted me with their experiences and hardships of raising a child with special needs. In examining the current literature on childhood disability, I read countless research articles detailing the negative experiences and adverse outcomes for caregivers. The negative focus in research seemed to be a consequence, in part, of the assumption that informal caregiving creates added challenges beyond parents' capacity to cope (Aneshensel & Mitchell, 2014; McConnell & Savage, 2015). However, the literature did not fully capture parents' experiences from those who I had worked with. Further, most studies did not take into consideration parents' inner strengths and strategies which may help protect (and even encourage) wellbeing. Research which approached childhood disability from a positive, strengths-based perspective was very limited.

In directing my thesis towards parents' experiences of self-care and wellbeing, I wanted not only to contribute to an area where research was currently lacking, but also to challenge the assumption that caregiving results predominately in adverse outcomes. I felt that qualitative research from a transformative framework would help give a voice to parents who have often been overlooked as valuable contributors to research and societal change in the past. With aspirations and training in applied clinical psychology, interviewing and listening to parents' stories as research methodology aligned with my beliefs about the client and/or research participant being the expert in their experiences. I also felt that focusing on parents' wellbeing and developing a resource for enhancing self-care was a way not only to give back to parents, but to give back to whole families. This is because improved parental wellbeing is likely to result in positive outcomes for their children, partners, family relationships, and overall family functioning as well (Algood, Harris & Hung, 2013).

My aim throughout this thesis was to advance understanding of how parents maintain wellbeing and resist the risk of adverse outcomes when raising a child with special needs. Further, due to having a clinical psychology training background, my goal was also to extend research findings to develop a practical resource to help parents in their journey as informal caregivers. The case for investigating parents' experiences of self-care and wellbeing when raising a child with HND in NZ is presented here. Rationale for the development and evaluation of a psychoeducational resource on self-care for parents is also presented.

Thesis Outline

This thesis consists of four main sections. The first section includes seven chapters which provide a broad introduction to the thesis topic, existing literature, and the overall aims and rationale for the current two studies. Chapter One introduces my position and main motivations for the current research. Chapter Two defines disability and provides an historical and current overview of disability within the NZ context. Chapter Three describes informal caregiving and introduces Bronfenbrenner's (1977) ecological systems theory as an important framework for understanding parents as informal caregivers.

Chapter Four presents the negative and positive impacts of informal caregiving on parents, highlighting that the existing research landscape in this area has predominately focused on negative health outcomes from a stress-illness framework. Chapter Five introduces positive psychology and the health promotion paradigm as an alternative underlying theoretical perspective for exploring parents' experiences of caregiving. Chapter Six defines self-care for informal caregivers and contends that promoting parents' self-care is an ethical imperative comparable to that of healthcare professionals. Chapter Seven provides a rationale for this thesis, and it introduces the current research methodology and overall aims for both Study One and Study Two.

Section Two, consisting of seven chapters, presents Study One: a qualitative study exploring parents' experiences of self-care while raising children with HND in NZ. Chapter Eight reports on the methods of this study, including details related to participants, procedures and ethical considerations. Chapter Nine provides an overview of findings, while Chapters Ten to Thirteen discusses the four main themes from Study One in-depth. Chapter Fourteen provides a discussion of Study One's findings, including theoretical and practical implications, limitations, and considerations for future research.

Section Three, consisting of three chapters, presents Study Two: a preliminary evaluation of a developed self-care psychoeducational booklet for parents raising children with HND. Chapter Fifteen reports on the methods of this second study, including details related to the design, participants, materials, and procedures. Chapter Sixteen presents the findings from Study Two, including descriptive statistics of participants' quantitative ratings, and two key themes from participants' qualitative comments. Chapter Seventeen provides a discussion of Study Two's findings, including theoretical and practical implications, limitations, and considerations for future research.

Finally, Section Four consists of one chapter concluding the thesis. Chapter Eighteen provides overall conclusions and reflections of both Studies One and Two, in relation to existing literature. Possible meanings of findings from Study One and Two are synthesised and discussed, and suggestions for future research are given.

CHAPTER TWO:

Disability and the New Zealand Context

Defining Disability

Impairment is part of the human condition; almost everyone will experience varying levels of impairment, either permanently or temporarily, at some point in their lives. Most extended families have a relative with a significant high-need impairment or condition, and many of these families end up taking responsibility for their support and care (World Health Organisation [WHO], 2011). Nevertheless, *disability* is an evolving concept resulting from impairment which has a diverse and multifaceted impact on individuals and the systems with which they interact. Disability is now viewed not only as just a health problem for the individual, but rather as a complex interaction between the "features of a person's body and the features of the society in which he or she lives" (WHO, 2018). *The International Classification of Functioning, Disability and Health* (ICF) defined disability as an overarching term referring to difficulties in any or all of three interconnected areas of functioning: including impairments, activity limitations, and participation restrictions (WHO, 2001). Impairments are problems in body function or structure; activity limitations are difficulties met by individuals when performing a task or action; and participation restrictions are problems experienced by individuals when involved with life situations (WHO, 2001; WHO, 2018).

Disability discourse is thoroughly saturated with readily differing perspectives which typically fall into numerous alternative models of disability (Haegele & Hodge, 2016). Models of disability are predominately influenced to varying degrees by two fundamental philosophies which either perceive people with disabilities as being reliant on society, or perceive people with disabilities as being consumers of what society has to offer (Nikora, Karapu, Hickey & Te Awekotutu, 2004). How disability is defined is dependent on the model used. This is because each model influences the language people use to describe those with disabilities, as well as their perceptions, expectations and interactions with the disability community (Haegele & Hodge, 2016). In order to understand what disability is, it is therefore useful to understand how the most dominant alternative models define disability.

The *Medical Model* views disability as the consequence of a medical problem or biological impairment (Haegele & Hodge, 2016). The individual's disability is seen as a physical abnormality or impairment within the person, which occurs largely independent from their social or environmental context (Berghs, Atkin, Graham, Hatton & Thomas, 2016). Treatment, if possible, occurs through concentrating on medically 'fixing' the underlying pathology. This is done in order to correct the abnormality and promote 'normal' body functioning. Although medical interventions (and therapeutic effects) which come from viewing disability in this way can be extremely beneficial, this model is often criticised for abnormalising those with disabilities (Berghs et al., 2016; Haegele & Hodge, 2016). Viewing disabilities as atypical has been shown to result in segregation, institutionalisation, discrimination, and restricting individuals' autonomy (Berghs et al., 2016; Haegele & Hodge, 2016; Nikora et al., 2004).

Due to criticism for the Medical Model abnormalising disability, the *Rehabilitation Model* was developed as an advancement of this (Nikora et al., 2004). This model views people with disabilities as needing professional rehabilitation services to help compensate for their impairments. Therefore, although disability is still viewed as a 'problem', the individual can learn how to function effectively with the use of strategies and aids in order to work towards optimal functioning (Dunn & Andrews, 2015). When achieved in collaboration with the individual, the rehabilitation approach can be empowering. However, this approach often results in authoritarian services that are viewed as 'experts' which can lead to client passivity and loss of control (Nikora et al., 2004).

Consequently, the *Social Model* of disability was developed as an appeal from the disability community for social and structural change in order to enable their full inclusion and participation in society (Haegele & Hodge, 2016; Mckenzie, 2013). It was developed to counteract the individualised medical model of disability and biological determinism, and to reclaim the experience of disability from healthcare professionals being regarded as the 'experts' (Berghs et al., 2016). This model does not view disability as a limitation within the individual. Rather, disability is the way that physical and social environments create exclusion, barriers, and limitations for certain groups of individuals (Berghs et al., 2016). Individuals' impairments therefore become neutral attributes or characteristics, and disability becomes a social construction which can be removed through changing society’s attitudinal, physical and institutional barriers. Through removing these barriers, equal opportunities are then provided for everyone (Dunn & Andrews, 2015; Haegele & Hodge, 2016; Nikora et al., 2004).

Closely related to the Social Model is the *Identity Model* of disability. This model views disability both as a neutral and natural characteristic, as well as a distinct diverse cultural experience that individuals identify with (Dunn & Andrews, 2015; Retief & Letsosa, 2018). As disability is viewed as a demographic characteristic, similar to gender, ethnicity or sexual orientation, disability may be valued as a positive part of person’s identity (Retief & Letsosa, 2018). Although disability is experienced individually, this model views the role of groups and community as important in understanding and accepting human differences and variation positively (Dunn & Andrews, 2015). Identification with the disability community allows for individuals to feel a sense of connectedness, pride, and shared cultural values and beliefs. However, an individual’s identity should not be assumed, as the extent to which they identify with disability culture varies dependent on their own values, beliefs, and identity formation (Andrews et al., 2013; Retief & Letsosa, 2018).

The Importance of Language

In addition to the changing notions of disability as a construct, the language used to characterise, define and discuss disability is also continually evolving worldwide. As such, it raises important questions regarding how to respectfully and inclusively refer to people with disabilities, and how disability can be appropriately presented both in written and spoken form (Crocker & Smith, 2019; Dunn & Andrews, 2015). Although language is primarily used as a means of communication, it has a direct impact on how peoples’ identities are represented. It also impacts how people feel, think and act towards others, particularly members of diverse groups such as the disability community (Crocker & Smith, 2019; Dunn & Andrews, 2015). A debate in both academic literature and in the disability community continues to exist between whether to use person-first language or identity-first language to refer to people with disabilities (Gernsbacher, 2017).

Person-first language was led by the People First disability advocacy movement in the 1970s, with the intention to separate the individual from their diagnosis or impairments, thereby decreasing the emphasis placed on diagnosis or “labelling” (Crocker & Smith, 2019; Dybwad, 1996). Referring to people first places the emphasis on the person before their disability, in order to promote their individuality and humanity; for example, referring to someone as “a person with a disability” rather than “a disabled person” (Dunn & Andrews, 2015; Gernsbacher, 2017). It was argued that this approach illustrates that disability may make up an aspect of the person’s identity without it becoming their defining characteristic or putting undue emphasis on their specific impairment (Schur, Kruse & Blanck, 2013). Joan Blaska (1993) summarises it well, stating:

> The philosophy of using person-first language demonstrates respect for people with disabilities by referring to them first as individuals, and then referring to their disability when it is needed. This philosophy demonstrates respect by emphasizing what people can do by focusing on their ability rather than their disability, and by distinguishing the person from the disability. (p. 27)

The person-first approach is beneficial in its ability to prevent people who share similar disabilities from being grouped together by acknowledging that multiple factors, such as socioeconomic status, ethnicity, physical health, and family situation, all influence an individual’s experience of their disability in markedly different ways (Dunn & Andrews, 2015). As an approach, it hopes to decrease the stigma of disability by applying person-first language to all, regardless of whether they have a disability or not (Gernsbacher, 2017). However, Gernsbacher (2017) cautions that core principles of person-first language are not being upheld in academic literature as his study found that it is used more frequently to refer to those with disabilities than to those without, particularly when referring to children, which may be accentuating stigma rather than reducing it.

Conversely, identity-first language emphasises disability as a neutral human attribute or variation central to a person’s identity (Gernsbacher, 2017). This approach is used to counteract historical oppression and marginalisation through allowing people’s disabilities to become the focus; for example, a person choosing to identify as an “autistic person” or simply as “autistic” (Brueggemann, 2013).

Identity-first language allows people to claim and value their disability as something to be proud of, which can promote autonomy and self-assurance for the individual (Brueggemann, 2013; Crocker & Smith, 2019). It also supports disability culture, which encourages belongingness, self-advocacy, solidarity and shared purpose among people with disabilities as a distinct and diverse group (Dunn & Andrews, 2015). Many who support this approach argue that person-first language creates an impression that disability lies within the individual person rather than being created from social factors (Crocker & Smith, 2019; Schur et al., 2013). They also argue that person-first language suggests that the person can be purposefully separated from their disability, which may have the unintended consequence of implying that disability is negative or undesirable (Dunn & Andrews, 2015; Schur et al., 2013).

Thus, the importance of language cannot be overstated, but as there is no clear universal convention, decisions need to be made around which approach will be used. With my research, I recognise that person-first language is not unanimously accepted or supported within the disability community, and I agree with many of the arguments of those who question or are against it. Nevertheless, I recognised the need to select consistent terminology, so chose to use person-first language with the view to emphasise disability as being only part of a child's identity. This decision was made following the guidelines given by Dunn and Andrews (2015), as this research includes parents of children from multiple disability groups. Further, I was not in contact with the children but rather their parents, so I was unable to ask them directly how they prefer to be referred to (Dunn & Andrews, 2015). It is my hope that this decision will not distract anyone reading this research; I would like to reiterate that the motivation was on the inclusion, wellbeing, and health-promotion of parents and their children.

An Historical Overview

Disability within NZ has a long history involving many changes regarding social policy, disability services, and societal expectations. The introduction of government policies specifically targeted at addressing the needs of those with disabilities are found dating back to the early 1900s, including addressing the educational needs of children with intellectual disabilities (National Health Committee [NHC], 2004). However, the movement of deinstitutionalisation was arguably the most significant paradigm shift for disability and informal caregiving in NZ, which occurred from the mid-1970s onwards (Maidment, 2016).

Deinstitutionalisation involved a change in focus from long-term institutional care of individuals with disabilities, which at the time often occurred away from the person's family, to community and home-based care practices (Maidment, 2016). This paradigm shift resulted in over 10,000 individuals being moved from institutions into the community in just over a decade (Maidment, 2016; NHC, 2004). Shifting the focus of care to community-based settings was based on the notion of improving individuals' independence, quality of life and inclusion in society. It also resulted in the development and implementation of the New Zealand Public Health and Disability Act (2000) and the New Zealand Disability Strategy (2001) (Bonardi, 2009; Chowdhury & Bensen, 2011).

The aim of the New Zealand Disability Strategy, which was based on the social model of disability, was to ensure that all people living in NZ felt valued and part of an inclusive society without prejudice (Ministry of Health, 2001). The New Zealand Disability Strategy continues to evolve in line with NZ's current policy environment, with the 2016 version stating it aims to guide government agencies on disability issues until 2026 (Ministry of Social Development, 2016). Nevertheless, this paradigm shift to community-based care has resulted in a dependence on caregivers in NZ to address the day-to-day physical, emotional and practical support needs for people with disabilities (Glendinning & Arksey, 2008; Maidment, 2016). This reliance on caregivers reflects the ideology of familialism, whereby, public policy is now based on the increased expectation that primary care needs of individuals will be met by close friends and family members (Chan, 2010; Maidment, 2016). However, given that the New Zealand Disability Strategy aims to provide appropriate disability services which are largely client-focused, informal caregiver's needs are often overlooked (Maidment, 2016; Ministry of Social Development, 2016).

NZ is considered a leader in disability issues internationally due to its active participation in drafting the United Nations Convention on the Rights of Persons with Disabilities, signed in 2007 and ratified in 2008 (Child Poverty Action Group [CPAG], 2015). The Convention was developed as an international Human Rights Treaty with the purpose to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (The United Nations [UN], 2008, p. 4). Although NZ's credentials appear sound, many argue that there continues to be concerns with respect to the implementation of the Convention in NZ (CPAG, 2015; Human Rights Commission, 2016; Malatest International, 2017). These concerns are documented by the UN's Disability Convention Independent Monitoring Mechanism's Report (2017) and the Interim Report on the Right to Inclusive Education (2016) (CPAG, 2015; Human Rights Commission, 2016; Malatest International, 2017). Therefore, there remains a need in NZ to continue exploring ways to enhance the inclusion and rights of people with disabilities, along with their families and caregivers.

The New Zealand Context

Currently in NZ there are over 95,000 children under the age of 15 affected by a disability, which is equivalent to 11% of the child population (Statistics New Zealand, 2013). Further, around half of all children with disabilities (48%) report limitations arising from more than one impairment type, with conditions existing since birth being the most common cause of limiting impairment (Statistics New Zealand, 2013). A smaller proportion of children access disability-related supports, with only around 8,700 children receiving government-funded support (Murray, 2018). As these statistics show, existing systems of care for children in NZ typically require parents and families to be willing and able to undertake unforeseen informal caregiving roles in-home (Murray, 2018; Raina et al., 2005). These caregiving roles usually last the course of their child's lifetime (Raina et al., 2005). The NZ health system is fully funded through taxes and does not rely on people having medical insurance. However, there is still a substantial shortfall in funding, and services are stretched and under-resourced (Grimmond, 2014).

The estimated value of unpaid informal care in NZ was found to lie within the region of $7.3 billion to $17.6 billion in 2013 (Grimmond, 2014). This estimated value equates to the average informal carer dedicating 30 hours per week to their caregiving role, which is more than a quarter of their awake time each week. Despite the essential and time-consuming role informal caregivers provide in maintaining the wellbeing of those who are ill, disabled or elderly, this form of welfare provision remains largely invisible in current NZ policy (Maidment, 2016). Further, although informal caregivers are more likely to be eligible for certain welfare benefits or be employed part-time, households of unpaid caregivers are more likely to be unemployed and typically earn 10% less than those with no caregiving responsibilities (Grimmond, 2014; Murray, 2018). NZ families who have children with disabilities are significantly more likely to experience income poverty when compared to families without children with disabilities (Murray, 2018). Children with disabilities are also disproportionately living in one-parent households (30%) when compared to children without disabilities (17%) (Murray, 2018; Statistics New Zealand, 2016).

There are over 490,000 individuals in NZ who currently provide unpaid, informal care for someone who has a disability, frailty or illness (Statistics New Zealand, 2016). Women in NZ are also more than twice as likely to be carers, making up 63% of unpaid informal care being provided (Grimmond, 2014). This trend matches that of other Western countries, including Britain and Australia, and is usually explained in relation to gender inequality and socially constructed gender roles (Goodhead & McDonald, 2007; Winder & Bray, 2005). Many argue that acknowledgement of gender roles (with women attending to 'domestic' care duties, along with the opportunity cost this creates for women in areas such as employment), has long been unaccounted for in assessing the impact of informal caregiving (Gardiner, Brereton, Frey, Wilkinson-Meyers & Gott, 2014; Maidment, 2016). Gender inequalities within the disability community also remain underrepresented in public policy (Gardiner et al., 2014; Maidment, 2016). In addition to identifying gender issues in caregiving research, literature has also pointed to differing enactments of caregiving across cultures (Alpass et al., 2013). In NZ, the indigenous culture is Māori, and a small body of research has explored their experiences of informal caregiving (Nikora et al., 2004).

Literature about informal caregiving with Māori in NZ typically uses the term 'whānau caregiving', which can be defined as "a person linked to the person with a disability by whakapapa and who has inherited or assumed the role out of a sense of duty, obligation and love" (Nikora et al., 2004, p. 50). Māori have been found to be more likely to provide informal or whānau care than non-Māori in NZ, with 23% of Māori women being caregivers in comparison to 16% of NZ European women (Alpass et al., 2013). This may be explained by the higher disability morbidity rates among Māori compared with non-Māori, as well as caregiving traditionally being a culturally engrained value for Māori (Alpass et al., 2013). For example, most Māori elders or kaumatua will remain in whānau households as they age, with very few being found to reside in residential care (Ministry of Health, 2004). This likely occurs as Māori elders are viewed as being the source of whakapapa and whānau knowledge, as well as having the role of being primary decision-makers and leaders within their family (Maidment, 2016). Raising children is also typically shared by the wider whānau or family, as there is a culture of interdependence whereby all family have a role in providing care for their children (Markie-Frost, 2017).

Summary

In sum, informal caregivers make up a significant sector within NZ across cultures. As current societal structures require parents of children with disabilities to undertake often unforeseen caregiving roles in-home, they have become the backbone to our health system, performing tasks previously completed by health professionals. However, this is not without personal cost to those individuals, physically, psychologically, financially, and professionally. Therefore, parents require support in their roles through research, policy, and practice to improve sustainability of care. Further, having parents' needs highlighted and visible, and their voices heard, is an additional need in the literature. The following chapter defines informal caregiving and introduces Bronfenbrenner's (1977) ecological systems theory as an important framework for understanding how parents adapt to raising a child with special needs through considering how they interact within multiple systems.

CHAPTER THREE:

Parents as Informal Caregivers

Defining Informal Caregiving

The term caregiver is widely used throughout existing literature to describe parents' informal role as a carer for their child's disability needs (Goodhead & McDonald, 2007; Townsend, 2018). The term caregiver is also defined in numerous ways, with many variations for parents including 'family caregiver', 'informal caregiver' and 'primary caregiver' (Townsend, 2018). For the purposes of this research, the terms parent, carer, caregiver, and informal caregiver were used interchangeably to describe parents' caregiving role. The NHC's (1998) definition for informal caregiving was adopted for this research, defining it as:

> Caring for a friend, family member or neighbour who because of sickness, frailty or disability can't manage everyday living without help or support … [it] is not usually based on any formal agreement or services specifications. Informal caregiving is characterised by relationships and social expectations.

There is an important discrepancy in roles between formal and informal caregivers. Formal caregivers, who provide community-based or home-based care for those with disabilities, are paid a wage, work defined hours, and receive support and training from recognised organisations (Falchero, 2008). They can take leave from work, are economically visible, and have likely chosen this field as their occupation (Falchero, 2008). Conversely, the role of an informal caregiver is often assumed and unplanned. It comes with unspecified tasks and responsibilities, as well as undefined rewards (Collings, 2006; Townsend, 2018).

Informal caregiving is not required by an employment agreement or official arrangement, but rather, it is enacted out of choice and family obligation (Townsend, 2018). It occurs in the context of family and whānau relationships shaped by affective bonds, and the role is typically societally and economically invisible (Collings, 2006; Goodhead & McDonald, 2007). Parents are effectively on-call at all times as an informal caregiver for their child's needs, and they often provide linkages with formal providers, such as respite carers, healthcare professionals, and hospitals (Townsend, 2018).

Although the terms parent and informal caregiver will be used interchangeably for this research, there is an important distinction between what would be defined as 'typical' parenting and the extended role of informal caregiving for children with disabilities (Crowe, Carvlin-Miller & Concotelli-Fisk, 2019). This is illustrated by Winder and Bray's (2005) definition of an informal caregiver being "a person who performs tasks for another person that the recipient is unable to perform independently and should typically be able to perform given their age and developmental stage" (p. 2). Parents' roles extend from typical parenting to incorporate informal caregiving as their responsibilities range beyond usual care within their child's developmental trajectory due to having additional disability needs (Crowe et al., 2019). This extension of roles creates distinct caregiving challenges as children require additional support for their disability into adulthood, which necessitates ongoing commitment from their parents (Barrett, Hale & Butler, 2014). These challenges include added physical, financial, social, and emotional caregiving tasks (Barrett et al, 2014; Crowe et al., 2019).

The Informal Caregiving Role

Typical responsibilities for raising children without disabilities, and managing a family, include parents being able to meet their children's physical and emotional needs, disciplining and reinforcing their behaviours, teaching them skills for communication and independency, and completing household tasks such as cleaning, paying bills and preparing meals. However, parents as informal caregivers have many added responsibilities to care for their child's disability needs (Crowe et al., 2019; Goodhead & McDonald, 2007; Pinquart, 2017). These added responsibilities can include helping their child with activities of daily living (beyond what is expected for their age and developmental stage); for example, helping their child with eating, bathing, dressing, toileting, functional transfers, and maintaining continence (Crowe et al., 2019; Goodhead & McDonald, 2007; Pinquart, 2017).

Parents may need to provide emotional support and/or undertake an active role during their child's physical therapy, medical appointments, or healthcare procedures. They may also be required to undertake nursing tasks in-home, such as administering and managing multiple medications, injections, tube feedings, and operating medical equipment (Feinberg, Reinhard, Houser & Choula, 2011; Pinquart, 2017). Estimates of informal caregivers being required to handle these health-related tasks in-home range from 23-53% of all parents of children with special needs, with many having received little training or preparation for these tasks (Feinberg et al., 2011).

Other additional responsibilities for parents can include coordinating and arranging various disability services and supports, hiring and supervising formal care workers, organising and attending medical appointments and procedures, communicating with a range of healthcare professionals, and serving as an advocate in implementing and making decisions for their child's disability care plan (Feinberg et al., 2011; Goodhead & McDonald, 2007; Pinquart, 2017). Further, parents are often required to provide constant supervision and monitoring of their child to ensure their safety, manage challenging behaviours associated with their child's disability, provide social stimulation and emotional support for their child, and arrange entertainment and timetables for them (Goodhead & McDonald, 2007). Although many of these tasks appear to fall under typical parenting responsibilities, caring for a child with disabilities often comes with unique challenges which require greater time and effort from the parent (Goodhead & McDonald, 2007; Isa et al., 2016).

Bronfenbrenner's Ecological Systems Theory

Bronfenbrenner's (1977) ecological systems theory provides a useful framework when exploring the multifaceted impact of informal caregiving on parents and families, as well as how parents develop effective coping strategies to manage stress when caring for a child with special needs. It is a valuable framework to better understand how family engagement occurs in multiple contexts, including school, home, work, and the community (Taheri, Perry & Minnes, 2017). It also highlights that interactions within these various contexts both directly and indirectly impact a family's and individual's development (Bronfenbrenner, 1977; Taheri et al., 2017). Further, the ecological framework provides a strengths-based perspective, as it acknowledges the importance of supportive relationships and environments for families, parents and children (Taheri et al., 2017). Such a perspective makes this framework appropriate for exploring the complex factors which both facilitate and obstruct healthy growth and relationships for parents', their families, and their environments (Buchanan, Miedema & Frey, 2017).

Ecological systems theory is represented visually as a set of four concentric circles surrounding an individual, with each circle representing a different context or environmental level, as seen in Figure 1 (Bronfenbrenner, 1977; Onwuegbuzie, Collins & Frels, 2013). These levels are interconnected, and include the microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Bronfenbrenner, 1977). The first level is the microsystem consisting of the individual's immediate environment with which they actively participate and live, including their family, friends and physical surroundings (Onwuebuzie et al., 2013; Xu, 2019). The second level is the mesosystem consisting of the interrelations, relationships or connections amongst individuals, their microsystem and their exosystem. For example, the interactions between parents and teachers, or the relationship between family experiences and school experiences (Weiss, Lopez, Kreider & Chatman-Nelson, 2014; Xu, 2019).

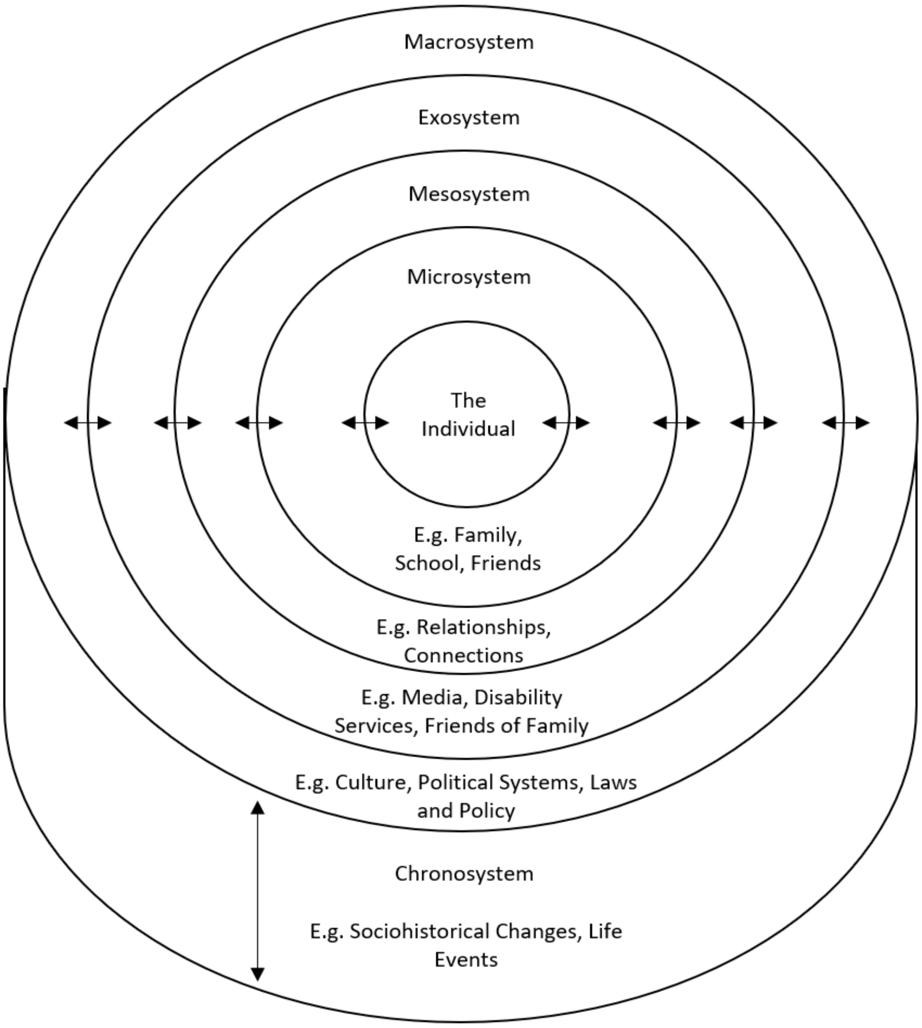

Figure 1. Diagram visually depicting Bronfenbrenner's (1977) ecological systems theory.

The third level is the exosystem, referring to contexts that do not actively involve the individual, but which still indirectly influence them and their microsystem (Onwuebuzie et al., 2013; Weiss et al., 2014; Xu, 2019). For example, a child's experience at home may be influenced by their parent's work environment and experiences. If their parent lost their job, it would result in reduced income for the family and, therefore, reduced opportunities for the child. The fourth level is the macrosystem referring to the larger cultural context surrounding the individual (Onwuebuzie et al., 2013; Xu, 2019).

The cultural context includes larger societal belief systems, cultural norms and values, ideologies, political systems, social policies and laws, which all indirectly influence the individual (Xu, 2019). It also incorporates cultural groups an individual identifies with, regarding the culture's heritage, beliefs and values (Onwuebuzie et al., 2013; Weiss et al., 2014). To a large extent, the macrosystem determines the resources, opportunities and constraints placed on an individual and their family system (Weiss et al., 2014; Xu, 2019). For example, social policy reform instigated at a national level will influence a parent's access to financial support and disability services, changing the conditions under which they can care for their child. The macrosystem should be viewed as fluid rather than static, as it is constantly developing and evolving over time (Weiss et al., 2014).

The fifth level to the ecological systems theory is the chronosystem, representing the element of time (Weiss et al., 2014). This level refers both to the individuals' life course from birth to death, as well as to the historical context with which they reside (Weiss et al., 2014). It includes environmental and sociohistorical changes and events which occur during an individuals' lifetime, as well as their own experiences and life transitions (Onwuebuzie et al., 2013; Weiss et al., 2014).

Overall, this conceptual framework is a useful approach to understanding an individual in relation to their larger social and environmental context, which is important when exploring the complex nature of human experiences (Buchanan et al., 2017; Friedman & Allen, 2011). When attempting to understand the experiences of a parent of a child with disabilities, it is important to also consider the function of the systems in which they exist. In doing so, interventions can be developed in order to strengthen areas of weakness or dysfunction, and to best support the individual within their subsystems and relationships (Friedman & Allen, 2011).

The ecological systems framework is concerned with understanding the nature of interactions and relationships between the individual and their greater environment. It recognises that all individuals are dynamic, in that they both change and create reactive change to the systems in which they reside (Dunst, 2016; Friedman & Allen, 2011). In other words, relationships and interactions are seen as reciprocal, and individuals are seen as both the cause and effect of change in their situation. Further, interactions become three-dimensional within ecological systems theory, as individuals relate to others on a horizontal level, as well as vertically relating to the macrosystems in which they exist (Dunst, 2016; Friedman & Allen, 2011). Moreover, these interactions occur in a multidirectional manner, as multiple layers of systems are reciprocally interacting with the individual (and with each other) in a constantly fluctuating manner, meaning that all layers are interrelated (Dunst, 2016; Friedman & Allen, 2011). It can be thought of as a system of interlocking gears, whereby, activity in any specific ‘gear’ or system will influence activity in each of the other interrelated systems (Dunst, 2016).

As causality occurs in a reciprocal and intertwined loop within the larger system, facilitating systematic change (such as improving parents’ self-care and wellbeing) does not occur through understanding linear causation, as supported by a reductionist approach (Dunst, 2016; Germain, 1991). Rather, change becomes possible through identifying the systems’ strengths (Friedman & Allen, 2011; Germain, 1991). Important concepts for understanding the nature of interactions between individuals and their environment were identified by Germain (1991), and include adaptation, life stress, coping, power, and human connectedness. Adaptation involves the reciprocal interaction between an individual and their environment that ultimately results in change (Germain, 1991). This change will either occur by the individual in order to meet their environmental demands, or by the environment, so physical and social settings become more receptive to the person’s needs (Friedman & Allen, 2011).

Life stress is a concept which relates to the friction created whenever two contexts or systems interact, and it includes both external demands and the individuals’ internal experience of stress. Two different individuals in the same situation will likely have different perceptions or experiences of stress and ability to cope (Friedman & Allen, 2011; Germain, 1991). Coping is a concept that falls under life stress, and it relates to a person’s ability to both problem-solve and regulate their emotions to alleviate negative feelings caused by stress (Friedman & Allen, 2011). Power is a second concept that falls under life stress, and it is concerned with how dominant groups or systems exert their position of power to influence subordinate groups. It can occur at all systemic levels, including within families or at a macro-level regarding government and social policy (Friedman & Allen, 2011). Finally, human connectedness is a concept concerned with an individual’s ability to form relationships and attachments to others (Germain, 1991).

Ecological Systems Theory and Informal Caregiving

When exploring parents’ experiences of informal caregiving, Bronfenbrenner’s (1977) ecological systems theory is a useful framework to understand how parents cope and adapt to life stress created by raising a child with a disability (Friedman & Allen, 2011). For parents, caregiving commitments are strongly grounded in the relationship with their child and immersed in family and community expectations. Parents’ relationships with their child, family, and community must be viewed as dynamic and evolving, as parents often start functioning as informal caregivers before they even become aware of it themselves (Seltzer & Li, 2000). This occurs as additional caregiving responsibilities develop naturally over time from ordinary parental tasks as their child’s disability needs remain (Seltzer & Li, 2000). For example, parents may be responsible for continuing to feed, bath, and dress their child after an age which is considered normal development. The dynamic nature of the relationship is influenced by the parents’ fluctuating satisfaction and motivation towards caregiving, shifting between stages of “commitment, dissociation, obligation and repudiation” (Goodhead & McDonald, 2007, p. 9). The relationship also evolves based on changes in the health and wellbeing of the child, the new and altered caregiving roles that occur as the child and parent age, grief for the caregiver associated with the loss of previous roles, and exchanges and interactions with other family members (Goodhead & McDonald, 2007).

The caregiver-recipient relationship must also be considered within the embedded context of other multidirectional social and family relationships, as well as larger social systems such as communities, institutions and cultures of which the relationship resides (Goodhead & McDonald, 2007; Gouin, Estrela, Desmarais & Barker, 2016). According to the ecological framework, other social relationships and larger social structures have important bidirectional and multidirectional influence on the child’s development, the caregiver-recipient relationship, and the parent’s experience of informal caregiving (Gouin et al., 2016). For example, the parent and their child typically interact with numerous healthcare services which are shaped by current and historical public policies. The policy environment reflects the larger societal context of attitudes, expectations and demographics, which then also directly influence social relationships and individuals’ attitudes (i.e., discrimination of disabilities, and value placed on caring for others) (Gouin et al., 2016). In turn, the parent and their child outwardly influence social relationships and community attitudes, as well as larger social structures by prompting policy change (Goodhead & McDonald, 2007). Therefore, by focusing on interventions aimed at enhancing parents’ self-care and wellbeing, this may have a positive bidirectional and multidirectional impact on the child’s wellbeing, the parent-child relationship, family functioning, and larger social systems (Goodhead & McDonald, 2007).

There is a growing body of research utilising the ecological framework to explore the experiences of informal caregiving, thereby enhancing understanding and supports in order to positively impact the child, parent and family systems (Algood et al., 2013). For example, findings suggest that parenting styles, family dynamics, and environmental factors impact understanding and management of children’s disabilities (Algood et al., 2013; Gfroerer, Kern, Curlette, White & Jonyniene, 2011; Johnson, Liu & Cohen, 2011; Whiting, Nash, Kendall & Roberts, 2019). At a micro-level, research suggests that positive family support, strong social support systems, good parental psychological health, parents’ acceptance and understanding of the disability, sufficient parental coping and problem-solving skills, and a positive parent-child relationship are all essential for parenting success when raising a child with disabilities (Cuzzocrea, Murdaca, Costa, Filippello & Larcan, 2016; MacDonald & Hastings, 2010; Milshtein, Yirmiya, Oppenheim, Kroen-Kaire, & Levi, 2010; Minnes, Perry & Weiss, 2015). Highlighting the importance of bidirectional interactions, child characteristics also influence parenting success, as communication challenges for children (such as those with autism) may decrease the responsiveness of parents (Howe, 2006). Reduced parent responsiveness has been shown to then result in further implications including child distress, and the development of insecure or disorganised attachment between parent and child (Howe, 2006).

At a meso-level, research has frequently explored parents' marital relationship when caring for a child with disabilities (Garcia-Lopez, Sarria, Pozo & Recio, 2016; Gau et al., 2012). Research suggests that parents report lower marital happiness and harmony, and more marital adjustment difficulties in comparison to parents of children without disabilities (Garcia-Lopez et al., 2016; Gau et al., 2012; Oelofsen & Richardson, 2006). Religion is another meso-level factor which influences parents' wellbeing, as findings suggest that religion provides a positive means of support for families when raising a child with disabilities (O'Hanlon, 2013; Ylven & Granlund, 2009).

At a macro-level, research has shown that the effectiveness of interventions, the types of support available to families, the families daily functioning, and the child's overall health, are all influenced by the culture and lifestyle of the family (Hanline & Daley, 1992; Hruschka, 2009). Racial and ethnic minorities are more likely to report that their cultural values and concerns are not met by healthcare professionals in comparison to dominant cultures (Sorkin, Ngo-Metzger & Alba, 2010). Racial and ethnic minorities are also more likely to receive inadequate support and disability services due to disparities in the health care system (Sorkin et al., 2010). Community attitudes and stigma of disability have been shown to increase depression and overall difficulties for parents when raising children with disabilities, mainly due to experiences of stereotyping, rejections, and exclusion (Cantwell, Muldoon & Gallagher, 2015; Kinnear, Link, Ballan & Fischbach, 2016).

Summary

As evident by research findings regarding informal caregiving, factors affecting parents' practices and wellbeing are multifaceted and involve complex interactions between numerous systems (Algood et al., 2013; Cuzzocrea et al., 2016; Garcia-Lopez et al., 2016; Howe, 2006; Kinnear et al., 2016; MacDonald & Hastings, 2010; Minnes et al., 2016; Whiting et al., 2019). This provides a strong rationale for exploring individual's experiences from an ecological framework, as understanding and creating positive change requires a consideration for the multiple systems in which a person is embedded (Taheri et al., 2017). However, there is a gap in current literature regarding understanding factors related to enhancing or mitigating parent wellbeing while raising a child with disabilities. This is due to most findings being focused on negative outcomes or risk factors for parents as informal caregivers (Algood et al., 2013).

Multiple studies have illustrated that parents of children with special needs who have good coping skills tend to experience less distress and fewer depressive symptoms, regardless of the severity of their child’s condition, compared to parents with limited coping skills (Churchill, Villareale, Monaghan, Sharp & Kieckhefer, 2010; Lei, Goh, Oei & Sung, 2015; Minnes et al., 2015). Therefore, interventions aimed at enhancing parents coping skills may foster increased wellbeing for parents, potentially leading to positive multidirectional changes in the multileveled systems with which they interact (Algood et al., 2013; Taheri et al., 2017). The next chapter presents the existing landscape for research regarding parents as informal caregivers, which has tended to focus predominately on the negative impact for parents and families when raising a child with special needs.

CHAPTER FOUR:

The Impact of Informal Caregiving

The dominant approach to research in the field of childhood disability has been based on the assumption that informal caregiving negatively impacts the parent (McConnell & Savage, 2015). It is believed this occurs because caregiving demands create added stressors, threats, and challenges beyond the parent's capacity to cope and adapt (Aneshensel & Mitchell, 2014; McConnell & Savage, 2015). Consequently, research has largely focused on stress, coping processes, and outcomes for parents and families, particularly regarding psychological distress and family dysfunction (Acton, 2002; McConnell & Savage, 2015). This restricted perspective has been helpful to highlight associated risks among parents of children with disabilities, along with justifying the need for socio-political action, psychoeducation and formal supports for families (McConnell & Savage, 2015). However, it can be argued that expanding the research agenda to advance health promotion and adaption for parents and families will more readily help them to sustain wellbeing and succeed despite the odds (Acton, 2002; McConnell & Savage, 2015).

Physical Impact

Multiple studies have consistently found that parents who provide informal care report poorer physical health and significantly more adverse health outcomes when compared to parents of children without disabilities, regardless of their child's disability type (Miodrag, Burke, Tanner-Smith & Hodapp, 2015; Reed, Sejunaite & Osborne, 2016; Vonneilich, Ludecke & Kofahl, 2016). Studies specific to parents of children with autism spectrum disorders found that parents experienced greater perceived stress and adverse health outcomes than parents of children without disabilities, including greater perceived pain and somatic symptoms, more frequent disruptions from physical health problems, and lower physical health-related quality of life (Allik, Larsson & Smedje, 2006; Gallagher & Whiteley, 2013; Hayes & Watson, 2013; Khanna et al., 2011; Miodrag et al., 2015; Reed et al., 2016).

Murphy, Christian, Caplin and Young (2007) explored parents' perspectives of physical health through the implementation of focus groups and questionnaires. Although limitations of causation exist with qualitative research, parents reported experiencing chronic stress due to the unpredictable and uncontrollable nature of their caregiving demands, and more than half indicated their physical health was negatively impacted by the demands of caregiving (Murphy et al., 2007). Nearly all parents had experienced chronic fatigue and sleep deprivation while caring for their child, and most parents reported one or more chronic physical ailments caused specifically by long-term caregiving, such as back and shoulder pain from lifting their child regularly, and direct injuries from their child's impulsive or violent behaviour (Murphy et al., 2007). However, parents ranked their own health needs as lowest priority, with most reporting having "little if anything left at the end of the day" to invest in themselves (Murphy et al., 2007, p. 183).

Similarly, using an extensive questionnaire with 70 participants, Gallagher and Whiteley (2013) found that parents reported physical health problems specific in the domains of sleep, headaches, back pain, and gastrointestinal and respiratory issues. This was further supported by Miodrag et al.'s (2015) meta-analysis of 19 manuscripts which suggests that parents of children with disabilities experience increased health symptoms than those without disabilities, including headaches, backaches, muscle soreness, chronic fatigue, and sleep deprivation. In comparison to informal caregivers for adults or the elderly, parents looking after children with disabilities were found to have poorer self-rated health and more chronic health conditions (Ourada & Walker, 2014). Consequences of having poorer health outcomes for parents include experiencing increased risk for impaired family functioning and caregiving duties, recurrent hospitalisations for themselves and their children, and possible unwanted decisions to place their children in care systems outside of the home (Kelly & Hewson, 2000; Llewellyn, Dunn, Fante, Turnbull & Grace, 1999).

In using a cross-sectional survey design, Khanna et al. (2011) findings suggest parents of children with disabilities attribute clinically significant lower health-related quality of life to functional impairment, lack of social support, subjective (emotional consequence of caregiving) and objective burden (observable and tangible impact of caregiving), and maladaptive coping strategies. Therefore, they argued that it is critical for interventions to be developed to improve health-related outcomes for parents which are focused on enhancing mental and physical health, increasing social supports, improving family functioning, and implementing healthy coping strategies (Khanna et al., 2011). Vonneilich et al.'s (2016) findings further support this, indicating that social support, financial burden, in-home supports, and family coping strategies all significantly impact parents' health-related quality of life. They also argue for increased implementation of effective educational and self-help interventions for parents to negate negative health outcomes (Vonneilich et al., 2016).

Psychological Impact

The negative impact of informal caregiving on parents' psychological health is also significantly substantiated in academic literature (Bonis, 2016; Savage & Bailey, 2004; Schulz & Sherwood, 2009; Vasilopoulou & Nisbet, 2016). Parents of children with disabilities often report higher than normal rates of psychological distress and clinically significant levels of stress, anxiety, and depression when compared to the general population (Cantwell et al., 2015; McConnell & Savage, 2015). In a meta-analysis of 84 studies, Pinquart and Sorenson (2003) found that caregivers experience greater rates of stress and depression, and lower rates of subjective wellbeing and self-efficacy than non-caregivers. Gallagher, Phillips, Oliver and Carroll (2008) found that in comparison to parents of children without disabilities, parents of children with intellectual disabilities reported substantially greater levels of depression and anxiety. Further, they found that almost two thirds of the parents of children with intellectual disabilities met the criteria for clinical depression, and three quarters met the criteria for clinical anxiety (Gallagher et al., 2008).

Parents' experiences of chronic stress, perceived burden, and psychological distress, particularly when combined with poor coping strategies, also increases the likelihood that they will experience 'caregiver burnout' (Angermeyer, Bull, Bernert, Dietrich & Kopf, 2006; Taki et al., 2009; Truzzi et al., 2012). Burnout is a psychosocial syndrome made up of three primary components, including emotional exhaustion, depersonalisation or cynicism, and reduced sense of personal achievement (Angermeyer et al., 2006; Truzzi et al., 2012). Emotional exhaustion refers to lack of energy and the draining of emotional resources; depersonalisation refers to an indifferent or cynical attitude towards the care recipient; and reduced personal achievement refers to the negative perception of one's work as being unproductive (Truzzi et al., 2012). Burnout typically occurs when parents expend all their energy and time on their child's needs, and in the process neglect their own health and wellbeing (Truzzi et al., 2012).

Predictors of parents’ psychological distress have been found to include social support and problematic child behaviours and needs, with poorer perceived support and greater problematic behaviours being associated with increased psychological morbidity (Gallagher et al., 2008; Hsiao, 2016; White & Hastings, 2004). Gallagher et al. (2008) found that further moderators of psychological morbidity for parents include sleep quality and perceived caregiver burden, with high subjective caregiver burden and poorer sleep quality being related to higher levels of depression and anxiety. In this context, caregiver burden encompasses the components of negative social and personal consequences (i.e., lack of employment, social isolation), psychological burden (i.e., chronic stress, feelings of entrapment), and guilt (Ankri, Andrieu, Beaufils, Grand & Henrad, 2005; Gallagher et al., 2008). Multiple studies have found that guilt is the strongest predictor of psychological morbidity for parents (Benderix, Nordstrom & Sivberg, 2006; Gallagher et al., 2008; Lenhard, Breitenbach, Ebert, Schindelhauer-Deutscher & Henn, 2005). This may be because parents who have feelings of guilt often report lacking confidence in their caregiving abilities and decision-making, which in turn is further linked to increased distress, anxiety, and depression (Benderix et al., 2006; Lenhard et al., 2005).

Although indigenous research was not a focus of this thesis, exploring existing (albeit limited) caregiving research within a NZ context was vital. For Māori in NZ, expectations of the “ideal whānau” may also impact parents’ perceived stress and emotional turmoil (Nikora et al., 2004). The term “ideal whānau” is defined as a set of cultural assumptions and expectations which have considerable influence on decision-making within Māori iwi (Collins & Willson, 2008). Nikora et al. (2004) found that certain whānau members tend to be perceived as being obligated to assume the role of caregiver dependent on either their close relationship to the child or their status within the whānau and wider iwi. For example, the caregiving role for the child may fall to the eldest daughter in the whānau or to someone without a partner. Therefore, the decision or expectation for an individual to assume the caregiver role may create conflict for the individual regarding their own wants and aspirations. This in turn, increases the likelihood that the individual will experience emotional turmoil or distress (Nikora et al., 2004).

Some argue higher levels of psychological distress occurs for parents of children with disabilities, as assuming an informal caregiving role results in increased burden and chronic stress, creating physical and emotional strain for extensive periods of time (Olsson & Hwang, 2002; Schulz & Sherwood, 2009). Further, caring for a child with disabilities can be uncontrollable and unpredictable in nature, require high levels of attentiveness, and can create additional strain on family relationships and employment (Gallagher & Whiteley, 2013; Schulz & Sherwood, 2009).

Although the dominant perspective in research is that parental distress and poor psychological health is a reaction to caregiver demands, many argue this should rather be viewed as a transactional relationship (McConnell & Savage, 2015). For example, it is possible the correlation between childhood disability and parent psychological distress may be caused or exacerbated by parent distress being the antecedent to the child's disability needs, pre-existing socioeconomic disadvantage, or disablism beliefs held by society or the family (Jarrett, Mayes & Llewellyn, 2014; McConnell & Savage, 2015). Nevertheless, supporting the interrelationship between reducing parents' perceived stress, optimising family functioning, and providing formal and informal supports is critical in negating the risk for parents experiencing psychological distress (Hsiao, 2016).

Impaired Family Functioning

Common aspects found to be negatively impacted for families when caring for a child with disabilities include employment, financial security, marital and sibling relationships, and family functioning (Dew, Balandin & Llewellyn, 2008; Parish & Cloud, 2006; Shtayermman, 2013). There are many additional needs and requirements when raising a child with disabilities in terms of specialised therapies, medications and medical procedures, home modifications and adaptive equipment, and specialised education services. These needs are not always sufficiently covered by government financial assistance for disability, and not all families will meet strict disability eligibility criteria to cover such expenses (Parish & Cloud, 2006; Saunders et al., 2015). The economic implications of caring for a child with disabilities are further impacted by decisions made by parents to forego financial income due to spending less time in paid employment in order to accommodate their child's caregiving needs (Parish & Cloud, 2006; Saunders et al., 2015). When parents of children with disabilities decide to stay in fulltime employment, this tends to result in them relying on securing some form of paid childcare (Parish & Cloud, 2006).

There is increased risk for heightened marital stress for parents of children with disabilities (Mitchell, Szczerepa & Hauser-Cram, 2016; Shtayermman, 2013). Marital stress can be defined as an accumulation of stressors within the parents' relationship in terms of breakdown in communication, difficulties resolving conflict, and difficulties accepting and supporting each other (Shtayermman, 2013). Caring for a child with disabilities has been associated with reports of decreased marital happiness, more marital adjustment difficulties, and less of a sense of marital consensus in the parents' relationship when compared to parents of children without disabilities (Gau et al., 2012; Mitchell et al., 2016; Oelofsen & Richardson, 2006).

Further, siblings of children with disabilities have also been shown to experience a greater risk for psychological and adjustment disorders, difficulties with peer relationships, and aggression (Hastings, 2003; Sharpe & Rossiter, 2002). However, Dew et al. (2008) argue that most studies which have focused on negative sibling impact relied upon parents, primarily mothers, as the main informers. Further, mothers have consistently been found to have a more negative perspective of this impact than the siblings themselves, which may reflect the mothers' own stress and parenting guilt (Dew et al., 2008; Lauderdale-Littin & Blacher, 2017; Sharpe & Rossiter 2002). Dew et al.'s (2008) findings suggest that when siblings themselves report on the impact of having a sibling with disabilities, they are mostly positive about their experiences.

In terms of overall family functioning, raising children with disabilities has been found increase the risk for perceived lower levels of family adaptability and cohesion, and associated dysfunctional family interaction (Gau et al., 2012; Higgins, Bailey & Pearce, 2005). Higgins et al.'s (2005) findings suggest that most families who have a child with ASD fall outside the range of healthy family functioning, as demonstrated by reduced flexibility, warmth, and connection compared with normative data. They believed this occurs as additional stress from not being able to engage in joint family activities may result in the risk of family disconnection or an inability to meet the needs of all family members at one time (Higgins et al., 2005). Also, high levels of parenting stress for caregivers of children with ASD have been found to be associated with problematic parenting behaviours in limit setting, communication, and involvement with their child (Osborne & Reed, 2010).

Does Disability Type Matter?

The negative impact of informal caregiving has been found to be more closely related to the extent of care required for the child, rather than to the specific type of disability the child is diagnosed with, whether it is a physical, intellectual or developmental disorder (Cummins, 2001; Dyches, Smith, Korth, Roper & Mandleco, 2013). Moreover, it is argued that there is a ceiling effect once the level of care required is perceived as substantially ‘high-need’. When the level of care ceiling is reached, differences in the type of disability become relatively trivial in terms of family burden and caregiver stress (Breslau, Staruch & Mortimer, 1982; Cummins, 2001). For example, Lewis et al. (2006) found no differences in levels of parental depression, life satisfaction and coping skills when comparing parents of children with fragile X syndrome, children with comorbid autism and fragile X syndrome, and children with Down syndrome. Rather, parent’s subjective wellbeing has been shown to be significantly influenced by factors including their age and level of income, whether they live without a partner, whether they pursue meaningful goals, and whether their child has multiple disabilities increasing their level of care required (Hammond, Weinberg & Cummins, 2014).

Positive Impact

Though much of the focus in research remains on the negative impact of informal caregiving, positive aspects are becoming increasingly considered to be important regarding the strengths and resources parents utilise (McConnell, Savage, Sobsey & Uditsky, 2015; Zarit, 2012). The positive outcomes of caregiving for parents have been found to include increased pleasure or satisfaction in providing care, their child being a source of happiness and joy, and the situation providing an opportunity for parents to learn and develop as a person (McConnell et al., 2015; Scorgie & Sobsey, 2000; Taunt & Hastings, 2002). Additional positive outcomes for families have been found to include strengthened family relationships, a new or developed sense of purpose in life, cultivation of new skills and abilities that potentially open up new career options, personal growth (i.e., more compassionate and tolerant, less egocentric), expanded friendships and social networks within the community, developed spirituality, and changes in values and attitudes (McConnell et al., 2015; Scorgie & Sobsey, 2000; Taunt & Hastings, 2002).

Taunt and Hastings (2002) explored the positive outcomes of having a child with a development disability through a content analysis of semi-structured interviews and open-ended questionnaires with a total sample of 47 participants. They found that siblings and extended family members tend to share many positive outcomes with the parents, including improved sensitivity and care, increased closeness and support, newly learnt skills and understanding related to disability, and greater maturity and sense of responsibility (Taunt & Hastings, 2002). Beach (1997) supports this with findings suggesting that family caregiving likely increases more positive sibling interactions, greater empathy for siblings towards others, greater bonding between the sibling and their parents, and positively influences the sibling's peer relationship selection and maintenance.

Broese van Groenou, de Boer and Iedema (2013) explored how care demands, motivation, coping style and support networks are associated with positive evaluations for informal caregivers through multivariate linear regression of 1,685 participants. They found that although caregiving is a mixed experience, positive evaluation can be dependent on caregivers' disposition or preference for informal care over formal care, their values and attitudes towards helping others, feeling like they are doing a 'good thing' as a parent, and getting assistance from others (Broese van Groenou et al., 2013). Carbonneau, Caron and Desrosiers (2010) support this finding, and argue that determinants of positive outcomes with caregiving include having enrichment and pleasant events in everyday life which bring balance to the difficult task of caregiving. Caregivers' sense of self-efficacy and effectiveness also results in confidence and satisfaction in their role (Carbonneau et al., 2010). Further, the quality of the caregiver-recipient daily relationship, the parent's feelings of accomplishment, and parents' perceived meaning of their caregiving role also impact their evaluation of being an informal caregiver (Carbonneau et al., 2010).

Summary

The dominant landscape for research regarding parents as informal caregivers has largely been based on the assumption that informal caregiving negatively impacts parents and creates added challenges beyond their capacity to cope (Aneshensel & Mitchell, 2014; McConnell & Savage, 2015). This restricted perspective has been helpful for recognising possible risks for parents and families when raising a child with special needs, as well as providing a justification for socio-political action, psychoeducation and formal supports for families (McConnell & Savage, 2015). However, it can be argued that positive aspects of caregiving should receive more attention in research, to negate the negative impact caregiving can have on parents' physical and mental wellbeing (Carbonneau et al., 2010). In turn, the potential benefits associated with having a child with disabilities can start to be realised and methods to more readily help parents sustain wellbeing and succeed (despite the odds) can be identified (Acton, 2002; McConnell et al., 2015). The following chapter expands on this argument by introducing positive psychology and the health promotion paradigm as underlying theoretical perspectives to exploring parents' experiences of caregiving.

CHAPTER FIVE:

A Positive Psychology Approach to Improving Parents' Wellbeing

Positive Psychology

Caregiver burden, stress, and associated negative outcomes have been the dominant focus of informal caregiving research for decades (Marino, Haley & Roth, 2017; McConnell & Savage, 2015). This dominant focus tends to align with the historical medical model of disability and was influenced by the deficit-orientated history of psychology which emerged in the 20th century (Shogren, Wehmeyer & Singh, 2017). During this time, the psychology field was shaped by the classification and remediation of mental illness, largely due to the vast needs of veterans returning from World War II (Shogren et al., 2017). As such, psychology essentially adopted a medical model of human functioning which emphasised humans as passive foci that become "damaged" and require repair (Linley, Joseph, Harrington & Wood, 2006; Shogren et al., 2017). However, emerging models of disability and research regarding informal caregiving are largely strengths-based and closely linked to the field of positive psychology (Marino et al., 2017; Shogren et al., 2017).

The field of positive psychology emerged and has vastly grown over the past 20 years, largely due to the work of Mark Seligman and his colleagues (Seligman, 1998; Seligman & Csikszentmihalyi, 2000; Seligman, Steen, Park & Peterson, 2005). Positive psychology focuses on understanding and emphasising individuals' strengths and the positive aspects of their experiences, rather than focusing on negative outcomes for individuals or attempting to repair their "pathological" reactions to stress or trauma (Martz & Livneh, 2016; Shogren et al., 2017). Positive psychology theory underlies psychosocial adaptation of disability for individuals and their caregivers (Livneh & Martz, 2016; Wright, 1983). Psychosocial adaptation is the positive course of development whereby individuals come to accept and respond to disability with positive value changes and coping strategies, rather than succumbing to the disabling condition (Livneh & Martz, 2016; Wright, 1983). Through focusing on individuals' successes, achievements, positive characteristics and values, research comes to understand how best to promote life satisfaction, eliminate societal and attitudinal barriers, and successfully manage difficulties encountered in daily life for those with disabilities and their caregivers (Livneh & Martz, 2016; Marino et al., 2017; Wright, 1983).

Positive psychology often asserts various overlapping categories of positive traits, particularly regarding constructs of virtues and character strengths, such as optimism, hope, wellbeing, resilience and self-determination (Livneh & Martz, 2016; Peterson & Seligman, 2004). When examining the contributions of positive psychology to adaptation to disability and improving caregivers' wellbeing, two assumptions must be made (Livneh & Martz, 2016). Firstly, positive character traits, such as strengths and virtues, are assumed to have existed prior to the onset of disability. Consequently, research should focus rather on the subjective states or experiences of informal caregivers, which include more traditional coping strategies and efforts (i.e., planning, using humour, meaning making). These aspects are more accessible to research and can more accurately be studied and measured, and as these states fluctuate, they are more readily able to help caregivers in the process of adapting to their child's disability (Livneh & Martz, 2016).

Secondly, it must be recognised that emphasising positive strengths and coping strategies should not be regarded as discounting parents' loss, pain, and difficulties in adapting to their child's disability (Livneh & Martz, 2016). Approaching parents' experiences of caregiving from an underlying positive psychology perspective will likely result in improved wellbeing, as many argue that building on the positive rather than directly working on the problem is often the most effective solution (Livneh & Martz, 2016; Shogren et al., 2017). Further, in most cases the "problem" (i.e., caregiving stress and demand) for parents cannot be changed, yet their perceptions and reactions can be managed by helping them adopt and develop their strengths and abilities (Livneh & Martz, 2016; Shogren et al., 2017).

The Health Promotion Paradigm

The health promotion paradigm falls under the field of positive psychology, and it involves a shift in focus from 'curing illnesses' based on the historical medical model within health systems to a more holistic and multidimensional conceptualisation of wellness and care (King, 1994). Health promotion is concerned with empowering individuals and communities to have control over and improve their health and wellness. Health, therefore, becomes viewed as a physical, social and mental resource for everyday living rather than the main objective for living (O'Donnell, 2008). Most definitions accept that both individual and societal ecological systems play a critical role in influencing health promotion, including individual motivation, education and lifestyle factors, community empowerment, access to environments which allow positive health practices, and socio-political reforms (O'Donnell, 2008; Whitehead, 2004). Focusing on the importance of health promotion through exploring effective self-care strategies for parents is reflective of Pender's (1996) Health Promotion Model.

Pender's Health Promotion Model was originally developed in 1982, and revised in 1996, to assist nurses in understanding the major determinants of health behaviours for individuals in order to develop interventions to promote health and wellness. The revised model is based on expectancy-value theory, whereby individuals engage in actions in which they expect will result in valued outcomes (Pender, Murdaugh & Parsons, 2011). It is also based on social cognitive theory, whereby health-promoting self-care is influenced by an individual's characteristics, including their thoughts, behaviours and affects, as well as their interaction with the environment, including behavioural contingencies (Heydari & Khorashadizadeh, 2014; Pender et al., 2011).

In Pender's model, the likelihood of engaging in effective self-care strategies is influenced by an individual's characteristics, including physical (i.e., age, gender), sociocultural (i.e., ethnicity, education) and psychological factors (i.e., subjective stress, caregiver need). The likelihood of engaging in self-care is also influenced by the individual's behaviour-specific cognitions, such as their perceived importance of self-care, self-efficacy, and perceived barriers to engage in self-care (Acton, 2002; Pender, 1996). Self-care is also influenced by interpersonal variables (i.e., family expectations, interactions with healthcare professionals), and environmental variables (i.e., access to self-care activities, immediate competing demands). Each system is argued to moderate an individual's motivation and readiness to engage in health-promoting self-care behaviour (Raingruber, 2014).

The underlying assumptions of Pender's Health Promotion Model include that all individuals have the capacity for reflective self-awareness, value positive personal growth, and want to actively regulate their own behaviour. Further, assumptions include that all individuals will experience healthy behaviour change, through modifying individual variables and their interaction with interpersonal and environmental systems (Pender et al., 2011). The model argues that individuals are more likely to commit to and engage in health-promotion behaviours if significant others model, support and help with the behaviour, including their family, peers and health care professionals (Pender et al., 2011). Also, the model argues that commitment to a self-care plan is more likely to occur when competing demands, such as children's disability needs, do not require immediate attention or conflict with the target health-promoting behaviour (Pender et al., 2011). Therefore, it was essential this current research explored effective self-care strategies from the parents' perspectives in order for results to reflect parents' experiences and accommodate for their competing demands when raising a child with HND.

The current research incorporated the health promotion paradigm in that it focused on health education for parents. Health education as a theoretical construct involves actions designed to develop and impart health-related information as a way to influence individuals' learning, values, beliefs, attitudes, and motivations (Sharma, 2017). The overall purpose of health education is to enhance individuals' understanding and knowledge, and lead to skill development, and behaviour modification in the area of health promotion. Health education is typically targeted at an individual or microsystem level by disseminating information that endorses health promotion strategies and processes (Sharma, 2017; Whitehead, 2004). Therefore, one aim of the current research was to draw from experiences of parents to develop a resource which motivates parents to engage in self-care behaviours. This incorporated the health promotion paradigm by targeting parents' behaviour-specific cognitions, such as their perceived importance of self-care and perceived barriers to engaging in self-care, through providing experiences and supported advice from parents in similar circumstances (Pender et al., 2011).

The assumptions of health education as a construct include that individuals' value and prioritise their health and well-being as important, and it is therefore reasonable to act on the basis that recipients wish to avoid or reduce negative health outcomes (Sharma, 2017). Although people can be supported through the process of behaviour change and modification, it is presumed that each individual is ultimately personally responsible for any action they choose to undertake, which allows them to maintain a sense of agency and self-determination (Sharma, 2017; Whitehead, 2004). This research adopted a preventative approach to health education regarding self-care, in that it explored proactive strategies parents utilise to enhance their wellbeing, rather than adopting a medical approach of 'repairing' health and wellbeing after parents experience negative outcomes (Whitehead, 2004). As the current research was intended to inform parents, possibly leading to behavioural change and positive health and wellbeing outcomes, it was considered that self-care strategies must incorporate realistic demands based on the priorities and preferences of parents as caregivers. It is argued that this can be achieved by first exploring the experiences and self-care strategies individuals currently find achievable within their reality (Whitehead, 2004).

Summary

The dominant focus on informal caregiving for parents of children with special needs in the literature has historically focused on burden and associated adverse outcomes (Shogren et al., 2017). However, emerging research regarding parents as informal caregivers is closely linked to the field of positive psychology, which is a theoretical perspective focused on understanding and emphasising individuals' strengths and the positive aspects of their experiences (Marino et al., 2017; Shogren et al., 2017).

Pender's (1996) Health Promotion Model falls under the field of positive psychology and focuses on empowering individuals and communities to improve their health and wellbeing. Through focusing on individuals' strengths and positive experiences, it is argued that research will come to better understand how best to promote wellbeing and life satisfaction, eliminate societal and attitudinal barriers to disability, and successfully manage difficulties encountered in daily life for those with disabilities and their caregivers (Livneh & Martz, 2016; Marino et al., 2017; Wright, 1983). The next chapter defines self-care for informal caregivers and argues that promoting parents' self-care is an ethical imperative comparable to that for healthcare professionals (Acton, 2002; Marino et al., 2017; McConnell & Savage, 2015).

CHAPTER SIX:

Self-Care for Parents as Informal Caregivers

Defining Self-Care

Due to the arguably heavy toll on parents’ health and wellbeing resultant from caregiving and family demands, research into self-care may help healthcare professionals better understand and design interventions to facilitate health promotion for parents (Acton, 2002). Self-care is a term used in the context of health promotion; however, the literature reveals few attempts at providing an operational definition for it and no clear agreement amongst those provided (Richards, Campenni & Muse-Burke, 2010). For example, Pincus (2006) vaguely defines it as an action “"one does to improve their sense of subjective well-being. How one obtains positive rather than negative life outcomes" (p. 1). Carrol, Gilroy and Murra (1999) describe self-care as including "intrapersonal work, interpersonal support, professional development and support, and physical/recreational activities" (p. 135). In contrast, Acton (2002) defines it as actions taken by an individual to improve their health, maintain optimal daily functioning, and increase overall wellbeing independent from illness or health symptoms. Additionally, many researchers have defined self-care by describing specific activities they believe constitutes self-care (Richards et al., 2010). Although there is no clear consensus, some general components and assumptions regarding self-care have been identified.

In conceptualising self-care, many typically hold the assumption that humans each have a need to care for oneself, and that self-care is a form of premeditated, deliberate action within each person’s control (Easton, 1993). Further, there is the assumption that self-care is a behaviour learned through culture and habit rather than mere instinct (Easton, 1993). Self-care is also assumed to be moderated by a person’s self-efficacy, or their confidence in their ability to perform relevant self-care behaviours in specific situations (Eller, Lev, Yuan & Watkins, 2018). Positive consequences of self-care have been shown to include decreased risk of health complications, attainment of desired outcomes, decreased use of health services, increased life satisfaction, reduced expenditure on healthcare costs, improved coping and sense of control, enhanced sense of wellbeing and quality of life, symptom control, and improved recovery from illness or surgery (Richard & Shea, 2011).

The general components that comprise self-care tend to include physical, psychological or emotional, spiritual and social aspects. The physical component mainly refers to participating in physical activity to improve physical health and wellness (Richards et al., 2010; Richard & Shea, 2011). However, it also involves additional aspects including nutrition and diet, environmental factors, medical needs, and sleep. The psychological component refers to pursuing self-reflection and therapeutic activities to alleviate distress, promote personal growth and improve emotional wellbeing (Richards et al., 2010). The spiritual component is loosely defined due to the many diverse, cross-cultural ways it is interpreted; however, it typically incorporates the belief and value systems an individual has, how they find a sense of purpose and meaning in life, and the connection they make with life (Richards et al., 2010). Finally, the social component is made up of the relationships and interactions which develop and occur for individuals, particularly regarding their support network (Richards et al., 2010; Richard & Shea, 2011).

For this research, the definition of self-care provided by Godfrey et al. (2011) was adopted. Godfrey et al. (2011) examined the diverse multitude of self-care descriptions across disciplines and incorporated their findings into comprehensive operational definition. Their definition states that:

> Self-care involves a range of care activities deliberately engaged throughout life to promote physical, mental and emotional health, maintain life, and prevent disease. Self-care is performed by the individual on their own behalf, for their families, or communities, and includes care by others. In the event of injury, disability or disease, the individual continues to engage in self-care, either on their own or in collaboration with healthcare professionals. Self-care includes social support and the meeting of social and psychological needs. Self-care provides the continuity of care between interactions with the healthcare system, enabling individuals to manage their disease or disability and maintain well-being. (p. 11)

By adopting this definition, the current research accepted a holistic view of health and wellbeing. Therefore, parents' health and wellbeing were viewed as multidimensional, and self-care was explored in terms of the interrelationships of physical, psychological, spiritual and social dimensions for the individual in their environment (Godfrey et al., 2011, Mark & Lyons, 2010; Richard & Shea, 2011).

Self-Care for Informal Caregivers

Few studies have focused on a positive health promotion paradigm of self-care with family caregivers, with many studies opting to research negative health outcomes resultant from caregiving duties within a stress-illness framework (Acton, 2002; Marino et al., 2017; McConnell & Savage, 2015). Fewer still have focused specifically on the experience of self-care for parents of children with disabilities, who experience unique competing parenting, financial, caregiving, and relationship demands. However, many argue that research which focuses more on positive outcomes and ways to enhance meaning, health and wellbeing will help to empower and build resilience for informal caregivers, as well as reduce the risk of them experiencing negative outcomes (Acton, 2002; Farran, 1997; Marino et al., 2017; McConnell & Savage, 2015; Savundranayagam & Brintnall-Peterson, 2010).

One of the few studies which specifically focus on self-care and health promotion for parents as informal caregivers was Larson (2010), who explored how caregivers with high self-rated psychological wellbeing describe making meaning in their role, compared to caregivers with low self-rated wellbeing. In a sample of 39 participants, Larson (2010) found that intensity of caregiving demands alone did not account for differences in the level of self-rated wellbeing. Rather, the relinquishment of perceived control (rather than personal control) over outcomes for larger life situations resulted in higher self-rated wellbeing (Larson, 2010). Maintaining a balanced perspective on caregiving demands was also found to occur more consistently for parents with high self-rated wellbeing. For example, persistent caregiving demands were constructively minimised by parents through strategies including looking at the bigger picture, and consciously attending to blessings or strengths that they are grateful for (Larson, 2010). High self-rated wellbeing was further associated with viewing caregiving as a conscious choice and something to find purpose in, as well as intentionally focusing on positive experiences in the present moment (Larson, 2010).

An additional two studies focused on self-care and health promotion for informal caregivers found facilitating factors for health promotion included self-care, advocacy, community supports, and social support (Griffith & Hastings, 2017; Khanlou, Mustafa, Vazquez, Davidson & Yoshida, 2017). Further, effective health promotion strategies supported by parents included self-motivation, positive reappraisal, coping skills, and self-esteem building at a micro-level (Griffith & Hastings, 2017; Khanlou et al., 2017). At a meso- and macro-level, parents' strategies included social inclusion, support groups, day-care services and parenting programmes, mental health and holistic family services, community events and online support, and emergency helplines (Griffith & Hastings, 2017; Khanlou et al., 2017). Nevertheless, both studies had confounding factors due to the specificity of participants being mothers (Griffith & Hastings, 2017) and immigrant mothers (Khanlou et al., 2017). These factors limit both studies' generalisability as gender and immigrant status have the potential to amplify or create unique challenges when caring for a child with disabilities (Griffith & Hastings, 2017; Khanlou et al., 2017).

A third study was Waddell, Wilson and Mattison (2018), who completed a meta-analysis of 14 manuscripts, including five systematic reviews and nine primary studies, to explore what approaches were effective for supporting caregivers of those with neurodevelopmental disabilities. They found that parents as caregivers benefitted from a number of self-care approaches, including therapy, counselling, coaching, education, respite, mindfulness or meditation, and care coordination (Waddell et al., 2018). They also found mixed levels of effectiveness for support groups, including online support forums (Waddell et al., 2018). The most frequently discussed approach to health promotion was education, which focused on improving parents' understanding of the disability, parenting skills, or how parents can play a therapeutic role in managing their child's disability (Waddell et al., 2018). However, there were various limitations discussed for the included manuscripts, including a lack of control groups, short follow-up periods or incomplete data at post-intervention, small sample sizes, and reliance on cross-sectional data (Waddell et al., 2018).

Although not particularly aimed at self-care strategies, some studies have focused on interventions which have improved parents' wellbeing by facilitating the development of coping skills (Lindo, Kliemann, Combes & Frank, 2016). Lindo et al. (2016) completed a meta-analytic review of six eligible studies and found that parents' wellbeing may improve from behavioural parent training courses to manage their child's difficult behaviours. They found that parents likely benefit from interventions to develop coping skills, including relaxation and mindfulness strategies, self-monitoring, cognitive reframing, communication techniques, problem-solving strategies, and decision-making and conflict-resolution techniques (Lindo et al., 2016). Both Cachia, Anderson and Moore (2016) and Rayan and Ahmad (2017) specifically focused on mindfulness-based interventions for improving parenting distress and wellbeing when parenting a child with disabilities. Both studies supported the efficacy of mindfulness strategies for supporting parents' wellbeing, reducing their distress, and concomitantly improving their child's difficult behaviours (Cachia et al., 2016; Rayan & Ahmad, 2017).

An Ethical Imperative

Although few studies have focused on self-care for parents of children with disabilities, self-care among healthcare professionals has become increasingly recognised as an "ethical imperative" and obligation in order to maintain healthy functioning and decrease the risk of compassion fatigue and burnout (Bamonti et al., 2014; Barnett, Cooper & College, 2009). It has become well recognised that personal concerns, including physical and mental health, can affect healthcare professionals' competence and ability to help their clients in their specialist role (Moss, Good, Gozal, Kleinpell & Sessler, 2016). As such, professionals who do not adequately address their own self-care needs may not be competent to provide adequate care for their clients (Bamonti et al., 2014; Moss et al., 2016).

Unfortunately, health care professionals have traditionally underestimated the impact of personal concerns, stressors and lifestyle factors on their ability to professionally work and care for their clients (Dattilio, 2015; Salyers et al., 2017). The neglect of self-care needs and personal wellbeing for health care professionals has been repeatedly documented in academic literature, with findings including increased risk for anxiety and depression, chronic stress, burnout, countertransference, vicarious traumatisation, personal losses, secondary trauma, personal and professional relationship conflicts, and compassion fatigue for the professional (Bearse, McMinn, Seegobin & Free, 2013; Dattilio, 2015; Salyers et al., 2017; Walsh, 2011).

Burnout and compassion fatigue have both gained particular notoriety for health professionals in recent years within the academic literature (Dattilio, 2015; Moss et al., 2016). Compassion fatigue is a condition which develops in response to working with or caring for those who are suffering from the consequences of traumatic events

(Salyers et al., 2017). It is characterised by deep physical and emotional exhaustion, and it can result in an inability to express or experience empathy towards others or respond appropriately to distress expressed by others. Those who experience compassion fatigue usually have a depleted emotional reserve and, therefore, have little left to give to others (Dattilio, 2015; Salyers et al., 2017).

Given that healthcare professionals' wellbeing and the quality of care they provide have been shown to be interdependent, effective self-care strategies are not only an ethical imperative for personal wellbeing, but for their clients' wellbeing also (Maben, Adams, Peccei, Murrells & Robert, 2012; Mills, Wand & Fraser, 2015; Salyers et al., 2017). Professionals' reduced quality of work due to neglecting their self-care has been shown to include professionals becoming less therapeutic and more short-tempered with their clients, having reduced time and energy to give to clients, having a detrimental effect on the professional-client relationship, and increasing the risk of harm for the client (de Figueiredo, Yetwin, Sherer, Radzik & Iverson, 2014; Hanson, 2015; Salyers et al., 2017). Contributing factors to the development of compassion fatigue and burnout include job stress, excessive workload and emotional demands, reduced personal autonomy, lack of support, exposure to pain and death, inadequate financial income, and the aggressive behaviours of the client (de Figueiredo et al., 2014; Hanson, 2015; Salyers et al., 2017; Verweij et al., 2016).

It can be argued that family caregiving results in comparable psychological impairments that face healthcare professionals, due to similarly distressing demands and stressors placed on them by their family member (Acton, 2002; Marino et al., 2017; McConnell & Savage, 2015). Further, many parents are required to take on healthcare roles themselves with administering medical procedures in home, participating in physical therapies, and managing medications for their child (Acton, 2002; Smith, Swallow & Coyne, 2015). Parents' responsibilities for managing their child's disability (while balancing competing family needs) often requires extraordinary long-term physical, emotional, social and financial resources from the parent, leaving little time for parents to attend to their own self-care needs (Murphy et al., 2007; Marino et al., 2017). Therefore, although few studies exist regarding the health promotion and self-care for parents as informal caregivers, it can be argued that parents' self-care is an ethical imperative similar (if not greater) to that for healthcare professionals (Acton, 2002).

Effective Self-Care for Healthcare Professionals

Although it is not the primary focus of this research, due to the overlap in roles, briefly exploring effective self-care strategies for healthcare professionals is beneficial when considering strategies for parents as informal caregivers. Positive coping strategies which enhance health professionals sense of wellbeing have been found to include being appreciated by others, having reliable working relationships, having a disposable income, participating in leisure activities, laughing and having positive personal relationships, and spending time with family and friends (Lim, Hepworth & Bogossian, 2011; McCann et al., 2013). Other uplifting coping strategies for healthcare professionals while at work have been found to include taking time out, seeking emotional support, and relying on belief systems, such as spirituality or religion (Lim et al., 2011).

Personal self-care has also been established as an important process for health promotion, which involves the healthcare professional recognising and attending to multiple dimensions in their life. These dimensions include the person’s inner lives, family and friend relationships, work environment, participation in community, and attending to beliefs or spirituality, as seen in ecological systems theory (Sanchez-Reilly et al., 2013). Successful strategies for personal self-care have been found to include prioritising close relationships, maintaining a healthy lifestyle through ensuring sufficient sleep, exercise, nutrition and time-off for vacation, participating in recreational activities and hobbies, practicing mindfulness and meditation, and spiritual development (Sanchez-Reilly et al., 2013).

Dattilio (2015) provides guidelines around self-care for practitioners, including being self-aware of their vulnerability to daily stressors in order to detect early signs of distress, reducing sources of distress, developing effective coping strategies when stressors cannot be reduced, utilising evidence-based mental health therapies, setting and reviewing realistic and achievable goals, and intentionally choosing a self-care plan that fits into their current schedule. In terms of self-care in relation to caring for others, findings also support that health professionals seek opportunities for education and professional growth, have realistic expectations and utilise time management skills, avoid isolation, normalise feelings of self-doubt and incompetence, and raise self-awareness through reflection (Theriault, Gazzola, Isenor & Pascal, 2015).

Self-Care Psychoeducational Resources

Given the substantial evidence that parents of children with disabilities are at increased risk for adverse outcomes, along with there being few studies that have explored health promotion and self-care, there is a clear need for research to promote the wellbeing of parents as informal caregivers (Acton, 2002; Marino et al., 2017; McConnell & Savage, 2015). Research has shown the effectiveness of passive psychoeducational resources, such as leaflets or booklets, for providing education and improving knowledge relevant to health in specific population groups (Srivastava & Panday, 2016). Such resources can also be therapeutic by providing materials and advice aimed to educate the recipient about the nature, treatment, and prevention of psychological distress (Gilson et al., 2018; Srivastava & Panday, 2016).

Although not specifically focused on parents, Savundranayagam and Brintnall-Peterson (2010) explored a 6-week psychoeducational intervention aimed at building self-efficacy and enhancing self-care for family caregivers. The intervention used strategies for enhancing self-efficacy, including skill mastery, modelling, reinterpretation of attitudes toward caregiving, and persuasion, to teach caregivers how to manage their emotions, communicate assertively and engage in self-care behaviours (Savundranayagam & Brintnall-Peterson, 2010). This study found that the psychoeducational intervention resulted in improvements in self-efficacy, self-reported confidence, and self-awareness for the 325 participants.

Moreover, newfound awareness of self-neglect of unmet needs for participants, along with a sense of ‘permission’, prompted an increase in self-care behaviours. These behaviours included relaxation, exercise and stress management, and a reduction in health risk behaviours (Savundranayagam & Brintnall-Peterson, 2010). Boise, Congleton and Shannon’s (2005) study also focused on the same 6-week psychoeducational intervention with 226 family caregivers of those with Alzheimer’s disease and found significant positive outcomes. These outcomes included improved self-care behaviours, enhanced emotional well-being and caregiver self-efficacy, and increased knowledge and use of community services.

Elliot, Burgio and DeCoster (2010) focused on a psychoeducational intervention targeted at enhancing the health and well-being of family caregivers for those with Alzheimer’s disease, titled Resources for Enhancing Alzheimer’s Caregiver Health II.

This multicomponent intervention package addressed caregiver self-care and health behaviours, and it included educational materials on self-care and preventative health practices. The study included 495 family caregivers assigned to either a control or intervention group. They found that the intervention package resulted in better health in four domains, including general self-rated health, sleep, mood improvement and physical improvement, along with reductions in caregiver burden at a 6-month follow-up (Elliot et al., 2010).

Specific to parents of children with disabilities, Gilson et al. (2018) developed a psychoeducational resource using interviews with parents to inform the content of the booklet. The resource focused on improving mental wellbeing for parents with evidence-based strategies for health promotion, including education on mental health, normalising difficult experiences and barriers to help seeking, and strategies to promote wellbeing such as building social relationships, discussing emotions, and asking for help (Gilson et al., 2018). Findings suggest that the resource helped to improve parents' wellbeing, as well as provide a practical and cost-effective tool to disseminate health promotion information to a large number of people (Gilson et al., 2018). Therefore, although psychoeducational resources do not replace the need for immediate support for parents experiencing acute distress, they have significant practical potential for raising awareness of health promotion for informal caregivers and may facilitate access to immediate supports if needed (Gilson et al., 2018).

Summary

In sum, although few studies have focused on a positive health promotion paradigm for parents raising children with disabilities, emerging findings are showing promising support for research from this perspective (Acton, 2002; McConnell & Savage, 2015). Exploring parents' experiences of wellbeing as informal caregivers from a positive health promotion paradigm has shown that parents may benefit from self-care strategies and psychoeducational interventions, including positive reappraisal, respite, education, advocacy, coping skills, psychosocial support, and mindfulness (Gilson et al., 2018; Halstead et al., 2017; Khanlou et al., 2017; Larson, 2010; Lindo et al., 2016; Waddell et al., 2018). Further, it can be argued that promoting parents' self-care is an ethical imperative comparable to that for healthcare professionals in order to maintain parents' wellbeing, as well as the sustainability and quality of care they provide to their child in an informal caregiver role (Acton, 2002; Marino et al., 2017; McConnell & Savage, 2015; Salyers et al., 2017). The next chapter introduces the current research, including a summary and rationale for this research, the underlying methodology, and overall study aims.

CHAPTER SEVEN:

Introduction to the Present Research

Summary and Rationale

With over 95,000 children affected by a disability in NZ – and current societal structures requiring parents to assume unforsaken caregiving roles – parents as informal caregivers make up a significant sector within NZ (Murray, 2018; Statistics New Zealand, 2013). Nevertheless, the dominant approach to research in the field of childhood disability has been based in the assumption that informal caregiving results in adverse outcomes for parents (Marino et al., 2017; McConnell & Savage, 2015). Consequently, research has largely focused on the negative impact of caregiving for parents and their families (Acton, 2002; McConnell & Savage, 2015). However, it can be argued that by adopting a positive psychology and health promotion perspective, research can better come to understand how best to promote wellbeing and reduce societal and attitudinal barriers for parents and their children (Livneh & Martz, 2016; Marino et al., 2017).

Few studies currently exist which specifically focus on self-care and health promotion for parents as informal caregivers (Acton, 2002; Halstead et al., 2017; Khanlou et al., 2017; Larson, 2010; Waddell et al., 2018). However, many argue that research which focuses on ways to enhance wellbeing will help to empower and build resilience for informal caregivers, as well as reduce the risk of them experiencing negative outcomes (Acton, 2002; Farran, 1997; Marino et al., 2017; McConnell & Savage, 2015; Savundranayagam & Brintnall-Peterson, 2010). As parents often assume caregiving roles that overlap with healthcare professionals, it can be argued that self-care should be viewed as an ethical imperative for parents, comparable to that of healthcare professionals, in order to maintain wellbeing and their ability to care for their child’s disability needs (Bamonti et al., 2014; Moss et al., 2016).

Limitations occur with currently available studies which focus on positive health-promotion for parents, including that they are relatively out-of-date, they caution generalisability due to small sample sizes, and there are few of them which specifically concentrate on the experience of parents as caregivers or explore self-care in a holistic way (Acton, 2002; Halstead et al., 2017; Khanlou et al., 2017; Larson, 2010; Waddell et al., 2018). No studies have explored self-care and wellbeing for parents of children with HND in NZ, which shares a unique history and culture that may potentially influence parental self-care activities in a distinct way. There are also few studies which have produced psychoeducational resources relevant to enhancing parental self-care and perceived wellbeing from a health-promotion paradigm (Gilson et al., 2018).

The benefits of this research include that it will address:

- The lack of current research regarding holistic self-care for parents of children with HND within a positive health promotion paradigm;
- The absence of literature regarding parental caregiving need and wellbeing within a NZ context;
- The lack of psychoeducational resources available to parents of children with disabilities aimed at enhancing parents' self-care and perceived wellbeing based on current academic findings.

The findings from the current research (and the resultant psychoeducational resource) will potentially enable parents, healthcare professionals, researchers, and the general public in NZ gain greater understanding in the area of childhood disability and caregiver wellbeing. By increasing understanding, parents may better adjust to the difficulties of a new diagnosis and improve their capacity to manage their child's disability. In accordance with ecological systems theory, this increased understanding may enhance the child's wellbeing, the parent-child relationship, and overall family functioning (Friedman & Allen, 2011). Also, healthcare professionals will be able to provide support that is more meaningful to parents as informal caregivers, in order to prevent self-care decline and identify when things are "going wrong". Furthermore, current findings will inform future research and the design of interventions and resources to facilitate self-care for parents of children with disabilities. Enhancing awareness and understanding for the NZ public may facilitate a more supportive societal environment for the family and the child with special needs.

Methodology

Qualitative inquiry is an interpretive, naturalistic approach to understanding the world, whereby research focuses on interpreting the meanings people give to phenomena in their natural setting (Creswell & Poth, 2017). It is a useful approach to exploring and understanding the experiences and meaning an individual or group ascribe to particular social problems, such as parents' experiences of self-care when raising a child with HND. Qualitative inquiry establishes patterns or themes within the data collected; this ensures the voices of the participants are heard, and a complex description and interpretation of the problem is contributed to the literature informing social change (Creswell & Poth, 2017).

The four main philosophical assumptions underlying qualitative research include firstly, that there are multiple realities to capture, as different individuals present different and unique perspectives. Secondly, knowledge and understanding of phenomena comes from the subjective experiences of people, so researchers must limit the "distance" or objective separateness between themselves and those being researched (Creswell & Poth, 2017; Guba & Lincoln, 1989). Thirdly, the inquirer or research must admit the value-laden nature of the inquiry and actively acknowledge both their own values and biases, as well as the value-laden nature of the information collected from participants (Creswell & Poth, 2017; Denzin, 1989). Finally, the methodology used is characterised as inductive and shaped from the research, developing increasingly detailed knowledge of the phenomena through the research process rather than handed down entirely by existing theories or findings (Creswell & Poth, 2017).

The philosophical assumptions underlying qualitative inquiry are often applied within interpretive frameworks, such as post-positivism or social constructivism. As these frameworks are ever expanding, any discussion will only provide a partial description of possibilities (Creswell & Poth, 2017). For the purposes of this research, a transformative framework was used to aid parents in improving their self-care and sense of wellbeing. The transformative framework views knowledge as subjective and a reflection of power and social relationships within society (Mertens, 2003). Therefore, from this perspective the purpose of qualitative inquiry is to construct knowledge to aid individuals in improving society.

The transformative framework is often used for marginalised groups and societies, including the disability community, who may benefit from positive psychology to build hope and resilience (Creswell & Poth, 2017; Mertens, Holmes & Harris, 2009). In accordance with a transformative framework, research should contain an action agenda for reform which may improve the lives of participants, such as through health promotion (Creswell & Poth, 2017; Kemmis & Wilkinson, 1998). Therefore, research becomes practical and collaborative, working ‘with’ participants rather than ‘on’ or ‘to’, as the researcher engages the participants to actively work together with their inquiries (Kemmis & Wilkinson, 1998). In this way, the voices of the participants are heard, and the research and resulting resources are meaningful for all involved (Creswell & Poth, 2017; Kemmis & Wilkinson, 1998).

Unlike quantitative forms of inquiry (which require statistical methods for establishing validity and reliability), qualitative research incorporates methodological strategies to ensure the “trustworthiness” of findings (Noble & Smith, 2015). Some of these strategies include acknowledging biases in sampling and interpretation that may have influenced findings, ensuring sufficient depth of data collection and analysis through data saturation, including rich and thick verbatim descriptions of participants accounts and experiences, and seeking respondent validation or feedback from participants so findings adequately reflect their experiences (Long & Johnson, 2000; Noble & Smith, 2015). Although there is no absolute construct to define data saturation or method to determine when it has been reached, data saturation is expected to have occurred once there is enough information to replicate the study, no further themes emerge from data collection, and further coding of collected data is no longer feasible (Fusch & Ness, 2015).

In accordance with Bronfenbrenner’s (1977) ecological systems theory, parents experiences of self-care and wellbeing when raising a child with disabilities is best understood by exploring interactions within the multileveled systems which they are embedded (Friedman & Allen, 2011). In doing so, interventions aimed at enhancing parents’ wellbeing may also lead to further positive multidirectional changes in those systems with which they interact (Algood et al., 2013). Due to a lack of existing literature, current research methodology that was best suited to explore parents’ experiences was qualitative inquiry from a transformative framework, using methods of semi-structured interviews and thematic analysis (Creswell & Poth, 2017).

Thematic analysis is a method of interpreting and analysing data within qualitative inquiry. It is used to systematically identify, organise, and offer insight into patterns or themes across a data set (Braun & Clarke, 2006; Braun & Clarke, 2012; Javadi & Zarea, 2016). This method allows for researchers to interpret shared or collective meanings and experiences, and to identify those experiences relevant to answering a particular research question (Braun & Clarke, 2012). It is an accessible approach as it offers a way of disseminating results to a wider audience, where not everyone is a qualitative “expert”. Also, it is an inductive approach, as analysis is driven by the data rather than existing concepts or theories applied by the researcher (Braun & Clarke, 2006; Braun & Clarke, 2012; Javadi & Zarea, 2016).

Specific to Study One, methodology included a purposive sampling criterion for parents of children with cerebral palsy and autism. As it is argued that differences in disability type becomes relatively trivial in terms of family burden and caregiver stress once the level of care required is perceived as substantially ‘high-need’, recruitment for Study One focused specifically on parents of children diagnosed with cerebral palsy or autism spectrum disorders (Breslau, Staruch & Mortimer, 1982; Cummins, 2001). Cerebral palsy was chosen as it is the leading cause of life-long physical disability worldwide with infantile onset (Oskoui, Coutinho, Dykeman, Jette & Pringsheim, 2013). Also, it is a permanent disability (regarding the development of movement and posture), often accompanied by intellectual and behavioural difficulties and/or disabilities (Oskoui et al., 2013).

Autism was chosen as it is a life-long behavioural disability with infantile onset, and it has a high prevalence of 1 in 160 children worldwide (WHO, 2016). Autism often results in severe impairment in social communication, and the presence of restricted, stereotypical behaviours (Baxter et al., 2015). Both autism and cerebral palsy have an onset in infanthood or birth, follow a persistent life-long course, and can be highly disabling particularly regarding developmental milestones (Oskoui et al., 2013; Baxter et al., 2015). Therefore, both disabilities were likely to result in high levels of caregiving demand and stress, and consequently be rated high-need by parents. Limiting Study One to parents of children with high-need cerebral palsy and autism simplified the recruitment process while still being reflective of HND, along with covering multiple dimensions of disability including behavioural, intellectual and physical.

Following the transformative framework, current research also needed to contain an action agenda for reform through the development of a psychoeducational resource (Creswell & Poth, 2017; Srivastava & Panday, 2016). Research has already shown the effectiveness of passive psychoeducational resources for health promotion and improving knowledge relevant to health in specific population groups (Gilson et al., 2018; Srivastava & Panday, 2016). As parents were engaged in the research process through the development of an educational resource, research findings needed to be accessible and understandable to them. Hence, Study Two included parents’ evaluation of the resource booklet to ensure a collaborative approach which resulted in a resource that is practical and meaningful to parents raising children with disabilities.

Overall Aims

In sum, the aim of this current research was to first explore self-care and wellbeing for parents of children with HND from the parents’ perspectives. Study One achieved this by incorporating a positive health promotion paradigm with the implementation of qualitative methodology from a transformative framework. The specific method utilised was conducting semi-structured interviews with parents and thematic analysis. Semi-structured interviews were selected for the mode of data collection as they help facilitate rapport and the expression of empathy, allow for flexibility, and enable exploration of novel areas of parents’ perspectives and experiences (Smith & Osborn, 2008). The research questions that were the focus for Study One included:

1. How is self-care and wellbeing currently experienced and enacted for parents of children with HND?
2. What strategies of self-care do parents currently find effective for enhancing their sense of wellbeing?

Following this, the aim for Study Two was to develop and evaluate a psychoeducational resource aimed at enhancing parents’ self-care and perceived wellbeing. This resource booklet was shaped by a positive health-promotion paradigm, and it was developed by integrating findings from Study One and the current literature. The resource was designed to help support parents who have received a disability diagnosis for their child by providing useful strategies regarding their self-care in everyday life. Evaluation of this resource was achieved through a questionnaire given to parents, and descriptive statistical analysis and thematic analysis of their responses. The research questions for Study Two included:

1. How do parents of children with disabilities appraise the self-care resource?

2. What recommendations and considerations do parents make regarding the content and format of the self-care resource?

These aims are elaborated on and addressed in the following chapters.

SECTION TWO

CHAPTER EIGHT:

Study One: Exploring Parents’ Experiences of Self-Care while Raising Children with High-Need Disabilities in New Zealand

Study One aimed to explore parents’ perspectives and experiences of self-care while raising children with special needs in NZ. Due to a lack of existing literature focused on enhancing caregiver self-care and wellbeing, the goal for this study was to firstly source rich and in-depth knowledge of parents’ perspectives on their personal experiences of self-care; and secondly, to provide them with a voice often missing in research. The study outlined and discussed in the following section approached this by collecting qualitative data via semi-structured interviews with parents. The specific aims of Study One were to:

a. explore how self-care is currently experienced and enacted for parents whilst raising children with HND; and
b. identify what strategies of self-care parents currently find effective for enhancing their sense of wellbeing.

Thematic analysis was used to uncover themes central to the research aims above (Braun & Clarke, 2006). At the time of writing, there was limited research available internationally on parents’ experiences of self-care from a positive health paradigm, and an absence of literature regarding parents as informal caregivers within a NZ context. Study One aimed to address this gap in knowledge, as well as provide valuable insight into the experience of raising children with HND in the NZ context. Results from Study One were subsequently used in the development of a psychoeducational resource booklet on self-care for Study Two.

Method

Participants

Eleven parents volunteered to participate in this study, including nine mothers and two fathers. Of the participants, seven identified as NZ European, three identified as Māori, and one identified as Dutch. Although exact ages of the participants were not asked in this study, participants indicated they fell in the range of 25-34 years to 55-64 years at the time of interview. Eight participants indicated they were full-time caregivers and not in paid employment, and three participants indicated they were either part-time or full-time in paid employment. Participants ranged in education from secondary school certificate to Masters' degree level.

Six participants had children with autism, and five had children with cerebral palsy. Inclusion criteria specified participants' children had to either have cerebral palsy or autism; these two conditions were chosen to simplify the recruitment process while still being reflective of HND. The children had various significant co-existing disabilities, including intellectual disability, dystonic and spastic quadriplegia, global developmental delay, epilepsy, various visual impairments, brain injury, pachygyria, Tourette's disorder, attention-deficit/hyperactivity disorder, obsessive-compulsive disorder, anxiety disorders, and microcephaly. The children with HND ranged in age from six to 24 years old at the time of interview. Ten parents indicated they had more than one child, ranging between having two to five children. Two parents indicated they had more than one child with disabilities.

The study recruited participants by relying on the concept of thematic saturation, or the point at which no new themes were observed in the data (Namey, Guest, McKenna & Chen, 2016). A purposive sampling approach was used with the inclusion criteria being that participants must be the parent of a child with a HND. For this study, being a parent was defined as being the primary caregiver (living with the child) who was the most responsible for the day-to-day decision making and care of that child (Raina et al., 2005). The child had to be aged 5 years or older, and have at least one recognised diagnosis of cerebral palsy or autism that the parent perceived as high-need. A lower age limit of 5 years was decided on as parents of these children would likely be experiencing caregiving demands beyond that of typical parenting responsibilities, along with having adequate lived experience of both caregiving stress and self-care. It was agreed with my supervisors that parents of children over the age of 18 years could be included in this study provided the parent was still responsible for the day-to-day decision making and care of their child, and their child was still living with them, with the level of care required being perceived as high-need. Indeed, we were keen to include these parents as their voices and experiences are particularly missing in the research.

Participants needed to have scored 41 points or above on the Zarit Burden Interview (ZBI; Zarit, Orr & Zarit, 1985) to meet the criteria of “high-need” disability (Bello-Mojeed, Omigbodun, Ogun, Adewuya & Adedokun, 2013). Participants were also required to be aged 18 years or above, English speaking, and a current NZ citizen. To protect participant wellbeing, parents who were currently engaged with mental health services for their own health and well-being needs were not eligible to participate.

Recruitment

Recruitment of participants occurred using snowball sampling, utilising my personal networks to disseminate information about the research. Recruitment also occurred by distribution of printed flyers in relevant disability services within the Whanganui and Palmerston North regions (see Appendix A). Potential participants were asked to contact myself to express their interest, and those who met the inclusion criteria were emailed or posted relevant research materials, including an information sheet (see Appendix B), written informed consent (see Appendix C), a demographic information form (see Appendix D), and the ZBI questionnaire (see Appendix E) to complete and return, along with a list of counselling services for if participants became distressed or emotional in recounting their experiences (see Appendix F). Acceptance for interviewing was in order of response. Eight participants were recruited by responding to the distributed flyers, and three were recruited through personal networks. As data saturation was reached, the decision was made to end interviewing after 11 participants (Namey et al., 2016). There were five parents who did not meet the inclusion criteria due to being outside the recruitment area. For these parents, an explanation was provided, along with an invitation to participate in Study Two.

Measure

The ZBI (Zarit et al., 1985) was used as a screening tool for establishing whether the child’s disability was subjectively considered “high-need” by the parents interviewed. The ZBI is a self-administered, 22-item questionnaire used to assess perceived caregiver burden when taking care of one’s relative (Zarit et al., 1985). It was originally designed for caregivers of elderly relatives with Alzheimer’s disease. However, studies have commonly adapted it to other populations, including parents of children with disabilities, making it the most commonly used measure of caregiver burden (Bachner & O’Rourke, 2007). Summation of ratings gives the severity of the burden or level of need experienced by the caregiver.

Scores ranging between 0 to 20 represents little or no burden; 21 to 40 indicates mild-to-moderate burden; 41 to 88 indicates moderate to severe burden. As with other studies, this study classified the level of burden into low and high need with a score of 41 points or above being classified as high-need (Bello-Mojeed et al., 2013). The ZBI has been shown to have excellent internal consistency ($\alpha = .91$), and good test-retest reliability ($r = .71$, $p < .001$) (Gallagher et al., 1985; Hebert, Bravo, & Preville, 2000). Concurrent validity has also been shown by correlating total ZBI scores with a single global rating of burden ($r = .71$), and with responses to the Brief Symptom Inventory ($r = .41$) (Bachner & O’Rourke, 2007; Zarit & Zarit, 1990).

Procedure

The procedure involved meeting with each participant for a semi-structured interview. Prior to commencing interviews, parents were reminded participation was voluntary and written informed consent was collected. To ensure confidentiality and safety, two interviews were held in a private meeting room in the Palmerston North City Library, and nine interviews were held in a similar private room in professional offices located in central Whanganui.

Participant interviews ranged from 45 to 135 minutes in length. Open-ended questions were pre-developed to gently guide the interview to focus on participants’ experiences of self-care and wellbeing from a health promotion paradigm, while allowing dialogue to be relatively free flowing so the participant could share their most pertinent experiences (see Appendix G). The interview schedule was developed following literature review, in collaboration with my supervisors. After a period of developing rapport at the beginning of each interview, conversation shifted to focus on areas including strategies of self-care that have been effective for enhancing parents’ wellbeing, resources and support systems they have utilised, and their recommendations and advice for other parents regarding self-care. All interviews were digitally audiotaped for transcription and thematic analysis. At the end of interviewing, each participant was given the opportunity to debrief, and was asked whether they would like to be sent a summary of findings at the conclusion of Study One (see Appendix H). In appreciation for their time and efforts contributing to this study, participants were each gifted a $20 supermarket voucher.

Transcription was then completed via a professional transcription service, who signed a written confidentiality agreement to ensure participants' information and identities were protected (see Appendix I). Although transcription of interviews by the researcher is typically seen as the first stage in analysis for qualitative studies, due to time constraints and additional commitments of the researcher, a professional transcriber was required to assist this process (Braun & Clarke, 2006). After transcription, participants were sent their transcripts for editing via email or post with an attached Authority for the Release of Transcripts form (see Appendix J). Only minor spelling amendments were made by participants.

Ethical Considerations

Ethical approval for this study was gained through Massey University Human Ethics Committee: Southern B (Application 16/21; see Appendix K). During interviewing, there was the potential for some participants to become distressed or emotional in recounting their experiences. The study addressed this possibility by acknowledging in the information sheet given to participants that discussion around their experiences may raise certain emotions or cause distress, and should they have any concerns they were encouraged to email the researcher directly. Also, participants were provided with a list of available counselling services alongside the information sheet. Although tearful at times, no participants appeared distressed during interviews or contacted me regarding any concerns. Rather, similar to others' experiences of qualitative research, many participants considered the process of being interviewed therapeutic in itself, as they were able to have the space to tell their story and be listened to (Rossetto, 2014).

There was the possibility of a conflict of role as three participants had a prior professional relationship with me. This is because I have worked as a respite carer for children with disabilities. The dual relationship was acknowledged with these participants prior to commencement and discussed collaboratively. I ensured that the participants knew that their participation was voluntary and would not affect our professional relationship (Massey University, 2015). Whilst acknowledging the complexity of dual relationships, it has been argued that some dual relationships may have benefits for the participant and research process, as “the additional human connectedness through a dual relationship is far more likely to be affirming, reassuring and enhancing, than exploitative” (Tomm, 2002, p.32). Interviews with the three participants did not appear to be negatively affected by our previous employment relationship; rather, I believe it aided rapport and open conversation with the parents due to our already developed trust and comfort with one another.

Analysis

The data collected for analysis included amended verbatim transcripts from all participants’ interviews. The files were stored on a password-protected drive, and numerical codes replaced participant names prior to transcription to ensure confidentiality. Thematic analysis, as outlined by Braun & Clarke (2006), provided a logical approach for analysis in line with the research aims for Study One. The transcripts were analysed based on semantic meaning, using surface-level interpretation to preserve participants’ representations of their experiences. The steps of analysis involved familiarising myself with the data, generating initial codes, searching for themes by collating all relevant codes into potential themes, reviewing and refining themes with oversight from my supervisors, defining and naming the themes, and writing-up the analysis (Braun & Clarke, 2006). Due to use of a professional transcriber, I listened back to the interview audio alongside reading the completed transcripts multiple times to ensure transcription accuracy and to familiarise myself to the data.

Thematic analysis was used to answer the research questions for Study One by providing themes that reflected the subjective experience of parents’ self-care and wellbeing. Each theme indicated some level of patterned response or meaning from within the data collected which was of some importance the research aims (Braun & Clarke, 2006).

Summary

Study One aimed to explore parents’ perspectives and experiences of self-care while raising children with HND in NZ. It achieved this by collecting qualitative data via semi-structured interviews with 11 participants. Thematic analysis of interview transcripts was then used to uncover themes central to the research aims. The following five chapters present key findings and themes identified during analysis for Study One. To ensure confidentiality when presenting findings, participants were allocated pseudonyms and any identifying information has been removed or changed. The next chapter introduces the four key themes for Study One and discusses additional findings not directly related to the research aims.

CHAPTER NINE:

Study One Findings

Introduction

Four key themes were identified for Study One using thematic analysis of interview data, exploring parents' self-care experiences and currently used strategies when raising a child with HND. These four themes will be presented within the subsequent four chapters, which focus on parents' Formal Supports and Resources, Informal Relationships, Values and Goals, and their use of Time.

Under each of the four overarching key themes, subthemes were expanded on within their own sections. These subthemes can be best introduced using the following figure which illustrates how the subthemes were organised under the four main themes related to specific self-care experiences and effective strategies parents discussed.

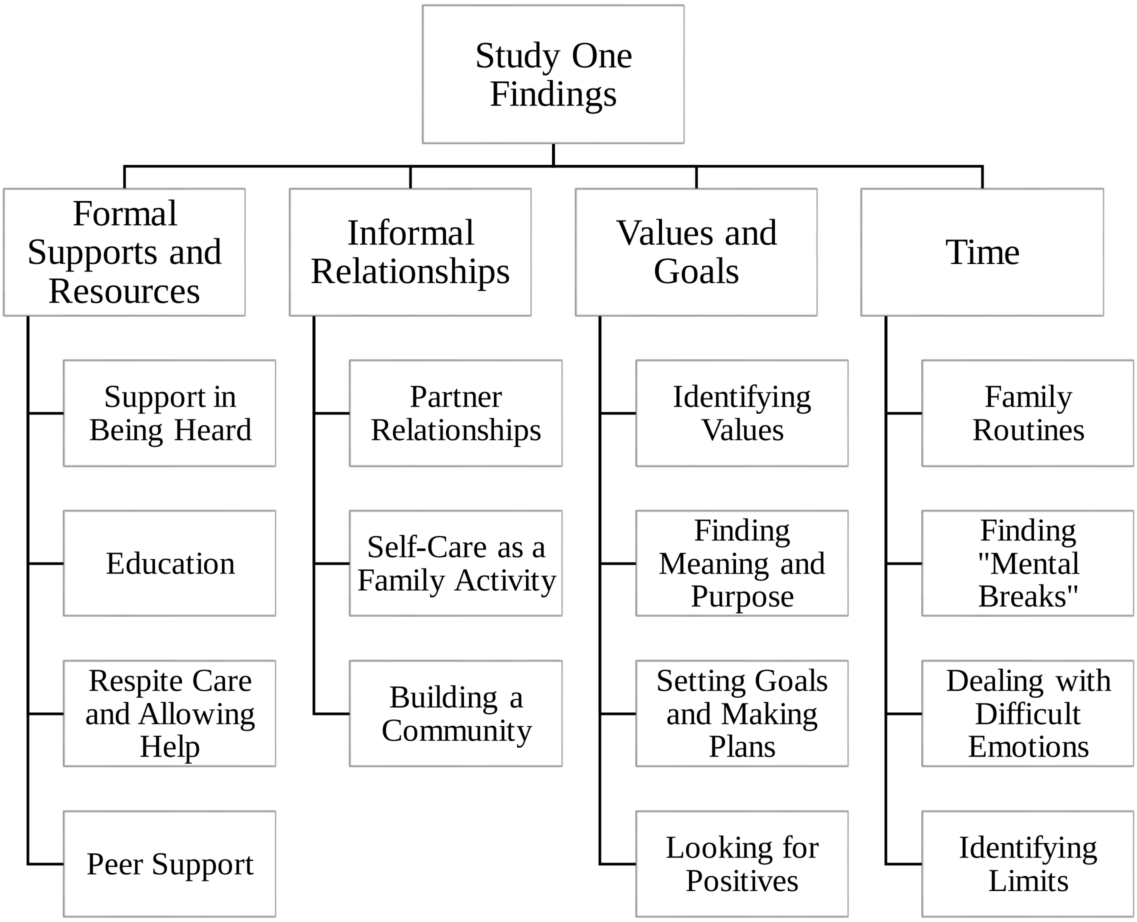

Figure 2. Thematic map of themes and subthemes from Study One related to parents' self-care experiences and effective strategies when raising a child with HND.

Current findings for Study One have been presented in relation to existing literature, thereby systematically incorporating aspects of the discussion into the findings' chapters in order to promote coherency and prevent repetition (Burnard, Gill, Stewart, Treasure & Chadwick, 2008).

Additional Findings

Although not directly linked to Study One's research aims, additional findings revealed in this study will also be briefly presented. These additional findings focus on areas including: the preferred language parents used when discussing their child with special needs; a lack of discernible difference between self-care experiences and effective strategies between parents of children with autism and cerebral palsy; and a shared need for parents to discuss the difficult and negative aspects of raising a child with HND.

Preferred Language Use

The current study supports the use of person-first language when discussing children with special needs, with participants placing emphasis on the assertion that disability only makes up part of a child's identity (Dunn & Andrews, 2015; Schur et al., 2013). All participants from this study typically used person-first language throughout the interviews, such as "my child with special needs", often subsequently shortened to "my child". Also, all parents tended to use a non-specified, non-judgemental phrase of "special needs" over the use of "disability" or specific disability diagnoses and medical terms. When participants were asked what phrasing they preferred to use to describe their child's level of need, level of care or disability severity, all of them chose to use 'high-needs' or 'very high-needs'.

The majority of parents (7 participants) specifically mentioned they preferred 'high-needs' over other terms, including 'low-functioning' and 'burden'. Parents discussed how using strengths-based language regarding their child's disability helped them to move towards acceptance, improve their relationship with their child, and positively reappraise their situation (Gupta & Singhal, 2004; Beighton & Wills, 2017):

> He's very smart at lots of things, it's just things that interest him, so he's got strengths. And that's the problem with a lot of the terminology, it doesn't take into account the fact that he's good at things… I think most advocacy groups for any

> disability will tell you that strength-focused is definitely the way. Because also if you focus on their strengths, it tells you how to teach them basically. It gives you an idea of where they should be, because you are focusing on what they like. *Anna*

Similar to previous findings, three participants discussed the tension parents experience between wanting a diagnosis or “label” in order to access resources and gain understanding of their child’s disability, as well as fighting against the label in order to protect their child and family from stigmatisation and discrimination (Lalvani, 2015). However, these parents argued for the necessity of receiving a diagnosis in order to move towards building a strong network of supports and resources for the family and improve their own resilience, self-support and acceptance:

> Most times I have found out that I am a bit of a rare thing where I wanted the diagnosis… once I did that I was quite strategic about setting up a game plan… Whereas, I’ve seen parents in the past struggle with having their child labelled and it’s an absolute mental burden on themselves, and it’s got nothing to do with their kids because they love their kids to death, they just can’t get over the stigma of the name. And I’m trying to tell them, I understand at where you’re at but having that label and that tag opens up so many doors to you, and if you don’t take full advantage of it, you’re going to be behind the 8-ball for years to come. *Tamati*

Differences in Disability Type

A second additional finding from Study One was that there were no discernible differences in self-care experiences or effective self-care strategies between parents of children with autism and cerebral palsy. Thematic analysis showed similarities across all parents interviewed regarding their experiences in raising a child with HND regardless of disability type, as well as common self-care strategies participants enacted and found helpful for improving wellbeing. This finding supports existing literature which argues that the impact of informal caregiving is more closely related to the intensity and extent of care required for the child, rather than the child’s specific disability type (Cummins, 2001; Dyches et al., 2013; Lewis et al., 2006; Schulz & Sherwood, 2009).

Further, this study supports the perspective that although there are many types of childhood disability and substantial variation in capacity and resources available for families to meet additional caregiving demands, there are shared elements to the caregiver experience (Barrett, Hale & Butler, 2014). Whilst acknowledging that different caregiving situations may result in varying negative impacts for parents, exploring commonality related to the caregiver experience for parents (regardless of disability type) can be useful for building a shared identity, health promotion and advocacy for parents – as well as providing valuable knowledge for healthcare professionals to deliver better care for families within the disability community (Barrett et al., 2014; Cummins, 2001; Dyches et al., 2013).

Sharing Difficult Experiences

The third additional finding from Study One was that all participants interviewed had a shared need to discuss the difficult and negative experiences of raising a child with HND. Despite the focus of the interview being to explore self-care experiences and identify effective strategies from a positive and health promotion approach, each interview had a large proportion of time spent with the parent talking about the negative aspects of being an informal caregiver which was consistent with other qualitative studies (Beighton & Wills, 2017; Rapanaro, Bartu & Lee, 2008; Skotko, Levine & Goldstein, 2011). It is possible that these parents may have discussed difficult experiences to help me as the researcher better understand their context and lived experience, and in doing so, justify their need for self-care.

Although further research is required to understand what leads parents to spend a large proportion of time discussing negative or difficult aspects of raising a child with special needs in research settings, it highlights the need for researchers and healthcare professionals to show empathy and provide emotional validation when interacting with parents within the disability community (Gair, 2012; O’Toole, 2012). Emotional validation may help parents acknowledge their difficult emotions and move towards resolution, as it can often lead to the person feeling more able to express, understand and control their emotions (O’Toole, 2012). In showing empathy and validating parents’ emotions, this may result in improved intervention outcomes, richer qualitative data, and reduced distress for parents as informal caregivers (Gair, 2012; O’Toole, 2012; Silvers, Bauman & Ireys, 1995).

Summary

Study One identified four key themes exploring parents’ self-care experiences and currently used strategies when raising a child with HND, including Formal Supports and Resources, Informal Relationships, Values and Goals, and Time. Study One also supported additional findings not directly linked to the research aims, including parents’ preferred language use, a lack of discernible difference between disability types, and a shared need for parents to discuss difficult experiences of raising a child with special needs. The next chapter presents the first key theme which focuses on parents’ self-care strategies related to accessing formal supports and resources for themselves and their families.

CHAPTER TEN:

Theme One: Formal Supports and Resources

Similar to previous research, findings suggest that successful self-care for parents of children with disabilities relies not on parents' internal strategies, but on the relationships and supports they receive at an exo- and macro-level (Bronfenbrenner; 1977; Goodhead & McDonald, 2007; Gouin et al., 2016). For parents in the disability community, these supports extend from typical parenting to include formal disability supports, funding and resources. The self-care strategies discussed by parents in relation to accessing formal supports and resources included: being heard when working with healthcare professionals; using education as a tool for empowerment; utilising respite care and getting comfortable with accepting help from others; and accessing peer support for "expert" advice and validation of their experiences.

Support in Being Heard

As part of their role, many parents as informal caregivers are required to interact and communicate often with multiple healthcare professionals to meet their child's needs. Aligned with the family-centred approach to healthcare, nearly all participants (9 parents) emphasised the value in being collaborative and "heard" with healthcare and disability services as part of their self-care (Smith, Swallow & Coyne, 2015). Nevertheless, all participants reported many barriers to being heard by healthcare professionals. These barriers included: a lack of funding and resources available in NZ; the power disparity between themselves as consumers and the healthcare professionals seen as "experts"; the confusion amongst a web of differing and interconnected disability services; a range of conflicting medical terms and jargon being used between services and professionals; and a loss of dignity for themselves and their child in having to "fight" for services they are entitled to.

Due to the many barriers that have historically marginalised the disability community physically, economically, socially and educationally within NZ culture, discourse with NZ caregivers tends to focus on the necessity to advocate strongly, to 'fight' and 'battle' for their family members' needs, and to become agents of change within society (Good et al., 2017; Maidment, 2016). Similar to common discourse within NZ, most of the current parents described it as a "fight" against the professionals and services to uncover what they are entitled to as a family, to find out accurate information and be referred to correct organisations, and to get sufficient funding and supports put in place for their family (Good et al., 2017). However, Anna argued that approaching healthcare and disability services in a positive, open, and collaborative way can be far more effective in achieving favourable outcomes for the family than approaching services ready to “fight” and contest against them:

> Everyone talks about everything being a fight. Now I don’t believe that the things that I get from my son are based on me fighting at all… We’ve always found that the more open we are with allowing organisations in, the more help we get. There are a lot of families who are unable to do that and that’s what I try to counsel people in… I know that the Ministry of Education can be difficult to deal with and I know that sometimes it feels like they don’t want to help you, but the more open you are with them about that, the more help you do receive because that’s just how it is. *Anna*

The discrepancy between Anna’s experience of collaboration with healthcare professionals within the system and others’ experiences of being required to “fight” against the system for services may reflect the changing landscape of healthcare provision in NZ (Foster, 2015). Despite over 50 years of research, theory, and training on family-centred care, there continues to be difficulties in effectively operationalising this model of care within NZ’s healthcare system (Foster, 2015). Family-centred care requires professionals to interact with families in a participatory and collaborative way, to ensure the family are empowered and actively involved in their care decisions and interventions (Foster, 2015; Smith et al., 2015).

As healthcare provision continues to be professionally led (rather than family-centred) in many settings within NZ, supporting parents and families to be assertive and empowered in healthcare decisions and interventions is crucial (Foster, 2015; Good et al., 2017). Most parents (9 participants) in this study discussed a process or journey to becoming comfortable in being assertive with professional organisations. They often described how initially it felt very unnatural to do so and went against their values and beliefs of interacting with healthcare “experts”. Strategies participants suggested to become more comfortable with assertiveness included educating oneself regarding disability and what services are available, and networking with services and other parents of children with disabilities to gain awareness:

> I definitely would have asked more questions. I was told a lot of things and I just took them as gospel... I would have taken advantage of a lot more help that was out there. I would have educated myself a lot more, but then we didn’t have the internet, or it wasn’t as big as what it is now. *Aroha*

Education and networking allowed parents to feel confident and self-assured that they had the knowledge, language and skills to be “equal partners” with healthcare professionals and feel capable to work with them in collaboration. Knowing their legal rights, and viewing professional services as organisations which work for them, also helped some parents feel able to assert themselves:

> I think back to that time; I didn't know how to get rid of [a support worker]. I didn't know what to say or do. Whereas now… I would probably just say, "Look, I don't think we are a good fit. Is there someone else who can take over?” *Debra*

Additional strategies parents discussed for improving their confidence in being assertive with healthcare professionals included: reflecting on successful experiences of being assertive; writing down their family’s needs on paper and rehearsing what they wanted to say prior to their appointment; and breaking down their family needs into prioritised, smaller and more manageable adjustments and requests:

> I would advise people that they have to sit down and put on paper what they need because there is a little bit of shift I feel in that families become more important because when we break down, what then? So, put on paper what you think you need at the moment, which can change by next week but then you can ask for a review again, ask that and most probably you will get it, and in case not, ask the reason and attack the reason. *Colette*

For some parents who found it difficult to be heard and assertive with healthcare professionals, they discussed finding an advocate to work alongside and support their family as an alternative strategy. Advocates were either informal (such as friends and family members whom parents trusted to help them), or formally organised with professional disability advocacy groups either locally or nationwide. They helped parents and reduced their stress and anxiety when interacting with healthcare professionals by providing a trusting relationship, supporting them to organise and attend different service meetings, reminding them to discuss all of their concerns during these meetings, providing additional knowledge and skills, and speaking for them when emotion got in the way of getting their message across:

> It’s not in my nature to be confrontational or anything, and when I do feel like I’m in a confrontational situation I tend to babble and cry, which I hate. So, I used to get my friend to come and she would get my point across for me and do it in a way that would make them listen. *Aroha*

Being assertive and speaking up often helped participants to shift their perspective from viewing services as non-budging, non-empathetic and non-collaborative, to a perspective that services are adaptable and able to meet their needs, albeit incrementally at times. Becoming comfortable with being heard and assertive amongst healthcare professionals often came over time for parents. However, many parents found certain assertiveness strategies particularly helpful when interacting with healthcare services, including education, networking, rehearsing, “chunking” and prioritising needs, and using an advocate.

Assertiveness strategies discussed by these parents, amongst other supported assertiveness and communication skills, have been found to be helpful for improving parents’ active participation and effective communication in interactions with healthcare professionals (D’Agostino et al., 2017; Ryan & Quinlan, 2018). Although not specific to parents of children with disabilities, assertiveness training as a therapeutic intervention has consistently been found to be beneficial for improving individuals’ self-esteem and relationship satisfaction, and reducing symptoms of depression and anxiety (Speed, Goldstein & Goldfried, 2017). As identified by participants, education is beneficial not just for improving confidence and assertiveness, but for improving parents’ overall self-care and wellbeing in many areas.

Education

Education is an essential tool for families accessing formal supports and healthcare, as it empowers them to become more autonomous in their families’ health management (Waddell et al., 2018; Yeh, Wu & Tung, 2018). Education can be used to help families make better choices (aligned with their values), and to increase their participation in healthcare decisions; this can lead to better management of their health and disability needs, better health and disability outcomes, and improved satisfaction with healthcare provision (Jotterand, Amodio & Elger, 2016; Yeh et al., 2018). Supporting these findings, education as a tool for self-care was discussed by the majority of parents (8 participants) in the current study. Parents reported focusing on their own education as useful to help improve their sense of expertise and mastery regarding their child's disability needs, along with empowering them to be heard amongst healthcare professionals, schools and disability services.

Although it overlaps with the previous section in being heard amongst healthcare professionals, education also helped parents improve individual wellbeing and their parent-child relationship. Particularly, parents discussed educating themselves in their child's disability to help validate their experience and improve their understanding for what was happening for their child. It also involved parents researching different disability services and funding processes within NZ to become better informed of what services and resources the family were entitled to. In doing so, education provided the language, sense of power, and self-assurance for parents to advocate for their family's needs, leading to enhanced wellbeing for their whole family:

> I suppose to a point I became a bit obsessed about it in the sense of just learning about things and how can I help my child become a better individual than what was perceived out in the public as the status quo for someone that has autism or someone who is in a wheelchair. I was always asking the question why can't they have more, why can't they do more? Why should I treat them any differently?
> *Tamati*

Most participants accessed education and resources through disability, peer support and mental health services, and through attending workshops in the areas of parenting and disability. Parents also described accessing education through self-directed learning via books and the internet. Nevertheless, two participants emphasised caution in terms of utilising the internet as it can offer incorrect, unhelpful or discouraging information. Through accessing these outlets of information, parents discussed the positive shift it created for them as it increased their understanding and tolerance for their child's difficult behaviours or caregiving demands, and improved their confidence in raising a child with a disability:

> [Education] just gives me confidence to know that I'm doing the right things, what to look for sometimes, and not to worry so much about some things. *Valery*

Gaining knowledge and understanding through education often helped parents move towards acceptance of "the disability", often discussed as separate or external from their child (linked to the use of person-first language). It also motivated them to continue to question and challenge their access to supports and resources, as well as challenge their beliefs regarding their child's development and ability to grow, learn and achieve. By challenging their beliefs, ongoing education and learning added to parents' sense of hope and achievement, thereby improving their overall wellbeing, as they were able to see their child accomplish skills and goals previously believed to be unattainable:

> I did feel that The Joys of Play [workshop] really opened things up for me a lot in the sense that everything just seemed to be so hard, and it changed my perspective into I've actually just got the most beautiful, misunderstood child, and really appreciating the way his brain worked. *Taylar*

Two parents described viewing education as an ongoing process that mapped onto changes for their child and family over time. Therefore, they viewed education as a tool that also helped to prepare their family for each life stage and transition as their child aged, allowing them to build resilience and coping strategies, and to plan for the future. These finding supports existing research which suggest that formal psychoeducation interventions with parents of children with disabilities are effective in improving knowledge regarding the condition and meeting the needs of the parents as caregivers (Krishnan, Ram, Hridya & Santhosh, 2018). Further, they have been shown to be effective in increasing parents' psychological wellbeing and self-determination ratings, and improving parental depressive symptomology and problem-solving (DaWalt, Greenberg & Mailick, 2018; Krishnan et al., 2018).

Respite Care and Allowing Help

There are a variety of legislation and policies across NZ government which provide funded supports for families, particularly in the form of respite care (Esplin, Moore & Rook, 2018). Respite care provides parents a break (or temporary relief) from caregiving, often through employing a hired individual to provide care for their child for a period of time. It has been shown to reduce parents’ levels of stress, anxiety and depression, increase their participation in more positive events, and improve marital quality and family outcomes (Bonis, 2016; Krakovich, McGrew, Yu & Ruble, 2016). The current findings support this, as all parents discussed respite care as being an important formal support for enhancing their wellbeing and family functioning as a whole.

Nevertheless, over half of the participants discussed the difficulties they experienced when accessing or utilising respite care. External difficulties parents experienced included being able to maintain a sense of privacy and family cohesion when carers came into their home, finding carers that they trusted and who were flexible to the families’ needs, and dealing with feelings of frustration and disappointment when they were unable to attend events or activities due to being unable to organise respite care. Parents reported experiencing a loss of freedom and spontaneity due to needing to arrange respite care in advance, keep an eye on how much respite care they have used out of what was allocated to them by disability services, and weigh up whether an event was worth the hours of respite care being used. One parent also explained how she found utilising respite care emotionally fraught once her child returned, as respite care allowed her to experience the life she had before her child’s disability:

> We wanted to have a normal family, and I found out when we started with carer relief, my son would go out of the house for a couple of hours or for the day and then come back, that I was disgruntled – I don’t want to say hated – but disgruntled about his disability. It was harder to pick up giving care again when my son had been away because for that short period of time you can taste a normal life again that you didn’t have. *Colette*

Similar to Colette’s internal difficulty with utilising respite, more than half of parents (7 participants) discussed their dilemma of initially allowing themselves to ask for and accept help from others, particularly regarding respite care. For many, this difficulty arose from their beliefs that (as a parent) they are primarily responsible for the care of their child, and that their child may experience feelings of abandonment; there were also concerns about burdening their wider family if they were to seek help. Participants also found it hard to trust in others to care for their child as well as they could; consequently, they experienced fear around spending time away from their child and guilt about giving the responsibility of caring for their child’s disability to others. Parents’ negative beliefs and feelings of fear and guilt led to five participants avoiding accessing formal respite early on in their child’s life. In hindsight, all five believed avoiding respite was unhelpful:

> At the beginning, I was always doing stuff with my daughter and wanting to do stuff to help her, and I was always around. And I was thinking that no one could do a better job than me. And so, I was probably more at home with my daughter… thinking no one else can cope with her, so I won't let them try. *Rachael*

> [At first it was] guilt and the fear that no-one else would be able to look after my son… it was the guilt of putting other people under pressure of looking after him… and we didn’t want him to feel abandoned and we didn’t want him to feel that, “I’m a disabled child and they don’t want me”… We didn’t want him to feel that, and we didn’t want anyone else to feel the pressure of looking after a disabled child, so yeah. It’s stupid stuff when you look back. *Kate*

Strategies parents found effective to mitigate these internal and external barriers to asking for help and utilising respite care was to initially “give it a go” and be open to whatever the outcome is. For two parents, they found it too difficult to reach out and ask for help, so they relied on first accepting help when it was offered by someone, such as a family member, until their confidence improved. Many parents found that starting with shorter periods away from their child, using friends and family members who they knew and trusted, and ensuring they planned enjoyable and distracting activities during this time, were helpful strategies to alleviate their worries and guilt when accepting help from others. One parent also discussed organising respite care so it was “fail safe” and likely to be undemanding, familiar and enjoyable for the child and carer. This was achieved by building the child-carer relationship prior to taking respite, informing the child of what was going to happen, and informing the carer of helpful tips and advice relevant to caring for their child.

> If you are eligible for carer support and it is there… just try it and have someone come in, you can always change your mind if it’s not working. But it’s just one less thing that you have to do, it’s one less thing that you have to worry about… And it can be hard having a stranger come into your house, but eventually it becomes part of your routine. *Aroha*

Other strategies parents found helpful were to build-up a team of respite carers whom the parents' trust to care for their child and whom the child enjoys spending time with, in order to have multiple options when organising respite care:

> I always advise people to have at least three people on their roster for Respite, have a primary as your number one go to, but have another two that you're quite comfortable using as well. But you've got to be comfortable in using them. Sort out what works for you, whether it's your kids going to their place or them coming to your place and you leave. Like I always tell the parents, at the end of the day you dictate the terms, not them. *Tamati*

Three participants mentioned it was particularly important to have a team of carers as they did not have a strong family network they could rely on. Parents explained that through building trust that others are capable of looking after their child, they were able to experience a shift of caregiving responsibility and allow themselves to enjoy a break from negative feelings of worry, stress, and a sense of needing to "know everything" as a parent. Strategies also included scheduling regular periods of respite as part of their families' routine, rather than when it felt necessary, as a preventative approach to maintaining wellbeing and family relationships:

> Unless you want to live your entire life constantly putting out fires, I think that you have to plan ahead, book respite regularly and get a feel for how many times you need it… I think respite weekends together are essential… because you're always trying to balance time with the kids, time for yourself and time for your partner, and there's just not that much time in a day... So, I think regular respite is really important. *Kate*

The final strategy parents discussed relating to accepting help was to reflect on the benefit of respite, including that it allows parents the opportunity to focus on their self-care and relationships with others, and it improves their patience, endurance and internal reserves for caring for their child. For all participants, respite care lead to improved parenting and family functioning, and reduced caregiver workload. Respite care also facilitated independence, interpersonal skills and personal growth for their child, and improved community awareness and acceptance of disability through building positive relationships between their child and their team of carers, friends and family members:

> If someone's offering [help] and they know that there's a child with challenging behaviours but they're offering, they're actually trying to bless you and you're taking that away from them by not allowing them. And actually, you've got to cut the cord a little bit so that your child can have a little bit of independence… It's allowed my mother to be a grandparent and bond with my child for example. And it's helped them get an understanding. *Taylar*

Existing literature has shown that respite care can benefit parents of children with disabilities, including improving their overall psychological wellbeing and family functioning (Bonis, 2016; Krakovich et al., 2016). However, it was not apparent in the literature that there has been a focus on how parents may mitigate barriers to accessing help, promote help-seeking behaviours, or better utilise respite care. Therefore, findings from the current study are unique and warrant further exploration from future research.

Peer Support

Peer support, provided by individuals who share similar experiences, is a well-established modality for improving outcomes in people with a wide range of risk factors and diagnoses, including parents as informal caregivers (Bray, Carter, Sanders, Blake & Keegan, 2017). The benefits of peer support for parents of children with disabilities have consistently been shown to include improving their social identity, providing valuable learning from the experiences of others, enabling personal growth and empathetic understanding, and improving problem-solving and practical support (Bray et al., 2017; Shilling et al., 2013). Further, peer support promotes social companionship, self-efficacy and a sense of belonging for parents, and it reduces feelings of isolation (Shilling et al., 2013). The current study aligns with previous research, as all parents viewed peer support as a vital strategy for their self-care.

Participants all perceived and advocated that the most expert source of support comes from parents who had similar caregiving experiences, rather than coming from trained healthcare professionals. All participants believed networking with other parents, preferably those who have a child with similar needs, helped them navigate through the difficult "web" of healthcare and disability services. Through networking with other parents, participants found this led to them gaining new empathy and insight with their child, and new knowledge regarding helpful parenting and behavioural strategies. It also provided them with advocacy when required, and a shared connection, contributing to them feeling less alone and detached from the rest of their community. Most participants (who talked about dealing with negative feelings, such as guilt and hopelessness), mentioned that reaching out to other parents in a similar situation helped give them hope, validation and a more positive outlook when caring for their child:

> Sometimes you just want to walk away… you just want to give up the fight or you want to give up, not in a suicidal way, you just sometimes can't be bothered. So yeah, I really think having someone, especially someone who knows, maybe not what you're going through but knows you can do this, you can do that, try this, try that. Or even having someone come in and do it for you, just try, just do what works, and so many things are not going to work, but there might be just that one person that makes you hope again or see the light at the end of the tunnel. *Aroha*

> That was huge having someone who had gone through the journey, and who is still going through it but has gone through it a lot longer than us. It is so healing for us to see that you can survive it. *Kate*

Two participants touched on their avoidance of accessing peer support early on in their child's life due to non-acceptance of the disability and a desire to have a "normal" life. Both participants viewed this as unhelpful in hindsight, as they believed peer support was an important source of knowledge, advice, and healing for the family. These parents acknowledged that they required time to process and come to a point of understanding and acceptance before they felt ready to access peer support:

> I didn't want to socialise with people who had disabled kids. How stupid was I? Because you can learn so much from those parents… I wanted a normal life. I didn't want to be reminded all the time that we had a disabled child. I think it's that, no acceptance, you have to get to that acceptance I suppose. *Colette*

Strategies participants discussed when networking and accessing peer support included to reach out to other parents as early on as they felt comfortable, as they believed doing so made the process of knowing what disability and healthcare services to access easier for them. Through vicarious learning from those with lived experience, peer support helped parents' conserve their energy and reduce a lot of confusion, stress and anxiety related to unknowingly navigating the different healthcare services available. Other strategies parents gave included prioritising and planning regular opportunities to have “download time” and engage with others who understand and share similar experiences. In doing so, this provided them an opportunity to routinely seek others’ opinions and advice for pressing issues, and to validate their own experiences and emotions (regardless of disability type):

> …To hear other people’s stories, you see a lot of us just sitting there nodding. And even though all of us have got children with special needs, all their needs are different, and they all have different diagnoses, but underneath all of that is the same emotion, same frustration. And it’s not just with having a child, it’s with education, school, and health. *Aroha*

Opportunities to engage in peer support were found through friends, formally organised peer support services within NZ, organised support groups such as “coffee groups”, networking with parents met through workshops, schools and disability services, and through online support forums such as disability groups on Facebook. Although all participants found peer support to be helpful, four parents discussed the importance of finding support networks that were positive, proactive and uplifting. They recognised that the culture in support networks could often lead to negative, comparative and depressing conversation, particularly regarding the inability to access more disability support and funding. Strategies parents gave regarding finding positive peer supports were to brainstorm and identify what they wanted from the support, whether it was education and helpful advice, sharing and normalising of experiences, and/or connection with a wider community. Parents then explored which supports fit with what they were wanting, and removed themselves from groups which were unhelpful or unmotivating for them:

> Well depending on the chat that’s going, if it’s all bitching and complaining about how a department has let you down then that’s really not helpful at all, but if you’re chatting about the good things that have happened and the good services that are out there then it’s valuable. *Mark*

> I think it’s a really lovely aspect of it, because coffee groups can be the worst thing for parents because they end up comparing stuff and it can be really discouraging, but a group like that where everybody is kind of in the same boat and they provide each other with a lot of moral support because they’re going through similar experiences can be a really useful thing. *Allie*

The strategies parents found to be useful for accessing support in the current study are supported by existing research which found that central to peer support success for parents of children with disabilities was the sharing of parents' experiences (Shilling, Bailey, Logan & Morris, 2014). Additional elements for success included that parents needed to be able to learn from the experiences of others, to speak freely in a safe and non-judgmental environment, and to receive adequate support and encouragement from their befriender (Shilling et al., 2014). In sum, accessing positive and uplifting peer support can be beneficial for parents as a form of self-care and validation of their experiences, and can lead to improved wellbeing and family functioning.

Summary

Theme One of Study One focused on effective strategies parents used at an exo- and macro-level to better access formal supports and resources for themselves and their families as a form of self-care (Bronfenbrenner, 1977). These strategies included being heard with regards to healthcare professionals, using education, utilising respite care and accepting help, and accessing peer support. The next chapter presents Theme Two, which presents self-care strategies and experiences parents discussed related to maintaining and improving their informal relationships with their child, family, friends and community.

CHAPTER ELEVEN:

Theme Two: Informal Relationships

In addition to improved interactions at an exo- and macro-level regarding receiving formal supports, current findings suggest that successful self-care for parents of children with disabilities also relies on their informal relationships at a micro-level (Bronfenbrenner, 1977; Goodhead & McDonald, 2007; Gouin et al., 2016). Reflective of previous findings, parents emphasised the importance of having a strong network of informal social support around them and their family to help improve their wellbeing and family functioning (Boehm & Carter, 2016; Halstead et al., 2017; Lindo et al., 2016). The self-care strategies discussed by parents in relation to informal relationships focused on strengthening their partner relationships, engaging in self-care as a family activity, and constructing a community of support around their family.

Partner Relationship

There is a common understanding amongst healthcare professionals and parents that there is a higher risk of marital dissatisfaction, reduced cohesion and divorce when parenting a child with disabilities (Garcia-Lopez et al., 2016; Mitchell et al., 2016). Conversely, parenting a child with disabilities has also been shown to strengthen partner relationships, give new or increased sense of purpose within the relationship, and lead to parents becoming more compassionate and tolerant towards others (McConnell et al., 2015; Taunt & Hastings, 2002). Understanding how to nurture a positive partner or co-parenting relationships for parents of children with disabilities is relatively sparse in the literature. However, supported strategies have been found to include parents working together as a team to manage lifestyle adjustments and stresses (Birnbaum, Lach, Saposnek & MacCulloch, 2012; Saini et al., 2015), agreeing on a division of tasks (Ogston-Nobile, 2014), utilising effective communication skills (Saini et al., 2015), and instilling a sense of hope regarding the partner relationship (Saini et al., 2015). The current study both supports and adds to existing strategies for developing and maintaining positive partner relationships.

Nearly all parents (10 participants) discussed their varying difficulties and added stressors which developed or escalated within their partner relationships, or contributed to the lack of a partner relationship, related to having a child with special needs. Most participants appeared to do this to feel heard and validated, as well as to forewarn other parents of potential problems with having a child with disabilities. Five participants reflected on problems and tension arising in their relationship due to differing levels of acceptance, self-stigma, and understanding of their child's disability:

> My husband has no concept, no understanding, and I think he might be a bit ashamed like it's some kind of a disability reflected on him. So, he and my son butt heads a lot and I'm constantly having to jump in. And we have this unfortunate circle of a victim-persecutor-rescuer. *Taylar*

> The physical part of caring my husband is doing really well, it is the emotional part that he is lacking tremendously. My husband will let a sigh out which our son can hear, which makes me very angry because I see the pain in our son's eyes. *Colette*

These differing levels of acceptance and understanding between partners typically occurred related to wanting and receiving a diagnosis or "label" for their child, viewing their child's behaviour as "naughty" rather than being related to the disability, having conflicting parenting and caregiving styles and beliefs, and disallowing "the disability" to interfere with the parent's own wants, goals and dreams.

To avert and counteract these tensions arising and escalating within partner relationships, participants discussed utilising strategies including approaching their relationship as a "team", whereby both parents decided together who completes what parenting, caregiving and family tasks (Birnbaum et al., 2012; Saini et al., 2015; Ogston-Nobile, 2014). For many, this agreement reflected a shared and balanced routine which both parents felt was fair and equal, and which allowed both parents to incorporate what they valued and found meaningful. Two participants believed this agreement needed to be regularly reviewed and modified related to the changing needs and demands of the family. Parents also discussed using humour, having a positive outlook and goals for the future, utilising healthy communication, and working on a shared understanding, acceptance and commitment to "the disability" as strategies to maintain partner relationships. By parents externalising the disability as the difficulty or problem, and not their child or partner, this helped enable a team approach (Saini et al., 2015):

> [A positive outlook] has probably kept us together, like me my husband are still together, and my son is now eight and I don't see any plans for us to split up or have any issues. We always joke, like a lot of people, that if we split up one of us would have to take our son, so that kind of keeps us together. But we look at it as a tag-team situation, so we tag one person in so the other person can deal with their mental health which probably is the way we cope… What happens is you tend to blame the other person for what's happening with your child rather than trying to look at it together as in "this is what we should do" as an approach, rather than "you didn't do that" ... So, we try not to blame each other for things that happen because a lot happens, and it makes you cross and then you automatically want to blame somebody. *Anna*

When parents felt that agreements were not being upheld, that there were differing opinions or levels of understanding, acceptance and commitment, and that they were not unified in their relationship, many discussed experiencing feelings of neglect and a build-up of resentment or frustration towards their partner. This build-up of negative feelings towards their partner tended to result in a cyclical worsening of communication, understanding and cohesion. In order to interrupt the downward spiral in their relationships, parents discussed strategies including genuine apologies, continuous honest communication (Saini et al., 2015), making time and space for one another (regardless of whether they feel like it at the time), and making plans to look forward to as a couple (and as a family), as a way of instilling hope for the relationship (Saini et al., 2015):

> I think that doing whatever it takes to remember who you are as a couple is so essential, and forcing yourself at first. It keeps running through my head, "fake it till you make it". So, forcing yourself to have time together, even if it means that you do find out that you actually hate at each other… I think even more so with a disabled child, it is so important to remember who you are as a couple and to focus on who you are as a couple rather than everything else... and doing it regularly, not every six months. Yeah, I mean every night, actually even for 10 minutes. Because even if it feels forced, it's still better than the alternative and it is only 10 minutes. Even if you're sitting there in each other's company frozen and silent, it's still 10 minutes in a room where you are forced in a position to maybe find something nice to say. *Kate*

Honest communication included parents being open with their partner regarding their needs, experiences and feelings, regardless of how negative or undesirable they believed them to be. Further, parents discussed needing to feel that they were being genuinely and empathically listened to by their partners. Four parents attributed the failing of their partner relationship and divorce to the significant reduction in time and energy they had to give to their relationship, due to the varying demands of caring for their family and their child’s disability:

> My husband gets very jealous that he doesn’t get enough of my time, but he just doesn’t get that there isn’t any more time left. *Taylar*

> I think that lots of men crave the attention of their wives, and that attention as soon as you have children is already decreased, but even more so with a disabled child… In our case, it comes down to communication. My husband has never been a big talker anyway… not to the family, but to hear him say, “Oh, I wanted more attention or more contact with other women because you are giving too much attention to our son”. And then he said, “Don’t get me wrong, you couldn’t do anything else but that was the case”. He should have started talking about that years before then, but he didn’t. *Colette*

Positive techniques five parents used to maintain a healthy partner relationship included utilising respite care to schedule regular alone time together, and purposefully reflecting on their partner’s positive attributes and giving this feedback to their partner:

> Too often I think I’m finding the negatives in what my husband’s not doing and I’ve just got to constantly remind myself that there are things that he is doing well, so it’s a kind of like catering to a child. If I want to see it then that’s what I’ve got to do. *Taylar*

Participants also discussed acknowledging within themselves that there will always be inequalities, differing of opinions and difficulties within partner relationships, as with all relationships, and that they needed to allow space for these difficulties and differences in order to collaboratively work through them. Finally, three parents emphasised sitting down with their partner and devising a plan of what they want their relationship, family and life to look like, to help work together towards the same goals and instil hope for the future (Saini et al., 2015). Strategies for improving and maintaining partner relationships discussed by parents in this study not only support existing interventions for parents of children with disabilities, but also align with commonly used relationship counselling and intimacy training skills, such as behaviour modification and positive reinforcement (Kardan-Souraki, Hamzehgardeshi, Asadpour, Mohammahpour & Khani, 2016; Saini et al., 2015).

Self-Care as a Family Activity

All participants discussed the difficulty of finding time to participate in commonly “prescribed” self-care activities, such as going to the gym, getting eight hours of sleep, or making time for themselves due to their many parenting and caregiving demands. Additionally, most parents discussed added impeding difficulties, such as financial restraints, being a solo parent, organising limited respite care, and personal worries and beliefs around accepting help from others. Parents’ difficulties in this study match existing findings within the literature (Dew et al., 2008; Parish & Cloud, 2006; Saunders et al., 2015; Shtayermman, 2013).

To combat these difficulties, nine parents emphasised the importance of finding enjoyable activities they could do both with their child and with their family as a whole, which the parents themselves deemed “self-care” for their own wellbeing. Activities discussed were widespread, creative and as adaptive to the families’ needs; for example, participants discussed shared activities such as fishing, baking, gaming, travelling, walking, listening to music, and going on ‘ghost hunts’ and motorbike trail rides. The emphasis for parents was to regularly participate in inclusive activities that everyone enjoyed, including themselves, which were realistic, achievable and convenient within their family’s reality:

> We went on a motorbike trail ride and that was something that was quite cool, something totally different for him… It’s just good to bond with him again, have that time together and create another story that we can talk about later on… Do stuff with your kids... Just something random because that is the stuff that they remember. They don’t remember playing cards every day, but if you go and do something totally different like go on a motorbike ride, they’ll talk about that for months. *Mark*

Current findings align with behavioural activation, which is an empirically supported intervention approach typically used for treating depression (Mazzucchelli, Kane & Rees, 2010). Behavioural activation is a strategy based on Skinner's (1974) operant conditioning theory, whereby individuals or groups participate in rewarding activities that they find pleasurable or meaningful to improve their mood and wellbeing (Mazzucchelli et al., 2010). As a self-care strategy or therapeutic intervention, behavioural activation has been shown to enhance informal caregivers and non-clinical populations' subjective wellbeing and reduce their risk for depression and other mental health disorders (Au et al., 2015; Mazzucchelli et al., 2010). Two participants talked about preparing a number of different activities which everyone enjoyed as part of their "toolbox" of self-care strategies. In doing so, they felt more readily able to participate in activities regularly, particularly when their child became agitated or they felt at their limit of tolerance:

> I could not get her back to sleep, so we would go for a drive and I'd go to a Wild Bean Café and get a coffee. And I'd just drive around town because she loves the car and I know it calms her down, which calms me down… coffee is one of my favourite things, so we'd go for a drive, I'd have a coffee and we're both happy. *Allie*

Planning family activities ahead of time was also helpful for two single parents, who had few other adults to share responsibilities with and rely on. One parent discussed planning activities with their child and family in ways so that they were set-up to succeed. For their family, this meant setting and sticking to a time-limit, considering environmental factors which may impact on their child, forecasting for any difficulties which may arise, and ending the activity on a positive (rather than a negative moment) in order to create pleasant memories:

> We also try and do things, positive things, together as a family, so we set ourselves up to not fail basically. So, we'll take our son somewhere, but we will set a time limit and we know how long that is, and even if the temptation is while we're having a good time to stay longer. We always try and end it on a high so that we always have a positive experience and we have nice memories. Because ending when he is having a screaming meltdown is the quickest way for us to be like, "God

> that was awful, we’re never doing that again”, and then isolating ourselves and that doesn’t work either. *Anna*

Three participants described a therapeutic and healing aspect of participating in self-care activities with their child. For these parents, engaging in enjoyable activities helped them build positive memories with their child which they could reflect on during more difficult times, and strengthened their parent-child relationship. Engaging in joint activities also helped them to separate their child from “the disability”, to widen their perspective and build acceptance towards “the disability”, and to gain a sense of achievement and happiness by feeling like they are “doing something right” as a parent (Au et al., 2015):

> We just sat there last night when we were waiting for everyone to arrive at dinner and worked on fondant together. We were both completely quiet and he was just trying to grab it with his hands… I guess it’s self-care in the way that you’re starting to heal those parts of you that thinks of your son as a problem child, but actually it was literally ten minutes of peace where I was doing something that I needed to get done that I also enjoyed, and we were just in each other’s presence and no demands really on each other. And I think that anything that heals… anything that allows me to fall in love more with this boy that we have now is a good thing… So yeah, I think it is self-care, even if it does involve my son. Because there is a lot of healing that still needs to go on and I feel like it’s really happening, healing between us as well, and how we feel about our child. *Kate*

Six participants described the added challenge for them as parents of multiple children in having to “juggle” parenting and caregiving demands between their children. Similar to previous studies, difficulties parents discussed included them having to share an unequal amount of attention between their children due to caregiving demands, and their worries regarding whether siblings were feeling less loved, less important or that their family situation was unfair (Hastings, 2003; Sharpe & Rossiter, 2002). Difficulties for parents also included experiencing anguish, grief and guilt when recognising what their child with disabilities cannot do in comparison to their siblings, and with their other children having to spend significant time elsewhere with extended family and friends for parents to better balance parenting, caregiving demands and their own self-care:

> We feel a lot of that pain for our son, and some of it we may not need to feel, but there is just that ongoing pain that there are things he can't do, and partly because he can't physically do it. Like the movie theatre… they've got no disability access, so we never ended up going. There are things like that that break your heart all the time, just him not being able to access the world as well as my daughter can, and that'll be for the rest of his and our lives. *Kate*

Strategies parents with multiple children used to address these difficulties included dedicating time for each sibling to spend one-on-one time with their parents, planning separate fun activities with each child, planning enjoyable activities together as a whole family, involving the other children in the extra caregiving activities required for their sibling when appropriate, and putting energy into making all children feel equally loved and cared for. Similar to other studies, parents also advocated for building a community of supportive and trusted friends and family helpful for managing and balancing their children's' needs (Findler, Jacoby & Gabis, 2016; Opperman & Alant, 2003), and purposefully reflecting on the positive outcomes that occur for siblings when exposed to someone with a disability, such as increased empathy, inclusion, patience and understanding (Timmons, Ekas & Johnson, 2017):

> I think you can only do it if you have really good friends and a really good family. Because every time [my daughter] goes away, she's doing something that's really fun for her… I think we do really, really well with juggling both kids. I think this weekend having my son [with a disability] by himself with us was awesome and I think he loved it, he got all his dad's attention, but we did it beautifully, it was like a frickin' symphony. *Kate*

> That's a good thing about having a special needs child, is that their siblings are really nice, like they have a good empathy and understanding. *Rachael*

Both Opperman and Alant (2003) and Moyson and Roeyers (2012) found that children with disabilities and their siblings also benefit from accessing social support outside of their parents and immediate family relationships, particularly peer support as they can receive validation and co-construct ideas from others viewed as their equals. However, there is a clear gap in the literature regarding siblings of children with disabilities, particularly related to improving their wellbeing and family relationships from a positive psychology perspective (Opperman & Alant, 2003; Pavlopoulou &

Dimitriou, 2019; Tint & Weiss, 2016). Although outside the scope of the current study, strategies discussed by parents for improving their relationships with their children may be beneficial for siblings' wellbeing. Nevertheless, future research from the siblings' perspective is required to build on these findings as this has often been overlooked in the literature (Moyson & Roeyers, 2012; Opperman & Alant, 2003; Pavlopoulou & Dimitriou, 2019).

Building a Community

Strong networks of social supports have been found to lead to decreased levels of stress, increased resilience, and improved wellbeing and family outcomes for parents of children with disabilities (Halstead et al., 2017; Lindo et al., 2016). Reflective of these findings, all parents in the current study discussed building a community of support persons around their family as a self-care strategy, to reduce stress and feelings of isolation. Having a community of supportive people surrounding them helped parents regularly access positive social interaction and validation, share the responsibility and caregiving demands for their child, and feel connected to a wider community based on common values (Halstead et al., 2017; Lindo et al., 2016).

Parents' communities typically consisted of friends and extended family members, employment and hobby networks, new friendships and connections within the disability community; they also had their more formal "team" of respite carers, support persons, and disability and healthcare professionals previously mentioned. Many believed having a strong community of support not only allowed them to gain practical assistance, emotional support, and a sense of connection, but it also helped their children to gain these benefits as well (Findler et al., 2016; Opperman & Alant, 2003):

> I think recognising how much other people have a part to play in my self-care, like being part of a bigger community of people that are supporting me… I also strongly believe that it's a community that raises a child and I have a really good support network and wouldn't want to do it on my own. I want [my child] to have other people in her life that she's connected to and attached to, so it's kind of worked out well that I have to have other people caring for her, and she gets used to other people caring for her as well. *Allie*

Four parents included various cultural, spiritual and religious networks as part of their supportive community based on values and beliefs important to their family. Aligned with existing research findings, parents felt these networks helped their family gain a sense of belonging, spiritual connection and guidance, moral support, practical help, and acceptance (Pandya, 2017). Having cultural, spiritual and religious networks allowed parents to continue to live in accordance with their values and beliefs, find deeper connection and meaning in their everyday life, and contribute to their overall sense of wellbeing and family functioning:

> I do get a lot of support from the Samoan community and even if it's just moral support, they are all so supportive of my decision and just embrace us as part of their community. They kind of consider me part of their culture now. But it's really nice to have that network and I know that any of them would help me out in a heartbeat if I need anything, you know I'd have to ask but they would jump at the opportunity to help us… keeping that cultural link has been important in terms of my self-care and making sure that my child is included as well. *Allie*

Also aligned with existing research findings, parents discussed extending their supportive community to include more formal psychosocial intervention when required (Cachia et al., 2016; Lindo et al., 2016; Rayan & Ahmad, 2017; Waddell et al., 2018). Five parents highlighted how important it was for them to access support from social workers, counsellors and psychologists, particularly early on when receiving their child's diagnosis, to help deal with their trauma, grief, and lack of awareness associated with having a child with special needs. These parents also emphasised the importance of accessing formal psychosocial support for their whole family if required, including their partner, child, and their child's siblings in order to address their family's grief and trauma:

> Disabled families that are created by having a disabled child should be handed [support] as soon as they're born. I mean we got handed a social worker… You're traumatized, you're in such shock you don't know how much support you need, and I think they should be allocated to every single [family]… One of the things I would say is you probably don't even think you need it and that means that you really, really need it. *Kate*

> I think that when my son was probably younger, like two to five, sort of about that age, I personally think that every family should be offered counselling. I don't think there’s enough support around families, and especially the siblings. Because the parents are so busy watching out for their child with special needs and trying to keep up with their own lives. You pay attention to the other siblings, but probably not as much as you should. I think that's a huge gap in the system. *Debra*

Nearly all parents (10 participants) mentioned the importance of scheduling regular opportunities to engage in enjoyable social interaction with those within their supportive community. However, most of these parents (6 participants) discussed how having a child with disabilities can make participating in regular social interaction and maintaining friendships more difficult. The reasons these parents gave for friendships becoming harder to maintain included that social interactions are required to fit in around their child’s needs and routine, and they experienced financial difficulties and lack of time to participate in activities deemed a ‘luxury’, such as visiting a café with friends. Four parents discussed having occasionally experienced feelings of guilt for spending time away from their child (Findler et al., 2016), and embarrassment regarding their child’s disability:

> It's made friendships harder. I remember taking my son to a friend's place and he got disorientated and didn't really know the way out… And he lashed out and smashed their window. I was so embarrassed. So, I'm very hesitant about where I take him, because he doesn't cope well in new situations. So, for me, friendships are people actually coming to us in his home environment, so he can carry on and do what he is doing… I think it's harder to make friends when you've got a child that you can't take places. Like as a thirteen-year-old and having a sixteen-year-old, you'd expect to be able to just go out for half an hour and have a coffee with such-and-such. You can't do that. *Debra*

Parents discussed the need to identify friends who understand that plans may not work out or may need to change last minute, who will not place blame on the parent or child for “the disability”, who are willing to understand and accept the reality of having a child with special needs, and will be accepting of the family’s needs and ask “what else can we do?”. Strategies parents used to incorporate regular social interaction with friends included making plans well in advance, including the child and their siblings where possible, and having reliable methods such as having friends come to the family house or organising to go somewhere which is enjoyable and known to their child. Parents discussed the importance of saying “yes” and taking people up on offers to socialise, having regular social interaction which does not centre on their child, and being comfortable in asserting their needs to their friends:

> I think taking time out is good – essential. I think having relationships outside of the home, and not just focused on what’s going on with you and your special needs child, but talking about other things and having a laugh. *Aroha*

Two participants discussed starting small and attaching socialising to other responsibilities when they felt guilty about leaving their child, before building it into a habit as part of their routine. For example, one participant started going early to pick up the children from school in order to interact with the other parents, and another parent completed errands such as supermarket shopping with her friends. Six parents believed it was crucial to have support people, whether it be friends, family or professional support persons, who they trust and felt comfortable in “offloading” their experience of raising a child with special needs to, especially to vent any negative feelings and difficult thoughts without judgement. Similar to the therapeutic technique of active listening, these participants stressed the importance of these support people having an understanding of their child’s disability and being able to empathically listen to them without feeling required to provide a solution to their problems (Bodie, Vickery, Cannava & Jones, 2015):

> My sister and my mother are great support. They understand well as they’re both nurses… and they understand autism and they have a special spot for my son. I needed that, I needed someone to be on my side, because I’ve had a lot of other people trying to be helpful and tell me “he just needs a good smack”. *Taylar*

> People don’t like the idea of having to talk to somebody but actually it’s really important. Because otherwise that stuff stays inside you, and I think it does affect the way that you then feel about your child or feel about your situation. And that’s a really negative place to be in too. *Anna*

As being a parent of a child with disabilities can be demanding, five participants highlighted the importance of being able to identify their limits regarding socialising and to say “no” to other people’s requests. Part of this involved parents being able to stand back, reassess and prioritise the situation in terms of their own needs, interests and obligations. The other part of this involved parents being able to recognise people who were draining too much of their time, energy and internal reserves, or who were harmful in terms of their lack of understanding and negative judgements. In identifying these potentially harmful relationships, parents discussed needing to assertively implement rules and boundaries in order to protect their own wellbeing, such as spending less time with these people, putting less effort in to the relationship, or removing them from their everyday life:

> Other friends I’ve tried to have just sit there and say, “Oh just give him the strap, just give it to him once, he’ll never do it again”. I’m sorry, I don’t need that in my life. I’ve got enough judgement, and I know my child, you don’t know my child, trust me smacking him is not going to work. So again, you know, just cutting strings and just trying to surround myself with the people that are like chicken soup for the soul. *Taylar*

> My friendships have changed, there’s people that I just have very little to do with now because of time and circumstance but I also think well, yep you can come to me now. I’ve spent the last ten odd years going to visit other people and going out of my way to meet other people, and then they can’t return the favour because I’m stuck at home with a child then that’s their problem and I’m not going to waste time on one of those friendships… You do see who your friends are, and I do feel like the friends that I have now are the people that are really supportive of my decision… And it has really surprised me who those people are actually, it’s not necessarily the people who I thought it would be, but it’s nice. *Allie*

Although some parents felt negatively about friendships and relationships which lacked support and understanding for their family, four participants discussed the positive changes which occurred within their surrounding relationships and community. These positive changes included parents creating genuine friendships, witnessing personal growth and acceptance in their friends due to their child’s disability, and being able to identify those whom they can trust to go out of their way to be generous and supportive. For three participants, they were able to reframe these changing relationships as a positive shift towards developing a more respectful, empathetic and authentic community surrounding their family:

> I think it is such a long journey, and the people in your life are going to change for better or for worse, but things are going to change and it's not necessarily a bad thing. I've just met new people who have come into my life and who have given me hope. Just the conversations that we've had and little things that I've learnt. There is bad but there is also so much good, and so many good people out there. *Aroha*

Thus, current findings reflect what researchers have long acknowledged regarding the importance of social relationships in influencing an individual's wellbeing and quality of life (Boehm & Carter, 2016). Unfortunately, many findings regarding building a community of support from the current study cannot be compared to existing research for parents as informal caregivers due to a gap in the literature. However, parents' strategies for building and maintaining friendships, such as regular social interaction and empathetic listening, are reflective of evidenced-based strategies for sustaining positive relationships (Bodie et al., 2015; Hojjat & Moyer, 2017).

Summary

Theme Two of Study One focused on building and maintaining informal relationships as a form of self-care, including strategies parents used to strengthen partner relationships, engage in self-care as a family activity, and construct a supportive community around their family. The next chapter presents Theme Three, which involves parents' self-care strategies for incorporating values and meaning in their life, developing goals and future plans, and promoting positive reappraisal of their situations.

CHAPTER TWELVE:

Theme Three: Values and Goals

Aligned with more traditional views of self-care, current findings suggest that parents of children with disabilities also engage in self-care strategies at a micro- and individual level regarding decisions they make for themselves and their families, as well as how they choose to view the world and their current situations (Bronfenbrenner, 1977; Pender et al., 2011). Not only did the following experiences and strategies reflect existing research specific to parents as informal caregivers, but they also aligned with various empirically supported therapeutic techniques developed to address individuals' distress and promote wellbeing (Hayes, Strosahl & Wilson, 1999). Self-care strategies and experiences included in this chapter focus on parents identifying their values and incorporating them into finding meaning and purpose in their everyday lives, developing goals and future plans to instil hope, and using positive reappraisal and humour to shift out of a negative outlook.

Identifying Values

Identifying personal values and promoting values-consistent behaviour is a therapeutic technique used by many empirically supported psychological therapies, such as ACT – Acceptance and Commitment Therapy (Baer, 2015; Hayes et al., 1999). Utilising values is seen as essential to improving wellbeing, as they have been shown to intrinsically motivate an individual's behaviour, which leads to a deeper sense of meaning, vitality and engagement with life (Baer, 2015). Pursuit of goals which reflect individuals' values is also associated with increased goal attainment, reduced distress and depression, and higher overall rated wellbeing (Baer, 2015; Bramwell & Richardson, 2018). Reflective of these findings, all participants from the current study discussed living by their values as a contributing factor to self-care. Through recognising their values, parents were able to use these to help guide decisions and to find meaning and purpose in their everyday life.

All participants acknowledged that their values were shaped by their culture and upbringing, but few expressed that culture and upbringing explicitly played a significant role in their current self-care practices. The two participants who felt their culture played a significant role in their self-care linked this specifically to engaging in religious practices, such as praying and attending church. Nevertheless, participants recognised that through identifying and continuing to live by their values as a self-care strategy, they felt less worried and stressed; they also experienced strengthened support and relationships, and they felt more empowered and motivated toward tackling everyday demands:

> Being connected to a church community is a natural source of support for me… My belief is that church is about the people and so getting support from the church is getting support from the people in the church… I don't know if it's my spiritual values or just having people there that I know who care, that community, that connection… Although I think from my own personal belief system, the spiritual stuff is important as well. I do have spiritual beliefs and I guess that sense of hope and faith in something bigger than yourself can be really important in terms of self-care, well for me it is. *Allie*

Four participants discussed difficulties they experienced regarding feeling a loss of identity and purpose after having their child with special needs, with one parent stating they still believed they were going through a challenging process of remembering who they were before their child:

> Trying to think about myself now, I'm so out of the habit I almost need someone to help me learn how to think about myself… I don't know how to have dreams about what I want to be when I grow up. I've completely lost the ability to focus on my own life… It's completely lost to me. I don't know how to get it back. *Kate*

For these parents, recognising and behaving in accordance with their values helped them rebuild their sense of identity and re-establish purpose and meaning in their everyday life. Values discussed predominately focused on family and relationships, spirituality, connecting with nature, giving to others, making decisions in everyday life, and employment. For all participants, life decisions were not seen as black-and-white; rather, they were viewed on a spectrum in which parents were able to shape and adapt their decisions in life to their family's current situation, needs and wants as influenced by their values:

> You really need to try and stick to what you believe. Just because you've got a disabled child, it doesn't mean you have to change the world. There are ways to do

> things, and I think lot of people get caught in that, “Oh we can’t do this and that”. Well if you say you can’t then of course you can’t, but if you say how can I do that, you’ll find a way. *Mark*

> Now my whole life is not wrapped around work, but I do work because I have responsibility to do it and because I want to live a certain lifestyle. So yeah, it’s a means to an end, but I do derive purpose from it because the nature of the work that I do.... I can do both and it’s not an either-or situation for me. I feel really privileged to be in a position where I can bring up my daughter but also do a job that I find a lot of purpose and meaning in and feel like I’m helping a number of people. *Allie*

Although all participants felt it was important to live in accordance with their values as a strategy of self-care, similar to previous findings, four parents felt it was important to also be open to allowing positive change in values which may occur through having a child with special needs (Gupta & Singhal, 2004; Pelchat, Levert & Bourgeois-Guerin, 2009). This finding aligns with research on posttraumatic growth for parents of children with disabilities (Konrad, 2006; Zhang, Yan, Barriball, While & Liu, 2015).

Posttraumatic growth is a phenomenon which can occur through the struggle of tragedy, trauma or loss, whereby individuals’ paradoxically experience amplified or transformed personal strength, values, assumptions and beliefs about the self, world and others (Konrad, 2006; Zhang et al., 2015). Having a child with a disability is not a ‘tragedy’ per se, but it can involve physical and emotional trauma, and a sense of loss for the parent’s ‘imagined’ or ‘idealised’ child they might have been anticipating. Similar to other studies, positive changes current participants discussed from having a child with special needs included becoming more thoughtful, accepting and caring towards others (Gupta & Singhal, 2004; Pelchat et al., 2009; Zhang et al., 2015). Further, current participants discussed experiencing deeper relationships, enhanced resiliency towards facing difficult everyday situations, and a significant shift of perspective and understanding related to the disability culture and community (Gupta & Singhal, 2004; Zhang et al., 2015).

In accordance with the positive changes and widened perspectives that occurred for parents, three participants realised that their priorities shifted to align with their changed perspectives (Gupta & Singhal, 2004; Pelchat et al., 2009). Being able to identify changes in values resultant from having a child with special needs was important for these parents to reflect on when consciously using values as a self-care strategy to guide decisions and find purpose in everyday life:

> I think my priorities have changed since I've taken her on and I do have a different attitude to life. Whereas, I think I was always quite high-strung and my whole life was work. I was always stressed, and I was always busy. Now I'm busier than I've ever been but I still feel like I've got lots of downtime… after dinner we'll sit on the couch and chill out, and I wouldn't have done that before but now I do because of her. In some ways, she's slowed me down… And I just look at her and the way she thrives from just being loved and cared for, I think that is the most important thing. That's what all of us need at the end of the day is to be loved, and to know that we are loved unconditionally is definitely more important than everything else. And that's what she has taught me, the value in that. *Allie*

Thus, identifying personal values appears to be beneficial for parents in intrinsically motivating behaviour that leads to a deeper sense of meaning and purpose in life, guiding decision-making, and rebuilding their sense of identity. In raising a child with HND, parents may also experience posttraumatic growth and positive changes in their value systems (Zhang et al., 2015).

Finding Meaning and Purpose

Tied to the importance of being able to identify and live according to values, participants discussed how finding meaning and purpose in life was critical to their self-care and wellbeing. Similarly, Beighton and Wills (2017) argued that most parents are required to revaluate and adapt their life goals, plans and priorities when they have a child with special needs. This requires parents to reduce the mismatch between their appraised meaning of having a child with special needs (their perceived degree of threat, controllability, implications) and their global meaning (their fundamental values, beliefs, desires) (Beighton & Wills, 2017; Park, 2013). Beighton and Wills (2017) argued that parents can reduce this mismatch by adapting and reordering their goals and priorities, and by participating in experiences through which they find existential meaning (Park, 2013). Having meaning and purpose in life has been shown to help positively reappraise difficult events, trigger effective coping skills, and consequently lead to improved health-related outcomes (Czekierda, Banik, Park & Luszczynska, 2017).

A notable way that many participants experienced meaning and purpose in life was to help others (Lee, Park & Recchia, 2015). Through altruistic acts such as volunteering, advocating for other parents of children with special needs, and working in the field of disability and rehabilitation, six participants found that in giving to others, they themselves also experienced improved wellbeing (Lee et al., 2015). For these participants, it made sense for them to choose ways of helping others which aligned with their values, knowledge, and experiences of disability. These parents discussed that through giving to others, they were able to gain a sense of validation, solidarity and gratitude when reflecting on their own experiences:

> I'm happiest when I'm helping people. While it can be totally stressful, I'm happy once I get the result and I'm happy once they become happy… I don't mind spending my own free time helping others because I mean I wish half of the information was as easy to come by back in my day. *Tamati*

> I really love caregiving, and that's been my job. I've worked for a caregiving agency with complex cares and brain injury, and in rest homes. I've been a rehabilitation facilitator for mental health services… it does make you feel valued… I think I'm probably a person that needs to feel needed. It's just that you feel fulfilled and satisfied that you've come away and you've helped somebody. *Valery*

Other ways parents found meaning in everyday life included having positive relationships, participating in enjoyable or purposeful activities, and by having future plans to look forward to. Also, parents found meaning in having a sense of security, having a spiritual or religious connection, achieving emotional and family wellbeing, and being grateful for "small positives" in life, such as a hot shower or getting cuddles from their children (Beighton & Wills, 2017; Lee et al., 2015):

> What I find meaningful… My family, they mean the world to me. So being there for them and being able to be there for them. Being happy, I say that like I'm not but I am. I think it is an emotional wellbeing… Enjoying the little things, despite everything I've got going on, there are some good things in my life. *Aroha*

One of the biggest decisions which all parents discussed was the balance their family made between employment and time (Beighton & Wills, 2017). For all parents, deciding to work was primarily a choice between having more time or money. However, for many there was an added layer contributing to their decision to work, as they found meaning and purpose in their jobs. For example, these parents valued helping others, successfully completing work related tasks, interacting with others outside of their family and friend community, and contributing to society. For four parents who chose to continue formal employment alongside caring for their child, they viewed work as self-care and "timeout" from caregiving demands. By going to work, these parents experienced a mental break from family responsibilities, a sense of control in one aspect of their lives, reconnection with their own identity, and participation in something they felt was meaningful. Although some of these parents felt guilt and added stress in balancing their time between work and family, they felt justified to continue working due to financial benefits, improved emotional wellbeing, and better family functioning:

> They probably don't realise that I guess I reconnect with myself while I'm at work, and my own mental therapy is at work. To me, getting a job done makes me feel good, as good as just taking time for yourself at home. *Mark*

> I do have a bit of guilt about being a working parent and a solo parent because I feel that she's not my whole world and my whole life is not set up just for her. I've still got other responsibilities and other things going on in my life, and sometimes I feel a bit guilty about that… But part of the reason why I keep my job is so that I can give her the life that she's never had, and I need finance to do that, so I need to keep my job… I also strongly believe that it's a community that raises a child, and I have a really good support network and wouldn't want to do it on my own. *Allie*

Six participants chose to become a stay-at-home parent due to having a child with disabilities, although many of these parents still found meaning and purpose in working. These parents felt unable to return to work due to caregiving demands; however, they discussed the importance of being able to find equivalent meaning and purpose in everyday life which was adapted to their current situation and family needs. Three parents accomplished this through viewing caregiving for their child as a full-time job and turning "disability" into a passion. These parents gained a sense of accomplishment in educating themselves about disability, networking with disability services, and advocating for other parents with similar experiences:

> It was always a choice. Do you want more money, or do you want more time? And I just selected more time. And more money would be nice as well, but I actually think time is more important. *Rachael*

> My new drive is obviously the kids… Everything has always been about the kids and a lot of my free time is spent information gathering and getting involved with certain things, to better my knowledge to prepare myself for what's coming in the years ahead. *Tamati*

> I think to an extent living for somebody else other than yourself is ultimately the most rewarding thing. Not that I was entirely living for myself before, but it was a different kind of situation, you did things with your own stuff in mind whereas now I've got somebody else to think about. And my purpose has changed from being so self-serving to making sure that she is happy and that her life is good. So, I do get a sense of purpose from that instead of thinking about myself. *Allie*

Participants who chose not to work in paid employment discussed the importance of finding ways to receive feedback and appreciation from others in order to maintain a sense of purpose and accomplishment. They suggested that feedback should come from their partner relationship, from friends and family, or through connecting with other parents with shared experiences. Receiving feedback and appreciation helped reduce parents' feelings of isolation and resentment, strengthen their relationships, and reconnect with their community. One stay-at-home parent also reflected on the importance of giving feedback and appreciation to their partner who was working, in order to validate their role as a provider in the family and negate their possible feelings of guilt and doubt in being separated from the family:

> It's really important to get some feedback when you're a stay-at-home mum and unfortunately a lot of that falls on your partner, for those who have them. I'd hate to think for those who don't, how hard that must be. And when there is no gratitude from your partner, you resent all that. Because everyone says work is so hard. Being a stay-at-home mum is hard! Most of my friends have gone back to work, not because they had to financially but because they needed to be able to think about

> something else that wasn't child related. They needed to have adult conversation and they needed feedback from the rest of the world. *Kate*

> She always had a bit of self-regret in the sense that she went to work, she was the mother, the mother wasn't at home, it was not the role that mothers should be playing… One day I caught her and she was having a bit of a cry on the couch. I asked her if she was alright and then she broke down and pretty much told me how she was feeling… She couldn't see what she was contributing to the family and the kids. And I pretty much turned her around and told her "don't you ever second doubt yourself". I said, "without you doing what you do I can't do what I need to do… you're the most important part of the plan… because if you're not working and you're not out there providing, that means I've got to go out and do it. *Tamati*

In sum, finding meaning and purpose in life, whether it be from altruistically helping others, caring for their child, going to work or otherwise, appears to be critical for parents' self-care and wellbeing when raising a child with disabilities (Beighton & Wills, 2017; Lee et al., 2015). Following their child's diagnosis, parents may experience a change in what they find meaningful in everyday life, possibly through posttraumatic growth regarding their trauma or grief, or they may be required to adapt their goals and find meaning through new or alternative means due to changed family demands and responsibilities (Beighton & Wills, 2017; Lee et al., 2015; Zhang et al., 2015).

Setting Goals and Making Plans

Having future goals (along with realistic plans for how to attain these goals) is central to individuals maintaining wellbeing, constructing hope, sustaining motivation to accomplish tasks, and coping more effectively with negative life events (Ogston, Mackintosh & Myers, 2011; Shenaar-Golan, 2016). Consistent with previous studies, eight participants discussed setting realistic and achievable goals for their family, their children and themselves as an effective self-care strategy. Through having clear goals, parents felt able to have a more positive and constructive outlook, build hope for their family, and create a narrative to work towards (Ogston et al, 2011; Shenaar-Golan, 2016). For four parents, it was particularly difficult to envision a future for their child; this led to them feeling hopeless, distressed and avoidant when creating future plans for their child. However, six parents held strong views on what they wanted their child to achieve in life and had put goals in place to plan for this. For these six parents, having goals and future plans for their child was an important process to instil hope in their family and to find meaning and purpose within their own lives:

> It’s more about my vision… I just have this thing of getting my kids to adulthood, and my son being able to participate in the community as a contributing member of society, having his own decisions and choices that he can make himself. My youngest one, I hope to see him have his own independence. We will still always be involved in his life as it’s just the way he is, but at the end of the day I also see it being essential not having that responsibility. *Tamati*

> Everyone likes light at the end of the tunnel. So, if you don’t have a goal of where you’re going, if you just feel it’s a day to day thing - and some days it is, some days it wears - but if you’ve got a place that you’re going to, I think that helps. *Anna*

Parents discussed the importance of having conversations with their children, discussing their child’s wants and aspirations as a family, networking with other parents about their goals and plans regarding their own families, and educating themselves about what future options are available for their child in order to develop realistic and achievable goals for their child. Three parents also discussed implementing a plan regarding their aspirations and what they want their relationships, family and life to look like in the future. Parents achieved these plans by breaking down their goals into steps, chunking their plans into various stages, and looking at specific time periods such as “the next five years” (Bexelius, Carlberg & Lowing, 2018):

> Before it felt overwhelming, the idea of her finishing school and what then… But now I feel like there's some hope because I know that there are options out there, and I also know that I’ve been down one path and then realised I don’t want to keep going down that path. So, I’ve got an idea in my head in what I would like my future and her future to look like. And I think networking, meeting with people who know has helped… So, educating yourself but have hope. *Aroha*

Similar to previous findings, seven parents reflected on the significant impact their child had in preventing or changing their own original goals, aspirations and life plans (Neff & Faso, 2015; Wong, Mak & Liao, 2016). Changes in goals and plans typically centred on areas of travel, employment, studying, relationships, financial, and residential living. For most of these parents, their child became central to most life decisions and their priorities shifted towards focusing on maintaining their child's happiness and wellbeing, even at the expense of their own. For five parents, the shift towards their child becoming their main priority aligned strongly with their values of caring for others. This led to these parents experiencing happiness and enhanced wellbeing through seeing their child succeed, despite not being able to accomplish previously held goals and aspirations:

> I think most of the decisions that I make now are in respect of her, and are for her wellbeing and her happiness, and I do get joy from that. It definitely does help me feel like this is all worth it and I haven't gone crazy and made a stupid impulsive decision [to adopt] that I'm going to regret. I have no regrets about my decision but there are certainly some testing times. But ultimately, it's so rewarding I wouldn't change it. And I guess part of that keeps me going as well, because I get enjoyment from seeing her happy, that sustains me to carry on even when times are hard. *Allie*

A few participants discussed experiencing frustration or disappointment related to be unable to pursue previously held goals or ambitions. These parents managed their disappointment by acknowledging their negative feelings and grief, talking with others within their supportive community, engaging in distraction techniques, and seeking more formal support (such as counselling) when required to help process and accept that certain goals were unattainable. Following acceptance, participants discussed a process of goal re-engagement to modify or develop new goals and future plans which are achievable within their family context (Neff & Faso, 2015). Having alternative goals and plans helped many parents balance feelings of disappointment, grief and frustration with newly constructed hope, anticipation and wellbeing:

> I think before I had my son I probably looked at doing the rest of my degree and I looked at doing all sorts of other things, and everything got put on hold. I went part-time because there is no way I would have managed a full-time job with a special need's child. But the understanding, I suppose, of special needs and other kids' parents' perspectives - It totally opens you up to a different world. *Debra*

Overall, having realistic goals and plans for the future is central to instilling hope and maintaining motivation for parents when raising a child with disabilities. Parents may need to process difficult emotions and grief for previously held goals and aspirations which may need to change due to having a child with special needs. Newly developed goals should focus not just on parents’ own aspirations, but aspirations for their child and family as well.

Looking for Positives

Positive reappraisal is a coping approach which incorporates cognitive strategies for reframing a situation in order to see it in more positive light (Gupta & Singhal, 2004). This approach enables an individual to reframe a difficult situation or event more positively by encouraging them to focus on the values of their efforts, often helping them to sustain their motivation over longer periods of time (Gupta & Singhal, 2004; Beighton & Wills, 2017). Further, having a positive outlook and affect have been shown to promote creativity and flexibility, enhance processing of information and problem-solving, and help offset adverse physiological effects of stress (Gupta & Singhal, 2004; Beighton & Wills, 2017; Martin, Clyne, Pearce & Turner, 2019). Aligned with existing research, nearly all parents (10 participants) from the current study discussed using positive reappraisal and gratitude as effective self-care strategies to shift out of a negative outlook and balance their perspectives of raising a child with disabilities.

Similar to previous studies, methods parents used to facilitate positive reappraisal included purposefully reflecting on and being grateful for what their family has, the love they have for their child, and the effort they are putting in to caring for their child and family (Beighton & Wills, 2017; Hastings & Taunt, 2002). Other methods parents used to facilitate positive reappraisal included purposefully reflecting on their child’s development and progress so far, more difficult experiences their family got through, and what tools and internal strengths they drew from to survive those more difficult times (Hastings & Taunt, 2002). Through reflecting on positive aspects of their lives that are going well, this helped parents gain a sense of control and self-awareness of their achievements in everyday life as a parent (Gupta & Singhal, 2004). Having self-awareness of their achievements and efforts, along with a sense of control, helped parents feel empowered to confront and challenge more difficult aspects of their current situation and move towards greater overall wellbeing and family functioning (Gupta & Singhal, 2004; Beighton & Wills, 2017):

> I kind of give myself a mental pat on the back. If they’ve got to school, they’re not fighting, they’ve both got smiles and they’ve had a kiss goodbye, until 3 o’clock

> unless the school rings me beforehand, yeah, one day down. Another day down. *Taylar*

> I think when everything is a bit chaotic, if there is at least one thing in your life that is okay, like I'm feeling good about myself. At least it's one thing that I can feel on top of when everything else is mad. *Allie*

For these parents, being grateful and looking for positives typically began by purposefully making a choice to approach every day from that perspective. In order to think themselves into a positive frame of mind each day, these participants actively chose to find something to be grateful for, they engaged in self-care activities, and they purposefully noticed strengths in their whole family (Gupta & Singhal, 2004; Beighton & Wills, 2017). Parents discussed differing ways of incorporating gratitude, including reflecting on people who are subjectively worse off than their family, comparing oneself to others dealing with challenging situations, being thankful for aspects which are going well in their lives, and focusing on their family's strengths and how their experiences have had a positive effect on others (Beighton & Wills, 2017). Further, having a strengths-based approach was emphasised by three parents as a valuable tool to help shift their family's perspective to one of hope and empowerment, making it easier for the family to be positive and grateful (Martin et al., 2019):

> I think perspective is everything. And if you can have an attitude of gratitude regardless… there's always something to be grateful for and I have so much to be thankful for and I have such a good life. And I think when I look at my daughter and the life she's had, I feel like I can't really complain about anything… I think finding something to be grateful for even when it's hard just kind of brings you back to reality... There is always somebody who has got it worse off than you… I've got such a good life really and I've got so much to be thankful for and that just keeps me down to earth. *Allie*

> I think I'm realistic as well. There are things that we want. Everyone wants things that they can't have, or they need something that they haven't got, or whatever. I just look at our life overall sometimes... It makes me feel better because I think, well I've got a better life than a lot of people. *Rachael*

Gupta and Singhal (2004) reasoned that when parents use positive reappraisal as a coping strategy, this is not done in a way to discredit genuine difficulties they face or indicate that they are in a state of denial. Rather, it shows how parents and families are able to successfully weave their lives around their achievements versus the hardships they face in everyday life (Gupta & Singhal, 2004). The current study aligned with this argument, as two parents drew attention to the balance which needed to occur between positive reappraisal and the acknowledgment that some aspects of caring for a child with disabilities is hard and that they as parents may not always cope:

> Gratitude is a really big thing and I think it's an overlooked tool... Kiwis aren't very good about that because it's that whole harden up, drink some concrete, get over it, you know… And that's that bit that's actually quite detrimental to people's wellbeing, is if you're always told to just get over it and that you shouldn't be [struggling]. Whereas being able to take stock and know that some things are hard and that you're not coping very well, but being thankful for what is going well, that's a huge, huge thing. So yeah definitely being grateful is a big part of it for sure. *Anna*

Anna's reference to commonly held cultural expectations and societal attitudes in NZ to 'harden up' and be 'tough' also highlights how an individual's macrosystem has a direct impact on individuals' lives and coping, and potentially their mental wellbeing (Weiss et al., 2014; Whiting et al., 2019).

Prosocial humour styles are associated with improved family communication, adjustment and satisfaction in families of children with disabilities, along with reduced hopelessness for parents (Rieger & McGrail, 2015; Tavakolizadeh & Ghochani, 2017). Similar to these findings, three participants discussed using humour as a helpful strategy to shift their perspective of difficult situations being distressing or frustrating toward them feeling capable of tolerating the situation and possibly even enjoying it. These parents believed humour helped them to reconcile their family relationships and reduce the apparent severity of the "problem" or difficult situation they faced. For example, one parent discussed how using humour and positive reappraisal in certain situations helped them to externalise the "problem" behaviour from their child (Saini et al., 2015). This allowed them to maintain a strong relationship with their child, focus on solving the problem at hand, and later reflect on the difficult situation more favourably:

> It’s probably about trying to look for that positive. You do have to see, even in the worst situations - like some of the behaviours that my son has exhibited in the past have been really almost soul destroying because they are things that are just so antisocial, so terrible you think “oh, no one else understands that”. But we try and laugh about it, and we try and look for that positive and, you know, “wouldn’t be hilarious if somebody else walked in now and saw that”, all that kind of stuff. *Anna*

In sum, positive reappraisal, gratitude and humour are effective self-care strategies for parents to help positively reframe difficult situation and negative emotions experienced when raising a child with special needs. These strategies may be helpful to promote cognitive flexibility and improve problem-solving for parents, as well as help offset physiological effects of stress.

Summary

Theme Three of Study One focused on parents incorporating values and meaning into their everyday lives, developing goals for the future, and using positive reappraisal to help promote wellbeing and instil hope for them and their families. Techniques, often endorsed by positive psychology, of altruism, externalising, humour, and gratitude were identified as ways which helped parents move through grief and trauma to a place of living in line with their new values and perspectives. The next chapter presents Theme Four, which involves self-care experiences and strategies that incorporate the element of time. Parents organised time in ways to promote their wellbeing by using routines, finding time for “mental breaks”, identifying early warning signs for their own limits ahead of time, and setting aside time to process difficult emotions such as grief and guilt.

CHAPTER THIRTEEN:

Theme Four: Time

Following their child’s diagnosis, parents often experience a transition fraught with difficult emotions and grief as they move towards acceptance of their child’s disability and their new caregiver role (Brown, 2013; Fernandez-Alcantara et al., 2015; Fernandez-Alcantara et al., 2016). The transition parents are required to journey through often requires time, and this process typically occurs in a non-linear or recurrent manner due to various challenges they face as their family move through different life stages (Fernandez-Alcantara et al., 2016). Therefore, this chapter focuses on parents’ experiences and self-care strategies at a chrono-level, incorporating the element of time (Bronfenbrenner, 1977; Weiss et al., 2014). The following strategies discuss how parents use time to enhance their wellbeing by implementing routines, making space for “mental breaks”, processing difficult emotions such as grief and guilt, and identifying early warning signs to prevent them reaching their limits.

Family Routines

Predictable family routines have been shown to help children with disabilities thrive by improving their emotion regulation, allowing them to better adjust to difficult transitions and maintain their wellbeing (Davis et al., 2017; Young-Southward, Cooper & Philo, 2017). Further, functional routines may lead to greater family satisfaction and improved health and wellbeing for parents as well (Jones, Hill & Miller, 2018; McConnell, Savage, Breitkreuz & Sobsey, 2016). Reflective of existing research, seven participants from the current study discussed the benefit of creating functional routines which incorporated varying self, family and caregiving demands as an effective self-care strategy. Through being organised and implementing successful routines, this allowed these parents to be efficient with their time and accomplish varying competing everyday demands. Routines also helped parents to remember to complete certain tasks required of them, particularly during busy and stressful periods. Through implementing effective routines, this often freed up more time for parents to relax and find enjoyment in everyday life, engage in self-care activities, and dedicate quality time to their family:

> If you can pinch time [by being organised], that’s how you gather time later to do things. *Tamati*

> I do [have a routine], it's a chaotic one, but it's a routine, nonetheless. It does help… You just know what needs to be done by a certain time. That you know where you have to be, and when you have to be there, that's what helps for me. *Aroha*

Participants also discussed that having an effective routine was helpful for the whole family; other family members tended to become more aware of their role and responsibilities, the family environment was less hectic and stressed, families operated more efficiently and cohesively, and their children thrived in a more structured environment (Davis et al., 2017; Young-Southward et al., 2017). However, parents emphasised a balance which needed to occur between having a structured routine and allowing their family the flexibility to "go with the flow" without their routine becoming fixed or ritualised. Through allowing flexibility with their routines, parents were able to maintain resilience and adaptability within the family to cope with change and unpredictable events. Being organised and having a functional routine also provided many of these parents the energy to better cope with occasional unpredictable and stressful life events:

> I think most families who have a child like mine would say that routine is important, but without it becoming ritualised so that then you can't do anything else around it. And that's the bit that we always struggle with, there's always that balance of giving my son enough routine that he's happy, but without him ruling everything we do. Because things change and sometimes you have to go somewhere else, and we have to do something different. *Anna*

> I think you've got to have a structured routine, it's vital. I mean but at the same time it's not so vital that you can't have a day off from it and be like "stuff the housework, I'm going to have a lazy day and I'm not going to do anything, I'm just going to lock myself up and read a book all day and stay in bed". That is fine, but it can't be two days in a row. *Tamati*

Similar to previous findings, all parents discussed difficulties they experienced in balancing time between their family and caregiving demands, family and friend relationships, other everyday demands, employment, and time for their own self-care (Gau et al., 2012; Higgins et al., 2005). Due to the difficulty in balancing competing demands, all parents discussed frequently neglecting their own self-care and viewing their own wellbeing as lowest priority.

Eight participants discussed frustrations they experienced with having to adapt themselves to their child’s routine, particularly at the expense of their own time and needs (Gau et al., 2012; Higgins et al., 2005). For these parents, they described a sense of feeling “trapped” by their child’s disability demands. Many of these parents described an added layer of restriction in that they felt deep guilt and shame in spending time on themselves as part of their everyday routine, with four parents stating they put their child before themselves even during their free time. For these parents, any opportunities they had to focus on their own self-care was instead spent on educating themselves about their child’s disability, completing chores around the home, or networking within the disability community:

> Truthfully, there is no particular time for myself. I get two and a half hours a week where I take my son off to play group, and the little one and I come here and do a parenting course to work out how I can be a better mother to my 11-year-old. *Taylar*

> I don’t know about other mothers, but I feel that I’m living a one and a half-life. I’m living my own life, what I can, and then my son’s half-life as well. *Colette*

The strategies parents used to start prioritising their own self-care and wellbeing included reflecting on the positive effects of self-care when they successfully balanced time to meet their own wellbeing needs (Gupta & Singhal, 2004). This somewhat aligned with existing research which argues that parents’ routines are more sustainable if it is meaningful for everyone and weaves together varied family interests, goals and needs (McConnell et al., 2016). The positive effects of self-care parents discussed included feeling healthier both mentally and physically, feeling more positive and hopeful for the future, and being more clear-headed and patient with others. Parents also discussed feeling less tired, worried and stressed, and happier and more relaxed. Five parents described the flow-on effect from engaging in self-care strategies, including that they had improved family relationships and they were better equipped to cope with more difficult periods in their life:

> I do think that without looking after yourself and keeping your frame of mind at least reasonably healthy, you can't see those good things… Without being at a reasonable level of good mental and physical health, you're just not going to see it… I think without a positive frame of mind, or even semi-positive, when you're in the deepest, darkest bonds of depression, you fail to see anything that can give you hope. *Kate*

Parents also started prioritising their own self-care and wellbeing by using their child as motivation to be healthy. Through using their child as motivation, parents discussed needing to prioritise and monitor their own health and wellbeing in order to maintain their ability to effectively care for their child and carry out caregiving demands. Through finding motivation to be healthy outside of themselves, parents discussed how they were more willing and able to ensure that their own fundamental needs were being met through exercise, eating well, sleep, and maintaining their physical health. Parents were also more willing and able to regularly engage in enjoyable activities, such as catching up with friends, allowing time to "do nothing", and "treating" themselves such as going to a café or getting a massage:

> If you're constantly giving, giving, giving, eventually there's not going to be anything left. So, if you have that time for yourself where you're enriching yourself in one way or the other, of course you're going to be a better mother… If you don't feed yourself, you can't be a good mother. I firmly believe that if you're not good, they're not good. I think more and more I realize that we actually come first, not the kids. *Kate*

> It was the first time that I had been to physio in my life, and if it had of been just me I probably would have just continued on and stuck it out. But yeah, because I'm finding it hard to just help her into her wheelchair and stuff, I had to think "get yourself to a doctor". *Aroha*

> Self-care is definitely important obviously because I think without self-care, that's why there's such a high rate of marriage break-ups, from - well I think from suicide right through. The statistics have been really high around disability for that reason, because you can only pour from a full jug, can't you? So, if you're empty or if you feel empty then you're not giving anyone the best. And that's quite hard because it

> does become about your child so much that you forget that actually you need time. *Anna*

Seven parents deliberately counteracted the guilt and shame experienced from putting themselves first by purposefully scheduling time in their weekly routines for their own needs and self-care. Scheduled time for these parents typically occurred early morning before their child was awake, during the day when their child was in school or with a respite carer, and in the evenings once their child was in bed. These parents also discussed counteracting guilt and shame by lowering expectations they put on themselves to complete chores at home, by participating in self-care activities which allow them to mentally "switch off", and by initially attaching self-care to other responsibilities until it built into a habit in their everyday routine:

> That's another reason why I get up at five because that's the only time that I really get 'me time', quiet time, no radio, no nothing on. It's just lovely and peaceful and that's from 5 till 7 now. *Valery*

> Don't feel ashamed about spending time on yourself. If you are one of the people that do struggle, attach it to something, like I said everyone has a shopping day. So, if you go into town why not make it a big deal and meet your partner in town for lunch or have a coffee with a friend. Start off small. *Tamati*

Therefore, family routines which also incorporate parents' own wants and needs help not only children with special needs thrive, but their parents as well. Successfully implementing routines may lead to improved wellbeing for parents, as well as greater family functioning and satisfaction overall.

Finding "Mental Breaks"

Reflective of previous findings which argue that parents as informal caregivers are required to be 'on-call' at all times for their child's needs, nine participants discussed the inability they felt to mentally "switch off" from caring for their child at all times (Townsend, 2018). Seven parents attributed the inability to switch off directly to their caregiving duties, with ongoing demands including regularly needing to dispense medications for their child throughout the day or constantly supervising their child for any seizures or any medical concerns (Townsend, 2018). Many of these parents discussed how even when their child was being cared for by other responsible adults, they often still felt unable to gain a "mental break" from worrying about their child and whether they were receiving adequate care. Strategies parents used to help switch off when their child was being cared for by others included starting small and building trust in others over time that they were capable of caring for their child, and engaging in enjoyable and distracting activities when away from their child to reduce worry and keep their mind occupied:

> A day in the life of working with my son is – well, he's six years old with the physical needs of a baby, so every single physical thing required we have to do for him. So, a normal day is pretty physically strenuous, and emotionally you're constantly having to fight fears for him. *Kate*

> I need to be able to trust others because I won't be here forever for my son, and he needs his own life… So, we need to find people who we trust can do at least to a certain extent the care that I think he should have. *Colette*

Also reflective of previous findings, five participants described the near constant worries they have about the future for their child which prevented them from getting a mental break in everyday life (Pryce, Tweed, Hilton & Priest, 2017). Parents discussed worrying about their child's transition to adulthood, uncertainty about their child's future abilities, how they will continue to meet their child's needs as they age, and what will happen when they are no longer there for their child due to illness, injury or death (Pryce et al., 2017):

> It's trying to find a mental break, not just a physical break and I think that's the problem that most people have is realizing that you have to have a mental break where he's taken care of and you aren't thinking about him, and that's been the struggle. Thinking about him is just as exhausting and hard as physically being there with him… There's barely a day that goes by where you don't for even a second be terrified that he will never have any pleasure out of his life. *Kate*

> No one's ever known what he's going to be like when he's 18, 24 or 34 or you know, so we haven't really known how to prepare for it. If you don't know where you want to go, you don't know how to get there. *Mark*

Strategies parents discussed which helped them achieve a mental break from rumination, worry and anxiety about the unpredictability of raising their child included them first acknowledging and accepting their worries, along with the sacrifices they as parents have made (Pryce et al., 2017; Reid, Gill, Gore & Brady, 2016). Having acknowledged their worries, parents felt more able and willing to work on a plan for their child's future for when they are no longer able to care for their child (Ogston et al, 2011; Shenaar-Golan, 2016). For many parents, having a long-term plan for their child gave them a sense of assurance and comfort which contributed to their wellbeing. Parents also described coping with worries about their child and getting a mental break by reaching out for support from others, accessing more formal psychosocial support and therapy when needed, and engaging in mindfulness and grounding exercises (Bazzano et al., 2015; Reid et al., 2016):

> I was looking at it like, "OK if I'm taken out, how are the kids going to cope?" They are so dependent on me and my parents are in their seventies now. Anyway, I've got the assurance that my sister would take all three and she's raised three boys and she's a nurse and she has some understanding… I had to have a back-up plan… It's a huge part that plays in the back of most parents' minds, especially when you've got children that just need you so much. *Taylar*

> Yeah, I've definitely used mindfulness exercises when things have got really, really bad… they helped like band-aid type help, you know. Just before you start thinking those really ugly thoughts, try and think of what you can see and hear. It sounds so ridiculous… but it's distracting yourself from thinking horrible thoughts. *Kate*

Overall, although parents find it challenging to mentally switch off from their caregiving role, acknowledging and validating their feelings (discussed more below), building trust in others to care for their child, engaging in enjoyable and distracting activities to keep their mind occupied, and having a long-term plan for their child's future are helpful ways to manage their worries.

Dealing with Difficult Feelings

To incorporate the full experience of wellbeing for parents of children with disabilities, acknowledgement and consideration of parents' difficult emotions needs to be included (Brown, 2013). Existing literature highlights that many parents experience significant grief, loss, uncertainty, resentment and chronic sorrow both in the context of their child's diagnosis and recurrently as their child moves through various life stages, alongside experiencing periods of wellbeing and positive emotions (Brown, 2013; Coughlin & Sethares, 2017; Fernandez-Alcantara et al., 2015; Fernandez-Alcantara et al., 2016; Gilson et al., 2018). Similar to previous findings, all participants in the current study discussed experiencing difficult emotions related to caring for their child's disability, primarily with reactions of resentment, grief, hopelessness, and being overwhelmed.

Most parents (nine participants) discussed experiencing a period of strong grief and guilt in relation to receiving their child's diagnosis (Brown, 2013; Fernandez-Alcantara et al., 2015; Fernandez-Alcantara et al., 2016). Their reactions typically encompassed grief and guilt for their child in having to live with a disability, grief for their whole family in having to accept change and potential discrimination, and grief and guilt for themselves in "causing" the disability and adapting to their new caregiving role. Additionally, many parents discussed major sacrifice and loss related to receiving the disability diagnosis, including unemployment, changing relationships, and time and financial expenses in engaging with disability services (Fernandez-Alcantara et al., 2015; Fernandez-Alcantara et al., 2016):

> There is nothing for parents like when diagnosis happens… it is nearly the worst-case scenario because you want your child to be normal. Whether it's far away from normal or close to normal, they are not normal. *Colette*

When asked what helped parents work through the grief and guilt associated with receiving a diagnosis, these nine participants discussed that it was a case of allowing themselves time and space to "feel" and process all the varying emotions and reactions associated with grief as they occurred (Fernandez-Alcantara et al., 2016):

> So, I guess it's that as well, it's being open and allowing people that time. Because it is horrible, it's a grieving process when you're first diagnosed and nothing's going to change that. But then it can be positive. It's just you need to have the right tools to do it. *Anna*

> Time. I do think that I accept it now, but it's only been maybe since a couple of years ago. It takes a long time… I was told that it takes at least 12 years to get over [the diagnosis], but I needed longer. *Colette*

For most of these participants the process of acceptance and healing occurred naturally with the passage of time (Fernandez-Alcantara et al., 2016). However, three parents discussed added barriers from NZ’s mainstream culture (in relation to attitudes to adversity) requiring them to ‘toughen up’ and ‘get on with it’. These widely held cultural and societal attitudes and beliefs at a macro-level were believed to be unhelpful for these parents in prolonging their process of grief and acceptance:

> Yeah, I’m an honest person. But that’s hard here in NZ because when you say in Holland, “Hi, how are you?”, people can say, “Oh, I’ve had a bad day today”. Here you will hardly ever hear that, just “I’m good, thank you.”... I think English people have difficulty with letting themselves go. I find also that the majority of people who have an English ancestry are a bit distant and it might make it harder for them, I don’t know. *Colette*

Nevertheless, being able to recognize and make room for difficult emotions was an important first step for these parents in permitting themselves time to heal and move towards wellbeing. For three parents, acknowledging their emotion meant allowing themselves space to have a “meltdown” and cry as much as they could, which they found helpful and cathartic to do. After being able to recognise and allow time for emotions, participants discussed helpful strategies they used to problem-solve, reframe and distract themselves from the cause of their grief or loss (linked with finding mental breaks). These strategies align with evidenced-based strategies to facilitate effective coping for chronic sorrow for parents with children with chronic health conditions and disabilities: acceptance of the process of grieving; emotional validation; and engaging in stress-relieving practices and distraction (Coughlin & Sethares, 2017; Gordon, 2009)

Four participants emphasised the importance of working through the problems causing their negative feelings, finding solutions, and talking to someone they trust to help plan for and implement varying solutions to their problems (Cuzzocrea et al., 2016; Lindo et al., 2016; Milshtein et al., 2010). Reaching out to others in their community and seeking more formal psychosocial support (linked with Theme Two) when needed was seen by all eleven participants as being helpful not only for problem-solving, but for instilling hope and working through negative emotions (Cuzzocrea et al., 2016; Lindo et al., 2016; Milshtein et al., 2010):

> Well, it is a bit like grief in a way, with certain stages I think. So normally, I would cry. And then I am quite good at finding solutions… working through the problem and talking to somebody… and trying to work a way around things. Just talking it out sometimes helps. And getting out and doing something. Or having a glass of wine and just trying to chill and relax. *Rachael*

> It certainly helped having good therapists and good specialists, people who have seen this all the time and can give you hope. And once you know that there's a possibility, you start looking for [hope] more, and that could also go really badly, but definitely having positive comments from outside of yourself helps to see things. But I actually think that on the whole we've seen things long before anyone else has. We are the world's experts on my son. So yeah, I think it's something that has to come with time and as long as you're not a hundred percent clouded by pain, you can see it. *Kate*

Distraction was another strategy five parents found helpful to use when experiencing negative feelings to give themselves time to process the emotion while still being able to maintain an enjoyable and functioning life. For these parents, distraction occurred through participating in pleasurable or relaxing activities (also seen as behavioural activation). Two participants emphasised how crucial it was to maintain their sense of functioning when experiencing negative emotions through purposeful distraction such as sustaining relationships, maintaining a sense of routine in everyday life, keeping engaged with meaningful activities, and upholding their responsibilities:

> The best thing when I am upset is if I have some appointment or something booked, and I have to go and be a friend. I never cancel. I sometimes think, "Oh, I should just stay home, I'm miserable. I'll just stay home", but I always force myself to go because I know that afterwards I will always feel better. I'm going to feel better after I have been out of the house and I'm just talking to a friend, and we are not talking about why I'm upset, like we are talking about other stuff. That actually when I come home I'm much brighter and I'm in a heaps better mood. *Rachael*

> My son really wanted to go for a walk, but I really couldn't be bothered. But once I got out there I thought this was actually really good, like you just walk, and he wanders along and talks about trees and everything. It's actually really therapeutic.

> And when I have felt those negative times, it's been quite good to be able to just go out and walk. *Debra*

The final strategy parents discussed was the ability to reframe their difficult emotions or the situations which led to having these emotions (Gupta & Singhal, 2004; Beighton & Wills, 2017). Ways parents achieved this included being able to separate or externalise “the disability” from their child and purposefully looking for positives in the situation (linked with Theme Three). Also, parents discussed finding ways to spend pleasurable quality time with their family members in order to provide an alternative, positive narrative (Gupta & Singhal, 2004). Through strategies of allowing time, problem-solving, positive distraction, seeking psychosocial support, looking for positives and reframing the situation (all linked with the previous three themes), parents felt able to process their negative or undesirable emotions, endure more difficult times, and build hope for the future:

> There is a lot of healing that still needs to go on and I feel like it’s really happening, healing between us parents as well, and how we feel about our son. It’s been coming bit by bit putting those pieces together. We feel differently about him and separate him from how he was when he was two… There’s our son’s disability and then there’s our son, and I’ve always said that I love our son more than anything in the world, but his disability can go and fuck itself. I hate his disability. And I guess what I hate about it is when it impinges on my son, and when it overshadows him. And I don’t know if that’s healthy or unhealthy to see it as two separate things but…I think it’s good because we need to. We have seen that there is this beautiful human being under that disability and it’s slowly emerging more than the disability – I mean the disability is still right in your face, but in my heart, he is overtaking the disability. *Kate*

In sum, many parents experience difficult emotions at various stages while raising a child with HND, particularly early on following their child’s diagnosis. Often acknowledging their emotions and allowing time to sit with and process their grief helps parents to work through difficult emotions. Other strategies which may help include behavioural activation, problem-solving and finding solutions, positive reframing, seeking social support, and distraction as discussed in the previous three themes.

Identifying Limits

Although no apparent literature exists specific to parents of children with disabilities, identification of early warning signs of not coping is a commonly used therapeutic technique to prevent escalation of distress (Linehan, 1993; Padesky & Greenberger, 1995). Being able to identify their early warning signs allows individuals to become more aware of their limits and potential risk situations ahead of time, as well as implement plans and self-management strategies to prevent an exacerbation of distress or negative emotions (Linehan, 1993; Padesky & Greenberger, 1995; Randal et al., 2009). Eight participants in the current study discussed being able to identify their warning signs for distress (or limits as parents and caregivers) as an important preventative strategy to their self-care. Through being aware of their limits, these parents discussed being able to proactively act on their distress by engaging in helpful strategies (Randal et al., 2009). Strategies parents found helpful included seeking support, removing themselves from the situation, and engaging in mindfulness, grounding and enjoyable activities (Linehan, 1993; Padesky & Greenberger, 1995; Segal, Williams, & Teasdale, 2002):

> Well I try to block it out… and try and focus on the moment. I try and do my mindfulness exercises and five things I can hear and see, because you've just got to get on with it and get the day done… I find the mindfulness actually does help even though it doesn't solve anything. And that's the thing, it's learning to solve this second and worry about 10 years some other time. Start planning for that when you're in the mode for planning for that. *Kate*

Parents were able to identify when they were reaching their limit by noticing their warning signs, which typically included having a short temper and limited patience with their children, feeling "grumpy" and upset, crying more easily and more frequently, experiencing more physical tension, feeling low and depressed, and experiencing a loss of hope and direction (Randal et al., 2009). Being able to identify their warning signs often required parents to be mindful and take a figurative "step back" in order to become aware of their own individual idiosyncrasies and triggers (Segal et al., 2002):

> I think physically there are signs, like sometimes I can feel my jaw clench and I can sort of feel my body tense. When I do that, I know enough to just take some deep

> breaths, so I’ve learned some tools over the years, but they don’t always work. *Aroha*

> [My warning sign is] a sigh, a deep sigh, which I try to make sure that my son will never hear. So, it’s an inside sigh. *Colette*

The clearer parents were in understanding what situations resulted in them reaching their limits, the more willing and able they were to put in place helpful self-care strategies as part of a preventative approach to maintain their wellbeing. As well as being more motivated to put self-care strategies in place, these parents were also able to put helpful strategies in place earlier and more effectively (Randal et al., 2009). For one parent, their primary trigger was the inability for their child to communicate their needs and preferences, leading to the parent’s own distress. Other triggers discussed by parents included having a lack of sleep, experiencing tension in family relationships, needing to discipline their child’s behaviour, having a build-up of multiple stressors, and feeling a lack of time to accomplish all family and caregiving demands (Randal et al., 2009).

As already discussed in previous chapters, helpful self-care strategies parents used to prevent reaching their limits included meeting their own needs such as getting enough sleep and eating well, seeking psychosocial support, and making time for oneself. Parents also stated participating in enjoyable activities, having a clear routine, and having goals and future plans were helpful preventative strategies. Coping strategies participants used when they were at their limit or “breaking point” included positive reappraisal and engaging in deep breathing and mindfulness practices. Parents also suggested practicing self-compassionate and positive self-talk, asking others for help, lowering their high standards or expectations to make them more realistic, and positive distraction:

> There are times where I kind of zone out and see what’s going on but it’s not major. I’m not going to jump into every little thing. The other thing is if I can feel it, I stop and drop. The kids know what that is. That’s when my anger really gets to the point where I feel like I just want to punch a wall I stop and do 20 push-ups… It’s great because for one it tires me out. But it’s what I’m trying to teach the kids… I wanted to do something that the kids could see that mum stresses out sometimes too. *Taylar*

> Ride the waves. Sometimes it’s good, sometimes it’s scary as, and I think you have to trust... you’ve got to trust that surfboard and hope it’s going to get you where you want. And for me, it’s not looking too far ahead because I think if you look too far ahead it’s too easy to get overwhelmed... And sometimes you have to just let things go and don’t even bother with it, especially with behaviours. Sometimes with behaviours you’ve just got to let it go, and it’s not always easy, and it doesn’t look good for others looking in from the outside at times. But it’s far easier to let some behaviours just go and ignore it rather than make a big deal of it. *Valery*

Therefore, identifying early warning signs that parents are reaching their limits of coping may be helpful to prevent escalation of their distress and maintain their sense of wellbeing. Being aware of early warning signs can help parents avoid potential risky situations and implement self-care strategies earlier and more effectively.

Summary

Theme Four of Study One focused on how parents use the element of time to promote their wellbeing through implementing routines, finding time for mental breaks, processing difficult emotions as they arise, and identifying their early warning signs and limits to buy time and implement successful self-care strategies more effectively. The next chapter provides an overall discussion of Study One, including a summary of findings, the significance and implications of the study, strengths and limitations, and considerations for future research.

CHAPTER FOURTEEN:

Study One Discussion

The aim of Study One was to explore self-care and wellbeing of parents of children with HND from the parents’ perspectives. Study One included two specific research questions: how self-care and wellbeing are currently experienced and enacted for parents of children with HND; and what strategies of self-care parents find effective for enhancing their sense of well-being. This was explored in the context of a positive health-promotion paradigm and achieved via thematic analysis of interview data with 11 participants. Four key themes were identified: parents’ Formal Supports and Resources; Informal Relationships; Values and Goals; and their use of Time. Additional findings were also briefly mentioned, around participants’ preferred language use, a lack of discernible difference of self-care strategies between disability types, and a shared need for parents to discuss the difficult and negative aspects of raising a child with special needs. This chapter presents a discussion of Study One including a summary of key findings, and the theoretical and practical implications of these findings in relation to their contribution to existing literature. Limitations of Study One and suggestions for future research are also explored, providing a link between Study One and Study Two.

Summary of Findings

The first key theme centred on both parents’ difficulties with – and necessity of – accessing *formal supports and resources* for their child and family, to better allow for their own self-care. Difficulties parents experienced included barriers to being heard by disability services due to the lack of funding and resources at a societal level, and confusion and power differentials within the formal disability system. Due to this, parents described often feeling a loss of dignity for themselves and their child in having to fight for services they are entitled to. Nevertheless, parents emphasised the value in being collaborative with healthcare professionals as part of their self-care. Strategies for assertiveness were discussed by parents as effective methods to being heard by healthcare professionals, and included education, networking with disability services and other parents, knowing their legal rights, and using an advocate.

Parents viewed education as not only a tool for empowerment with healthcare professionals, but also as an effective way to improve their sense of validation and mastery regarding their child’s disability needs. Parents’ discussed utilising respite care regularly and becoming comfortable with accepting help from others as an important formal support for enhancing their wellbeing and family functioning. Finally, parents discussed the most “expert” source of support came from networking with peer support groups and other parents within the disability community who share similar experiences of raising a child with disabilities.

The second key theme was concerned with parents developing and maintaining supportive *informal relationships* as a form of self-care. Parents’ partner relationships were a central topic of discussion both in terms of potentially added stress and tension, as well as positive aspects of validation, intimacy and connection. Strategies parents discussed for maintaining a loving partner relationship included: working together as a team; utilising healthy communication and listening skills; creating a balanced family routine; spending quality time together; and positive reappraisal. Parents’ enactment of self-care also occurred within the relationships and interactions with their whole family. All parents reported difficulties related to participating in independent or conventional self-care activities. Due to these constraints, parents emphasised the importance of finding enjoyable activities they deemed “self-care” which they could do with their child and family together. Parents described that through regularly engaging in enjoyable activities with their family and child, there was a therapeutic outcome in which their family relationships are strengthened through building positive memories and experiences together.

Extending further out from the family unit, parents reported enacting self-care through building a community of trusting and supportive relationships around themselves and their family. Through building a supportive network, parents discussed experiencing increased wellbeing due to increased opportunities for positive social interaction, shared responsibility of caring for their child, and connection to a wider community. This community typically consisted of friends and extended family members, employment and hobby networks, new friendships and connections within the disability community, various cultural and religious networks, and more formal supports and disability services. Having a strong community of support created space for families to gain practical assistance, emotional validation, acceptance and guidance, and a sense of connection and belonging. Parents also discussed extending their community to include more formal psychosocial support, such as social workers, counsellors and psychologists, when required to address issues of trauma, grief and change.

The third key theme involved parents identifying and living to their *values and goals* as strategies of self-care. Parents reported that identifying their values helped to guide decision-making, enhance their sense of identity, and influence their ability to find meaning and purpose in everyday life. Parents typically discussed a process of grief associated with learning about their child’s diagnosis, which resulted in feeling a loss of identity and purpose for some. For these parents, recognising their values and going through a process of posttraumatic growth helped to regain their identity and provide direction in building a life with their child that aligned with what was important to them.

Although all parents believed it important to live in accordance with their values as a strategy of self-care, some acknowledged their need to be open to experiencing positive changes in their value system due to having a child with special needs. Related to identifying values as a strategy of self-care, parents also discussed finding meaning and purpose in life as critical to contributing to their wellbeing. Parents reported experiencing purpose in various areas (often aligned with altruism), including employment, informal caregiving, advocating for their child and other families within the disability community, volunteering, having a spiritual or religious connection, and participating in meaningful and enjoyable activities.

As well as identifying values and finding meaning in everyday life, parents also reported setting goals and making plans for the future as part of their self-care. Through setting realistic and achievable goals for themselves, their child and their family, parents reported experiencing a shift towards a more positive and constructive outlook. Having goals also helped parents build hope and create a meaningful narrative for themselves and their child. Having goals for their child’s future was a particularly important strategy of self-care for parents to counteract feelings of hopelessness.

Lastly, parents discussed gratitude and positive reappraisal as helpful strategy of self-care for shifting out of a negative frame of mind. Through purposefully reflecting on aspects of their lives that are going well, the effort and love they are putting in to caring for their child, and being grateful for what their family has, parents discussed experiencing a sense of control and self-awareness of their achievements and successes in everyday life. Using humour and having a strengths-based approach was emphasised by parents as valuable strategies to help positively reappraise difficult situations. Externalisation of the disability and positive reappraisal was a key and repeated wellbeing strategy for parents, often leading to a strengthened parent-child relationship.

The fourth key theme incorporated the element of *time.* All parents described difficulties in balancing time between differing everyday demands. Due to competing demands and limited time, all parents discussed frequently neglecting their own self-care and viewing their own wellbeing as lowest priority. However, many parents found they experienced a process of learning to prioritise their wellbeing, as they realised the importance of implementing self-care for both themselves and their family.

Parents reported using family routines as an effective strategy to meet everyday responsibilities and find time for their own self-care. Through being organised and implementing routines, parents reported experiencing greater efficiency with their limited time and a sense of accomplishment in completing tasks. Having a routine was also deemed helpful for the whole family, as everyone tended to become more aware of their role and responsibilities, family environments became less hectic and stressed, and children appeared to thrive in a more structured and predictable environment.

Many parents described feeling unable to mentally “switch off” from the responsibility of caring for their child. Even when their child was being cared for by other adults, these parents still felt unable to gain a break from worrying or thinking about their child. Strategies parents discussed for finding mental breaks from their responsibilities and worries included acknowledging their worries and sacrifices, accessing psychosocial support, engaging in mindfulness and grounding exercises, developing goals and future plans, and lowering expectations they put on themselves as a parent and caregiver.

Parents’ experiences of self-care in relation to the element of time also incorporated how they dealt with difficult emotions. All parents experienced difficult feelings related to caring for their child’s disability, including anger, grief, hopelessness and being overwhelmed. Parents discussed that dealing with these emotions typically occurred naturally over time. If required, parents also reported helpful strategies for managing difficult emotions which included effective problem-solving, psychosocial support, purposeful distraction, reframing the situation, and maintaining a sense of routine and function in everyday life.

Finally, parents discussed being able to identify their early warning signs or limits as an important preventative strategy to self-care and preventing escalation of their distress. Through being aware of their limits, parents reported being able to proactively act on their distress by engaging in helpful strategies, such as meeting their own needs, seeking support, removing themselves from the situation, making time for themselves, and engaging in mindfulness and enjoyable activities.

Theoretical Significance

As well as aligning with many previous findings already mentioned when presenting the four key themes, Study One has made an important contribution to the current literature by incorporating existing theories. Study One utilised theories including Bronfenbrenner’s (1977) Ecological Systems theory, the narrative paradigm, positive psychology and strengths-based approach, and Pender’s (1996) Health-Promotion Model.

Ecological Systems Theory

Firstly, this study incorporated Bronfenbrenner’s (1977) Ecological Systems theory as a framework of exploring parents’ experiences of raising a child with high need disabilities. As evident by research findings regarding informal caregiving, factors affecting parents’ practices and wellbeing are multifaceted and involve complex interactions between multileveled systems (Cuzzocrea et al., 2016; Garcia-Lopez et al., 2016; Kinnear et al., 2016; Whiting et al., 2019). This provided a strong rationale for exploring individual’s experiences from an ecological framework, as understanding and creating positive change requires a consideration for the multiple systems in which a person is embedded (Taheri et al., 2017). These multi-levelled contexts included exploring parents’ immediate environment or microsystem; their mesosystem of relationships within their immediate environment; indirect influences of parents’ exosystem; broad cultural and societal influences of parents’ macrosystem; and how their experiences changed over time as part of their chronosystem (Weiss et al., 2014).

Current findings tentatively support that parents’ experiences of self-care and wellbeing when raising a child with special needs occurs within - and is indeed directly influenced by - their multileveled systems. For example, parents discussed both how their self-care was directly influenced by their family and informal relationships in a bidirectional way, and how caring for a child with special needs could create stress and tension within these relationships at a micro- and meso-level. Parents also discussed how their interactions with formal supports and resources played an important role in their self-care and family functioning at a micro- and exo-level. This included parents' ability to be heard and assertive in their interactions with these services, as well as building a community of trusted formal and informal supports around their family. Further, parents discussed resolving difficult emotions and working towards acceptance for their child's disability over time as an important chrono-level contributor to enhancing their wellbeing.

An unusual finding related to Bronfenbrenner's (1977) Ecological Systems theory was that most parents did not talk about their culture as playing a significant role in their current self-care practices. This may be explained by the majority of participants identifying as NZ European, the dominant culture within NZ. It is argued that members who belong to dominant cultures are typically not asked to reflect on their cultural identity because it is viewed as the norm, often leading to the "invisibility" of dominant culturally sanctioned practices (Cruz & Sonn, 2011; Frankenberg, 1993). This finding may also be explained by participants being unaware of how sociocultural influences at a macro-level impact their self-care at an individual or micro-level (Cruz & Sonn, 2011).

It is also possible that participants may have been surprised and unprepared to consider a more abstract dimension of self-care at the time of interviews, or that the interviewer's questioning may have been insufficient to fully capture the parents' perspectives. Nevertheless, although parents overtly reported that culture did not impact their self-care, culture appeared to influence their self-care in more covert ways, through their discussions of values, goals and aspirations as being important contributors to wellbeing. Also, parents' discussions highlighted figurative barriers to self-care due to mainstream NZ societal attitudes to adversity making parents feel they needed to be "tough" or "harden up". However, further research is required to explore the impact of sociocultural influences on parents' experiences of self-care.

The Narrative Paradigm

Secondly, although Study One has not purposely adopted a narrative methodology, current findings show support for the narrative paradigm as a valuable approach to both explore parents' experiences and to enhance their sense of wellbeing. The narrative paradigm perceives people as innate story tellers who, when presented with disruption to their everyday lives, will create stories and narratives to make sense of these disruptions which change and reshape their lives (Whiffin, Ellis-Hill, Bailey, Jarrett & Hutchinson, 2017). Therefore, the way in which these narratives are constructed reveals something about the meaning attributed to the experience, the wider social world, and the social identities of the storyteller (Stephens & Breheny, 2013; Whiffin et al., 2017).

Throughout the interviews, parents both exemplified and expressed the need to share their life stories and narratives as a means of validation, and as a way to make sense of their identity and experiences as an informal caregiver. Further, all parents discussed numerous effective self-care strategies which centred on expressing and sharing their narratives. For example, "offloading" to friends and family, accessing peer support and formal psychosocial supports, and finding alternative ways to express their stories through writing and other means. Parents also emphasised strategies to enhance their ability to share their narrative through utilising more healthy and assertive means of communication and approaching 'disability' from a strengths-based perspective.

Current findings align with the narrative paradigm which argues that narratives and life stories serve both to enhance understanding of participants experiences through research and narrative analysis, and to provide therapeutic gain for individuals through meaning-making and self-continuity (Dunlop & Walker, 2013). Similar findings linking the narrative paradigm to enhanced wellbeing have found that individuals' ability to find meaning, positive growth and transformation in their life narrative correlates with higher levels of "eudaimonic" wellbeing (which is the combination of happiness and higher levels of ego development) openness, and family resilience (Bauer, McAdams & Pals, 2008; Lilgendahl & McAdams, 2011; Saltzman, Pynoos, Lester, Layne & Beardslee, 2013).

Narrative approaches to psychosocial support and therapy have been recommended to be helpful in allowing family caregivers to foster hope in their situations, and to create identities outside of their caregiving role (Duggleby, Williams, Holtslander, Cunningham & Wright, 2012; White, 2007). Narrative therapy also has the key technique of externalisation, which was woven throughout these parents' accounts and experiences during interviews, and which parents identified as a strategy to help facilitate coping and connection with their child (Duggleby et al., 2013; White, 2007).

Strengths-Based Approach

Thirdly, current findings exemplify a strength-based perspective adopted by the field of positive psychology, which incorporates strategies such as gratitude, altruism, mindfulness and value clarification. The strengths-based perspective emphasises positive experiences and traits, and is concerned with how individuals' strengths, virtues and abilities can be utilised and built on, to make life more hopeful and meaningful (Niemiec, Shogren & Wehmeyer, 2017). Further, the goal from this perspective is not to disregard challenging environmental circumstances and negative experiences, but rather to explore possible alternative solutions to problems encountered (Niemiec et al., 2017). Current findings which exemplify this perspective included parents emphasising accessing psychosocial and peer supports which is positive and uplifting, using strengths-based language, purposefully being grateful and positively reappraising difficult situations, participating in enjoyable family activities to create positive memories, giving to others and finding meaning in everyday life, using humour, and living to their values.

The current findings also align with major theoretical shifts within the disability field from traditional deficit-based models concerned with identifying functional limitations, to strengths-based approaches; recognising that those with disabilities also have many strengths and competencies that need to be explored and utilised when considering supports and resources (Niemiec et al., 2017; Wehmeyer et al., 2008). Although few studies have explored a strengths-perspective in regard to informal caregivers, Colvin and Bullock (2016) argue that adopting a strengths-based approach for family caregivers is important to help foster resiliency, self-perception of competence, self-empowerment, perseverance and effective decision-making. Therefore, adopting a strengths-based approach can be considered self-care as it contributes to parents' ability to function adaptively and thrive within their caregiver role despite stressful and difficult life circumstances (Colvin & Bullock, 2016).

Health Promotion Paradigm

Finally, the current study incorporates the health promotion paradigm and Pender’s (1996) Health Promotion Model regarding how background factors influence health and self-care behaviours. Pender’s model assumes that health behaviours are influenced by individual characteristics and experiences, behaviour specific cognitions and affects, and situational and interpersonal influences (Pender et al., 2011). Current findings aligned with all three of these aspects, including that parents’ self-care and wellbeing was influenced by individual characteristics, such as parents’ own values, mental health, stress, and acceptance of their informal caregiver role. Parents’ self-care and wellbeing were also influenced by behaviour-specific cognitions and affect, including their perceived barriers in terms of time and resources, and their perceived benefits of self-care activities. Lastly, situational and interpersonal influences also impacted and moderated parents’ self-care, and included parents’ relationships, competing demands, informal supports, and access to formal supports and resources. All parents from Study One exhibited capacity for reflective self-awareness, value for positive personal growth, and motivation to actively regulate their own self-care behaviours, aligning with the underlying assumptions of Pender’s model (Pender et al., 2011).

Practical Implications

Findings from Study One offer a rich and in-depth understanding of parents’ experiences of self-care and wellbeing when raising a child with HND, which has provided valuable ideas for positive change in practical and clinical settings. It was both my intention, and the intention of all parents interviewed, that findings from this study would be used to help other parents of children with disabilities in their journey, and for this research to contribute to a greater understanding of how to best respond and support parents as informal caregivers. Practical implications from this study include viewing self-care and wellbeing holistically, working in collaboration with parents, offering psychosocial support to families, and developing psychoeducational interventions and resources.

Holistic Wellbeing

Firstly, the current study highlights the importance of considering wellbeing and self-care in a holistic and multidimensional way, including physical, social, emotional and spiritual aspects of health and wellbeing (Morenga et al., 2018; Richard & Shea, 2011). For example, effective self-care strategies incorporating physical aspects of wellbeing included parents’ engaging in routines and physical activities as a family, and meeting their own fundamental needs through exercise, eating well, sleep, and maintaining their physical health to prevent them from reaching their limits. Social self-care strategies for parents included assertiveness and communication skills to maintain positive formal and informal relationships. Psychological or emotional self-care strategies for parents included positive reappraisal, acknowledging difficult emotions, and identifying their limits. Finally, self-care strategies incorporating spiritual aspects of wellbeing included parents identifying and living to their values and finding meaning in their everyday lives.

Viewing self-care and wellbeing in a holistic way aligns closely with Mason Durie’s (1994) Māori model of health, Te Whare Tapa Whā, which is often aspired to and incorporated in formal healthcare and disability services within NZ (Morenga et al., 2018). Through considering and exploring all holistic dimensions of self-care and wellbeing for parents and families, researchers and healthcare professionals can better understand how to support families within the disability community and ensure balance, stability and wellbeing for the person as a whole (Durie, 1994; Glover, 2005; Morenga et al., 2018).

Working in Collaboration

Secondly, findings from the current study highlight the importance for healthcare professionals and researchers to investigate and promote wellbeing in collaboration with individuals, and by incorporating and honouring consumer perspectives (Creswell & Poth, 2017; Smith et al., 2015). For researchers, this approach may be achieved within a transformative framework, working collaboratively with participants and actively seeking their feedback so findings adequately reflect their experiences (Creswell & Poth, 2017; Long & Johnson, 2000; Noble & Smith, 2015). In this way, the voices of the participants are heard, there is an action agenda for reform, and research findings are meaningful for all involved (Creswell & Poth, 2017; Kemmis & Wilkinson, 1998). For healthcare professionals, working in collaboration and seeking consumer perspectives aligns closely with the family-centred approach to healthcare often aspired to within NZ (Foster, 2015; Smith et al., 2015).

Unfortunately, there continues to be difficulties in effectively operationalising this model of care within NZ's healthcare system (Foster, 2015; Good et al., 2017). These difficulties were exemplified by current findings, as parents described many barriers to being heard by healthcare professionals and they discussed often feeling as if they needed to "fight" for services they are entitled to (Good et al., 2017). As part of their informal caregiving role, many parents are required to frequently interact and communicate with multiple healthcare services to meet their child's needs. When family-centred care is successfully implemented, this may help to ensure parents and families are empowered and actively involved in their healthcare decisions and interventions (Foster, 2015; Smith et al., 2015).

Psychosocial Support

The third practical implication for healthcare professionals from current findings includes the importance of helping families within the disability community access psychosocial supports, including healthcare and disability services, respite care, mental health support, peer support, advocacy and social supports when required (Cachia et al., 2016; Lindo et al., 2016; Rayan & Ahmad, 2017; Waddell et al., 2018). All parents discussed experiencing substantial life changes, difficult emotions, grief and loss, and at times reaching their limits related to raising a child with HND. These experiences not only occurred for themselves, but for their children, partner and wider family as well.

At present, parents have largely found it difficult to navigate the various healthcare, disability and support services available. However, many of these parents exhibited (and expressed) a need to share their life stories as a means of validation and a way to make sense of their identity and experiences as an informal caregiver (Dunlop & Walker, 2013). As current societal structures in NZ require parents to assume unforeseen and undervalued informal caregiving roles, finding methods of better promoting available psychosocial supports for parents (and making pathways clearer for families to access these supports) seems a worthwhile investment to improve their sustainability of care (Murray, 2018; Raina et al., 2005).

Psychoeducational Intervention

Lastly, the fourth practical implication for healthcare professionals from the current study includes the potential benefit of developing psychoeducational interventions and resources regarding self-care for parents when raising a child with special needs. Many of the holistic self-care strategies that parents found effective in the current study align with various empirically-supported therapeutic techniques, including behavioural activation, assertiveness training, psychoeducation, values work, communication skills, problem-solving, setting goals and positive reappraisal (Baer, 2015; Bexelius et al., 2018; Gupta & Singhal, 2004; Krishnan et al., 2018; Mazzucchelli et al., 2010; Speed et al., 2017).

As many of the parents' self-care strategies align with supported therapeutic techniques, this lends itself to developing psychoeducational interventions and resources which can provide this information to parents new to the disability community. In turn, this may help improve parents' knowledge and awareness, reduce possible distress, provide emotional validation, and address their self-care and wellbeing needs as informal caregivers (Gilson et al., 2018; Krishnan et al., 2018; Srivastava & Panday, 2016). Given the substantial evidence that parents of children with disabilities are at increased risk for adverse outcomes, along with there being few studies which have explored health promotion and self-care, there is a clear need for researchers and healthcare professionals to find and develop methods to promote the wellbeing of parents as informal caregivers (Acton, 2002; Marino et al., 2017; McConnell & Savage, 2015).

Limitations and Considerations for Future Research

Study One provided new insight and understanding of the experience of self-care and wellbeing for parents when raising children with HND within NZ, along with identifying effective self-care strategies that parents use. Nevertheless, it is important to note the limitations to this study and to consider ideas for future research.

Although generalisation of findings is not a goal of qualitative research, limitations of this study are reflected in the recruitment and characteristics of the participant sample (Creswell & Poth, 2017). Firstly, although effort was made to include a diverse range of parents, reflective of NZ's varied population and cultures, it is possible that because recruitment was self-selected, participants came into the study with particular experiences and perspectives of self-care, informal caregiving and disability. For example, parents may have been politically motivated to participate due to wanting to help enhance support for informal caregivers. Secondly, the participant sample consisted predominantly of mothers and those who identified as NZ European. Due to this, it is unclear whether these findings are reflective of fathers' experiences and those from other cultures within NZ who may experience differing stressors, supports and perspectives.

Possible reasons for demographic bias towards females could be related to research which shows that mothers are more likely to take on the role of caring for their child within the family (Gardiner et al., 2014; Grimmond, 2014; Maidment, 2016). Affleck, Glass and Macdonald (2012) reported that gender bias towards females occurs frequently in qualitative health research which explores emotionally complex topics. They argue that despite the strengths of semi-structured interviews, other methods may be better suited for researching topics in which populations of varying gender and culture may find difficult to speak about, or where certain participants may lack verbal communication skills (Affelck et al., 2012). Therefore, future research into this area should consider additional methods to further incorporate informal caregivers within NZ with differing gender and demographic characteristics currently underrepresented in research. Nevertheless, despite possible gender bias for qualitative research, two fathers did participate which is a strength for this study and adds to preliminary findings for this demographic. As the current study also had unique findings regarding how parents may mitigate barriers to accessing help, promote help-seeking behaviours, and better utilise respite care, future research is also needed to further explore this area.

The limited response from Māori, Pacific and Asian populations could be explained by language and communication barriers due to research information and interviews being conducted in English, as well as differing cultural perspectives and interpretations of disability to that advertised and explained by the researcher. The underrepresentation of Māori (and those from ethnic minority groups within NZ) within disability research may be addressed through working alongside representatives of these communities to adapt research methods, accessibility and language used (Pihama, Cram & Walker, 2002).

In accordance with the Treaty of Waitangi (1840), NZ has a responsibility to improve representation of Māori in all aspects of life, including health promotion and academic research. Due to this, research incorporating an indigenous Māori world view of self-care and disability in NZ is imperative (Pihama et al., 2002). Kaupapa Māori research may offer alternative conceptualisations and strategies of self-care and wellbeing for parents as informal caregivers that would likely result in important practical implications for providing support specific to this NZ population (Pihama et al., 2002).

Another limitation to the current study may be the inclusion criteria, which focused only on parents of children with cerebral palsy and autism. Although current findings supported the notion that the impact and experiences of informal caregiving were more determinant on the level of care required rather than disability type, caution should be made in assuming that current findings can be generalised to parents of children with other disability types. To further investigate whether disability type (over level of need required by informal caregivers) is a significant influencing factor of self-care, future research could incorporate larger sample sizes with a broader inclusion criterion based on multiple disability types. Future research could also specifically focus on comparing differences in self-care and wellbeing for informal caregivers of children with differing disability types.

This study focused on parents who perceive their child’s disability as resulting in a subjective “high needs” level of care through screening parents with the ZBI measure (Zarit et al., 1985). However, although the ZBI has been utilised as a measure for similar studies to distinguish parents’ level of need, it was not developed for this specific demographic group (Zarit et al., 1985). Further adding to limitations in using the ZBI questionnaire is the measure’s use of the term “burden”, which may not fully correspond with parents’ preferred language use, interpretation and experience of a high level of care required for their child. Using what might be experienced as derogatory language in the measure may have resulted in social desirability bias for participants when answering the questionnaire. For example, parents may not have wanted to respond truthfully to questions which implied their child as a burden, or to their caregiving demands and home life as being overly negative and burdensome. Future research may address these limitations by utilising or developing a more appropriate screening measure for identifying parents’ subjective level of need in caring for their child.

Finally, findings of this study represent a cross-sectional snapshot of a group of 11 parents within a particular time, place and cultural context. As characteristic of qualitative research, these parents may have shared differing perspectives at another time (or in other contexts) to what they chose to share during their interviews (Creswell & Poth, 2017). As this study had a relatively small sample size of parents who volunteered to share their experiences and views, a limitation of this research may include that findings have not captured the breadth of experiences and opinions held by the broader NZ population of parents as informal caregivers. Limitations regarding the current methodology may also include social desirability bias by the participants. Further, the position of the researcher as a caregiver for children with disabilities, and with training to be a clinical psychologist (and the influence this may have had on analysis and interpretation of accounts), must be considered (Creswell & Poth, 2017).

Nevertheless, this study provided new insights into a previously unrepresented research population within a NZ context, which future research can grow and develop. Suggestions to address limitations related to the use of cross-sectional semi-structured interviews may include increasing the sample size, utilising a mixed methods approach, and implementing qualitative longitudinal research methods. Qualitative longitudinal research is concerned with understanding phenomena which evolves through time, which may be particularly relevant for understanding the experience of self-care and disability for informal caregivers (Carduff, Murray & Kendall, 2015).

Summary

Study One addressed a gap in existing literature by exploring parents' experiences of self-care and wellbeing when raising a child with HND in NZ, and by identifying self-care strategies that parents currently find effective. These aims were explored in the context of a positive health-promotion paradigm and achieved via thematic analysis of interview data with 11 participants. Four key themes were identified including parents' Formal Supports and Resources, Informal Relationships, Values and Goals, and their use of Time. Findings from Study One aligned with existing theories including Bronfenbrenner's (1977) Ecological Systems theory, the narrative paradigm, positive psychology and strengths-based approach, and Pender's (1996) Health-Promotion Model. Further, current findings held practical implications including viewing self-care and wellbeing as holistic constructs, working in collaboration with parents, offering psychosocial support to families, and developing psychoeducational interventions and resources.

Despite limitations, this study has provided an in-depth perspective into the challenges and experiences of parents as informal caregivers and has made an important contribution to theory and practice in field of disability. The next chapter introduces Study Two, which builds on this study through the development of a psychoeducational booklet based on current findings. This booklet was designed to help support parents who have received a disability diagnosis for their child, by providing useful strategies regarding their self-care in everyday life. The booklet was shaped by a positive health-promotion paradigm and developed by integrating self-care strategies from Study One with existing research.

SECTION THREE

CHAPTER FIFTEEN:

Study Two: Preliminary Evaluation of a Developed Self-Care Resource for Parents of Children with High-Need Disabilities

Study Two aimed to evaluate a psychoeducational resource booklet developed for enhancing parents' self-care and perceived wellbeing while raising children with HND in NZ. This resource booklet was shaped by a positive health-promotion paradigm, and it was written and constructed by integrating findings from Study One with relevant existing literature (see Appendix L). The resource was designed to help support parents who have received a disability diagnosis for their child by providing useful strategies regarding their self-care in everyday life.

Given the substantial evidence that parents of children with HND are at increased risk for adverse outcomes, along with there being few studies that have explored self-care from a positive health-promotion perspective, there is a clear need for research to promote the wellbeing of parents as informal caregivers (Acton, 2002; Marino et al., 2017; McConnell & Savage, 2015). Passive psychoeducational resources, such as leaflets or booklets, have been shown to be effective for providing therapeutic benefits, education, and improved knowledge relevant to health in specific population groups (Gilson et al., 2018; Srivastava & Panday, 2016). Although psychoeducational resources do not replace the need for immediate support for parents experiencing acute distress, they have significant practical potential for raising awareness of health promotion and may facilitate access to immediate supports if needed (Gilson et al., 2018).

This study outlined and discussed in the following section provides a preliminary evaluation of the developed resource by collecting descriptive statistics and qualitative responses via questionnaires given to parents having read the booklet. The specific aims of Study Two were to:

a. explore how parents of children with HND appraise the self-care resource; and

b. identify what recommendations and considerations parents would make regarding the content and format of the self-care resource.

The current study addressed a gap in the literature as existing research focused on producing psychoeducational resources relevant to enhancing parent's self-care and perceived wellbeing are scarce (Gilson et al., 2018). Further, the current study aligns with a transformative framework, as from this perspective research should have a practical agenda to use knowledge gained to improve society and the lives of participants (Creswell & Poth, 2017; Mertens et al., 2009). Therefore, research becomes collaborative by the researcher engaging participants to actively work together, as seen across Study One and Two. Through working together, the participants voices is heard, and the research outcomes become meaningful for all involved (Creswell & Poth, 2017; Kemmis & Wilkinson, 1998).

Method

Design

Study Two utilised a qualitative and quantitative cross-sectional survey method to explore parents' feedback and recommendations regarding the developed self-care booklet. The questionnaire included both open questions and rating scales (using 5-point Likert scale), and it was administered at one point in time (see Appendix M). According to the literature, surveys are a valuable method for soliciting self-reported information from individuals (de Vaus, 2014; Mitchell & Jolley, 2012; Watkins, Meiers, & Visser, 2012). Advantages of surveys include that they are more time-efficient for participants compared to focus groups or interviews, they are relatively inexpensive to conduct, there are no geographical boundaries, and they provide anonymity so there are fewer ethical issues concerning researcher influence and social desirability bias (de Vaus, 2014; Mitchell & Jolley, 2012; Watkins et al., 2012).

Participants

Fourteen parents voluntarily participated in this study, including 12 mothers and two fathers. Of the participants, 12 identified as NZ European, one identified as Māori, and one identified as Dutch. Participant's ages ranged from 34 years to 64 years (*M* = 49). Six participants indicated they were full-time caregivers and not in paid employment, seven participants indicated they were either part-time or full-time in paid employment, and one participant chose not to answer. Participants ranged in education from secondary school certificate to Masters' degree level.

Five parents had a child with one high-need disability diagnosis, whereas nine parents had children with various significant co-existing disabilities. The participants' children had co-existing disabilities including cerebral palsy, brain injury, cortical visual impairment, epilepsy, autism, intellectual disability, tumours, blindness, learning disabilities, ADHD, selective mutism, Tourette's disorder, and anxiety disorders. The participants' children ranged in age from nine years to 26 years old ($M = 15$). Ten parents indicated they had more than one child, ranging between having two to five children. Two parents indicated they had more than one child with disabilities.

A purposive sampling approach was used with the inclusion criteria being that participants must be the parent of a child with a recognised disability diagnosis (given by a health professional) which the parent perceived as high-need. For this study, being a parent was defined as being the primary caregiver living with the child who is the most responsible for the day-to-day decision making and care of that child (Raina et al., 2005). The child had to be aged 5 years or older and living with their parent most days. A lower age limit of 5 years was decided on as parents of these children would likely be experiencing caregiving demands beyond that of typical parenting responsibilities, along with having adequate lived experience of both caregiving stress and self-care. The decision was made that parents of children over the age of 18 years could be included in this study provided the parent remained responsible for the day-to-day decision making and care for their child. Participants were also required to be aged 18 years or above, comfortable reading and writing in English, and a current NZ citizen.

Recruitment and Procedure

Recruitment of participants occurred using snowball sampling, including contacting participants from Study One who previously indicated their interest in Study Two and utilising my personal networks to disseminate information about the research. Participants were also recruited for Study Two from families who showed interest in Study One but were initially unable to participate in interviews (i.e., due to geography, lack of eligibility, and constraints due to time or their child's disability needs). Potential participants were asked to contact myself to express their interest via email. Those who met the inclusion criteria were posted a pack of relevant research materials, including an information sheet (see Appendix N), self-care booklet (see Appendix L), and feedback form (see Appendix M), along with a return post envelope. Completed forms were returned within two months of receipt. A total of 30 packs were sent out to potential participants, with 14 participants returning completed feedback forms within the allocated timeframe indicating their consent to being included in Study Two. The final sample included seven parents who participated in Study One, and seven participants who were recruited via snowballing.

Although residential location was not collected as part of demographic details for privacy reasons, participants were recruited from throughout NZ rather than being restricted to specific regions. At the end of the feedback form, each participant was given the opportunity to indicate whether they wanted to be sent a summary of the findings (see Appendix O), an updated self-care booklet incorporating the parents' feedback, and to enter the draw to win one of five $30 supermarket vouchers at the conclusion of the study. The offer to win a $30 supermarket voucher was included as a token of appreciation for participants' time and efforts in contributing to this study.

As quantitative data for this study was analysed with descriptive statistics only using frequency analysis, the qualitative criteria regarding thematic saturation was sufficient and adequate for determining sample size for Study Two. As data saturation was reached with the qualitative questions in the survey, the decision was made to end recruitment after 14 participants responded in the interests of the timeframe for the clinical psychology training programme (Namey et al., 2016).

Materials

Self-Care Booklet. The content of the self-care booklet was based on results from Study One and a comprehensive literature review. The booklet was written by myself and drafts were reviewed by my primary supervisor using an iterative process. The booklet format was designed in collaboration with a print designer in the Whanganui region. The resultant booklet content, structure and layout is presented in Appendix L.

The booklet consisted of 17 self-care strategies, such as "Working with Healthcare Professionals", "Respite Care", and "Using Gratitude". As well as the 17 strategies, there was an introduction and contents page and a final page with relevant contacts for further information and support. Within each strategy, there were typically three sections. The first section introduced the strategy and how it relates to parents' of children with special needs; the second section (titled "Seeking Solidarity") highlighted common challenges that parents may face with raising a child with special needs; the third section (titled “Supported Strategies”) provided an empirically supported exercise or advice for parents to practice and try out.

The order and layout of the three sections was done intentionally to visually depict common practice in emotional validation, whereby the listener first acknowledges the person’s emotions and challenges, before moving towards resolution (O’Toole, 2012). This was strived for in the booklet as showing empathy and validating parents’ emotions is shown to result in improved intervention outcomes and reduced distress for parents as informal caregivers (Gair, 2012; O’Toole, 2012; Silvers, Bauman & Ireys, 1995).

Measures

The ***Feedback Questionnaire*** was adapted from similar studies which aimed to explore consumer perspectives on developed psychoeducational resources (Juraskova et al., 2008; Lubotzky et al., 2015). The 18-item questionnaire included 14 feedback scales (with additional space for comments) and four open-ended questions to elicit parents’ views on the content and format of the resource (see Appendix M; Lubotzky et al., 2015). This was a non-generalizable and non-standardized measure which provided preliminary feedback from participants to be used both descriptively and qualitatively in analysis.

Feedback items and questions reflected areas such as booklet format, content, clarity, usefulness, and areas for improvement. An example feedback item was “This booklet provided helpful information regarding self-care”. Response options for the feedback scales were on a 5-point Likert scale, ranging from “Strongly Disagree” to “Strongly Agree”. Higher scores reflected positive feedback on the format, content and utility of the resource pack. Open-ended questions were also included to provide an opportunity for participants to make unique and more in-depth comments and appraisals of the resource. An example open-ended question was “What did you like about this booklet? What was the most useful aspects (if any)?” The instructions and questionnaire format allowed participants to leave any question unanswered in keeping with the ethics of voluntary participation.

Demographic Information was collected, including participants' gender, ethnicity, age, marital status, employment, education/highest qualification, number of children, and number of children with a disability. Clinical information regarding participants' children was also collected, including their gender, age, and disability diagnoses (see Appendix M). This information was deemed important to include in order to understand the sample representativeness and to identify possible confounds during analysis.

Analysis

The data collected for analysis included both participants' quantitative ratings on the Likert-scale items, and their qualitative feedback for the open-ended questions and in spaces for further comments. Participants' quantitative ratings on the Likert-scale items were analysed via descriptive statistics and frequency analysis. Participants' qualitative responses were analysed using the same thematic analysis processes as those employed in Study One (as outlined by Braun and Clarke, 2006). Written responses were analysed and sorted by question, then by theme. From this, initial themes were further revised and refined with oversight from my supervisors, and interpretations of the results were written up for this thesis. The results were communicated through the current thesis, a summary of findings sent to participants (see Appendix O), and an offer of an updated self-care booklet to be gifted to participants and relevant health services (to be finalised after thesis submission).

Ethical Considerations

The current study was evaluated by peer review with the guidance and consultation of my supervisors and judged to be low risk; therefore, it was not reviewed by a human ethics committee. Rather, notification was made to Massey University Human Ethics Committee (Application number 4000017867; see Appendix P). There was the small possibility of a conflict of role as some participants may have had a prior professional relationship with me due to my work as a respite carer. However, the dual relationship was acknowledged with these participants during the recruitment phase, participation was voluntary for all parents, and participants had the option of returning the feedback form anonymously should they prefer (de Vaus, 2014; Massey University, 2015).

The research, confidentiality and consent processes were explained to respondents both on the information sheet and the feedback form, and informed consent was implied if the feedback form was completed and returned (de Vaus, 2014). A summary of findings (see Appendix O), updated resource booklet, and entry into the draw to win one of five $30 supermarket vouchers was offered to participants following the completion of the research, which required parents to provide contact information should they choose. This was specifically limited to one page so any identifying information could be scanned and stored separately in a password-protected folder on the computer of the researcher until the completion of the study, after which it will be destroyed. The anonymous feedback forms were scanned and stored in a different password-protected folder on the computer of the researcher, to be destroyed after a 5-year storage period (Massey University, 2015).

Summary

Study Two aimed to evaluate a psychoeducational resource booklet developed for enhancing parents' self-care and perceived wellbeing while raising children with HND in NZ. It achieved this by collecting questionnaires from 14 participants to elicit parents' feedback within a transformative framework. Descriptive statistics and thematic analysis of parents' responses was used to uncover preliminary findings and themes central to parents' appraisal and future recommendations for the booklet. The next chapter presents the key findings identified during analysis for Study Two.

CHAPTER SIXTEEN:

Study Two Findings

Introduction

The current chapter presents the main findings from Study Two, in relation to parents’ preliminary feedback on the developed self-care booklet. The first section presents participants’ quantitative ratings on the feedback scales provided in the questionnaire. The second section describes the two key themes regarding parents’ qualitative statements made about booklet from the open-ended questions: parents’ Positive Remarks; and their Ideas for Change. Under each of the two key themes, subthemes were expanded on within their own sections. These subthemes can be best introduced using the following figure which illustrates how the subthemes were organised related to specific feedback on the booklet.

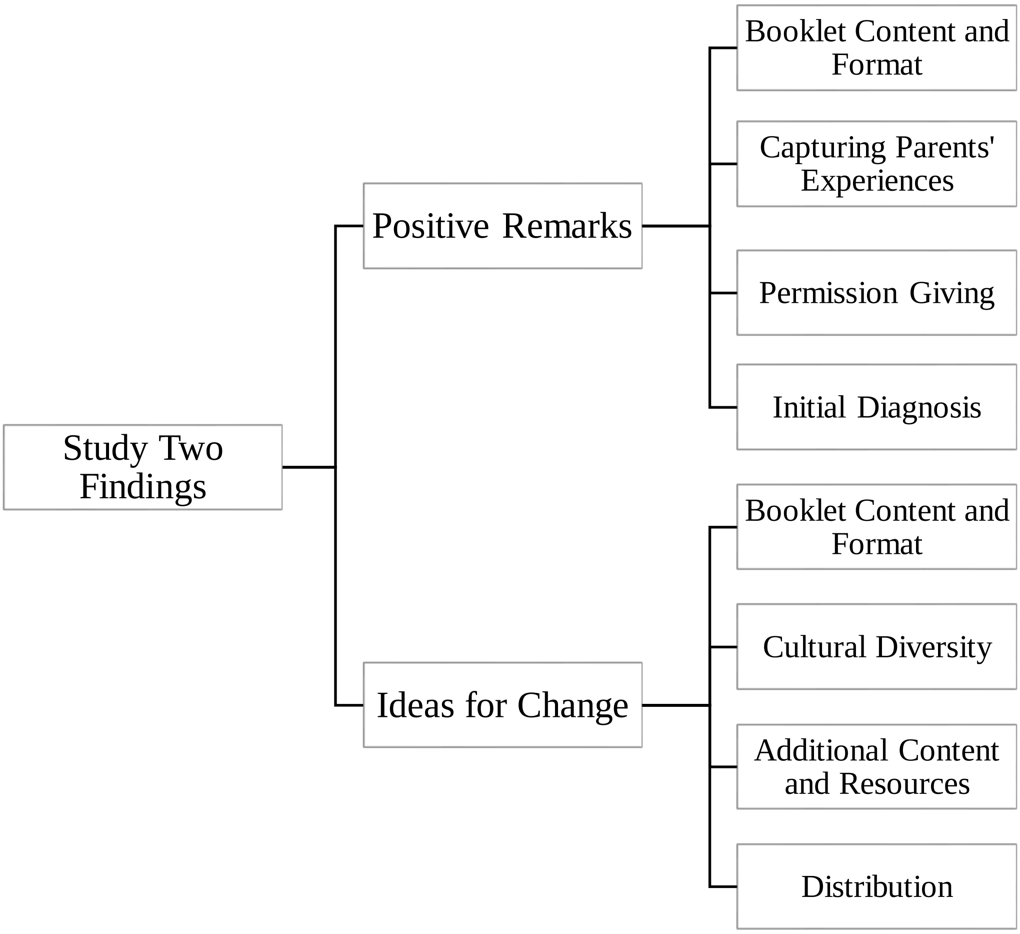

Figure 3. Thematic map of themes and subthemes from Study Two related to parents’ qualitative feedback on the developed self-care booklet.

Quantitative Ratings

Based on the quantitative feedback scales from Study Two, all participants (n=14) who responded found the self-care booklet useful and interesting. All participants (n=14) believed the booklet provided helpful information regarding self-care, the language used was clear and easy to understand, and that they would recommend the booklet to other parents of children with special needs (see Table 1).

Table 1
Study Two Feedback Scales: Participant's Quantitative Ratings on Format and Content of the Self-Care Booklet (*N* = 14)

Item	Individual Ratings				Combined Ratings		
	*Disagree	Neutral	Agree	Strongly Agree	Strongly Disagree/ Disagree	Neutral	Strongly Agree/ Agree
Useful			6	8			14
Interesting			6	8			14
Importance of Self-Care		1	5	8		1	13
Helpful Information			4	10			14
Better Understanding		2	5	7		2	12
Encouraged		1	6	7		1	13
Relevant		1	4	9		1	13
Right amount	1	1	5	7	1	1	12
Language			5	9			14
New Information	1	4	8	1	1	4	9
Information Needed	1	7	4	2	1	7	6
Overall Format	2	1	2	9	2	1	11
Overall Structure		1	3	10		1	13
Recommend			2	12			14

* As there were no Strongly Disagree ratings, this column has been excluded from the individual ratings section in this table. Some percentages do not add up to 100 due to unavoidable inaccuracies caused by rounding.

The majority of participants found the self-care booklet helped them understand the importance of self-care (n=13), gave them a better understanding of self-care (n=12), and encouraged them to engage in self-care strategies (n=13). The majority also found the booklet relevant for their situation raising a child with special needs (n=13), that it had the right amount of information and detail (n=12), and that they liked the overall structure of how the booklet was laid out (n=13). Although not as highly rated, the majority of participants liked the overall format of how the booklet looked (n=11).

Although the majority agreed (n=9), there was more of a mixed response from participants on whether the booklet provided new information for them (2 participants were neutral). Further, although there were mixed responses, the majority of participants were either neutral (n=7) or disagreed (n=1) with the statement that the booklet provided them information that they needed.

Qualitative Themes

Theme One: Positive Remarks

Booklet Content and Format

All participants made positive remarks regarding the self-care booklet content and format. In terms of the booklet content, most parents (10 participants) found the included information useful and pertinent to their situation in raising a child with special needs:

> *I liked the whole booklet, very useful for those who have special needs children growing up.* - Sarah

> *The booklet is a gem – a treasure trove of information.* - Paula

> *Lots of excellent information and strategies*. - Rachael

Most participants stated that they liked how the booklet was presented, including the photos, sections, quotes, and bullet points. Six participants commented on the booklet being easy to read and comprehend, with good language use and a layout that was not too overwhelming:

> *Easy to pick up and read in short bursts as parents of special kids are very busy.* - Paula

> *It was logical in the way sections followed each other. Nice pictures and it was an easy read, not overwhelming.* - Eleanor

> *Beautifully presented, pages not too busy. Easy to navigate, 'boxed quotes', broken into bullet points for easy comprehension.* - Taylar

Participants also made positive remarks regarding the amount of information and level of detail included in the booklet:

> *Just right [with the] amount of information and detail. Clear, helpful and non-judgemental language.* - Taylar

> *I think it's just the right amount of information. There's always a huge amount of info in the disability space – This booklet has a clear focus on self-care and the right amount of info.* - Allie

Capturing Parents' Experiences

The majority of parents (13 participants) stated that the self-care booklet matched their experiences of being an informal caregiver. Many participants reported that they successfully use many of the self-care strategies listed, and that they could identify with the situations and experiences of other parents discussed throughout the booklet:

> *Looking for positives has always helped me, along with making time for family and friends, and the value of other parents on this journey.* - Paula

> *I feel it covers all of the issues that I have experienced and required guidance on.* - Kate

> *I identified with most situations. It was helpful to realise others have been through the same.* - Taylar

Participants made no comments about the self-care booklet including any information that did not align with their experiences. Participants did not disagree with the included information, nor found the information unhelpful for their situation in raising a child with HND.

For many of these parents, reading the self-care booklet was reassuring for them to know that they are not alone in their journey:

> *After over 20 years being a parent of a special needs child, I think I have all the information, but it was reassuring to know that I'm doing the right things for my wellbeing.* - Rachael
>
> *[I liked] the presentation, useful information, but most importantly, to know we are not alone.* - Valery

Permission Giving

Three participants gave positive remarks on how the booklet can be used to help parents acknowledge that it is okay to engage in self-care alongside their caregiving and parenting demands. In this way, the booklet can be used as a 'permission giving' tool or intervention to reduce parents' concerns or feelings of guilt in prioritising their own needs:

> *I think it is great to have self-care reinforced as something that is 'allowed'… A great guide for those needing a place to start or affirmation that it is ok to have self-care.* - Eleanor
>
> *If I need to do it, I eat before giving food to my son. I always felt guilty about that, but I needed to eat first to have enough patience. This booklet made me realise I should not feel guilty.* - Colette

Initial diagnosis

Finally, nearly all parents (13 participants) commented on how this booklet as an intervention is best located at the time of initial diagnosis. Many of these parents stated that they already knew the majority of the information discussed in the booklet through learning from their experiences over time, trial and error, and having lived as an informal caregiver for many years:

> *As I have already cared for my disabled child for 26 years, some of the information I had already learned by experience along the way… It would have had a bigger impact and positive effect if this information had been available many years ago.* - Colette

> *I wish this book was around when my son was first diagnosed at 6 months. It has taken me years to learn all this through trial and error and fighting for my son's rights.* - Christina

> *I am through the worst of it and have worked through a lot of this. This would have been extremely useful at my son's birth…I am further along on the journey and have learned a lot of this the LONG way.* - Kate

Many of these comments were given by participants as an explanation for their ratings alongside the two feedback scales asking about whether the booklet contained new information for them or information that they needed. These comments possibly provide an explanation for participants mixed quantitative ratings for these two statements. As parents already knew a lot of the booklet content from learning it over time, this contributes to the finding that the booklet successfully captures parents' experiences when raising a child with special needs. Further, half the participants contributed to the information in the booklet from Study One which likely also adds to current mixed findings for the booklet providing new or needed information, as the booklet included information these parents already knew.

Two participants stated that the first years of becoming an informal caregiver were the most difficult time for them. Many of the participants commented on how the booklet would be most helpful for parents to receive at the time of their child's initial diagnosis to assist them with their self-care through these first few years:

> *I would have liked to read something like this when my child was first diagnosed, the early years are the hardest… it's definitely something new parents need to be aware of.* - Rachael

> *When I was a newly diagnosed mother, this would have been very, very helpful… A really good starting place for parents starting their journey.* - Eleanor

> *Great advice every mum should know. Wish I'd known sooner how important self-care is to be able to support others.* - Taylar

Although many parents stated they already knew most of the self-care strategies through lived experience, three participants stated they had still learned new strategies or clarified their understanding of particular strategies from having read the booklet.

Two participants stated that reading the booklet was a useful reminder to engage in self-care that they already knew but had been neglecting:

> *I often forget to prioritise this – it was a good reminder of the need to but also the 'how to'.* - Allie

Therefore, participants mostly found that this booklet successfully captured their experiences of self-care when raising a child with special needs, and that it had a good format and content. Further, most participants believed that the booklet was best located as an intervention for parents during the time of initial diagnosis; and that it could also be used as a 'permission giving' tool for parents to feel okay about prioritising their own needs and self-care, with practical ideas about how to 'do' self-care. The next theme discusses participants' ideas for change regarding the booklet.

Theme Two: Ideas for Change

Booklet Content and Format

Along with the positive remarks already discussed regarding booklet format and content, some participants commented on areas that they did not like and would like changed throughout the self-care booklet. For two parents, the booklet was too long and dense in information, making it difficult for them to read. To address this issue, one parent suggested the development of an additional brief resource to sit alongside the booklet, such as an easy to read "map or diagram" to help navigate the booklet. That participant also suggested a worksheet or checklist of the self-care strategies from the booklet that can be photocopied and hung-up around the house as a reminder.

Four participants identified that there were some phrasing and spelling edits that needed to be made throughout the booklet prior to finalising it. Further, three participants commented on the colour use and photos. These parents felt that the colours utilised throughout the booklet could be more positive, and that the photos could be more genuine, diverse-obvious, and reflective of New Zealand families:

> *Although I liked the format, I found the photographs disingenuous. I felt that they jarred with the information.* - Kate

> *Change some of the photos to include some more diverse-obvious special needs and use New Zealand families.* - Paula

> *The colours are hard to read at night-time… Consider more positive colours, such as greens and blues, and use more pictures of nature.* - Christina

Cultural Diversity

Although only commented on by one participant, Christina, who identified as New Zealand European and had a son who identified as Māori, I believe her statement on cultural diversity is important to include in the current study. Christina stated that she found the self-care booklet very targeted towards a New Zealand European audience, without much consideration for cultural diversity within NZ (which is both nationally recognised as being bicultural, as well as being strongly multicultural). She stated that the booklet should be more inclusive of other cultures within NZ, especially Māori, Pasifika and Asian cultures. She believed the booklet could include other cultures' experiences, situations and perspectives:

> *The entire booklet is very "mono cultural"... Māori and Pasifika (and many Asian cultures) have extended whānau helping with children with special needs… [The booklet could] include strategies which extend beyond one person as the primary caregiver.* - Christina

Additional Content and Resources

Four participants gave suggestions on additional booklet content for this self-care booklet, and for separate psychoeducational resources for parents within the disability community in NZ. Regarding additional booklet content for this resource, two participants suggested adding sections to cover strategies on maintaining safety for children and parents, legal processes and information, and strategies for caring for children with special needs once they become adults:

> *Consider including a chapter about safety. We know that high proportions of children with special needs are abused as they are vulnerable. I think whānau need tips on what to do to raise awareness here.* - Christina

> *Consider adding the human rights commission and health and disability commission into this booklet, and a separate chapter on how to complain.* - Christina

> *Perhaps a section for older special needs i.e., adults. My son is now 26…some tips on that type of thing would be good.* - Sarah

Two participants also suggested additional resources that parents may benefit from when raising a child with special needs. One parent suggested developing a resource on families' rights within the education section when raising a child with special needs, as well as strategies and procedures for navigating the education system. Another parent suggested a resource to support siblings of children with special needs, stating they are often "missed" in current systems of care:

> *I would love to see siblings getting more support, somewhere to go to, talk to – a support team person – they suffer more than we know. They are often 'missed'.* - Debra

Distribution

Finally, four participants made suggestions for how best to distribute the finalised booklet to parents and families. Their suggestions included distributing the booklet in hospitals, paediatric services, GP practices, early childhood centres, schools, disability support agencies, neonatal units. One participant also suggested making the booklet available online.

In sum, participants in the current study made multiple suggestions for change regarding the developed self-care booklet, particularly related to the booklet content and format. These findings indicate the importance of images and how people feel images convey whether something is relevant to them. Participants also made suggestions for change regarding the inclusion of diverse cultural perspectives, additional content and resources, and ideas regarding the distribution of the finalised booklet.

Summary

This chapter presented the preliminary findings from Study Two regarding 14 parents' feedback on the developed self-care booklet. The main findings included participants' quantitative ratings on the feedback scales, as well as two key themes from their qualitative statements including parents’ Positive Remarks and their Ideas for Change. The next chapter provides an overall discussion of Study Two, including a summary of findings, the theoretical significance and practical implications of the study, the study’s limitations, and considerations for future research.

CHAPTER SEVENTEEN:

Study Two Discussion

The aim of Study Two was to evaluate a developed psychoeducational resource aimed at enhancing parents' self-care and perceived wellbeing. This resource booklet was shaped by a positive health-promotion paradigm, and it was developed by integrating findings from Study One and the current literature. Study Two included two specific research questions; how parents of children with HND appraise the self-care resource; and what recommendations and considerations they have regarding the content and format of the booklet. Preliminary evaluation of this resource booklet was achieved via descriptive statistical analysis and thematic analysis of questionnaire data with 14 participants. Descriptive statistical analysis was used for parents' ratings on the included Likert feedback scales, and thematic analysis was used on their qualitative comments given in the questionnaire feedback form. This chapter presents a discussion of Study Two including a summary of key findings, and the theoretical and practical implications of these findings in relation to their contribution to the literature. Limitations of Study Two and suggestions for future research are also explored.

Summary of Findings

Based on the Likert feedback scales, all 14 participants who responded indicated that they found the self-care booklet useful and interesting, that the booklet provided helpful information, that the language used was clear and easy to understand, and that they would recommend the booklet to other parents of children with special needs. The majority of participants indicated that the booklet helped them understand the importance of self-care, that it gave them a better understanding of self-care, and that it encouraged them to engage in self-care strategies. The majority also indicated that the booklet was relevant for their situation raising a child with special needs, that it had the right amount of information and detail, and that they liked the overall structure of how the booklet was laid out.

While not as highly rated, the majority of participants indicated they liked the overall format of how the booklet looked. Although the majority agreed, there was more of a mixed response from participants on whether the booklet provided new information for them. Further, although there were mixed responses, the majority of participants were either neutral or disagreed with the statement that the booklet provided them information that they needed.

These findings were consistent with participants' qualitative feedback given on the self-care booklet, with the two key themes being parents' *Positive Remarks* and their *Ideas for Change.* The first theme incorporated participants' positive remarks on the booklet, including that it had useful information which was relevant to their situation in raising a child with special needs. Most participants stated that they liked how the booklet was presented, they found it easy to read and comprehend, and they thought the booklet had the right amount information. The majority stated that the self-care booklet matched their experiences of raising a child with special needs, and that they could identify with the situations and experiences of other parents discussed in the booklet. There was no information in the booklet that parents disagreed with or did not find helpful. For many parents, reading the booklet was reassuring to know that they are not alone in their journey.

Some participants also commented on how the booklet can be used to reduce feelings of guilt and help parents acknowledge that is it okay to engage in self-care and prioritise their own needs. Nearly all participants commented on how the booklet is best located at the time of initial diagnosis, as many of them already knew a lot of the information by learning it through experience over time. Many participants stated that the booklet would be most helpful for parents to receive at the time of their child's diagnosis to assist them with their self-care through the first few years, which is often the most difficult time.

The second key theme identified was parents' ideas for change for the self-care booklet. A couple of participants found the booklet too long and dense in information. To address this, one parent suggested the development of an additional brief resource to sit alongside the booklet, such as an easy to read "map or diagram" to help navigate the booklet, or a worksheet or checklist of the self-care strategies listed in the booklet. Some participants identified phrasing and spelling edits which will need to be made before finalising the booklet. Three participants commented on the colour use and photos in the booklet, stating they would like more positive colours used and for the photos to be more genuine and diverse-obvious of special needs in NZ.

One participant commented on wanting the booklet to be more inclusive of different cultures' experiences, situations and beliefs within NZ. Some participants gave suggestions on additional content for the current booklet, as well as ideas for additional resources. Suggestions for this self-care booklet included adding sections covering strategies on maintaining safety for children and parents, legal processes and information, and strategies for caring for children with special needs once they become adults. Suggestions better suited for additional resources included families' rights within the education section, strategies for navigating the education system, and support for siblings of children with special needs. Participants also commented on ways they believed the booklet could be distributed to parents and families throughout NZ.

Theoretical Significance

Building on Study One, this research has also made an important contribution to the current literature through incorporating existing theories. In particular, Study Two incorporated theories including the transformative framework (Mertens, 2003), positive psychology (Seligman, 1998), and the health promotion paradigm (O'Donnell, 2008; Pender, 1996).

Transformative Framework

Study Two aligns with a transformative framework as it used knowledge gained from Study One and existing literature to give back to participants in a practical and collaborative way via the development of a psychoeducational resource (Creswell & Poth, 2017; Mertens, 2003). The current research incorporated critical methodological assumptions of a transformative framework, including the inclusion of a qualitative dimension as a way of establishing a dialogue between parents of children with HND and myself as the researcher (Mertens, 2010). Further, the current research aimed to address the needs of the disability community in partnership with parents through a cycle of inquiry (Creswell & Poth, 2017; Mertens, 2010). By incorporating a cyclical approach to research, results of Study One as the first cycle of inquiry fed into decisions made about this research as the next cycle, thereby enhancing validity of the information produced (Mertens, 2010; Mertens et al., 2009).

As issues facing marginalised groups are studied and exposed, such as those from the disability community, research creates a platform for the participants voices to be heard (Creswell & Poth, 2017). Thus, information gained collaboratively through research helps to raise awareness from the participants' perspectives, improve lives and create change for society. This was seen in the current study by the development of a psychoeducational resource (Creswell & Poth, 2017). In order to successfully achieve these aims in research, building trust and relationships with participants (whilst engaging in critical self-reflection) is paramount to obtaining valid data (Mertens et al., 2009). Through adopting a transformative framework, this research places priority on the empowerment of parents in the disability community, and on the furtherance of social justice for this population.

Positive Psychology

Secondly, Study Two provided an example of utilising positive psychology as an approach to research (Marino et al., 2017; Shogren et al., 2017; Seligman, 1998). By incorporating findings from a strengths-based perspective from Study One and existing health promotion literature, the current study developed a resource focused on ways parents as informal caregivers can psychosocially adapt and thrive when raising a child with HND (Livneh & Martz, 2016; Wright, 1983). Participants' largely positive response to the booklet likely indicates that it is a useful resource to help parents come to accept and respond to disability with positive coping strategies (Livneh & Martz, 2016; Wright, 1983).

Through incorporating findings from Study One, this research presents a resource which reflects self-care strategies that parents of children with HND currently find effective for promoting their wellbeing (Livneh & Martz, 2016; Marino et al., 2017; Wright, 1983). By approaching the self-care booklet from an underlying positive psychology perspective, this research aligns with the argument that building on the positive of parents' experiences (rather than directly working on the 'problem' of caregiver stress) is likely the most effective way of improving their sense of wellbeing (Livneh & Martz, 2016; Shogren et al., 2017).

Health Promotion Paradigm

Finally, the current study incorporated the health promotion paradigm (O'Donnell, 2008; Whitehead, 2004). Although the current study only provides a preliminary evaluation of the self-care booklet, participants' largely positive response supports the incorporation of a holistic and multidimensional conceptualisation of self-care and wellbeing (King, 1994). Providing a resource that educates and motivates parents as informal caregivers to engage in self-care is reflective of Pender’s (1996) Health Promotion Model. This model is based on the expectancy-value theory, which argues that parents engage in actions which they expect will result in valued outcomes (Pender et al., 2011). As the developed booklet was based on parents’ current experiences and enacted self-care strategies, participants’ positive feedback for the booklet may have reflected their increased expectation that the self-care strategies included in the booklet would result in positive outcomes (Pender et al., 2011; Raingruber, 2014). Having increased expectations in the effectiveness of the self-care strategies (due to them being modelled off other parents’ experiences), possibly moderates motivation and readiness to engage in health-promoting self-care behaviour (Raingruber, 2014).

Finally, this booklet incorporated the health promotion paradigm by targeting parents’ behaviour-specific cognitions, such as their perceived importance of self-care, by providing experiences and supported advice from parents in similar circumstances (Pender et al., 2011). The overall purpose of the booklet was to provide health education to enhance individuals’ understanding and knowledge, thereby leading to skill development and behaviour modification in the area of self-care and wellbeing (Sharma, 2017; Whitehead, 2004). As the current research was intended to inform parents and motivate possible positive wellbeing outcomes, it was imperative that self-care strategies incorporated realistic demands based on the priorities and preferences of parents as informal caregivers (Whitehead, 2004). Current findings tentatively support this claim, as participants’ qualitative statements and ratings indicated that the booklet was relevant for their situation and experiences.

Practical Implications

Findings from Study Two offer preliminary feedback for a psychoeducational resource designed to assist parents of children with disabilities in their journey, and to contribute to a greater understanding of how to best respond and support parents as informal caregivers. Practical implications from this study include the importance of seeking consumer perspectives, and the effective use of psychoeducational resources.

Consumer Perspectives

Firstly, current findings argue the need for psychoeducational interventions to incorporate consumer perspectives (in this instance being the parents’ themselves) in relation to their preferences, opinions, and need for information and supports (Gilson et al., 2018; Smith et al., 2015). In identifying the areas or specific strategies which are effective within parents' realities and experiences of raising a child with HND, this increases the likelihood that the developed intervention leads to positive outcomes for parents and their families (Gilson et al., 2018; Smith et al., 2015). By seeking parents' perspectives (both prior to the development of this resource in Study One, and by asking for feedback on the developed booklet in the current study), findings suggest that the booklet is compelling and easy to use for the intended audience (Lyon & Koerner, 2016). Participants' largely positive feedback and ratings for the self-care booklet support its use as an acceptable and responsive evidence-based intervention for parents of children with HND (Lyon & Koerner, 2016; Sanders & Kirby, 2015).

The current study shows promise for the approach of including consumer perspectives and needs through direct parent participation in the initial development, evaluation and redesign for the psychoeducational resource (Boote, Baird & Beecroft, 2010). Nevertheless, as current findings are preliminary and cross-sectional with a small sample, the developed self-care booklet requires ongoing evaluation and adjustment to ensure that it is responsive to the local NZ context and it remains relevant over time (Chambers, Glasgow & Strange, 2013; Lyon & Koerner, 2016). From the current findings, it is not yet possible to assert that the developed booklet is effective in improving parents' self-care. Further, cultural diversity needs to be addressed in the on-going development and evaluation of the booklet by incorporating culturally diverse consumer perspectives within NZ. In doing so, this will help to correct cultural heterogeneity and enhance the overall quality and usability of the resource (Kujala & Kauppinen, 2004; Lyon & Koerner, 2016).

Psychoeducational Intervention

Secondly, the current findings tentatively support the use of psychoeducational interventions and resources for parents of children with special needs. Consistent with existing literature, participants' feedback indicated that many of them benefitted from reading the developed self-care booklet (Gilson et al., 2018; Krishnan et al., 2018; Srivastava & Panday, 2016). Participants' ratings and comments suggested that the booklet helped them improve their knowledge and awareness of self-care, and it provided them with emotional validation and a sense of 'permission' to engage in self-care (Gilson et al., 2018; Krishnan et al., 2018; Srivastava & Panday, 2016).

Although current findings are preliminary and cannot assert that the booklet is effective in improving parents' self-care, future evaluation of the booklet may indicate that it is a useful preventative intervention for reducing parents' distress and improving wellbeing (Krishnan et al., 2018; Srivastava & Panday, 2016). Nevertheless, this is suggested as participants' current comments state that the booklet would have been beneficial for them particularly at the time of initial diagnosis as a first-step intervention (Gilson et al., 2018; Krishnan et al., 2018; Lukens & McFarlane, 2006).

Current findings align with existing literature which have found that passive psychoeducational resources, such as booklets or leaflets, are effective for improving knowledge relevant to health, encouraging wellbeing through the inclusion of evidence-based strategies, and assisting individuals with managing periods of transition and crisis (Gilson et al., 2018; Lukens & McFarlane, 2006). Due to this, psychoeducational resources can address the determinants of poor mental health, and they can alleviate distress as a preventative, first-step approach (Gilson et al., 2018; Lukens & McFarlane, 2006).

Given the substantial evidence that parents of children with special needs are at increased risk for adverse outcomes, that self-help resources and interventions continue to be scarce in this area, and that the current study only provides a preliminary evaluation of the developed self-care booklet, there is a clear need for further research in this area (Gilson et al., 2018; Marino et al., 2017; McConnell & Savage, 2015). Further research and development of beneficial and cost-effective interventions aimed at improving wellbeing for parents as informal caregivers is essential to support parents' capacity to provide quality care for their child with special needs. Also, additional areas for support identified in this study would also benefit from further research and developed interventions, including navigating the education system for children with disabilities and improving the wellbeing for siblings of children with special needs.

Limitations and Considerations for Future Research

Study Two provided further insight into the experience of self-care and wellbeing for parents when raising children with HND in NZ, along with a preliminary evaluation of a developed psychoeducational and therapeutic resource for parents. Nevertheless, it is important to acknowledge the limitations of this study and to consider ideas for future research. First, due to time constraints, the current study did not include any pre-post measures or validated quantitative measures to distinguish whether parents' awareness or motivation to engage in self-care had been enhanced having read the booklet. As the current study provided a preliminary evaluation of parents' feedback, a more systematic evaluation with a greater number of participants is required to capture parents' views of the resource and to address its usability and effectiveness within a NZ context (i.e., via online surveys). Further evaluation of the booklet would subsequently inform additional revisions of the resource through a cycle of inquiry, turning the booklet into a 'living document' and ensuring that it remains responsive and effective to parents' needs over time (Lyon & Koerner, 2016; Mertens, 2010).

A second limitation was the small sample size of 14 participants who volunteered to share their views of the booklet. Further, the methodology incorporated only a cross-sectional snapshot of these participants' views within a particular time, place and cultural context. Due to this, the current findings may not capture the breadth of perspectives held by the broader NZ population. Also, as the study had no upper age limit for the child's age, the sample consisted of many parents of children who were teenagers or young adults. As only preliminary findings were sought, the inclusion criteria did not look specifically at disability type or objectively measure for disability severity. Due to this variation within the sample, the current study does not account for possible differences in opinions amongst parents of children in different age groups, or amongst parents of children with different disability types or severity.

Although every effort was made to include a diverse range of parents (reflective of NZ's varied population and cultures), the current sample consisted largely of mothers and those who identified as NZ European. Due to this, it is unclear whether current findings are fully reflective of fathers' opinions and those from other cultures within NZ, who may have different experiences and perspectives. Therefore, future evaluation of the booklet and research into this area should consider additional methods to further incorporate informal caregivers within NZ with differing gender and demographic characteristics currently underrepresented in research.

The limited response from Māori, Pacific and Asian populations could be explained by language and communication barriers due to research information and the self-care booklet being presented in English, as well as differing cultural perspectives and interpretations of disability to that of the researcher. Although already stated in Study One, the underrepresentation of Māori (and those from ethnic minority groups within NZ) within disability research may be addressed through working alongside representatives of these communities to adapt research methods, accessibility and language used (Pihama, Cram & Walker, 2002). Future research in the area of self-care for parents and whānau caregivers incorporating an indigenous Māori world view in NZ is imperative (Pihama et al., 2002). Further, future research could also focus on evaluating the developed self-care resource for its cultural appropriateness and sensitivity. Following this, the booklet could be adapted as appropriate for use with parents and carers of different cultural and linguistic backgrounds within NZ. Adapting the self-care resource may result in differing delivery methods from a psychoeducational booklet as appropriate for Māori and those from ethnic minority groups. For example, different methods of delivery could include workshops, peer support groups, social media or software application (i.e., mobile “app”).

Finally, limitations regarding the current methodology may include social desirability bias by the participants. Although the questionnaire had the option for participants to remain anonymous, some of the parents were known to the researcher due to their participation in Study One and from my personal networks within the disability community from my work as a respite carer. Further, my position within the research as a carer for children with disabilities, with clinical psychology training (and the influence this may have had on the development of the booklet, and on the analysis and interpretation of parents’ feedback), must be considered (Creswell & Poth, 2017). Overall, although this study provides promising initial feedback on the developed booklet and clear ideas for change (which will be implemented following thesis submission), there remains considerable scope for evaluating and improving the self-care resource within a NZ context.

Summary

Study Two addressed a gap in existing literature by developing and evaluating a psychoeducational resource booklet designed to enhance parents’ self-care and perceived wellbeing while raising children with HND in NZ. This booklet was shaped by a positive health promotion paradigm, and it was constructed by integrating findings from Study One and existing literature. Preliminary evaluation of the self-care resource was achieved via descriptive statistics and thematic analysis of questionnaire data with 14 participants. Participants' quantitative ratings of the booklet were largely positive regarding the booklet content, usability, and format. Further, two key themes were identified regarding participants' qualitative comments – Positive Remarks and their Ideas for Change.

Building on Study One, findings from Study Two incorporated existing theories including the transformative framework (Mertens, 2003), positive psychology (Seligman, 1998), and the health promotion paradigm (O'Donnell, 2008; Pender, 1996). Further, current findings held practical implications including the importance of seeking consumer perspectives, and the use of psychoeducational resources. Despite limitations and a need for further research in this area, the current study has made an important contribution to increasing understanding in the disability field. Also, the resultant resource appears promising as a therapeutic, evidence-based tool for enhancing parents' self-care and perceived wellbeing when raising children with special needs. The changes for the self-care booklet as recommended by parents from this study will be enacted on following the conclusion of this thesis. The next chapter provides overall conclusions and reflections on both Study One and Study Two to conclude the thesis.

SECTION FOUR

CHAPTER EIGHTEEN:

Overall Conclusions and Reflections

This research project was inspired by the need for further support and understanding for parents and families of children with special needs in NZ, which I became aware of through my personal experiences as a respite carer and friend within the disability community. Although the majority of the families I knew were able to access supports and resources for their children, the focus appeared largely restricted to the child's individual wellbeing, without much consideration for their wider family or systems who are also significantly impacted by disability (Murray, 2018). Therefore, the current research project aimed to give back to parents and caregivers. Also, in accordance with ecological systems theory, an increased understanding in parents' experiences and wellbeing may have a flow on effect for improving their child's wellbeing, the parent-child relationship, and overall family functioning as well (Friedman & Allen, 2011; Goodhead & McDonald, 2007; Gouin et al., 2016; Whiting et al., 2019).

Through my personal experiences, I noticed a dichotomy for parents as informal caregivers between the incredible toll that caregiving responsibilities can have on their physical health, emotional and spiritual wellbeing, and relationships, alongside parents' incredible resilience, courage and inner strength to carry on every day despite these challenges. However, existing literature within the disability field did not appear to reflect this dichotomy, as the dominant approach focused largely on the adverse outcomes of informal caregiving for parents of children with special needs (Acton, 2002; Marino et al., 2017; McConnell & Savage, 2015). Research which approached childhood disability from a positive, strengths-based perspective was very limited. Therefore, a strength of the current research project included that it addressed this gap in the literature by first exploring self-care and wellbeing for parents of children with HND from the parents' perspectives (Study One), and then developing and evaluating a psychoeducational resource aimed at enhancing parents' self-care and perceived wellbeing (Study Two).

From Study One, four main themes arose regarding effective self-care from parents' experiences: building formal supports and resources; maintaining informal relationships; considering values and goals; and balancing time. Findings from Study One aligned with existing theories including Bronfenbrenner's (1977) Ecological Systems theory, the narrative paradigm, positive psychology and strengths-based approach, and Pender's (1996) Health-Promotion Model. Further, findings from Study One held practical implications for viewing self-care and wellbeing as holistic constructs, working in collaboration with parents, offering psychosocial support to families, and developing psychoeducational interventions and resources.

Preliminary findings from Study Two, including parents' quantitative ratings and qualitative feedback on the developed self-care booklet, was largely positive and identified two key themes: parents' positive remarks; and their ideas for change. These preliminary findings built on Study One and incorporated existing theories, including the transformative framework (Mertens, 2003), positive psychology (Seligman, 1998), and the health promotion paradigm (O'Donnell, 2008; Pender, 1996). Further, Study Two held practical implications which included the importance of seeking consumer perspectives, and the effective use of psychoeducational resources.

The current research highlights the importance of working alongside participants to benefit both advancements in academic literature, as well as practical and societal change as a way of 'giving back' (Mertens, 2010). Working in partnership and collaborating with participants through a cycle of inquiry acknowledges that participants are the expert of their reality and knowledge, which can be empowering for those within minority groups (Creswell & Poth, 2017; Mertens, 2003). As many of the holistic self-care strategies parents found effective from Study One aligned with various empirically-supported therapeutic techniques, I believe this supports the argument that participants and consumers provide invaluable perspectives when researchers work 'with' them, rather than 'on' or 'to' them as many historical approaches endorse (Baer, 2015; Bexelius et al., 2018; Creswell & Poth, 2017; Gupta & Singhal, 2004; Krishnan et al., 2018; Mazzucchelli et al., 2010; Mertens, 2003; Speed et al., 2017).

By directing this research project towards parents' experiences of self-care and wellbeing from a positive health promotion and transformative framework, current findings contribute to the literature by giving a voice to parents of children with special needs and by challenging the assumption that caregiving results predominantly in adverse outcomes (Creswell & Poth, 2017; Marino et al., 2017; McConnell & Savage, 2015). As this approach to research requires trust between the participant and researcher, I believe my previous experiences in the disability community and my clinical psychology training were beneficial for this research project.

I acknowledge that there may have been bias due to me having known some of the participants in an employment setting, as well as me bringing my own assumptions to the analysis and interpretation of findings. However, I believe having some awareness of the challenges, strengths, and practical knowledge in the disability community aided my ability to build rapport, validate participants' experiences and difficulties, and interpret the meaning within their qualitative statements (Mertens, 2010; Tomm, 2002). My training in clinical psychology and my strength-based approach to working with clients or research participants may also have biased data collection and interpretation. However, as findings from Study One highlighted a shared need for the participants to discuss the challenging and negative experiences of raising a child with HND alongside their self-care strategies, I believe this indicated that most parents felt comfortable discussing various 'good' and 'bad' aspects of being an informal caregiver with me.

Shared limitations from both studies in this research included possible demographic bias by the two samples not being fully reflective of NZ's varied population and cultures, as the majority of participants identified as New Zealand European women. Therefore, future research into this area should consider additional methods to further incorporate informal caregivers in NZ with differing gender, cultural, and demographic characteristics currently underrepresented in research. This is particularly so for Māori, as NZ has a responsibility to improve representation of Māori in all aspects of life, including health promotion and academic research, in accordance with the Treaty of Waitangi (1840).

I am mindful of my own cultural biases being a NZ European woman and limitations in effectively completing research with other cultural groups. However, I would strongly support advocating and working alongside Māori (and those from all ethnic minority groups within NZ) to adapt research methods, accessibility and language used for disability research in this area (Pihama et al., 2002). Further, Kaupapa Māori research may offer alternative conceptualisations of self-care and wellbeing for parents as informal caregivers that would likely result in important practical implications for providing support specific to this NZ population (Pihama et al., 2002). In working alongside Māori, I welcome and believe it imperative to adapt the developed self-care booklet – or to create additional, more appropriate supports and resources – to better accommodate a Māori world view.

As the current study was exploratory in nature (due to there being limited existing literature in this area), and there being no similar studies conducted in a NZ context, the methodology of qualitative inquiry, a transformative framework, thematic analysis and preliminary evaluation across the two studies was appropriate (Braun & Clarke, 2012; Creswell & Poth, 2017; Mertens, 2003; Noble & Smith, 2015). Nevertheless, current findings represent a cross-sectional snapshot of two small samples within a particular time, place and cultural context. As this research had a relatively small sample size of parents who volunteered to share their experiences and views for the two studies, a limitation includes that findings may have not captured the breadth of experiences and opinions held by the wider NZ population of parents as informal caregivers. Limitations regarding the current methodology may also include social desirability bias from participants. Suggestions to address limitations for future research include increasing sample sizes, utilising a mixed methods approach, and implementing qualitative and quantitative longitudinal research methods (Carduff et al., 2015; Creswell & Poth, 2017).

Nevertheless, this research project provided a 'voice' and new insights into a previously unrepresented research population within a NZ context for which future research can grow and develop. The current findings have made an important contribution to theory and practice in the disability field, and they challenge the assumption within existing literature that informal caregiving predominately results in adverse outcomes (McConnell & Savage, 2015). Study One provided new understandings of the experiences of self-care and wellbeing for parents raising children with HND. It also highlighted the complex, multi-layered aspects to self-care which requires support from wider systems in a child and parent's life (Bronfenbrenner, 1977; Gouin et al., 2016). Study Two provided support for findings from the first study. Further, it resulted in a therapeutic, evidence-based psychoeducational resource which appears promising for enhancing parents' self-care and perceived wellbeing when raising children with special needs.

The benefits of this research project include that current findings (and the resultant resource booklet) will potentially contribute to enhancing understanding in the area of childhood disabilities and caregiver needs within NZ. These findings work towards helping parents better adjust to the difficulties of a new diagnosis and caring for their child's disability. Current findings may also contribute towards helping health practitioners provide support that is more meaningful to parents as informal caregivers, and towards informing future research and the design of interventions to better facilitate self-care and wellbeing for parents of children with disabilities. At a systems level, enhancing awareness and understanding of disability for the NZ public may facilitate a more supportive societal environment for families and children with special needs. At an individual level, enhancing awareness and understanding of disability may provide hope for parents to be able to thrive in their journey as informal caregivers.

> *If you're constantly giving, giving, giving, eventually there's not going to be anything left. So, if you have that time for yourself where you're enriching yourself in one way or the other, of course you're going to be a better mother… I firmly believe that if you're not good, they're not good. I think more and more I realize that we actually come first, not the kids.*
>
> (Kate, full-time mother of a 7-year-old son with cerebral palsy, personal communication, May 2017)

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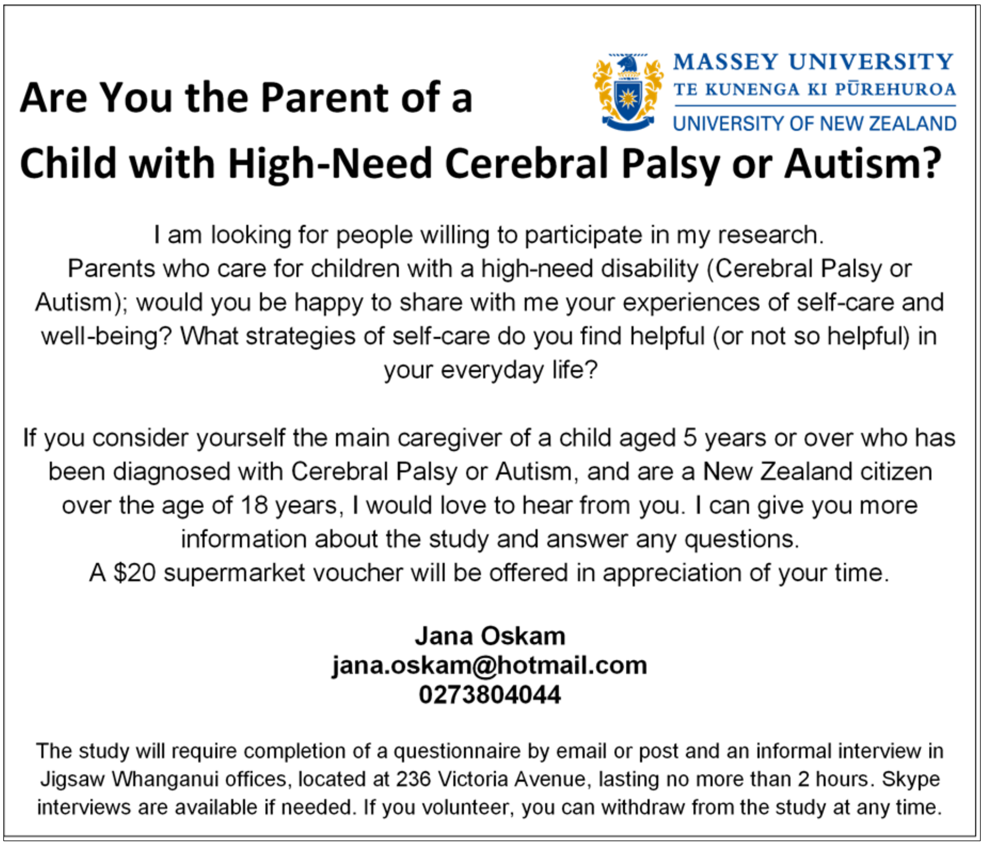
APPENDIX A:

Advertisement Flyer for Study One



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UNIVERSITY OF NEW ZEALAND

Are You the Parent of a Child with High-Need Cerebral Palsy or Autism?

I am looking for people willing to participate in my research. Parents who care for children with a high-need disability (Cerebral Palsy or Autism); would you be happy to share with me your experiences of self-care and well-being? What strategies of self-care do you find helpful (or not so helpful) in your everyday life?

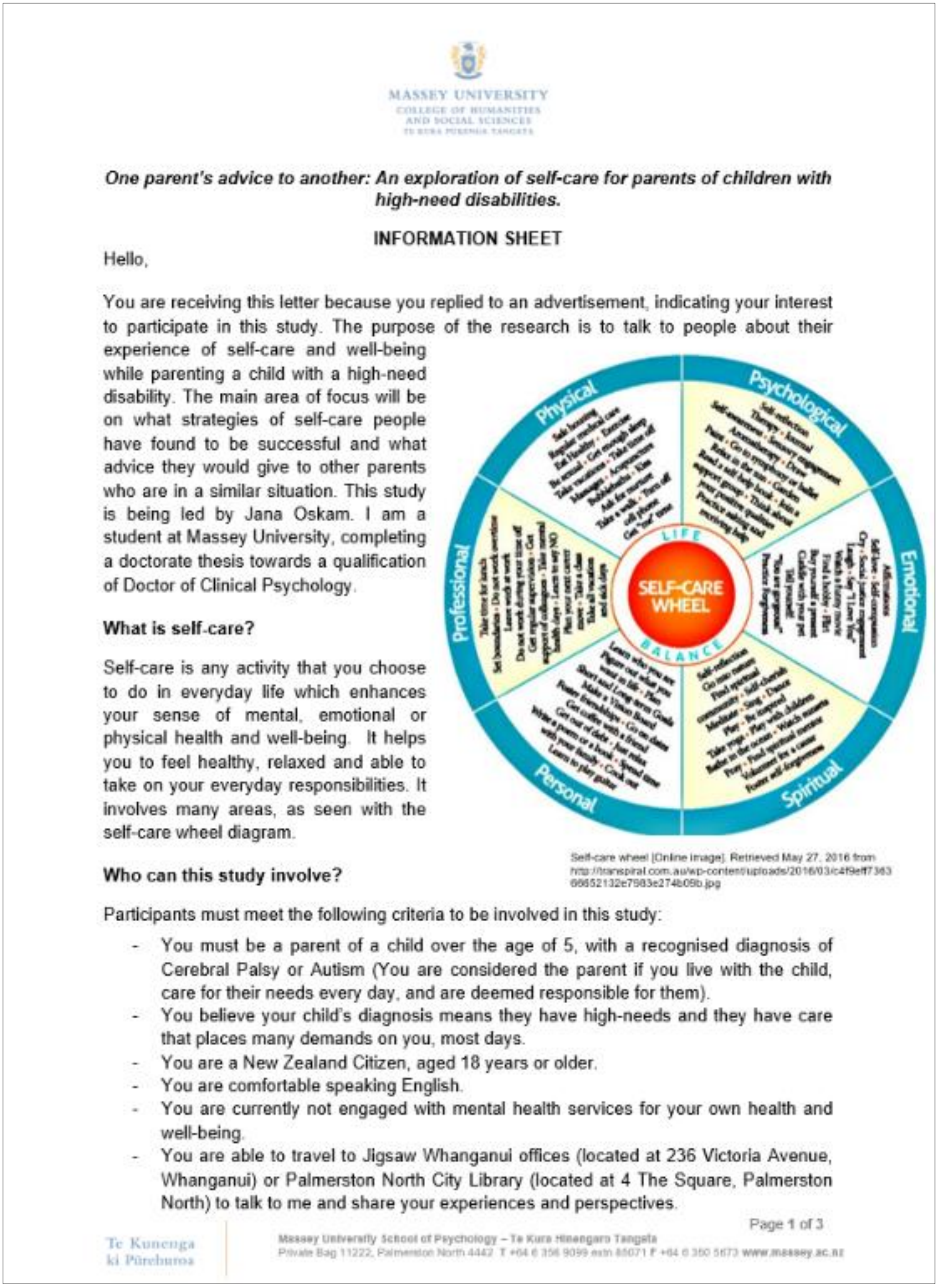
If you consider yourself the main caregiver of a child aged 5 years or over who has been diagnosed with Cerebral Palsy or Autism, and are a New Zealand citizen over the age of 18 years, I would love to hear from you. I can give you more information about the study and answer any questions.
A $20 supermarket voucher will be offered in appreciation of your time.

Jana Oskam
jana.oskam@hotmail.com
0273804044

The study will require completion of a questionnaire by email or post and an informal interview in Jigsaw Whanganui offices, located at 236 Victoria Avenue, lasting no more than 2 hours. Skype interviews are available if needed. If you volunteer, you can withdraw from the study at any time.

APPENDIX B:

Information Sheet for Study One



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TE KURA PŪKENGA TANGATA

One parent's advice to another: An exploration of self-care for parents of children with high-need disabilities.

INFORMATION SHEET

Hello,

You are receiving this letter because you replied to an advertisement, indicating your interest to participate in this study. The purpose of the research is to talk to people about their experience of self-care and well-being while parenting a child with a high-need disability. The main area of focus will be on what strategies of self-care people have found to be successful and what advice they would give to other parents who are in a similar situation. This study is being led by Jana Oskam. I am a student at Massey University, completing a doctorate thesis towards a qualification of Doctor of Clinical Psychology.

What is self-care?

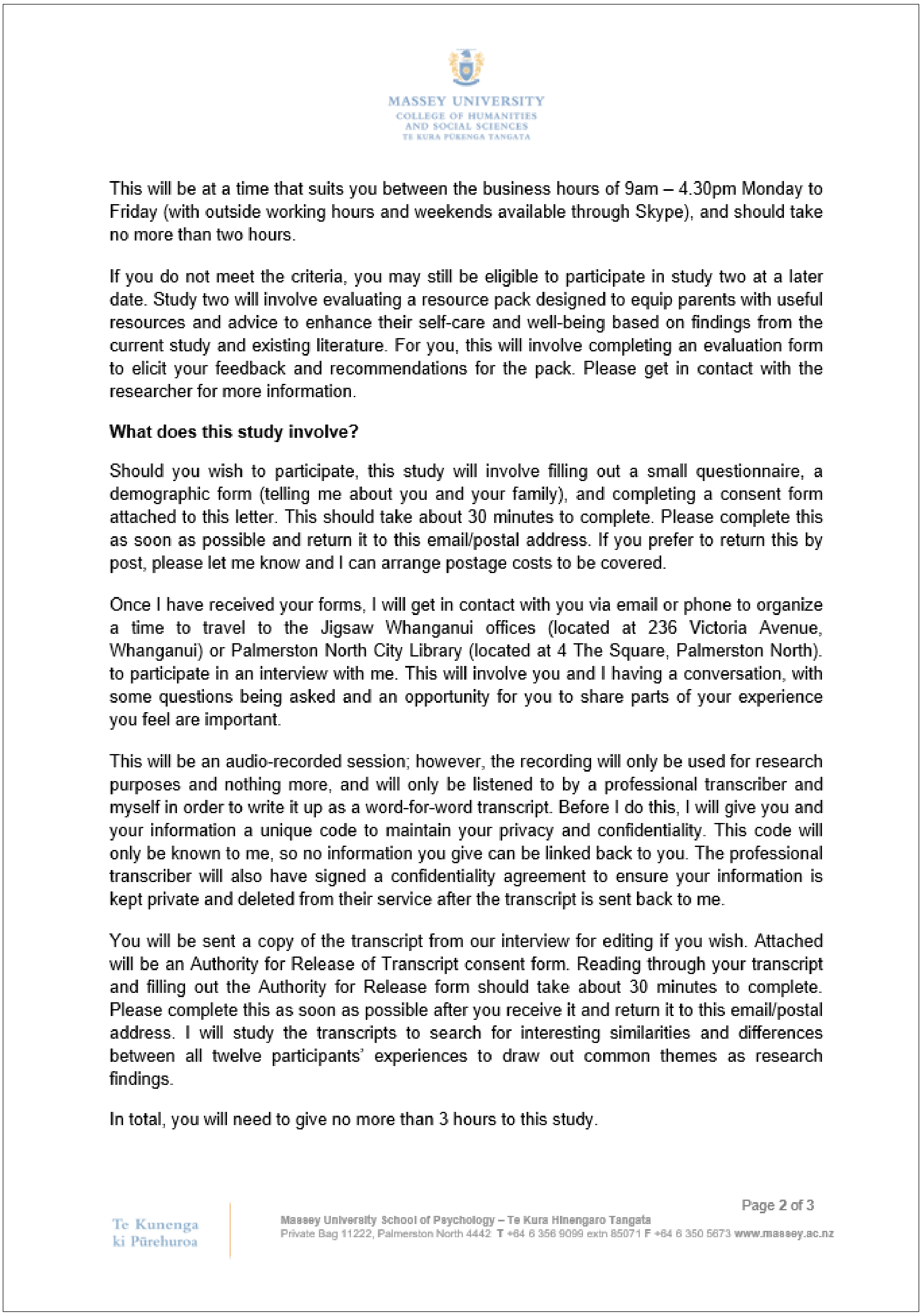
Self-care is any activity that you choose to do in everyday life which enhances your sense of mental, emotional or physical health and well-being. It helps you to feel healthy, relaxed and able to take on your everyday responsibilities. It involves many areas, as seen with the self-care wheel diagram.

Self-care wheel [Online image]. Retrieved May 27, 2016 from http://transpiral.com.au/wp-content/uploads/2016/03/c4f9eff7363 66652132e7983e274b09b.jpg

Who can this study involve?

Participants must meet the following criteria to be involved in this study:

- You must be a parent of a child over the age of 5, with a recognised diagnosis of Cerebral Palsy or Autism (You are considered the parent if you live with the child, care for their needs every day, and are deemed responsible for them).
- You believe your child's diagnosis means they have high-needs and they have care that places many demands on you, most days.
- You are a New Zealand Citizen, aged 18 years or older.
- You are comfortable speaking English.
- You are currently not engaged with mental health services for your own health and well-being.
- You are able to travel to Jigsaw Whanganui offices (located at 236 Victoria Avenue, Whanganui) or Palmerston North City Library (located at 4 The Square, Palmerston North) to talk to me and share your experiences and perspectives.



This will be at a time that suits you between the business hours of 9am – 4.30pm Monday to Friday (with outside working hours and weekends available through Skype), and should take no more than two hours.

If you do not meet the criteria, you may still be eligible to participate in study two at a later date. Study two will involve evaluating a resource pack designed to equip parents with useful resources and advice to enhance their self-care and well-being based on findings from the current study and existing literature. For you, this will involve completing an evaluation form to elicit your feedback and recommendations for the pack. Please get in contact with the researcher for more information.

What does this study involve?

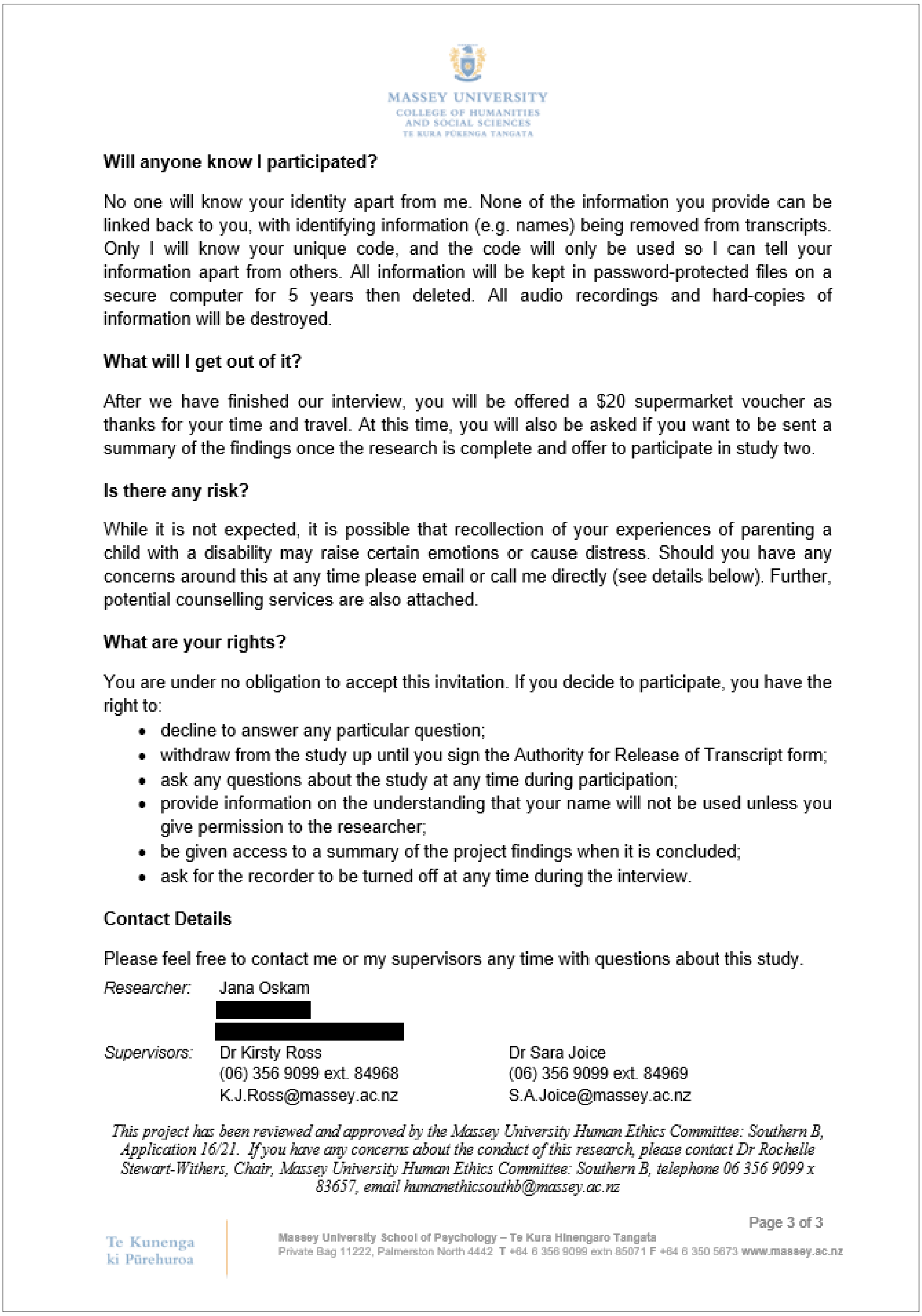
Should you wish to participate, this study will involve filling out a small questionnaire, a demographic form (telling me about you and your family), and completing a consent form attached to this letter. This should take about 30 minutes to complete. Please complete this as soon as possible and return it to this email/postal address. If you prefer to return this by post, please let me know and I can arrange postage costs to be covered.

Once I have received your forms, I will get in contact with you via email or phone to organize a time to travel to the Jigsaw Whanganui offices (located at 236 Victoria Avenue, Whanganui) or Palmerston North City Library (located at 4 The Square, Palmerston North). to participate in an interview with me. This will involve you and I having a conversation, with some questions being asked and an opportunity for you to share parts of your experience you feel are important.

This will be an audio-recorded session; however, the recording will only be used for research purposes and nothing more, and will only be listened to by a professional transcriber and myself in order to write it up as a word-for-word transcript. Before I do this, I will give you and your information a unique code to maintain your privacy and confidentiality. This code will only be known to me, so no information you give can be linked back to you. The professional transcriber will also have signed a confidentiality agreement to ensure your information is kept private and deleted from their service after the transcript is sent back to me.

You will be sent a copy of the transcript from our interview for editing if you wish. Attached will be an Authority for Release of Transcript consent form. Reading through your transcript and filling out the Authority for Release form should take about 30 minutes to complete. Please complete this as soon as possible after you receive it and return it to this email/postal address. I will study the transcripts to search for interesting similarities and differences between all twelve participants' experiences to draw out common themes as research findings.

In total, you will need to give no more than 3 hours to this study.



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Will anyone know I participated?

No one will know your identity apart from me. None of the information you provide can be linked back to you, with identifying information (e.g. names) being removed from transcripts. Only I will know your unique code, and the code will only be used so I can tell your information apart from others. All information will be kept in password-protected files on a secure computer for 5 years then deleted. All audio recordings and hard-copies of information will be destroyed.

What will I get out of it?

After we have finished our interview, you will be offered a $20 supermarket voucher as thanks for your time and travel. At this time, you will also be asked if you want to be sent a summary of the findings once the research is complete and offer to participate in study two.

Is there any risk?

While it is not expected, it is possible that recollection of your experiences of parenting a child with a disability may raise certain emotions or cause distress. Should you have any concerns around this at any time please email or call me directly (see details below). Further, potential counselling services are also attached.

What are your rights?

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study up until you sign the Authority for Release of Transcript form;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;
- ask for the recorder to be turned off at any time during the interview.

Contact Details

Please feel free to contact me or my supervisors any time with questions about this study.

Researcher: Jana Oskam
[redacted]

Supervisors:	Dr Kirsty Ross (06) 356 9099 ext. 84968 K.J.Ross@massey.ac.nz	Dr Sara Joice (06) 356 9099 ext. 84969 S.A.Joice@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 16/21. If you have any concerns about the conduct of this research, please contact Dr Rochelle Stewart-Withers, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83657, email humanethicsouthb@massey.ac.nz

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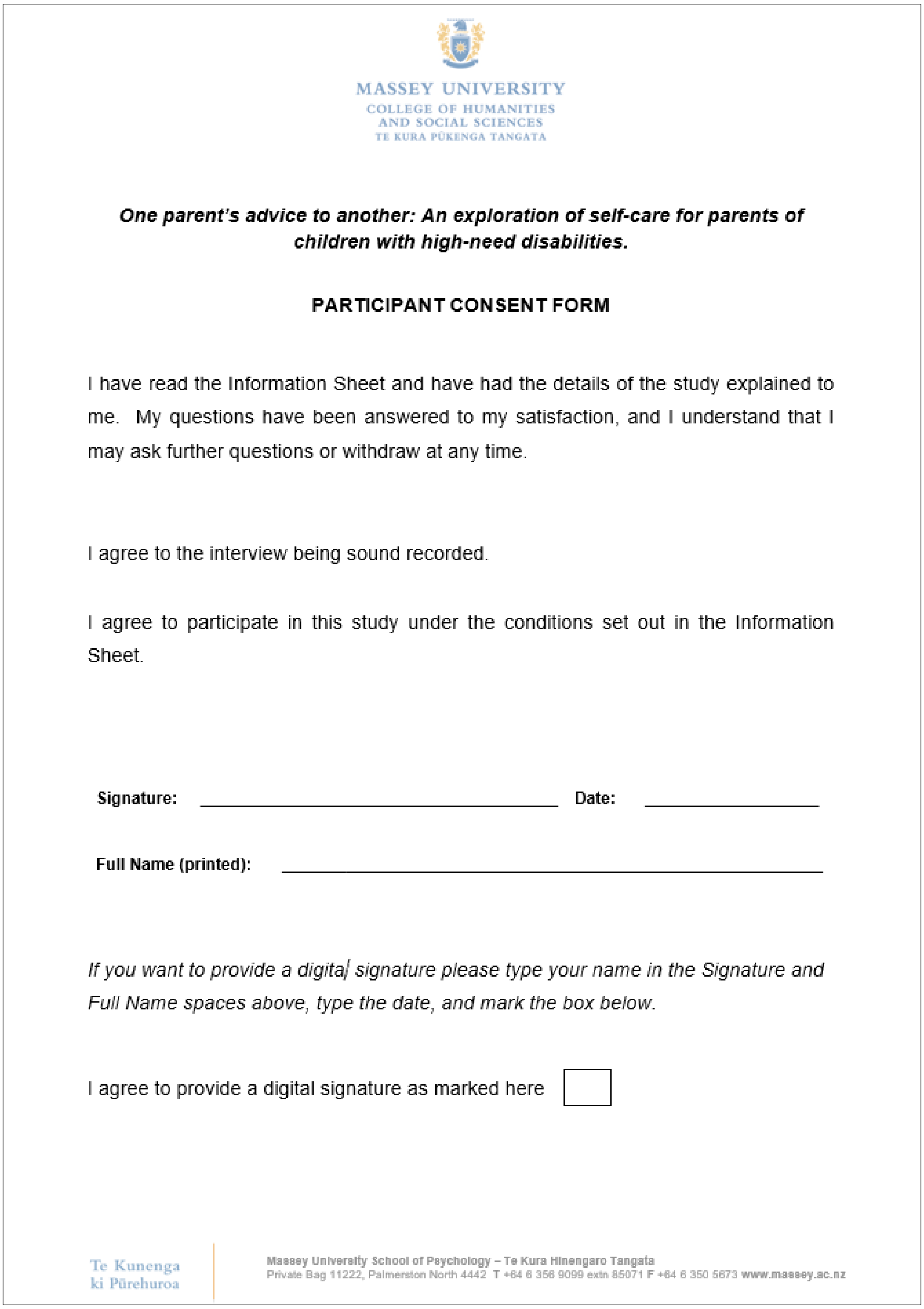
APPENDIX C:

Consent Form for Study One



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One parent's advice to another: An exploration of self-care for parents of children with high-need disabilities.

PARTICIPANT CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions or withdraw at any time.

I agree to the interview being sound recorded.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: ______________________________ **Date:** _______________

Full Name (printed): ______________________________________

If you want to provide a digital signature please type your name in the Signature and Full Name spaces above, type the date, and mark the box below.

I agree to provide a digital signature as marked here ☐

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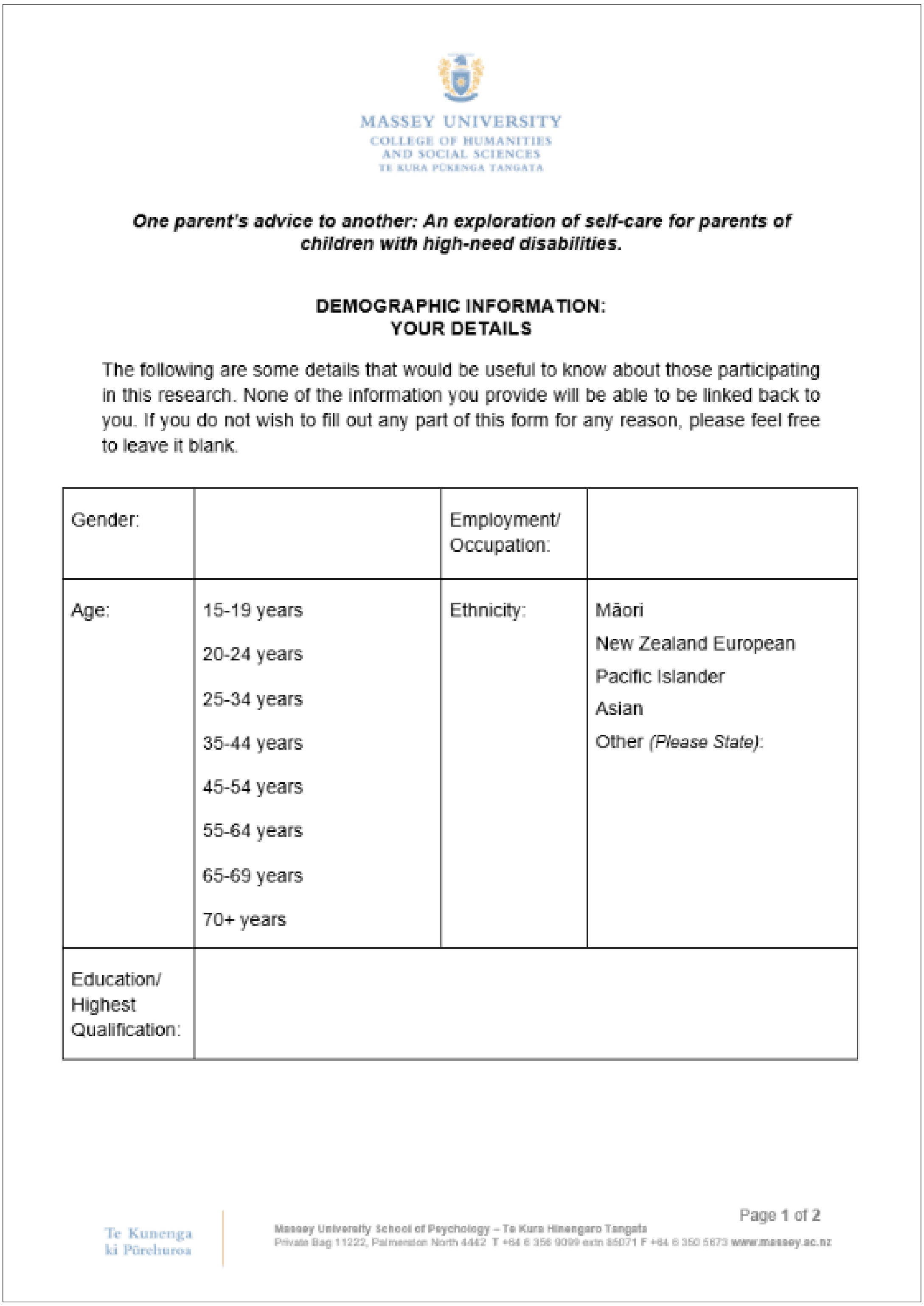
APPENDIX D:

Demographic Information Form for Study One



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One parent's advice to another: An exploration of self-care for parents of children with high-need disabilities.

DEMOGRAPHIC INFORMATION:
YOUR DETAILS

The following are some details that would be useful to know about those participating in this research. None of the information you provide will be able to be linked back to you. If you do not wish to fill out any part of this form for any reason, please feel free to leave it blank.

Gender:		Employment/ Occupation:	
Age:	15-19 years 20-24 years 25-34 years 35-44 years 45-54 years 55-64 years 65-69 years 70+ years	Ethnicity:	Māori New Zealand European Pacific Islander Asian Other *(Please State)*:
Education/ Highest Qualification:			

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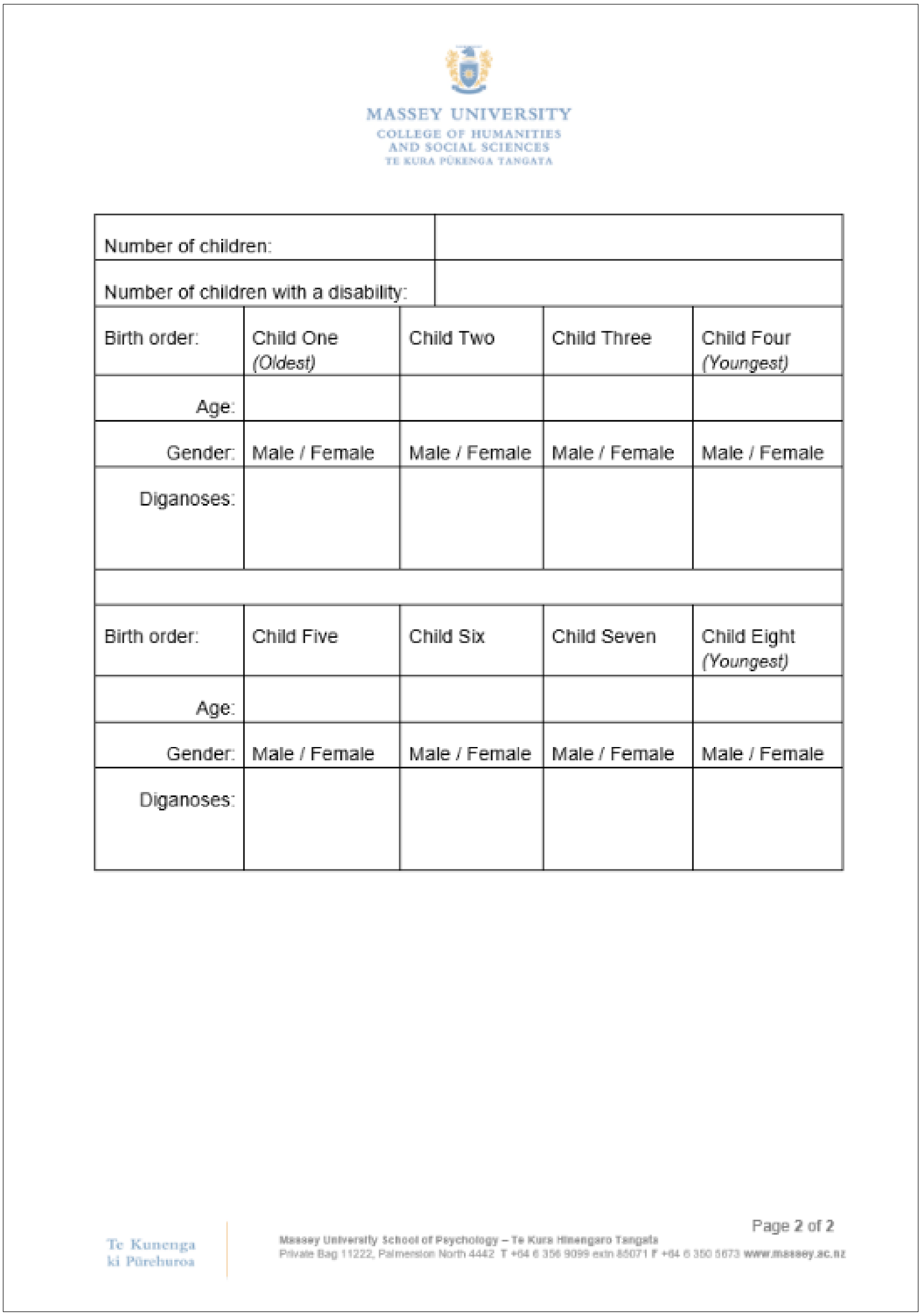

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Number of children:				
Number of children with a disability:				
Birth order:	Child One *(Oldest)*	Child Two	Child Three	Child Four *(Youngest)*
Age:				
Gender:	Male / Female	Male / Female	Male / Female	Male / Female
Diganoses:				
Birth order:	Child Five	Child Six	Child Seven	Child Eight *(Youngest)*
Age:				
Gender:	Male / Female	Male / Female	Male / Female	Male / Female
Diganoses:				

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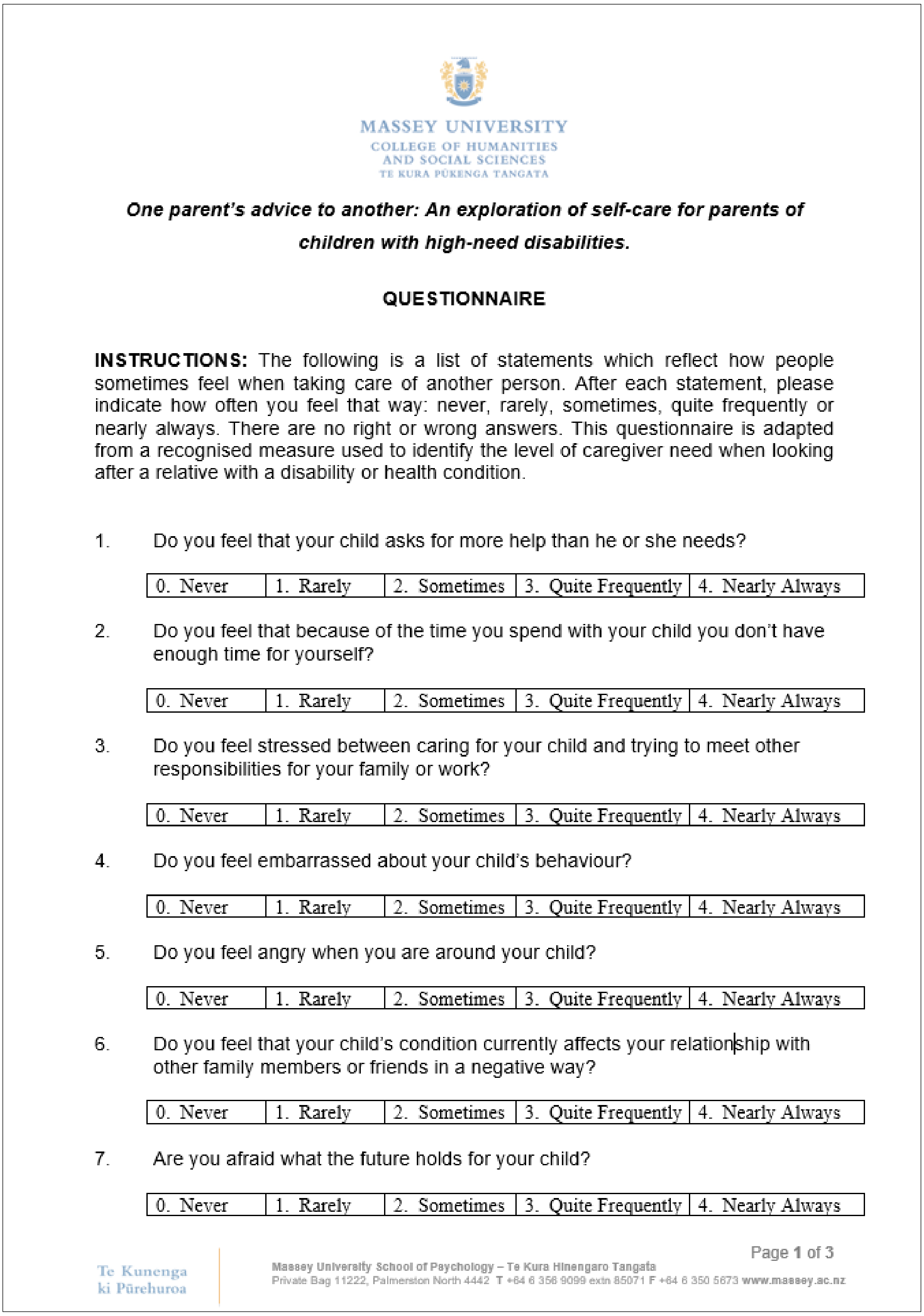
APPENDIX E:

ZBI Screening Measure for Study One



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QUESTIONNAIRE

INSTRUCTIONS: The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, please indicate how often you feel that way: never, rarely, sometimes, quite frequently or nearly always. There are no right or wrong answers. This questionnaire is adapted from a recognised measure used to identify the level of caregiver need when looking after a relative with a disability or health condition.

1. Do you feel that your child asks for more help than he or she needs?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

2. Do you feel that because of the time you spend with your child you don't have enough time for yourself?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

3. Do you feel stressed between caring for your child and trying to meet other responsibilities for your family or work?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

4. Do you feel embarrassed about your child's behaviour?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

5. Do you feel angry when you are around your child?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

6. Do you feel that your child's condition currently affects your relationship with other family members or friends in a negative way?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

7. Are you afraid what the future holds for your child?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

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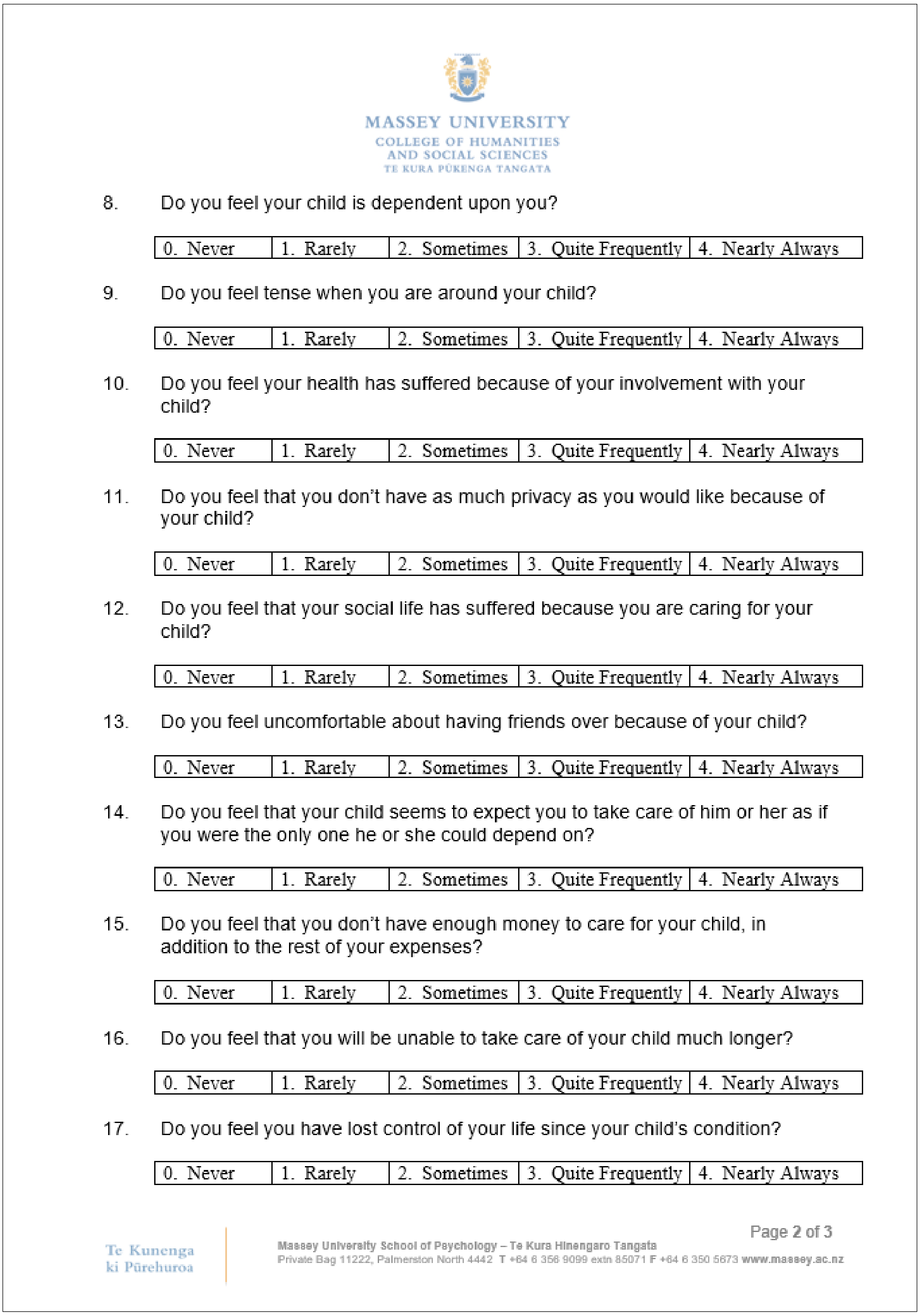

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8. Do you feel your child is dependent upon you?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

9. Do you feel tense when you are around your child?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

10. Do you feel your health has suffered because of your involvement with your child?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

11. Do you feel that you don't have as much privacy as you would like because of your child?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

12. Do you feel that your social life has suffered because you are caring for your child?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

13. Do you feel uncomfortable about having friends over because of your child?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

14. Do you feel that your child seems to expect you to take care of him or her as if you were the only one he or she could depend on?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

15. Do you feel that you don't have enough money to care for your child, in addition to the rest of your expenses?

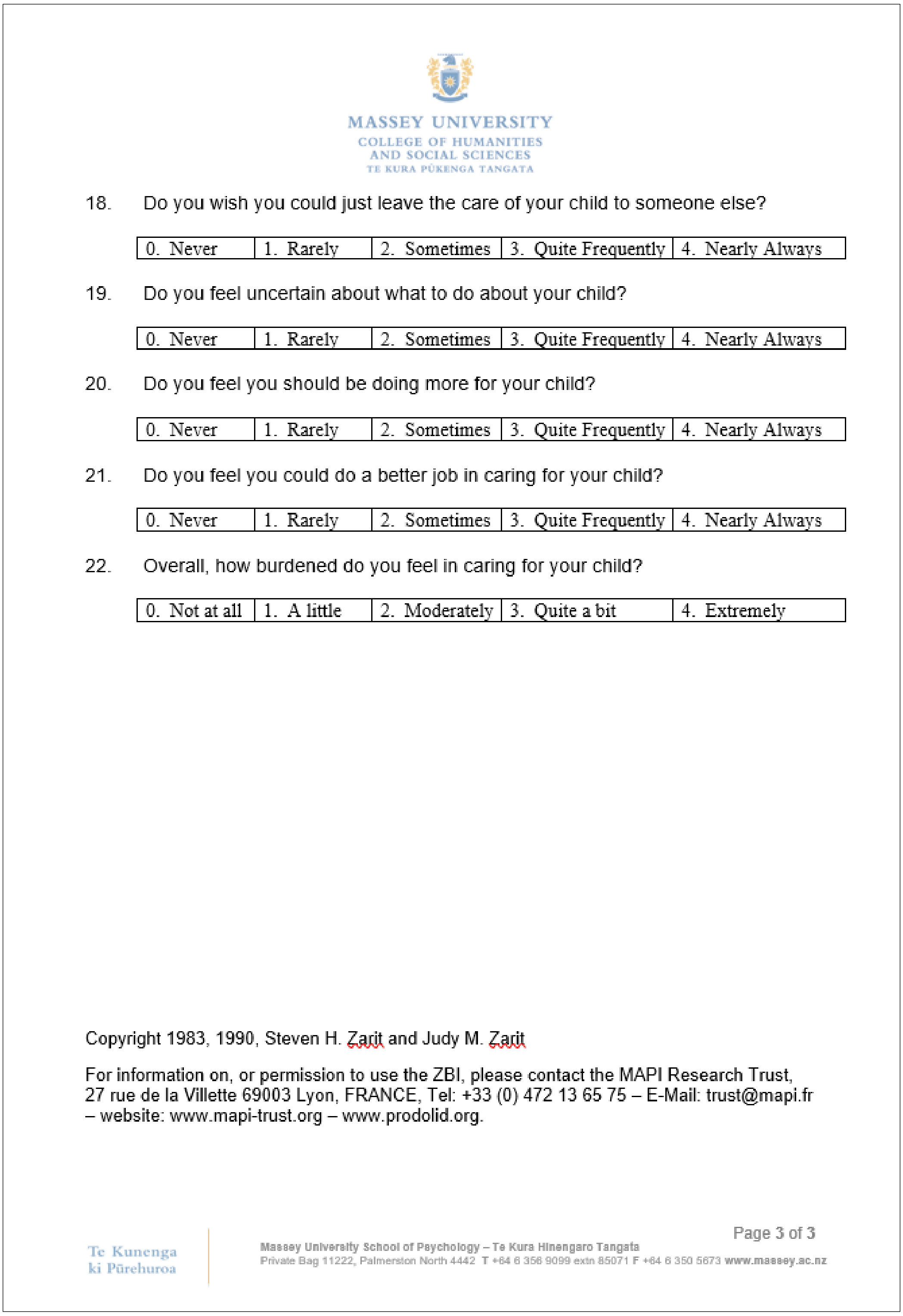
0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

16. Do you feel that you will be unable to take care of your child much longer?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

17. Do you feel you have lost control of your life since your child's condition?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always



18. Do you wish you could just leave the care of your child to someone else?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

19. Do you feel uncertain about what to do about your child?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

20. Do you feel you should be doing more for your child?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

21. Do you feel you could do a better job in caring for your child?

0. Never	1. Rarely	2. Sometimes	3. Quite Frequently	4. Nearly Always

22. Overall, how burdened do you feel in caring for your child?

0. Not at all	1. A little	2. Moderately	3. Quite a bit	4. Extremely

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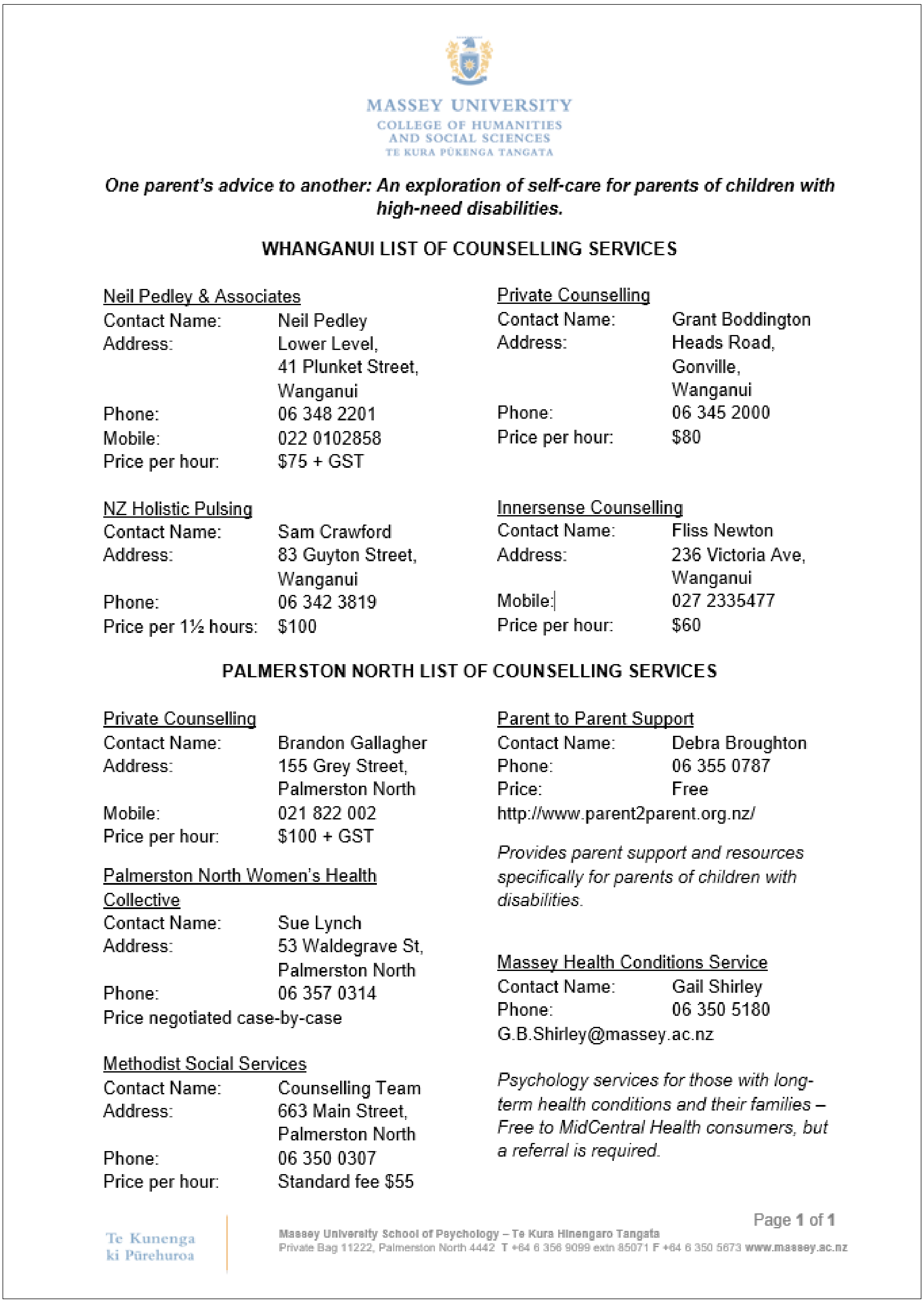
APPENDIX F:

Counselling Services List for Study One



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WHANGANUI LIST OF COUNSELLING SERVICES

Neil Pedley & Associates
Contact Name: Neil Pedley
Address: Lower Level,
41 Plunket Street,
Wanganui
Phone: 06 348 2201
Mobile: 022 0102858
Price per hour: $75 + GST

NZ Holistic Pulsing
Contact Name: Sam Crawford
Address: 83 Guyton Street,
Wanganui
Phone: 06 342 3819
Price per 1½ hours: $100

Private Counselling
Contact Name: Grant Boddington
Address: Heads Road,
Gonville,
Wanganui
Phone: 06 345 2000
Price per hour: $80

Innersense Counselling
Contact Name: Fliss Newton
Address: 236 Victoria Ave,
Wanganui
Mobile: 027 2335477
Price per hour: $60

PALMERSTON NORTH LIST OF COUNSELLING SERVICES

Private Counselling
Contact Name: Brandon Gallagher
Address: 155 Grey Street,
Palmerston North
Mobile: 021 822 002
Price per hour: $100 + GST

Palmerston North Women's Health Collective
Contact Name: Sue Lynch
Address: 53 Waldegrave St,
Palmerston North
Phone: 06 357 0314
Price negotiated case-by-case

Methodist Social Services
Contact Name: Counselling Team
Address: 663 Main Street,
Palmerston North
Phone: 06 350 0307
Price per hour: Standard fee $55

Parent to Parent Support
Contact Name: Debra Broughton
Phone: 06 355 0787
Price: Free
http://www.parent2parent.org.nz/

Provides parent support and resources specifically for parents of children with disabilities.

Massey Health Conditions Service
Contact Name: Gail Shirley
Phone: 06 350 5180
G.B.Shirley@massey.ac.nz

Psychology services for those with long-term health conditions and their families – Free to MidCentral Health consumers, but a referral is required.

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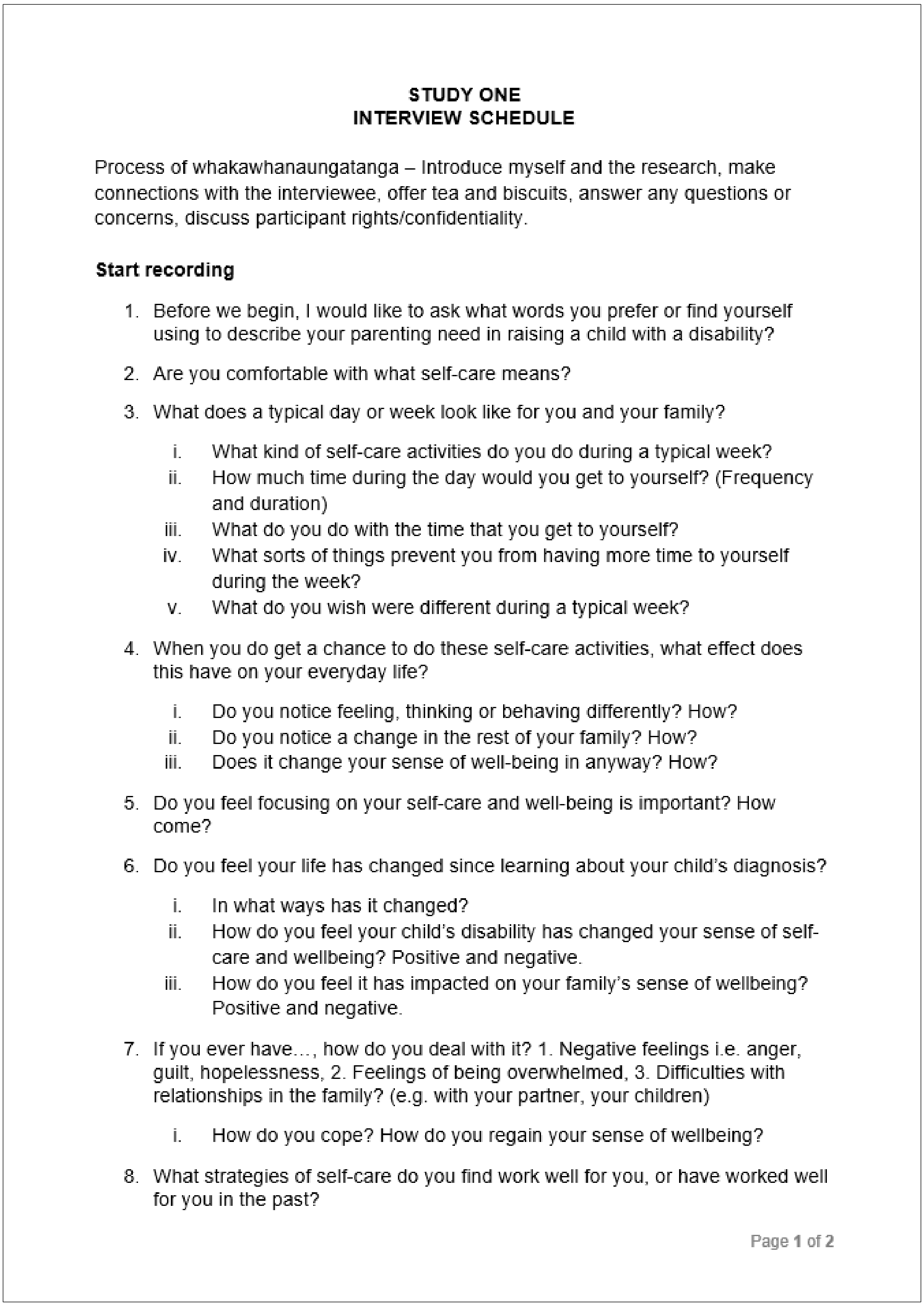
APPENDIX G:

Interview Schedule for Study One



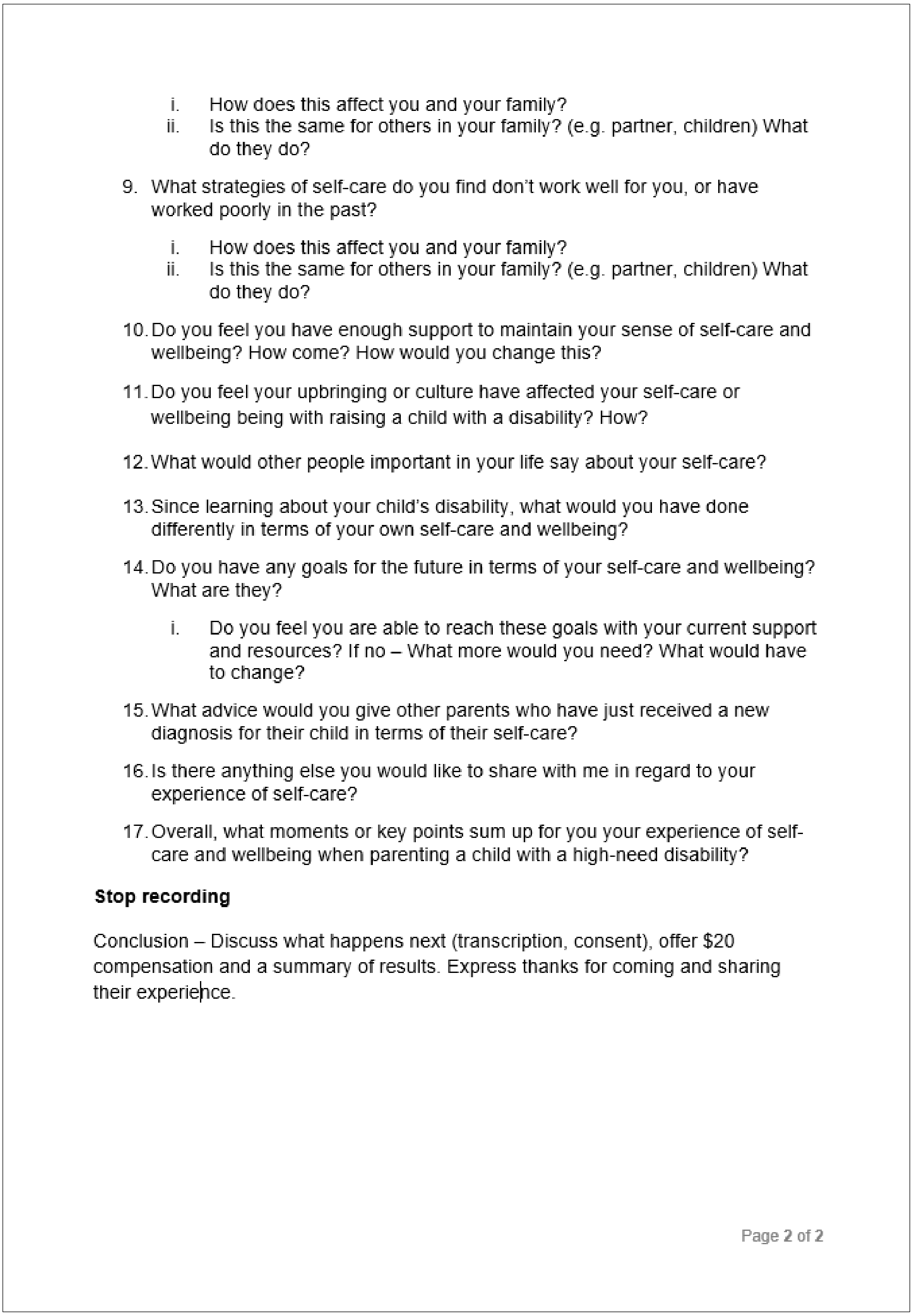
STUDY ONE
INTERVIEW SCHEDULE

Process of whakawhanaungatanga – Introduce myself and the research, make connections with the interviewee, offer tea and biscuits, answer any questions or concerns, discuss participant rights/confidentiality.

Start recording

1. Before we begin, I would like to ask what words you prefer or find yourself using to describe your parenting need in raising a child with a disability?
2. Are you comfortable with what self-care means?
3. What does a typical day or week look like for you and your family?
    i. What kind of self-care activities do you do during a typical week?
    ii. How much time during the day would you get to yourself? (Frequency and duration)
    iii. What do you do with the time that you get to yourself?
    iv. What sorts of things prevent you from having more time to yourself during the week?
    v. What do you wish were different during a typical week?
4. When you do get a chance to do these self-care activities, what effect does this have on your everyday life?
    i. Do you notice feeling, thinking or behaving differently? How?
    ii. Do you notice a change in the rest of your family? How?
    iii. Does it change your sense of well-being in anyway? How?
5. Do you feel focusing on your self-care and well-being is important? How come?
6. Do you feel your life has changed since learning about your child's diagnosis?
    i. In what ways has it changed?
    ii. How do you feel your child's disability has changed your sense of self-care and wellbeing? Positive and negative.
    iii. How do you feel it has impacted on your family's sense of wellbeing? Positive and negative.
7. If you ever have…, how do you deal with it? 1. Negative feelings i.e. anger, guilt, hopelessness, 2. Feelings of being overwhelmed, 3. Difficulties with relationships in the family? (e.g. with your partner, your children)
    i. How do you cope? How do you regain your sense of wellbeing?
8. What strategies of self-care do you find work well for you, or have worked well for you in the past?

Page **1** of **2**



    i. How does this affect you and your family?
    ii. Is this the same for others in your family? (e.g. partner, children) What do they do?

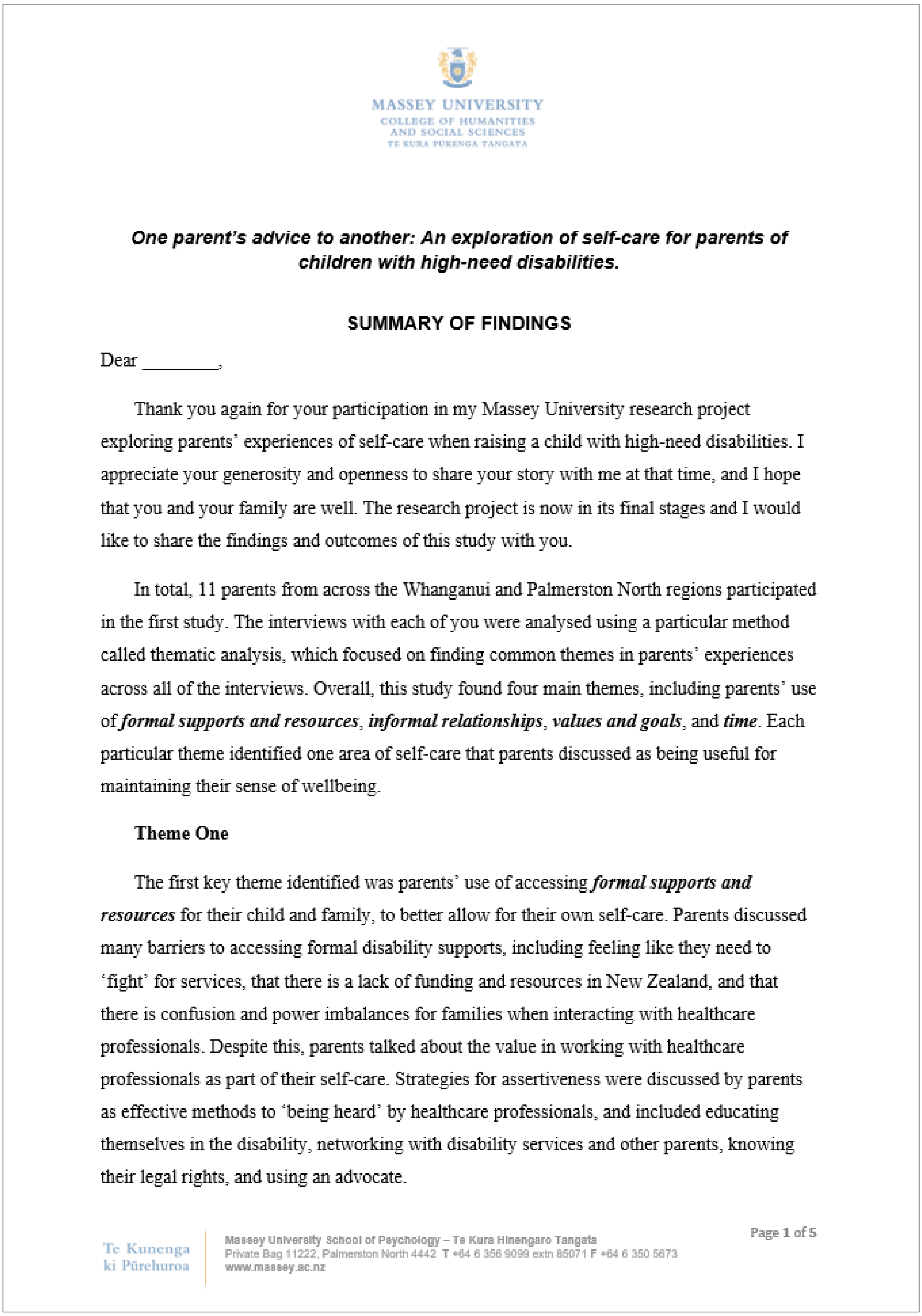
9. What strategies of self-care do you find don't work well for you, or have worked poorly in the past?
    i. How does this affect you and your family?
    ii. Is this the same for others in your family? (e.g. partner, children) What do they do?
10. Do you feel you have enough support to maintain your sense of self-care and wellbeing? How come? How would you change this?
11. Do you feel your upbringing or culture have affected your self-care or wellbeing being with raising a child with a disability? How?
12. What would other people important in your life say about your self-care?
13. Since learning about your child's disability, what would you have done differently in terms of your own self-care and wellbeing?
14. Do you have any goals for the future in terms of your self-care and wellbeing? What are they?
    i. Do you feel you are able to reach these goals with your current support and resources? If no – What more would you need? What would have to change?
15. What advice would you give other parents who have just received a new diagnosis for their child in terms of their self-care?
16. Is there anything else you would like to share with me in regard to your experience of self-care?
17. Overall, what moments or key points sum up for you your experience of self-care and wellbeing when parenting a child with a high-need disability?

Stop recording

Conclusion – Discuss what happens next (transcription, consent), offer $20 compensation and a summary of results. Express thanks for coming and sharing their experience.

APPENDIX H:

Summary of Findings for Study One



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TE KURA PŪRENGA TANGATA

One parent's advice to another: An exploration of self-care for parents of children with high-need disabilities.

SUMMARY OF FINDINGS

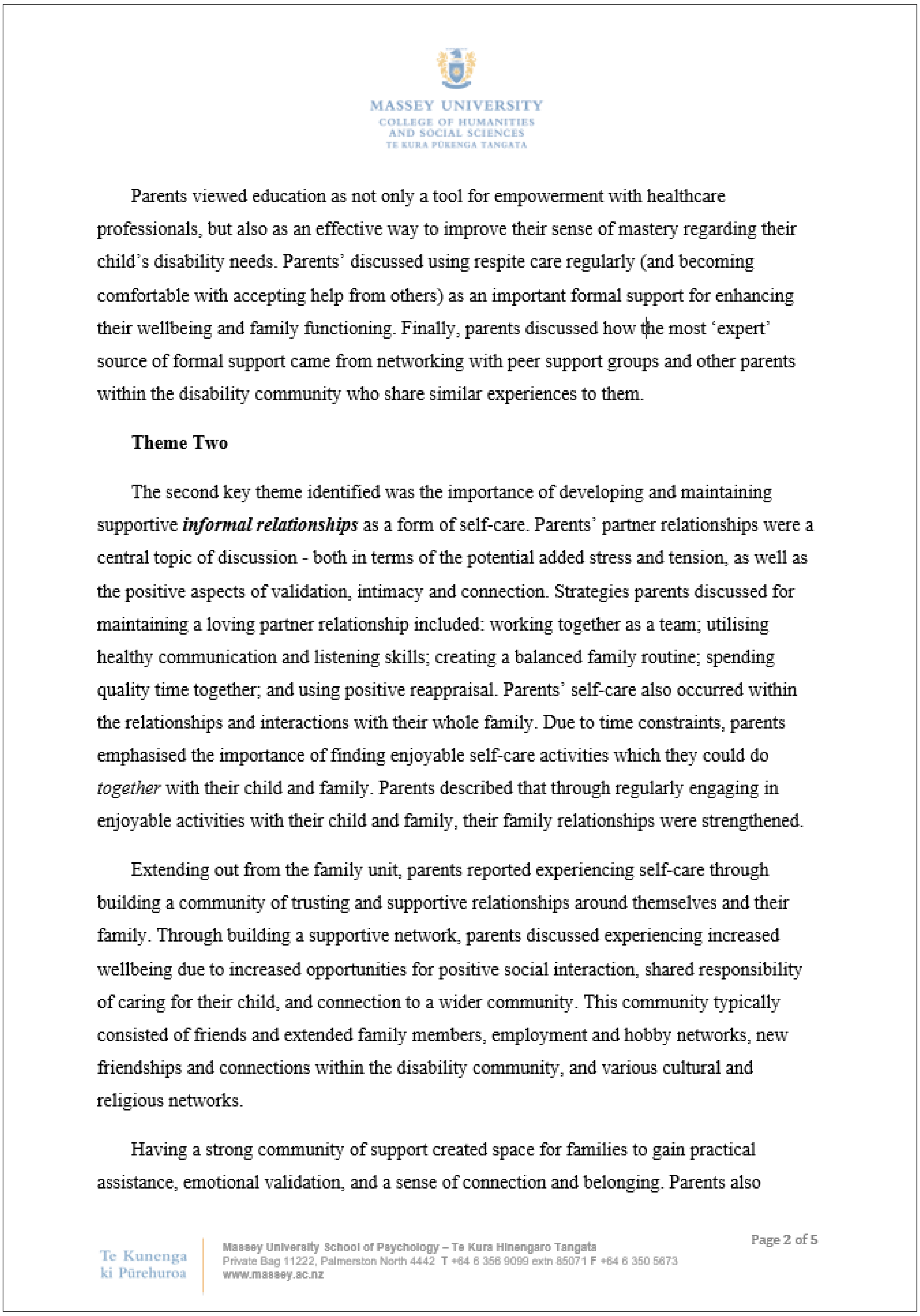
Dear ________,

Thank you again for your participation in my Massey University research project exploring parents' experiences of self-care when raising a child with high-need disabilities. I appreciate your generosity and openness to share your story with me at that time, and I hope that you and your family are well. The research project is now in its final stages and I would like to share the findings and outcomes of this study with you.

In total, 11 parents from across the Whanganui and Palmerston North regions participated in the first study. The interviews with each of you were analysed using a particular method called thematic analysis, which focused on finding common themes in parents' experiences across all of the interviews. Overall, this study found four main themes, including parents' use of ***formal supports and resources***, ***informal relationships***, ***values and goals***, and ***time***. Each particular theme identified one area of self-care that parents discussed as being useful for maintaining their sense of wellbeing.

Theme One

The first key theme identified was parents' use of accessing ***formal supports and resources*** for their child and family, to better allow for their own self-care. Parents discussed many barriers to accessing formal disability supports, including feeling like they need to 'fight' for services, that there is a lack of funding and resources in New Zealand, and that there is confusion and power imbalances for families when interacting with healthcare professionals. Despite this, parents talked about the value in working with healthcare professionals as part of their self-care. Strategies for assertiveness were discussed by parents as effective methods to 'being heard' by healthcare professionals, and included educating themselves in the disability, networking with disability services and other parents, knowing their legal rights, and using an advocate.



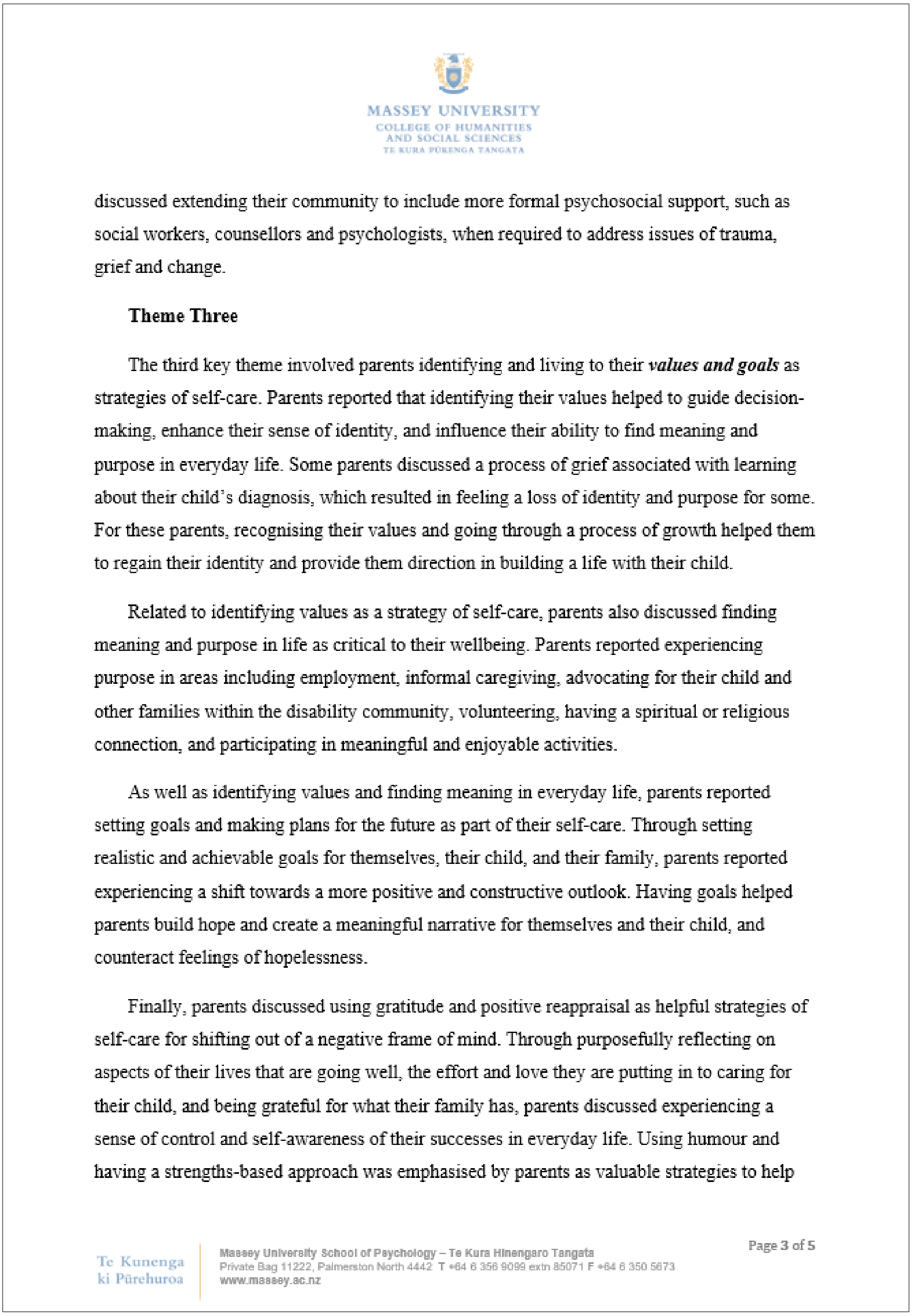
Parents viewed education as not only a tool for empowerment with healthcare professionals, but also as an effective way to improve their sense of mastery regarding their child's disability needs. Parents' discussed using respite care regularly (and becoming comfortable with accepting help from others) as an important formal support for enhancing their wellbeing and family functioning. Finally, parents discussed how the most 'expert' source of formal support came from networking with peer support groups and other parents within the disability community who share similar experiences to them.

Theme Two

The second key theme identified was the importance of developing and maintaining supportive ***informal relationships*** as a form of self-care. Parents' partner relationships were a central topic of discussion - both in terms of the potential added stress and tension, as well as the positive aspects of validation, intimacy and connection. Strategies parents discussed for maintaining a loving partner relationship included: working together as a team; utilising healthy communication and listening skills; creating a balanced family routine; spending quality time together; and using positive reappraisal. Parents' self-care also occurred within the relationships and interactions with their whole family. Due to time constraints, parents emphasised the importance of finding enjoyable self-care activities which they could do *together* with their child and family. Parents described that through regularly engaging in enjoyable activities with their child and family, their family relationships were strengthened.

Extending out from the family unit, parents reported experiencing self-care through building a community of trusting and supportive relationships around themselves and their family. Through building a supportive network, parents discussed experiencing increased wellbeing due to increased opportunities for positive social interaction, shared responsibility of caring for their child, and connection to a wider community. This community typically consisted of friends and extended family members, employment and hobby networks, new friendships and connections within the disability community, and various cultural and religious networks.

Having a strong community of support created space for families to gain practical assistance, emotional validation, and a sense of connection and belonging. Parents also



discussed extending their community to include more formal psychosocial support, such as social workers, counsellors and psychologists, when required to address issues of trauma, grief and change.

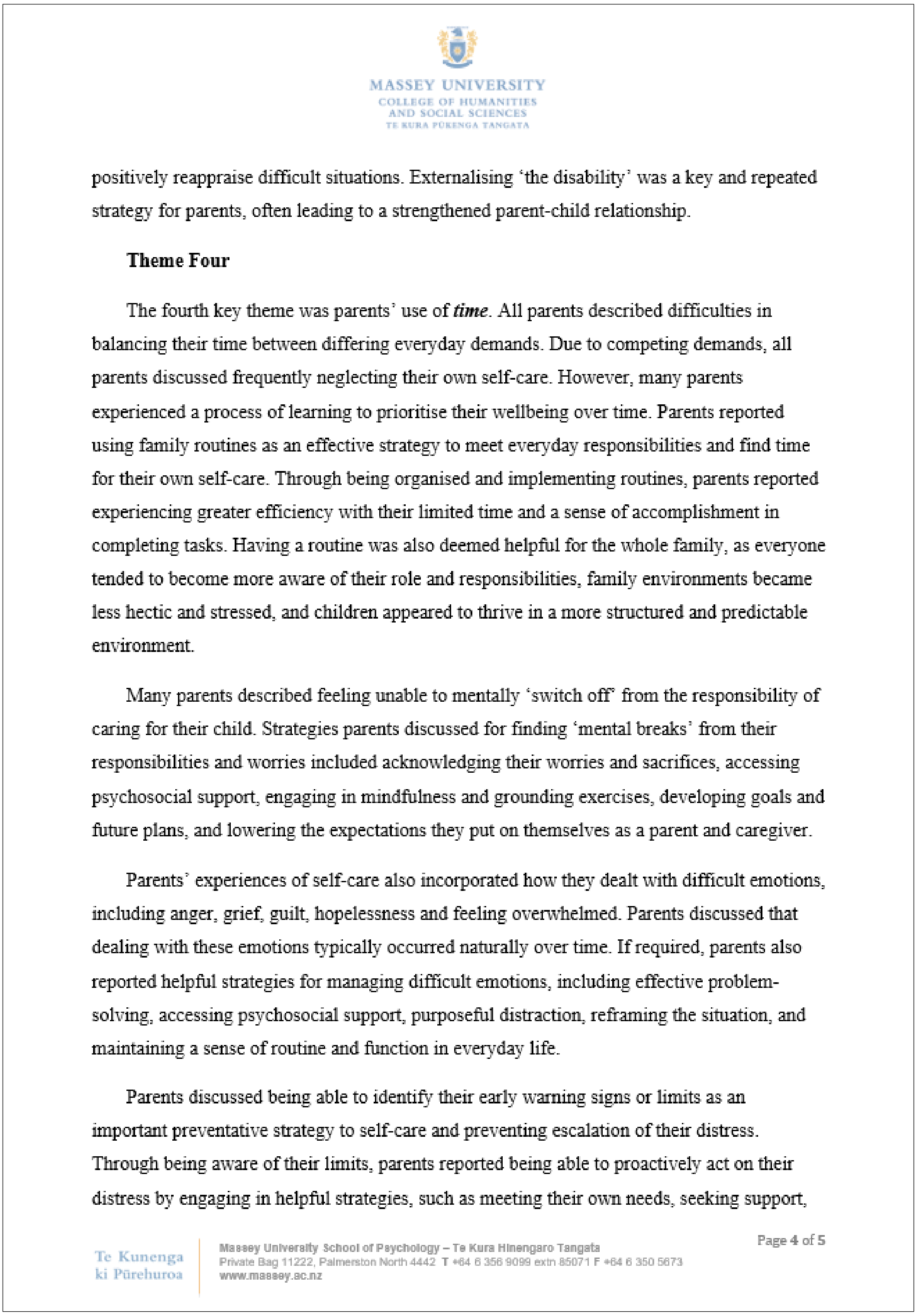
Theme Three

The third key theme involved parents identifying and living to their ***values and goals*** as strategies of self-care. Parents reported that identifying their values helped to guide decision-making, enhance their sense of identity, and influence their ability to find meaning and purpose in everyday life. Some parents discussed a process of grief associated with learning about their child's diagnosis, which resulted in feeling a loss of identity and purpose for some. For these parents, recognising their values and going through a process of growth helped them to regain their identity and provide them direction in building a life with their child.

Related to identifying values as a strategy of self-care, parents also discussed finding meaning and purpose in life as critical to their wellbeing. Parents reported experiencing purpose in areas including employment, informal caregiving, advocating for their child and other families within the disability community, volunteering, having a spiritual or religious connection, and participating in meaningful and enjoyable activities.

As well as identifying values and finding meaning in everyday life, parents reported setting goals and making plans for the future as part of their self-care. Through setting realistic and achievable goals for themselves, their child, and their family, parents reported experiencing a shift towards a more positive and constructive outlook. Having goals helped parents build hope and create a meaningful narrative for themselves and their child, and counteract feelings of hopelessness.

Finally, parents discussed using gratitude and positive reappraisal as helpful strategies of self-care for shifting out of a negative frame of mind. Through purposefully reflecting on aspects of their lives that are going well, the effort and love they are putting in to caring for their child, and being grateful for what their family has, parents discussed experiencing a sense of control and self-awareness of their successes in everyday life. Using humour and having a strengths-based approach was emphasised by parents as valuable strategies to help



positively reappraise difficult situations. Externalising 'the disability' was a key and repeated strategy for parents, often leading to a strengthened parent-child relationship.

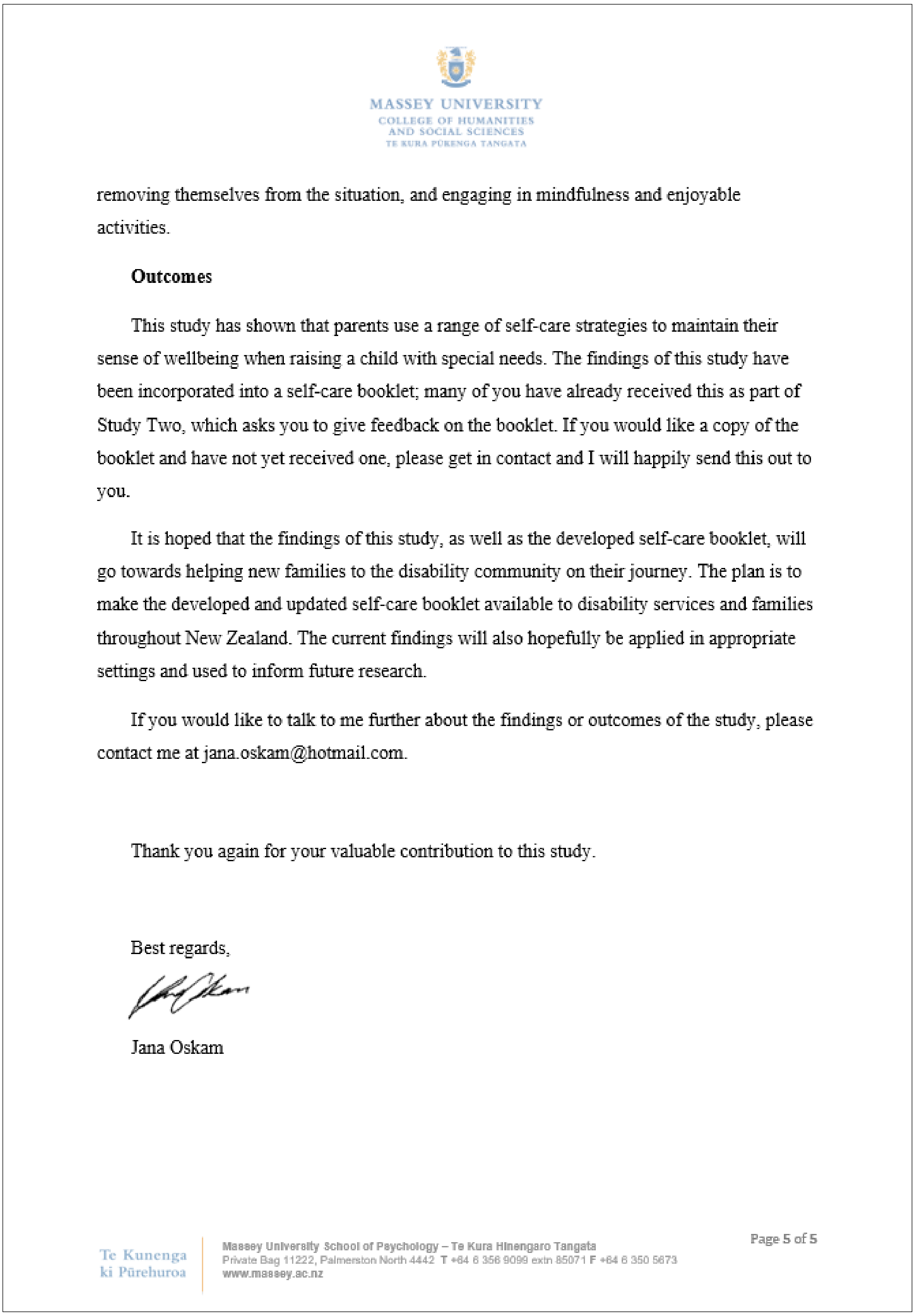
Theme Four

The fourth key theme was parents' use of ***time***. All parents described difficulties in balancing their time between differing everyday demands. Due to competing demands, all parents discussed frequently neglecting their own self-care. However, many parents experienced a process of learning to prioritise their wellbeing over time. Parents reported using family routines as an effective strategy to meet everyday responsibilities and find time for their own self-care. Through being organised and implementing routines, parents reported experiencing greater efficiency with their limited time and a sense of accomplishment in completing tasks. Having a routine was also deemed helpful for the whole family, as everyone tended to become more aware of their role and responsibilities, family environments became less hectic and stressed, and children appeared to thrive in a more structured and predictable environment.

Many parents described feeling unable to mentally 'switch off' from the responsibility of caring for their child. Strategies parents discussed for finding 'mental breaks' from their responsibilities and worries included acknowledging their worries and sacrifices, accessing psychosocial support, engaging in mindfulness and grounding exercises, developing goals and future plans, and lowering the expectations they put on themselves as a parent and caregiver.

Parents' experiences of self-care also incorporated how they dealt with difficult emotions, including anger, grief, guilt, hopelessness and feeling overwhelmed. Parents discussed that dealing with these emotions typically occurred naturally over time. If required, parents also reported helpful strategies for managing difficult emotions, including effective problem-solving, accessing psychosocial support, purposeful distraction, reframing the situation, and maintaining a sense of routine and function in everyday life.

Parents discussed being able to identify their early warning signs or limits as an important preventative strategy to self-care and preventing escalation of their distress. Through being aware of their limits, parents reported being able to proactively act on their distress by engaging in helpful strategies, such as meeting their own needs, seeking support,



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removing themselves from the situation, and engaging in mindfulness and enjoyable activities.

Outcomes

This study has shown that parents use a range of self-care strategies to maintain their sense of wellbeing when raising a child with special needs. The findings of this study have been incorporated into a self-care booklet; many of you have already received this as part of Study Two, which asks you to give feedback on the booklet. If you would like a copy of the booklet and have not yet received one, please get in contact and I will happily send this out to you.

It is hoped that the findings of this study, as well as the developed self-care booklet, will go towards helping new families to the disability community on their journey. The plan is to make the developed and updated self-care booklet available to disability services and families throughout New Zealand. The current findings will also hopefully be applied in appropriate settings and used to inform future research.

If you would like to talk to me further about the findings or outcomes of the study, please contact me at jana.oskam@hotmail.com.

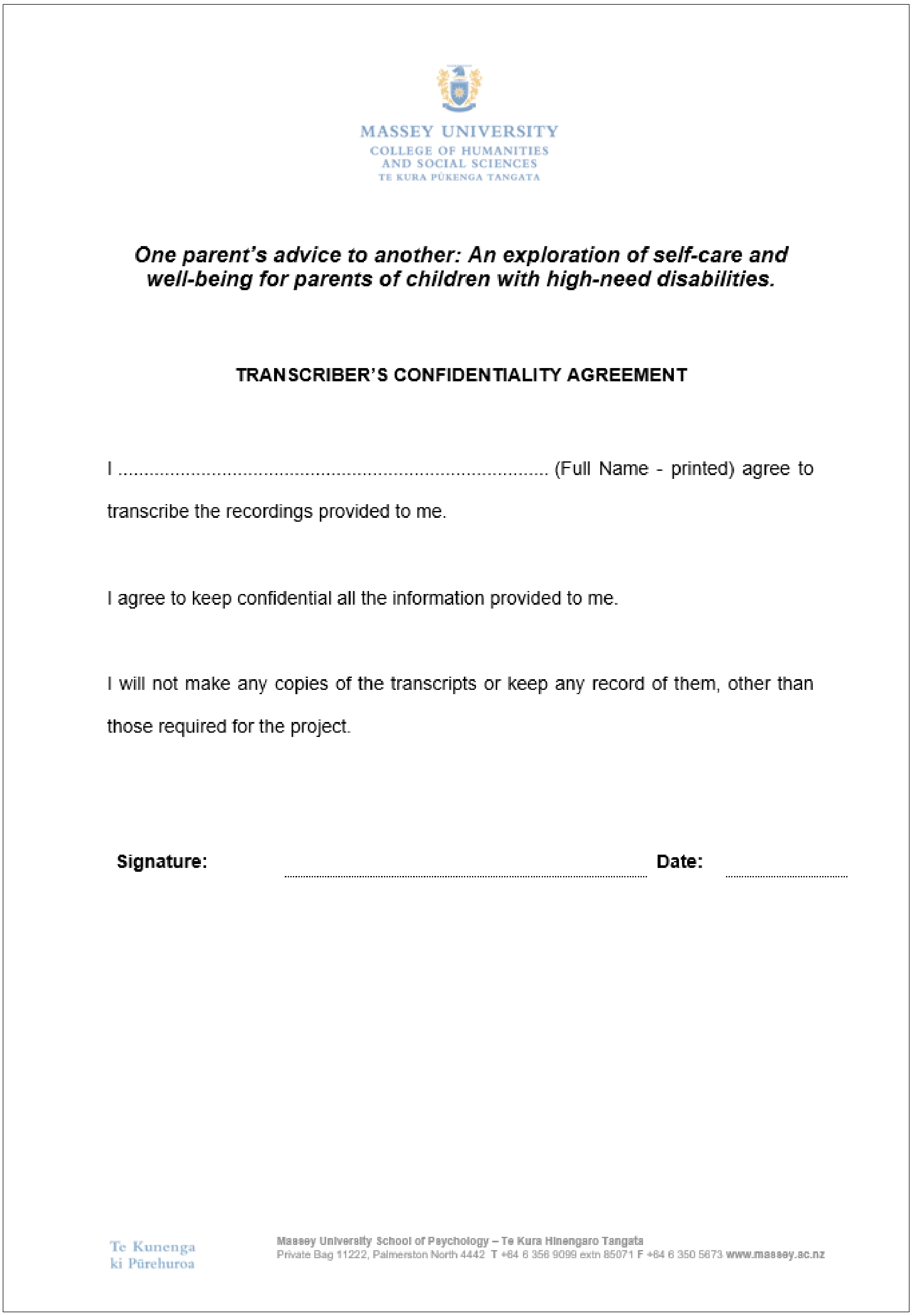
Thank you again for your valuable contribution to this study.

Best regards,

Jana Oskam

APPENDIX I:

Transcription Consent Form for Study One



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TE KURA PŪKENGA TANGATA

One parent's advice to another: An exploration of self-care and well-being for parents of children with high-need disabilities.

TRANSCRIBER'S CONFIDENTIALITY AGREEMENT

I .... (Full Name - printed) agree to transcribe the recordings provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the project.

Signature: .... **Date:** ....

Te Kunenga
ki Pūrehuroa

Massey University School of Psychology – Te Kura Hinengaro Tangata
Private Bag 11222, Palmerston North 4442 T +64 6 356 9099 extn 85071 F +64 6 350 5673 www.massey.ac.nz

APPENDIX J:

Authority for Release of Transcripts Form for Study One

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TE KURA PŪKENGA TANGATA

One parent's advice to another: An exploration of self-care for parents of children with high-need disabilities.

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I agree that I have had the chance to read and correct the transcript of my interview with the researcher.

I agree that my corrected transcript and statements from this may be used in reports and publications based on the research.

I agree for my edited transcript to be held for five years then destroyed.

Signature: ______________________________ **Date:** ____________

Full Name (Printed): ____

If you want to provide a digital signature please type your name in the Full Name space above, type the date, and mark the box below.

I agree to provide a digital signature as marked here: ☐

Te Kunenga
ki Pūrehuroa

Massey University School of Psychology – Te Kura Hinengaro Tangata
Private Bag 11222, Palmerston North 4442 T +64 6 356 9099 extn 85071 F +64 6 350 5673 **www.massey.ac.nz**

APPENDIX K:

Ethics Permission for Study One

MASSEY
UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Date: 07 July 2016

Dear Jana Oskam

Re: Ethics Notification - **SOB 16/21 - One parent's advice to another: An exploration of self-care and well-being for parents of children with chronic high-need disabilities.**

Thank you for the above application that was considered by the Massey University Human Ethics Committee: **Human Ethics Southern B Committee** at their meeting held on **Thursday, 7 July, 2016**.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

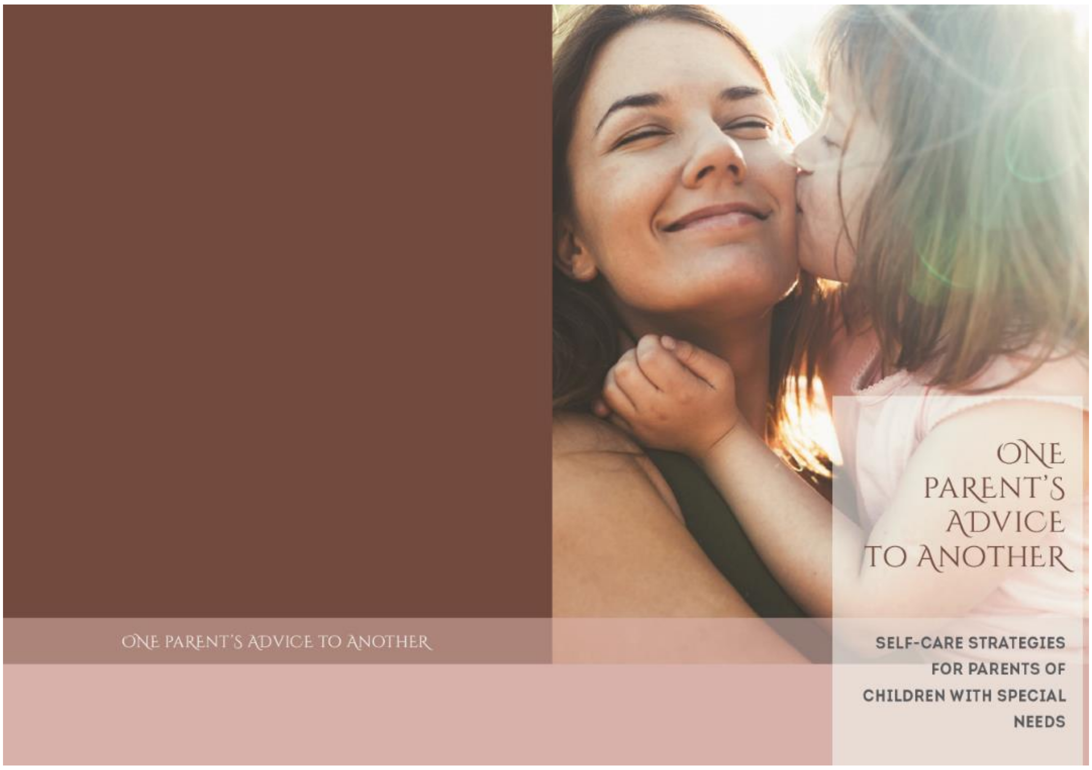
Dr Brian Finch
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 350 5573; 06 350 5575 F 06 355 7973
E humanethics@massey.ac.nz W http://humanethics.massey.ac.nz

APPENDIX L:

Developed Self-Care Booklet for Parents

Outer Cover

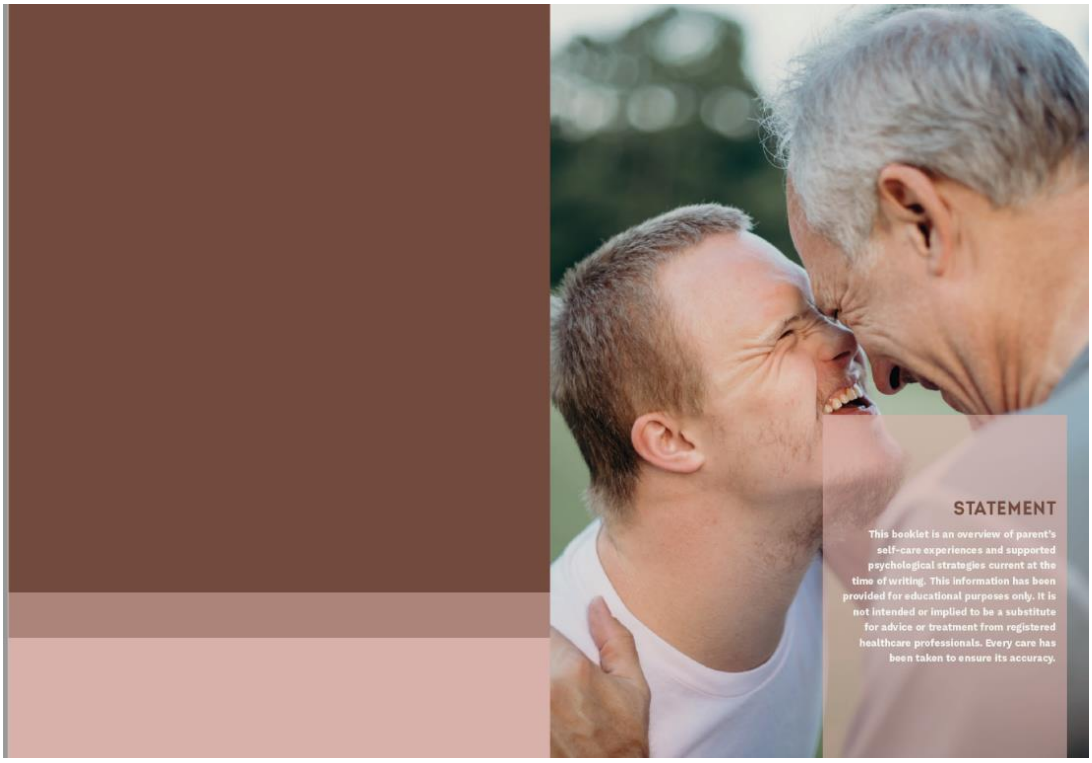


ONE PARENT'S ADVICE TO ANOTHER

ONE
PARENT'S
ADVICE
TO ANOTHER

SELF-CARE STRATEGIES
FOR PARENTS OF
CHILDREN WITH SPECIAL
NEEDS

Inner Cover



STATEMENT

This booklet is an overview of parent's self-care experiences and supported psychological strategies current at the time of writing. This information has been provided for educational purposes only. It is not intended or implied to be a substitute for advice or treatment from registered healthcare professionals. Every care has been taken to ensure its accuracy.

Inner Pages

CONTENTS

INTRODUCTION

Kia ora,
If you are reading this, it is likely you are the parent or whanau of a child with special needs.

We understand that being a parent of a child with special needs comes with unique challenges and experiences. Therefore, we've complied this booklet with input and advice from other parents (and some professionals), to provide you with information and tips on how to care for yourself along the way.

The focus has been on self-care strategies – or ways that you can deliberately take care of your mental, spiritual, emotional, and physical health. It has been designed as a practical tool to educate and empower you and your family.

While reading this booklet, you will come across two sections – Seeking Solidarity and Supported Strategies. Seeking Solidarity is a section dedicated to highlighting common difficult experiences and challenges many parents face when raising a child with disabilities. These experiences were included to normalise the difficulties you may face and to show that you are not alone.

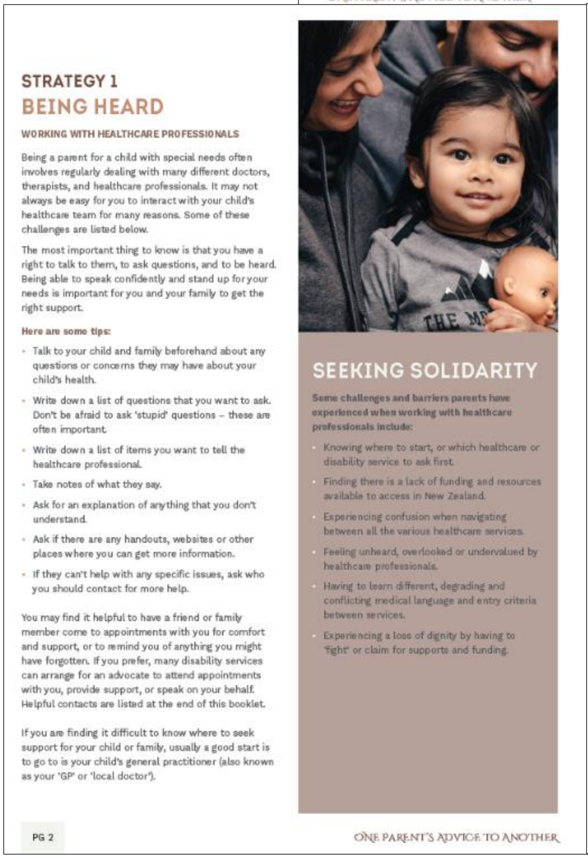
Supported Strategies is a section dedicated to providing practical advice and psychological skills that have been shown to work. These skills are supported both by parents and healthcare professionals. It is hoped that they will provide a starting point to making healthy changes in your everyday life.

Ngā manaakitanga

"If you're constantly giving, giving, giving, eventually there's not going to be anything left. So, if you have that time for yourself where you're enriching yourself in one way or another, of course you're going to be a better parent... I firmly believe that. If you're not good, they're not good. I think more and more I realize that we actually come first, not the kids."

ONE PARENT'S ADVICE TO ANOTHER

PG 1



STRATEGY 1

BEING HEARD

WORKING WITH HEALTHCARE PROFESSIONALS

Being a parent for a child with special needs often involves regularly dealing with many different doctors, therapists, and healthcare professionals. It may not always be easy for you to interact with your child's healthcare team for many reasons. Some of these challenges are listed below.

The most important thing to know is that you have a right to talk to them, to ask questions, and to be heard. Being able to speak confidently and stand up for your needs is important for you and your family to get the right support.

Here are some tips:

- Talk to your child and family beforehand about any questions or concerns they may have about your child's health.
- Write down a list of questions that you want to ask. Don't be afraid to ask 'stupid' questions – these are often important.
- Write down a list of items you want to tell the healthcare professional.
- Take notes of what they say.
- Ask for an explanation of anything that you don't understand.
- Ask if there are any handouts, websites or other places where you can get more information.
- If they can't help with any specific issues, ask who you should contact for more help.

You may find it helpful to have a friend or family member come to appointments with you for comfort and support, or to remind you of anything you might have forgotten. If you prefer, many disability services can arrange for an advocate to attend appointments with you, provide support, or speak on your behalf. Helpful contacts are listed at the end of this booklet.

If you are finding it difficult to know where to seek support for your child or family, usually a good start is to go to is your child's general practitioner (also known as your 'GP' or 'local doctor').

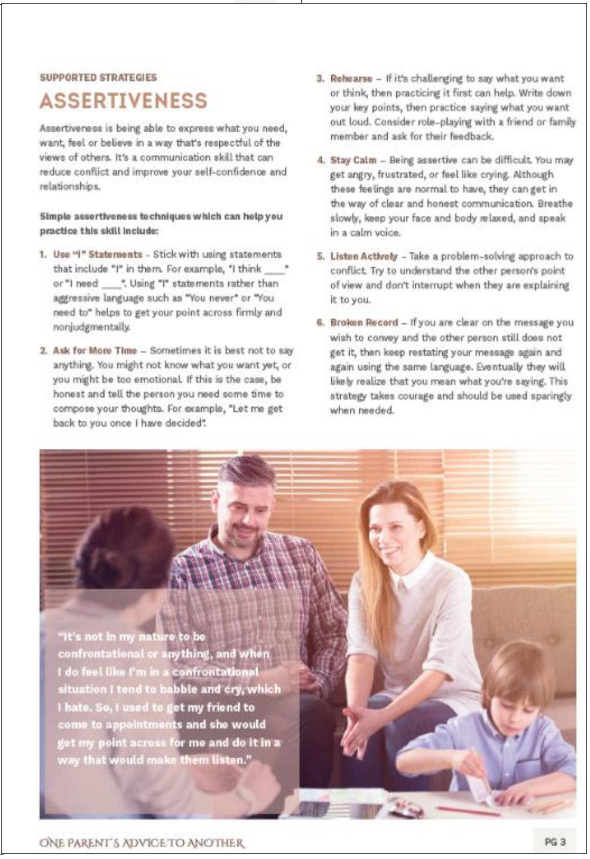
PG 2

SEEKING SOLIDARITY

Some challenges and barriers parents have experienced when working with healthcare professionals include:

- Knowing where to start, or which healthcare or disability service to ask first.
- Finding there is a lack of funding and resources available to access in New Zealand.
- Experiencing confusion when navigating between all the various healthcare services.
- Feeling unheard, overlooked or undervalued by healthcare professionals.
- Having to learn different, degrading and conflicting medical language and entry criteria between services.
- Experiencing a loss of dignity by having to 'fight' or claim for supports and funding.

ONE PARENT'S ADVICE TO ANOTHER



SUPPORTED STRATEGIES

ASSERTIVENESS

Assertiveness is being able to express what you need, want, feel or believe in a way that's respectful of the views of others. It's a communication skill that can reduce conflict and improve your self-confidence and relationships.

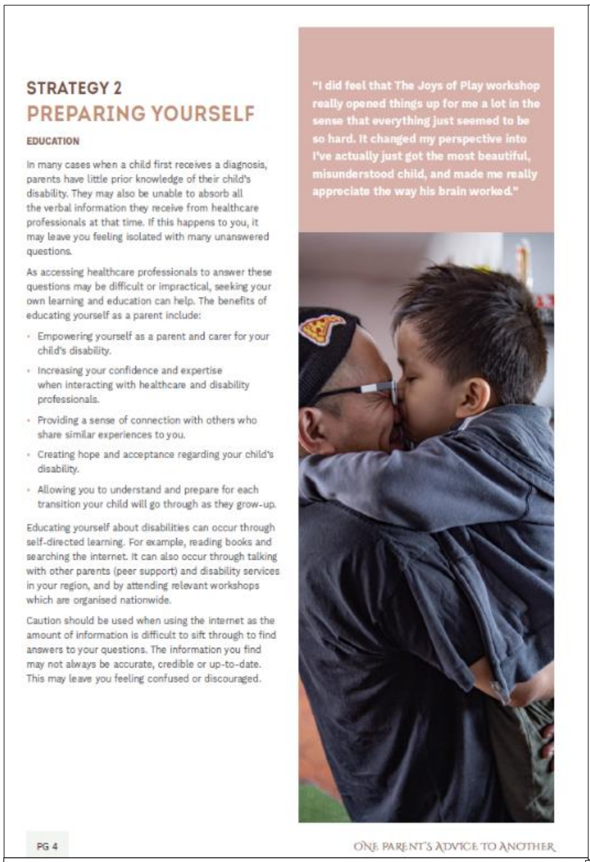
Simple assertiveness techniques which can help you practice this skill include:

1. **Use "I" Statements** - Stick with using statements that include "I" in them. For example, "I think ____" or "I need ____". Using "I" statements rather than aggressive language such as "You never" or "You need to" helps to get your point across firmly and nonjudgmentally.
2. **Ask for More Time** – Sometimes it is best not to say anything. You might not know what you want yet, or you might be too emotional. If this is the case, be honest and tell the person you need some time to compose your thoughts. For example, "Let me get back to you once I have decided".
3. **Rehearse** – If it's challenging to say what you want or think, then practicing it first can help. Write down your key points, then practice saying what you want out loud. Consider role-playing with a friend or family member and ask for their feedback.
4. **Stay Calm** – Being assertive can be difficult. You may get angry, frustrated, or feel like crying. Although these feelings are normal to have, they can get in the way of clear and honest communication. Breathe slowly, keep your face and body relaxed, and speak in a calm voice.
5. **Listen Actively** - Take a problem-solving approach to conflict. Try to understand the other person's point of view and don't interrupt when they are explaining it to you.
6. **Broken Record** – If you are clear on the message you wish to convey and the other person still does not get it, then keep restating your message again and again using the same language. Eventually they will likely realize that you mean what you're saying. This strategy takes courage and should be used sparingly when needed.

"It's not in my nature to be confrontational or anything, and when I do feel like I'm in a confrontational situation I tend to babble and cry, which I hate. So, I used to get my friend to come to appointments and she would get my point across for me and do it in a way that would make them listen."

ONE PARENT'S ADVICE TO ANOTHER

PG 3



STRATEGY 2
PREPARING YOURSELF

EDUCATION

In many cases when a child first receives a diagnosis, parents have little prior knowledge of their child's disability. They may also be unable to absorb all the verbal information they receive from healthcare professionals at that time. If this happens to you, it may leave you feeling isolated with many unanswered questions.

As accessing healthcare professionals to answer these questions may be difficult or impractical, seeking your own learning and education can help. The benefits of educating yourself as a parent include:

- Empowering yourself as a parent and carer for your child's disability.
- Increasing your confidence and expertise when interacting with healthcare and disability professionals.
- Providing a sense of connection with others who share similar experiences to you.
- Creating hope and acceptance regarding your child's disability.
- Allowing you to understand and prepare for each transition your child will go through as they grow-up.

Educating yourself about disabilities can occur through self-directed learning. For example, reading books and searching the internet. It can also occur through talking with other parents (peer support) and disability services in your region, and by attending relevant workshops which are organised nationwide.

Caution should be used when using the internet as the amount of information is difficult to sift through to find answers to your questions. The information you find may not always be accurate, credible or up-to-date. This may leave you feeling confused or discouraged.

> **"I did feel that The Joys of Play workshop really opened things up for me a lot in the sense that everything just seemed to be so hard. It changed my perspective into I've actually just got the most beautiful, misunderstood child, and made me really appreciate the way his brain worked."**

PG 4

ONE PARENT'S ADVICE TO ANOTHER

SEEKING SOLIDARITY

Is Diagnosis Helpful?
Depending on your family's circumstance, receiving a diagnosis for your child can be a positive or negative experience. For some families, they feel relieved they can put a name to their child's difficulties. A diagnosis can help them discuss and understand what treatments or therapies might work best for their child.

For other families, they may feel the diagnosis does not fit their experience or is distressing for them. They may not like the "label" or stigma that is attached to the diagnosis.

Some families do not receive a diagnosis even after a long period of time and many assessments, and others may receive many different diagnoses over their child's lifetime.
Unfortunately, not everyone you meet will understand your child's disability. Some people may have misconceptions about what certain diagnoses mean. They may use language you find dismissive or hurtful. This can be very upsetting – especially if that person is a family member, friend or healthcare professional.

Whether your experience of receiving a diagnosis for your child is positive, negative, or a mixture of both, it is important to remember you are not alone. You also don't have to put up with others treating you or your family disrespectfully.

Ways to consider dealing with stigma:

- Read reliable information and show it to others – to improve understanding about what the diagnosis means.
- Get involved with your child's treatment – to make your voice heard, guide decision-making, and better understand how to best help your child.
- Get in contact with an advocate or peer support person – to help stand-up for your choices and validate your experiences.
- Know your rights – to ensure you are best cared for in all situations.
- Talk about your experience – to help improve other people's awareness and attitudes of disabilities.

> **"Most times I have found out that I am a bit of a rare thing where I wanted the diagnosis... once I got that, I was quite strategic about setting up a game plan... Whereas, I've seen parents in the past struggle with having their child labelled and it's an absolute mental burden on themselves, and it's got nothing to do with their kids because they love their kids to death, they just can't get over the stigma of the name."**

ONE PARENT'S ADVICE TO ANOTHER

PG 5

STRATEGY 3
ACCEPTING HELP

RESPITE CARE

Respite is being able to take a break from your parenting and caring responsibilities for a period of time. Accessing respite will allow you to take time-out to feel rested and re-energised. It will also provide your child new experiences through spending time with others.

Depending on what resources are available to your family, respite can be organised formally with disability services or arranged privately with people known to your family. For example, friends or extended family whanau.

Possible options for respite include:

- Arranging with family, friends or respite carers to hang out with your child while you take a break either at or away from home.
- Having support workers spend time with your child out in the community.
- Arranging for your child to participate in an activity or programme they enjoy.
- Having an overnight break while your child stays with family, friends, respite carers, or a trusted organisation that cares for children with special needs.

The amount of funded formal respite support available is based on your family's needs. To access respite support and services talk to your local Needs Assessment Service Coordination organisation (NASC). Contact information is provided at the end of this booklet.

When considering whether to use respite care, it can be helpful to consider the possible benefits of taking a break. These benefits include:

- Having time to focus on your own self-care and relationships.
- Replenishing your patience, tolerance and energy.
- Improving your parenting and family functioning.
- Reducing your workload caring for a child with special needs.
- Providing your child and family opportunities for new experiences.
- Developing your child's confidence, social skills, and independence.
- Improving community awareness and acceptance of disabilities.

SEEKING SOLIDARITY

Some parents find asking for help from others difficult, especially when it comes to taking a break for their own self-care needs. Difficulties or concerns parents have experienced related to accessing respite have included:

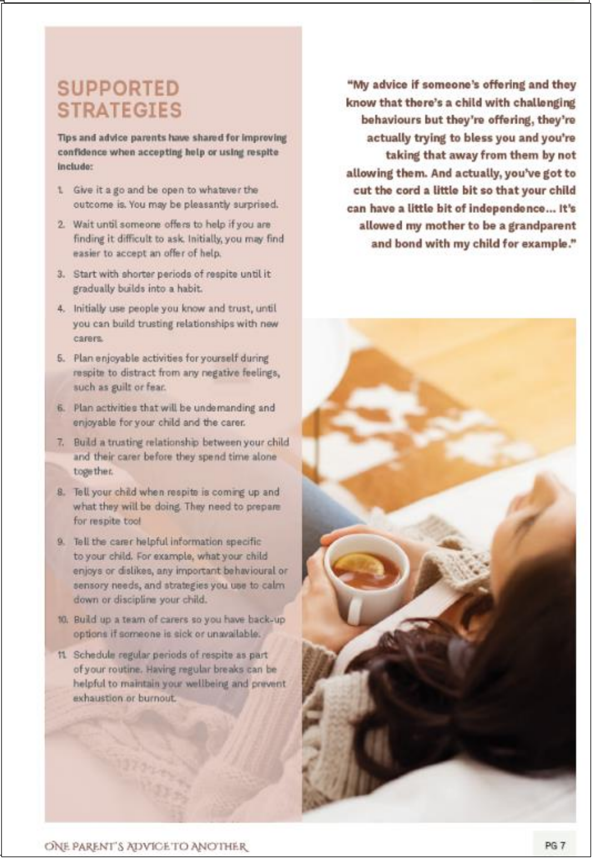
- Being assertive to ask for and ensure that they are receiving enough respite for their family's needs.
- Maintaining a sense of privacy and family cohesion when having respite carers enter their home.
- Finding respite carers which the parents trust and who can be flexible to their family's needs.
- Feeling frustrated or disappointed when respite care is not available. Especially when parents miss events they had been looking forward to.
- Experiencing a loss of freedom and spontaneity with needing to arrange respite care for their child before being able to go out.
- Having limitations with set hours of available respite care or having few respite carers to rely on.
- Experiencing feelings of guilt, failure, or fear when having others care for their child or being away from their child.

If you have experienced any of these difficulties or concerns, know that you are not alone. Many parents who shared similar concerns and still gave respite a go, found that respite has been extremely helpful for improving their wellbeing and how their family functions day-to-day.

> **"I think if you are eligible for carer support and it is there, just try it and have someone come in. You can always change your mind if it's not working. But it's just one less thing that you have to do, it's one less thing that you have to worry about... It can be hard having a stranger come into your house, but eventually it becomes part of your routine"**

PG 6

ONE PARENT'S ADVICE TO ANOTHER



SUPPORTED STRATEGIES

Tips and advice parents have shared for improving confidence when accepting help or using respite include:

1. Give it a go and be open to whatever the outcome is. You may be pleasantly surprised.
2. Wait until someone offers to help if you are finding it difficult to ask. Initially, you may find easier to accept an offer of help.
3. Start with shorter periods of respite until it gradually builds into a habit.
4. Initially use people you know and trust, until you can build trusting relationships with new carers.
5. Plan enjoyable activities for yourself during respite to distract from any negative feelings, such as guilt or fear.
6. Plan activities that will be undemanding and enjoyable for your child and the carer.
7. Build a trusting relationship between your child and their carer before they spend time alone together.
8. Tell your child when respite is coming up and what they will be doing. They need to prepare for respite too!
9. Tell the carer helpful information specific to your child. For example, what your child enjoys or dislikes, any important behavioural or sensory needs, and strategies you use to calm down or discipline your child.
10. Build up a team of carers so you have back-up options if someone is sick or unavailable.
11. Schedule regular periods of respite as part of your routine. Having regular breaks can be helpful to maintain your wellbeing and prevent exhaustion or burnout.

> **"My advice if someone's offering and they know that there's a child with challenging behaviours but they're offering, they're actually trying to bless you and you're taking that away from them by not allowing them. And actually, you've got to cut the cord a little bit so that your child can have a little bit of independence... It's allowed my mother to be a grandparent and bond with my child for example."**

ONE PARENT'S ADVICE TO ANOTHER

PG 7

STRATEGY 4

REDEFINING “EXPERTISE”

PEER SUPPORT

Peer support is being able to connect with other parents who share similar experiences and circumstances to you.

Peer support provides a listening ear from other parents who understand the unique joys and challenges of caring for a child with special needs. They can share their experiences with you and offer practical solutions to any problems you may be facing.

Many parents find that the most "expert" source of support and resources comes from networking and talking with other parents. These supports and resources can be equal to, if not better, then those provided by healthcare professionals.

Often raising a child with a disability is an experience that isn't planned, and at times can be a challenging journey. Peer support can help inform, educate, mentor, inspire and support you as you navigate your family's journey. This can lead to:

- Increased empathy and insight into your child.
- New knowledge regarding helpful parenting and behavioural strategies.
- Advocacy for your family if required.
- Shared connection and a sense of community.
- Validation that any negative feelings, experiences or difficulties you face are normal.
- Hope and a positive outlook for the future.
- Increased motivation and acceptance of your child's disability.
- Conserved energy as you do not have to put in as much effort figuring out challenges alone.
- Reduced confusion, stress and anxiety.

You can find peer support through:

1. Talking with friends.
2. Accessing formally organised peer support services.
3. Going to locally organised support groups.
4. Networking at workshops, schools or disability services.
5. Searching for online support forums.

SEEKING SOLIDARITY

Some parents have found they wanted to avoid talking to other parents of children with special needs. Typically, this occurred early-on in their family's journey when their child was first diagnosed.

For these parents, this decision was driven by them wanting to have a "normal" life and their difficulty with accepting their child's disability. Often, these parents needed time to process all that had happened. Only when they had come to understand and accept this, did they feel ready to access peer support.

If this is something you experience, that is okay. Take your time and trust that you can decide if, or when, talking to other parents will be helpful for you.

PG 8

ONE PARENT'S ADVICE TO ANOTHER

“I didn't want to socialise with people who had disabled kids. How stupid was I? Because you can learn so much from those parents... I wanted a normal life. I didn't want to be reminded all the time that we had a disabled child. I think it's that, no acceptance, you have to get to that acceptance I suppose.”

SUPPORTED STRATEGIES

PROBLEM-SOLVING

Some peer support group cultures can be negative, judgemental and discouraging. These negative cultures can be harmful to your wellbeing. It is important to be able to engage in peer support that is positive, proactive and uplifting for you. Try this:

1. Brainstorm and identify what you want from a peer support group. Is it education, friendship, advice, sharing of experiences, connection to a wider community, or something else?
2. Explore what peer support options are available to you in your community. Talk to people around you, read local news, or research online. List all the possible options you find.
3. Look at the pros and cons of each listed option. Do any appear to best fit with what it is you want from peer support? Pick the best option from the list.
4. Try out the best option. Was it what you were looking for? Do you feel better or worse for it? If you do not know initially, give it some time to form relationships with the other parents. Set a time limit to trial the support group, such as four visits or a month.
5. After the trial period is over, review whether you are getting the support you wanted from the group. Does it have a positive culture? Is it leaving you feeling connected to a wider community?
6. If not, go back to the list of options available to you and try the next best. Follow these same steps until you find a good fit. You could also consider setting up your own support group, possibly with friends you have made along the way.

“That was huge having someone who had gone through the journey, and is still going through it, but has gone through it a lot longer than us. It is so healing for us to see that you can survive it.”

ONE PARENT'S ADVICE TO ANOTHER

PG 9

STRATEGY 5

MANAGING LOVE

PARTNER RELATIONSHIPS

Parents face unique challenges in romantic relationships when caring for a child with special needs, no matter whether they are married, in a relationship, or dating. When parents have struggles in their partner relationships, usually it can be related to being overwhelmed by the emotional, physical and mental toll that caring for their child has taken. Often this leaves parents feeling disconnected in their relationship, and unsure about how to rebuild the intimacy that has been lost.

It is very easy to allow the challenges of raising a child with disabilities define who you and your partner are. It can happen without realising it. However, being the parents of a child with special needs is just a part of your relationship. You cannot let it be the only part. To begin to rebuild intimacy, both of you must be willing to commit to strengthening your relationship. Parents' advice and tips for ways you can do this are:

- Approach parenting and caregiving tasks as a team. Decide together who does what so you both feel the routine is balanced and fair. Review the routine regularly as your family's needs will change over time.
- Take note of the things your partner does for you that you appreciate each day. Once a week, sit down together and compare your experiences.
- Acknowledge that there will be inequalities or differences of opinion between you at times and make space for these.
- Find interests and activities that you both enjoy doing together and participate in these regularly. These do not have to be time-consuming or expensive, but achievable with your family's routine and needs.
- Spend time apart where you can both focus on your own self-care and engage in activities you find meaningful.
- Create a plan together for how you want your family, relationship, and lives to be in five-years' time. Break this plan down into smaller goals so you can review your progress together.
- Find humour in your relationship and family. Focus on the positives and achievements you both experience.
- Practice healthy communication, including giving genuine apologies and talking honestly about your needs, experiences and feelings no matter how negative or undesirable you think they are.
- Set regular time to spend with each other alone, without your children around. This could be as small as 10 minutes together a night when the children are in bed.
- Seek formal support, such as couples counselling, if you find things are not improving over time.

PG 10

SEEKING SOLIDARITY

Potential added stressors that occur in partner relationships when raising a child with special needs can include:

- Tensions due to different levels of acceptance, humiliation or understanding between partners for their child's disability. For example, differences in wanting a diagnosis, or viewing their child's behaviour as "naughty".
- Differences with one parent not allowing their child's needs to interfere with their own wants, goals, or dreams.
- Conflicting parenting or caregiving styles and beliefs.
- Unfair distribution of parenting or caregiving demands between parents.
- Less time and energy to communicate and be intimate as partners.

Often when these stressors occur, there can be a build-up of negative feelings between partners, including feelings of blame, frustration, neglect, and resentment. Without a change in behaviour, these stressors and negative feelings can worsen over time.

For couples who feel this way, have hope. Things can improve if both of you are prepared to commit to your relationship.

ONE PARENT'S ADVICE TO ANOTHER

SUPPORTED STRATEGIES

REFLECTIVE LISTENING

A way to improve communication is to practice reflective listening. This is where you make an effort to hear the complete message the other person is communicating, not just the words they are saying.

When using reflective listening, you repeat back what the person said in your own words. This shows that you didn't just hear them, but you are trying to understand them.

To do this, you must pay full attention to the other person carefully without becoming distracted, losing focus, or forming counter arguments in your mind while they are speaking.

1. Show that you are listening by looking at the speaker directly. Do not start speaking until they have finished.
2. Try to reflect what you think they are telling you. If possible reflect their emotions, even if they didn't clearly describe them. You may be able to pick up on this by their tone of voice or body language.
3. Switch up your phrasing – Try using "I hear you saying that...", "I think you're telling me that...", "It sounds like you feel...".
4. Focus on reflecting the main points. Don't worry too much about the little details, especially if the person has a lot to say.

   An example:
   Speaker: "I get so angry when you spend so much money without telling me. We're trying to save for a house!"
   Listener: "It sounds like you feel really frustrated when I spend so much money. It must seem like I don't care that we are trying to save for a house"

“I think that doing whatever it takes to remember who you are as a couple is so essential, even if you're forcing yourself at first. It keeps running through my head, “fake it till you make it” ... I think even more so with a disabled child, it is so important to remember who you are as a couple and to focus on who you are as a couple rather than everything else... and doing this regularly, not every six months.”

ONE PARENT'S ADVICE TO ANOTHER

PG 11

STRATEGY 6
"WHAT ABOUT ME?"

SIBLING RELATIONSHIPS

Siblings of children with disabilities have unique needs themselves. Often, your child with special needs will likely get the bigger share of your attention due to extra caregiving demands. If your other children experience difficult feelings because of this, it will likely increase your feelings of guilt or stress.

Your children may have trouble coping with being the sibling of a child with special needs at times. They may have many different and conflicting feelings, including feeling worried, jealous, angry, resentful, guilty, or pressure to perform.

Sometimes these feelings can be so intense or distressing, that your child may need professional counselling or therapy to help them cope. Talking with other kids going through the same thing can also be helpful for them, either in person or online. If you are concerned about your children or notice any big changes in their behaviour, talk to your GP around what support options are available.

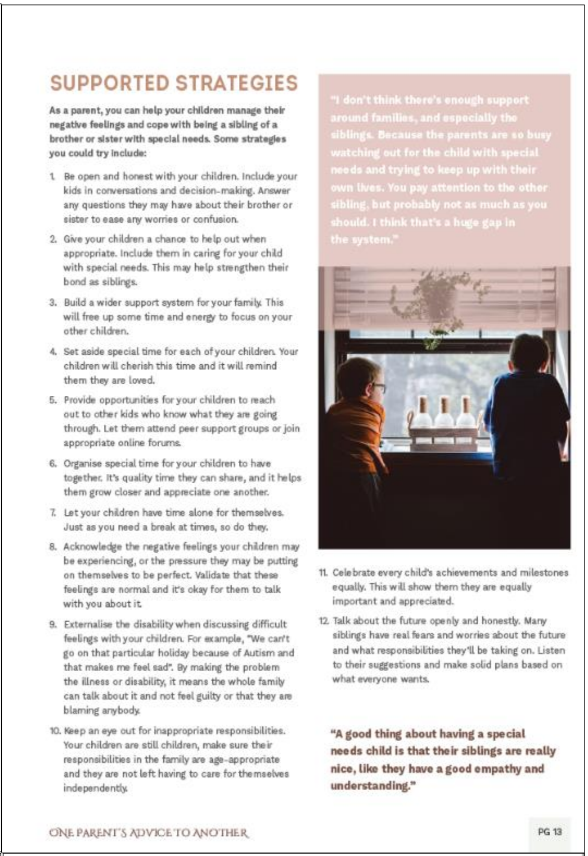
Whilst having a sibling with special needs can be challenging, it can also come with wonderful benefits. Your children have more of a chance of developing many good qualities. These qualities can include increased patience, kindness, acceptance of differences, compassion, and empathy for others.

SEEKING SOLIDARITY

When families have multiple children, often parents find it difficult to juggle their attention, parenting, and caregiving demands between siblings. If this is you, it may leave you feeling worried that your children believe they are less loved or important, or that the situation is unfair.

You may also experience sadness or grief when you notice what your child with special needs cannot do when compared to their siblings as they age and develop.

These are common experiences, but you can help ease these feelings by "tuning in" to the individual needs of each child.



SUPPORTED STRATEGIES

As a parent, you can help your children manage their negative feelings and cope with being a sibling of a brother or sister with special needs. Some strategies you could try include:

1. Be open and honest with your children. Include your kids in conversations and decision-making. Answer any questions they may have about their brother or sister to ease any worries or confusion.
2. Give your children a chance to help out when appropriate. Include them in caring for your child with special needs. This may help strengthen their bond as siblings.
3. Build a wider support system for your family. This will free up some time and energy to focus on your other children.
4. Set aside special time for each of your children. Your children will cherish this time and it will remind them they are loved.
5. Provide opportunities for your children to reach out to other kids who know what they are going through. Let them attend peer support groups or join appropriate online forums.
6. Organise special time for your children to have together. It's quality time they can share, and it helps them grow closer and appreciate one another.
7. Let your children have time alone for themselves. Just as you need a break at times, so do they.
8. Acknowledge the negative feelings your children may be experiencing, or the pressure they may be putting on themselves to be perfect. Validate that these feelings are normal and it's okay for them to talk with you about it.
9. Externalise the disability when discussing difficult feelings with your children. For example, "We can't go on that particular holiday because of Autism and that makes me feel sad". By making the problem the illness or disability, it means the whole family can talk about it and not feel guilty or that they are blaming anybody.
10. Keep an eye out for inappropriate responsibilities. Your children are still children, make sure their responsibilities in the family are age-appropriate and they are not left having to care for themselves independently.

"I don't think there's enough support around families, and especially the siblings. Because the parents are so busy watching out for the child with special needs and trying to keep up with their own lives. You pay attention to the other sibling, but probably not as much as you should. I think that's a huge gap in the system."

11. Celebrate every child's achievements and milestones equally. This will show them they are equally important and appreciated.
12. Talk about the future openly and honestly. Many siblings have real fears and worries about the future and what responsibilities they'll be taking on. Listen to their suggestions and make solid plans based on what everyone wants.

"A good thing about having a special needs child is that their siblings are really nice, like they have a good empathy and understanding."

STRATEGY 7
GET CREATIVE

SELF-CARE AS A FAMILY ACTIVITY

Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important things you can do as a parent. When your needs are taken care of, your children will benefit too. Many parents talk about the struggles they have initially when it comes to self-care, as they feel they do not have enough time, money, or energy left over to spend on themselves. They often dedicate all their time and effort into their children, partners, jobs, caregiving responsibilities, and family.

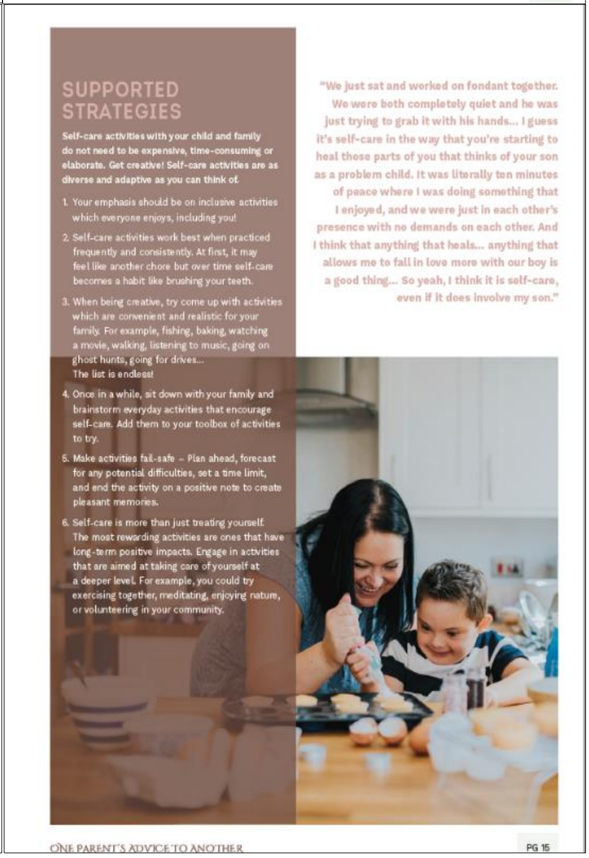
Parents can also have added barriers to self-care, including being a solo-parent, having financial constraints, or having negative beliefs about self-care. For example, that self-care is selfish or that needing time-off is admitting you've failed.

However, not taking care of yourself can leave you at risk for depression, anxiety, chronic illness, and a decline in quality of life.

If you feel unable to find enough alone time to engage in self-care, one of the best first steps you can take is to do self-care activities together with your child or family. Finding activities that both you and your child find uplifting and enjoyable is worth it as not only does it help you operate at your best, it helps your child learn good habits too.

The benefits of engaging in self-care together also include:

- Building positive memories with your child and family. These memories are helpful to reflect on during more difficult times.
- Strengthening your relationship with your child. Doing positive things together has a therapeutic and healing effect on relationships.
- Learning more about the characteristics and personalities of your child. Parents talk about how this helps them to separate their child from the disability.
- Gaining a sense of achievement that you are doing something good as a parent. It can make you happy seeing your child and family happy too.

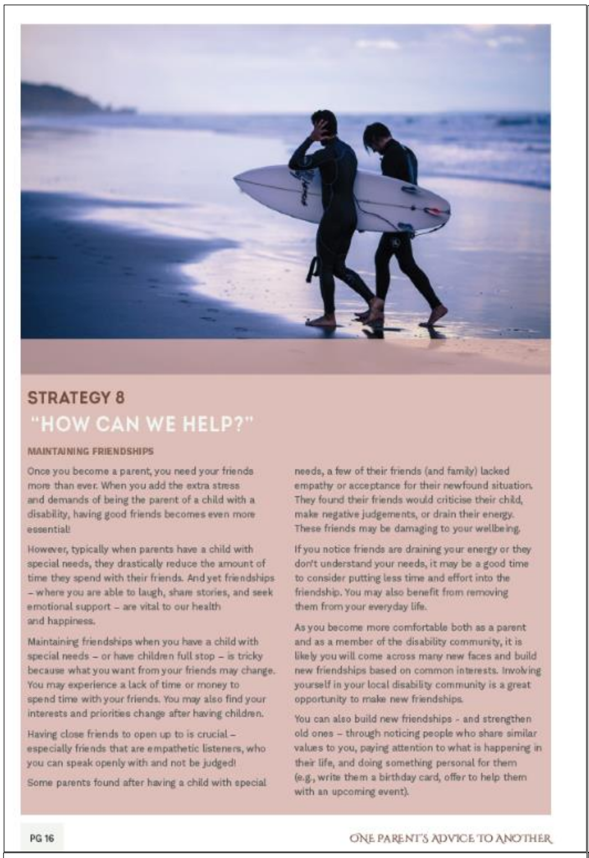


SUPPORTED STRATEGIES

Self-care activities with your child and family do not need to be expensive, time-consuming or elaborate. Get creative! Self-care activities are as diverse and adaptive as you can think of.

1. Your emphasis should be on inclusive activities which everyone enjoys, including you!
2. Self-care activities work best when practiced frequently and consistently. At first, it may feel like another chore but over time self-care becomes a habit like brushing your teeth.
3. When being creative, try come up with activities which are convenient and realistic for your family. For example, fishing, baking, watching a movie, walking, listening to music, going on ghost hunts, going for drives...
   The list is endless!
4. Once in a while, sit down with your family and brainstorm everyday activities that encourage self-care. Add them to your toolbox of activities to try.
5. Make activities fail-safe – Plan ahead, forecast for any potential difficulties, set a time limit, and end the activity on a positive note to create pleasant memories.
6. Self-care is more than just treating yourself. The most rewarding activities are ones that have long-term positive impacts. Engage in activities that are aimed at taking care of yourself at a deeper level. For example, you could try exercising together, meditating, enjoying nature, or volunteering in your community.

"We just sat and worked on fondant together. We were both completely quiet and he was just trying to grab it with his hands... I guess it's self-care in the way that you're starting to heal those parts of you that thinks of your son as a problem child. It was literally ten minutes of peace where I was doing something that I enjoyed, and we were just in each other's presence with no demands on each other. And I think that anything that heals... anything that allows me to fall in love more with our boy is a good thing... So yeah, I think it is self-care, even if it does involve my son."



STRATEGY 8

"HOW CAN WE HELP?"

MAINTAINING FRIENDSHIPS

Once you become a parent, you need your friends more than ever. When you add the extra stress and demands of being the parent of a child with a disability, having good friends becomes even more essential!

However, typically when parents have a child with special needs, they drastically reduce the amount of time they spend with their friends. And yet friendships – where you are able to laugh, share stories, and seek emotional support – are vital to our health and happiness.

Maintaining friendships when you have a child with special needs – or have children full stop – is tricky because what you want from your friends may change. You may experience a lack of time or money to spend time with your friends. You may also find your interests and priorities change after having children.

Having close friends to open up to is crucial – especially friends that are empathetic listeners, who you can speak openly with and not be judged!

Some parents found after having a child with special needs, a few of their friends (and family) lacked empathy or acceptance for their newfound situation. They found their friends would criticise their child, make negative judgements, or drain their energy. These friends may be damaging to your wellbeing.

If you notice friends are draining your energy or they don't understand your needs, it may be a good time to consider putting less time and effort into the friendship. You may also benefit from removing them from your everyday life.

As you become more comfortable both as a parent and as a member of the disability community, it is likely you will come across many new faces and build new friendships based on common interests. Involving yourself in your local disability community is a great opportunity to make new friendships.

You can also build new friendships - and strengthen old ones – through noticing people who share similar values to you, paying attention to what is happening in their life, and doing something personal for them (e.g., write them a birthday card, offer to help them with an upcoming event).

SUPPORTED STRATEGIES

ADVICE FOR FRIENDSHIPS

As a parent:

- Schedule regular catch-ups with your friends.
- Say "Yes!" when friends ask to hang-out.
- Practice being comfortable asserting your needs to your friends. For example, you may prefer them coming to your house, or going somewhere quiet which your child enjoys.
- If you find it difficult to find time – Start small and attach it to other responsibilities. For example, go early to school pick-up to talk with the other parents, or ask your friend to complete errands with you.
- Reflect on the benefits of social interaction for you. Do you feel less stressed or isolated? Are you able to gain a sense of connection or offload some of your problems?

As the friend of a parent:

- Schedule regular catch-ups with your friend!
- Accept that plans may not work out or may change last minute.
- Understand and accept the reality of having a child with special needs – Do not blame your friend or their child.
- Do not give up if plans change – Ask "How can I help?" or "What else can we do?". This could include giving your friend a phone call or visiting them at home instead.
- Make plans well in advance – Your friend may need to organise someone to care for their child. This takes time to sort out.
- Include your friend's children where possible. This may help reduce their stress or need to plan respite.
- Have reliable strategies that work for your friend and their child – What activities does your friend's child find enjoyable and relaxing? Can you and your friend spend quality time while they participate in this?
- Build a good relationship with your friend's children. Educate yourself to increase your understanding of their child's disability.
- Offer your friend an empathetic ear – Sometimes the best way to help friends is to let them vent without trying to fix their problems or criticise them.

"If someone offers you a chance to get out and socialise with adults, take it. Don't worry about your house being turned upside down and that you're going to go home to a tornado, take it, because otherwise it drives you nuts."

STRATEGY 9

YOU ARE NOT ALONE

BUILDING A COMMUNITY OF SUPPORT

There is wisdom in the saying, "It takes a village to raise a child". Building a community of genuine, supportive, generous, cooperative and trustworthy people around you and your family is invaluable.

The benefits of having a community of support surrounding your family include:

- Positive social support and interaction as a form of self-care.
- Shared responsibility of caring for your child.
- Feeling a sense of connection or belonging to a wider community based on shared values.
- Practical help and assistance.
- Emotional support and validation.
- Experiencing acceptance and finding deeper meaning in everyday life.
- Spiritual connection and guidance.
- Therapeutic and healing benefits for your whole family, and improved family functioning.

Supportive people in your community can be extended family, existing friendships, new friendships and connections within the disability community, people from your work or hobby groups (e.g., sports teams, art or dance classes, and exercise groups), and people from your cultural or religious groups.

Finding genuine people to include in your supportive community often requires you to be your authentic self. Talking about things that matter to you and opening up about what is close to your heart will attract trustworthy and genuine relationships. This may take a few false starts before you find the right friendships and supports.

Once you start building a community of supports, the next challenge is asking them for help. Often people who genuinely want to help you and your family might not know how. You may need to be fairly direct and make specific requests to make it easier for them to pitch in without feeling out of their depth. For example, "Could you watch the kids on Monday after school so that I can get a haircut?".

Your community also consists of your formal team of respite carers, disability and healthcare professionals, and peer support people. Sometimes you may find you also benefit from additional psychosocial support for your family – such as social workers, counsellors, or clinical psychologists.

Many parents have found this helpful for their families, particularly early on when receiving their child's diagnosis. Often around this time, families can experience significant trauma and grief. They also may have limited awareness and understanding of their child's disability.

There is a range of mental health and wellbeing resources and service available in New Zealand, including phone and online services and information, as well as face to face support. As these services vary throughout the country, it would be impossible to list them all. Some useful contacts are listed at the end of this booklet, or arrange to speak with your GP.

"I recognise how much other people have a part to play in my self-care, like being part of a bigger community of people that are supporting me... I also strongly believe that it's a community that raises a child and I have a really good support network and wouldn't want to do it on my own. I want her to have other people in her life that she's connected to and attached to."

SUPPORTED STRATEGIES

SAYING "NO"

Most of us are guilty of overscheduling ourselves or not turning down an invite. When you say no to a social invitation, it is easy to feel like you are letting the other person down. The truth is, turning down social invitations can make you happier and your relationships more genuine.

Being able to identify your limits when it comes to social commitments can be a valuable skill to prevent you from becoming exhausted or overwhelmed. When considering social invitations, it can be helpful to stand back and assess/prioritise your own needs, interests and obligations. A simple way to do this can be to ask yourself, "If I accept this invitation, how am I going to feel about it later?"

Tips to help you gracefully say NO to social invitations – and free up the time and energy that you need for yourself – include:

1. Be direct from the start – Your first instinct may be to say "Maybe" or "I don't know" as you don't want to hurt the other person's feelings. However, if you can gather the courage to say a more final "No" from the start, then you are being more respectful of the other person's time and effort.
2. Start with gratitude – Start with a genuine thank you for the invitation and don't be afraid to say no in the end. This can be especially helpful if you are responding via text or email as it will appear warmer and more thoughtful.
3. Use "No" as a complete sentence – You do not always have to offer an explanation as to why you are saying no. Setting yourself a requirement to have to provide an explanation will only make you feel more guilty declining invitations.
4. Don't make up an excuse – Honesty is the best policy, even if you are worried that your reason for doing so isn't legitimate. Friends may see through your lie immediately and may then interpret this as you not wanting to spend time with them.
5. Offer an alternative – Be assertive with your no but suggest another specific plan that more suits your interests and schedule. This will demonstrate you are still invested in the relationship.
6. Buy time – When a person catches you off guard, you may become flustered and automatically accept their invitation. Instead of responding straight away, tell the person you will think about it and get back to them within a certain timeframe. This will give you time to weight the pros and cons of the request and prepare a thoughtful response.

STRATEGY 10

WHAT IS IMPORTANT

IDENTIFYING VALUES

Your values are the beliefs that define what is most important to you, and what you are willing to stand up for. Personal values guide your choices in life and create a road map for the kind of life you aspire to lead. The more your choices align with your values, the better you will feel about yourself.

Understanding your values will help you recognise areas of your life that need more attention. It will also help guide your decisions around what to prioritise in the future. For example, a parent who values family might try to spend extra time at home, while a parent who values their career may do just the opposite.

When raising a child with special needs, many parents experienced a loss of identity and purpose in life as they started prioritising their child's needs at the expense of their own. Through identifying their values and what is most important to them, these parents found they were able to restore their identity over time. Parents have also found that having a child with special needs has resulted in positive changes in their values. For example, becoming more accepting and thoughtful of other's differences, valuing caring for others, shifting their perspective of the disability community, and increasing their resiliency to manage difficult everyday situations.

Parents have found that recognising and living to their values helps with:

- Enhancing their wellbeing and happiness.
- Guiding decision-making and problem-solving.
- Increasing their ability to find meaning and purpose in everyday life.
- Reducing negative feelings, including guilt, stress and worry.
- Strengthening family functioning and relationships.
- Increasing their sense of gratitude, motivation, and empowerment.
- Providing peace and acceptance for their choices and experiences.
- Enhancing their sense of identity.

SUPPORTED STRATEGIES

VALUE CLARIFICATION

Sometimes our values are not totally clear to us, and it may take a bit of reflection to figure out the principles, beliefs or ideas that we most value.

If you want to explore your personal values in more detail and examine which types of values are more or less important to you, try out this activity.

Instructions: Read the list of values provided on the next page and include any additional values you've identified that are not listed already. Mark the 5 most important values to you in the "Top 5" column, and the 5 least important values to you in the "Bottom 5" column.

Once complete, rank the order of your most important values (numbering them 1 to 5, with 1 indicating the most important).

Now that you have identified what values are most important to you, reflect on how you are successfully incorporating these values in your everyday life. Also, reflect on whether any of these values are being neglected in your life and consider ways in which you could incorporate them more successfully.

> **"I think my priorities have changed since I've taken her on and I do have a bit of a different attitude to life. I think I was always quite high-strung and my whole life was work. I was always stressed, and I was always busy. Now I'm busier than I've ever been but I still feel like I've got lots of downtime... after dinner we'll sit on the couch and chill out, and I wouldn't have done that before but now I do because of her, and in some ways, she's slowed me down in a weird way.**
> **And I just look at her and the way she thrives from just being loved and cared for, I think that is the most important thing. That's what all of us need at the end of the day is to be loved, and to know that we are loved unconditionally is definitely more important than everything else. And that's what she has taught me, the value in that."**

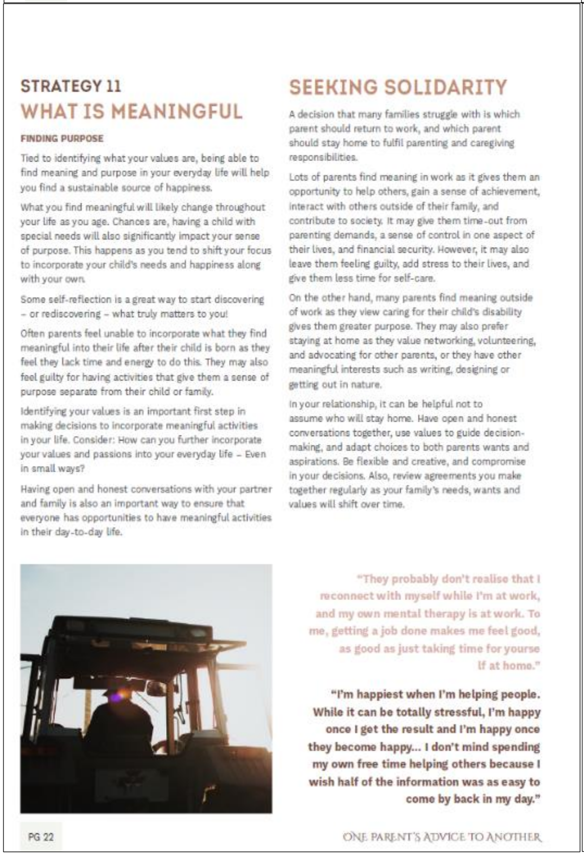
PG 20

ONE PARENT'S ADVICE TO ANOTHER

VALUE	TOP 5	BOTTOM 5
1. Being physically healthy		
2. Being emotionally healthy		
3. Being there for my family		
4. Completing my education		
5. Having a meaningful or enjoyable job		
6. Being wealthy		
7. Being in a romantic relationship		
8. Being seen as attractive by others		
9. Living according to my spiritual or religious beliefs		
10. Raising healthy and happy children		
11. Travelling and exploring the world		
12. Following the traditions of my culture		
13. Being respected by others		
14. Having significant power in the world		
15. Having a close group of friends		
16. Being able to support my family financially		
17. Helping others		
19. Continuing to learn new things		
20. Making a positive contribution to my community		
21. Having fun and enjoying life		
22. Having a calm and peaceful life		
23. Connecting with nature		
24. Other:		
25: Other:		

ONE PARENT'S ADVICE TO ANOTHER

PG 21



STRATEGY 11

WHAT IS MEANINGFUL

FINDING PURPOSE

Tied to identifying what your values are, being able to find meaning and purpose in your everyday life will help you find a sustainable source of happiness.

What you find meaningful will likely change throughout your life as you age. Chances are, having a child with special needs will also significantly impact your sense of purpose. This happens as you tend to shift your focus to incorporate your child's needs and happiness along with your own.

Some self-reflection is a great way to start discovering – or rediscovering – what truly matters to you!

Often parents feel unable to incorporate what they find meaningful into their life after their child is born as they feel they lack time and energy to do this. They may also feel guilty for having activities that give them a sense of purpose separate from their child or family.

Identifying your values is an important first step in making decisions to incorporate meaningful activities in your life. Consider: How can you further incorporate your values and passions into your everyday life – Even in small ways?

Having open and honest conversations with your partner and family is also an important way to ensure that everyone has opportunities to have meaningful activities in their day-to-day life.

SEEKING SOLIDARITY

A decision that many families struggle with is which parent should return to work, and which parent should stay home to fulfil parenting and caregiving responsibilities.

Lots of parents find meaning in work as it gives them an opportunity to help others, gain a sense of achievement, interact with others outside of their family, and contribute to society. It may give them time-out from parenting demands, a sense of control in one aspect of their lives, and financial security. However, it may also leave them feeling guilty, add stress to their lives, and give them less time for self-care.

On the other hand, many parents find meaning outside of work as they view caring for their child's disability gives them greater purpose. They may also prefer staying at home as they value networking, volunteering, and advocating for other parents, or they have other meaningful interests such as writing, designing or getting out in nature.

In your relationship, it can be helpful not to assume who will stay home. Have open and honest conversations together, use values to guide decision-making, and adapt choices to both parents wants and aspirations. Be flexible and creative, and compromise in your decisions. Also, review agreements you make together regularly as your family's needs, wants and values will shift over time.

> **"They probably don't realise that I reconnect with myself while I'm at work, and my own mental therapy is at work. To me, getting a job done makes me feel good, as good as just taking time for yourse lf at home."**

> **"I'm happiest when I'm helping people. While it can be totally stressful, I'm happy once I get the result and I'm happy once they become happy... I don't mind spending my own free time helping others because I wish half of the information was as easy to come by back in my day."**

PG 22

ONE PARENT'S ADVICE TO ANOTHER

SUPPORTED STRATEGIES

PROS AND CONS

Weighing up the pros and cons of a decision is a quick and easy process. It can be a helpful strategy to use when making decisions based on what is meaningful to you, or how to incorporate meaning and purpose into your life. For example, deciding whether to return to work.

This strategy can speed up decision-making, improve your understanding of the situation, and help you avoid becoming "stuck" with certain decisions. It helps you approach decisions objectively, without letting your "gut feeling" impact your choice – sometimes this feeling can be inaccurate!

This strategy is also particularly useful when making decisions as a family. It encourages each person consider others' perspectives without criticism, and it can help you reach a balanced decision together. For example, deciding who should be responsible for a certain parenting responsibility.

1. First, write the decision you have to make at the top of a sheet of paper. Next, divide it in half vertically. Label one side "Pros" and the other "Cons."
2. Sometimes you will have a decision between two options – Divide the paper in half horizontally. This creates a grid. Label the top row with the first option and the bottom with the second option.
3. Then, list all of the possible positive consequences for each option in the Pros column, and all the possible negative consequences in the Cons column.
4. Consider both short-term and long-term consequences of each option and ensure these are all written down.
5. It may already be obvious what decision you should implement at this stage. If not, consider the points you've written down, and assign a positive or negative value to each one. For example, a score of +5 may be strongly favourable, while -1 may be mildly unfavourable. Try to score as objectively as possible.
6. Once you've finished, add up the scores in each column, and subtract the total cons from the total pros. A positive overall score indicates that you should go ahead with the decision.
7. Remember, always use your common sense. If you suspect that the solution isn't appropriate, take some time to identify any factors you may have missed.

ONE PARENT'S ADVICE TO ANOTHER

PG 23

STRATEGY 12

WHAT THE FUTURE HOLDS

SETTING GOALS AND MAKING PLANS

Goal-setting is slightly different for families of children with special needs. You may find you don't move through stages the way other families do. You may also face more unknown factors when looking toward the future.

Still, the goals and plans you put in place now will help you no matter what the future holds. When you take time to reflect on how you would like yourself, your child and your family to grow, you are investing in your family's success. When families come together to work toward common goals and plans, they are more likely to take the necessary steps to succeed.

It can be easy to get caught up in the chaos of family life without stopping to consider what is most important to you, and what direction you want to lead your family. However, having a clear concept of your goals will build hope and increase motivation for the whole family. Working collaboratively with your family, will also increase empathy, respect, commitment and family morale.

When considering goals for your family, you should consider what you want your child's life to look like in the future. A lot of factors are out of your control when raising a child with special needs, which can leave you feeling lost or powerless. Having goals and aspirations for your child can therefore give you back some sense of control and direction.

Goals for your family and child should come from talking with them about their aspirations if possible. Other options could be to brainstorm ideas with your partner or family, or to network with other parents about the goals and plans they have for their family. You could also educate yourself about what options for your child are available in your local area, and network with disability services to start turning your plans into action.

For example, it is helpful to consider what milestones you want your child to meet, what level of independence your child is working towards, and where they may attend school, work or live as they grow older.

SEEKING SOLIDARITY

Having a child with special needs is typically not planned and you may find aspects of this can interrupt your own original aspirations, goals and life plans. Parents have found that having a child with disabilities can create a significant shift in their priorities, and their child can become a major deciding factor in the goals and aspirations they feel able to pursue (such as whether they can work, travel, or have more children). Some parents experience this as a loss of freedom, resulting in feelings of jealousy, disappointment, grief and frustration.

If you are dealing with these feelings, or anything similar, you first need to acknowledge and accept your emotions. Give yourself time and space to grieve the loss of your original goals and aspirations.

Over time, these feelings will likely lessen, and you will come to accept these changes in your life. However, if the feelings continue and are distressing, it may be helpful to reach out for support from friends, family, peer support, or formal supports such as counselling.

Once you've accepted the changes in your life, it's time to be creative. Consider ways you could modify your previous aspirations and goals to make them achievable with your current circumstances. Use your values to guide decision-making, and talk with others if you need some inspiration.

"I just have this thing of getting my kids to adulthood, and my son being able to participate in the community as a contributing member of society, having his own decisions and choices that he can make himself. My youngest one, I hope to see him have his own independence. We will still always be involved in his life as it's just the way he is, but at the end of the day I also see it being essential not having that responsibility."

SUPPORTED STRATEGIES

GOAL SETTING

Having big life goals with many time-consuming steps can be very stressful and overwhelming. These are the types of goals that you always say you will start "tomorrow" or "next week", but those times never seem to come.

Learning to break your goals into smaller tasks will help you to overcome the stress and procrastination they create. Also turning your goals into SMARTER goals – specific, measurable, achievable, realistic, timed, evaluated, and readjust – will help to give you direction and allow you to track your progress.

To turn your ambitions into SMARTER goals, follow these steps – It will help to write them down and keep them somewhere safe.

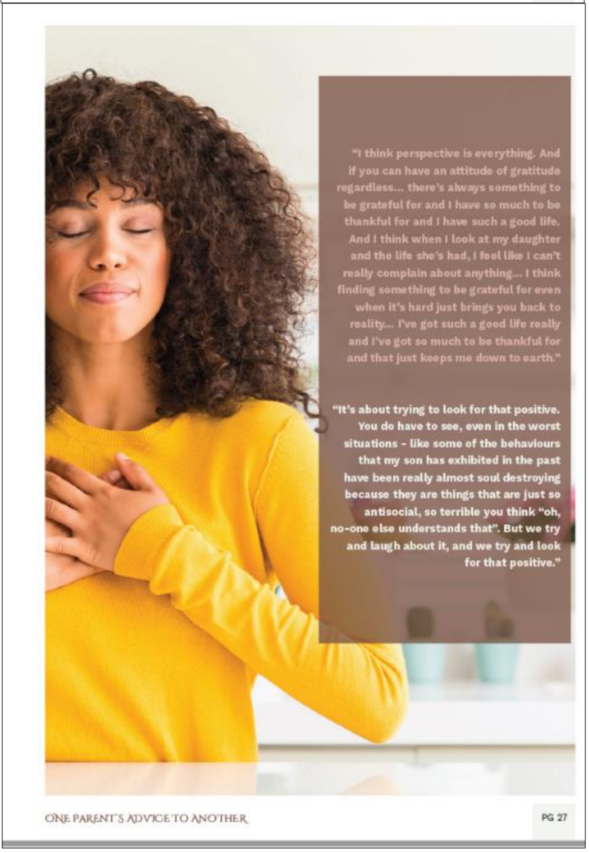
1. What is it that I want to achieve? – List why you want to reach this goal.
2. Make your goal detailed and SPECIFIC – Answer who, what, where, when and how. List at least 3 action steps you will need to take.
3. Make your goal MEASURABLE – How will you measure or track your goals? How will you know when you've reached your goal?
4. Is your goal ACHIEVEABLE? – Is it within your control to achieve it? What additional things do you need to achieve this goal? Who can you talk to for support?
5. Is your goal REALISTIC? – How will you find the time to complete it? Do you need to learn anything more about it?
6. Make your goal TIMED – Put a deadline on your goal and set some benchmarks along the way. What is the halfway date and end date? Any additional dates or milestones?
7. How will you EVALUATE your goal? – What methods will you use to review your goal at each checkpoint or milestone?
8. Ensure you can READJUST if needed – If you find yourself continuously hitting a brick wall with reaching your goal, how can you readjust your approach and techniques to make it more achievable?

"Everyone likes light at the end of the tunnel. So, if you don't have a goal of where you're going, if you just feel it's a day to day thing - and some days it is, some days it wears - but if you've got a place that you're going to, I think that helps."

STRATEGY 13

LOOKING FOR POSITIVES

SUPPORTED STRATEGIES



"I think perspective is everything. And if you can have an attitude of gratitude regardless... there's always something to be grateful for and I have so much to be thankful for and I have such a good life. And I think when I look at my daughter and the life she's had, I feel like I can't really complain about anything... I think finding something to be grateful for even when it's hard just brings you back to reality... I've got such a good life really and I've got so much to be thankful for and that just keeps me down to earth."

"It's about trying to look for that positive. You do have to see, even in the worst situations - like some of the behaviours that my son has exhibited in the past have been really almost soul destroying because they are things that are just so antisocial, so terrible you think "oh, no-one else understands that". But we try and laugh about it, and we try and look for that positive."

"I think most families who have a child like mine would say that routine is important, but without it becoming ritualised so that then you can't do anything else around it. And that's the bit that we always struggle with, there's always that balance of giving my son enough routine that he's happy, but without him ruling everything we do. Because things change and sometimes we have to go somewhere else, and we have to do something different."

STRATEGY 14
BALANCING TIME

CREATING ROUTINES

Parents can feel at times like they are just keeping their heads above water trying to juggle all of life's demands – Getting kids up and to school, going to work, fitting in time for friends and family, doing chores, paying bills, going to the supermarket... the list goes on and on!

Creating a functioning routine for yourself and your family can help you get things done more efficiently, remember important tasks, and find time to dedicate to yourself and to having fun with your family. Routines help everyone in the family know what is expected of them and when.

Some routines might be for things you need to do everyday (e.g. getting ready for bed or for school), and others can be weekly or occasional ones (e.g. going to the supermarket or to the park).

Every family has different needs and wants unique to them, so there are no strict rules about what kind of routines you should have. What works well for one family might be too structured or too relaxed for another.

Having effective routines are a preventative approach to self-care. The many benefits of having successful routines include:

- You can use your limited time more efficiently.
- It frees up your headspace so you can think more clearly and calmly.
- Being organised can create more time for prioritising your own self-care through the week.
- You gain a sense of achievement when you complete tasks through the day.
- It provides an important reminder for responsibilities, particularly during stressful times. For example, remembering to give your child certain medications, or remembering important appointments.
- Over time, important responsibilities can become a habit. For example, setting time in the day for physical therapy with your child.
- Predictability helps your children feel safe and secure. Routines also help your children learn to become more independent.

What works well for a family can change at times. Flexibility in your routines is important to consider when circumstances change, and unexpected things come up. For example, if you go on a holiday or your child becomes unwell. Some flexibility in your routines help you and your child stay adaptable and resilient to change. However, you might find that after a break you need to bring routines back in gradually.

SEEKING SOLIDARITY

Some parents find they have to fit-in and adapt to their child's routine, which at times can be quite structured or restricted. This occurs particularly when children have set medication, physical therapy, and appointment times. Or when children are quite demanding of your time at home due to physical limitations or behavioural needs.

This can leave parents feeling trapped as though their life closely revolves around their child. Parents may feel unable to prioritise their own needs or experience immense guilt and shame when they spend time on themselves. For example, parents may feel unable to spare time to have a shower, be unable to sleep-in, or need to constantly supervise their child when in their care.

It can be a tricky balance for parents at times to meet both the needs of their child and themselves. Some ways parents have negotiated this has been to purposely schedule in time for themselves. For example, they will schedule in an hour in the morning before their child wakes up, or they will reserve time in their evenings after their child is in bed.

Parents have also lowered their own expectations to complete chores and tasks at home (e.g. laundry, cleaning), in order to dedicate that time to themselves. They participate in activities which help them to mentally "switch-off", or they attach their self-care to other responsibilities. For example, going to see a friend before picking their child up from school.

SUPPORTED STRATEGIES

Tips for parents when making routines:

- Make sure routines are well planned (everyone understands them), regular (they are part of everyday family life), and predictable (they happen in the same order each time).
- Start by building routines around the times people wake, eat and sleep.
- Be realistic and allow enough "dither time" for your family to get through the routine, especially if it is new to them.
- Pay close attention to the night before. If bags are packed, uniforms are washed, and lunches are made, there will be less to do in the morning.
- Create visual or social stories of routines for your child as a helpful reminder. For example, a set of photos which shows the steps of their morning routine.
- If you can, remember to rotate duties with your partner and family so it is fair for everyone.
- Do things in bunches – Consolidate your chores. Dedicating a day to laundry, supermarket shopping, or vacuuming can be more efficient than sporadically doing these through the week.
- Automate everything you can – Use features or services that get things done automatically for you. For example, automatic bill payments, or automatic prescription refills.

"I do have a routine, it's a chaotic one, but it's a routine, nonetheless. It does help... You just know what needs to be done by a certain time. You know where you have to be, and when you have to be there, that's what helps for me."

STRATEGY 15
SWITCHING OFF

FINDING "MENTAL BREAKS"

Many parents have spoken about difficulties with being able to switch off and find a "mental break" in their day where they are not caring for their child's needs or worrying about their child's future. All parents worry about their children, however, for parents of children with disabilities this can look vastly different.

In the present moment, you have a lot of added daily responsibilities for your child. These include administering medications, meeting their medical needs, supervision and watching for seizures, physical therapies, parenting responsibilities, attending appointments, helping with eating, bathing, dressing, toileting, and mobility, and so on...

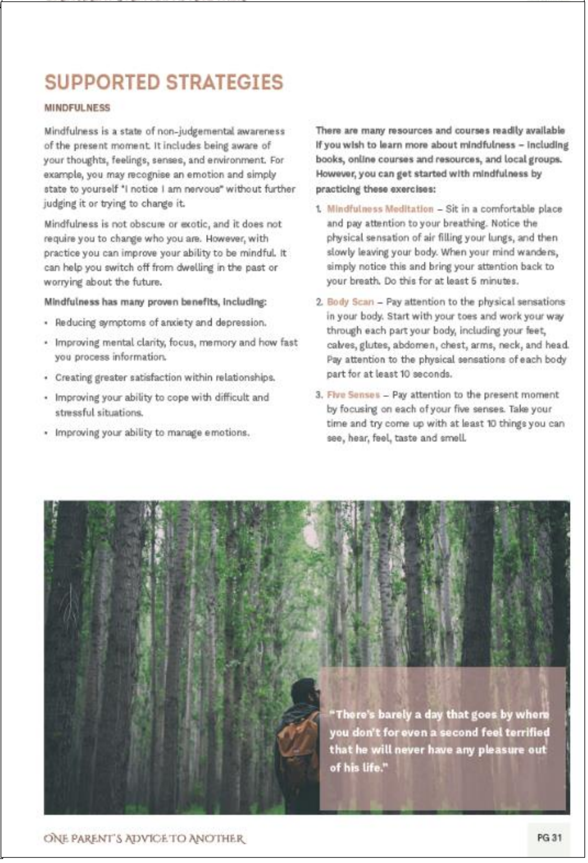
"It's trying to find a mental break, not just a physical break and I think that's the problem that most people have is realizing that you have to have a mental break where he's taken care of and you aren't thinking about him. That's been the struggle, thinking about him is just as exhausting and hard as physically being there with him."

On top of day-to-day responsibilities, you often may find that you are thinking about fears and worries for the future, including:

- How your child will transition to adulthood.
- How your child's disability may change or worsen as they age and develop.
- What your child may or may not be capable of learning.
- How you will be able to meet your child's needs as you both age.
- What will happen when you are no longer able to care for your child due to injury, illness or death.

To have a mental break from these worries and responsibilities and allow yourself to switch off:

1. Acknowledge that your worries and sacrifices exist and make sense.
2. Experiment with enjoyable and distracting activities. For example, reading, watching movies, sitting in the sun, doing exercise, etc.
3. Set goals and work on a long-term plan for worst case scenarios. For example, what will happen for your child if you became ill, injured or died.
4. Reach out and access support from your community of friends and family. If you are still concerned, consider accessing formal supports like therapy or counselling.
5. Practice relaxation and mindfulness strategies.



SUPPORTED STRATEGIES

MINDFULNESS

Mindfulness is a state of non-judgemental awareness of the present moment. It includes being aware of your thoughts, feelings, senses, and environment. For example, you may recognise an emotion and simply state to yourself "I notice I am nervous" without further judging it or trying to change it.

Mindfulness is not obscure or exotic, and it does not require you to change who you are. However, with practice you can improve your ability to be mindful. It can help you switch off from dwelling in the past or worrying about the future.

Mindfulness has many proven benefits, including:

- Reducing symptoms of anxiety and depression.
- Improving mental clarity, focus, memory and how fast you process information.
- Creating greater satisfaction within relationships.
- Improving your ability to cope with difficult and stressful situations.
- Improving your ability to manage emotions.

There are many resources and courses readily available if you wish to learn more about mindfulness – including books, online courses and resources, and local groups. However, you can get started with mindfulness by practicing these exercises:

1. **Mindfulness Meditation** – Sit in a comfortable place and pay attention to your breathing. Notice the physical sensation of air filling your lungs, and then slowly leaving your body. When your mind wanders, simply notice this and bring your attention back to your breath. Do this for at least 5 minutes.
2. **Body Scan** – Pay attention to the physical sensations in your body. Start with your toes and work your way through each part your body, including your feet, calves, glutes, abdomen, chest, arms, neck, and head. Pay attention to the physical sensations of each body part for at least 10 seconds.
3. **Five Senses** – Pay attention to the present moment by focusing on each of your five senses. Take your time and try come up with at least 10 things you can see, hear, feel, taste and smell.

"There's barely a day that goes by where you don't for even a second feel terrified that he will never have any pleasure out of his life."

STRATEGY 16

IT WILL BE HARD SOMETIMES

DEALING WITH NEGATIVE FEELINGS

A common problem all people face is how to deal with negative emotions – How do we deal with stress or hurt when it keeps occurring? Are we supposed to hide our anger or frustration away and pretend it does not exist? Do we ignore sadness or grief until it disappears?

All negative emotions serve a purpose. They act as signals to you that something in your life isn't working and needs to change. Negative emotions come from a triggering event, such as an overwhelming parent workload, or they come from your interpretation and thoughts of such events.

Ignoring negative feelings is not the healthiest way to deal with them – Usually it does not make them go away (It can even cause them to worsen or come out in different ways – such as using alcohol or drugs, getting angry at the wrong person, crying over "nothing"). In the long run, they can also significantly impact your physical and emotional health.

There are three main steps to dealing with negative emotions – **1. Look within** and try figure out what you are feeling and what is creating the stress and negative emotions in your life. **2. Change what you can** to cut down on your stress and negative emotion trigger. **3. Find a healthy outlet** for dealing with negative emotions – Such as enjoyable activities, humour and laughter, regular exercise, mindfulness, etc.

> **"There is a lot of healing that still needs to go on and I feel like it's really happening, healing between us parents as well, and how we feel about our son. It's been coming bit-by-bit, putting those pieces together. We feel differently about him and separate him from how he was when he was two... There's our son's disability and then there's our son, and I've always said that I love our son more than anything in the world, but his disability can go f*** itself. I hate his disability... We have seen that there is this beautiful human being under that disability and it's slowly emerging more than the disability – I mean the disability is still right in your face, but in my heart, he is overtaking the disability."**

SEEKING SOLIDARITY

There are unique experiences of grief and sadness which often occur for parents of children with special needs. Common experiences parents encounter include:

- Having a traumatic birth of their child.
- Receiving their child's diagnosis.
- Coming to terms with their changing role in their family to include caregiving responsibilities for their child.
- Realising the impact of the disability on their child, especially when their child misses certain milestones or major life events.
- Noticing the impact that the disability has on the whole family, including the potential discrimination and sacrifices they all have to face (e.g., change in employment, time and financial restraints, distribution of parent's attention).
- Placing guilt on themselves for having "caused" the disability.
- Losing friendships or family and professional relationships.

Having a natural emotional reaction to any of these experiences does not make you a terrible parent or an awful person. It makes you human. It is okay to grieve.

SUPPORTED STRATEGIES

GRIEF

Grief is a natural response to losing someone or something that is important to you. You often feel a range of emotions, from sadness, to anger, to loneliness. Before you had your child, you likely had an idea of what it would be like raising them and watching them grow into adulthood. You also probably imagined what kind of relationship you would have with your child, how you would parent them, and what things you would like to teach them.

These dreams and visions you had in your mind may now appear quite different to your reality at home day-to-day with your family. Having a child with a disability may be one of the most painful experiences you will confront. **It is okay to grieve for your lost dreams and visions** – for what you thought would be that isn't.

Grieving for the child and family life you thought you would have does not mean you do not love your child. Rather, grieving is a process where you start to separate from your shattered dreams and begin creating a new vision for you and your family.

Advice other parents (and professionals) have given:

- There is no "correct" way to grieve. At one end of the spectrum, you may suffer significant symptoms of trauma. At the other end of the spectrum, you may experience few feelings of sadness and take a pragmatic approach to raising your child. These are all healthy, natural reactions.
- Give yourself time, space and care to grieve. Allow yourself to cry, to talk to others who understand and can validate your reactions, and to engage in self-care activities important to you. If it continues to impact your everyday life, consider going to therapy or counselling.
- Typically, grief does not end. It comes in waves, and at times will surprise you. This is a natural process and over time you will figure out ways which work for you to cope with these emotions as they arise. For example, watching a favourite movie or having a good cry.
- You have a right to feel shock, denial, fear, pain, anger, sadness, depression, blame, yearning, helplessness, and physical discomfort. Grief comes in many shapes and sizes. Be kind to yourself – Feeling guilty for having these emotions will only make them stronger or last longer.
- It's important to balance grief with motivating yourself to find new dreams and new ways to create joy in you and your family's life. You can experience grief while also working towards acceptance and feeling hopeful for the future.
- Keep engaged with life. Grief does not have to prevent you from participating in activities that are meaningful for you. Spend enjoyable quality time with family, sustain your connections with your community, and maintain your sense of routine and function day-to-day.
- If certain difficulties are prolonging your grief, try problem-solving to find a solution. If you cannot solve it that day, then "park" the problem until you can come back to it. Use purposeful distraction – Sleep on it, look for positives or gratitude, engage in enjoyable and relaxing activities, or try mindfulness.

STRATEGY 17

WHEN ENOUGH IS ENOUGH

ACCEPTING YOUR LIMITS

As a parent, the wheels are always turning – There is always more you can be doing, thinking about, or planning for. There are always jobs and chores to catch-up on, problems to solve, and chaos to contain!

As part of self-care, it can be helpful to accept your limits and how much you can really do before you need to take a break. When we are physically injured – say we hurt our ankle – often it will not get better until we rest and allow ourselves to heal. The same goes for our mental and emotional health. The more you push and fight to keep going, the worse state you'll end up.

However, accepting your current limits and lowering your standards (even just a little bit!) will help you find freedom and happiness. When you let go of the vision of being the "perfect" parent, you will be able to let out a big sigh of relief!

Accepting where you are right now – including what your limits, emotions, restrictions, and **STRENGTHS** are – is the perfect starting place. A way to help you do this could be to let go of some of your expectations – what you think the perfect house looks like, what the perfect body looks like, what the perfect family looks like, etc. Instead, focus on what is here right now and what it is to be you.

By keeping moving within your limits, this will help you achieve a greater sense of wellbeing.

Identifying your unique mental, physical, behavioural, and emotional early warning signs are critical to noticing when you are reaching your limits.

Early warning signs for parents have included:

- Having a shorter temper and limited patience with their children.
- Feeling grumpy and upset – or crying more easily.
- Feeling physical tension – such as a sore back, neck or shoulders.
- Withdrawing from friends and family – or staying at home more.
- Noticing a change in appetite – eating more or less through the day.
- Constantly feeling tired or noticing a change in sleep – either having trouble sleeping or over sleeping.
- Feeling restless or moving slower than usual.
- Having a large weight gain or loss.

If you start to notice your early warning signs, act on them as soon as possible. This will prevent you from experiencing long-term difficulties such as burnout, depression, and fatigue.

Helpful strategies are listed throughout this booklet, but the most effective things you can do are:

- Remove yourself from the situation and take a break if it is safe to do so.
- Give yourself time to acknowledge your emotions and express them.
- Participate in enjoyable and relaxing activities.
- Reach out for support from your community of friends and family.
- Stay healthy – Get enough sleep, good nutrition, and exercise. Stay away from drugs or alcohol which can make you feel worse.
- Set a clear routine with goals and plans to look forward to.

> **"If I can feel it, I stop and drop. The kids know what that is. That's when my anger really gets to the point where I feel like I just want to punch a wall, I stop and do 20 push-ups... It's great because for one it tires me out. But it's what I'm trying to teach the kids... I wanted to do something that the kids could see that mum stresses out sometimes too"**

> **"I think physically there are signs I'm at my limit, like sometimes I can feel my jaw clench and I can sort of feel my body tense. When I do that, I know enough to just take some deep breaths, so I've learned some tools over the years"**

SUPPORTED STRATEGIES

HUMOUR

Using your sense of humour is a powerful coping technique to deal with life's challenges! Aside from the health benefits of laughter releasing 'feel-good' endorphins, having a sense of humour about difficult experiences will 1. help you bond with others, 2. look at things in a different way, 3. normalise your experience, and 4. keep things from appearing too overwhelming. Try these:

1. Start with a smile – Even if it's fake, it will lead to a genuine one. Laughter will come more easily, and any stress will disappear more readily.
2. Take a step back – If you can see your situation as an outside observer would, it's easier to recognise the funny parts.
3. Notice the extremes – If your situation is particularly frustrating or difficult, recognise the potential humour in just how ridiculous it is. Take the situation to an even greater extreme in your mind, that it becomes even more ridiculous. For example, when your child won't sleep, imagine that hours pass and then days. Visualise yourself turning into a sleep deprived monster going about your daily life. Going to work, parties and weddings, etc... you get the picture.
4. Have a funny friend – Find a friend that you can be open with and laugh about life challenges. You can each share your frustrations and darkest thoughts and laugh about them in the process. Even when they aren't there, you can lighten your mood in a difficult situation by thinking about retelling it to them later.
5. Watch funny shows and movies – Or read funny books and online forums. Not only are they entertaining, but they can show you how people find humour in universally frustrating situations. Realising that some annoying situations are actually funny, can help you endure them with a smile.
6. Make it a game – Turn predictable or repetitive difficult situations that are out of your control into a special game. You can then begin to value them in their own special way instead of letting them upset you. For example, create a competition for who has the "most difficult bedtime experience" each week with your friends, or begin counting how many times your child wakes up through the night.

FINAL WORDS

USEFUL CONTACTS FOR FURTHER INFORMATION AND SUPPORT

Mental Health and Wellbeing Support

If you are worried about yours or someone else's mental health, the best place to get help is your GP or local mental health provider. If you or someone else is in danger, call police immediately on 111.

There are services are available to provide support or help you find extra support when you need it. Most of them are free and have trained people ready to help you. These include 24-hour helplines and websites based in New Zealand, such as:

- Need to talk? – **Free call or text 1737**
- The Depression Helpline – **0800 111 757**
- Lifeline – **0800 543 354** or **free text 4357**
- Samaritans – **0800 726 666**
- Youthline – **0800 376 633**
- **www.thelowdown.co.nz**
  (support for young people, free text 5626)
- **www.depression.org.nz**
  (support for adults, free text 4202)
- **www.skylight.org.nz**
  (grief, loss and trauma support and information)
- **www.griefcentre.org.nz**
  (support, advice and counselling)

Disability Organisations and Peer Support

There are many support groups and organisations operating in the disability community throughout New Zealand. Some support organisations are disability-specific, such as:

- Royal NZ Foundation of the Blind – **www.blindfoundation.org.nz**
- IHC – **www.ih.org.nz**
- Autism NZ – **www.autism.org.nz**
- Altogether Autism – **www.altogetherautism.org.nz**
- NZ Down Syndrome Association – **www.nzdsa.org.nz**
- Cerebral Palsy Society – **www.cerebralpalsy.org.nz**
- Brain Injury Association – **www.brain-injury.nz**

Other disability organisations offer peer support to all parents and carers regardless of what disability type, such as:

- Parent to Parent – **0508 236 236** or **www.parent2parent.org.nz**
- Carers New Zealand – **0800 777 797** or **www.carers.net.nz**
- Disabled Persons Assembly NZ – **www.dpa.org.nz**

If you are looking for advocacy support, to get questions answered, or to talk through your options for making a complaint in New Zealand:

- Nationwide Health & Disability Advocacy Service – **0800 555 050** or **www.advocacy.org.nz**
- CCS Disability Action – **0800 227 2255** or **www.ccsdisabilityaction.org.nz**

For further information about applying for formal respite care or who your local Needs Assessment and Service Coordination (NASC) service is visit:

- Ministry of Health – **www.health.govt.nz**

AUTHORS

This booklet was written as part of the requirements for the degree of Doctor of Clinical Psychology with Massey University, New Zealand. If you have any feedback or would like further information regarding this booklet, please contact us:

RESEARCHER
Jana Oskam
027 380 4044
jana.oskam@hotmail.com

SUPERVISOR
Dr Kirsty Ross
(06) 356 9099 ext. 84968
K.J.Ross@massey.ac.nz

SUPERVISOR
Dr Don Baken
(06) 356 9099 ext. 84975
D.M.Baken@massey.ac.nz

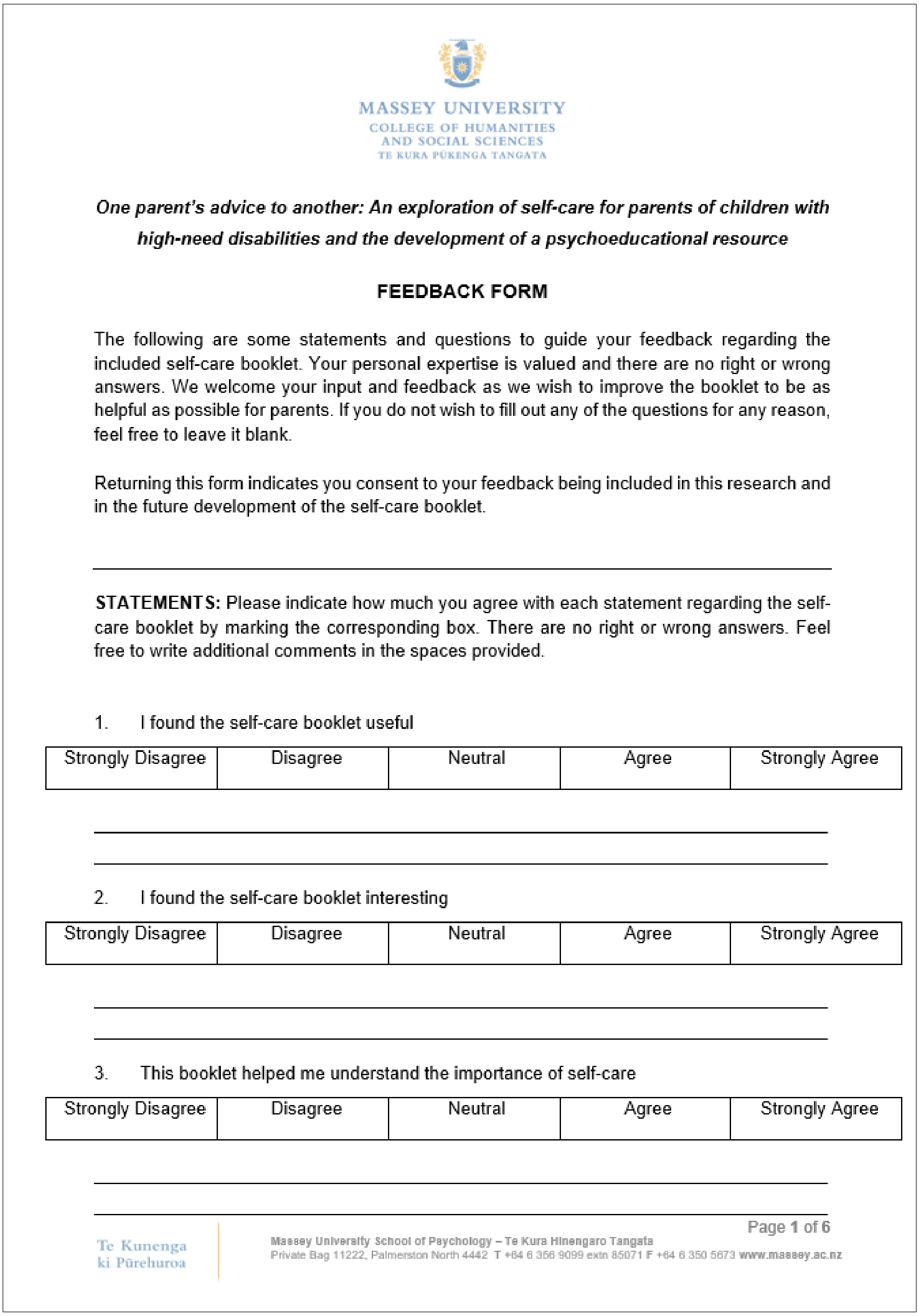
PG 36

ONE PARENT'S ADVICE TO ANOTHER

Please note: This version of the booklet is what was sent to participants in Study Two. Updates from participant's feedback will be made to the booklet prior to it being finalised and distributed, which will occur after thesis submission.

APPENDIX M:

Feedback Form for Study Two



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TE KURA PŪKENGA TANGATA

One parent's advice to another: An exploration of self-care for parents of children with high-need disabilities and the development of a psychoeducational resource

FEEDBACK FORM

The following are some statements and questions to guide your feedback regarding the included self-care booklet. Your personal expertise is valued and there are no right or wrong answers. We welcome your input and feedback as we wish to improve the booklet to be as helpful as possible for parents. If you do not wish to fill out any of the questions for any reason, feel free to leave it blank.

Returning this form indicates you consent to your feedback being included in this research and in the future development of the self-care booklet.

STATEMENTS: Please indicate how much you agree with each statement regarding the self-care booklet by marking the corresponding box. There are no right or wrong answers. Feel free to write additional comments in the spaces provided.

1. I found the self-care booklet useful

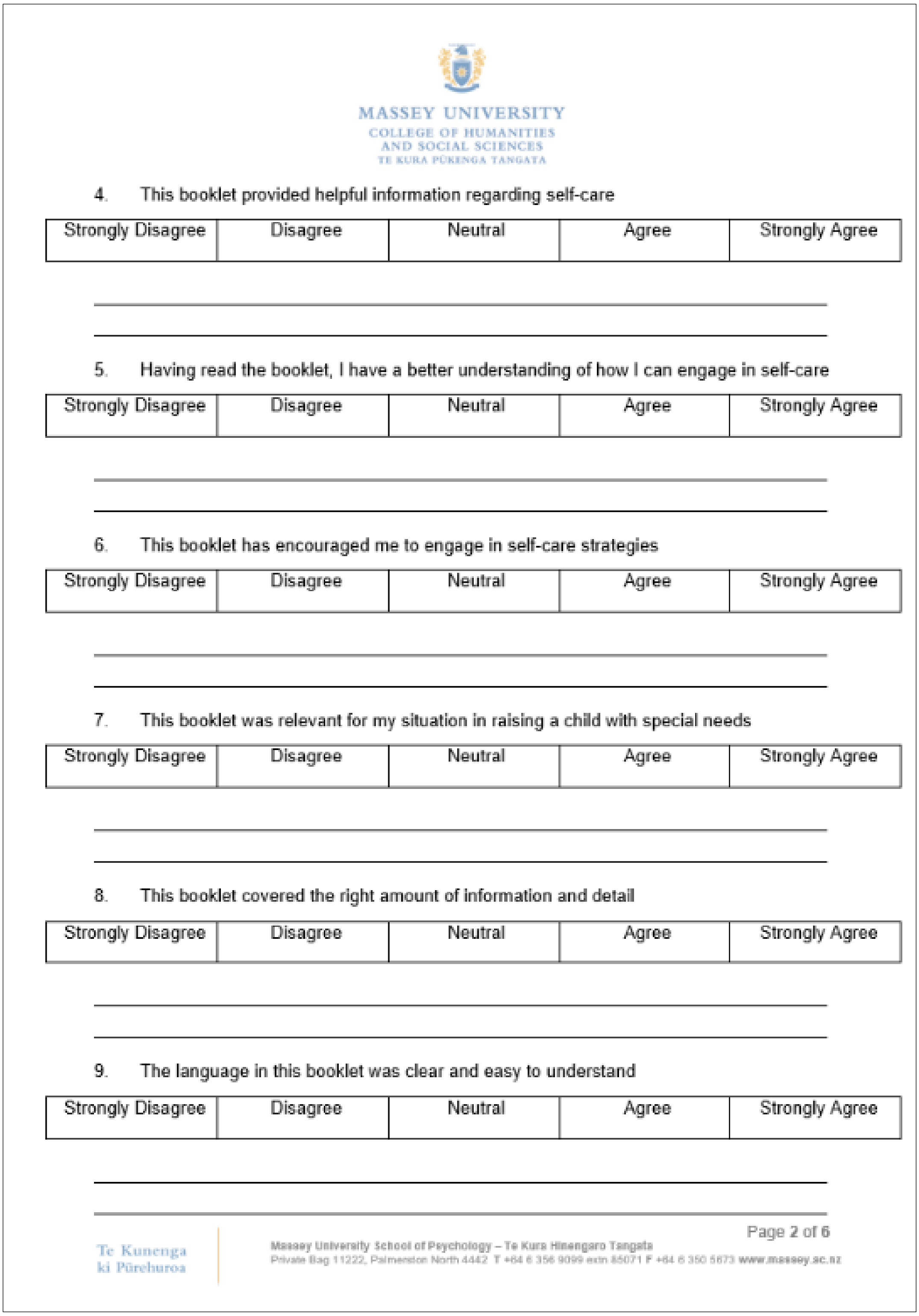
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

2. I found the self-care booklet interesting

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

3. This booklet helped me understand the importance of self-care

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree



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4. This booklet provided helpful information regarding self-care

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

5. Having read the booklet, I have a better understanding of how I can engage in self-care

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

6. This booklet has encouraged me to engage in self-care strategies

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

7. This booklet was relevant for my situation in raising a child with special needs

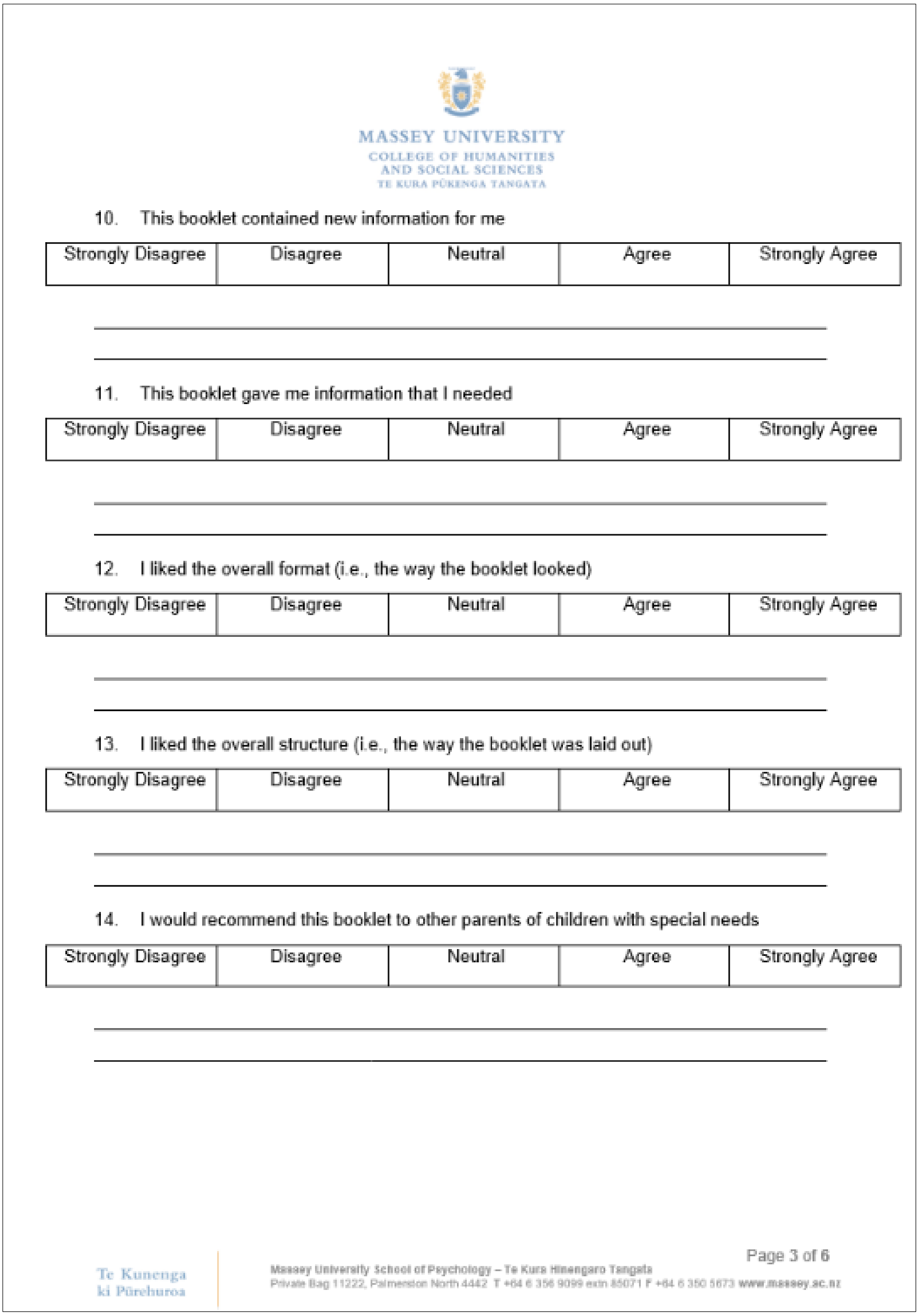
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

8. This booklet covered the right amount of information and detail

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

9. The language in this booklet was clear and easy to understand

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree



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10. This booklet contained new information for me

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

11. This booklet gave me information that I needed

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

12. I liked the overall format (i.e., the way the booklet looked)

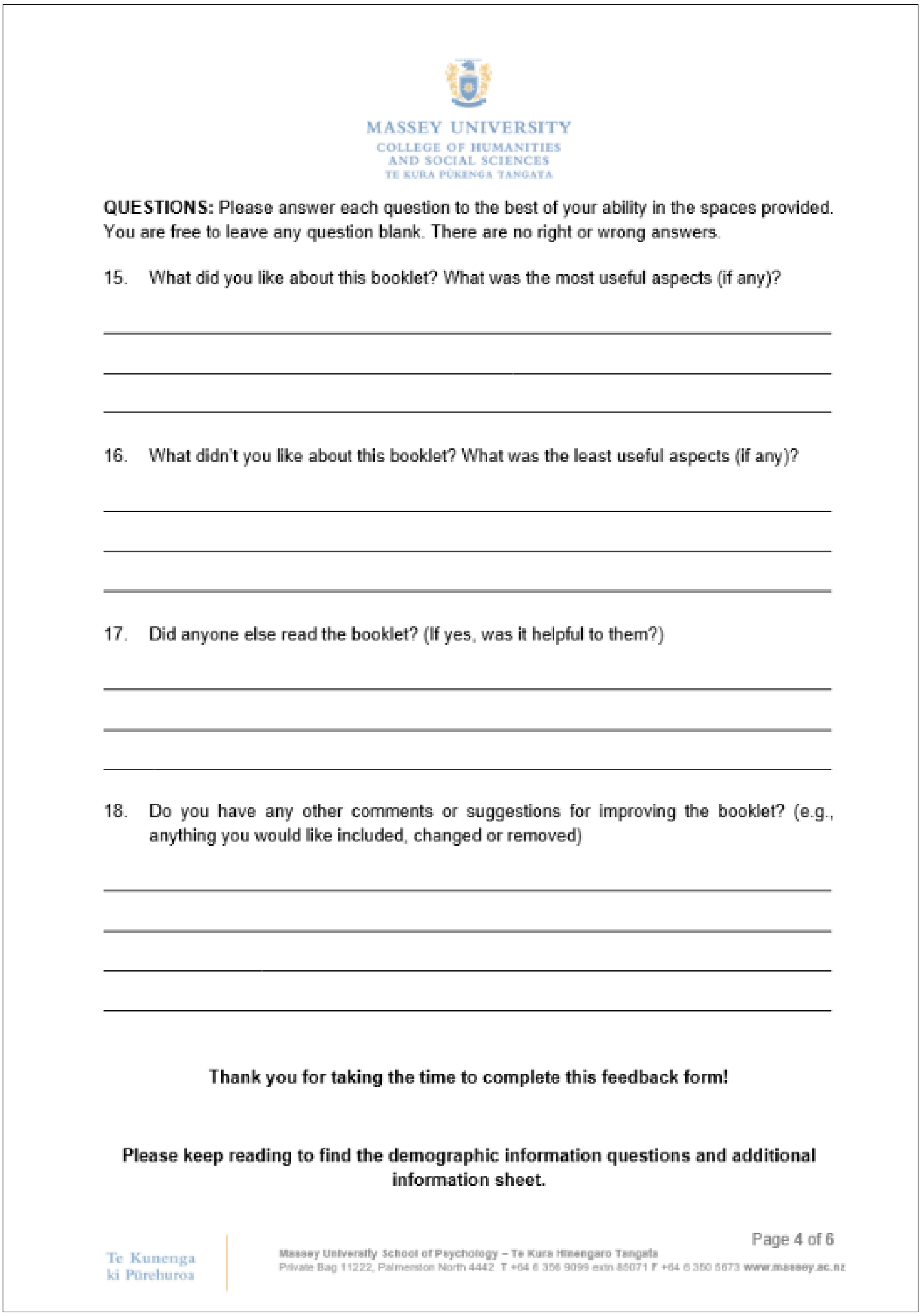
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

13. I liked the overall structure (i.e., the way the booklet was laid out)

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

14. I would recommend this booklet to other parents of children with special needs

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree



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QUESTIONS: Please answer each question to the best of your ability in the spaces provided. You are free to leave any question blank. There are no right or wrong answers.

15. What did you like about this booklet? What was the most useful aspects (if any)?

____

____

____

16. What didn't you like about this booklet? What was the least useful aspects (if any)?

____

____

____

17. Did anyone else read the booklet? (If yes, was it helpful to them?)

____

____

____

18. Do you have any other comments or suggestions for improving the booklet? (e.g., anything you would like included, changed or removed)

____

____

____

____

Thank you for taking the time to complete this feedback form!

Please keep reading to find the demographic information questions and additional information sheet.

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ki Pūrehuroa

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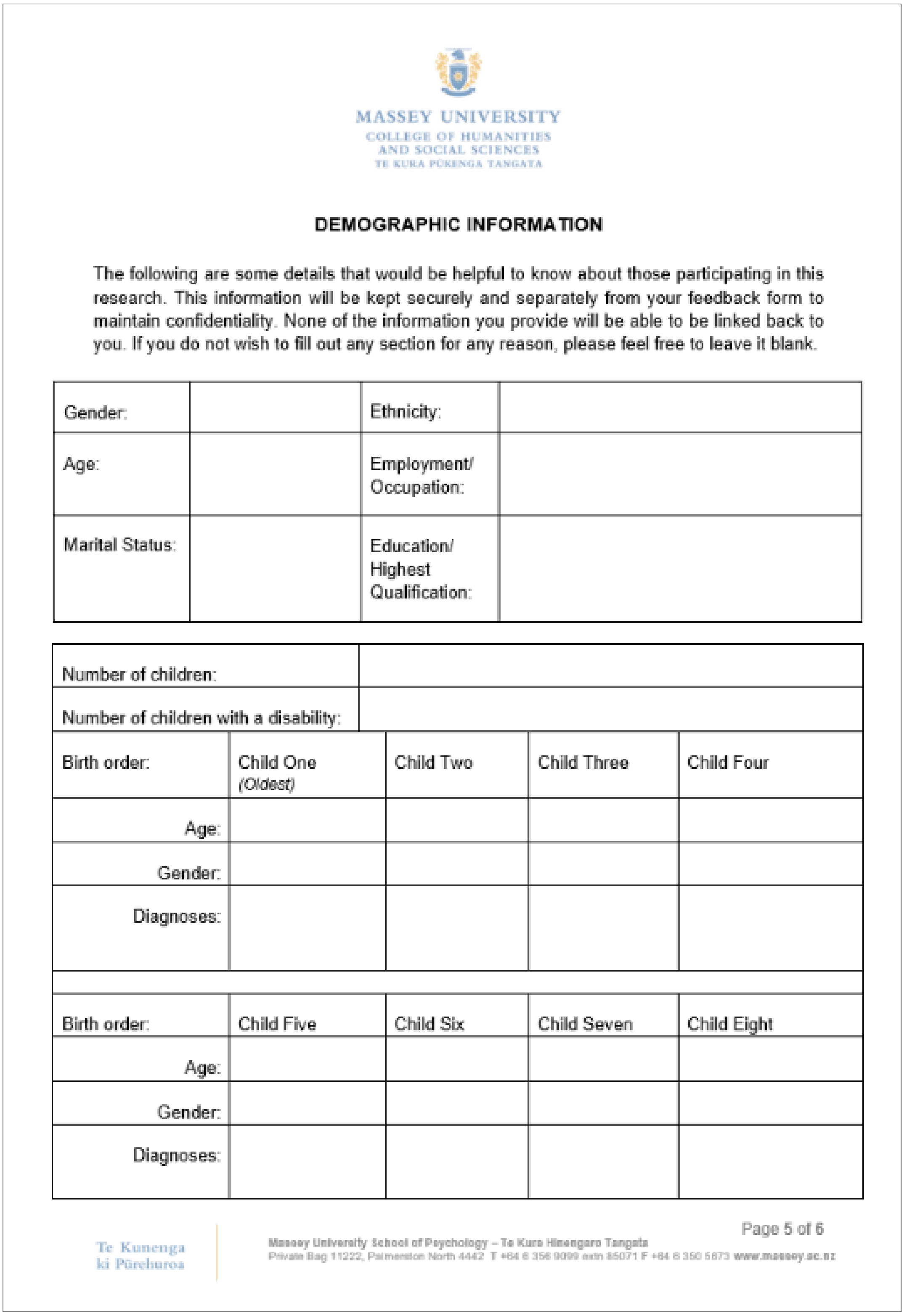
Private Bag 11222, Palmerston North 4442 T +64 6 356 9099 extn 85071 F +64 6 350 5673 www.massey.ac.nz



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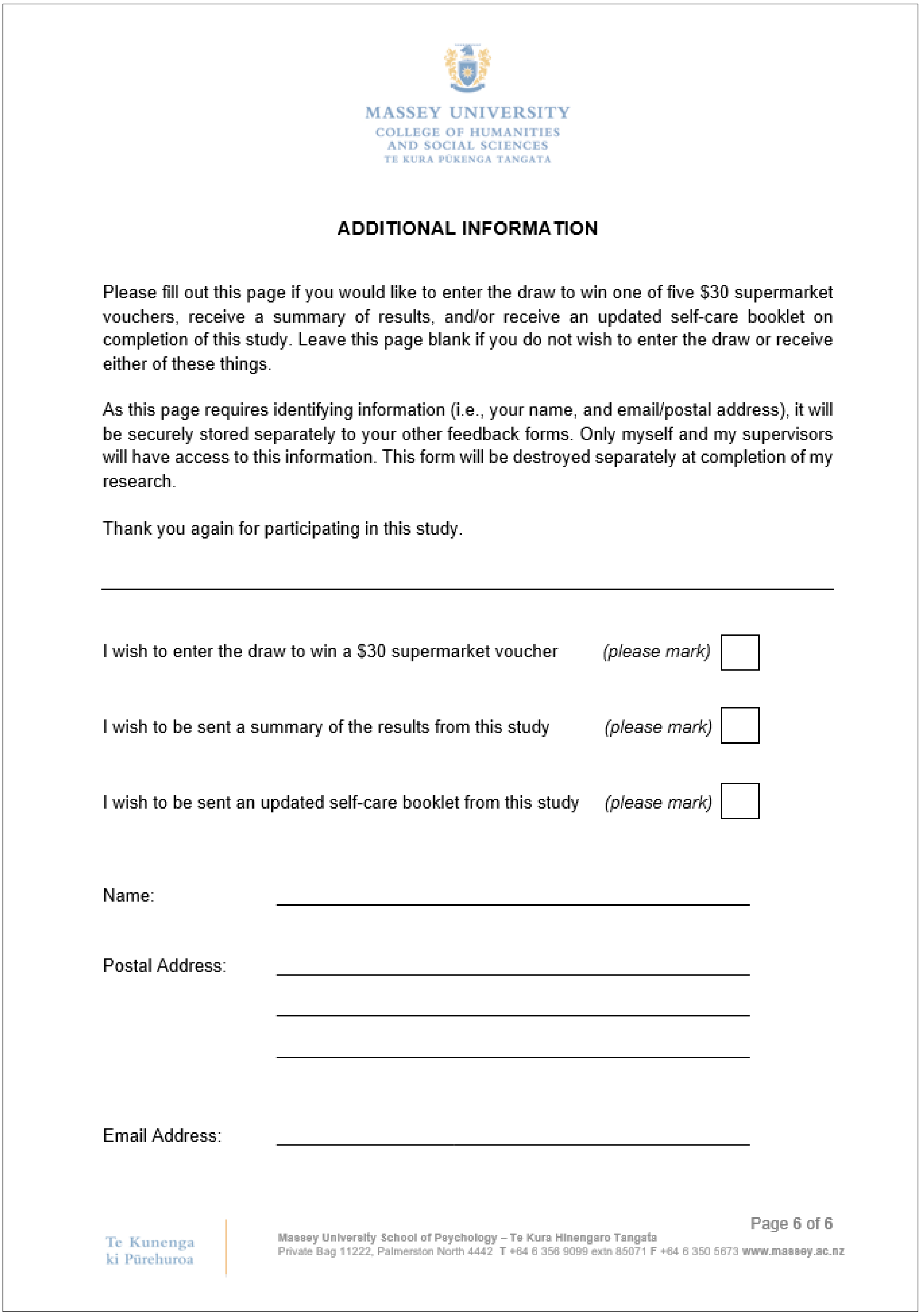
DEMOGRAPHIC INFORMATION

The following are some details that would be helpful to know about those participating in this research. This information will be kept securely and separately from your feedback form to maintain confidentiality. None of the information you provide will be able to be linked back to you. If you do not wish to fill out any section for any reason, please feel free to leave it blank.

Gender:		Ethnicity:	
Age:		Employment/ Occupation:	
Marital Status:		Education/ Highest Qualification:	

Number of children:	
Number of children with a disability:	

Birth order:	Child One *(Oldest)*	Child Two	Child Three	Child Four
Age:				
Gender:				
Diagnoses:				
Birth order:	Child Five	Child Six	Child Seven	Child Eight
Age:				
Gender:				
Diagnoses:				



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ADDITIONAL INFORMATION

Please fill out this page if you would like to enter the draw to win one of five $30 supermarket vouchers, receive a summary of results, and/or receive an updated self-care booklet on completion of this study. Leave this page blank if you do not wish to enter the draw or receive either of these things.

As this page requires identifying information (i.e., your name, and email/postal address), it will be securely stored separately to your other feedback forms. Only myself and my supervisors will have access to this information. This form will be destroyed separately at completion of my research.

Thank you again for participating in this study.

I wish to enter the draw to win a $30 supermarket voucher *(please mark)* ☐

I wish to be sent a summary of the results from this study *(please mark)* ☐

I wish to be sent an updated self-care booklet from this study *(please mark)* ☐

Name: ______________________

Postal Address: ______________________
____
____

Email Address: ______________________

Page 6 of 6

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APPENDIX N:

Information Sheet for Study Two

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TE KURA PŪKENGA TANGATA

One parent's advice to another: An exploration of self-care for parents of children with high-need disabilities and the development of a psychoeducational resource.

INFORMATION SHEET

Hello,

My name is Jana Oskam and I am a Doctor of Clinical Psychology student at Massey University. I am interested in improving parents' self-care when raising a child with high-need disabilities as research confirms that parent wellbeing is important. My supervisors for this study are Dr Kirsty Ross and Dr Don Baken, Massey University.

You have received this letter because you showed interest in participating in this current study. This interest likely came during recruitment for Study One where I interviewed parents regarding their advice and current experiences of self-care.

Invitation

You are invited to take part in this present study which aims to get parents' feedback for the included self-care booklet. This booklet was put together with advice gathered from New Zealand parents of children with high-need disabilities. Your feedback will go towards developing the self-care booklet further, before making it available to parents and disability services throughout New Zealand.

If you choose to take part, you will need to read the self-care booklet and complete the feedback form (all included with this letter). Participation is entirely voluntary. Returning the evaluation form will indicate your consent to your feedback being included in this research and in the future development of the self-care booklet.

Who can take part in this study?

To participate in this study, you need to:

- Be the parent of a child with a recognised disability diagnosis.
  (You are considered the parent if you live with the child, care for their needs most days, and are considered responsible for them. This can include grandparents, adopted parents, step parents, etc.)
- Believe your child's disability results in them having **high-needs** which place many demands on you, most days.
- Be a New Zealand Citizen, aged 18 years or older.
- Be comfortable reading and writing in English.

What does this study involve?

This study will involve reading the included self-care booklet and completing the feedback form. You can write as much or as little as you like. The feedback form should take you approximately 30 minutes to complete. Please feel free to keep the self-care booklet, and return the feedback form to me either by email or post (with included envelope and postage).

Page **1** of **2**

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Near the end of the form, you will find a section asking for your demographic information. This information is helpful to know about those participating in this research. The demographic form will be stored separately from your feedback to ensure your confidentiality and privacy.

Finally, the last page is where you can mark whether you wish to be sent a summary of results of this study and/or an updated self-care booklet, and if you wish to be entered into the draw for one of five $30 supermarket vouchers. As this requires your name and either a postal or email address, this page will be securely stored separately and destroyed as soon as the study is complete, to maintain your privacy.

Will anyone know I participated?

As the feedback form is anonymous and does not ask for you or your family's names, none of the information you provide can be linked back to you. Feedback forms will be kept safely secured for a five-year period, accessible only to myself and my supervisors. After five years, they will be destroyed. The results of this study will be presented as group results, and no individual will be identifiable in the write up. This research will be published as part of my thesis, and may also be presented at conferences and submitted to scientific journals.

What are your rights?

Please be aware you are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular question;
- Provide information on the understanding that your name will not be used;
- Ask any questions about the study at any time before, during or after participation;
- Withdraw from the study (within 4 weeks of returning the feedback form);
- Have access to a summary of the project findings when complete.

Thank you...

I would greatly appreciate your participation in this study. Thank you for considering this invitation. Please feel free to contact me or my supervisors at any time if you have questions about this study.

Researcher	***Supervisor***	***Supervisor***
Jana Oskam	**Dr Kirsty Ross**	**Dr Don Baken**
027 380 4044	(06) 356 9099 ext. 84968	(06) 356 9099 ext. 84975
jana.oskam@hotmail.com	K.J.Ross@massey.ac.nz	D.M.Baken@massey.ac.nz

This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research that you wish to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director, Research Ethics, telephone 06 356 9099 x 86015, email humanethics@massey.ac.nz

Page 2 of 2

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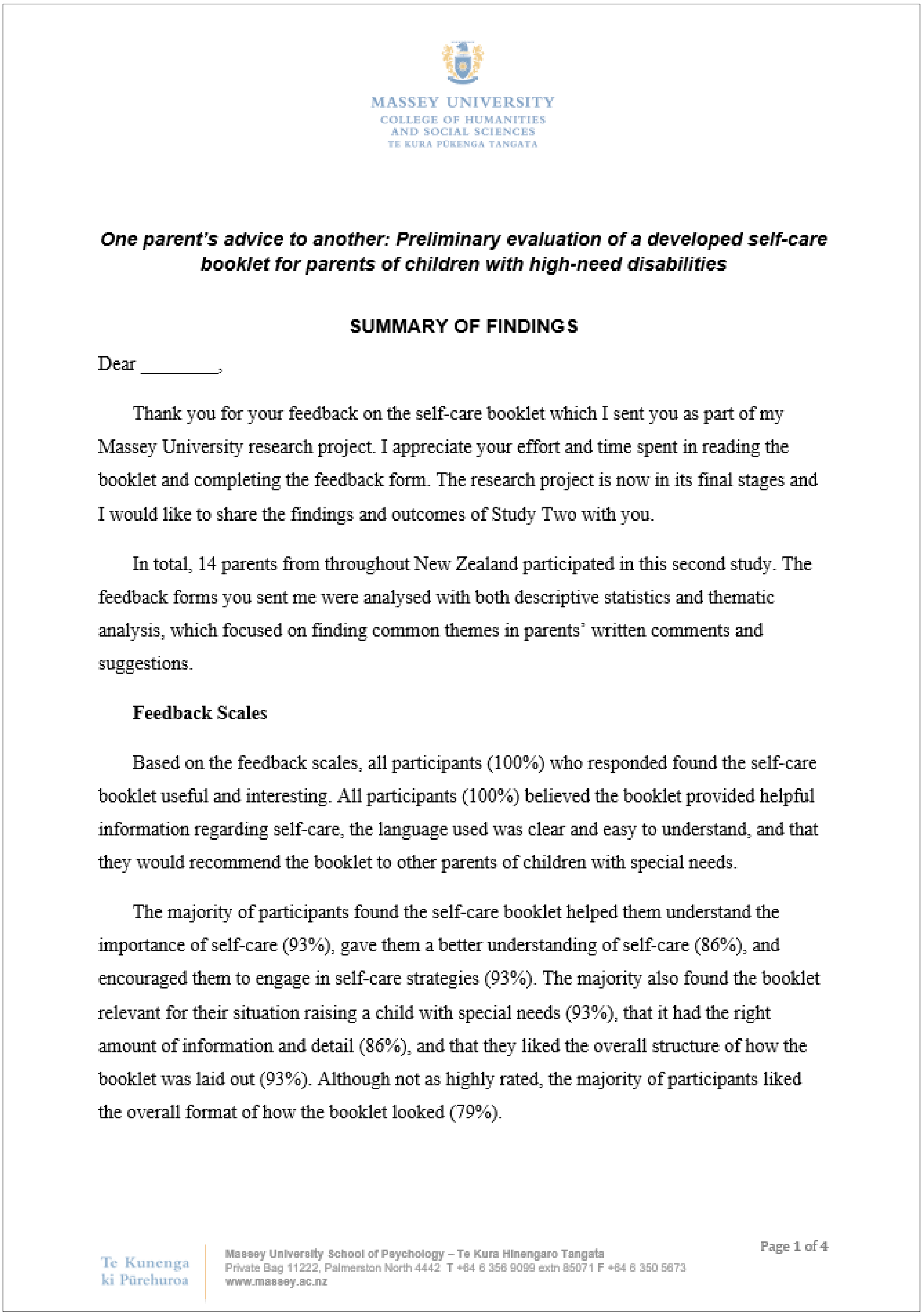
APPENDIX O:

Summary of Findings for Study Two



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One parent's advice to another: Preliminary evaluation of a developed self-care booklet for parents of children with high-need disabilities

SUMMARY OF FINDINGS

Dear ________,

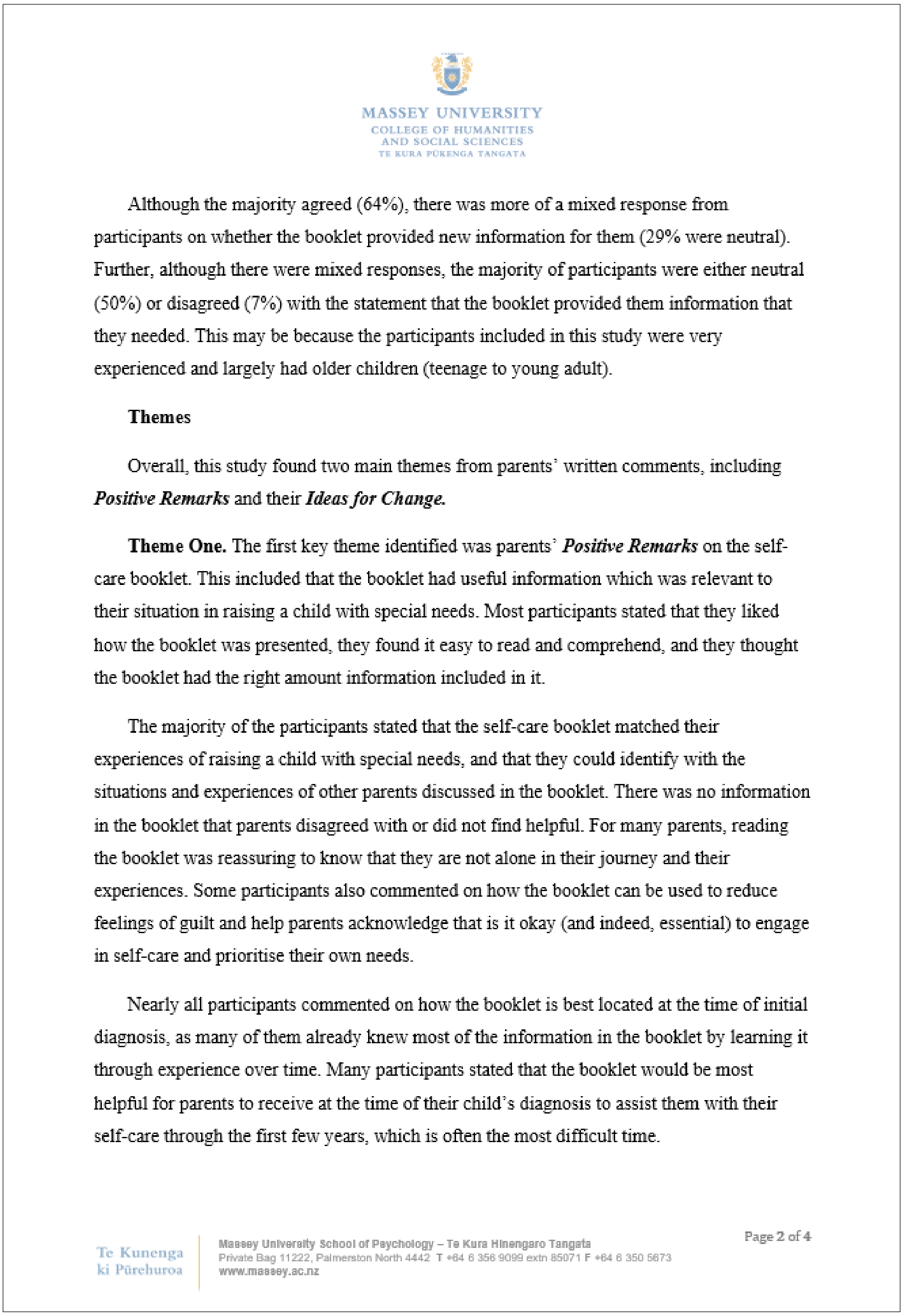
Thank you for your feedback on the self-care booklet which I sent you as part of my Massey University research project. I appreciate your effort and time spent in reading the booklet and completing the feedback form. The research project is now in its final stages and I would like to share the findings and outcomes of Study Two with you.

In total, 14 parents from throughout New Zealand participated in this second study. The feedback forms you sent me were analysed with both descriptive statistics and thematic analysis, which focused on finding common themes in parents' written comments and suggestions.

Feedback Scales

Based on the feedback scales, all participants (100%) who responded found the self-care booklet useful and interesting. All participants (100%) believed the booklet provided helpful information regarding self-care, the language used was clear and easy to understand, and that they would recommend the booklet to other parents of children with special needs.

The majority of participants found the self-care booklet helped them understand the importance of self-care (93%), gave them a better understanding of self-care (86%), and encouraged them to engage in self-care strategies (93%). The majority also found the booklet relevant for their situation raising a child with special needs (93%), that it had the right amount of information and detail (86%), and that they liked the overall structure of how the booklet was laid out (93%). Although not as highly rated, the majority of participants liked the overall format of how the booklet looked (79%).



Although the majority agreed (64%), there was more of a mixed response from participants on whether the booklet provided new information for them (29% were neutral). Further, although there were mixed responses, the majority of participants were either neutral (50%) or disagreed (7%) with the statement that the booklet provided them information that they needed. This may be because the participants included in this study were very experienced and largely had older children (teenage to young adult).

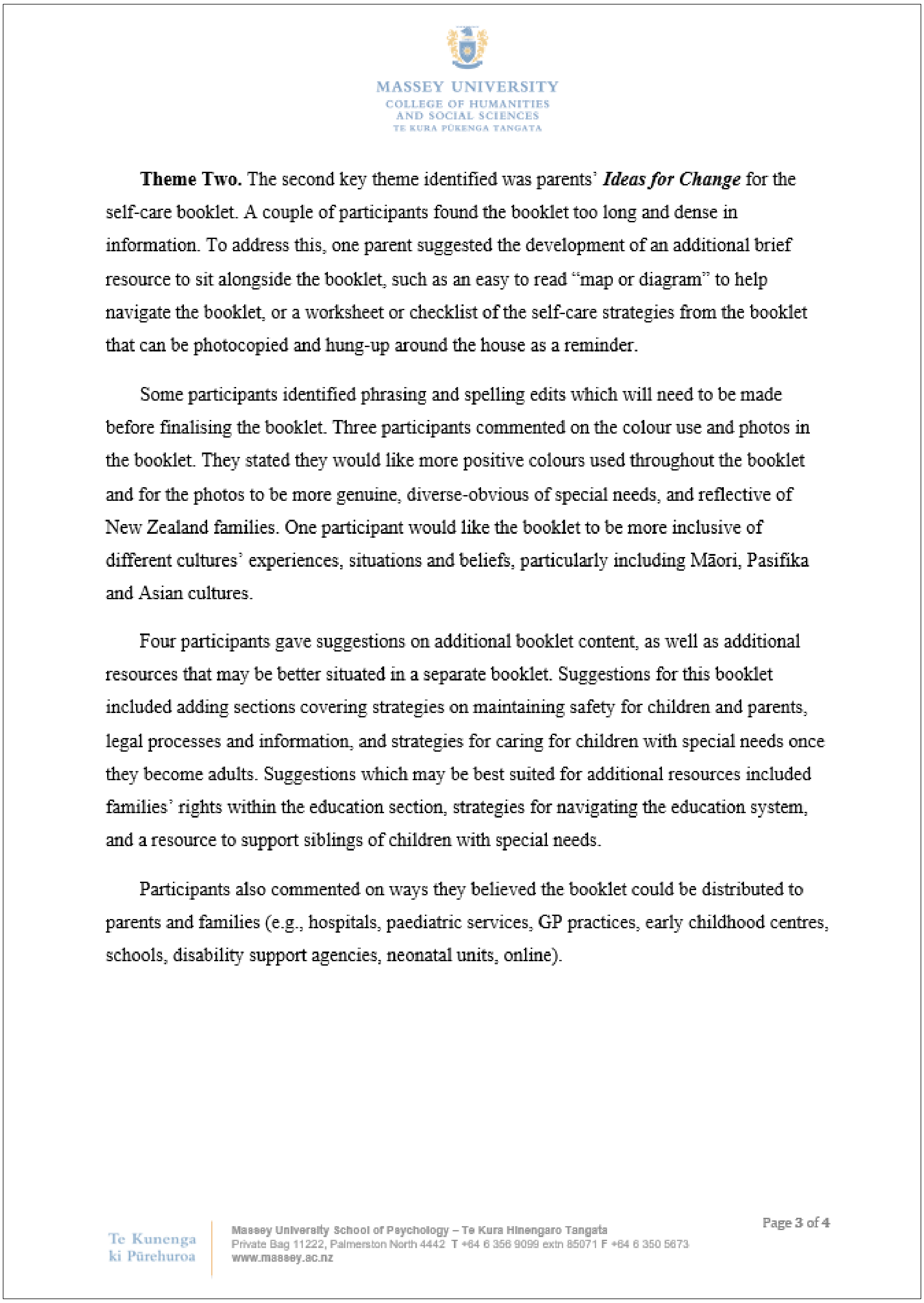
Themes

Overall, this study found two main themes from parents' written comments, including ***Positive Remarks*** and their ***Ideas for Change.***

Theme One. The first key theme identified was parents' ***Positive Remarks*** on the self-care booklet. This included that the booklet had useful information which was relevant to their situation in raising a child with special needs. Most participants stated that they liked how the booklet was presented, they found it easy to read and comprehend, and they thought the booklet had the right amount information included in it.

The majority of the participants stated that the self-care booklet matched their experiences of raising a child with special needs, and that they could identify with the situations and experiences of other parents discussed in the booklet. There was no information in the booklet that parents disagreed with or did not find helpful. For many parents, reading the booklet was reassuring to know that they are not alone in their journey and their experiences. Some participants also commented on how the booklet can be used to reduce feelings of guilt and help parents acknowledge that is it okay (and indeed, essential) to engage in self-care and prioritise their own needs.

Nearly all participants commented on how the booklet is best located at the time of initial diagnosis, as many of them already knew most of the information in the booklet by learning it through experience over time. Many participants stated that the booklet would be most helpful for parents to receive at the time of their child's diagnosis to assist them with their self-care through the first few years, which is often the most difficult time.



Theme Two. The second key theme identified was parents' ***Ideas for Change*** for the self-care booklet. A couple of participants found the booklet too long and dense in information. To address this, one parent suggested the development of an additional brief resource to sit alongside the booklet, such as an easy to read "map or diagram" to help navigate the booklet, or a worksheet or checklist of the self-care strategies from the booklet that can be photocopied and hung-up around the house as a reminder.

Some participants identified phrasing and spelling edits which will need to be made before finalising the booklet. Three participants commented on the colour use and photos in the booklet. They stated they would like more positive colours used throughout the booklet and for the photos to be more genuine, diverse-obvious of special needs, and reflective of New Zealand families. One participant would like the booklet to be more inclusive of different cultures' experiences, situations and beliefs, particularly including Māori, Pasifika and Asian cultures.

Four participants gave suggestions on additional booklet content, as well as additional resources that may be better situated in a separate booklet. Suggestions for this booklet included adding sections covering strategies on maintaining safety for children and parents, legal processes and information, and strategies for caring for children with special needs once they become adults. Suggestions which may be best suited for additional resources included families' rights within the education section, strategies for navigating the education system, and a resource to support siblings of children with special needs.

Participants also commented on ways they believed the booklet could be distributed to parents and families (e.g., hospitals, paediatric services, GP practices, early childhood centres, schools, disability support agencies, neonatal units, online).

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Outcomes

This study has shown that the developed booklet is a good start for addressing self-care with parents in New Zealand when raising a child with special needs. The findings of this study will go towards improving the booklet before finalising it and making it available within New Zealand.

It is hoped that this self-care booklet will go towards helping new families to the disability community on their journey. The current findings will also hopefully be applied in appropriate settings and used to inform future research.

If you would like to talk to me further about the findings or outcomes of the study, please contact me at jana.oskam@hotmail.com.

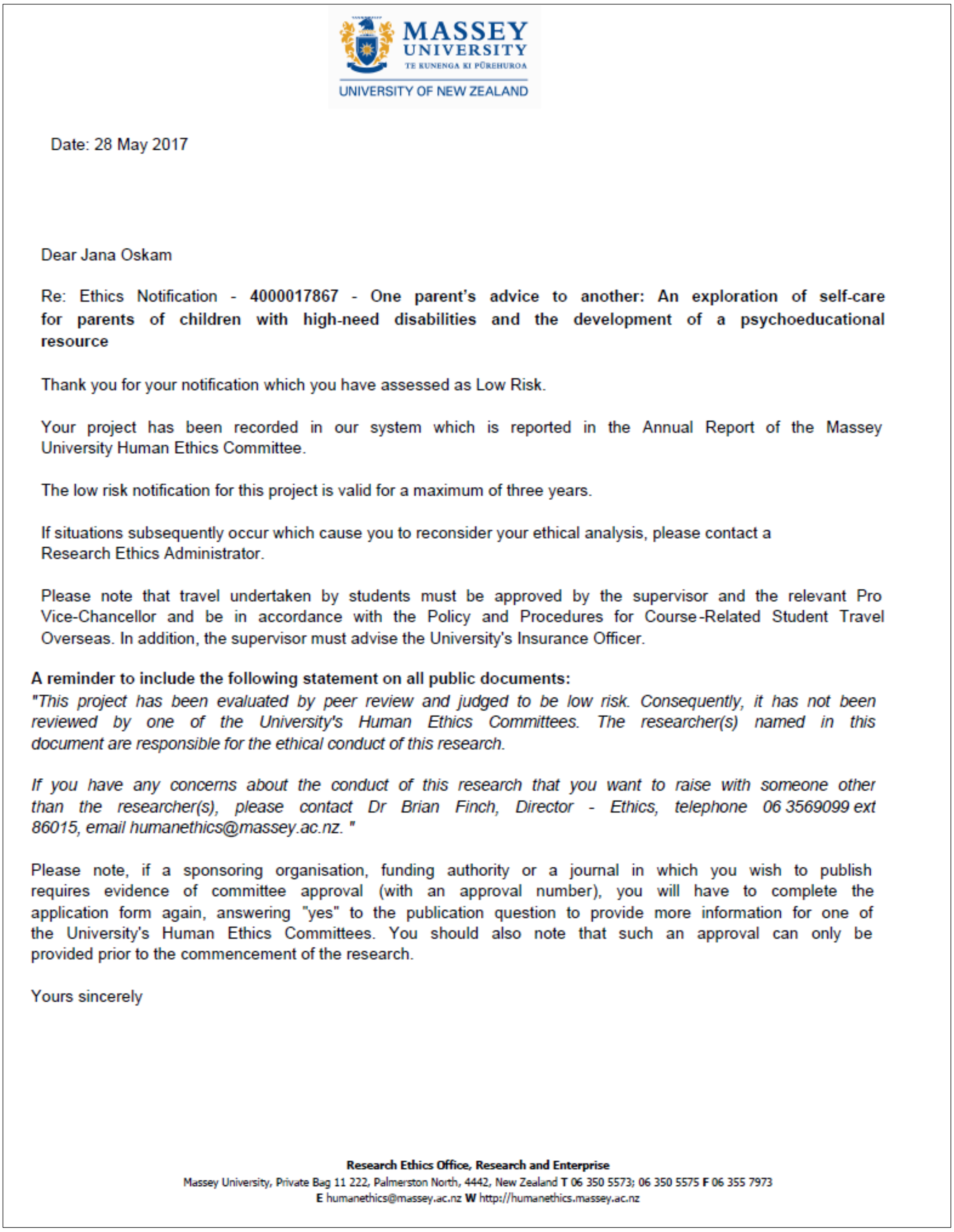
Thank you again for your valuable contribution to this research.

Best regards,

Jana Oskam

APPENDIX P:

Ethics Notification for Study Two



MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Date: 28 May 2017

Dear Jana Oskam

Re: Ethics Notification - **4000017867 - One parent's advice to another: An exploration of self-care for parents of children with high-need disabilities and the development of a psychoeducational resource**

Thank you for your notification which you have assessed as Low Risk.

Your project has been recorded in our system which is reported in the Annual Report of the Massey University Human Ethics Committee.

The low risk notification for this project is valid for a maximum of three years.

If situations subsequently occur which cause you to reconsider your ethical analysis, please contact a Research Ethics Administrator.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

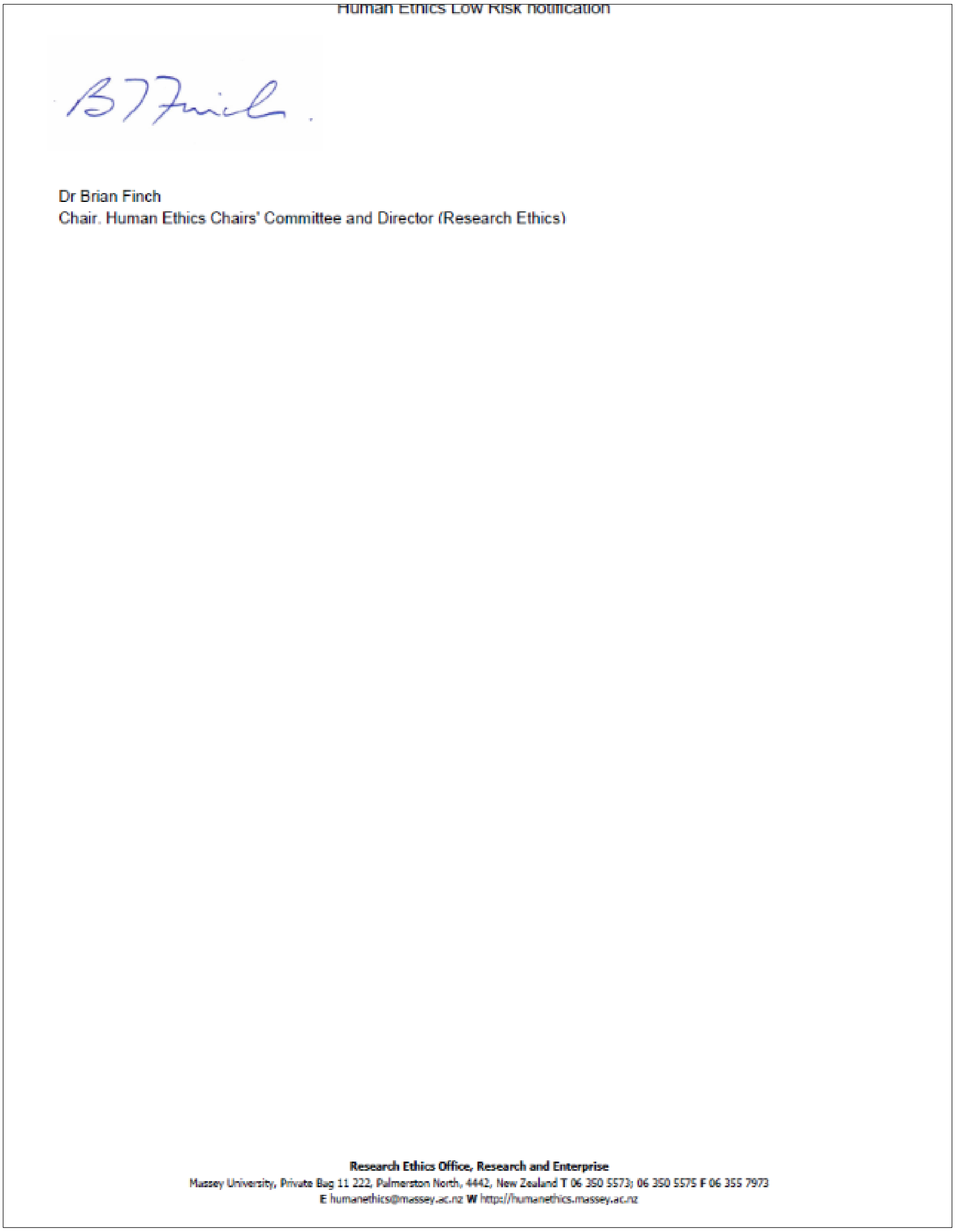
A reminder to include the following statement on all public documents:
"This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named in this document are responsible for the ethical conduct of this research.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact Dr Brian Finch, Director - Ethics, telephone 06 3569099 ext 86015, email humanethics@massey.ac.nz. "

Please note, if a sponsoring organisation, funding authority or a journal in which you wish to publish requires evidence of committee approval (with an approval number), you will have to complete the application form again, answering "yes" to the publication question to provide more information for one of the University's Human Ethics Committees. You should also note that such an approval can only be provided prior to the commencement of the research.

Yours sincerely

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand **T** 06 350 5573; 06 350 5575 **F** 06 355 7973
E humanethics@massey.ac.nz **W** http://humanethics.massey.ac.nz



BJ Finch

Dr Brian Finch
Chair. Human Ethics Chairs' Committee and Director (Research Ethics)

APPENDIX Q:

Clinical Case Study

Clinical Psychology Training Programme

Doctor of Clinical Psychology

School of Psychology
Manawatū Campus
Massey University

Case Study Six: Clinical Research

One parent's advice to another: An exploration of self-care for parents of children with high-need disabilities

Jana Oskam
Student ID [redacted]
2018

Word Count: 5,406

Signature:	Signature:
Date:	Date:
Jana Oskam Intern Psychologist	Dr Kirsty Ross Senior Clinical Psychologist Senior Lecturer
Community Mental Health & Addictions Service – Whanganui DHB	*Massey University – Palmerston North*

Abstract

Currently in New Zealand 11% of the child population aged 0 to 14 years are living with a disability (Statistics New Zealand, 2013). Existing systems of care for these children require parents to assume unforeseen caregiving roles in-home that typically last the course of the child's lifetime. For parents, the added demands of providing long-term care for children with high-need disabilities often results in diminished family functioning, chronic stress, and poor psychological and physical health outcomes. Although evidence suggests that effective self-care may act as a mediator against caregiver stress, few studies have approached this from a health-promotion paradigm. Furthermore, limitations occur with the few studies that do focus on health-promotion for family caregivers, including that they are relatively out-of-date, and none specifically concentrate on the unique experience of parents as caregivers. Currently no studies have explored self-care within a New Zealand context. My doctoral research comprises of two studies; however, the current case study will focus on study one which aimed to address current research limitations by exploring self-care and wellbeing from the parents' perspectives of children with high-need disabilities using semi-structured interviews and thematic analysis. This case study outlines current literature, the methodology and summary of findings from study one, and a discussion and self-reflection regarding how this research has informed my clinical practice.

Please Note: This case study was completed during the period of an internship as part of a Doctor of Clinical Psychology; and represents the work of Jana Oskam under supervision of Dr Kirsty Ross. This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 16/21.

Literature Review

The New Zealand Context of Disability

Currently in New Zealand there are over 95,000 children under the age of 15 affected by a disability, which equals 11% of the child population (Statistics New Zealand, 2013). Further, around half of all disabled children (48%) report limitations arising from more than one impairment type, with conditions existing since birth being the most common cause of impairment (Statistics New Zealand, 2013). Existing systems of care for these children typically require parents to be willing and able to undertake unforeseen informal caregiving roles in-home that usually last the course of the child's life-time (Raina et al., 2005). Despite the essential role informal caregivers provide in maintaining the wellbeing of those who are ill, disabled or elderly, this form of welfare provision remains largely invisible in current New Zealand policy (Maidment, 2016).

Demographics of informal carers in New Zealand indicate that women are twice as likely to be carers, making up 63 percent of unpaid informal care currently provided (Grimmond, 2014). Many argue that acknowledgement of gender roles with women attending to 'domestic' care duties, along with the opportunity costs this creates for women in areas such as employment, has long been unaccounted for in assessing the cost of informal caregiving and remains under-represented in public policy (Gardiner, Brereton, Frey, Wilkinson-Meyers & Gott, 2014; Maidment, 2016). Another significant demographic group in New Zealand includes Maori caregivers. Maori have been found to be more likely to provide informal or whanau care than non-Maori in New Zealand, with 23 percent of Maori women being caregivers in comparison to 16 percent of New Zealand European women (Alpass et al., 2013). This disparity may be explained by the higher disability morbidity rates among Maori compared with non-Maori, as well as caregiving being a culturally engrained value (Alpass et al., 2013).

What is 'Informal Caregiving'?

The term informal caregiver is defined and endorsed by Goodhead and McDonald (2007), who paraphrase it as

> "caring for a friend, family member or neighbour who because of sickness, frailty or disability can't manage everyday living without help or support … [it] is not usually based on any formal agreement or services specifications. Informal caregiving is characterised by relationships and social expectations (NHC, 1998)."

The role of informal caregiving is often assumed and unplanned, with unspecified tasks and responsibilities and undefined rewards (Collings, 2006). Informal caregiving is not regulated by an employment agreement or official arrangement but occurs out of choice and family obligation in the context of family relationships, and the role is societally and economically invisible with parents effectively being on-call at all times (Collings, 2006; Goodhead & McDonald, 2007).

The distinction between what would be classed as ‘typical’ parenting and the extended role of informal caregiving for a child with a disability has been illustrated by Winder and Bray (2005). They define an informal caregiver as being “a person who performs tasks for another person that the recipient is unable to perform independently and should typically be able to perform given their age and developmental stage” (pg. 2). Therefore, for parents of children with disabilities, their role extends from ‘typical’ parenting to informal caregiving as it goes beyond usual care within the family life course and child developmental trajectory. This creates distinctive caregiving challenges that imply ongoing need from the child, and requires ongoing commitment by the parent (Barrett, Hale & Butler, 2014). Additional commitments include added physical, financial and social/emotional caregiving tasks, such as assisting with physical therapy and daily medical procedures (i.e., feeding tubes and managing medications), coordinating a range of different disability services and supports, and providing constant supervision and help with personal care (Barrett et al, 2014; Feinberg, Reinhard, Houser & Choula, 2011).

The Negative Impact of Informal Caregiving

For parents, the demands of providing long-term care for children with disabilities in addition to the inherent demands of parenthood often results in adverse repercussions in family functioning and high levels of chronic stress (Minor, Carlson, Mackenzie, Zernicke & Jones, 2006). Evidence suggests that long-term caregiving and resultant chronic stress is linked to poor psychological and physical health outcomes in parents, with many parents and children experiencing trauma, mental health disorders, and lower levels of subjective wellbeing due to the initial diagnosis (Gallagher, Phillips, Oliver & Carroll, 2008). In terms of physical health, studies consistently report greater perceived stress and related negative health outcomes, including more perceived pain and somatic symptoms, greater levels of chronic fatigue and sleep deprivation, disruptions from physical health problems, and lower physical health-related quality of life than parents of children without disabilities (Allik, Larsson & Smedje, 2006; Gallagher & Whiteley, 2012; Hayes & Watson, 2013; Khanna et al., 2011; Miodrag, Burke, Tanner-Smith & Hodapp, 2015; Murphy, Christian, Caplin and Young, 2007). Parents typically rank their own health needs as lowest priority, with most reporting having “little if anything left at the end of the day” to invest in themselves (Murphy et al., 2007, p. 183).

The emotional challenges of chronic stress, burden and psychological distress, particularly when combined with poor coping strategies, increase the likelihood of caregiver burnout as parents may expend all their energy and time on their child and in the process neglect their own health and wellbeing (Angermeyer, Bull, Bernert, Dietrich & Kopf, 2006; Taki et al., 2009; Truzzi et al., 2012). Burnout is a psychosocial syndrome made up of three primary components, including emotional exhaustion, depersonalisation or cynicism, and reduced sense of personal achievement (Angermeyer et al., 2006; Truzzi et al., 2012). Emotional exhaustion refers to lack of energy and the draining of emotional resources, depersonalisation refers to an indifferent or cynical attitude towards the care recipient, and reduced personal achievement refers to the negative perception of one's work as being unproductive (Truzzi et al., 2012).

What is Self-Care?

Due to the heavy toll on parents' health and wellbeing resultant from caregiving and family demands, research into self-care for parents of children with high-need disabilities may help health professionals to better understand and design interventions to facilitate health promotion for parents (Acton, 2002). Self-care is a term regarding positive health promotion and is defined as actions taken by an individual to improve their health, maintain optimal daily functioning, and increase overall wellbeing independent from illness or health symptoms (Acton, 2002).

Self-care involves many components of health including physical, psychological, spiritual and social support (Richards, Campenni & Muse-Burke, 2010). Examples of self-care actions falling across these different components of health include exercise, sleep, nutrition, self-reflection, communication, religion, meditation, mindfulness, professional support networks, and personal relationships (Richards et al., 2010). Although few, if any, studies have explored the benefits of self-care for parents of children with disabilities, it is well accepted that effective self-care techniques can negate distress due to ongoing work-related stressors and demands, stress-related psychological impairments, such as depression, exhaustion, burnout and anxiety, and vicarious traumatization and compassion fatigue for healthcare professionals (Tyssen, Vaglum, Gronvold & Ekeberg, 2001). Evidence suggests that promotion of effective self-care may act as a mediator to reduce the effect of caregiver stress, increasing health and wellbeing for parents and further enhancing their ability to care for their afflicted family members (Acton, 2002).

Self-Care and the Health Promotion Paradigm

Few studies have focused on a positive health promotion paradigm of self-care with family caregivers, with many studies opting to research negative health outcomes resultant from caregiving duties within a stress-illness framework (Acton, 2002). Focusing on the importance of health promotion through exploring effective self-care strategies for parents is reflective of Pender's (1996) Health-Promotion Model. In this model, the likelihood of engaging in effective self-care strategies is influenced by individual characteristics, including physical (i.e., age, gender), sociocultural (i.e., ethnicity, education) and psychological factors (i.e., caregiver stress and need), as well as behaviour-specific cognitions, such as perceived importance of self-care, self-efficacy and barriers to effective self-care (Acton, 2002; Pender, 1996). In utilising Pender’s model, some studies suggest that research regarding family caregivers should focus less on negative outcomes, such as depression and burden, which many studies currently do within a stress-illness framework. Instead, they suggest that research focus more on positive outcomes in order to enhance caregivers’ meaning and wellbeing (Acton, 2002; Farran, 1997). Overall, research has shown that the more demanding caregiving duties are, the less likely it is that caregivers will take time to care for their own health, with Sisk (2000) noting that participants who perceived greater caregiver burden practiced less self-care behaviours. Caregivers practice significantly fewer self-care behaviours and have more barriers to health promotion than do non-caregivers (Acton, 2002).

Rationale for the Present Research

Limitations occur with the currently available studies that focus on positive health-promotion for family caregivers, including that they are relatively out-of-date, there are few of them, and none specifically concentrate on the unique experience of parents as caregivers. Instead, these studies incorporate spousal caregivers or caregivers of the elderly as participants (Acton, 2002; Sisk, 2000). No studies have explored self-care and wellbeing for parents of children with high-need disabilities in New Zealand, which shares a unique history and culture that may potentially influence parental self-care activities in a distinct way.

The research findings will potentially enable parents, health practitioners, researchers and the general public in New Zealand to gain greater understanding in the area of childhood disabilities and caregivers’ needs. By increasing understanding, parents may better adjust to the difficulties of a new diagnosis and improve their capacity to manage their child’s disability. This increased understanding may enhance overall family functioning, and the parent-child relationship. Health practitioners will be able to provide support that is more meaningful to parents as informal caregivers. Furthermore, the findings will inform future research and the design of interventions and resources to facilitate self-care for parents. Enhancing awareness and understanding for the New Zealand public will facilitate a more supportive environment for families and the children with special needs.

Overall Aims

The aim of this research was to first explore self-care and wellbeing of parents of children with high-need disabilities from the parents' perspectives. Study one was approached through a positive health-promotion paradigm, with the implementation of qualitative methodology of semi-structured interviews and thematic analysis.

The research questions for study one included:

3. How is self-care and wellbeing currently experienced and enacted for parents of children with high-need disabilities?
4. What strategies of self-care do parents currently find effective for enhancing their sense of wellbeing?

Method

Participants

Study one recruited 11 participants, including nine mothers and two fathers. Of the participants, seven identified as New Zealand European, three identified as Maori, and one identified as Dutch. Six participants had children with autism, and five had children with cerebral palsy. The study recruited participants by relying on the concept of thematic saturation, or the point at which no new themes are observed in the data (Namey, Guest, McKenna & Chen, 2016). A purposive sampling approach was used with the inclusion criteria being that participants must be the parent of a child with a high-need disability. For this study, being a parent was defined as being the primary caregiver living with the child, and who is the most responsible for the day-to-day decision making and care of the child (Raina et al., 2005). The child must have been aged 5 years or older and have at least one recognised diagnosis of cerebral palsy or autism that the parent perceives as high-need. Screening for cerebral palsy and autism simplified the recruitment process while still being reflective of high-need disabilities. Participants needed to have scored 41 points or above on the Zarit Burden Interview (ZBI; Zarit, Orr & Zarit, 1985) to meet the criteria of high-need disability (Bello-Mojeed, Omigbodun, Ogun, Adewuya & Adedokun, 2013).

Measures

The ZBI (Zarit et al., 1985) was used as a screening tool for establishing whether the child's disability was subjectively considered "high-need" for the parent. The ZBI is a self-administered, 22-item questionnaire used to assess perceived caregiver burden when taking care of one's relative (Zarit et al., 1985). It was originally designed for caregivers of elderly relatives with Alzheimer's disease. However, studies have commonly adapted it to other populations, including parents of children with disabilities, making it the most commonly used measure of caregiver burden (Bachner & O'Rourke, 2007). Summation of ratings gives the severity of the burden or level of need experienced by the caregiver. Scores ranging between 0 to 20 represents little or no burden, 21 to 40 indicates mild-to-moderate burden, 41 to 88 indicates moderate to severe burden. As with other studies, this study classified the level of burden into low and high need with a score of 41 points or above being classified as high-need (Bello-Mojeed et al., 2013). The ZBI has been shown to have excellent internal consistency ($\alpha = .91$), and good test-retest reliability ($r = .71$, $p < .001$) (Gallagher et al., 1985; Hebert, Bravo, & Preville, 2000). Concurrent validity has also been shown by correlating total ZBI scores with a single global rating of burden ($r = .71$), and with responses to the Brief Symptom Inventory ($r = .41$) (Bachner & O'Rourke, 2007; Zarit & Zarit, 1990).

Procedure

The procedure involved meeting with each participant for a semi-structured interview regarding their experience of self-care and wellbeing in terms of parenting a child with high-need disabilities, strategies of self-care that have been effective and ineffective for enhancing their wellbeing, resources and support systems they have utilised, importance placed in self-care and wellbeing, and recommendations for other parents and development of future resources. From arrival, participants gave no more than two hours during a single period to complete their interview. All interviews were audiotaped for transcription and thematic analysis.

Analysis and Results

The transcripts were analysed through thematic analysis, in which the steps of analysis involve familiarising one's self with the data, transcribing verbal data into written form, generating initial codes from the data, searching for themes by collating all relevant codes into potential themes, reviewing and refining themes, defining and naming the themes, and writing-up the analysis (Braun & Clarke, 2006). Due to use of a professional transcriber, I listened back to the interview audio alongside reading the completed transcripts to ensure transcription accuracy and to familiarise myself to the data. Thematic analysis was used to answer the research questions by providing themes that reflected the subjective experience of parents' self-care and wellbeing. Each theme indicated some level of patterned response or meaning from within the data collected which was of some importance the overall research aim (Braun & Clarke, 2006). The results will be communicated through a summary of results sent to participants, through a written research article submitted for publication in a relevant academic journal, and through a doctoral thesis in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology.

Summary of Findings

Four main themes arose in study one from exploration of parents' experiences and advice related to self-care, including: building *formal supports and resources*, maintaining *relationships*, considering *values and goals*, and balancing *time*. Within each of these four themes, there were subsidiary strategies of self-care that parents discussed.

Theme One: *Formal Supports and Resources*

Firstly, parents commonly described both the difficulty and necessity of accessing *formal supports and resources*, such as adequate healthcare and respite, for their child and family to better allow for their own self-care. In terms of difficulties, all parents felt they currently experienced many barriers to being heard by healthcare and disability services due to the lack of funding and resources at a societal level, and confusion and power differentials within the disability system. Due to this, parents described often feeling a loss of dignity for themselves and their child in having to fight for services they are entitled to. These barriers permeated throughout all levels of access to supports and resources, down to the language use and diagnostic criteria varying services utilised. For parents, language use impacted on their wellbeing through influencing their perspective and interaction with their child and "the disability". Whether purposefully or not, all parents tended to use person first language; and non-specified, non-judgemental, broad phrases related to their child's "special needs" rather than "disability". The use of language and terminology was discussed as an effective strategy which, if approach in a strengths-based way, could instil hope, acceptance, empowerment and dignity for the whole family.

Strongly related to language use and support in being heard when accessing disability services, parents discussed how education was imperative to improving their own sense of mastery and credibility within the disability system. Through educating themselves in their child's disability, their legal rights and the different formal supports available, parents felt empowered to be assertive and advocate for their family's needs. Education also contributed to parents' sense of a shared identity with other families raising children with disabilities. Through accessing different outlets of information, including self-directed learning, peer support and disability workshops, parents found it helped to enhance their own understanding, tolerance and confidence in caring for their child's disability. Parents believed ongoing education contributed to their self-care as it helped them move towards acceptance of the disability and increased their hope and motivation to challenge their child's ability and access to formal supports.

The two most notable forms of formal supports and resources parents discussed which made the biggest impact on their experiences of self-care included accessing respite care and peer support. Parents current experience of accessing formal respite care typically centred around two opposing concepts of disadvantage and opportunity. Most parents found varying disadvantages in utilising respite care including the need to contest their beliefs related to burden, guilt and responsibility for their child in asking for help; and experiencing a sense of loss of privacy, family cohesion and spontaneity. However, all parents found that in utilising respite care, it created opportunities to engage in activities that they enjoyed and valued resulting in improved wellbeing and family relationships. Finally, parents discussed the most "expert" source of support and resources came through peer support and networking with other parents who share similar experiences of caring for a child with disabilities. Peer support added to these parents' experiences of self-care through building validation and connection within the disability community, leading to deeper acceptance, understanding and empathy for their child.

Theme Two: *Relationships*

In discussion with parents, it was demonstrated that self-care was a concept which occurred not only within themselves but within their *relationships* with others. For nearly all interviewed, their relationship (or lack of) with their partner was a central topic of self-care both in terms of added stress and tension, as well as positive aspects of validation, intimacy and connection. As advice, parents often forewarned of their own experiences related to problems arising within their partner relationship due to differing levels of acceptance, humiliation, and understanding of their child's disability. Strategies of self-care parents believed counteracted these tensions within partner relationships included approaching life demands as a team, utilising effective and healthy communication techniques, and creating a shared and balanced routine regarding the care of their child. Parents reported that an essential aspect of healthy communication encompassed skills related to being honest and open about their needs, experiences and feelings, regardless of how negative or undesirable they believed they were. Parents also discussed encouraging and unifying strategies for partner relationships included humour, creating time and space for one another, having goals and a positive outlook, and sharing understanding and commitment regarding "the disability".

Parents experience and enactment of self-care also occurred within their relationships and interactions with their whole family. All parents reported difficulty related to financial constraints and finding time and energy to participate in conventional self-care activities. Because of these constraints, nearly all interviewed emphasised the importance of finding enjoyable activities they deemed "self-care" which they could do both with their child and with their whole family. Parents reported that shared family activities needed to be inclusive and uplifting for all involved, as well as realistic and achievable with their reality and available resources. Parents described that through regularly engaging in these activities with their family and child, there was a therapeutic and healing outcome in which their parent-child relationship was strengthened through building positive memories and experiences. Parents reported they also experienced enhanced wellbeing and happiness as they felt they were "doing something right" as a parent.

Extending out from the family unit, parents also reported that enhanced wellbeing and self-care arose for them through building a community of trust and support around themselves and their family. Through building this supportive network, parents discussed experiencing increased wellbeing due to opportunities for positive social interaction as a form of self-care, shared responsibility of caring for their child, and connection to a wider community based on shared values. This community typically consisted of friends and extended family members, employment and hobby networks, new friendships and connections within the disability community, various cultural and religious networks, and more formal supports and disability services. Having a strong community of support created space for families to gain practical assistance, emotional support and validation, acceptance and guidance, and a sense of connection and belonging. Parents also discussed extending their supportive community to include more formal psychosocial support, such as social workers, counsellors and psychologists, when required to address issues of change, trauma and grief.

Theme Three: *Values and Goals*

Although practical self-care experiences and strategies for parents typically involved interaction with systems outside of themselves, all interviewed discussed how identifying and living to their own *values and goals* contributed to their subjective wellbeing. Parents reported that identifying their values and goals helped to guide their decision-making processes, enhanced their sense of identity, and influenced their ability to find meaning and purpose in everyday life. Surprisingly, although all parents acknowledged that their values were shaped by their culture and upbringing, few felt their culture explicitly played a significant role in their current self-care practices and experiences. The two parents who felt their culture played a role in their self-care experiences linked this specifically to engaging in religious practices, such as praying and attending church.

Parents typically discussed a process of loss, grief and acceptance which they experienced in learning about their child's diagnosis, which resulted in feeling a loss of identity and purpose for some. For these parents, recognising their values helped to regain their sense of identity and provide direction in building a life with their child that aligned with what was important to them also. Although all parents believed it important to live in accordance with their values as a strategy of self-care, some acknowledged their need to be open to experiencing positive changes in their value system due to having a child with special needs. The positive changes these parents experienced included becoming more thoughtful, accepting, patient, and caring towards others. Also, participants discussed experiencing enhanced resiliency with difficult everyday situations, increased understanding and acceptance of the disability community, and a resultant shift in their values and priorities to align with this.

As well as identifying values and finding meaning in everyday life, parents also reported experiencing self-care through setting goals and making plans for the future. Through setting realistic and achievable goals both for themselves and their child, parents reported experiencing a shift towards a more positive and constructive outlook. Having goals also helped parents build hope for their whole family and create a meaningful narrative for themselves and their child. For half of these parents, having strong views and goals for their child's future was a particularly important strategy of self-care in order to counteract feelings of hopelessness and avoidance, and instil hope and meaning within their family. Most parents discussed the significant impact their child's disability had on preventing and changing their own previously held goals and aspirations. For these parents, their experiences captured both negative changes, such as experiencing a loss of freedom, frustration and disappointment, as well as positive changes. Positive changes centred around parents experiencing a shift in priorities towards maintaining their child's happiness and wellbeing and gaining a sense of purpose through caring for their child.

Theme Four: *Time*

The final theme was concerned with parents' experiences of self-care in relation to *time*. All parents described difficulties in balancing time between caregiving demands, maintaining relationships, other everyday family and work demands, and finding time for their own self-care. Due to these competing demands, all parents discussed frequently neglecting their own self-care and viewing their own wellbeing as lowest priority. However, many parents found they experienced a process of learning to prioritise their wellbeing as they realised the importance of implementing self-care for both themselves and their family. These parents identified that through using their child as a motivation to be healthy and implementing regular self-care strategies, they were consequently more mentally and physically healthy. Through finding motivation to be healthy outside of themselves, parents discussed how they were more willing and able to ensure that their own wellbeing needs were being met. Through engaging in regular self-care, parents also reported having improved family relationships and being better equipped to cope with everyday demands and difficulties.

Ineffective strategies of self-care that parents experienced over time included participating in activities in which the parents felt obliged and deemed "healthy", and which were unrealistic and impinged on their limited time, energy and resources. Ineffective self-care strategies parents experienced included continuing to utilise healthcare and support services which did not work well for them or their family, and continuing to go out of their way for others where they felt it was not reciprocated or appreciated. Some parents reported avoidance of self-care and their own needs was ineffective due to being harmful to their mental and physical health, relationships, and family functioning. For all parents, time became more valuable in having a child with special needs. Therefore, when parents felt their time and effort was not valued by others, this had a negative effect on their own sense of worth and meaning.

Due to the value placed on time in having a child with special needs, most parents discussed using a family routine which incorporated varying self, family and caregiving demands as an effective strategy of self-care. Through being organised and implementing successful routines, parents reported experiencing greater efficiency with their limited time and a sense of accomplishment in completing tasks. Parents also reported experiencing more free time when implementing effective routines, which provided them greater opportunity to engage in self-care and dedicate quality time to their family. Having a routine was discussed by parents as being helpful for their whole family as everyone tended to become more aware of their role and responsibilities, the environment became less hectic and stressed, and their children thrived in a more structured and predictable environment. Being flexible within their routine and preparing ahead of time for what may happen during the week were notable features of an effective routine discussed by parents.

Discussion

Study one explored self-care and wellbeing of parents of children with high-need disabilities from the parents' perspective. It did this through a positive health-promotion paradigm, with the implementation of qualitative methodology of semi-structured interviews and thematic analysis. Four main themes arose regarding parents' experiences and advice related to self-care, which included building formal supports and resources, maintaining relationships, considering values and goals, and balancing time. These findings support existing literature which argues that effective self-care can negate stress-related psychological impairments and compassion fatigue, and promote health and wellbeing for parents (Acton, 2002; Tyssen et al., 2001). Further, these findings provided effective strategies of self-care which parents have been able to utilise in amongst the constraints of time, energy and resources they face as informal caregivers. Through approaching self-care in a health-promotion framework, the current study supports Pender's (1996) Health-Promotion model which argued that this approach is most effective for identifying positive outcomes and strategies to enhance caregiver's sense of meaning and wellbeing (Acton, 2002; Farran, 1997).

Limitations with the current study include possible demographic bias by the sample not being reflective of New Zealand's varied population and culture as most participants identified as New Zealand European women. Therefore, future research should consider additional methods to further incorporate informal caregivers within New Zealand with differing gender and demographic characteristics currently underrepresented, including research incorporating an indigenous Maori worldview of self-care and disability. Although current findings supported that self-care experiences and strategies were similar among parents of children with autism and cerebral palsy, caution should be made in assuming these results can be generalised to parents of children with other disability diagnoses. To further investigate whether disability type is a significant influencing factor of self-care, future research could incorporate larger sample sizes with a broader inclusion criterion based on multiple disability types. Limitations regarding the current method may also include social desirability bias and misinterpretation by the researcher. Suggestions to address limitations related to the use of cross-sectional semi-structured interviews may include increasing the sample size, utilising a mixed methods approach, and implementing qualitative longitudinal research methods.

Nevertheless, this study provided new insights into a previously unrepresented research population within a New Zealand context for which future research can grow and develop. The current study provided new understandings of the experiences of self-care for parents when raising children with special needs. The benefits of the current findings include that they add to a lack of research regarding self-care within a health promotion paradigm, and a lack of research of parental caregiving need and wellbeing within a New Zealand context. Therefore, the research findings will potentially contribute to enhancing understanding in the area of childhood disabilities and caregivers' needs within New Zealand, and to helping parents better adjust to the difficulties of a new diagnosis and caring for their child's disability. Findings may also help health practitioners provide support that is more meaningful to parents as informal caregivers, and help inform future research and the design of interventions to facilitate self-care for parents of children with disabilities.

Self-Reflections

The current research has influenced my clinical practice as a psychologist in many ways, including that it highlights how clients are the expert of their own reality. As psychologists we are equipped with strategies and tools that are "research-based" which can help alleviate individual's suffering, however the current research emphases that without listening and working alongside the client and their reality, the tools we have will not work. By working alongside the client or research participant as the expert, it becomes apparent that they often already know the answers to what will improve their sense of wellbeing. Therefore, the role of clinical psychology is to help them with identifying this and assist them into putting it into practice. Each individual comes with their own background, culture, limitations and resources, and therefore as clinical psychologists we must be able to adapt to their reality and be creative with them in matching and adapting strategies to ensure their success.

The current research also emphasised to me the importance of reflecting and noticing the language that I use with clients and research participants from various backgrounds, and to make a conscious effort to check-in with the client regarding what language and terminology they prefer. Through using the client's language, this exhibits a sense of respect and active listening which can help build rapport. Also, in using a strengths-based approach with language use, particularly in the area of disability, this can have a therapeutic benefit of helping to instill hope and convey dignity and empowerment for the client and family. This may also help to provide an alternative narrative for families when in engaging with formal supports as currently it is rare for healthcare professionals to use the family's language without the negative undertones that usually comes with healthcare jargon.

Finally, through this research I experienced validation that many of the strategies emphasised by parents reflected common themes from most evidenced-based therapeutic approaches including cognitive-behavioural therapy (CBT). Common strategies identified by parents which are also used with CBT include psychoeducation, having goals, living to values, reflecting on positives, seeking social support, and scheduling in self-care and relaxation. Although strategies of self-care identified by parents were similar to that endorsed from evidence-based therapies, parents' ways of incorporating them into their lives were markedly different as they needed to be creative and practical in modifying these strategies to their family's unique limitations and resources.