Raising a Child with an Autism Spectrum Disorder:

The Experience of Stigma by Association,

its Impact on Caregiver Wellbeing, the Influence of Signature Strengths,

and the Experience of Growth

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Katie Weastell

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Abstract

The life of a child with an Autism Spectrum Disorder (ASD) is known to include many difficulties, not only due to social, behavioural and communication difficulties, but also as the child does not fit society's specifications of 'normal.' Stressors encountered by caregivers raising a child with an ASD are well documented; however one often overlooked stressor for caregivers is *stigma by association*. Research to date has begun to explore the impact of stigma by association on the wellbeing of caregivers raising children with an ASD. However research is scarce, and has not yet addressed how some caregivers who experience stigma by association manage to resist this negative influence. Through two studies this thesis explored the experience of caregivers of children with ASDs New Zealand, looking in particular at stigma by association and whether personal signature strengths (particularly hope, gratitude and curiosity) may decrease its impact on caregiver wellbeing. It also examined whether, in spite of documented negative outcomes for caregivers, there is in fact room for a caregiver to experience growth as a byproduct of raising a child with an ASD.

Participants took part in interviews (Study One, six participants), or completed an online questionnaire (Study Two, 100 participants). All caregivers spoke of difficulties associated with raising their child which on the whole reflected previous research. Difficulties included practical restrictions, personal costs and social stigma. Every caregiver was found to have experienced stigma by association. Study Two participants had all encountered both enacted and internalised stigma by association in the previous six months, and stigma by association had a significant negative relationship with caregiver wellbeing. Positively, if a caregiver possessed higher levels of hope or gratitude, mediation analysis found the presence of these strengths decreased the influence of stigma by association on wellbeing. Promisingly, all caregivers were also able to identify many ways in which they had grown as a byproduct of the experience of raising their child, whether it was through increased positive emotions, experiences, or personal development. Findings suggest that in spite of caregiver's challenges they may not only survive, but thrive.

Acknowledgements

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Preface

An interview with All Black Cory Jane about his experience raising his nine-year-old son Cassius, diagnosed with tuberous sclerosis, ADHD (attention deficit and hyperactivity disorder) and autism:

> Interviewer: *CJ what is harder, being a professional sportsman, or having a child with such special needs?*
>
> Cory Jane: *Well there's a lot of pressure in rugby, it's a tough job; but there's a lot at home too. It's an ongoing everyday problem there too; you've got to deal with the schools and specialists and stuff like that. There's a lot of stuff that is harder at home; so rugby's kinda a break to me, and I get to get my frustration out in rugby and then when I go home it's the harder job, kind of, takes over. So um, it's the balance, and I'm good at separating rugby from living, which is good.*
>
> Interviewer: *Do you think that, because you are well known, it changes how you deal with it?*
>
> Cory Jane: *Even situations say, we might be out at the mall or something like that, and Cassius will have one of his moments, and people will be like, "you know, you can't let people see you like that." I'm like, once he starts going into that, I couldn't care less who I am, you know, in public I gotta deal with what's going on in front of me. So, um, it's tough but sometimes when I, when people come up to you and say, "your kid's spoiled" or "he's being naughty," or stuff like that, you forget who you are and you just tell them to 'f' off; or, you know, you're dealing with enough stuff and you don't need some person that don't even know you to step in and say stuff like that. So, there's those moments; but then there's heaps of fun moments and good moments too.*

<div align="center">Interview by Polly Gillespie (Gillespie, 2015)</div>

Every student that decides to embark on the process of writing a thesis must choose a focus out of the multitude of areas of psychology available to them. This decision is aided in part by the choice of university, often further by a decision to specialize, such as with clinical psychology, and often further by career aspirations. Yet the topic areas remain countless. It is often here where common advice is given to postgraduate students to ensure that the topic they choose is an area of curiosity to them, as it is often the student's interest in the topic that

helps them reach completion (Lunenburg & Irby, 2008). Prior to beginning the formal scientific part of the thesis, I have provided a brief reflection on why I chose this topic, and the context of this decision. The interview with Cory Jane encompasses one example of my motivations.

Autism spectrum disorders (ASD's) are a significant difficulty affecting up to 116 in every 10,000 children in New Zealand (NZ; Amaral, Geschwind & Dawson, 2011). On first sight a child with an ASD may appear 'normal,' yet behind this appearance the child likely experiences considerable difficulties with communication skills, understanding social rules, and restrictive and repetitive atypical behaviours; as well as numerous co-morbid psychological and health problems. This contrast between the child's appearance and their abilities and behaviours contributes to additional stress for both the child and their caregivers in the form of social stigma.

It was 2011, while working as an applied behaviour analysis (ABA) therapist with children with autism, when I first became aware of the significance of stigma surrounding ASDs. While I witnessed and was told of many instances where these children's parents were discriminated against based on their child's abilities and behaviours, it was not until years later that I learned this experience had a name: *stigma by association.* During my work as a therapist I became interested in various issues related to the child and family's experience of autism. Of particular interest to me was the contrast between theories developed during the 1940's and 1950's about autism etiology (such as Freudian suggestions that cold and unemotional parents were to blame) and the generous, loving and heavily devoted caregivers (whether mother, father or legal caregiver) I saw day in and day out. However, frustratingly it appeared that instead of seeing what I saw, which contradicted early theories (as has substantial research evidence since this time), the wider public still seemed to blame these caregivers for their child's difficulties (just like the experience of Cory Jane,) and offered little in the way of support. Stigmatisation added to the limitations these caregivers already experienced, and often created barriers to these families utilizing resources available to them in their community (for example one child enjoyed the local swimming pool, however his mother found managing his behaviour [in order to avoid upsetting other pool users] so tiring she rarely felt she had the energy to take him). It was clear to me that in order to improve the lives of these caregivers, and subsequently improve the lives of these children; public attitudes would need to change.

Unfortunately, while a portion of NZ public health funding is directed towards reducing the stigma associated with common mental health difficulties such as depression (for example the 'Like Minds Like Mine' campaigns; https://www.likeminds.org.nz/) less prevalent disorders such as the ASDs have not been as fortunate. In fact, children with ASDs and their families struggle to access publicly funded early interventions, let alone obtain national public health support to reduce stigma and discrimination.

So in the absence of external resources to reduce stigmatization, are caregivers destined to remain isolated and positioned as "other?" I believe not. For most of the parents I worked with stigma by association was certainly present as a complicating factor in their lives, however some parents appeared able to cope with this experience better than others. This ability did not appear to be influenced by their child's symptom severity, or their access to treatment supports, but rather, some form of internal resource.

During the early stages of this research as I read countless research articles detailing all the negative experiences of caregivers of children with ASD's, my plan was to provide further evidence for why and how caregivers not only survive, but can thrive in spite of experiences such as stigma by association. Unfortunately, research on experiences of caregiver stigma by association was limited, primarily qualitative, and focused on the experience of mothers. There was even less evidence on inner strengths which may help protect and even encourage caregiver wellbeing.

The case for investigating caregivers of children with ASD's experience of stigma by association in NZ and the potential for a caregiver's 'signature strengths' to protect wellbeing is presented here, with the aim of advancing understanding of how caregivers may resist the impact of stigma by association. This is followed by an overview of ways in which caregivers experience growth through the experience of raising a child with an ASD.

Overview of the Thesis Structure

This thesis consists of four sections. This first section consisting of six chapters introduces the thesis focus, relevant terms, contexts and purpose. Chapter One describes autism spectrum disorders (ASDs), and the important role of primary caregivers. Chapter Two reviews the challenges experienced by caregivers raising a child with an ASD, and examples of these challenges specific to the New Zealand context within which this study is set. The relevance and prevalence of stigma is outlined in Chapter Three, along with an introduction to stigma by association, and the introduction of the first research hypothesis: that stigma by association

has a negative impact on the wellbeing of caregivers of children with an ASD. The next chapter, Chapter Four, introduces positive psychology and the second research hypothesis: that a caregiver's inner resources, in particular signature strengths such as hope, gratitude and curiosity, can help reduce the impact of stigma by association on caregiver wellbeing. Chapter Five extends the introduction to positive psychology, specifically examining the possibility of personal growth for caregivers, and suggests the third research hypothesis: that in spite of the challenges associated with raising a child with an ASD, a caregiver can experience growth. The final chapter in this section - Chapter Six - serves to introduce the research studies.

Section two consists of Study One: a qualitative research study exploring caregiver experiences of raising a child with an ASD, stigma by association, and growth. Chapter Seven in this section reports on the design and methods of this interview study. Chapter Eight provides an overview of results, while Chapter Nine discusses these findings, their relevance to existing research and the following study.

Section three consists of Study Two: a quantitative study of the experiences of stigma by association, wellbeing and growth in caregivers of children with ASDs. The design and methods of this survey study are outlined in Chapter Ten, including a description of the development of a measure of stigma by association. Chapter Eleven provides a report on statistical analyses and a small piece of thematic analyses of the results of Study Two, and Chapter Twelve discusses these results in comparison to previous research findings.

Finally, section four and the final chapter (Chapter Thirteen) reviews the findings of Studies One and Two. Possible meanings of these findings, how these compare to what is already known through the literature, and what these finding suggest for future research is discussed and the research concluded.

SECTION ONE

Chapter One:

Autism Spectrum Disorders and the Importance of Primary Caregivers

"It really does take a village to raise a child"

(Ministries of Health and Education, 2008, p. 215)

Autism spectrum disorders (ASDs) are neuro-developmental conditions usually identified in early childhood which present as complex and lifelong social, communication, and behavioural difficulties. Although reportedly first identified in 1943 by child psychiatrist Leo Kanner, the majority of mental health professionals looked upon children with autistic symptoms as having "childhood schizophrenia" (Tidmarsh & Volkmar, 2003). It was not until the 1980 publication of version three of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-III*; APA) that ASDs were formally recognised within psychology (Tanguay, 2010). Today there remains a lack of consensus on the definition of an ASD.

Epidemiology of Autism Spectrum Disorders

Tracing research on autism through history reveals a variety of terms used to describe what we know today as ASDs. This variation in language complicates the search for research evidence as the definition of an ASD is ever changing (for example the recent update of the *DSM* to edition five; *DSM-5*). There is also limited information on the prevalence of ASDs.

Diagnoses on the Autism Spectrum

As noted above, there is a variety of ways in which an ASD may be referenced in research literature. In one setting a set of symptoms may be referred to as *Asperger's*, in another *autism spectrum disorder*, another *pervasive developmental delay* and yet another *high functioning autism*. Adding complexity - within the current NZ public health system there are three criteria sets officially used within the clinical professions to confirm the presence of an ASD, one being the *DSM-IV-TR* (Diagnostic and Statistical Manual, 4th edition, text revision; APA, 2000), another, the recently released *DSM-5* (5th edition; APA, 2013) and the other, the World Health Organization's *International Classification of Diseases,* 10th revision (*ICD-10*; 2004). Within psychological practice in NZ the DSM criteria are utilized most frequently (Fitzgerald and Myers, 2014).

Within the *DSM-IV-TR* (APA, 2000) an autistic disorder is referred to under the classification of *pervasive developmental disorder* and is defined as:

"…severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities. The qualitative impairments that define these conditions are distinctly deviant relative to the individual's developmental level or mental age... [this category includes] Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (APA, 2000. p. 69).

The spectrum of pervasive developmental disorders is divided into five diagnostic subcategories. According to the DSM-IV-TR *autistic disorder* is diagnosed if an individual displays difficulties with six or more symptoms across the three areas of communication, social interaction and repetitive/stereotyped behaviours or interests, and must present before three years of age. *Asperger's disorder* is similar to autistic disorder, however a person diagnosed with Asperger's usually displays normal communication development as well as "typical" levels of cognitive and self-help skill development. *Rett's disorder* is referred to as the most physically disabling of the ASDs, is much rarer than autistic and Asperger's disorders, and is most often seen in females as a regression in social, language, and motor skills. Similar to autistic disorder, *childhood disintegrative disorder* presents as difficulties with communication, social interaction and repetitive/ stereotyped behaviours. However differentiating this disorder is the later onset (up to ten years of age) and normal development until disintegrative losses begin. Lastly, the fifth diagnosis, *pervasive developmental disorder not otherwise specified* (PDD-NOS) is used when impairments similar to the above diagnoses are present, but not all criteria are met.

In the DSM-5 the diagnostic subcategories of autistic disorder, Asperger's disorder, childhood disintegrative disorder, and PDD-NOS have been removed based on a reported lack of research evidence supporting distinctions (Broadstock, 2014). In place of subcategories the DSM-5 has introduced severity indicators and descriptive "specifiers" aimed at describing the types of supports an individual may require and now references *autism spectrum disorder* rather than pervasive developmental disorder. As Rett's disorder is genetically identifiable as a neurological disorder this is no longer included in the ASD category (Broadstock, 2014). Less significant changes have also been made, such as changes to the rigid requirement of symptom presence prior to age three, symptom domain re-arrangement, inclusion of unusual sensory sensitivities, and changes to minimum number of diagnostic criteria. The changes to DSM-5 category and subcategories are more in line with common practice referencing the

autism spectrum (i.e. *New Zealand Autism Spectrum Disorder Guideline*, Ministries of Health and Education, 2008). While the DSM-5 is more in line with current thinking about an ASD spectrum, at the time of study development consensus had not been reached on the use of the DSM-5 within public health services (The New Zealand Psychological Society, 2014). Therefore *DSM-IV-TR* terminology is used when referring to specific diagnoses for the purpose of this study (see Appendix A for the full *DSM-IV-TR* diagnostic criteria).

Prevalence of ASDs

Another issue for researchers interested in experiences of autism spectrum disorders in New Zealand (NZ) is the lack of NZ specific prevalence data. International estimates place the incidence of all ASDs at between 12 and 116 cases for every 10,000 people (Amaral, Geschwind, & Dawson, 2011; Fombonne, 2003). However even these estimates are best guesses, because while awareness of ASD increases and more adults receive diagnoses—not suggesting late onset, but rather late diagnosis,—many more adults also choose to avoid seeking a diagnosis altogether (Ministries of Health and Education, 2008).

Whilst the *DSM-IV-TR* (APA, 2000) specifies five different clusters of ASD symptoms, each ASD diagnostic subcategory can vary greatly in its presentation. A non-verbal 18 year old who enjoys social contact may share the same diagnosis as a verbally expressive 8 year old who prefers solitude as he lines up Lego in the hallway. So how does each diagnoses reliably link into the autism spectrum? Referring to three defining characteristics of ASD as identified by the *New Zealand Autism Spectrum Disorder Guideline* (Ministries of Health and Education, 2008), a person with any of the ASDs is likely to show impairments in social reciprocity, language and communication, and restrictive and/or repetitive behaviours or interests (aka RRBs), known as the ASD difficulties triad.

The ASD Difficulties Triad and our Social World

ASDs are unique not only because of their expression in childhood. The triad of difficulties in communication, behaviour and social interaction is distinctive to ASDs. As indicated above, each individual with an ASD has a unique combination of difficulties of differing magnitudes from the triad. These impairments often cause great difficulty for the individual with an ASD, necessitating assistance from others; yet their difficulties are such that they often inhibit the assistance of others.

Communication difficulties are usually evident in the individual's difficulty attending to, producing and understanding verbal and body language (Amaral, et al., 2011). Humans rely

heavily on language to relay information – whether it be about where to meet for a social gathering, where pain is felt following an injury, or the dangers of putting a knife in a toaster. Individuals with ASD either miss, or experience great difficulty in sharing, giving or receiving vital information. To possess a deficit in communication compromises the individual's ability to adapt to and participate in the social and physical world around them.

Furthering an individual with ASD's difficulties as a social being are common behaviours of a repetitive and restricted nature. These behaviours are broad in presentation, from stereotypy (such as hand flapping, rocking, and repetitive verbalisations) to obsessions and compulsions (for example counting, sensory fixation or aversion, or resistance to change). RRBs create a number of barriers for the individual with an ASD. For example, they may detract the individual's attention away from learning opportunities towards more intrinsically rewarding sensory experiences, create barriers to social engagement through resistance to routine change, or inhibit the child's ability to interact with peers (Williams, Wright, Callaghan, & Coughlan, 2002). Some RRBs involve self-injurious behaviour, an act which can evoke in observers a sense of fear and, if witnessed in the absence of understanding, lead the observer to avoid the child. Lastly, the more observably unusual the child's behaviour or abilities, the more likely the child's peers (and often wider community) are to judge the child as inappropriate or immature, increasing the likelihood they will reject the child (Attwood, 1998) .

If an individual with an ASD is able to overcome or compensate for difficulties with the mechanics of communication and/ or RRBs, they will likely continue to experience difficulty with advanced skills required for social interactions.   Social impairments have been retrospectively reported in children with ASD as young as six months of age, commonly as an absence of eye contact and seeking of shared experiences (Volkmar, Paul , Rogers, & Pelphrey 2014). Individuals with autism are reported to experience difficulty with understanding and use of body language, emotion, and social norms (Sigman, Spence & Wang 2006). These difficulties can lead to social misunderstandings, subsequent maladaptive behaviours such as avoidance or tantrums, and significant social difficulties. Constantino (2011) proposed that these difficulties can be "profoundly stigmatising" (p. 139), for an individual with an ASD, who often experiences teasing, exploitation and marginalisation. When a child experiences so many obstacles and threats to their wellbeing in interpersonal relationships, responsibility falls to the primary caregiver who through love - and through the lack of other options - must step up and support, advocate for, and protect their child.

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Chapter Two:

The Challenges of Raising a Child with an ASD

"The reality of autism is that it is relentless. It doesn't take off weekends or holidays."

(Sanford, 2016 para. 12)

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Supporting a Child with an ASD

The family environment has long been seen as important to a child's welfare and development (Sameroff, 1990). Positive caregiver involvement and support is known to be vital for any child to develop to their potential. The same can be said for a child with an ASD. However, if the child has ASD the caregiver will likely encounter a range of experiences which may limit their ability to provide the best developmental environment. For some, the diagnosis of ASD may lead to an experience of grief and loss; their child's difficulties may create stress due to increased responsibilities - or even distress at symptom effects. Others may be more able to frame their experiences as positive and as opportunities for growth. The experience of caring for a child with an ASD is one of diversity, however research has shown that throughout this diversity runs common themes. The following chapter reviews common challenges identified in literature associated with the experience of caring for a child with an ASD.

Difficulties Associated with Raising a Child with an ASD

In recent years, interest has developed around the experience of caregivers of children with developmental and psychological difficulties. Literature on the experience of raising a child with an ASD indicates this can be significantly more stressful than raising a child with other common disabilities. Caregivers face increased barriers to resources and reduced psychological and social wellbeing.

   Reduced Resources

ASD is known to be a costly disorder (Ministries of Health and Education, 2008) with both financial and personal resource costs to the caregiver. Each child on the autism spectrum requires individualised support. Some children's disabilities associated with their ASD qualify for Government funded support (for example a child may be able to access some publicly funded physiotherapy, speech language therapy, continence or educational support). However, even with funding support, the financial burden can still be significant. Financial expenses additional to those absorbed by caregivers of typically developing children include: costs of respite care, of accessing appropriate resources such as day time activities (as community resources suitable and accepting of this population are often hard to come by), loss of earnings if a caregiver has to provide additional care for a child or cannot find flexible

work, additional health costs, expenses of providing evidence based therapies which are currently not funded by the government (e.g. ABA [Applied Behavioural Analysis] therapy), and, if the child engages in destructive or escape behaviours - house safety and repair costs (Ganz, 2006; Gupta & Singhal, 2005; Hastings & Johnson, 2001; Hodgetts, Nicholas, & Zwaigenbaum, 2013; Norton & Drew, 1994; and Morgan, 1988).

Although the saying goes 'time is money,' for many caregivers of children with an ASD money cannot buy enough time. Time is indicated by research to be another limited resource for parents of children with an ASD. In a study of time demands on parents of children with autism, Sawyer, Bittman, La Greca, Crettenden, Harchak and Martin (2010) compared time pressures of these parents with parents of children without disabilities. Their findings suggested that, on average, these caregivers spent six hours of every day caring for the child with an ASD, close to two hours more per day than parents of children without disabilities. Cappe, Wolff, Bobet, and Adrien (2011) suggest that the family life as a whole must usually be organized around the child with ASD and planning for their future.

Social Strain

A natural consequence of increased time strain and financial pressure on caregivers is a reduction in the quantity or quality of social interactions such as marital, peer, and community relationships. Parenting a child with an ASD has been shown to potentially contribute to stress on the caregivers' spousal relationship, leading to decreased marital satisfaction (Rodrigue, Morgan, & Geffken, 1990). For example, one United States of America (USA) study demonstrated greater likelihood for divorce in parents of children with an ASD (24% as opposed to the standard rate of 14% (Hartley et al., 2010). However a larger study in the USA was unable to find such evidence (Freedman, Kalb, Zablotsky, & Stuart, 2012). At this point in time, more research investigating the correlation between marital dissatisfaction and caring for a child with an ASD is needed.

At a broader social level, caregivers have reported isolation from peers and their community as a common experience (Morgan, 1988). Dunn, Burbine, Bowers, & Tantleff-Dunn (2001) surveyed parents of children with autism and found that isolation – often a consequence of resource strain - was a significant problem, and very influential on how the parent coped with the stress associated with having a child with an ASD. In a qualitative study of parent's experiences Woodgate, Ateah, & Secco (2008) framed participant's experience of this isolation

as "living in a world of our own" (p. 1075). This isolation was described as self and other imposed, and will be discussed further in the next chapter.

Psychological Difficulties

One of the most pervasive challenges of raising a child with an ASD is increased stress. Raising a child is known to be stressful, but raising a child with an ASD can be remarkably difficult (Karst & Van Hecke, 2012). Elevated stress has been demonstrated in caregivers of children with an ASD versus children who develop typically (e.g. Dunn et al., 2001; Estes et al., 2009; Montes & Halterman, 2007). Caring for a child with an ASD is thought to be more stressful than caring for children with other chronic disabilities (e.g. Brobst, Clopton, & Hendrick, 2009; Dabrowska & Pisula, 2010; Weiss, 2002). Primary caregivers of children with an ASD frequently report feeling incompetent as a parent, that they have had to part with their own dreams and goals (for themselves and their child), and that their own physical health has suffered, all factors which contribute to decreased overall wellbeing (Allik, Larsson, & Smedje, 2006; Gupta & Singhal, 2005; King et al., 2006; Rodrigue et al., 1990; and Weiss, 2002). These factors, plus other stressors such as isolation and/ or financial difficulties place caregivers at an increased risk of psychological difficulties.

An American study of over 60,000 children with ASDs found that their mothers were 2.5 times more likely to report poor or fair mental health as opposed to mothers of children without an ASD (Montes & Halterman, 2007). A combination of risk factors and decreased mental health is believed to increase the likelihood a caregiver will suffer more complex psychological complications. One such complication is depression, which in comparison to the general population, is found at higher rates in parents of children with an ASD. For example, using the Beck Depression Inventory (Beck, 1978), Weiss (2002) compared depression levels in mothers of children with ASD, to those of mothers with children with Intellectual Disability (ID) or typically developing children. These mothers were found to have average scores indicative of moderate depression, whilst those of children with an ID or typically developing children scored in the mild and non-depressed score ranges. Similarly, Bitsika & Sharpley (2004) found that of Australian parents of children with an ASD, nearly two thirds reported clinical levels of depression on standardized inventories. A more recent exploration of maternal symptoms of depression by Taylor & Warren (2012) found that symptoms were "very high" (close to 78% percent) when the child was first diagnosed, with rates of depression decreasing to around 37% after a 12 months.

Another common psychological consequence reported by primary caregivers is anxiety. Whilst efforts have been made to increase support for parents (e.g. Brookman-Frazee & Koegel, 2004), levels of anxiety continue at high rates. In the study by Bitsika & Sharpley (2004) mentioned previously, over 50% of parents surveyed were considered to be "severely anxious" and Weiss's (2002) study reported mothers typically reported "moderate" anxiety.

The presence of an ASD can be life limiting and stressful for not only the child, but also their parent and caregivers. ASDs create difficulties which can make achieving typical day to day tasks seem daunting. Whilst the child with an ASD is so dependent on their caregiver for protection, sustenance, and opportunity – who can the caregiver turn to in order to ensure they sustain their own wellbeing? Naturally we would assume the wider family and community. However this can be very dependent on the society and culture within which the family is situated.

Raising a Child with an ASD in New Zealand
New Zealand is an island country, geographically isolated from much of the western nations it is so often compared to in the literature. Although demographically Europeans are the dominant ethnicity at 74%; Māori (14.9%), Asian (11.8%) and Pacific Peoples (7.4%) are seen as major contributors to NZ's unique demography (Statistics New Zealand, 2014). The three official languages of NZ are English, Māori, and New Zealand Sign Language.

There is only a small handful of literature examining the experience of raising children with an ASD in NZ. What can be gathered from recent history is that deinstitutionalization of mental health and disability care services in NZ over the 1970's, 1980's and early 1990's has meant the majority of support for children with an ASD is now likely to be provided in the family home by the child's caregivers. Some children with an ASD will have disabilities associated with their diagnosis which qualify for NZ government funded support (for example a child may be able to access publicly funded physiotherapy, speech language therapy, respite or educational support) whereas others will not qualify for any additional support. Often access to these publicly funded supports is not available to a child, not because they do not qualify, but instead because some support options work on a first come first served basis (i.e. ORS – Ongoing Resource Scheme education support funding [Fulton, 2014]). Stace (2010) suggests that in NZ's current climate "good outcomes for autism are dependent on having family to advocate and luck that they will be able to find services and supportive people" (p. 66).

In 2008 the Ministries of Health and Education consulted with groups within the NZ ASD community including adults with ASD, parents and families, medical, allied health and education professionals, health, wellbeing, education and social services and cultural representatives. From this they published a collaborative guideline for health, therapy and education service providers. Importantly, it was recognized that the family of a person with ASD can be crucial to the support needs of that person, yet those family members and caregivers also had their own additional needs for support due to the challenges of raising their child. Challenges identified by caregivers included:

- experiences evoking anxiety, sadness, anger, disappointment and helplessness,

- difficulties accessing support and education services,

- concerns about their child's welfare in the future,

- lack of tolerance, understanding and acceptance by their wider community,

- family routine and lifestyle disruptions, including less opportunity for social experiences,

- an intense load of caregiving responsibilities, with the workload often leading to 'burnout.'

The only known published research looking specifically at the perspectives of parents of children with an ASD in NZ was completed by Bevan-Brown on behalf of the Ministry of Education in 2004. This qualitative research involved 23 Māori caregivers (mothers, fathers and one grandmother) who described a number of barriers to accessing services for their children and the impact on their own wellbeing. Difficulties discussed included: service and funding shortages; geographical, cultural, procedural, and financial barriers to services; personal, family and financial stress; loss of support and lifestyle dreams; and discrimination. Some participants in Bevan-Brown's research also identified positive experiences, including: family supportiveness (although this varied), becoming "experts" on ASD, and gaining self-confidence through the experience. Whilst experiences that could be considered positive were included in Bevan-Brown's report, the intention of the report was to highlight the difficulties associated with raising a child with an ASD from a Māori cultural perspective.

On the whole research to date suggests that along with their child's difficulties with ASD, a primary caregiver can also expect to experience financial, workload, and time strain, isolation, a battle to access adequate resources, and subsequent marital dissatisfaction, stress, grief, loss, and decreased psychological and physiological wellbeing. While support for these caregivers would be expected to come from the wider community, there appears to be

another barrier which is often neglected in the literature, yet is important to consider in the child and caregiver's struggle for wellbeing, that being social stigma.

Chapter Three:

How Stigma Contributes to the Challenges of Raising a Child with an ASD

"If all stigmatised conditions were considered together and all outcomes examined we believe

that stigma would be shown to have an enormous impact on people's lives."

(Link & Phelan, 2006, p. 528).

The Nature of Stigma

Stigma is the process by which an identity or difference held by, or given to, an individual or group is perceived to signify that individual's or group's reduced value within their society. Earliest origins of the term *stigma* are thought to lie in ancient Greece, where *stizein* (a physical mark) was placed on a slave in order to advertise to members of the public their lower social value (Goffman, 1963; Lopez-Ibor, 2002). Erving Goffman, a widely cited scholar in the field of stigma, had an interest in the complex interactions between individuals. This interest lead him to explore the ways in which people used shared knowledge and meaning about what was "*normal*," and deviations from normal, in order to understand and anticipate actions of others. His resulting publication *Stigma; Notes on the Management of Spoiled Identity* (1963) is now seen as landmark work on the topic of social stigma. Goffman's (1963) work marked a progression in understanding of stigma from the previous referring to a physical mark, to the construction of stigma as "the situation of the individual who is disqualified from full social acceptance" (1963, p. 9). Goffman's early work encouraged great growth in empirical research spanning the fields of sociology, psychology and public health. Literature on stigma, extends from its origins through to current consequences and management. For the purposes of this thesis Goffman's definition of stigma will be honoured, with stigma defined as the understanding that a particular individual's or group's unique trait/s have been evaluated and deemed to be discrediting by the mainstream society (1963).

Today's stigmatised traits are as various as the contexts and relationships they exist within (Major & O'Brien, 2005). Unlike in times of ancient Greece, stigmas now associate with visible and/or invisible traits held, or believed to be held, by any individual. Goffman (1963) talked about three variations of stigmatised traits:

1. overt external (bodily attributes e.g. club foot, leprosy etc),
2. deviations in personal behaviours (for example dishonesty, substance addiction, mental illness etc.), and
3. *tribal* (e.g. nationality ,race or religion).

There are many examples of traits deemed as flaws by wider society. For example, racial minorities have been stigmatised throughout history, as have those with physical illnesses such as epilepsy, and HIV and/or AIDS (e.g. Austin, Dunn, Huster, & Rose, 1998; Badahdah, 2007; Fleming, Lamont, & Welburn, 2012; and Katz, Katz, & Cohen, 1976). A range of more recent references can be found detailing the stigma of sexuality, sex work, obesity, gender roles and mental illnesses such as schizophrenia (e.g. Amaral et al., 2011; Chen & Brown, 2005; Pandya, Bresee, Duckworth, Gay, & Fitzpatrick, 2011; Ragins, Singh, & Cornwell, 2007; Russell, 2011; Russell & Becker, 2012; and Sigelman, Howell, Cornell, Cutright, & Dewey, 1991). But what is it about the previously mentioned examples (and the many others) that means they in particular are stigmatised? Part of the answer to this question lies in an understanding of the process of stigmatisation.

The Development of Stigma

Corrigan and colleagues (2003) conceptualise stigma as a process of attribution, and propose that stigma is the product of three components: stereotypes, prejudice, and discrimination. Georg Simmel, a German sociologist and philosopher proposed that social interactions are heavily dependent on complex mechanisms of secrecy and trust (as cited in Craib, 1997). In order for social interactions to be possible, individuals within these interactions require a minimum amount of information about each other (Baert, 1998). When strangers first meet, this minimal information is obtained via previous experience and collectively established opinions, also known as *stereotypes*. Best defined as: shared beliefs or opinions about social groups made in an all-or-nothing manner which characterise a group as a whole based on common characteristics (Hinshaw, 2006; Perlick et al., 2001), stereotypes are not inherently negative. Stereotypes are theorised to aid conservation of attention and cognitive resources, allowing for efficient development and sharing of expectations and impressions of others who are not members of our own group, (Hinshaw, 2006). However, a limitation of stereotypes is that they are usually developed using over-generalisation and typically ignore individual characteristics which contradict the stereotype (Hilton & Van Hippel, 1996).

If a stereotype evokes an unpleasant emotive response within an individual, this stereotype may develop into *prejudice*. A prejudice can be described as an unreasonable, unjustified judgment of another based on a belief that the person's group stereotype poses a risk (Hinshaw 2006). Through a judgment based solely on the assumption that a person belongs with a particular group, we become biased against a person.

Whilst prejudice is an attitude, *discrimination* is a person's behavioural action (or inaction) towards another person or group in order to relieve emotional discomfort associated with prejudicial beliefs (Perlick et al., 2001). Discrimination can be directed at individual, group, and community levels with implications for those discriminated against as severe as the removal of human rights and even causing death.

Even though stereotypes, prejudices and resulting discrimination may develop based on incorrect or ill-informed assumptions about a person's or group's identity, without effortful correction, the prejudices become established as fact and a stigma is formed. Once established, stigmas are perpetuated by social conditioning and a sense of protection from risk (Myers, 2001). While having an appreciation for how stigma develops us helps begin to understand why people don't readily support caregivers of children with ASDs, in order to consider how this sort of barrier can be overcome requires further awareness of differing roles in and experiences of stigma.

Stigma Terminology

There are a variety of terms used for roles in the stigmatising process and experiences of stigma. In order to provide clarity, a brief overview of the terminology used in this thesis will be provided. Firstly, as referred to by Goffman in his seminal work (1963), there are three positions: *the stigmatised* (those who have been categorized as having bad characteristics), *the normal* - those who would be considered to represent typical, and *the wise* – those who are seen as typical, yet understand the position of and are accepted by the stigmatised. Descriptions of those who are normal and those who are stigmatised are also found in the literature termed as the *in group* and *other* respectively (e.g. Goffman, 1963; and Myers, 2001).

As research on stigma has advanced, so too have understandings and explanations of the different forms stigma may take. In research on mental illness stigma Corrigan and Watson (2002) further identified types of stigma known as *public* and *self-stigmas*; the former referring to the public's (or in group's) reactions towards those with mental illness, the latter referring to prejudices the individual with a mental illness imposes upon them-self. Self-stigma is often referred to as *internalised stigma* (e.g. Ali, Hassiotis, Strydom & King, 2012); the term internalised stigma will be used in this thesis.

Of relevance to this particular study are further sets of terms, *discredited/discreditable* stigmas and *enacted/perceived* stigmas. Goffman (1963) referred to discredited stigma as a situation

where an individual's stigmatised characteristic is visible and or witnessed by the normal, whereas if a person has a discreditable stigma their stigmatised characteristic is able to be concealed on some or in certain occasions and is therefore yet to be witnessed. A person with a discreditable stigma may be able to *pass* as part of the in group until their stigma is revealed and they become discredited. This distinction is particularly important in the case of ASDs, as most children would be classed as having discreditable stigmas. It is not until the child displays an atypical behaviour or difficulty that their status as other would be revealed and the stigma attributed.

Enacted and perceived stigmas on the other hand refer to stigmatizing events. Enacted stigma is used to refer to the experience of discrimination by the stigmatised. Perceived stigma refers to the linking of the shame of being stigmatised, with the appraisal of a potentially ambiguous situation as experienced stigma, or the fear that others' negative actions are because of stigma (Scambler & Hopkins 1986).

Using the above mentioned terminology in the context of this thesis, we begin to see how stigma may create further difficulties and stress for a caregiver of a child with an ASD. With the unpredictability that may come from a discreditable stigma, a caregiver may successfully navigate a social situation with their child on the first occasion, only to experience difficulty and subsequent stigmatization the second time, or as the child may look normal, people may interpret the absence of typically matching behaviour according to prejudices they already have (e.g. a child who does not reply to a greeting may be seen as rude). These experiences may add further anxiety or stress to an already challenging social outing. Caregivers also experience the position of the wise, where they understand the position of, and are accepted by their child, yet must experience the pain and frustration of seeing their child be discriminated against. These are just some of the ways in which stigma adds to the difficulty of raising a child with an ASD.

The Impact of Stigma

In the fields of public and social health, stigma is referred to as the "silent disease" (Henderson et al., 2012 p. 452) linked to low service use, inadequate funding of research and treatment services, and hindering access to wellbeing support for the stigmatised (Hu, Wang, & Fei, 2012; Markowitz, 2001; Ng, Nyunt, Chiam, & Kua, 2011; Sartorius & Schulze, 2005; Wahl, 1999). Internationally, it is believed that the most stigmatised people are those with mental illness and intellectual disabilities (Thomas, 2000; Tringo, 1970). Stigma has been said to have

consequences far more limiting and lasting than the illness or disability itself (Angermeyer, Schulze, & Dietrich, 2003).   Of particular interest in this thesis is the stigma experience associated with ASDs.

The Stigma of ASDs

Public beliefs about individuals with an ASD are highlighted in various studies. For example, through qualitative interviews with 15 mothers of children with Aspergers, researchers Gill and Liamputong (2011) found children with Aspergers were perceived as naughty and disorganised. Ecker's (2010) report on cultural differences in perspectives towards ASD found that in some cultures a child with an ASD was seen to be possessed by evil spirits, or the consequence of ancestors' wickedness. An analysis of forty-five autobiographies and first-hand accounts of the experience of having an ASD noted common public beliefs that people with ASD were unreliable, untrustworthy and less of a person (Davidson & Henderson, 2010). Other common negative stereotypes about children with ASDs are that they are crazy, destructive, and weird (Calzada, Pistrang, & Mandy, 2012; Farrugia, 2009; Gray, 1993; Kitzhaber, 2012; Kuenzli, 2012).

Based on the above mentioned stereotypes (or variations of these), research has shown children with ASD often experience stigma and discrimination. For instance, in a multinational study, the general public were found to have low expectations of the abilities of children with an ASD (Siperstein, Norins, Corbin, & Shriver, 2005). Research has also found children with ASDs are the subject of teasing and unkind treatment by other children (Calzada et al., 2012), and normal children and adults generally exclude children with an ASD from activities, and sometimes even schools (Lilley, 2012; Woodgate et al., 2008). As a consequence a child may internalise this stigma. This internalisation leads to poor self-esteem, increased anxious or depressive symptoms, and an increased likelihood the child will withdraw from social situations in attempt to conceal their status as other (Corrigan & Wassel, 2008). This poor treatment, devaluing and rejection can have painful emotional and life limiting effects on the child, and the family who witness this.

Stigma by Association

Few studies of stigma focus on ASDs, let alone look at the experience of stigma by association. Those studies that do generally include ASDs as an example of a collection of stigmatised identities. The term *stigma by association* (aka associative stigma, courtesy stigma, family stigma, or secondary stigma) was coined in 1963 by Goffman to represent an extension of personal stigma, where the normal can become *tainted* through simply associating with the

stigmatised.   Research has demonstrated that simply being a parent, sibling, caregiver, or friend of a person who is stigmatised may result in the same discrimination, exclusion, and avoidance experiences as those in the stigmatized group (e.g. Ostman & Kjellin, 2002). Simultaneously the stigma is often internalised by caregivers of a child with a stigmatised physical, mental, or developmental disability. Stigma by association is both the experience of being tainted by being associated (experienced stigma by association), and the subsequent belief in the prejudices which lead to this stigmatisation (internalised stigma by association, aka self-stigma by association or affiliate stigma). This experience has been shown to add significantly to the stress of having a child with such disabilities (Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Corrigan, Watson, & Miller, 2006; and Dimitropoulos, Carter, Schachter, & Woodside, 2008).

When examining variables impacting caregiver wellbeing, in particular when the caregiver is raising a child with an ASD, stigma by association is a variable that is often neglected, but significant. Most often, when a child has a disability their level of reliance on caregivers and family members increases. This reliance increases as the child's difficulties increase. If a child also experiences social difficulties (whether through complications of their disability or through stigma), social support is often primarily provided by caregivers and family members. If Goffman's theory about stigma by association is correct, then caregivers -- potentially the most essential and enduring resource for the child with a disability (Thomas, 2000) – are subjected to discrimination and social rejection simply by responding to the needs of their child (Gray, 2002).

Stigma by Association and ASDs

Studies which have examined the stigma experience of caring for a child with an ASD have been at an exploratory level and have mainly used qualitative methodology. Most of this research demonstrates that stigma by association is linked to decreased wellbeing via increased levels of stress, particularly in social interactions (Gray & Holden, 1992; Koegel et al., 1992).

In the early 2000's Gray researched the experience of stigma by association related to having a child with Autism, and examined concepts of felt (internalized) and enacted (experienced) stigma by association among parents of children with high functioning Autism (Gray, 2002). Gray interviewed 53 parents (32 mothers and 21 fathers) of children between the ages of 5 and 26 who had been diagnosed with high functioning autism through a local specialist clinic in

Australia. Gray's research found that over three quarters of parents experienced both forms of stigma. Experienced stigma reported by participants included avoidance by others, hostile staring and rude comments. Internalised stigma experiences included feeling embarrassment, unaccepted, and that others were critical of their care-giving abilities. Parents reported that as a result of experienced stigma they encountered an increase in conflict with educational authorities and experienced additional burden when attempting to accomplish life tasks. Participants reported they experienced the most stigma in public situations such as social outings and mainstream schooling where there was a high likelihood of meeting those who were not wise. Parents in this study believed that whether or not their child had been medically diagnosed as having autism did not affect the stigma they experienced. However, the level of aggression the child displayed was reported to increase the level of stigma experienced. Interestingly, mothers reported far greater levels of stigma than fathers, however Gray hypothesized this may have been because mothers usually took on the role of primary caregiver, therefore spending more time with the child, and that traditionally mothers were viewed as the parent with the highest degree of responsibility for their children's behaviours. Although Gray's research looked specifically at high functioning autism, this research provided good evidence of significant stigma experienced by caregivers of children with an ASD. A summary of Gray's relevant findings along with all other currently available stigma research related to caregivers of children with ASDs can be found in Table 3.1.

A more recent study by Farrugia in 2009 interviewed 16 parents of children with an ASD to explore their experience of caring for a child with an ASD. Similar to Gray's (2002) research the parents in this study also internalised stigma as embarrassment, and perceptions that others saw them as bad parents. Participants also mentioned similar themes of experienced stigma, including looks or glares and rude comments in the form of un-solicited advice. For these parents experienced stigma was said to have contributed to changes in their own social circles, loss of friends, and feeling as though they were restricted in the activities they could participate in within their community.

 Like Gray, Farrugia also found parents experienced more stigma if their child displayed higher levels of socially inappropriate behavior. However in contrast to Gray's research, having a medical diagnosis of an ASD was reported to assist parents in resisting internalized stigma. Farrugia's key findings as relevant to this thesis are also found in Table 3.1. Unfortunately, as the participants of Farrugia's study were all members of the same support group and little information was given about this support group, it is difficult to know whether this difference

in the usefulness of diagnosis was a genuine finding, or due to a sampling bias. Nevertheless, Farrugia's study, appears to provide further evidence for increased levels of stigmatization for parents of children with an ASD.

Of the identified qualitative research on caregiver stigma for family carers of children with an ASD, an interview and diary study by Gill and Liamputtong (2011) was the most up to date at the time of writing. Gill and Liamputtong, again Australian based, used newsletter advertising, personal network and snowball sampling to recruit 15 mothers of children with Asperger's. These mothers were interviewed about their experience of stigma; six of the interviewed mothers also contributed diary excerpts to the study. Although this study did not divide stigma into internalized or externalised experiences, both experience types were identified (as can be seen in the summary Table 3.1). Reported externalised experiences included decreased empathy from others, verbal abuse, and being treated like bad parents. Participants reported internalised stigma experiences included feeling *different* to other parents, embarrassment, worry that their parenting would be judged, and that others thought they were poor parents. The majority of these stigma experiences took place in public settings such as schools, and participants tended to attribute increased stigma to situations when their child's behavior was difficult (e.g. when a child had a meltdown in public). These stigma experiences reportedly lead to mothers decreasing their exposure to public situations (therefore increasing isolation) and often lead to battles with education authorities. Of interest, Gill and Liamputtong observed lower levels of stigma in families with high socioeconomic status, attributing this to increased access to social support and information. Whilst this finding cannot be interpreted as representing the general population of mothers due to the small sample size, it does provide insight into some of the difficulties caregivers' experience.

The only quantitative research study found through an extensive search of the literature on family caregiver stigma focused specifically on the experience of parents of children with an ASD in Hong Kong. Mak and Kwok (2010) conducted a questionnaire study of 188 parents of children with autism (of which 158 were mothers). Participants were identified through support agencies and schools, and questionnaires were distributed by mail with a response rate of 33.2%. Mak and Kwok constructed the questionnaire using nine measures with the purpose of testing whether Weiner's attribution theory (1993, in Mak and Kwok 2010) could explain the internalization of stigma among parents. Supporting findings of the previously described studies, Mak and Kwok found parents do experience and internalise stigma.

Internalized stigma for this parent population was linked with self-blame, as experienced stigma reportedly communicated a message that parents should be in control of and are responsible for their child's behavior. Because of these stigma experiences parents of children with an ASD were reported to spend much more time and effort managing their child in order to avoid further stigmatisation (through discreditation) with the only potentially moderating factor being levels of perceived support from significant others and friends (a similar finding to that of Gill and Liamputtong). An overview of findings from this study can be seen in Table 3.1. As this study was cross-sectional in nature, it is not possible to infer causal relationships between the factors examined, and due to its location in Hong Kong which the authors noted has a culture which places increased value on social identity (and therefore may increase the experience of stigma), parallels cannot be reliably drawn to the NZ population.

Table 3. 1

Stigma Experiences of Caregivers of Children with ASDs

Article	Internalised stigma	Experienced stigma	Consequences of stigma	Factors reported to increase stigma by association
Gray (2002)	Embarrassment Felt unaccepted Felt others criticized their child raising abilities	Avoidance Hostile staring Rude comments	Increased conflict with educational authorities Added burden	Child's aggressive behavior Increased visibility of the disorder Mainstream schooling Social outings
Farrugia (2009)	Felt like a bad parent Embarrassment	Looks/ glares Un-solicited advice Treated as 'bad parents'	Changes to social circles Loss of friends Restricted activities in the community	Child's socially inappropriate behaviour
Gill & Liamputtong (2011)	Felt different Embarrassed Worried others will judge Blamed	Perceived to be bad parents Verbally abused Lack of empathy	Parents avoid some public situations Increased conflict with educational authorities Isolation	Low levels of social support
Mak & Kwok (2010)	Self-blame Felt they should be more responsible	Seen as irresponsible Seen as lacking control	Increased time expenditure and effort	Perceived controllability Perceived responsibility Self-blame Low levels of support from significant others and friends
Bevan-Brown (2004)	N/A	Rude comments Perceived to be bad parents Unsolicited advice Ignored Dismissed	Increased conflict with educational authorities	Ethnicity

One NZ based interview study by Bevan-Brown (2008) was identified which did not explicitly explore stigma by association, but did contain a number of findings relevant to this thesis. Participants were 23 family caregivers of children with an ASD or ASD tendencies, who participated in 17 interviews exploring Māori perspectives of ASD. In particular caregivers were asked to share their experience of raising their child, comment on what they had found helpful or unhelpful, and provide suggestions for future supports. When caregivers spoke of unhelpful phenomena, stigma was referenced on a number of occasions. These stigma experiences included rude comments and unsolicited advice from strangers, and parents reported that they were given the impression they were bad parents. Participants reported that their knowledge or beliefs were often ignored or dismissed, and this was most felt when interacting with educational and health professionals. Similar to the aforementioned studies social support appeared to decrease the experience of stigma. Participants reported that their ethnicity appeared to compound the experience of stigma for both themselves and their child. A summary of stigma related findings from this study are found in Table 3.1.

As stigma by association in caregivers of children with an ASD is a relatively new area of research, only a handful of studies into this phenomenon exist. Of those existing studies, most are qualitative, explored the experience of, and factors which contributed to experienced and internalized stigma, and most participants were mothers. Frequent experiences of stigma by association are reported to range from rude looks through to verbal abuse and alienation, likely to impact negatively on the already compromised wellbeing of caregivers. The literature suggests that stigma by association is a common and important variable which must be considered when evaluating the challenges of raising a child with an ASD. While it is positive that attention to the stigma experiences of these caregivers is beginning to increase, there is limited exploration into what helps protect the wellbeing of caregivers who experience stigma by association, let alone what can be done to reduce how common this is.

Chapter Four:

Protecting The Wellbeing of Caregivers of Children with an ASD

"It is health that is the real wealth and not pieces of gold and silver"

Mahatma Gandhi

Previous chapters have provided insight into the difficulties of raising a child with an ASD. In particular, the focus has been on the importance of social interactions and the experience and effects of stigma. Despite substantial evidence suggesting that the experience of raising a child with an ASD is one of doom and gloom, caregivers do maintain their wellbeing. The following chapter explores firstly the concept of wellbeing, including how this construct is defined for the purposes of this thesis. Secondly, factors identified as protective of caregiver wellbeing – in particular how these fare in the face of stigma by association are explored, and thirdly, the possibility that individual signature strengths could act as protective factors in the face of stigma by association are examined.

The notion of focusing attention on individual psychological factors which facilitate positive mental health as opposed to those which contribute to ill-health is not new. The paradigm of positive psychology, a field which has experienced recent growth, provides a current opportunity and framework within which to explore individual psychological attributes which may protect and develop caregiver wellbeing in the face of stressors such as stigma by association.

Wellbeing: A Positive Psychological Perspective

Historically the study of wellbeing focused on the absence of psychiatric illness. Yet this approach was found to limit studies as it did not allow for distinction between variations in positive health (Stewart-Brown, 2002). From a positive psychological perspective *wellbeing* (also referred to as positive mental health) is a term used to represent the presence of positive emotions, experiences, perceptions of the future, and absence of illness (Tennant, et al., 2007).

At the individual level positive psychology focuses on the presence of healthy traits, capacity and skills (Seligman, 2002). An understanding and facilitation of wellbeing through not only the repair of the worst things in life, but also by building the best qualities in life are the objectives of positive psychology (Carr, 2005). Martin Seligman, a key proponent of the recent

growth in positive psychology, proposes that at an individual level there are three paths to happiness required to achieve wellbeing. These three paths are via:

1. the *pleasant life*: the creation of positive emotions (also known as positive affect, *hedonia* or *pleasure*),

2. the *good life*: engagement **i**n activities that optimize the use of individual strengths, and

3. the *meaningful life*: use of individual strengths in pursuit of goals serving something greater than oneself (2002).

It is theorised that even though having as much positive emotion as possible leads to the pleasant life, pursuit of pleasure alone has the least impact on wellbeing (Gable & Haidt, 2005). The good life and the meaningful life are encompassed by the term *eudaimonia* (Hefferon & Boniwell, 2010). Positive psychological theory suggests that the pursuit of eudaimonic experiences has the biggest impact on individual wellbeing (Carr, 2004; King & Napa, 1998; Seligman, 2002). When we ask a person about their general wellbeing, they are likely to respond referencing recent hedonic and eudaimonic experiences (Kammann & Flett, 1983).

Caregiver Wellbeing: Staying Well in the Face of Adversity

The majority of research on raising children with an ASD has focused on challenges caregivers encounter and the impact of these (as covered in Chapter Two). Yet evidence of considerable variation in the impact of these challenges on caregivers and evidence that caregivers can and do maintain wellbeing while raising their child leads one to wonder whether positive psychological protective factors are at play. A review of theory and research into variables believed to protect caregiver wellbeing can provide some insight into why these differences may exist. Factors identified through this following review can be divided into external and internal protective factors.

External Protective Factors

Factors which lie largely outside of the caregiver's realm of influence (such as child characteristics and social supports) are defined for the purpose of this thesis as external protective factors. The most commonly mentioned external protective factors in current research includes levels of social support and child pro-social behavior. The majority of research on protective factors appears to focus on social support. Findings suggest that social support is positively correlated with increased caregiver wellbeing (Bristol, 1984; Weiss 2002; Weiss, Robinson, Fung, Tint, Chalmers, and Lunsky 2013). For example Gray and Holden (1992) explored psychosocial wellbeing in parents of children with autism. Their findings indicated that social support was negatively related to parental anger and anxiety, consistent with

previous studies. In a more recent study examining stress and wellbeing in 119 mothers of children with an ASD, Ekas, Lickenbrock and Whitman (2010) found that partner and friend support was directly associated with maternal wellbeing, whilst family support was associated with increased optimism, which in turn increased wellbeing. Boyd (2002) reviewed literature on stress and social support in mothers of children with autism and concluded that those who received higher levels of informal social support had better emotional relationships with their child, whereas those who had low levels of social support were more likely to experience difficulties with depression and anxiety.

Of studies examining protective factors, some also explored whether child pro-social behaviour influenced caregiver wellbeing. A study of 196 parents of children with an ASD by McStay, Trembath and Dissanayake (2014) examining family adaptation indicated that severity of child externalizing behaviours (anti-social behaviour) was significantly related to increased parent stress. Similarly, Benson (2010) in his study of the distress and wellbeing of 113 mothers of children with an ASD reported child social behavior moderated the effects of stress on wellbeing. Interestingly, Boyd (2002) found that the more challenging a mother found her child's behaviour, the more likely they were to seek social support.

Further studies on external protective factors have suggested variables such as: family sense of coherence, age of symptom onset, and higher socioeconomic status may protect the wellbeing of caregivers of a child with ASD (Gill and Liamputong, 2011; Gray and Holden 1992; and McStay, Trembath, Dissanayake 2014). Agreement is yet to be reached on the importance of variables such as presence of a diagnosis (e.g. Farrugia, 2009, Gill & Liamputtong 2011, and Tomanik, Harris, Hawkins 2004), age of the child (e.g. Ekas & Whitman, 2010; Gray & Holden 1992; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013; and McStay, Trembath & Dissanayake 2014) and time since diagnosis (Kuhn and Carter 2006; and Pottie, Ingram 2008).

Internal Protective Factors
In addition to the external factors believed to help protect wellbeing reviewed above are those factors located largely within the caregiver's realm of influence. These variables (such as self-efficacy and positive coping strategies) are named internal protective factors for this thesis. Of the limited research on experiences of caregivers who have children with an ASD, a minority have examined internal factors which may protect wellbeing. Those internal factors which have been identified can be categorized as the caregiver's skills, perceptions and traits.

Of these three categorized areas the caregiver is likely to be most aware of the individual skills they utilize. The majority of research investigating which internal variables protect caregiver wellbeing has focused on coping skills. Coping can be defined as "conscious volitional efforts to regulate emotion, thought, behavior, physiology, and the environment in response to stressful events or circumstances" (Compas, Connor-Smith, Saltzman, Harding Thomsen & Wadsworth, 2001 p. 89).

In the context of parenting a child with an ASD, the skill most associated with positive health, and therefore identified as a protective factor is positive reframing (also known as cognitive restructuring). An example of successful use of positive reframing is demonstrated through research by Weiss, Cappadocia, MacMullin, Viecili and Lunsky, (2012) who surveyed 228 parents of children diagnosed with ASD. This study was able to demonstrate that psychological acceptance is negatively related to parental mental health problems. In keeping with findings from Weiss and colleague's study is research by King, Zwaigenbaum and King (2006) who conducted a focus group study with 19 parents of children with autism or Down syndrome. Through analysis of themes King and colleagues discovered that parents identified appreciation of the positive contributions made by their child to the family and society (a form of positive reframing) as a protective factor. These examples suggest we can have some confidence in the benefits of positive reframing for this population.

In addition to positive reframing, positive appraisals (aka positive cognitive appraisals) are also proposed to shield wellbeing from the impact of stress. Theorists and researchers Lazarus and Folkman proposed that cognitive appraisal, the "process of categorizing an encounter, and its various facets, with respect to its significance for well-being" (1984 p. 31) helps explain how even if individuals use similar coping strategies, variations in wellbeing remain. Appraisal requires an individual faced with a stressor to first evaluate the situation. Only if the situation is appraised to be stressful or threatening would coping efforts be considered. An example of research where parents use cognitive appraisal positively is Weiss and colleague's (2013) study of 138 mothers of individuals with an ASD. Through this study they found that the parent's appraisal of themselves as able (possessing self-efficacy) mediated the link between stressors and hardiness. Similarly Siman-Tov and Kaniel (2011) explored stress and personal resources in 176 parents of children with an ASD. In this study they found that both internal locus of control (a variation of self-efficacy) and social support increased parents abilities to cope with the stress of raising their child. These findings specific to caregivers of children with ASDs, and

more from the wider field of caring for a child with a disability suggest that *how* the caregiver perceives a stressful situation with their child can have important consequences for their overall wellbeing.

Within studies of the experience of raising a child with a disability it would also appear that caregivers possess innate traits which can protect them from negative consequences often associated with stressors. This is also likely the case for caregivers raising children with an ASD. For instance traits such as *coherence, optimism,* and *hope* have support as protective factors in recent literature (e.g. Ekas, Lickenbrock, & Whitman, 2010; Kashdan et al. 2002; Lloyd & Hastings, 2009; and Mak, Ho, & Law, 2007). Gill and Harris (1991) examined individual traits of 60 mothers of children with autism to determine whether particular traits shielded them from increased stress. Findings suggested that mothers who maintained emotional and physical health possessed certain characteristics, termed a *hardy* personality. Those with hardy personalities were stated to possess traits of control (i.e. internal locus of control), commitment (sense of purpose), and the ability to embrace challenges (i.e. view change as a positive challenge) which mediated the relationship between the experience of raising their child and stress. Recent research into these traits has provided further evidence of the protective value of these characteristics (Weiss, 2002). Research which has examined the possibility that innate traits can protect caregiver wellbeing from the impact of the stress gives hope that each individual has agency to influence the outcome of their experience.

Investigations into how to protect caregiver wellbeing for those who have a child with an ASD is in its infancy, therefore data on contributing factors is limited. To date findings suggest that while some factors known to protect wellbeing are difficult for a caregiver to influence (e.g. higher levels of social support and socioeconomic status, family sense of coherence, the age of their child's diagnosis, and the levels of the child's anti-social behaviour), a caregiver does not need to be a victim to their circumstance. Research indicates that an individual caregiver's skills, perceptions and personal character traits can protect and potentially strengthen a caregiver's wellbeing in spite of their circumstances.

Wellbeing in the Face of Stigma by Association
Research has acknowledged that parenting a child with an ASD is stressful. Studies have also shown that caregivers can protect themselves from ill-health. Stigma by association has been identified as a likely stressor for caregivers of children with ASDs, however research in this area has shown considerable variation in the magnitude of the impact of this stigma on caregivers. This suggests that, similar to the other stressors faced by caregivers, there are factors which

interact between stigma by association and caregiver wellbeing, and help protect caregivers from the harm of stigma.

Enduring Stigma By Association When Raising a Child with an ASD
More than half a century ago Gordon Allport (1954) was one of the first to describe how victims of discrimination used a variety of compensatory responses to cope with discreditation. At the time of writing there is limited research specifically exploring factors which protect wellbeing in the face of stigma by association for caregivers of children with an ASD. Nevertheless, studies by Gray (2002), Gill and Liamputtong (2011), and Mak and Kwok (2010) into the experience of stigma by association in parents of children with an ASD have begun to identify potential protective factors.

Supporting the earlier described theory that child pro-social behaviour protects parental wellbeing in the face of stress Gray (2002) investigated the experience of parent stigma by association. In this qualitative study Gray interviewed 35 parents of children with an ASD. Findings suggested that highest levels of caregiver stigma by association were related to those who had children with violence and aggression difficulties. Through a more recent qualitative study Gill and Liamputtong (2011) interviewed fifteen mothers of children with Asperger's syndrome and explored potential externally influenced protective factors against stigma by association. Their results suggested that the presence of a diagnosis (defining and validating the child's difficulties), higher family socio-economic status, and higher levels of social support protected parents from increased negative effects of stigma by association. In the only identified quantitative study on stigma by association in parents of children with an ASD, Mak and Kwok (2010) also examined whether social support acted as a protective factor. Their study completed in Hong Kong with 188 parents of children with an ASD suggested that specifically, support from friends and significant others were correlated with wellbeing and were found to decrease experiences of internalised stigma by association.

While there is a small amount of research on factors which can protect against stigma by association, these factors are largely positioned external to a caregiver's locus of control. Based on a literature search at the time of writing it appears that factors which lie within a caregiver's sphere of influence are largely unexplored. Literature on the wider experience of stigma by association for those who experience mental illness or disability suggest internal factors such as an approach oriented style of coping (i.e. active coping [Carver, Scheier, Weintraub, 1989] or engagement coping, [Miller & Kaiser, 2001]) as opposed to avoidance

(disengagement) coping strategies may help protect a caregiver's wellbeing in the face of stigma by association. Or, considering previously described evidence for the positive influence of caregiver's skills, perceptions and personal character traits on overall wellbeing, perhaps these may also serve to protect wellbeing against stigma by association? From a positive psychological perspective, a possible framework for exploring internal individual traits which may aid a caregiver in maintaining wellbeing in the face of stigma by association is Peterson and Seligman's *signature strengths* (2004).

Individual Traits as Protective Factors

Peterson and Seligman (2004) theorise that wellbeing can be achieved through the engagement of an individual's *signature strengths* (also referred to in other literature as character strengths). Research has provided support for this theory by demonstrating that through signature strengths an individual can generate positive experiences such as optimism, confidence, vitality, and gain further insight and perspective into life (Hefferon & Boniwell, 2010). Of interest to this study is whether certain signature strengths equip caregivers with the ability to support their own wellbeing in the face of stigma by association.

Signature Strengths

In an effort to provide a common vocabulary for individual trait researchers, Peterson and Seligman developed a "manual of sanities," known as the *Virtues in Action Classification of Character Strengths.* This classification was designed to focus on "what is right about people and specifically… the strengths of character that make the good life possible" (Seligman, 2002, p. 4). Six virtues and 24 signature strengths were identified by canvassing historical, current and cross-cultural text, from Aristotle's writings and philosophies to values identified as beneficial in the Harry Potter series by J. K. Rowling. Peterson and Seligman defined virtues as "the core characteristics valued by moral philosophers and religious thinkers" (Peterson and Seligman, 2004, p. 13) and a signature strength was defined as the psychological components which contributed to the development of a virtue, and therefore presented various passages to realising the good life. Each individual strength was included in the *Virtues in Action Classification* (VIA) if it was considered to be valued in most cultures and met the following criteria:

- it is present in a range of the individual's behaviours, thoughts, feelings, and actions, generalisable across situations and times;
- it contributes to fulfilment of the good life for self and others;
- it must be morally valued in its own right;
- displaying the strength does not diminish others, but may rather benefit them;

- larger society provides institutions and associated rituals for cultivating these strengths and virtues;
- it can be measured;
- it can be distinguished from other character strengths (Hefferon & Boniwell, 2010).

It is important to note that strengths were not intended to be considered as individual categories, but rather as points on a continuum of individual difference which are stable yet open to influence by an individual's environment (Peterson & Seligman, 2004).

The finalised strengths and virtues in the *VIA* (as shown in Appendix B) are proposed to have an important influence on both how an individual copes with challenges, and achieves eudaimonia (Peterson & Seligman, 2004). For example, through research validating the VIA Inventory with adolescents (2006) and examining signature strengths in the workplace (2009) Park and Peterson identified that strengths such as hope, kindness, social intelligence, self-regulation and perspective in particular buffered against negative effects of stress and trauma.

In 2006 Park, Peterson and Seligman used the VIA to survey over 110,000 people across fifty-four nations. Through this survey it was found that internationally the most prevalent signature strengths, in descending order, were kindness, fairness, honesty, gratitude and judgment. However the commonality of a signature strength is not believed to be synonymous with wellbeing as according to Crosno, Rinaldo and Black, (2009) certain signature strengths can either ameliorate or aggravate a person's difficulty depending on their context.

Signature strengths are believed to colour an individual's perception of an event (Beaver, 2008) a factor which previously mentioned research (i.e. Weiss et al. 2013) suggests can have positive protective qualities for a caregiver of a child with an ASD. Park, Peterson, and Seligman (2004) studies of 5,299 individuals recruited through the internet to explore the connection between signature strengths and life satisfaction (a core component of wellbeing [Dulcan, 2009]) and found the signature strengths most positively associated with life satisfaction in descending order were: hope, zest, gratitude, curiosity and love. A more recent study in the United Kingdom by Proctor, Maltby and Linley also identified the same top five strengths as significant predictors of life satisfaction, however noted a slight change in order to (in descending order): hope, gratitude, love, curiosity and then zest (2011).

Unique signature strengths make up as a whole an individual's distinct character which is proposed to be shown in that individual's thoughts, feelings and actions, malleable across the lifespan, subject to the influence of context, and importantly – measurable (Park & Peterson, 2004). When considering how one caregiver may withstand the impact of stigma by association better than another with the aid of signature strengths, it seems natural to start by examining those signature strengths which have been shown to have the strongest correlations with wellbeing. As exploration of all five of the above mentioned signature strengths is beyond the scope of this research, three were chosen as the focus of this study. These were hope, gratitude and curiosity.

Hope

The construct of *hope* has been discussed across centuries of literature and has been defined for many contexts and purposes. As this thesis examines hope as a signature strength, the definition of hope as included in the VIA classification will be used where hope is: "expecting the best in the future and working to achieve it; believing that a good future is something that can be brought about" (Park, Peterson, & Seligman, 2004, p. 606). Hope is of particular interest to this research for a number of reasons. Firstly, as mentioned above, the hope signature strength is consistently associated with wellbeing. Research on hope has shown this construct can contribute to improved outcomes in areas such as education (e.g. Curry, Maniar, Sondag, & Sandstedt, 1999), physical health (for instance adjustment following spinal cord injuries; and engagement in health promotion, [Elliott, Witty, Herrick, & Hoffman, 1991; Floyd, & McDermott, 1998]), and psychological agency and adjustment (Kwon, 2002; Snyder, et al., 1996; and Tennen, & Affleck, 1999).

Secondly, hope is theorised to be future oriented, motivating individuals towards action (Hefferon & Boniwell, 2010). Literature supports this theory, with a number of examples from parenting and caregiving research linking hope with wellbeing. For example Kashdan and colleagues (2002) asked 252 parents of children with externalising disorders to complete questionnaires exploring their experience of hope and optimism in the face of the stress of raising their child. Their findings indicated that hope significantly predicted healthy psychological functioning. In one study on the stress experienced by 88 women caring for family members with Alzheimer's disease, Irvin and Acton (1997) reported that the relationship between stress and wellbeing was mediated by hope. In research on hope and worry in mothers of children with an ASD (*N* = 199) or Down syndrome (*N* = 60), Ogston, Mackintsoh and Myers (2011) reported that mothers with higher hope reported lower worry.

Based on previous research and theory it is proposed for the purpose of this study that hope as a signature strength can support the wellbeing of a caregiver facing stigma by association by encouraging a future focused and action oriented approach to life (both positively associated with healthy coping.)

Gratitude

Gratitude is defined in the VIA classification as "being aware of and thankful for the good things that happen; taking time to express thanks" (Park et al., 2004, p. 606). As a signature strength, gratitude is thought to reflect an ability to perceive benefit from someone or something (Peterson & Seligman, 2004). Gratitude has a long history within the fields of philosophy and religion yet has received relatively little attention in psychological wellbeing research. As a signature strength gratitude, like hope, is included in this research due to its consistent finding as positively related to wellbeing (i.e. Proctor, Maltby & Linley, 2011 and Park, Peterson, & Seligman, 2004). For example gratitude has been found to increase positive energy, improve cardiovascular and immune functioning, and potentially increase longevity (Emmons & McCullough, 2003; McCraty, Atkinson, Tiller, Rein, & Watkins, 1995; Snowdon, 2001).

Gratitude as a signature strength is theorised at an individual and interpersonal level to foster positive emotions, experiences, and personal growth (Peterson & Seligman, 2004). Examining gratitude and its relation to positive emotions and depression Lambert, Fincham and Stillman (2012) examined questionnaire responses of 2,973 participants over eight studies. Their findings suggested gratitude promoted both positive emotions and positive reframing, which helped to reduce depressive symptoms. Using a questionnaire method to study the coping styles of their 236 participants, Wood, Joseph and Linley (2007) found that gratitude correlated positively with active seeking of emotional and instrumental social support, and was associated with positive reframing, growth, approach-oriented problem solving and active coping. Extending this research, Wood, Maltby, Gillet, Linley and Joseph (2008) used a longitudinal study of undergraduate students to investigate the role of gratitude in the development of social support, stress and depression. Their findings suggested that the presence of gratitude protected individuals from stress and depression and fostered social support.

Examining gratitude in the interpersonal domain, McCullough, Emmons and Tsang (2002) studied the disposition towards gratefulness of 238 adults. Results indicated that participants

who rated themselves and were rated by others as most grateful tended to be seen as more helpful, supportive, forgiving, empathic and agreeable. Similarly, using a sample of 427 Chinese undergraduate students Kong, Ding and Zhao (2014) reported that students with high gratitude scores were more likely to receive greater social support. Research suggests gratitude supports an individual to achieve improved wellbeing through positive reframing which increases positive emotions and social support. Given gratitude has been theorised to encourage positive reframing which has been linked with improved wellbeing for caregivers of children with an ASD (Weiss et al. 2012), and increased social support - identified as able to decrease the impact of stigma by association for this population (Gill & Liamputong, 2011; and Mak & Kwok, 2010) gratitude as a signature strength is theorised to act as a protective factor for caregivers facing stigma by association.

Curiosity

For many the term curiosity will bring to mind the popular phrase 'curiosity killed the cat,' however in psychological research this construct suggests possibilities which are far from life limiting. In the VIA classification of signature strengths, *curiosity* is defined as "taking an interest in all of ongoing experience; finding all subjects and topics fascinating; exploring and discovering" (Park et al., 2004, p. 606). In particular it has been proposed that curiosity encourages individuals to take an approach oriented position on new experiences inspiring an individual to embrace challenges as an opportunity to acquire new information and learning. It is for these particular elements, its' steady presence as one of the top four signature strengths, and evidence of its' positive role in the social realm that curiosity has been chosen as a focus in this study. Curiosity is believed to be one of the most commonly found signature strengths (Peterson, Ruch, Beermann, Park, & Seligman, 2007; and Linley et al., 2007), however in spite of its prevalence, the potential of curiosity's abilities as a protective factor have largely been ignored.

Current theories of curiosity suggest this strength improves wellbeing by extending the individual's capacity to self-initiate life enhancing activities, appraise experiences and environments for the potential for novel information and understanding, and seek new information and challenges (Kaczmarek, Baczkowski, Enko, Baran & Theuns, 2014; and Kashdan et al., 2013). Existing research exploring the experience of individuals experiencing adversity have identified curiosity as positively correlated with positive subjective experiences, general positive affect, willingness to challenge stereotypes, recovery from illness, greater sense of meaning, and pursuit of growth (Kashdan, Rose, & Fincham, 2004; Kashdan & Steger,

2007; McCrae & Costa Jr., 1997; and Peterson, Park, Pole, D'Andrea, & Seligman, 2008). The curious individual's ability to initiate growth behaviours and invest more cognitive resources in understanding their experiences (and reframe and re-appraise as required) counteract a focus on negative aspects of life – a risk factor for depression (Baumeister, Bratslavsky, Finkenaure, & Vohs, 2001) and discourages intolerance of uncertainty – a risk factor for anxiety disorders (Dugas, Gosselin, & Ladouceur, 2001). In a study of 91 Spanish university students, Gustems-Carnicer & Calderson (2015) found curiosity positively correlated with cognitive problem-focussed coping (and therefore wellbeing), which was theorised to help students through active, direct and goal oriented adaptation to situations of stress.

Of particular relevance to this study, the curiosity signature strength has been found to benefit individuals within social encounters. Research into curiosity and its influence in social interactions has shown that individuals high in trait curiosity are more open and receptive to experiences in the present moment, and tolerate deviations from expected responses instead of allowing the past to colour their perceptions and reactions (Langer, 1992). They have also been found to experience greater positive emotions and closeness during initial meetings with strangers (e.g. Kashdan, McKnight, Fincham and Rose 2011), and greater satisfaction and social support in existing relationships (a protective factor against stigma by association for caregivers of children with an ASD; Burpee & Langer, 2005; Gallagher & Lopez, 2007). For instance, Berry, Willingham, and Thayer (2000) conducted a daily diary study of young adult members of 131 friendship dyads over four weeks and found that those reporting high levels of curiosity reported less conflicts, less defensiveness, and a greater willingness to forgive an associate's transgressions. Given that individuals with high levels of curiosity are theorised to actively explore and seek to understand rather than avoid difficulties in interpersonal relationships, it is theorised for the purpose of this study that caregivers who experience stigma by association and also report comparatively high levels of curiosity will experience better wellbeing.

In summary, growing evidence shows that individual signature strengths can buffer against the negative effects of stress, preventing ill health in their wake (Park & Peterson, 2006). The protective powers of signature strengths have been tested in relation to education, employment and youth resilience with positive effects. Of relevance to caregivers of children with ASDs who experience stigma by association, signature strengths such as hope, gratitude and curiosity have been linked to known protective factors such as approach oriented coping

styles, increased social support, and positive re-framing. It is therefore theorised that caregivers who possess signature strengths such as hope, gratitude and curiosity will experience greater wellbeing due to protective factors associated with these signature strengths.

Chapter Five:

Positive Outcomes for a Caregiver of a Child with an ASD?

"My daughter has given me a special opportunity to confront my weaknesses and make them my strengths." (Rise, 2016)

The basic premise of positive psychology is that to be happy an individual requires more than the identification and treatment of their problems; they require the promotion of optimal lifelong development. Evidence is accumulating that signature strengths play an important role in this development, not only as broad protective factors, preventing or decreasing problems, but also as enabling conditions that promote thriving. Research readily suggests that having a child with an ASD contributes to reduced wellbeing; however what this research also tells us is that many caregivers manage also to maintain their wellbeing. A number of theorists now acknowledge that stressful experiences do not always result in negative outcomes; some people may experience positive shifts generated in part by changes enforced by a stressful experience (Somerfield & McCrae, 2000). As mentioned earlier, wellbeing is avoiding ill health (via protective factors), encountering positive experiences and engaging in personally meaningful pursuits (growth). So far this review has concentrated on potential protective factors of caregiver wellbeing in the face of stigma by association, but what about positive experiences and growth? Over the past ten years there has been a noticeable shift within the literature towards recording positive experiences reported by caregivers of children with disabilities. From the handful of research available (mostly of a qualitative nature) the positive outcomes experienced by caregivers of a child with an ASD are summarised below.

Caregiver Growth Associated with Raising a Child with an ASD
Exploring whether not only protection of wellbeing, but also gains in wellbeing are possible for caregivers of children with ASDs Bayat investigated what families of children with autism believed contributed to them gaining strength in spite of adversity (2007). Results from this retrospective survey of 175 parents suggested that those who used internal processes such as attributing positive meaning to disability showed greater wellbeing. Similarly, Pottie and Ingram (2008) have provided evidence that caregivers can not only protect, but improve wellbeing. Their 12 week daily diary study of 93 parents showed that those participants who used positive reframing of their experiences with their child noted an increase in daily positive mood. In perhaps the largest research study noting positive parental experiences, Myers, Mackintosh and Goin-Kochel (2009) asked 493 parents to answer the open-ended question: *"how has your child in the autism spectrum affected your life and your family's life?"* Out of

the 24 total resulting themes, 9 were deemed positive. Of these nine themes, positive emotions were noted as important benefits arising from the caregiving experience, and included feelings such as compassion, tolerance, patience and joy. Further studies since this time have also noted positive emotions as important benefits. These emotions also included joy experienced through seeing their child grow, laugh, and develop, as well as hope, love, and optimism (Altiere & von Kluge, 2009; Bultas & Pohlman, 2014; Ekas & Whitman, 2011; and Kayfitz, Gragg & Orr, 2010).

Myers and colleagues also reported that parents experienced an increased sense of appreciation (or gratitude) through their experience of caring for their child (2009). Specific to this study, gratitude was directed towards an appreciation of the unique qualities of the child with an ASD, a finding reflected in results of an interview study by Altiere and von Kluge (2009).   In this and related studies, gratitude also extended past the experience of ASD. Parents spoke of appreciating the value of life, personal wellbeing, other people's experiences, diversity, and "the little things" (Altiere & von Kluge, 2009; Bayat, 2007; King, Zwaigenbaum & King 2006; Myers et al., 2009; and Zhang, Yan, Barriball, While, & Liu 2015). These experiences of appreciation and positive emotion are theorised to be important for caregivers, not only for their ability to elicit pleasure from the experience on that occasion, but the ability of positive emotions to encourage sustained caregiver wellbeing (for example Ekas & Whitman, 2011; and Kayfitz et al., 2010).

Fredrickson (2001) talked about how the experience of pleasure can encourage longer term wellbeing in terms of the broaden-and-build theory. The broaden-and-build theory proposes that when people experience positive emotions such as joy, hope and optimism, this broadens their awareness of a range of cognitive, perceptive and action options, whereas negative emotions narrow this range. Therefore in contrast to negative emotions, positive emotions are believed to lead to a broader thought-action repertoire, thereby promoting cognitive and behavioural flexibility and increased ability to identify available opportunities. This helps build upon the individual's intellectual, physical, emotional and social resources which in turn increase the likelihood of future positive emotions and the availability of resources over time (Gable & Haidt, 2005). In short, positive emotions enable the identification and utilisation of personal and environmental resources, which lead to further positive emotions, triggering an upward spiral towards wellbeing over time (Cohn & Fredrickson, 2009).

Experimental studies have provided evidence to support the above broaden-and-build theory. For example Fredrickson and Branigan (2005) found that by inducing positive emotions they could increase a participants' scope of visual attention and thought-action repertoire. Further research has shown that positive emotions can enhance an individual's creativity and sense of other's emotions (Rowe, Hirsh, & Anderson, 2007; and Waugh & Fredrickson, 2006). In a longitudinal study Fredrickson and colleagues (2008) randomly assigned working adults to engage in a loving-kindness meditation. Results indicated that this practice increased daily experiences of positive emotions which in turn increased the individual's mindfulness, purpose in life, social support, decreased symptoms of illness and predicted increased life satisfaction. Findings such as those noted above suggest that the frequent experience of positive emotions does in fact lead to more successful and enhanced outcomes and increased wellbeing for an individual.

Whilst there is no specific research on whether caregivers of children with an ASD do experience the broaden-and-build phenomena, qualitative research exploring the experience of these caregivers suggests they experience growth (a byproduct of the broaden-and-build process). For example, caregivers in a study by Altiere and von Kluge (2009) spoke about experiencing enriched relationships including family cohesion and friendships, spousal relationships, and relationships with the child. Caregivers also reported enhanced quality of career and spirituality.

Not only have research participants noted growth in relationships and life experiences, there have also been references to how caregivers have developed new skills, or greater capacity as individuals. One of the most commonly documented gains noted by caregivers is in capacity for patience (Altiere & von Kluge, 2009; Myers et al., 2009; Nurullah, 2013; and Zhang et al., 2015). Potentially aiding, or stemming from this capacity parents have also noted growth in their ability to be aware of, accept, and show compassion towards individual difference and disability (Altiere & von Kluge, 2009; Kayfitz et al., 2010; Myers et al., 2009; Nurullah, 2013; and Zhang et al., 2015). Caregivers have also reported they had advanced their parenting skills, gained a sense of maturity from the experience of raising a child with an ASD, developed self-awareness and confidence in their own ability to manage wider life challenges and had gone on to advocate on behalf of those with ASD and their families (Altiere & von Kluge, 2009; Bultas & Pohlman, 2014; Depape & Lindsay, 2014; Nurullah, 2013; and Zhang et al., 2015).

Perhaps most significant for enduring caregiver wellbeing, research has shown that some primary caregivers can and do gain a new sense of purpose and meaning for their own life (eudaimonia). Most recently, Bultas and Pohlman conducted an interview study with mothers of preschoolers with an ASD (2014). Through this study the researchers examined the possibility of a *'silver lining'* despite the adversities associated with parenting a child with an ASD. Mothers in this study identified that having their child added a purpose and helped create meaning as it helped them focus on what they felt was most important in their life. Other studies of caregivers with children who have an ASD have also noted these opportunities or developments. For example Altiere & von Kluge's (2009) study elicited talk about how parents had to develop a new meaning of what it meant to be a mother. Participants in Bayat's (2007) questionnaire study of 175 parents of children with an ASD identified the ability to make positive meaning of the disability as a strength in caregivers, perhaps connected to the experience of gratitude described earlier. Altiere and von Kluge's (2009) study of 52 parents also reported that they found their experience with their child helped them identify life priorities, a finding reflected by a similar qualitative study by King and colleagues (2006).

Research encompassing the positive experiences or benefits of raising a child with an ASD is in its infancy. Existing research suggests that primary caregivers of children with an ASD can not only protect their wellbeing, but have positive emotions and encounters, experience growth in personal skills, interpersonal skills, relationships, spirituality, and a sense of meaning. Fredrickson's (2001) broaden-and-build theory suggests that positive experiences such as these will lead to greater wellbeing through an upward spiral. This study addresses and assesses factors which decrease caregiver wellbeing (including stigma by association), and utilizes a positive psychological perspective to examine ways in which wellbeing could be protected (i.e. via signature strengths). The opportunity will also be taken to see whether, in spite of all the documented negative experiences associated with raising a child with an ASD, a caregiver can in fact experience increased wellbeing, or growth as a byproduct of parenting their child.

Chapter Six:

Introduction to the Present Research

"They judged us before they got to know us"

(Bevan-Brown, 2004, p. 29)

The preceding chapters have shown that for children living with an ASD, life contains many challenges. As a consequence the child's primary caregiver can face additional stressors which can subsequently lead to negative effects on caregiver wellbeing. Some research documenting the experiences of these caregivers exists, however most research neglects to include the stress induced by stigma by association, reportedly encountered by the majority of parents. The research that does take this stressor into consideration is thus far mainly qualitative, looks at mother's experiences and does not include the NZ population. There appears to be even less information on potential strengths these caregivers possess. The near absence of information in these areas led to the development of this research study.

A sequential mixed-methods design was employed to enable exploration of stigma by association and growth from multiple angles. The first study was a qualitative interview study (Study One: Exploring Caregiver Experiences of Raising a Child with ASD, Stigma By Association, and Growth in New Zealand) which aimed to access NZ caregiver perspectives on:

1) challenges encountered by unpaid primary caregivers (male and female) of children with ASDs;

2) whether stigma by association is encountered by and affects the wellbeing of NZ caregivers of children with ASDs; and

3) whether caregivers can recognize ways in which they have grown as a byproduct of their experience raising their child.

Once common challenges caregivers face were identified, further understanding had been gained on experiences of both stigma by association and growth in NZ caregivers, and convergence with current research assessed Study Two was completed. Study Two (Surveying the Experience of Stigma by Association, Wellbeing, and Growth in Caregivers of Children with ASDs) utilized a quantitative survey methodology to build on findings from Study One. The goal was to examine a cross-section of participant perspectives from across NZ to develop a current understanding of the effect of stigma by association on caregiver wellbeing.

In addition, research in the area of positive psychology has shown that an individual's unique signature strengths (which are not fixed and can develop over time) have the ability to protect wellbeing. As previously noted, the signature strengths of hope, gratitude, and curiosity may possess important qualities which can help a caregiver maintain wellbeing in the face of stigma by association. Therefore Study Two also aimed to:

4) examine whether signature strengths of hope, gratitude, or curiosity may help caregivers withstand the negative impact of stigma by association on wellbeing.

Finally, as research has hinted that caregivers of children with ASDs can not only maintain wellbeing, but potentially engage in personal growth, Study Two built on Study One findings to address the fifth research aim:

5) to explore whether, in spite of the challenges caregivers of children with ASDs face, a caregiver can experience growth as a byproduct of raising their child.

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

SECTION TWO

Chapter Seven:

Study One: Exploring Caregiver Experiences of Raising a Child with ASD, Stigma By Association, and Growth in New Zealand

"Don't judge a person until you've walked two moons in their moccasins"

(North American Native proverb)

The present study aimed to explore the experience of caregivers raising children with an ASD in NZ in order to understand the experiences of caregivers which may be relevant to the larger Study Two. The study outlined and discussed in the following section collected qualitative data through interviews with primary caregivers of children with an ASD. The goal was to source rich and in-depth knowledge of participant perspectives on their social and personal experiences. The specific aims of this study were to:

   a. examine whether caregivers of children with an ASD in NZ experience similar challenges to those already identified in international research,

   b. identify whether the phenomena of stigma by association is present in the NZ context, and

   c. explore the possibility that caregivers experience growth as a byproduct of raising their child.

Thematic analysis (Braun & Clarke, 2006) was used to uncover themes central to the three research aims above. At the time of writing there was limited research available on the experiences of caregivers raising children with an ASD in NZ, and internationally research on this experience was mainly limited to the experience of mothers. This study aimed to fill the gap in knowledge and provide valuable insight into the experience of raising a child with an ASD in the NZ context.

Method

   Participants

For the purpose of this study the sample consisted of people who identified as a primary caregiver of a child with an ASD living in the Wellington region. The six primary caregivers (four women and two men) who participated in this study were aged between 38 and 49 (M = 43, SD = 4) and identified with a range of ethnicities including American, Australian, European, Italian, Maori and NZ/European. Their children were five males and one female aged between 7 and 14 years old (M = 10, SD = 2.96).

Recruitment

During the month of June 2013 five associates (work colleagues, friends of family, and friends of friends) known to the researcher who had children between the ages of 2 and 18 years old with an ASD were contacted via email or phone and invited to participate in this study. Of five initial contacts, four were available to participate. Further participants were recruited using snowball sampling by asking participants to pass on details of the research to other caregivers who may be interested in participating. A further two participants contacted the researcher expressing interest and were subsequently interviewed. Acceptance for interviewing was in order of response. Initial plans were to interview eight participants. Due to time restrictions and as data saturation was reached, the decision was made to end interviewing after six participants. Supporting this decision, Morse (1994) theorised that for phenomenological research, at least six participants must be interviewed to achieve data saturation. Ethical approval for this research was gained through Massey University Human Ethics Committee: Southern A (Application 13/28, 10.06.13 see Appendix C).

Procedure

Potential participants who showed interest in the study were sent an email containing the semi-structured interview schedule, information sheet and consent form (see Appendix D, E and F). As research participation was voluntary each potential participant was reminded that they had the right to decline participation. Once a caregiver agreed to take part, each was asked to identify their preference of interview location between a private and confidential neutral space (a private university office) or at the participants' home. Open ended questions (see Appendix D) were pre-developed to focus on positive and negative experiences of life with a child with an ASD and to allow dialogue to be relatively free flowing so the participant could share experiences most pertinent to their experience. Before each interview participants were given the opportunity to ask questions and signed consent forms. Each interview began with questions about the participant's motivation to take part, and about the child they would refer to today. This was done in an attempt to give people the space and time to talk about any topics or issues they felt were relevant to their experience and their child, rather than immediately focusing on what the researcher wanted to know.

Interviews ranged between 48 and 62 minutes long, and were digitally audio recorded (using a Sony IC Digital Voice Recorder) to remove the need for note taking (intended to encourage more free flowing discussion). Each participant was given the opportunity to debrief at the end of the interview and provided with a $20 supermarket gift card as an acknowledgement of

the time and efforts of the participant. Each participant was sent a copy of their individual transcript within 1-2 weeks of the interview, asked to check the transcript for accuracy, and correct statements they believed were inaccurately recorded. No changes were made by participants.

Analysis

Each interview was transcribed verbatim (using Express Scribe Pro 5.56; NCH Software, 2013). The files were stored on a password-protected drive, and used numerical codes to replace participant names. Thematic analysis (TA), as outlined by Braun & Clarke (2006), provided a logical framework for analysis of transcripts in line with this study. The data was analysed based on semantic meaning, using surface-level interpretations of the data to preserve participant representations of their experiences, in keeping with the phenomenological approach (Braun & Clarke, 2006). Themes were established based on a system of coding, noting frequently mentioned themes, meanings, or experiences, and then placing these into meaningful groups. Each meaningful group was checked in relation to the main research questions, and, based on these, organised into potential themes. Following this, a process of reviewing and analysing connections between the potential themes was undertaken. This involved condensing some themes, while expanding others. Themes were defined as needing to cohere meaningfully, be consistent, and hold clear distinctions between them (Braun & Clarke, 2006). The primary research supervisor was consulted to ensure thematic and data validity. An overall picture of primary caregivers' experiences was established by viewing and reviewing codes, meaningful groups, and themes.

The following results of Study One present key themes identified during analysis of interview data during which caregivers spoke of their reality raising a child with an ASD. Detailed transcription is not included in the extracts (e.g. non-verbal information, and intonation). In order to ensure anonymity of participants all caregivers and their children have been allocated pseudonyms and potentially identifying names and locations changed.

Chapter Eight:

Study One Results

"It certainly changes your outlook in a variety of ways."

(Harvey, Study One Participant)

Thematic analysis identified two overarching themes identified in participants' talk about their experiences. The majority of conversations focused on the difficulties of life as a caregiver of a child with an ASD. Subsequent themes related to this focus will be covered under the overarching theme *"having a child with an ASD is hard."* Caregivers also shared ways in which they believed they had benefited from their experiences with their child; these positive experiences are summarised under the overarching theme *"having a child with an ASD is not all bad."*

Having a Child with an ASD is Hard

"Definitely it is two sided I think, what doesn't kill you makes you weaker."

(Harvey)

Following initial questions the interview moved on to address the first aim of this study, finding out more about the experience of having a child with an ASD. The question posed was: "has your life changed since you found out (child's name) has an ASD? If yes, how?" In every single interview the participant inevitably spoke about how *"having a child with an ASD is hard,"* and how, when their child's ASD traits became apparent, so too did unexpected challenges and complications.   However, simultaneously participants took great pain to ensure that I, the interviewer did not think that when they talked about their dislike for autism, I did not confuse this as a dislike for their child. I too wish to ensure that you, the reader, also do not fall prey to this confusion and so, in reading the following section I hope you can take on the perspective of Kath:

> When I say these things I don't pin them to him. I'm very; in my way of talk I say
> that's the effect of autism, not him. He's him and the autism is this. (Kath)

When speaking about how having a child with an ASD is hard, participant talk could be summarized by three themes as outlined in Figure 8.1; *practical restrictions, personal costs,* and *social stigma.* These themes are examined in detail in the following section.
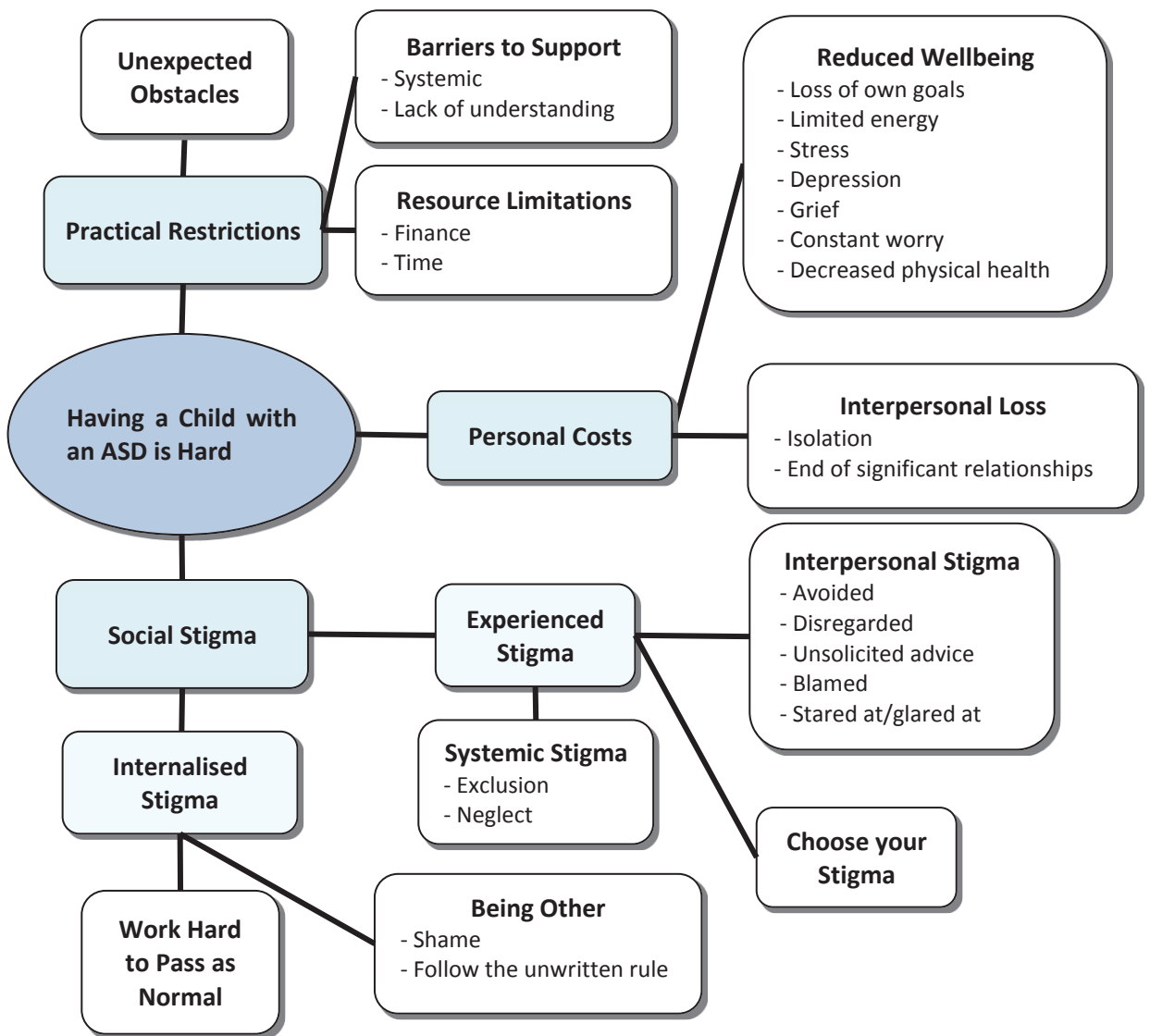
Figure 8. 1. Thematic map showing themes related to how caregivers identified having a child with an ASD is hard

Practical Restrictions

"You also lose the ability to do things."

(Harvey)

As discussed in previous chapters, raising a child with an ASD places a heavy demand on family resources. Practical restrictions as a theme was developed to represent three subthemes reflecting the difficulties caregivers reported facing within their day to day routines. These subthemes: *"unexpected obstacles,"* *"resource limitations,"* and *"barriers to support,"* are expanded on next.

Unexpected Obstacles

The subtheme *"unexpected obstacles"* was developed to represent difficulties mentioned by all participants when speaking about how ASD had an unanticipated effect on their lives. These difficulties were ways in which caregivers mentioned being unable to meet their own objectives (be it a family holiday, daily errands, or taking care of their child) as a consequence of their child's difficulties. For instance Harvey spoke about his daughter's difficulty understanding safety and dangers. This difficulty lead to restrictions for the wider family in order to keep her safe:

> *You also lose the ability to do things, partly because of the limitations that are imposed on your, you know, you have to cater for your child's needs, so you won't be able to go on your particular holiday or do particular things.* (Harvey)

Nicky found that her son's behaviour meant they had difficulty visiting places away from home:

> *It's the thing that makes it hard is him being in another environment that we can't control, you know, like we're at somebody's house and they've got all their, you know, trinkets or anything. You know, he just comes along and sweeps them off, or he runs through the house with food or, you know, like we can't control that. And it's just really difficult to do.* (Nicky)

Kath spoke about how her son's behaviour led to a long period of isolation in order to manage his behaviour:

> *I spent like 18 months where we couldn't go out because if I took him somewhere he'd be violent, he'd attack other children.* (Kath)

Caregivers also spoke of the obstacle created by their child's difficulty with communication, in particular speaking about how a relatively straight forward situation for a typical parent can be hugely complex for a parent of a child with an ASD:

> *… having a conversation with him isn't possible… that can have its frustrations, if he's sick it's incredibly difficult to find out what's wrong with him.* (Shane)

As can be seen above by this sample of examples, there were many instances described by caregivers where extra care, caution, and effort was required above and beyond typical parental duties when raising a child with an ASD. These challenges were additional to those experienced when raising a child without an ASD, and limited the caregiver's ability to engage with life in ways society would typically expect.

Resource Limitations

Caring for a child with an ASD is said to require extra caregiver attention and effort. The weight of the previously noted unexpected obstacles can be exacerbated by further limitations associated with caring for a child with an ASD. *"Resource limitations"* which presented when a child has an ASD appeared to be a significant issue, noted to be heavily emphasised by participants throughout the interviews. Major resource limits spoken about by participants were in the form of finance and time. Time limitations were mentioned directly by half of the participants, and referenced by all. For instance Harvey spoke of how difficulties caused by the ASD took time (which was already limited) to manage:

> *It [autism] added a lot of hours to our day and we didn't have a lot to spare.*
> (Harvey)

Bridget spoke about how this extra time spent managing the ASD had negative implications for her family's social wellbeing:

> *We sort of, we are a lot less social than we would be if Ethan wasn't autistic…*
> *because you know we don't have time to organise or to invite people to our place.*
> (Bridget)

Whereas Kath noted that if not for an understanding employer, the substantial time requirements of having a child with an ASD would have had serious employment consequences:

> *Um I've had to have flexible work so that if there's an issue I can be free to go*
> *resolve that… so if I've got a three o'clock meeting to discuss his individual*
> *education programme, well that's two hours of my work day gone. And luckily I've*
> *got a good employer.* (Kath)

Financial strain was referenced explicitly by four participants. Financial stress was linked to the costs of providing unfunded gold-standard therapies for two participants in this study, for example:

> *Therapy has probably cost me six or seven thousand dollars to be able to do this,*
> *so financially it's a huge stress.* (Kath)

For other participants costs which attributed to financial strain were more obscure, for example, Teresa, whose other son also had ASD traits stated:

> *My boys can't share [a bedroom] you know because they will just kill each other*
> *probably, but they just can't share a room... So even, the impact on my life is that I*

> *need to have another hundred dollars a week because I need to go and rent a four*
> *bedroom house rather than a three bedroom.* (Teresa)

We as a society often note the struggle to find enough time and money to satisfy our needs, yet it appears caregivers of children with ASDs feel this strain even more so. While raising a child logically comes with time and financial burdens, it appears these burdens are much more prominent for caregivers of children with ASDs, and as follows are often exacerbated by the further practical restrictions these caregivers encounter.

Barriers to Support

Caregivers also spoke with noticeable frustration about how when they attempted to access support or assistance - on top of experiencing limited resources - they encountered further access barriers. Key barriers identified could be organised under the themes *"systemic"* and *"lack of understanding."* The two systems spoken about by participants were the health and education systems. Four of the six participants spoke about how difficult they found accessing developmental support for their child, and how unresponsive they found the public health system, for example:

> *Getting support was next to impossible. We got a private diagnosis through a*
> *pediatrician when he was three. And then we went to the hospital, the hospital*
> *didn't so much as give us a pamphlet and told us to come back in twelve months*
> *because there was a waiting list at the time.* (Harvey)

All but one of the participants shared their dissatisfaction with support access processes provided by the public education system. The following excerpt about Shane's experience accessing the special education funding support process (ORS; Ongoing Resourcing Scheme) reflected the experience of most:

> *We went through the process of applying for ORS funding, which is an extremely*
> *lengthy and stressful process…* (Shane)

Harvey spoke about his experience with the education system's early intervention process:

> *The Ministry of Education has an early intervention team which is rather*
> *optimistically named. They did an initial assessment very quickly. They don't*
> *operate on a, they don't need a diagnosis to start working, which is great. They*
> *operate on need. But then they took nine months to swing into action, after those*
> *nine months they gave us [funding for] a [support] person and then it took*
> *another three months to find a teacher aid. So we lost a, we essentially lost a year*

at the time when you know, everyone, all the literature, everyone tells you you
need to start doing stuff. (Harvey)

Participants also shared how, because the public appears to know so little about the reality of ASDs, a further obstacle they faced was that of needing to educate people about their child's difficulties. All caregivers spoken to presented as understanding of the public's knowledge deficit, however also seemed fatigued by the burden of yet another task they had to manage. For example Harvey stated:

People don't just automatically understand these things. So maybe the kind thing
would have been to educate them as we have been educating on a lot of things.
But it takes energy and it's a hard thing to do and meanwhile you're dealing with a
lot of other things and so maybe you don't. (Harvey)

As can be seen in the results thus far, caregivers encounter an amplification of practical restrictions which some parents of typical children *may* encounter. It is therefore not unexpected that the effort required by these caregivers to navigate unexpected obstacles and barriers to support, and work around resource limitations would come at some sort of personal cost.

Personal Cost

Earlier chapters have provided an overview of literature identifying ways in which raising a child with an ASD can negatively affect caregiver wellbeing. Beyond the practical restrictions participants spoke of in results prior, all caregivers interviewed either directly mentioned, or indicated that the experience of raising a child with an ASD had come with a *"personal cost;"* the next theme identified during transcript analysis. The theme of personal costs represented frequently referenced talk about *"reduced wellbeing,"* and *"interpersonal loss"* which are subthemes under this theme.

Reduced Wellbeing

Participants generously shared their experience of how raising a child with an ASD impacted on their own wellbeing. Caregivers spoke about the detrimental effect on their energy, ability to live to their own values, physical, and psychological health. At least half of the participants spoke of how demanding the experience could be, for instance:

… you do have this ongoing challenge; it means you're actually a bit stressed out, a
bit tired all the time to deal with everything. (Harvey)

> *It's so ongoing, and it's every day, and there doesn't seem to be an end in sight.* (Nicky)

For some, the demands of the role meant they gave up on their own dreams and goals, for instance:

> *At various times in our lives we could have, we wanted to spend some time in Italy. When all the children were little that was the long term plan, but we know we can't do that because it took so long to get the support here that, to think of, you know, with getting support for a period of time over there and then coming back here and then regaining it from over here; that's just too much.* (Harvey)

One participant stated that at times their stress levels were so high they experienced distress:

> *It's very hard, it's very hard some days; and I get overwhelmed.* (Bridget)

Perhaps unsurprisingly, four of the six participants spoke of past and/or current difficulties with low mood and hopelessness:

> *Well, probably not a change for the better is that I now suffer from depression… But it was sort of a feeling that I went through. Well, and I've been through at times, not so much recently, but sometimes I'll just think, oh, my God, this is my life now.* (Nicky)

Harvey spoke about how his initial grief subsequent to his daughter's diagnosis did not pass:

> *I've heard it being described as a sort of, um, state of perpetual mourning… it certainly changes your outlook in a variety of ways.* (Harvey)

In addition to concerns about day to day life, caregivers also spoke about anxiety. For example in regards to his daughter's wellbeing Harvey stated: "I mean you worry, you worry a lot." All participants spoken to mentioned experiencing anxiety about their own, and their child's future, for instance:

> *I'm at an age now where you start thinking about retirement and all the wonderful things you're going to do when you retire. Trips you've got planned, places in the world you're gonna visit and so on, but, now I'm not sure how that will happen. I'm not sure if my son will be able to live independently from us, so, yeah.* (Shane)

Some worries were related to the child's ability to participate in society:

> *And I'll tell you that there's elements through the years that I've thought about - but that was clearly my own anxiety of projecting into the future - over a seven*

year old child thinking that he'll never get married, he'll never have a job, he'll never not live with us. (Bridget)

Finally, both directly, and likely as a consequence of the above consequences of raising their child with an ASD, caregivers noted their physical health had suffered. For instance Nicky said:

I've certainly neglected myself at times, you know, in terms of like seeking medical care and eating properly, you know. (Nicky)

Interpersonal Loss

The second subtheme included under the personal costs theme was that of "*interpersonal loss.*" Throughout interviews participants spoke of a variety of ways in which their social experiences were impacted by their status as a caregiver of a child with an ASD. Experiences shared included "*isolation,*" and "*loss of significant relationships.*"

Isolation was spoken about by four out of six participants. Nicky found that the change to her lifestyle in order to accommodate the ASD had reduced her ability to join social and family functions:

We used to be a family that maybe had a significant holiday every year. You know, maybe not the Gold Coast every year, but we might -- I don't know -- go to Auckland or, you know, or we would always be traveling to visit relatives, which we don't do at all anymore. Yeah, because, you know -- yeah, my family is really big on get-togethers, you know, and going to visit everyone. We just don't do that anymore. Yeah. (Nicky)

Participants in this study indicated that changes they endured subsequent to the difficulties of ASD entering their lives lead to the loss of significant relationships. Kath attributed the dissolution of her marriage to the stress of caring for a child with an ASD:

My relationship ended so I'm divorced, um I think in part due to the stress of that, which is, if you look at the research is very common.(Kath)

Teresa indicated she had lost friends, and perhaps also her marriage:

You lose your friends… socially a lot of people don't understand… even the impact for me like I kind of look at my life and think would I be in a different place physically and financially and possibly in my marriage? (Teresa)

Caregivers spoke of how they had noticed their experience raising their child had impacted on both their physical and mental wellbeing. Notably, a frequently referenced loss was that of important relationships. With so much interpersonal loss, and the apparent significance of this loss to the interviewed caregivers it is important to attend to what may fuel this loss, and whether social stigma is a key contributor.

Social Stigma

Another key theme identified as contributing to making life with an ASD hard was indeed *"social stigma."* Social stigma, as seen in the thematic map (Figure 8.1.) provides an overview of two key sub-themes representing experiences relayed by participants of: *"experienced stigma"* and *"internalised stigma."'* Each subtheme is described below.

Experienced Stigma

All caregivers spoken to as part of this study referred to instances where they had experienced stigma by association. These could be grouped into experiences of "interpersonal" and "systemic" stigma.

Interpersonal Stigma

Many of the participants recalled experiences where their status as a caregiver of a child with an ASD led to a loss of access to the interpersonal opportunities of parents of "typical" children. Some caregivers experienced avoidance (on top of their situationally imposed isolation):

> *If you've got a neuro-typical child then, you know, you get play dates all those*
> *things and you just go through life as normal; people look at you as a parent or a*
> *typical family. Now definitely people know that we have a child with autism, so all*
> *those things are not there.* (Harvey)

Bridget provided a further example of being avoided following an incident when her son accidentally 'outed' himself as having an ASD to other adults:

> *I noticed that for the remainder of that week they would not have eye contact with*
> *me or communicate with me.* (Bridget)

Kath said she was avoided by contacts and friends which she attributed to the prejudices they held about her son and herself:

> *Basically we probably lost a few friends on the way or the possibility of friends.*
> (Kath)

Participants spoke of many ways in which they were covertly and overtly disregarded in spite of their often high level of knowledge and experience in relation to managing the ASD. For instance, when speaking about an interaction with a teacher Teresa noted:

> *Sam was put into time out every single day for the first term. So I went in a few times, said "we really need to talk about this." I tried to be really good and use good language: "you're doing a really great job" and "I'm not really sure that this punishment strategy is where we need to go with Sam, he really doesn't respond well to that," "as a parent what can I be doing to support you to make sure that he's flourishing in the classroom?" She basically ignored me, wouldn't talk about it, it was all 'fine.'* (Teresa)

Caregivers also spoke of instances where, if they weren't being rejected or avoided, people would decide they were in need of unsolicited advice:

> *People say stupid things like "you know, if you parented differently," or "if you were stricter with him" or, yeah.* (Kath)

> *… all the different therapies people tell you to do like, "oh, take him off gluten," and "take out …" "if he's got any fillings, take it out."* (Bridget)

Some experiences portrayed greater stigmatisation, where people would voice their view about the caregiver's actions without consideration of other perspectives. These beliefs often placed the caregiver in the position of blame:

> *Finn will tend to roam or run so people go "oh, keep your child under control."* (Kath)

> *I had his child-care attendant tell me that he was slow in all his activities because I was babying him.* (Teresa)

Nicky and Kath both spoke about a more subtle form of stigmatisation noted by caregivers in this study, in the form of pointed looks and staring:

> *I can see it on their faces, you know, like "oh, what's going on there?" or, you know, and I just don't want to see that.* (Nicky)

> *I've had to tolerate a lot of stupidity, so people say things or people looking at you when you go out.* (Kath)

Systemic Stigma

Experiences of stigma by association at a systemic level were also relayed by a number of participants, in particular relating to their interactions with educational and health organisations.   One participant spoke of their experience with a school which represented a typical example of the type of exclusion of the child, family and caregiver's needs:

> We wanted Kieran to get into a unit, a special needs unit at the school, and it was full… so we said, well, he'll have to go into mainstream class then, and they were not happy. She [the deputy principal) made it pretty clear this was going to be a huge pain... I really felt just so bad after it, you know. I thought, god, you know, I just felt like all of it is a big nuisance and, you know, they'd be happier if we just went away. (Nicky)

Other experiences demonstrated how organizations perpetuated the interpersonal experiences of being ignored. Harvey contrasted his experience of child development services with the physical health services his son was provided with following his diabetes diagnosis in the following excerpt:

> Harvey: It [diabetes treatment] is all about social inclusion; it's all about leading a normal life and having all the social opportunities of every other. And because of that they're extremely practical, they [the health professionals] do everything in the beginning… you know, "be normal", "go out there and be normal," so removing obstacles in front of the individual for making as normal life as possible, this is what will happen.
>
> Interviewer: It seems quite a hopeful approach?
>
> Harvey: It's good, it's great, it works really well… So that, yes, that was strange because we kind of went through and we get all this support and it was amazing. And what in the hell we got with our other child and you sent us away without so much as a brochure for a year? We understand one issue is medical and potentially fatal but if you actually step back and you look at them as lives, you need to keep them both alive successfully, then you're still looking at what can you do to make this person's path as good as possible… The difference is very clearly felt; we're grateful that it's not as bad for Ben as it is for Melissa, but at the same time it's kind of galling.

Choose Your Stigma

All caregivers interviewed indicated they'd made efforts to avoid stigma by association, however some also spoke about how this effort came with the risk of falling prey to other

stigmas. For example one participant spoke about her difficulty deciding whether to conceal her child's stigmatized identity in the hope her child can pass as normal, but run the risk of looking like a bad parent if things go wrong, or reveal and hope for the best:

> *Do you tell someone that your kid has special needs and run the risk of this paternal low expectation response, do you not tell them and then wait until something wrong happens and then go "actually my child has autism?" And so it's a real bind as a parent and I often really have to toss up as to whether or not I go and speak to a school, or speak to the teachers before they see my child.* (Teresa)

Another caregiver spoke of feeling torn between ensuring their child was exposed to as many experiences as possible in their world (being a good parent) and ensuring he let others enjoy their own experience (being a good citizen):

> *Sometimes you think I should really do something with him, take him somewhere out in the world but you think, nah, fuck it, it's just too hard, it's too demanding, it takes too much energy. But then you feel bad that you think that, like you're just being lazy. But it's just hard – you're monitoring what he's doing, you're monitoring, um - how he's behaving and, as I say there's a sort of – why do I care what other people think? But then you think, other people have a right to be in the world without being disturbed or interrupted or, kind of, hassled by a kid doing weird shit. People go to a café, they have a right to be in a café and do their thing in a pleasant and uninterrupted way. I've got a right to be there too with my kid, but there's all those conflicting, you know social norms which, I suppose, are difficult to resolve.* (Shane)

Internalised Stigma

Study participants also spoke about many difficulties they experienced which indicated they had *"internalised stigma."* The most comments referenced examples were when caregivers spoke about experiences of *"being other,"* and times when they felt they had little choice but to "*work hard to pass as normal."*

Being Other

The experience of caring for a child with an ASD appeared to lead all participants to experience a feeling of "*being other.*" In relation to this positioning participants spoke about feeling *"shame;"* for example Bridget spoke about how she recognized her own shame whilst her son was happily being himself:

Last weekend we were with an exchange student that lives with us, he's an amazing hockey player and he had a home game and Ethan was off at one of the goal ends playing with a bouncy ball with his young sister. And he's sixteen years old, he's 6 feet 2 and he's playing with a bouncy ball you know, and I knew that people who would see him would think 'what was he doing.' Because he's this big boy playing with a bouncy ball with his little sister. I said "do you think that you would think it was weird if you were watching a game and then you looked over and you saw this big teenage kid playing with a bouncy ball with a little girl." And he said "well yeah I see what you mean but I'm just not interested in the hockey game, I don't understand it." And I thought well who's got the problem, it's me, and it's the rest of the people. (Bridget)

Several participants also made reference to their efforts to manage themselves and their experience of parenting their child with an ASD around others, as if they were following an unwritten rule:

I always try and monitor how much I talk about my kid, particularly if I'm talking about something difficult, or problematic, or whatever because you just don't wanna kind of wear out your welcome in terms of wearing out people's sympathy or empathy or whatever. (Shane)

Work Hard to Pass as Normal

Past experiences of not meeting their society's unwritten rules may have led to caregivers doing their best to ensure they and their children followed these rules, or passed as 'normal' as much as possible. One mother reflected on her awareness of this expectation, and how she and many other caregivers typically put great effort into fitting societal expectations:

"They've got good eye contact," "they don't say the most inappropriate things," "they're not flapping," and "they're not melting down all the time." I mean those classic symptoms we don't see those as much anymore because parents are so aware of them that we neuro-typically model those things out of our kids. (Bridget)

Caregivers also spoke of the extra personal resources the effort to pass as normal required. For instance Nicky spoke about her ongoing anticipation that her son would go against expectations:

Nicky: You know, because you're always on guard, I suppose, waiting for him to do
   something he shouldn't, you know.

Interviewer*: Yeah?*

Nicky*: I mean, that stuff is not major unless it's running on the road, you know,*
but yeah, we're trying to get him to stay seated while he's sitting at the table, you
know.

Caregivers spoken to during this study were courageous in both their willingness to share difficult experiences, and their enduring efforts to overcome the often significant barriers and restrictions (physical, psychological and social) to raise their child to the best of their ability. Yet in spite of their challenges, caregivers also spoke of positive experiences.

Having a Child with an ASD is Not All Bad
                    "It's a way of being, it's not a death sentence."

                              (Bridget)

Perhaps by the nature of the interview topic and how limited caregiver's opportunities to speak about their difficulties appeared to be - the majority of time during interviews was spent by caregivers speaking about the ways in which having a child with an ASD was difficult. However, every participant in this study could also identify a variety of ways in which they had grown as a result of having a child with an ASD. The key ways in which caregivers indicated they had changed came under the themes: *"positive emotions," "positive engagements"* and *"personal developments."* These 'ways' or subthemes are shown in Figure 8.2. and explained in the following section.

Positive Emotions
Ask any parent what the experience of raising a child is like and the majority will tell you it's hard. As has been shown in results thus far, caregivers of children with an ASD are even more likely to give this reply. But spend a bit more time listening to that parents' experience and you will likely also hear about intensified "*positive emotions."* The participants in this study spontaneously shared their own examples, threaded throughout their dialogue about their experience with their child; of strong positive emotions the most common of which became the themes of "*love,*" "*pride*" and "*gratitude."*
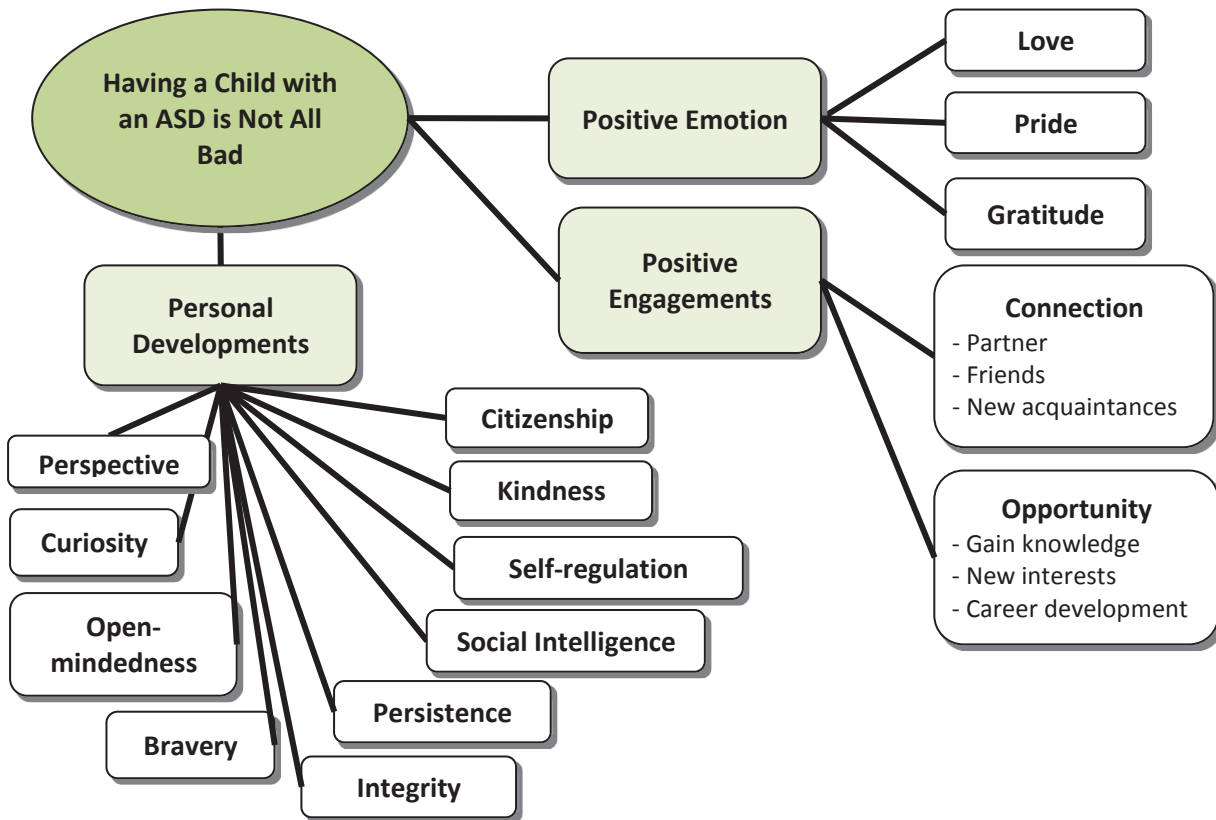
FIGURE 8.2. Thematic Map Showing Themes Related to how Having a Child With an ASD is not All Bad.

All participants shared examples of, and insights into, the "*love"* they possessed for their child. For example Bridget she referenced her love as a strong motivator when talking about how she avoided a trap she had seen other caregivers fall into of giving up on pursuing social activities when she felt judged by others:

> Interviewer*: Well actually that's interesting from my perspective. What was different for you that meant that you didn't go down that line?*
> Bridget*: I think I loved them so much that I just didn't care.*

At least half of the participants also indicated a sense of "*pride"* during moments when their child achieved something they had worked hard for, or superseded expectations. Bridget spoke of a recent example which demonstrated the emotion these caregivers experienced:

> *So my middle son Ethan, we took him skiing when he was ten – I'm going to cry – and we were up at Tongariro [ski-field] and we spent the whole afternoon. It took an hour and a half Katie to get his boots on. He was so uncomfortable but he was determined to get out on the hill. We finally get out there; we made it down in five hours three times. Everybody else went and did their own thing and it was just*

Ethan and I and we made it down that hill three times in five hours. And I kept thinking to myself in my neuro-typical brain "oh my God what a waste of time, what a waste of money," blah, blah, blah, "I'm not having any fun, he certainly couldn't be having any fun" and then I'd catch myself and go oh my gosh, look what he's doing, look what he's really trying, really capable of making this, difference. And his perception when we got on the ski lift at the end of the day and we were riding up - he said to me "mum now that I've mastered this hill the next time we come can we try a different one?" And I just started crying because to him the fact that he proved to himself that he could was all it took... the fact that he would do that gave me so much insight and incentive that if he was willing to do this thing that was so over the top for him, how much more could I do as his mother? Not only for him but for other people. (Bridget)

Five participants discussed how what to others could be seen as potentially insignificant experiences elicited positive emotions in them. For example Kath, when speaking of her ongoing difficulty managing her son's meltdowns expressed her gratitude for the kind gesture of a stranger:

We went to the mall one day, and he lost sight of me... he had a big meltdown in the middle of one of the toy shops in there, where we always go. We've done that for years, but because this doesn't make sense to people because he's big - and yet he was having this huge meltdown which of course is different to a tantrum. And the woman was just standing and looking at him going what the hell is this? And she goes to me "should I get him a glass of water?" And I said, no, it's okay. He's got autism. And she said, "oh, okay. What do we need to do?" and – and it was really - you get a lot of that. So I think people are kinder than not. (Kath)

Positive Engagements

"Positive engagements" was the next subtheme identified during analysis of transcripts. Common positive engagements spoken about by caregivers came under the themes of "*connection*" with others, and "*opportunities*."

Connection

In contrast to findings under the *"having a child with an ASD is hard"* subtheme *"interpersonal loss"* described previously, two participants indicated that the experience actually benefitted their relationship with their partner, for instance:

> *My husband and I, we've been pretty strong through this. You know, it's been*
> *really rough. But we've - yeah, we've really bonded together, I think, over it.*
> *Yeah… I think it's definitely pushed us together, I think, and made us stronger.*
> (Nicky)

Half of the participants also noted that the experience had lead them to gaining quality relationships with friends:

> *I mean, my personal friends, I haven't lost any because they're, you know I guess*
> *there's a reason they were my friends… And they, you know, I've always explained*
> *to them about autism, and they're very good with my boy, and they love him to*
> *bits, so that's fantastic for him. (Kath)*

Two participants also spoke about making new connections with people they would not have had if their child did not have an ASD:

> *Some of the people that we have come into our lives are just wonderful people,*
> *you know. (Nicky)*

Opportunity

Another way in which participants indicated they had gained through the experience of parenting their child was through unique opportunities presented by the ASD. All caregivers indicated they now knew more about ASDs and how this affects both an individual and their family. Caregivers also noted that along with the arrival of an ASD in their life came opportunities to engage with new interests, and alter their career trajectory. When speaking about the knowledge they had gained of ASD, participants noted how this knowledge could be generalised:

> *You know there's a lot of growth and learning about how a mind can operate*
> *differently. And I learned a lot about how minds work. How people work.*
> (Harvey)

From this experience, some participants noted that this had lead to new interests they would not have previously engaged with, for example:

> *I guess its opened a door to a whole load of other things that I wouldn't normally*
> *do, so even like I'm the chair of the X Autism Committee. (Teresa)*

While Kath indicated she was unsure whether this opportunity was any better than what she could have gained if her son did not have an ASD, she also indicated that the experience had introduced new elements to her life:

> If I was trying to be positive I would say well yeah - I've learned a lot about autism,.. I have discovered new things. But I think my life would have been just as good, if not better, without autism. (Kath)

In the following excerpt Nicky explained that her son's ASD had led to the development of new interests she had never considered engaging with:

> And the interest in psychology. I think I've always been interested in psychology, you know, probably all along, I suppose. But it's really brought that to the fore, you know, like learning about behaviour.   Yeah, and communication. Yeah, since I've become involved in X Trust, that's developed a lot because- just the dynamics of running an organization and communications between members and funders and, you know; so I never really did that kind of stuff before. I think I actually probably had the guts you know. I could have done it. I just didn't. You know, it just wasn't in my life. (Nicky)

While the above participants noted changes to their understanding and interests, Bridget and Harvey both indicated a more extensive change, in that they used their experience with ASDs to inspire their career:

> I think if autism had not come into my life I would not be therapeutically working the way that I am… and so for me professionally it gave me such a unique specialty into my career that I would not have otherwise pursued, I'm very confident of that. (Bridget)

> It's definitely made me more political, more, although in that direction in which I was already interested, so it's reinforcing thoughts that I had about what a functional society should look like. (Harvey)

Personal Development

When it came to asking participants to identify positive qualities they may have developed as a byproduct of their experience with their child, or even validate their own skills, this was not an easy task.   Most participants appeared uncomfortable acknowledging their own positive qualities, preferring to redirect the conversation to their child's positive traits or the charity of

others. Because of this only a handful of instances of *"personal development"* were directly spoken about. The most common ways in which participants identified they had grown – either directly or as identified through analysis of their talk about other experiences – could be grouped under the strengths of *"perspective,"* *"curiosity,"* *"open-mindedness,"* *"bravery,"* *"integrity,"* *"persistence,"* *"social intelligence,"* *"self-regulation,"* *"kindness,"* and *"citizenship."* Examples of these developments follow.

When asked about how they had changed as a result of parenting their child with an ASD, the most common strength spoken about by caregivers referenced *"perspective."* Four participants noted ways in which they had come to see their situation, and their world in a new light. Teresa gave a good example of this when she spoke about her view of her life now:

> *As they say… your tapestry of life is a lot richer in terms of, I think it teaches you to prioritise really in terms of rather than worrying about whether or not my kids are on the straight and narrow. You know it teaches you to value the really good things, like are my kids happy, do they feel safe, are they content, do they have compassion about other people. They are the qualities that I think they need more than they need to know Newton's or physics.* (Teresa)

Two participants spoke about how their child's differences had lead them to embrace *"curiosity"* and consider alternate ways of seeing the world, or approaching life's challenges. For example Harvey spoke about what he had learnt from his daughter:

> *She makes me aware of the fact that you need to try different things.* (Harvey)

Several participants demonstrated their growth of *"open-mindedness"* Bridget, for example, spoke about how raising a child with an ASD had led her to develop increased awareness of other people's experiences, and re-consider the ways in which she approached her own experiences:

> *… it's really opened up my eyes to so many different things, so many different ways of being… I think it gave me as a person an understanding of difference in a way that I don't think I would have embraced before.* (Bridget)

Participants also reported an increase in their strength of courage. Two caregivers noted this in the form of *"bravery."* For instance Nicky noted this development of bravery when advocating for her son's needs:

I think I've become more confident, yeah, definitely. I remember the first time I had to talk about or advocate for Kieran, like when he was about to start kindy. He had been in early childhood [childcare], but we were moving him to kindy because they had much better experience with autism. And it was about the time kindy were all changing their hours to longer days, less days and longer. And I knew that it was just not going to work for Kieran. And so there was a big meeting at the kindy between the kindergarten association and parents. And, yeah, so I stood up and said, well, because the main thing that didn't work about it was the Ministry of Education categorically said they would not fund an aide for longer than three hours in early childhood. So if he was there for six hours, that was three hours without any supervision. And he absolutely needed one-on-one supervision, so I had to get up and stand, you know, and talk about this in front of all the parents who I hadn't, most of them I hadn't actually met before. Yeah. I was shaking like a leaf, you know. (Nicky)

Four participants noted their courage developed in the form of "*integrity*;" presenting themselves and their situation as honestly and genuinely as possible, for example:

For us it might be a little bit different and um, maybe saying it out loud, you know just acknowledging it to people is a bit of a difference. You know, not making any excuses for things but just saying well this is why these things are a problem. (Kath)

Not explicitly reported, but noted as a theme throughout interviews was that at least half of the caregivers referenced a development in "*persistence*" in the face of challenges. For instance Teresa noted she had long been strong-willed, however her experience with her son increased her persistence with ensuring he got what he needed:

And you pull yourself together and you just, I'm a bit of a bloody minded kind of person actually and I don't tend to give up on something I'm passionate about, I give up on a lot of other things but I don't tend to give up on things I'm passionate about, and it's really easy to be passionate about your kids. (Teresa)

Potentially stemming from their learnings about their child's difficulties in social situations, fifty percent of participants noted their awareness of the motives and feelings of others, or

"social intelligence" had grown. Harvey noted this development benefited him when relating to other children:

> *Our third child has a friend who is on the spectrum. I know how to talk to him, I know how to get down to his level to talk to him - but generally it actually helps, talking to children in general. If you make yourself, you know if you establish a certain amount of space... And so it's helped us with the other kids but it helps kids in general, and with people also in general.* (Harvey)

Extending on this, Teresa, in a display of both social intelligence and perspective, related her and her family's understanding of other's positions in the world:

> *It does mean that we've had the privilege of having a lot of open conversations among our family that we might otherwise never have had you know about lots of different things in life. And, you know, difficulties that people have - and how the difference is not always bad.* (Teresa)

Perhaps of most significance to their own wellbeing, four out of the six participants noted how they had developed strengths in their *"self-regulation"* abilities. Most participants referenced the necessity of the development of such skills as patience, for example:

> *I guess I've learned - well I was always reasonably patient, but I've learnt to be a lot more patient. Because you have to be.* (Shane)

Two participants also noted that, because they had to adjust to managing higher stress levels, they had sought out and developed new and better self-regulation skills to manage these. For example Bridget spoke of now prioritizing the management of her own emotional wellbeing in order to care well for her son:

> *You know paying attention to the details. The freeness of being in nature, relaxing. I think that part has really made me slow down and rejuvenate a lot more than I used to.* (Bridget)

Throughout interviews it was noted that, whilst no participants explicitly reported growth in "*kindness*," this strength was very much present throughout the dialogue of five out of six participants. These examples could be observed in caregivers talk about their own child, for example in the following excerpt Kath spoke about giving her son space to soothe himself at a café in spite of social taboos:

> *And then he, you know, he was eating, and then he'd lie down under the table, and he'd go -- you could hear him go "ohhhh" - like that - then he'd come back up*

(laughs). Whereas that used to embarrass and trigger me and now I'm just like, what the hell, you know. (Kath)

Many examples of how this kindness had become *"citizenship,"* - where caregivers spoke of their efforts for the greater good of the ASD community - were also found. Both Harvey and Bridget spoke of working to ensure that what they and their child needed may also be provided for others:

I guess I felt like if I can't have what I need I can give what I know and, you know, what I'm capable of and my knowledge and abilities to those families. (Bridget)

So that's what makes you - leads to being politically involved is the thought that it's not just your child you know. She's got targeted funding so we could not care about ORRS. It's not reviewable anymore for her so who cares! But, I mean, it's not because you're not a great person it's just because you see situations... you just can't bear to think about your child not at least making things better in a place than it was. It was a bad experience [with a kindy] but we said something so at least we can make it better for the next. (Harvey)

Chapter Nine:

Study One Discussion

"I've learnt to be a lot more patient; because you have to be."

(Shane, Study One)

The aims of Study One were to explore the experience of NZ caregivers of children with an ASD and examine whether they experience similar challenges to those identified in existing research on this population, whether the phenomena of stigma by association is present in the NZ context, and whether these caregivers experience growth as a byproduct of raising their child. A summary of key findings of this study and their implications for this thesis are summarised below.

What Challenges are Encountered by Caregivers of Children with ASDs in NZ?

Reflecting on the findings of this study, overall the challenges faced by caregivers of children with an ASD in NZ reflect challenges spoken about by caregivers in previous international research. Key challenges for participants in this study included practical restrictions such as unexpected obstacles associated with raising their child, resource limitations, and barriers to support as well as personal costs of reduced wellbeing and interpersonal loss.

Caregivers spoke at length about the practical challenges of raising their child. Commonly noted unexpected obstacles revealed the extra care, caution, and effort required above and beyond typical parental duties. Reflecting findings from the study by Cappe et al., (2011) participants appeared to have to organise family life around the needs of the child with the ASD in order to ensure safety, decrease stress, and negotiate around communication difficulties. As described by Gray (2002) caregivers in this study whose children displayed more aggressive tendencies seemed to experience more challenges, the outcome of which was often increased isolation.

All participants in this study referenced how having a child with an ASD created financial and time restrictions above and beyond those typically experienced while raising children -as noted in Sawyer et al.'s (2010) study. Time pressures were linked to both the necessity of organizing life around the child, and other practical restrictions such as overcoming barriers to support and managing unexpected obstacles. Caregivers also experienced financial stress linked to costs of unfunded therapies, unexpected costs and the necessity of having flexible work (loss

of potential earning), a finding which supports difficulties identified by Bevan-Brown (2004), Gupta and Singhal (2005), and Hastings and Johnson (2001).

Ganz (2006), from a United States of America (U.S.) perspective reported that caregivers often incurred additional health and education costs. In contrast to the user-pays health systems used in the U.S., the majority of NZ health and education systems are tax funded. Whilst additional health and education costs were not a notable theme of this study, caregivers spoke of increased stress and numerous barriers to accessing health and education services for their child. It is likely that the difference in funding structures between the U.S. and NZ shifts the focus of this stressor from funding to obtaining access to these services. Results in this study supported findings of Bevan-Brown's (2004) NZ study, where the majority of caregivers interviewed found both the health and education systems more memorable for the stress they created, than the help they provided. In addition to the stress of accessing appropriate support for their child and themselves, participants spoke of finding they had to invest their limited time and energy on increasing family, friends, associates and professional understanding of ASDs. This finding is not unique to this study, as seen in Woodgate et al.'s study *"Living in a World of our Own"* (2008).

Overall, participants spoke at length about how the entrance of a child with an ASD into their lives had brought further life restrictions. Caregivers found the ASD itself brought unexpected difficulties which restricted theirs and their family's day to day living, and subsequently found their time and financial resources restricted. When caregivers turned to the wider community and public systems for support, they were often met with processes that amplified, rather than reduced these restrictions.

In addition to, and likely at least in part as a result of the practical restrictions they experienced, participants reported multiple ways in which the challenge or raising their child came at a cost to their personal wellbeing. All caregivers interviewed reported that raising a child with an ASD is stressful and tiring. Supported by previous studies the experience led caregivers to feel overwhelmed, experience decreased physical health, ongoing grief, anxiety about the future, believed they had to forfeit their own life dreams and for some, these difficulties lead to depression (i.e. Allik et al. [2006]; Bevan-Brown [2004]; Bitsika & Sharpley, (2004]; Dunn et al. [2001]; Estes et al. [2009]; King et al. [2006]; Montes and Hallerman [2007]; Taylor & Warren, (2012); and Weiss [2002]).

Likely both subsequent to, and perpetuating the negative effects on wellbeing, every participant in this study indicated their interpersonal relationships had been negatively affected through reduced contact, isolation or loss of relationships. This loss was attributed to direct and indirect consequences of having a child with an ASD and associated social difficulties. Social challenges in the form of stigma were also noted as costing the participants personally, and are discussed next.

Is the Phenomena of Stigma by Association Encountered by NZ Caregivers, and what are its Consequences?

Every participant in this study spoke of experienced and internalised stigma by association, a finding that reflects international study findings such as those by Gray (2002) and Mak & Kwok (2010). The most common examples of stigma by association reported by caregivers in this study included being avoided, disregarded, given unsolicited advice, blamed and stared at/ glared at.

The experience of being avoided was often spoken about by caregivers as enacted through lack of action by friends, family and associates. While this study did not allow the examination of the perpetrator's motivations for this avoidance, caregivers perceived this as stemming from a number of motivations, including the desire to evade possible difficulties or conflicts with the family. This finding echoed similar findings in studies such as Gray's (2002) study where parents spoke of being avoided, and Bevan-Brown's (2004) study where examples were framed as being ignored.

Extending on the experience of being avoided, this study's participants also spoke of how they were disregarded. Bevan-Brown (2004) found that her participants had similar experiences, however framed these within the theme "*ignored*." The term disregarded was used in this study to further elaborate on the experiences of stigma, and help delineate the passive lack of action represented by the theme *"avoided"* and the more active rejection of often well informed advice and viewpoints of the caregiver spoken about by participants in this study.

Similar to studies by Gray (2002), and Farrugia (2009), caregivers in this study also experienced unfriendly looks and staring. Whilst participants in this study did not speak of experiencing the more aggressive glares or verbal abuse noted in other studies (i.e. Farrugia 2009; and Gill & Liamputtong, 2011) the looks and stares spoken about in this study still appeared to evoke participants' feeling they were intruding (in spaces they had every right to occupy), or

behaving in ways that were unsanctioned. The absence of more aggressive experienced stigma noted in the above mentioned studies could be a characteristic of this sample, or may reflect a cultural difference between the experience of caregivers in NZ versus other previously studied contexts.

A number of studies have found that caregivers of children with an ASD were treated as, or perceived to be bad parents (e.g. Bevan-Brown, 2004; Farrugia, 2009; Gill & Liamputtong, 2011; and Mak & Kwok, 2010). The experiences of unsolicited advice referenced by this study's participants shows this perception is also present in the NZ context. The theme of blame also noted through analysis of participant talk in this study further demonstrates that caregivers of children with an ASD in NZ are regularly perceived to be at fault for their child's difficulties.

Most experienced stigma spoken about in this research study was noted in the interface between the caregiver and education and health services. Of interest, while from the outside the neglect and exclusion spoken about in given examples appeared on the surface to be directed towards the child, participants experienced these instances as also ignoring their own needs as a caregiver. These experiences echoed common examples of lack of empathy, dismissal, and being ignored cited in previous studies (Farrugia, 2009; Gill & Liamputtong 2011; and Mak & Kwok 2010).

A distinctive finding of this study was the experience of caregivers who felt they must 'choose a stigma.' This experience hinted at the dissonance caregivers encounter in their dealings with their community. As a caregiver they regularly felt forced to choose between the rights of their child, their own rights, and the rights of the wider public. Results in this particular stigma domain would be worth exploring in future studies, to understand further the difficulties and barriers influencing the decisions caregivers must make on a daily basis for their child.

Extending on this experience of having to choose a stigma, participants also spoke of experiences which suggested they also had to contend with internalised stigma by association, supporting previous research in this area. Similar to Gray's (2002) Australian study, participants identified that they experienced shame. They spoke of attempts to pass as normal which suggested that, similar to Gill and Liamputtong's study (2011), they too worried about the judgments of others and felt different. In contrast to Mak & Kwok's (2010) study,

participants did not identify experiences of self-blame, or speak of themselves as irresponsible. This contrast could be a reflection of cultural differences (as Mak & Kwok's study was conducted in China), or a result of the differing study methodology (questionnaire vs. interview).

Overall, results from this interview study provide evidence for the presence of both experienced and internalised stigma in caregivers of children with an ASD in New Zealand. Social interactions with a caregiver's friends and potential supports suffer, where support from services should be - caregivers instead find barriers, and caregivers often feel trapped between being seen as either a bad citizen or bad parent. In reaction to, and potentially perpetuating experienced stigma, internalised stigma leads caregivers to experience their social world as an 'other,' experiencing shame and fear they will wear out their welcome, and trying their best to shape their child and selves in order to reduce stigma. Experiences spoken about within this study are similar stigma experiences to those in other countries around the world, and the stigma attached to parenting a child with an ASD, both experienced and internalised, appears to have serious effects on the caregiver's, and potentially child's lives.   It would appear that while we would hope New Zealand could be forward thinking in areas of inclusion and equal rights, stigma by association is most certainly present and excludes and limits the lives of caregivers of children with an ASD in NZ.

Do Caregivers Recognise Experiences of Growth as a By-product of Raising Their Child?

In regards to the third research question asking whether caregivers experience growth as a byproduct of raising their child there were many positive emotions, experiences, opportunities, and personal developments noted by participants suggesting caregivers do experience growth.   All participants in this study identified positive emotions and engagements, as well as at least one way in which they had experienced personal growth.

As indicated by Stace (2011) when she explored how to include the experiences of families of children with ASDs in NZ autism policy, the positive emotion of love is an important and prevailing experience of caregivers of children with an ASD. Similarly, this study demonstrated that all interviewed caregivers felt a strong sense of love for their child, which was said to grow the more they fought for their child's rights to equality, and watched their child face their daily challenges. Participants also spoke of the pride that accompanied this observation of their child's persistence in the face of challenges, or was noted when a caregiver spoke of how their child inspired them. Pride has also been noted in research into positive experiences of parents

raising children with autism by Kayfitz et al. (2010). The other key positive emotion, in addition to love and pride, noted by participants in this study was that of gratitude. Gratitude has been identified in studies of caregivers of children with ASDs by both Bayat (2007) and Myers et al. (2009), whose participants also noted the increase and benefits of this emotion.

As well as the positive emotions identified, caregivers indicated they experienced a number of positive engagements as a byproduct of raising their child. Interestingly, whilst some participants spoke of a loss of connection with their spouses, two caregivers noted *greater* connections with their spouse. Participants also noted improvements in quality of family and friend relationships, as well as the establishment of new connections with others. This verifies findings of Bevan-Brown (2004) whose participants noted both losses and gains in interpersonal relationships, and Kayfitz et al.'s (2010) discovery that mothers of children with an ASD can experience growth in their social network. This suggests that while the impact of ASDs on relationships can appear harmful, co-occurring benefits of improvement in quality of relationships is possible.

Bevan-Brown noted in her study that caregivers become an 'expert on ASD' (2004). This expertise, as well as increased knowledge about disabilities, new interests, and new career pathways was a noted area of growth in the results of this study. Unique to this study was the identification of new caregiver interests, where participants noted their experience with their child lead to the growth of new interests and therefore new skills they would not have considered engaging with previously. For at least two participants in this study, the opportunities to learn more about ASDs, and engage in new interests led them to new career opportunities. These participants took challenges raising their child and used these to extend themselves in a meaningful way.

Adding to the noted growth via positive emotions and engagements was the variety of ways in which caregivers identified they had developed personally. Referencing the VIA classification (Appendix B as described earlier) participant's examples of personal growth fell under virtues of justice, wisdom, courage, humanity, and temperance. The strength of citizenship (encompassed by the virtue of justice) was the most commonly noted area of development amongst participants. Many references were made to ways in which caregivers demonstrated citizenship, through the sharing of resources and knowledge with, or for the benefit of, other caregivers of children with ASDs. Minor references have been made in previous research to

caregivers becoming "less selfish" (i.e. Bayat, 2007; and Zhang et al., 2015), however little has been previously documented about this caregiver quality in the literature.

Participants most often referenced development of strengths under the virtue of wisdom. They spoke about how their experience with their child expanded their awareness of, consideration of, and interest in other people's experiences and ways of seeing the world (open-mindedness, perspective, and curiosity). This open-mindedness and perspective mirrors findings from studies such as those by King and colleagues (2006) and Kayfitz and colleagues (2010). It also extends on Myers and colleagues (2009) finding (where parents stated they had a new understanding of disabilities) to include a new and wider understanding of people. This extension of open-mindedness to include curiosity has not been recognized in research to date.

Strengths under the virtue of courage were also regularly referenced by participants in this study. The most commonly referenced strength in this domain - integrity - suggested caregiver growth towards a more open and authentic state of being. As with the strength of curiosity, this caregiver quality has not previously been referenced within research on the experience of caregivers of a child with an ASD. Further strengths noted under the virtue of courage included persistence (persevering towards a goal in spite of barriers) and bravery (overcoming personal fears and taking risks). These strengths were noted by caregivers as necessary in order to meet their own and their family's needs. The development of persistence in caregivers is supported by previous research (i.e. King et al., 2006), however at the time of writing, references to bravery in caregivers of children with an ASD in the literature were absent.

The interpersonal virtue of humanity was represented in participant talk referencing their development in social intelligence. This strength is one that has been relatively well documented in research on the experience of caregivers (e.g. Altiere and von Kluge, 2009; and Zhang et al, 2015). This may be due to the nature of ASDs – in that one of their presenting features is difficulty within social interactions, or could be due to the difficulties having a child with an ASD can cause in the caregiver's social interactions, necessitating the advancement of skills in order to manage these difficulties. Many examples were also captured where caregivers spoke of their own development of kindness. This also reflects previous research findings, where caregivers have spoken about the growth of compassion and increased caring (e.g. Bayat, 2007; and Zhang et al. 2015).

The virtue of temperance is usually referenced in relation to restraint from excess (i.e. Bonniwell, 2012, p. 106). In the case of caregivers in this study, temperance, and more specifically self-regulation in the form of patience was a regularly noted development which represented not only restraint from excess – but also often restraint from fulfilling their own needs. This growth in patience has been noted in previous studies (e.g. Altiere & von Kluge, 2009; and Bayat, 2007), and similar to the strength of social intelligence was noted to be necessary in order to successfully manage their child and the wider challenges associated with the ASD.

In conclusion, the majority of literature to date exploring the experience of caregivers of children with an ASD emphasises that raising a child with an ASD is difficult and stressful. Results from this study suggest caregivers experience similar challenges to those identified internationally, including limited resources, barriers to support, unexpected obstacles, reduced wellbeing and interpersonal losses. In addition to these challenges, caregivers identified that the experience of stigma by association is both present in and relevant to the NZ context, with caregivers citing experiences of being avoided, disregarded, blamed, stared at or glared at, and given unsolicited advice, encountering systemic exclusion and neglect, and feeling they must choose between being labelled as a bad parent or bad citizen. These encounters had lead caregivers to internalise this stigma, leading them to feel shame, attempt to follow the 'unwritten rule,' and do their best to pass as normal.

While the results of this study demonstrate that being a caregiver of a child with an ASD in NZ is a challenging experience, they also suggest caregivers can and do have co-occurring positive experiences and experience growth attributed to the experience of raising their child. Positive experiences included emotions such as love, pride and gratitude, greater quality connections with partners, friends and new friends, and new opportunities to gain knowledge, interests and career developments. Caregivers identified they had grown within themselves at a variety of levels and had developed virtues including wisdom, courage, humanity, justice and temperance. These findings are important, not only because they give voice to the strength of caregivers of children with ASDs in NZ. They also imply that caregivers could experience all three paths to wellbeing: the pleasant life (positive emotions), the good life (positive experiences), and the meaningful life (meaningful development), suggesting caregivers likely do experience growth.

The evidence of the challenges, stigma by association, personal strengths and possibilities for meaningful growth experienced by caregivers of children with ASDs in this study are next used to support and guide the development of Study Two: Surveying the Experience of Stigma by Association, Wellbeing, and Positive Change in Caregivers of Children with ASDs.

SECTION THREE

Chapter Ten:

Study Two: Surveying the Experience of Stigma by Association, Wellbeing, and Growth in Caregivers of Children with ASDs

I said "do you think that you would think it was weird if you were watching a game and then you looked over and you saw this big teenage kid playing with a bouncy ball with a little girl?" And he said "well yeah I see what you mean but I'm just not interested in the hockey game, I don't understand it." And I thought well who's got the problem, it's me, and it's the rest of the people. (Bridget, Study One)

Findings of Study One suggested stigma by association is relevant to the NZ caregiver population and negatively affects caregiver wellbeing. Results also indicated caregivers encounter positive experiences and growth as a by-product of caring for their child. Study Two was a quantitative study developed utilising knowledge gained through Study One. Aims of this study were to:

1) examine the experience of stigma by association in NZ caregivers of children with ASDs,

2) explore whether stigma by association affects caregiver wellbeing,

3) assess whether signature strengths of hope, gratitude or curiosity offer protection from the impact of stigma by association on wellbeing, and

4) identify whether caregivers experience growth as a byproduct of parenting their child with an ASD.

The following section outlines the design and methods of Study Two including questionnaire design, a description of measures used including the process of development of a measure of stigma by association, the procedures, analysis and results.

Design and Methods

Study Two was a quantitative study involving cross-sectional analysis of a national sample of people who identified as primary caregivers of a child with an ASD and volunteered to complete an anonymous web-based questionnaire. The questionnaire data collection method was chosen as this allowed for the assembly of a higher level of detail which may be more difficult to obtain through other modes such as interviewing, and is thought to be effective at gathering information about sensitive issues (i.e. stigma by association; Bethlehem and Biffignandi, 2011). Having participants contribute anonymously would help reduce the effects

of social desirability biases, and lessen possible participant concerns about further experiences of stigmatisation.   The questionnaire aimed to access data detailing how respondents truly experience their position as a caregiver of a child with an ASD in NZ.

Target Sample

Participation in this study was limited to people who identified as a related primary caregiver of a child aged between three and 18 years old. The decision was made to limit participation to those who had lived with the child with an ASD for the majority of the past year as research has suggested that co-residence with a stigmatised individual is associated with increased shame, avoidance, social exclusion, and rejection (Lanquetot, 1984). The age of the child was also limited to between three and 18 years old as prior to age three the child's communication and social interaction difficulties are less likely to be noted by others (due to common variations in developmental norms), and after age 18 additional societal expectations (and therefore stigmas) are likely to become influential (such as expectations that the child gains employment and moves out of home). Participants had to be over age 16 in order to ensure the study did not inadvertently measure the additional stigmas this population has to contend with (such as those of being a teen parent) and live in NZ in order to control variability in cultural norms of social behaviour. In the case that a caregiver had more than one child with an ASD they were asked to respond to the questionnaire in reference to their oldest child.

Due to the type of analysis required for this research at least 100 participants were required (an approximate cases to variables ratio of 10:1). Given an assumed significance level of 0.05, and a power level of 0.80, a sample of somewhere between 100 and 250 would detect reasonably modest effect sizes (see Hair, Anderson, Tatham, and Black 1988, Table 4.7, page 165). A goal of 200 participants was sought in order to increase stability in results and to permit a margin of error for missing or incomplete data.

Ethical Considerations

Bersoff and Bersoff (2000) state that three basic participant rights must be addressed when using questionnaire surveys: informed consent, privacy, and confidentiality. The questionnaire was designed in such a way that both informed consent and privacy were outlined in the study's information sheet which also served as the opening page of the questionnaire (see Appendix G for a copy of the information sheet). In order to also maintain confidentiality, completion and submission of the questionnaire items implied consent, negating the need to collect consent forms. Privacy and confidentiality were ensured via the administration of the questionnaire via the internet using a survey system.   Participants who heard about the

questionnaire through advertising self-selected into this study using advertised website details. As the questionnaire was web-based, participants did not have any form of contact with the researcher, and were not identifiable unless they initiated contact with the researcher through advertised contact details.   The questionnaire was hosted on a Qualtrics survey system (http://qualtrics.com) using an existing Massey University School of Psychology Programmer/Analyst's licence.   This survey system was secured under the https protocol and the survey data anonymised whilst in use.   The survey data could only be accessed by the Programmer/Analyst using a usercode and password and was unable to be accessed by other internet users.   Survey data was downloaded by the Programmer/Analyst in an anonymous format and delivered to the primary researcher as requested for analysis.   Ethical permission and oversight for Study Two was granted by The Massey University Human Ethics Committee: Southern A (Application 13/27, 10.06.13 attached as Appendix H).

Measures

Several key criteria were considered important in the selection of measures for use in this study's questionnaire.   As the questionnaire was intended to explore multiple constructs at one time point, ideal measures would be brief in order to avoid response fatigue.   To fit within the thesis budget, and encourage future replication, measures would be easy to access and low cost.   In order to fit with the NZ context, the measures had to be available in the English language, use simple terminology (the aim was for a reading level able to be understood by an individual at secondary school), and ensure any jargon used was familiar to the NZ population. Measures which had normative data for the NZ population or a population similar to that of NZ were preferred, and measures had to have good evidence of reliability and validity.   As this questionnaire was inquiring about sensitive and potentially difficult topics, measures could not use language which may have been considered offensive or which may have further contributed to caregivers' experiences of stigma.   The following is a description of measures used in the questionnaire.

Measure of Stigma by Association

As identified in Chapter Four, stigma by association is rarely discussed as a stressor for caregivers of children with ASDs, yet according to Study One is likely both highly relevant to, and detrimental to the wellbeing of this population.   There are few psychological measures of stigma by association validated for use with parents of children with disabilities, and at the time of writing there were no known measures of stigma by association suitable for NZ parents of children with ASDs.   An overview of the development of a new measure of stigma by association is provided next.

To develop a comprehensive understanding of the stigma by association experience of caregivers of children with ASDs, common indicators and correlates of stigma by association needed to be identified. Firstly, a review of the literature on stigma by association and ASDs was conducted to identify common experiences linked to stigma by association (see p.p. 16 to 20). Next, a qualitative study was conducted which explored caregivers experiences of stigma by association (Study One). After considering which variables were commonly linked to the stigma by association experience within both the literature and results of Study One, literature was searched for self-report measures with a focus on constructs and key measure criteria noted previously.

The initial search for a measure of stigma by association for caregivers of children with ASD or similar difficulties resulted in the identification of one previously developed scale, the Affiliate Stigma Scale developed by Mak and Cheung (2008). However this measure was deemed unsuitable for this study due to its length, complex language, and jargon use. The absence of an appropriate measure lead to the development and validation testing of a measure of caregiver stigma by association.

Caregiver Stigma By Association Measure (C-SAM) Development

Item Development

The first step in item development was to ensure appropriate coverage of all relevant experiences of both experienced and internalised stigma by association. Thematic analysis of interviews from Study One resulted in the identification of caregiver stigma experiences including being avoided, disregarded, blamed, stared or glared at, excluded, neglected and given unsolicited advice. Internalised stigma experiences included caregivers feeling shame, unaccepted, and as though they must do their best to be 'normal.' Due to the complexity of the stigma experience, and in order to ensure all experiences of stigmatisation by association were captured, themes identified within the literature review were also included if they had been identified in two or more research studies, and had been noted as a stigma experience by at least two caregivers in Study One. Experienced stigma by association themes found through literature review which were additional to those identified in Study One included: caregivers being treated as bad parents, being seen as irresponsible and lacking control, verbally abused, dismissed, ignored and being denied empathy. Additional internalised stigma experiences included feeling *different*, embarrassment, criticised, like a bad parent, worried about judgement, blamed, and that they should be more responsible. As there was potential

duplication in themes through the use of differing terminology between studies, original texts were returned to in order to check thematic similarities and themes were combined if confirmed to be thematically related to develop a condensed theme pool as shown in Tables 10.1 and 10.2. Final themes used to construct the caregiver stigma by association measure included experiences of being avoided, devalued, treated as a bad parent, stared at or glared at, receiving rude comments, and being treated as other. Internalised stigma themes included feeling embarrassed, rejected, at fault, and fearing being devalued.

Table 10. 1

Development of Experienced Stigma Themes for use in the Caregiver Stigma By Association Measure

Original Experienced Stigma Theme Name	New Experienced Stigma Theme Name
Avoided	Avoided
Disregarded Dismissed Denied empathy	Devalued
Blamed Treated as bad parents Seen as irresponsible Seen as lacking control Given unsolicited advice	Treated as a bad parent
Stared or glared at	Stared or glared at
Given unsolicited advice Verbally abused	Rude comments
Ignored Excluded Neglected	Treated as other

Using themes generated in Tables 10.1 and 10.2, a pool of 26 items were developed which were thought to capture the essence and breadth of experiences identified. The first draft of the Caregiver Stigma by Association Measure (C-SAM) items aimed to explicitly ask about whether an individual had experienced a specific event, behaviour, or feeling, as this approach was believed to relieve the participant from having to decide what qualified as stigma related. In addition it was hoped that this technique, offering brief examples of events or experiences in question, would facilitate better memory retrieval for events related to the targeted construct of stigma by association.

Table 10. 2

Development of Internalised Stigma Themes for use in the Caregiver Stigma By Association Measure

Original Internalised Stigma Theme Name	New Internalised Stigma Theme Name
Shame Embarrassment	Embarrassed
Unaccepted Different Try to be normal	Rejected
Worried about judgement Try to be normal	Fear being devalued
Blamed Criticised Should be more responsible	At fault

Content Validity of C-SAM Items

Content validity of initial items was tested through the use of an expert panel. The expert panel was comprised of five people with experiences which included: having a child with an ASD, family therapist, ASD policy expert, psychology academic with experience in the field of stigma, psychologist, and manager of a service providing assistance to families with children with ASDs. Panel members were provided with an explanation of the study purpose, 26 draft C-SAM items, and a request to provide feedback on whether: common social experiences, feelings, thoughts had been missed, questions stood out as potentially causing respondents unnecessary discomfort, questions did not fit, questions were confusing or unclear, and if the respondent had any further thoughts or suggestions. Participant feedback helped identify problematic items and wording, which were re-examined, and a final set of 21 items chosen for the pilot study.

C-SAM Pilot

The aims of this pilot study were to assess C-SAM item validity and acceptability to respondents, and ensure breadth of coverage of stigma by association experiences, whilst also refining items. Giles (2002) suggests that when testing a survey, participants who are similar to the final target sample should be used, attempts should be made to use as large a sample as is reasonable, and that a minimum sample size should be the "number of items in the scale plus one" (p. 113). The target sample size for this pilot was therefore placed as above 22 participants, and criteria for participation were those used for the final questionnaire. The pilot C-SAM was web-based in order to mimic the final questionnaire model, therefore participants

were required to have access to the internet. The resulting 21 items were pilot tested on a convenience sample (using snowball sampling) of 33 caregivers of children with an ASD.

In order to avoid repetition, items were organised into groups based on examples of how the respondent may have felt when out in their community with their child, and examples of other people's behaviours they had noticed when out in the community with their child. For each item respondents were asked to rate the frequency of their experience using a six point rating scale (chosen in order to reduce the impact of central tendency bias) with anchors of: *always*, *frequently if not always*, *quite often*, *sometimes*, *once in a while*, and *never.*

The pilot information and measure were loaded on to Qualtrics (for a copy see Appendix I). The anchors were assigned the following numbers for coding purposes: 6 - *always*, 5 - *frequently if not always*, 4 - *quite often*, 3 - *sometimes*, 2 - *once in a while*, and 1 – *never.* Prior to distribution the measure was proofed by the researcher, the research supervisor, and two peers in order to identify formatting or language errors. The researcher, supervisor and Qualtrics administrator piloted the initial measure to check results matched responses, and to check overall coherence.

C-SAM Pilot Procedure

An email inviting potential participants to follow a link to the live trial was distributed to a convenience sample of caregivers of children with an ASD living in NZ during July 2013 (for a copy see Appendix J). Snowball sampling was used to recruit further participants by including in the email invitation a request to forward the link on to other potential participants. When participants followed the link they arrived at a website listing current live surveys within the Massey University Psychology Department. This site provided a brief overview of the pilot study along with a link to the survey. Once a participant clicked on this link they arrived at a page providing information on the research aim, who could participate, what happened if they participated, how the information they provided would be used, participant rights, and research contacts. If the participant wished to progress with the survey they were asked to click on the "*next*" icon which took them to a consent page where they were advised that providing answers to the questions implied consent, and to indicate by clicking on "*yes*" if they had read and understood the information sheet and consented to collection of their responses. If the participant chose "*yes*" they were taken to the pilot items. A progress bar showed participants how far they were through the survey as they progressed, and participants were able to alter responses after their initial response if they wished. In order to respect a respondents' right not to respond to a question, skipping questions was allowed.

Once a participant had completed the draft C-SAM items they were asked to provide feedback on aspects of the survey such as; time to complete the survey, clarity of items, fit of items, offensiveness or discomfort, whether any feelings or experiences were not covered, and any further suggestions (see Appendix I). Once the participant completed this section they clicked on *"finish"* which took them to the final page detailing the researcher's contact details once more as well as where to find future results of this study. The questionnaire was closed by the Qualtrics administrator once 30 participants had completed the survey.

C-SAM Pilot Results

In total 44 surveys were started and 33 participants completed all items in the survey (greater than 30 as three further participants had begun the survey prior to link closure). Of the 11 participants who did not complete the survey, five did not progress past consent. The remaining six either stopped responding at various points for unknown reasons, or their responses were over 50% incomplete (therefore in accordance with Hair et al.'s (2006) recommendation these results were not included in the final total). On review no clear patterns of item non-response were identified.

Overall, the 21 item scale demonstrated excellent internal consistency (α = .95). The mean scale result was 61.12 (the highest score of 97 indicated highest levels of stigma by association), with a standard deviation of 17.18 and 95% CI [55.08, 67.21]. Average time to complete the scale was reported at three minutes, with a range from one minute to ten minutes. Based on analysis from feedback questions and item total correlation analysis (attached as Appendix K), one item was removed owing to redundancy, and a time frame of the past six months added to assist caregivers when considering experiences to include. Feedback was received about the wholly negative focus of the C-SAM, however as the questionnaire for Study Two (which would include the C-SAM) intended to also include exploration of positive experiences, the C-SAM was not altered. The final C-SAM consisted of 20 items (*M* = 58.94, *SD* = 16.30, 95% CI [53.16, 64.72], α = .94) assessing both the perceived and internalised experiences of caregivers of children with an ASD. Data from this trial were not included in the final questionnaire.

Measures of Psychological Strengths

In order to explore the possible protective role of certain caregiver signature strengths on wellbeing, the review of literature on character strengths and wellbeing was conducted (see

pp. 27 to 33). As with the stigma correlates, once a decision was made on which signature strengths were thought to have the most important relationship with wellbeing when a caregiver experiences stigma, self-report measures which best matched this study's key measure criteria were identified. The key signature strengths measured in Study Two were hope, gratitude, and curiosity.

Hope

Hope was measured using the Adult Dispositional Hope Scale (ADHS; Snyder et al., 1991; also known as the Adult Hope Scale and the Adult Trait Hope Scale), a 12 item self-report measure of trait hope. The measure asked respondents to respond to statements using an eight point Likert-type scale with points of this scale ranging from *definitely false* to *definitely true.* The ADHS was designed to assess two factors; the participants' pathways to hope (planning to accomplish goals) and hope agency (goal-directed energy), however for this study the ADHS was used for its overall hope score with a highest possible score of 64 (four filler items are not scored) indicating highest levels of hope. For this study scores at or above the mean (M = 48; Lopez, Ciarelli, Coffman, Stone, & Wyatt, 2000) were interpreted to indicate higher than average hope.   Internal consistency for the ADHS has been demonstrated as between acceptable to moderate (α = .74 to .88, Snyder et al., 1991; and Sumerlin, 1997). Scores on the ADHS have been found to positively correlate with scores on the Life Orientation Test (Scheier & Carver, 1985), negatively correlated with scores on the Beck Hopelessness Scale (Beck et al., 1974), and Self Consciousness Scale (Fenigstein, Scheier & Buss, 1975) supporting convergent and discriminant validity.

Gratitude

Gratitude was measured using the Gratitude Questionnaire - Six Item Form (GQ-6) by McCullough, Emmons, and Tsang (2002). This scale was composed of six items and assessed participant appraisals of their own levels of gratitude. Participants indicated their agreement with items using a seven point Likert-type response scale (1 = *strongly disagree* to 7 = *strongly agree*) with the highest score of 42 indicating highest levels of gratitude. Two items were reverse scored to reduce response bias. For the purpose of this study McCullough and colleague's (2002) method of interpretation was used where participants who scored at or above the mean of 36.9 out of 42 were considered to possess higher than average levels of gratefulness.   The GQ-6 has been shown to be positively correlated with optimism, life satisfaction, hope, spirituality/religiousness, forgiveness, empathy, and pro-social behavior, and negatively correlated with depression, anxiety, materialism, and envy. The GQ-6 has been

shown to measure one factor, and have good internal reliability (α = .82 to .87; Froh et al. 2011; Jarden, 2011; and McCullough et al. 2002).

Curiosity

Curiosity was assessed using Kashdan and colleagues' 10 item Curiosity and Exploration Inventory, version two (CEI-II; 2009). This scale measured participants' subjective experience of curiosity using a two-factor model - level of motivation to seek out new knowledge and experiences (the 'stretching' subscale; five items) and the extent to which the respondent is willing to take on new, uncertain and unpredictable elements of daily life (the 'embracing' subscale; five items). Ratings of agreement with items were given on a five point Likert-type scale from 1 (*very slightly or not at all)* to 5 (*extremely*.) For the purpose of this study, the composite score was used where the highest score of 50 indicated the highest level of curiosity. Scores above the mean (*M* = 33.2; Kashdan et al, 2009) were interpreted as higher than average curiosity. Previous research in a variety of settings has provided evidence of 'good' internal reliability (α = .85 to .86), convergent and discriminant validity, and construct specificity (Kashdan et al., 2009; and Kashdan et al., 2011).

Measure of Caregiver Growth

Caregiver growth was measured using the Parental Changes Subscale (PCS) of Scorgie and Sobsey's Life Management Survey (LMS; 2000). The LMS-PCS is an 18 item scale designed to measure positive changes parents associated with having a child with an intellectual disability including personal transformations (changes in self-identity), relational transformation (changes in the way one relates to others), and perspectival transformations (changes in one's assumptions about life and what is important). Each item in the LMS-PCS is rated on a five point Likert scale ranging from 1 *(strongly disagree*) to 5 (*strongly agree*), for a total score ranging from 18 to 90 (*M* = 63.72). For the current study, a response choice of 'not applicable' was added to a question related to marriage based on an earlier recommendation by Scorgie and Sobsey (2000).   In a study of parents of children with disabilities this subscale demonstrated good reliability (α = .81 to .86*;* Diamond, 2005). There are no known published measurements of validity, however this measure appeared to have good face validity and its' content validity was supported by Study One and previous literature, therefore the decision was made to use this measure.

Measure of Psychological Wellbeing

In order to measure caregiver wellbeing, The Warwick-Edinburgh Mental Wellbeing Scale developed by Tennant and colleagues (WEMWBS; 2007) was used. This scale uses 14 items, all

positively worded, to assess positive aspects of mental health over the previous two weeks using a five point Likert-type scale ranging from 1 (*none of the time)* to 5 (*all of the time.)* Respondents could score a minimum of 14 and maximum of 70 with higher scores indicating higher wellbeing. Factor analysis supports a one-factor structure (Tennant et. al., 2007) and internal consistency has been reported as excellent (between α = .91 and α = .93; Tennant et al., 2007, and Lloyd & Devine, 2012). The WEMWBS has been shown to have a significantly negative correlation with the GHQ-12 (a measure of wellbeing using negatively phrased items) supporting construct validity.

In the largest study using the WEMWBS, the data from 7020 adult participants from the Health Survey for England (HSE; University College of London, 2011) was assessed and the WEMWBS had a reported mean score of 51.6 (SEM = 0.1, *SD* = 8.7), and skewness of 0.66 (indicating a clustering of scores at the high end of the scale). Consistent with Tennant et al. (2007) data from this study was included in analysis only when the WEMWBS was fully completed. Scores above the mean will be interpreted as above average wellbeing.

Measurement of Variables to be Controlled

As identified in the literature review (Chapter Four), there are a number of variables which influence caregiver wellbeing when raising a child with an ASD, especially when taking into account the impact of stigma by association. These variables were included in the questionnaire in order to provide comprehensive control of potential confounds in the relationships between stigma by association, caregiver strengths, caregiver growth and wellbeing. Key child variables to be controlled included: severity of the child's social difficulties, current and previous therapeutic support received by the child, time since diagnosis, child's gender, and age. Caregiver variables to be controlled included caregiver's perceived levels of social support, physical health, ethnicity, previous experience living with someone with an ASD, possible support from other adults in the home, gender, and socio-economic position. The following is a description of how these variables were measured.

Child's Social Difficulties

In one of the earliest studies on the parental experience of stigma, Baxter (1989) identified that the *noticeability* of a child's behavioural difficulties contributed to parental stigma. Since this time support for these findings in relation to ASDs has been provided by researchers such as Gray (1993, 2002) Bromley, Hare, Davison and Emerson (2004) and Ekas, Lickenbrock and Whitman (2010). When considering ways in which noticeability of the child's behavioural

differences could be measured it was found that previous studies either sourced participants from clinics where clinical evaluations were made available, sourced information about the child's social difficulties as part of a larger study, or used onerous screens. These options were deemed unsuitable for this study, therefore a suitable measure for inclusion in the questionnaire was sought.

A number of scales have been developed to assess ASD difficulties. Whilst many measures were available to assess a child's ASD related difficulties (for a review of relevant measures see Ozonoff, Goodlin-Jones, & Solomon, 2005; and Sappok, Heinrich, & Underwood, 2015) few of these measures met the key criteria for this study. The Social and Communication Disorders Checklist (SCDC; Skuse, Mandy & Scourfield, 2005) was chosen as the closest match with key criteria, as its items assessed the ASD behaviours most relevant to social difficulties. The SCDC is a 12 item scale originally developed as a brief and sensitive screen of autistic traits. It has been shown to have excellent internal consistency (α = .93) high test–retest reliability (α = .81), has the ability to discriminate between clinical and non-clinical samples, has a sensitivity of 0.90, and specificity of 0.69 (Skuse, Mandy & Scourfield, 2005). The SCDC uses a Likert-type scale where *0 = not true, 1 = quite or sometimes true* and *2 = very or often true* to rate the accuracy of statements about the child's behaviour over the past 6 months. A maximum score of 24 indicates the most severe difficulties. The mean value in typically developing children from the UK has been reported as 3.25 (*SD* = 4.15) for boys and 2.39 (*SD* = 3.14) for girls. In samples of children with ASD, typical mean values are approximately 16.6 (*SD* = 5.7; Skuse et al. 2005).

Therapeutic Support Received by the Child

Research conducted by Carcini (2008), Mak and Kwok (2010) and Werner and Shulman (2013) suggests caregiver wellbeing is influenced by the amount and type of professional support received by the child, both currently and historically. In order to assess current and historical professional support received, participants were asked to indicate the formal supports or interventions their child currently received from a list of eleven options (see Study Two questionnaire Appendix L). This list was constructed based on examples provided by Carcini (2008), Mak and Kwok (2010), and Werner and Shulman (2013), and revised to include NZ specific support options. To differentiate between a caregiver's wish to decline answering this question and an absence of any supports, the option *"none of the above"* was given. Whilst every effort was made to include all known forms of formal supports, an option of *"other"* was included in the case that an option had been neglected. In order to capture historical supports

received this exercise was repeated, this time asking what forms of support or interventions their child received in the past.

Time Since Diagnosis

There is debate around whether time since the child's diagnosis has an effect on caregiver's ability to cope. In a study of maternal self-efficacy in mothers of children with autism Kuhn & Carter (2006) found that time since diagnosis contributed to unique variance in self-efficacy levels. In relation to the experience of stigma by association in caregivers, Turner, Biesecker, Leib, Biesecker & Peters (2007) found that as time since diagnosis progressed, caregiver's ability to cope with stigma by association increased. Yet in a study of daily stress, coping and well-being in parents of children with autism by Pottie & Ingram (2008), time since diagnosis was not found to influence caregiver wellbeing. In order to determine whether this variable influenced caregiver wellbeing in the face of stigma by association time since diagnosis was included for measurement in this study. To capture this information participants were asked to indicate the approximate age of their child at diagnosis when providing information about their child.

Child Demographics

As both child age and gender have been suggested to contribute to variations in caregiver wellbeing in the face of stigma (Gray and Holden 1992; Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011; and Werner and Shulman 2015) these variables were both included for control in this study.   Other demographic information deemed important to include in order to understand sample representativeness and in order to control for possible confounds were the child's ethnicity and formal diagnosis.

Caregiver's Levels of Social Support

Studies by researchers such as Gill and Liamputtong (2011) and Werner and Shulman (2013) have shown that if a caregiver feels they have good social support they are more likely to cope well in the face of stigma. Comparing different types of social support, Hall and Graff (2011) found caregivers attributed partner support to decreased levels of stress associated with raising their child. Mak and Kwok's (2010) study found that both partner and friend support were associated with a reduction in the impact of affiliate stigma on wellbeing. In order to gather information on and control for the impact of social supports on the ability of signature strengths to protect caregiver wellbeing in the face of stigma by association, participants were asked three questions about current support received from their spouse or significant other, family, and friends. Using a seven point Likert rating scale from *very strongly disagree* to *very*

strongly agree, participants were asked to rate their agreement with the statement *"I get the emotional help and support I need from my spouse/partner/significant other."* This rating was repeated twice more, but instead referencing family and then friend supports.

Caregiver's Physical Health Satisfaction

In a study of mothers and fathers of children with ASDs, Allik, Larsson and Smedje (2006) found parents were more likely to suffer poor physical health in comparison to a control group, and mothers in particular were likely to have poorer physical health if their child had behavioural problems. As Pinquart and Sörensen's (2003) meta-analysis suggested there is a link between the role of caregiving and decreased physical health, and Hayes and Ross (1986) have linked physical and psychological wellbeing, a measure of physical health was included. In order to capture the participants' perception of their own physical health, each participant was asked to rate their satisfaction with their physical health on a sliding scale from 0 (*not at all satisfied*) to 10 (*completely satisfied.*)

Previous Experience Living With Someone with an ASD

Research has suggested that a potential protective factor of caregiver wellbeing is having previous experience living with someone with an ASD (for example Walton and Ingersoll, 2015). In order to assess whether this variable may have an impact on caregiver stigma by association or wellbeing a yes or no answer question asking *"apart from your child, have you ever lived with other family/ whanau members who have an autism spectrum diagnosis?"* was included.

Number of Other Adults in the Home

As suggested by Bevan-Brown (2004) the more adults living in a household, the lesser the caregiving burden reported by parents. Participants were therefore asked *"how many other adults (age 18+) usually live in the same household as you?,"* again in order to assess the impact of this variable on caregiver stigma by association or wellbeing.

Caregiver Demographics

Demographic information about the caregiver such as ethnicity, gender, and socioeconomic position (SEP) was collected as these factors have been shown to be associated with caregiver wellbeing in the face of stigma (Bevan-Brown, 2004; Hellman, Herman & Sirey, 2001; Gray, 1993; and Phelan, Bromet, and Link 1998). According to Aday & Cornelius (2006) items asking about income often have a high rate of non-response. In order to encourage higher response rates, an alternative measure of SEP of home ownership was used (as discussed in Galobardes,

Shaw, Lawlor, Lynch & Smith, 2006). Other demographic information gathered included age, relationship status, highest level of schooling completed, and current employment status.

Questionnaire Design

The data collection method used was a web-based questionnaire. This format was selected as it was perceived to have an ability to reach a larger population, provide greater anonymity to participants, and facilitate increased response rates (Ritter & Sue, 2007). Other advantages included increased efficiency of data handling, timeliness and cost-effectiveness (Cobanoglu, Warde, & Moreo, 2001; and Ritter & Sue, 2007).

As suggested by Ritter and Sue (2007), the web form of the questionnaire used a format based on conventional paper questionnaires. The questionnaire format allowed participants to leave a question unanswered in keeping with the ethics of voluntary participation, and participants were able to return to a page using the *"back"* arrow if they wished to review or change a previous response.

The questionnaire was divided into nine parts: 'questions about you,' 'questions about your child,' 'your child's skills and difficulties,' 'your personal views,' 'your personal wellbeing,' 'social experiences,' 'changes to your life,' 'your current social support,' and 'anything else.' Each part began with an explanation of the general theme of questions, as well as instructions on how to respond to questions. Radio buttons were provided for fixed choice responses and check boxes where more than one answer may be applicable (i.e. ethnicity).

The first page of the questionnaire was a welcome screen and served to provide participants with confirmation they had reached the correct location (the questionnaire), as well as providing comprehensive information about the survey (as can be seen in Appendix L). The second page was dedicated to instructions on the number of sections ("parts") in the questionnaire, how to respond to questions, advice on how to keep track of progress through the questionnaire (via a progress bar) and a word of encouragement. Page three of the questionnaire clarified the consent process, ensuring participants had read and understood the preceding information as well as affirmation of the participants' right to decline to answer any questions. If participants activated the *"yes"* radio button this indicated their consent to continue.

As Study Two had a targeted population, the next page participants were taken to was a screening question. This question confirmed whether participants were currently living in NZ, and were an unpaid caregiver of a child with an ASD. If the participant responded *"yes"* to this question, they were advanced to 'Part 1' of the questionnaire, if they responded *"no"* they were thanked for their interest, given an explanation as to who the questionnaire was limited to, provided with information on how to access results when available, and support contact details.

Within the questionnaire, two open–ended questions were asked with the intention of allowing participants to add further information about their experience. The first of these questions (question 31) followed the LMS-PCS subscale and asked: *"are there any other experiences or changes in your life you would like us to know about which have not been mentioned?"* The second open-ended question (question 33) was positioned at the end of the questionnaire in order to capture any relevant areas which the participant may have felt had not been explored (*"are there any other situations, thoughts, experiences or feelings you would like to add which we have not covered?"*)

When designing the questionnaire order, Ritter and Sue (2007) suggest the first questions should be easy to answer closed-ended questions requiring only brief input as it sets the tone for the rest of the questionnaire (too complex and the participant may assume the questionnaire will consistently require great effort and abandon the questionnaire). With this in mind, caregiver demographic questions were asked first.   Bethlehem (2009) advises that keeping questions about similar topics close together when possible makes answering the questions easier for respondents. Therefore demographic questions relating to the child were asked next. Van Peer, Hakemulder, & Zyngier (2012) suggest that questionnaires should start with less threatening general questions. While questions about the child's social difficulties may be considered threatening by some, the decision was made to place these next. This was because they progressed logically from questions about child demographics, and in order to avoid potential biases resulting from stigma questions placed later in the questionnaire. As measures of signature strengths, wellbeing and physical health assessed similar topics, these were placed next. Van Peer, Hakemulder, & Zyngier (2012) suggest that placing more sensitive questions towards the end of a survey allows a relationship between the participant and the survey to be built, which is believed to increase the likelihood the participant will respond, therefore the stigma measure was placed towards the end of the questionnaire. The measure of positive changes directly followed the stigma measure. This measure, with a more positive

focus and towards the end of the questionnaire, hoped to leave participants reflecting on positive experiences once they had completed the measure. The next part of the questionnaire covered brief questions about current social support, in part because this linked into the themes of stigma and change, and in part as a primer for participants to think about who they could turn to for support if they had found the questionnaire distressing. The final part and question of the survey gave participants an opportunity to provide any further information about experiences they felt were important that had not been covered.

Once participants had progressed through all nine parts of the survey they reached the *"End"* page of the questionnaire. This page thanked participants for their contribution, provided information on how to view results of the survey once available, and asked participants to click the 'next' button to submit their final answers. The final page of the survey provided support and contact information in the case that participants had found the questionnaire had raised issues they wished to discuss further.

After the questionnaire design phase concluded the questionnaire was sent for review to a supervisor experienced in working with bi-cultural populations to ensure item cultural sensitivity. Once bi-cultural sensitivity was ensured the questionnaire was sent to the Massey University Programmer/Analyst who uploaded the questionnaire onto the Qualtrics platform. The questionnaire was checked for accuracy and once the researcher was happy with the web version the questionnaire was trialed.

Questionnaire Trial

Prior to advertising of Study Two, links to the questionnaire were given to a convenience sample of ten adults of a variety of ages, five of whom had children, and three of whom had relatives with disabilities. Participants were asked to complete the online questionnaire and provide feedback via email on aspects of the questionnaire such as: accessibility, layout and readability, instruction clarity, order of 'parts,' whether any questions were difficult to understand, or may cause distress. Of the ten questionnaires distributed ten were submitted. No comments were received about accessibility, order of parts, question difficulty or cause of distress. One formatting error and three spelling and grammatical errors were identified and subsequently corrected. A copy of the finalised questionnaire is attached as Appendix L.

Recruitment

Several procedures were used to recruit participants. Once the questionnaire was published live on 26 August 2013 advertising began. Firstly an advertisement (attached as Appendix M)

containing a brief overview of the research and details for accessing the webpage was posted on community notice boards in the Wellington area. Secondly the research was advertised online using a *Facebook* advertisement (see Appendix N) which *Facebook* then presented to members registered as living in New Zealand over age 16 providing a link to more information about the study. When potential participants clicked on the advertisement they were directed to the welcome page of the questionnaire.   Lastly, an email message (Appendix O) was sent to relevant disability and family support service administrators (identified via a *Yellow Pages®* search) with a request for voluntary distribution via general newsletters, graduate student lists associated with Massey University, and sent to the researcher's acquaintances. This email contained an overview of the research and gave details for accessing further information and the questionnaire webpage. Using snowball sampling, recipients of this email were asked to forward this message on to other people who may be interested. Advertising stopped on 7 November 2013 and the questionnaire was closed on 23 November 2013.

Considerations Prior to Statistical Analysis

Participant Exclusion Criteria

A total of 127 caregivers completed all or part of the questionnaire. The data from 16 participants was removed from the final data as these participants fell outside of the target population (primary unpaid caregivers of a child with an ASD between the age of 3 and 18 living in NZ). Data from a further 11 participants was removed as they had not completed more than half of the questionnaire.

Missing Data

Tabachnick and Fidel (2013) suggest that missing data in excess of 5% has negative effects on results. Overall an analysis using Little's Missing Completely at Random test (MCAR) revealed that 1.05% of the total data values were missing, with no systematic pattern identified. As the data was assessed as randomly missing, and was posited to be of minor risk, default SPSS processes for exclusion of missing cases were used.

Outliers

Outliers were defined as being data points with a standardised *Z* score above 3.29 (Tabachnick & Fidell, 2013). Outlier scores were identified using boxplots. Each outlier was assessed in comparison to the 5% trimmed mean as outlined by Pallant (2005). As none of the outliers had a notable influence on the difference between the original mean to the trimmed mean, all cases were retained.

Data Transformation

Items were reversed when indicated by the scale developer (i.e. for the gratitude questionnaire: GQ-6) and total scale scores calculated for the child difficulties scale (SCDC), hope scale (ADHS; not including filler items) gratitude, curiosity, wellbeing and parental changes scales (GQ-8, CEI-II, WEMWBS, and LMS-PCS). Time since diagnosis was computed using the child's current age minus age at diagnosis. Total number of current supports received for the child were calculated by summing the number of endorsed support types. This process was repeated for total number of past supports received. A dichotomy between education levels was created by re-coding responses of "no school qualification," and "secondary school qualification" as "*education*: *secondary school and below,*" and "post-secondary certificate, diploma, or trade diploma" and "university degree" as "*education: post-secondary school.*" A relationship dichotomy between single and partnered was also created by recoding responses of "single," "widowed/ a widower'" and "divorced/ separated" as "*not in a relationship*" and "in a partnered/ de-facto relationship," and "married/ in a civil union" as "*in a relationship.*"

During questionnaire data cleaning it was noted that on the SCDC the original three point Likert-type scale had been replaced with a five point Likert-type scale where *0 = none of the time, 1 = rarely, 2 = some of the time, 3 = often,* and *4 = all of the time* in error during questionnaire construction. As the intention was to use the SCDC to assess difficulty severity, the SCDC score magnitude was still able to be used in this study, but this meant mean comparisons were not attainable in final analysis.

Several variables were noted to deviate from the assumption of normality (assessed via scatter plots, skewness and kurtosis values). Log transformation was attempted, however found to provide no noteworthy difference to analysis results. Non-parametric testing was also trialled for correlational analysis, however in comparison to parametric testing, again, no noteworthy differences to analysis results were found, therefore parametric models were used.

Quantitative Data Analysis

Statistical analysis for Study Two was carried out using SPSS for Windows version 23. Firstly descriptive statistics were analysed in order to assess sample demographics for representativeness and sample normality. Descriptive statistics were also used to provide in-depth understanding of the stigma by association experience as captured by the C-SAM, and positive changes experienced by caregivers as captured by the LMS-PCS. Cronbach's alphas were computed to investigate internal reliability of the C-SAM and all scales used in the

questionnaire. For comparison of literature means and means of scales for this study, t-test analysis was used. Because the C-SAM was a newly established scale, an exploratory factor analysis was conducted to assess the underlying structure of the measure, and to assess construct validity. To assess the relationship between signature strength variables, the stigma by association variable, and the control variables and wellbeing, Pearson r correlations and regressions were used. Normal P-P plot analysis suggested slight deviation from normality for both the GQ-6 and ADHS scores, however it has been argued that regression is robust in the face of such deviations (Tabachnick and Fidell 2013).

To investigate if variables of hope, gratitude, or curiosity could moderate the impact of stigma by association on wellbeing, an interaction term was created, then multiple regression modelling was performed to assess whether significant interactions existed between these variables. To explore whether hope, gratitude or curiosity could mediate the impact of stigma by association on wellbeing, linear regression modeling was performed to establish whether predictive relationships existed between these variables, which was then input into the statistical software programme MedGraph (Jose, 2013a). MedGraph assesses the statistical significance of the mediation by calculating Sobel's Z-score, confidence intervals and effect sizes. Linearity, independence of error, multicollinearity and adequate sample size (using Tabachnick and Fidell's, rule of thumb [2013; p. 123] at least $N \geq 50 + 8m$ [where m is the number of IVs]) assumptions were satisfied for all mediation analyses.

Qualitative Data Analysis

The two open–ended questions were analysed using the same thematic analysis processes as those employed in Study One (pg 42; as outlined by Braun and Clarke 2006). Written responses to open-ended questions were analysed and sorted by question, then theme. For this analysis, a theme was established if three or more participants had written about experiences in this area. For both question 31 and 33 responses covered a wide range of responses, and were not distinctly separate, therefore the decision was made to analyse responses together.

Chapter Eleven:

Study Two Results

"People need to stop making assumptions based on what they think they see and know… Offer

help instead of criticism, acceptance and patience instead of judgments and assumptions."

(Participant 67)

This chapter outlines findings from analysis of data generated through the Study Two Questionnaire. An alpha level of 5% was used for all analyses in this thesis unless otherwise specified, and Cohen's (1988) guidelines for correlation size interpretation were used. In order to address the aims of Study Two, (as noted on page 74) analyses were conducted to examine the following five research questions:

- Q1: Do NZ caregivers of children with ASDs experience stigma by association?

- Q2: Does stigma by association have a negative relationship with the wellbeing of caregivers of children with an ASD?

- Q3: Which factors are positively related to caregiver wellbeing?

- Q4: Is the presence of higher levels of signature strengths such as hope, gratitude, and curiosity associated with higher levels of wellbeing in the face of stigma by association

- Q5: In spite of the negative experiences associated with raising a child with an ASD, can caregivers experience personal growth?

Statistical Analysis

Descriptive Statistics

Sample Characteristics

Of the total initial sample of 127 respondents who consented to participate, 111 met participation criteria, and 100 completed the questionnaire past initial demographic items. Demographic characteristics of the final sample are outlined in Table 11.1. Of the participants, 94% identified as female, and the average age was 42.31 years (SD = 7.5) with ages ranging from 26 to 69 years old. In regards to ethnicity, 84% identified as New Zealand European, 12% as Maori, 2% as Pacific Islander, and 16% as belonging to another ethnic group.   NZ Government statistics (Statistics New Zealand, 2013a) indicate that 48.7% of our population is male and 51.3% female, a significant gender difference to this sample. In comparison to the national statistics for ethnicity of respondents (74% NZ European, 14.9% Maori, 7.4% Pacific peoples, 11.8% Asian, 1.2% Middle Eastern, Latin American, or African and 1.7% other,

Statistics New Zealand, 2013b) this sample was under-represented by Maori, Pacific Island and Asian caregivers.

Table 11. 1
Caregiver Demographic Characteristics, N = 100

Caregiver characteristic		*n* (and %)
Gender	Female	94
	Male	6
Ethnicity	New Zealand European/ Pakeha	84
	Maori	12
	Pacific Peoples	2
	European 'other'	12
	Other	4
Marital status	Single	10
	In a partnered/ de facto relationship	14
	Married/ in a civil union	60
	Divorced/ separated	15
	Data missing	1
Education	No school qualification	4
	Secondary school qualifications (e.g., School Certificate, University entrance, NCEA)	19
	Post-secondary certificate, diploma, or trade diploma	28
	University degree	43
	Other	6
Employment status	Full-time paid employment ($\geq$ 35 hours per week)	23
	Part-time paid work (<35 hours per week)	40
	Retired	1
	Full-time homemaker/ caregiver	19
	Full-time student	4
	Unable to work due to health or disability issue	2
	Unemployed	4
	Other	7
Home ownership	Yes	75
	No	25
Previous experience with ASD	Yes	15
	No	84
	Data missing	1
Relationship to the child	Biological parent	91
	Adoptive/ whāngai parent	3
	Unpaid caregiver	1
	Step parent	1
	Grandparent	3
	Foster parent	1
	Data missing	1

The majority of respondents indicated they were employed (full-time, 24%; or part-time, 40%), and 23% of respondents considered themselves to be full-time homemaker/caregivers or

home educators. Most respondents indicated they were in a relationship, (partnered, married or civil union; 74%), while 25% were single or divorced (1 missing data on relationships). Over three quarters of respondents had completed qualifications above high school level, and a similar number owned their own home, suggesting both higher education, and socio-economic status of this sample.

Respondents completed the questionnaire with reference to their oldest child with an ASD. Relationships to the child included biological parent (91%), adoptive/whāngai parent (3%), grandparent (3%), step parent (1%), unpaid caregiver (1%), and foster parent (1%). The child was in the care of the respondent full time for 96% of respondents, and the majority of the time for the remaining 4%. Table 11.2 presents the characteristics of the children as reported by participants. Ages of children ranged from 3 to 16 years old, with a mean age of 8.42 years (*SD* = 3.48). The majority of children had a diagnosis of autistic disorder (57%), whilst 31% were identified as having Asperger's disorder, 6% as having "ASD," 3% pervasive developmental disorder not otherwise specified (PDD-NOS), and 3% as *other*. Additional diagnoses included dyspraxia, fetal alcohol spectrum disorder (FASD), "anxiety disorder," attention deficit hyperactivity disorder (ADHD), epilepsy, and tuberous sclerosis. Participant responses indicated 65% of referenced children received their diagnosis before age six. Eighty-eight percent of children were currently receiving some form of professional support, with the majority receiving input from school support staff (54%), financial support (42%) and/or specialist physicians (paediatricians or psychologists; 50%). Responses indicated only 6% of children had not had any financial or professional intervention in the past. The majority had previously received support from specialised physicians (74%), therapy providers (speech, occupational therapy, or behavioural; 64%) and/ or school support staff (60%).

A mean item rating of the child's current difficulties over the past six months using the Social and Communication Disorders Checklist (SCDC; see Appendix P, Table P.1) of above 4 (*often* to *always*) suggested that the most commonly reported difficulty the child had was that they were *"difficult to reason with when upset"* reported by 75% of caregivers. The difficult behaviour reported to be experienced by caregivers the least was getting the child to *"respond when told to do something"* (mean score between 2 and 3). At least two thirds of respondents indicated that their child was *often* or *always: "unable to notice the effect of his/her behaviour on other members of the family"* (65%), *"very demanding of other people's time"* (70%), *"did*

not understand social skills" (70%) and *"did not realise if s/he offended people with her/his*

behaviour" (72%).

Table 11. 2
Child Demographic Characteristics, N = 100

		N (and %)	n Current	n Past (no longer used)
Gender				
	Male	85		
	Female	15		
Diagnosis				
	Autistic disorder	57		
	Asperger's disorder	31		
	PDD(NOS)	3		
	Other	7		
	Missing data	2		
Supports utilised				
	Support groups		10	22
	Respite care		34	37
	Financial assistance		42	37
	Counseling services		8	21
	Case management		7	11
	ASD support organisations		26	37
	School support staff		54	60
	Primary care provider (GP, nurse etc)		34	44
	Specialised physicians (Paediatrician, Psychologist)		50	74
	Therapy providers (Speech, Occupational Therapy, Behavioural)		22	64
	Traditional healer		1	3
	Other		7	2
	No current/ past supports		12	6

Sample Scale Analyses, Comparisons and Psychometrics

Comparisons between total scale scores of study variables and scores reported in the

literature for general population samples were conducted when data was available. Results of

mean comparisons suggested this study's sample experienced a lower level of wellbeing

(WEMWBS scale; N = 94, M = 46.5, SD = 9.25) than found in the University College of London's

(2011) adult sample (N = 7020, M = 51.6, SD = 8.7) at a statistically significant level, t(7112) =

5.64, p = <.001. Further, Cohen's effect size value, d = -0.59, suggested the size of the

differences between means was *moderate*.   Frequency analysis of wellbeing scale items

suggested that on average caregivers were least likely to endorse feeling they had energy to

spare or relaxed, and most likely to endorse feeling loved and able to make up their own mind

(see Appendix P, Table P2).

Mean comparisons with existing means for the curiosity scale (CEI-II; using the mean from Kashdan et al., 2009) and gratitude scale (GQ-6; using the mean from Mc Cullough et al., 2002) indicated a significant difference, with this study sample experiencing less curiosity, $t(404)$ = 4.13, p = <.001. d = -0.48, and gratitude, $t(4015)$ = 1.04, p = <.001. d = -0.48, however effect sizes indicated these differences were *small*. No significant difference was found in average levels of hope (ADHS scale) between the literature (Lopez et al., 2000) and this sample, $t(4015)$ = 1.04, p = .30 (see Table 11.3 for sample scale means). Data was unavailable for comparison between this sample and previous studies for the Positive Changes subscale (LMS-PCS), and the change to how the child's difficulties (using the SCDC scale) were rated meant means were unable to be compared to previous samples means. For literature scale means see Appendix P, Table P.3.

Table 11. 3
Descriptive Statistics and Internal Reliability of the Questionnaire Variables

Variable (Scale, *n* items)	N	M (SD)	95% CI	α
Wellbeing (WEMWBS, 14)	94	46.50 (9.25)	[44.61, 48.39]	.94
Curiosity (CEI-II, 10)	95	29.83 (7.55)	[28.29, 31.37]	.89
Gratitude (GQ-6, 6)	99	34.52 (5.40)	[33.43, 35.60]	.80
Hope (ADHS, 8)	97	48.70 (7.77)	[47.19, 50.32]	.87
Physical Health (1)	94	5.30 (2.26)	[4.85, 5.77]	-
Stigma by Association (C-SAM, 20)	96	54.75 (19.38)	[50.82, 58.68]	.96
Positive Changes (LMS-PCS, 18)	94	66.08 (9.98)	[64.04, 68.13]	.87
Social Support				
- Spouse/significant other (1)	97	4.26 (2.04)	[3.85, 4.67]	-
- Family (1)	96	3.76 (1.80)	[3.40, 4.12]	-
- Friends (1)	97	4.6 (1.40)	[4.31, 4.89]	-
Child's Difficulties (SCDC, 12)	96	41.4 (5.97)	[40.23, 42.63]	.80
Total number of Current Supports (1)	100	2.95 (2.07)	[2.54, 3.36]	-
Total number of Past Supports (1)	100	4.12 (2.45)	[3.63, 4.61]	-
Number of other Adults Available (1)	100	1.00 (0.73)	[0.86, 1.14]	-
Child Age at Diagnosis (years, 1)	92	3.45 (3.14)	[2.80, 4.09]	-
Time since Diagnosis (years, 1)	92	5.02 (3.61)	[4.27, 5.77]	-

Reliability analyses were conducted on scales used in the study and compared with previously reported data to assess whether the measures had consistently captured the proposed construct. Scale reliabilities of the WEMWBS, CEI-II, GQ-6, ADHS, and LMS-PCS measures for this sample reflected those previously reported in the literature (for further information on scale reliability, total score means and 95% confidence intervals see Appendix P, Table P.4). While the change to the rating scale used in the SCDC for this study meant a comparison could not be made to previous data; reliability analysis for this sample suggested a *good* level of inter-item reliability, α = .80.

C-SAM Psychometrics

As the Caregiver Stigma by Association Measure (C-SAM) was a new measure, an analysis of item means and intercorrelations, the factor structure, score characteristics, and psychometric properties was conducted. The following is a summary of these results.

C-SAM Factor Analysis

To examine the factor structure of the C-SAM, exploratory factor analysis was performed using the entire 20 items measuring the subjective stigma by association experience. Principal components analysis (PCA) with varimax rotation was used, where factors were allowed to correlate. This method of PCA was chosen because different stigma by association experiences were assumed to be related. The Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was .933, while Bartlett's test of sphericity was highly significant, x^2 = 1693, df 190, p <.001, indicating it was appropriate to proceed with the factor analysis. Scree plot and eigenvalue criteria (as outlined by Tabachnick and Fidell, 2013) suggested one large factor explained 55.78%of the total item variance (see Appendix P, Figure P.1 for scree plot). No items were removed due to low KMO values or multicollinearity. The results of the PCA are presented in Table 11.4 and suggest that the use of a total C-SAM score is appropriate.

Table 11. 4
Principal Component Analysis Results of One Factor Solution for the C-SAM

Item	Component 1
Stressed	.76
Self-conscious	.77
Frustrated	.74
Embarrassed	.71
Rejected	.79
Angry	.77
Vulnerable	.76
Tense	.72
Hopeless	.75
Worried	.79
Look down on me	.83
Seem to pity me	.59
Don't want to listen	.65
Tense around me	.75
Don't want to be around me	.77
Make rude comments	.66
Awkward around me	.82
Think I'm a bad caregiver	.76
Stare or glare at me	.84
Avoid me	.79

NOTE: a coefficient cut off of .45 was used for inclusion of a variable in interpreting a factor as per Tabachnik and Fidell (2013)

C-SAM Scale Validity and Reliability

The full C-SAM scale had an internal consistency of .96, comparable to the initial pilot internal consistency (.94). Inter-item correlation analysis and satisfactory corrected item-total correlations suggested that all items had large correlations with the total score. Table 11.5 reports the corrected item-total correlations and alpha if item removed for the scale.

C-SAM Score Characteristics

This sample's total C-SAM scores ranged from 20 to 109, covering the majority of the available score range (20 to 120). The mean score was 54.75 (*SD* = 19.38, *CI* [50.82, 58.68]) with a median score of 53. Individual item means ranged from 2.13 to 3.74 (see Table 11.5).

Table 11.5

Analysis Results of the Caregiver Stigma by Association Measure (C-SAM) Item Scoring and Item Correlations, N = 100

C-SAM Item	n responses	% endorsement of response categories*						Item M (SD)	95% CI	Corrected item-total correlation	Total scale α if item removed
		1	2	3	4	5	6				
Stressed	99	6.1	14.1	24.2	23.2	20.2	12.1	3.74 (1.41)	[3.43, 4.00]	.72	.96
Self-conscious	100	21	15	27	21	11	5	3.01 (1.45)	[2.69, 3.27]	.73	.96
Frustrated	100	5	24	23	28	16	4	3.38 (1.26)	[3.11, 3.62]	.71	.96
Embarrassed	100	32	28	14	15	9	2	2.47 (1.41)	[2.15, 2.71]	.66	.96
Rejected	100	44	22	11	17	3	3	2.22 (1.40)	[1.90, 2.46]	.74	.95
Angry	100	20	37	28	8	7	0	2.45 (1.11)	[2.19, 2.64]	.73	.96
Vulnerable	100	24	26	20	13	17	0	2.73 (1.41)	[2.43, 3.00]	.72	.96
Tense	100	8	18	21	25	19	9	3.56 (1.42)	[3.26, 3.84]	.70	.96
Hopeless	99	39.4	29.3	19.2	3	9.1	0	2.13 (1.23)	[1.87, 2.36]	.70	.96
Worried	100	11	18	28	20	15	8	3.34 (1.43)	[3.03, 3.61]	.78	.95
Look down on me	100	22	23	32	13	9	1	2.67 (1.26)	[2.37, 2.88]	.80	.95
Seem to pity me	100	28	26	25	14	7	0	2.46 (1.23)	[2.18, 2.68]	.54	.96
Don't want to listen to me	98	29.6	25.5	20.4	14.3	9.2	1	2.51 (1.35)	[2.22, 2.76]	.61	.96
Are tense around me	99	26.3	22.2	33.3	13.1	3	2	2.51 (1.22)	[2.22, 2.70]	.70	.96
Don't want to be around me	100	24	26	21	19	6	4	2.69 (1.39)	[2.36, 2.91]	.72	.96
Make rude comments	100	21	41	24	12	2	0	2.33 (1.01)	[2.10, 2.50]	.60	.96
Awkward around me	100	15	26	36	18	3	2	2.74 (1.13)	[2.47, 2.93]	.78	.95
Think I'm a bad caregiver	100	23	12	32	21	9	3	2.90 (1.37)	[2.57, 3.12]	.72	.96
Stare or glare at me	100	18	20	27	19	12	4	2.99 (1.40)	[2.67, 3.24]	.81	.95
Avoid me	99	29.3	21.2	23.2	18.2	5.1	3	2.52 (1.35)	[2.25, 2.79]	.75	.95

*Scale α = 0.96. *Responses: 1 – never, 2 – once in a while, 3 – sometimes, 4 – quite often, 5 – frequently if not always, 6 - always*

Exploratory Analysis

Q1: Do NZ Caregivers of Children with ASDs Experience Stigma by Association?

In order to assess stigma by association experiences of the sample, item response frequencies were assessed. The most commonly endorsed stigma experience over the past six months was *"feeling stressed when out with (the child) in the community"* (reported as *always, frequently if not always, or quite often* by 55.5% of respondents) followed by feeling tense (53% rated *always, frequently if not always* or *quite often*) and frustrated (48% rated *always,* frequently *if not always or quite often*). Mean item scores of 3 or higher (suggesting frequency of occurrence at least *sometimes*) were achieved for six of the twenty items, where caregivers reported the following experiences when out in the community with their child occurred at least *sometimes* over the past six months: feeling self-conscious, worried, and as though people stare or glare at them. All item means sat at a score of 2 or higher, suggesting that on average respondents at least *once in a while* encountered stigma by association over the past six months. Conversely, 44% of respondents reported that over the past six months when out in public with their child they had *never* felt rejected, 40% indicated they had *never* felt hopeless, and 32% said they had *never* felt embarrassed. These results suggest the majority of participants in this study experienced stigma by association often, with all participants having encountered at least one example of stigma by association over the past six months.

To explore whether individual caregiver variables contributed to variation in the severity of stigma by association, Pearson product-moment correlation coefficients were calculated to examine these relationships. Prior to correlation calculations, preliminary analyses were conducted to ensure no violations of assumptions associated with normality, linearity and homoscedascity. Results as seen in Table 11.6 suggest total stigma by association has a significant *medium* sized negative relationship with physical health satisfaction, hope, gratitude, positive changes, and caregiver age, a significant *medium* positive relationship with the reported level of child's difficulties, and a significant *small* positive relationship with caregiver socioeconomic position. No significant relationship was found between satisfaction with support from significant other, friends, or family and severity of stigma by association experience.

Table 11. 6

Pearson's Correlations Between Stigma by Association, Wellbeing, Signature Strengths, Positive Change, and Caregiver Variables

Variables (scale name)	r(p)					
	1	2	3	4	5	6
Key Variables						
1. Stigma By Association (C-SAM)						
2. Wellbeing (WEMWBS)	**-.54 (*)**					
3. Hope (ADHS)	**-.39 (*)**	**.67 (*)**				
4. Gratitude (GQ6)	**-.34 (*)**	**.61 (*)**	**.54(*)**			
5. Curiosity (CEI-II)	-.17 (.11)	**.35 (*)**	**.54 (*)**	**.26 .01**		
6. Positive Changes (LMS-PCS)	**-.39 (*)**	**.58 (*)**	**.42 (*)**	**.36(*)**	**.35 (*)**	
Control Variables						
Caregiver Physical Health Satisfaction	**-.37 (*)**	**.63 (*)**	**.32 (.002)**	**.40 (*)**	.04 (.74)	.20 (.06)
Social Support Family	-.11 (.28)	**.24 (.02)**	.08 (.43)	.10 (.36)	-.12 (.24)	.17 (.10)
Social Support Friends	-.19 (.07)	**.27 (.01)**	.18 (.08)	.02 (.83)	.04 (.67)	**.28 (.008)**
Child's Difficulties (SCDC)	**.42 (*)**	-.16 (.14)	-.16 (.13)	-.13 (.20)	-.01 (.94)	-.07 (.52)
Demographic Variables						
Caregiver Age	**-.37 (*)**	.12 (.27)	-.07 (.52)	-.03 (.78)	-.03 (.79)	-.06 (.55)
Number of Other Available Adults	.01 (.69)	-.04 (.69)	-.13 (.21)	.15 (.15)	**-.20 (.05)**	-.19 (.07)
Total Number of Current Supports Received	.19 (.06)	.01 (.94)	-.07 (.52)	-.07 (.51)	-.08 (.47)	**.23 (.03)**
Socio-economic population	**.24 (.02)**	-.02 (.86)	-.03 (.75)	-.02 (.84)	.06 (.56)	.14 (.18)

NOTEs: **bold** = significant. (*) = p <.001. Variables not reported above as no significant relationships were found include: Social Support Spouse/ Partner, Caregiver Previous Experience with ASD, Child Age, Time Since Diagnosis, Child Age at Diagnosis, Total Number of Past Supports Received and Caregiver Education Level (high school or post high school). Insufficient data was available to explore the following variables: Caregiver Gender, Child Gender, and Ethnicity.

Q2: Does Stigma by Association Have a Negative Relationship with the Wellbeing of Caregivers of Children with an ASD

Correlation coefficients were also used to assess the relationship between stigma by association and subjective wellbeing. Stigma by association had a *large* negative and significant relationship with wellbeing, with high stigma by association scores associated with low wellbeing scores, see Table 11.6. These results suggest the experience of stigma by association is negatively related to wellbeing.

Q3: Which Factors are Positively Related to Caregiver Wellbeing?

Correlation analysis was also used to explore the relationship between key and control variables and wellbeing. Preliminary analyses revealed that both ADHS and GQ-6 score distributions were negatively skewed, however a comparison of parametric and non-parametric models (Pearson's *r* and Spearman's *r*) suggested no prominent difference in findings. Therefore the decision was made to continue analyses using parametric models for the hope and gratitude variables. In order to explore the hypotheses that a relationship exists

in the expected directions, and independence of variables, the correlation coefficient was used to investigate the relationships between study variables and wellbeing.

As can be seen in Table 11.6, key variables of hope, gratitude, curiosity, and positive changes were all found to have positive and significant relationships with wellbeing. Hope, gratitude, and positive changes were found to have *large* positive relationships with wellbeing; while the strength of the relationship between wellbeing and curiosity was *medium* and positive.

Correlation coefficients were also used to assess the relationship between wellbeing and other caregiver variables. Results suggested that higher levels of physical health satisfaction, satisfaction with support from family, and satisfaction with support from friends were all significantly and positively related to higher wellbeing. Unsurprisingly physical health had a *large* positive relationship with wellbeing. Satisfaction with support from family, and satisfaction with support from friends were both found to have *small* sized positive relationships with wellbeing; yet, of note the relationship between satisfaction with support from spouse/ partner/ significant other was not significant. These correlational analyses suggest that caregiver factors such as personal strengths of hope, gratitude, curiosity, experiences of positive change, and variables such as support from family, support from friends and physical health are positively related to wellbeing.

Q 4: Is the Presence of Higher Levels of Signature Strengths such as Hope, Gratitude, and Curiosity Associated with Higher Levels of Wellbeing in the Face of Stigma by Association?

Moderation Analysis

As previous studies suggested the presence of signature strengths such as hope, gratitude or curiosity buffer the effects of stress on wellbeing a (see pp. 29 – 33), moderation analyses of the stigma by association and wellbeing relationship were conducted. To begin with, a standard regression analysis was performed to assess which of the variables that had been shown to significantly correlate with WEMWBS scores (see Table 11.6) were important in the prediction of WEMWBS scores.

Variables that significantly correlated with wellbeing (that is physical health satisfaction, stigma by association, hope, gratitude, curiosity, positive changes, satisfaction with support from family, and satisfaction with support from friends) were entered simultaneously as

predictor variables. The total model explained 78% of the variance in WEMWBS scores, $F(8,68)$ = 30.27, p <.001, R^2 = .76 with a large effect size, f^2 = 3.17. Each variable was then individually regressed with WEMWBS scores in order to explore how much they contributed to the prediction of subjective wellbeing scores. Results are presented in Table 11.7.

All variables were found to significantly predict variance in wellbeing scores. Physical health satisfaction scores predicted 39% of the variance in WEMWBS scores, stigma by association 29%, hope 45%, gratitude 38%, curiosity 12%, positive changes 34%, social support: family 6% and social support: friends 7%. As hope and gratitude scores significantly correlated with stigma by association scores they qualified for further investigation regarding their moderating potential (Jose, 2013b).

Table 11. 7

Results Individual Regression Analysis Results of Significant Correlates with WEMWBS Scores

Independent variable	β	B [95% CIs]	SE B	R^2	Cohen's f^2	p
Physical Health Satisfaction	.63	2.56 [1.88, 3.24]	.34	.39	0.64	<.001
Stigma by Association	-.54	-0.25 [-0.34, -0.17]	.42	.29	0.41	<.001
Hope	.67	0.77 [0.59, 0. 95]	.09	.45	0.82	<.001
Gratitude	.61	1.02 [0.75, 1.30]	.14	.38	0.61	<.001
Curiosity	.35	0.43 [0.18, 0.67]	.12	.12	0.14	.001
Positive Changes	.58	0.55 [0.39, 0.71]	.08	.34	0.52	<.001
Social Support Family	.24	1.21 [0.16, 2.26]	.53	.06	0.06	.024
Social Support Friends	.27	1.70 [0.41, 2.99]	.65	.07	0.08	.010

DV= WEMWBS scores

   Stigma by Association, Hope, and Wellbeing Moderation Analysis.
In order to assess whether hope moderates the relationship between stigma by association and wellbeing, an interaction term of the independent variable (IV; stigma by association) multiplied by the moderator variable (ModV; hope) was created (as per Jose 2013b). Next a hierarchical regression with wellbeing as the dependent variable (DV) and stigma by association entered as the predictor in block one, hope entered as the predictor in block two, and the interaction term as the predictor in block three was calculated. A significant main effect was found for hope, β = .56, p <.001, confirming the basic relationship that higher levels of hope were associated with increased wellbeing, however the interaction between stigma by association, hope and wellbeing was not significant, β = -.051, p = .52, suggesting hope did not act as a moderator.

   Stigma by Association, Gratitude, and Wellbeing Moderation Analysis.
The moderation analysis as outlined previously was repeated for the gratitude variable. Wellbeing was entered as the dependent variable (DV) and stigma by association entered as

the predictor in block one, gratitude entered as the predictor in block two, and the interaction term (stigma by association x gratitude) as the predictor in block three. A significant main effect was found for gratitude, β = .53, *p* <.001, confirming the basic relationship that higher levels of gratitude were associated with increased wellbeing however the interaction between stigma by association, gratitude and wellbeing was, again, not significant, β = -.103, *p* =.23.

Stigma by Association, Curiosity, and Wellbeing Moderation Analysis.
Moderation analysis was conducted for the curiosity variable. Wellbeing was entered as the dependent variable (DV) and stigma by association entered as the predictor in block one, curiosity entered as the predictor in block two, and the interaction term (stigma by association x curiosity) as the predictor in block three. A significant main effect was found for curiosity, β = .26, *p* = .005, confirming the basic relationship that higher levels of curiosity were associated with increased wellbeing. However the interaction between stigma by association, curiosity and wellbeing was not significant, β = .032, *p* =.71.

In summary, the hypothesis that signature strengths of hope, gratitude and curiosity buffer the effects of stigma by association via a moderation relationship was not supported for this sample of caregivers of children with ASDs.

Mediation Analysis

As results above suggested the chosen signature strengths did not moderate the relationship between stigma by association and wellbeing, further exploratory analyses were conducted, this time assessing mediating properties.

Stigma by Association, Hope, and Wellbeing Mediation Analysis.
Three regression analyses were conducted to assess the mediating effects of hope (using the ADHS) as per mediation procedures outline by Jose (2013b). First, as noted above, wellbeing scores were regressed onto stigma by association scores. Stigma by association scores were found to significantly predict wellbeing scores (see Table 11.7). Second, hope was regressed onto stigma by association; stigma by association was found to be a significant predictor of hope (Table 11.8).

Finally, wellbeing scores were simultaneously regressed onto stigma by association and hope scores (Table 11.8); the path from stigma by association, through hope to wellbeing was found to be significant, *p* <.001, and the standardised regression value reduced in comparison to the first regression (a condition of mediation, Jose 2013b). Using MedGraph (Jose 2013b) the

sample size, intercorrelations, unstandardised and standardised regression coefficient, standard errors, part correlations and R^2 values were entered in order to analyse the strength of the relationship.

Table 11. 8

The Unstandardised Beta Values, Standardised Beta Values, R^2, Effect Sizes, and Significance for a Regression of Wellbeing on Stigma by Association and Hope

	β	B [95%CI]	SE B	R^2	Cohen's f^2	P
Regression 1 (DV= Wellbeing)						
Stigma by Association	-.54	-0.25 [-0.34, -0.17]	0.042	.29	0.41	<.001
Regression 2 (DV = Hope)						
Stigma by Association	-.39	-0.16 [-0.24, -0.08]	0.039	.15	0.18	<.001
Regression 3 (DV = Wellbeing)						
Stigma by Association	-.33	-0.15 [-0.23, -0.08]	0.037			
Hope	.54	0.62 [0.44, 0.80]	0.091			
R3 Total				.54	1.17	<.001

Results as shown by Table 11.8 and summarised by Figure 11.1 suggest that the subjective wellbeing of caregivers was affected less by stigma by association if the caregiver reported more hope, as hope is a significant partial mediator of the relationship between stigma by association and wellbeing, Sobel's Z = -3.51, *p* < .001. Hope accounted for 49% of the basic interaction between stigma by association and wellbeing, R^2 = .54, F(1,87) = 51.31, *p* <.001 with a *large* effect size, f^2 = 1.17. Originally for every point increase in stigma by association scores, wellbeing scores decreased 0.25 points. However following mediation by hope scores, for every point increase in stigma by association scores wellbeing scores only decreased 0.15 points (unstandardised indirect effect -0.10, 95% *CI* [-0.16, -0.04]).
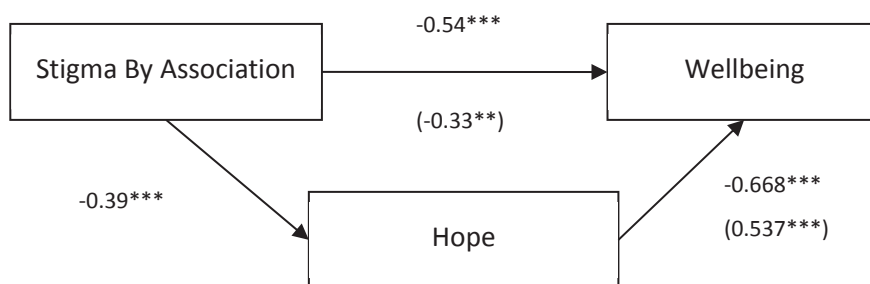
Figure 11. 1. Effects of stigma by association and hope on wellbeing, with standardised regression coefficients shown in parentheses (*N* = 87)

Stigma by Association, Gratitude, and Wellbeing Mediation Analysis
Regression analyses were again conducted, this time to assess the mediating effects of Gratitude (using the GQ-6 measure). Wellbeing scores regressed onto stigma by association scores were now known to significantly predict wellbeing scores (Table 11.7). Gratitude was

regressed onto stigma by association; stigma by association was found to be a significant predictor of gratitude (Table 11.9). Next wellbeing scores were simultaneously regressed onto stigma by association and gratitude scores (Table 11.9); the path from stigma by association, through gratitude to wellbeing was found to be significant (p <.001) and the standardised regression value reduced in comparison to the first regression.

Table 11. 9
The Unstandardised Beta Values, Standardised Beta Values, R^2, Effect Size and Significance for a Regression of Wellbeing on Stigma by Association and Gratitude

	β	B[95% CI]	SE B	R^2	Cohen's f^2	p
Regression 1 (DV= Wellbeing)						
Stigma by Association	-.54	-0.25 [-0.34, -0.17]	0.042	.29	0.41	<.001
Regression 2 (DV = Gratitude)						
Stigma by Association	-.34	-1.20 [-1.88, -0.52]	0.34	.12	0.14	.001
Regression 3 (DV = Wellbeing)						
Stigma by Association	-.36	-0.17 [-0.24, -0.09]	0.038			
Gratitude	.49	0.81 [0.54, 1.08]	0.135			
R3 Total				.49	0.96	<.001

MedGraph was again used to analyse the strength of the relationship. Results, as shown by Table 11.9 and summarised by Figure 11.2 suggest the subjective wellbeing of caregivers was affected less by stigma by association if the caregiver reported more gratitude, as gratitude is a significant partial mediator of the relationship between stigma by association and wellbeing (Sobel's Z = -2.99, p = .003). Gratitude accounted for 31% of the basic relationship between stigma by association and wellbeing, R^2 =.49, F(2,88) = 41.67, p <.001, with a *large* effect size, f^2 = 0.96. Originally for every point increase in stigma by association scores, wellbeing scores decreased 0.25 points. Following mediation by gratitude scores, for every point increase in stigma by association scores wellbeing scores only decreased 0.17 points (unstandardised indirect effect -0.09, 95% CI [-0.13 to -0.03]).

Figure 11. 2. Effects of stigma by association and gratitude on wellbeing, with standardised regression coefficients shown in parentheses (*N* = 88)

Stigma By Association, Curiosity, and Wellbeing Mediation

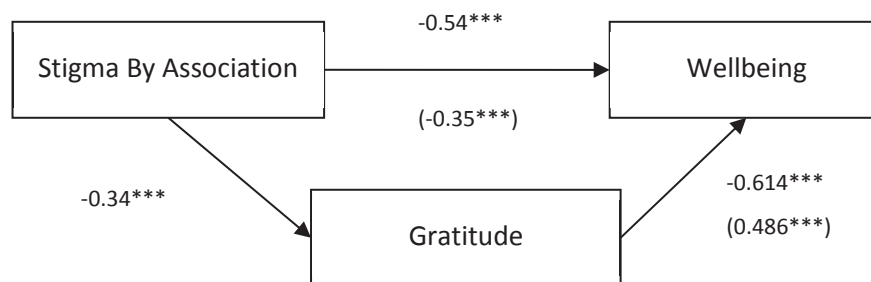As there was no significant relationship between curiosity and stigma by association ($r =$ -.17, $p = .11$) curiosity did not meet the precondition for testing mediation effects.

In summary, while there were no significant results suggesting a moderating relationship between signature strengths of hope, gratitude or curiosity and the stigma by association and wellbeing relationship, mediation analysis suggests that both hope and gratitude can significantly influence the interaction between stigma by association and wellbeing.

Q5: In Spite of the Negative Experiences Associated with Raising a Child with an ASD, can Caregivers Experience Personal Growth?

In order to assess the positive changes experienced by participants, frequency and mean of item responses to the positive changes subscale (LMS-PCS) were assessed. For the 98 respondents who responded to the scale (two participants dropped out prior to completing this scale), the total scale mean score was 66.09 ($SD = 9.98$) with a range of scores for the sum of all 18 items between 44 and 90 (minimum possible score 18 and maximum possible score 90). Table 11.10 reports on all 98 respondents' frequency of endorsements for each of the five response ratings per item, the mean item score and standard deviation for all 18 items.

All respondents indicated they had noticed at least three positive changes in themselves through the experience of raising their child, with on average 10.84 positive changes endorsed ($SD = 4.28$, range 3 to 17). Mean item scores of 4 or greater (rating *agree* and *strongly agree*), where caregivers reported positive changes in themselves due to their experience with their child were achieved for six of the eighteen items. The most common of these experiences was reported to be *"I have learned to speak out for my family member,"* (93 participants). The majority of participants also endorsed the following responses: *"I have learned that I can achieve rather than feel powerless," "I am more compassionate toward others," "I am stronger as a person," "I have learned to see life from a different perspective,"* and *"I have learned what is really important and valuable in life."*

Table 11. 10

LMS-PCS Item Rating Frequencies, Item Means, and Standard Deviations (N = 98)

LMS-PCS Item	*n* responses	1	2	3	4	5	Item *m (SD)*
		n endorsement of response categories*					
I have learned to speak out for my family member	98	0	0	5	36	57	4.53 (.60)
I have learned that I can achieve rather than feel powerless	97	0	2	24	40	31	4.03 (.81)
I am more compassionate toward others	98	0	2	7	37	51	4.42 (.72)
I have made a career change, which has lead to greater vocational satisfaction	98	9	27	23	17	22	3.16 (1.31)
I am stronger as a person	98	0	2	10	47	39	4.26 (.72)
I am more confident	97	0	10	27	38	22	3.74 (.93)
I take better care of myself	97	4	38	24	24	7	2.92 (1.05)
I have stronger spiritual convictions now	98	11	31	26	18	12	2.89 (1.20)
I have made many close friends with people I would have never met otherwise	98	6	30	17	25	20	3.23 (1.26)
I have learned to see life from a different perspective	98	0	4	8	43	43	4.28 (.78)
I have made a difference in the lives of other people	98	0	16	27	33	22	3.62 (1.01)
I make the most out of each day rather than living for the future	98	1	10	30	45	12	3.58 (.87)
I celebrate life more now	98	3	21	29	34	11	3.30 (1.03)
I have a different and more genuine view of what it means to be successful in life	98	1	9	21	44	23	3.81 (.94)
I have learned what is really important and valuable in life	97	1	3	18	42	33	4.06 (.86)
I have developed new skills that have helped me to do a better job in my career/vocation	97	2	10	24	36	25	3.74 (1.02)
I have developed attitudes that have helped me to do a better job in my chosen career/vocation	98	1	8	31	35	23	3.72 (.95)
My marriage/ relationship has emerged stronger	98	23	20	19	23	13	2.83 (1.38)

*1 = *strongly disagree*, 2 = *disagree*, 3 = *not sure*, 4 = *agree*, 5 = *strongly agree*.

Item mean scores below a score of three for the following statements indicated that many caregivers disagreed or strongly disagreed with these as positive changes: *"I take better care of myself," "I have stronger spiritual convictions now,"* and *"my marriage/ relationship has emerged stronger."* Responses from caregivers were relatively evenly distributed across all response categories for the items *"I have made a career change which has led to greater vocational satisfaction,"* and *"I have made many close friends with people I would have never met otherwise."* Items: *"I make the most out of each day rather than living for the future," "I have developed attitudes that have helped me to do a better job in my chosen career/vocation," "I celebrate life more now," "I have made a difference in the lives of other people"* and *"I am more confident"* revealed the most ambivalence in respondents with the most *not sure* responses (approximately 30% of all responses).

Together these results provide insight into changes caregivers commonly noticed in themselves as a result of their experience raising their child. The data suggested that all caregivers could identify ways in which they had grown, with most participants able to identify various areas in which they had experienced this growth.

On the whole, results this far have largely enabled us to address the posed research questions. In order to assess participant perceptions of whether the questionnaire missed important information, qualitative results from open ended questions were analysed next.

Qualitative Analysis

Responses to the two open ended questions represented both difficult and positive experiences, reflecting findings of Study One. Sixty-one participants responded to the question *"are there any other experiences or changes in your life you would like us to know about which have not been mentioned?,"* of which 59 were analysed further (the remaining two responses just stated "no"). Thirty-seven participants responded to the question *"are there any other situations, thoughts, experiences or feelings you would like to add we haven't covered?"* Thirty-three of these responses were analysed further (three of the remaining responses just stated "no," while the fourth was a participant's "thanks.") To aid interpretation, theme names were kept consistent with Study One where appropriate. Difficult experiences reported by Study Two participants were framed under the theme *"having a child with an ASD is hard"* and positive experiences framed as *"having a child with an ASD is not all bad."*

Study Two: Having a Child with an ASD is Hard

Caregiver responses representing experienced difficulties so closely mirrored difficulties discussed in Study One under the overarching theme "h*aving a child with an ASD is hard"* that a similar map could be produced representing these difficulties. This map is represented as Figure 11.3. Figure 11.3 shows main themes of *"practical restrictions," "personal costs"* and *"social stigma",* and the subthemes these themes represent. As the *"social stigma"* theme is of specific interest to Study Two, this theme will be covered following. For more information relating to themes of *"practical restrictions"* and *"personal costs,"* see Appendix Q.

Social Stigma

Linked to experiences of *practical restrictions* and *personal costs* themes were the experiences of *social stigma* referenced by Study Two respondents. Replicating findings of Study One, participants in Study Two identified numerous examples of both *"experienced stigma"* and *"internalised stigma."*
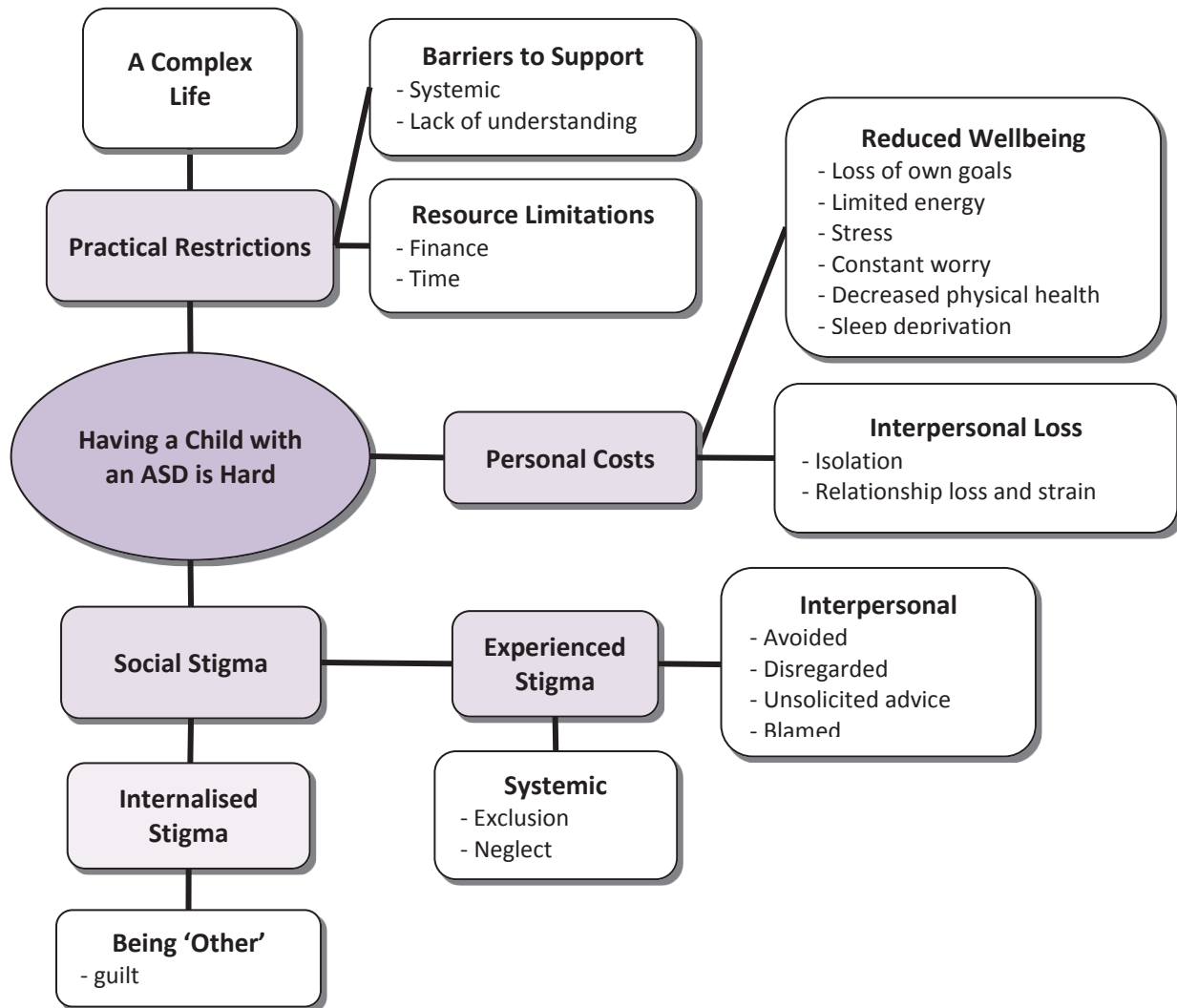
Figure 11. 3. Map of themes for Study Two related to the overarching theme: Having a child with an ASD is hard

Experienced Stigma

As per Study One findings, supplementary experienced stigma examples described by participants of Study Two included examples of both *"interpersonal stigma"* and *"systemic stigma."*

Interpersonal Stigma

Examples of interpersonal stigma described by participants included experiences which came under the themes *"disregarded," "avoided," "unsolicited advice,"* and *"blamed."* Six

participants felt it was important to add to their questionnaire responses experiences of feeling disregarded by others. For example:

> *… when you announce that your child has an ASD, my parents in law became angry at me when I tried to tell them and even implied it was all in my imagination.* (Participant 33)

Respondents referenced examples where they found, due to their child's ASD, that they were avoided:

> *Most people find it easier to ignore us than to get involved. Of course there are some wonderful people who have helped us who are the exception.* (Participant 115)

Respondents seemed frustrated by the way in which others felt they could offer unsolicited advice, and at times criticism:

> *People need to stop making assumptions based on what they think they see and know… Offer help instead of criticism, acceptance and patience instead of judgments and assumptions.* (Participant 67)

Extending on the previous example, participants spoke of instances where other's judgements of them and their child left them feeling blamed, for example:

> *All I can think of is the constant frustrations of dealing with schools that don't tolerate "bad behaviour" and have no interest in understanding the child. He's had good classroom teachers, but all else (esp.[sic] senior management) sent constant messages of him as a "bad kid" (which of course framed me as "bad mother.")* (Participant 56)

Systemic Stigma

Systemic stigma was also clearly a difficulty which respondents wished to cover further in Study Two, especially in regards to education, with 22 caregivers providing additional information about their difficult experiences with the education system. Specific systemic stigma examples came under themes of *"neglect"* and *"exclusion."*   Caregivers gave many examples of how they felt both health and education systems neglected their child's needs. Examples included failure to recognise the child's difficulties, and refusal or delayed action on the child's needs, for instance:

The school process was horrible - to the point that we were told that they did not feel they could handle our son. The school because of this is making our son sit next to a boy who does have ORS funding so his teacher aid can assist. (Participant 6)

It is very difficult to get help from the health system particularly in a rural setting, it took over 12 months to get a diagnosis for my son and then you find that once they get into the schooling system, if they have ORS funding, they get some support but all the rest of the support like SLT [Speech and Language Therapy], OT [Occupational Therapy] is basically stopped and unless they fall behind significantly this is never really brought back in. (Participant 57)

These instances of neglect often preceded examples where caregivers described how they felt they had no choice but to remove their child from these systems (resulting in exclusion):

We ended up taking our daughter out of school because she was so miserable and misunderstood there, which has been a huge shift for the entire family, but as a result she is happier - and so are the rest of us. (Participant 121)

Internalised Stigma

In comparison to experienced stigma, it appeared the participants had less they wished to add to the questionnaire in regards to internalised stigma experiences. The main theme identified through analysis of responses to open-ended questions for Study Two under the *"internalised stigma"* theme was that of *"guilt."* In Study One a similar theme of *"shame"* was identified, however for this study the name guilt was chosen to reflect participant wording, and examples reflected a sense that caregivers gave that they felt they could be doing more (in spite of all that they already do!). While only three participants referenced this guilt, each example was direct in this reference, for example:

Often feel guilty - not doing enough to help my son progress (he's severely autistic). (Participant 96)

In spite of the array of difficulties conveyed by respondents in Study Two, caregivers regularly volunteered information about ways in which having a child with an ASD is not all bad. Examples of these follow.

Study Two: Having a Child with an ASD is Not All Bad

The high level theme "*having a child with an ASD is not all bad*" represented themes identified from caregivers additions to the questionnaire of "*positive emotion,*" "*positive engagements*"

and "*personal development.*" A map of themes represented by the high level theme of "*having a child with an ASD is not all bad*" can be seen in Figure 11.4. Of interest to Study Two are the findings under the subtheme "*personal development*." These findings are described next, while further description of the subthemes of "*positive emotion*" and "*positive engagements*" can be found as Appendix Q.

Personal Development

As was found in Study One, respondents did not tend to boldly assert ways in which they felt they had grown as a result of raising their child with an ASD, however analysis of responses did reveal ways in which caregivers had developed within themselves. Identified examples were grouped under the subthemes: "*self-acceptance,*" "*perspective,*" "*citizenship,*" "*self-regulation,*" and "*social intelligence.*"
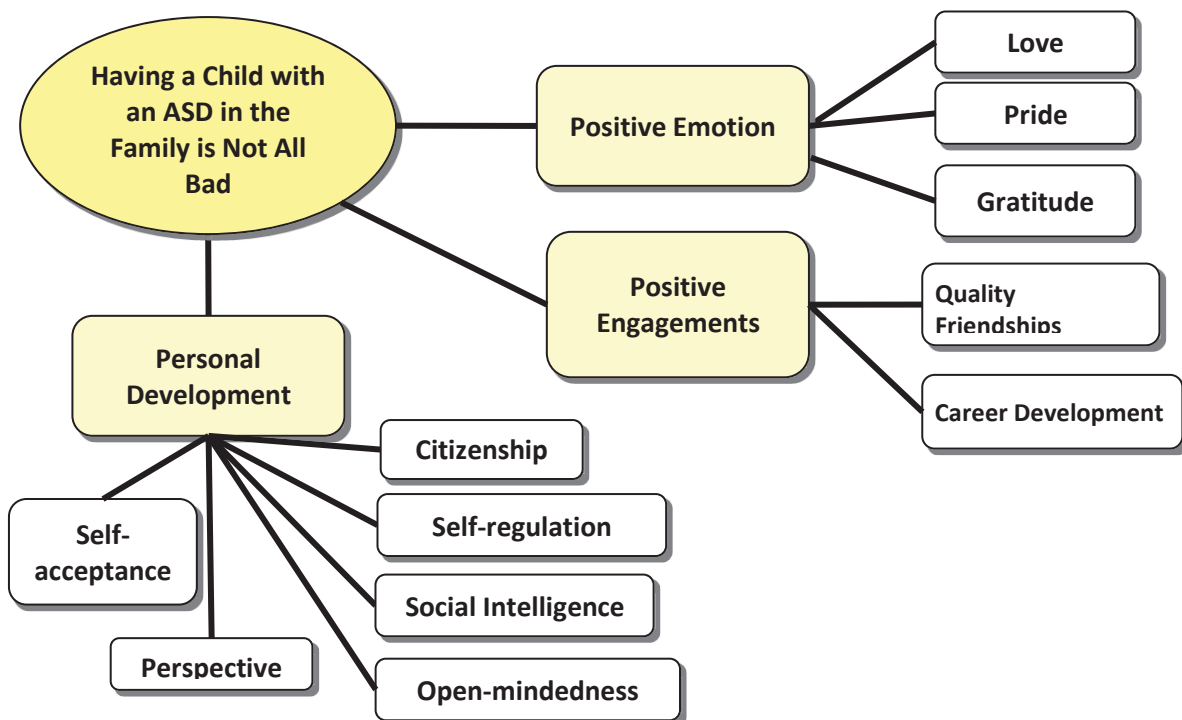
Figure 11. 4. Map of themes from Study Two related to the overarching theme: Having a child with an ASD is not all bad

An unexpected finding in the positive benefits noted by respondents in Study Two was the increase in "*self-acceptance,*" a new theme not previously identified in Study One. This theme in particular seemed most relevant to caregivers who also identified as having an ASD themselves, for example the following excerpt:

> *I've learnt more about my own ASD, so it has allowed me to accept myself as being*
>
> *someone rather than "different."* (Participant 57)

One respondent succinctly summarised their own growth in two sub-theme areas of the theme "*personal development*;" those being "*perspective*," and "*social intelligence*":

> *I have learned not to sweat the small stuff, and that communication is the key to everything.* (Participant 63)

Many of the respondents wished to note the importance of good social support, and shared how they were doing their best to ensure others gained support they may not have received themselves. An example of this form of "*citizenship*" follows:

> *This experience with my son has made me someone who always want to make sure our Samoan community are made aware about the needs and strategies that work for children with ASD through constant conversations and ensuring that they also need to change their worldview and attitude.* (Participant 113)

Several respondents reported, again in relation to difficult experiences they had encountered, that through their experience they had gained skills in "*self-regulation*." Like Study One, the most commonly referenced self-regulation skill was *"patience,"* for instance:

> *I have developed a greater sense of patience, and tolerance for people or children in general.* (Participant 98)

In summary, the results of quantitative analyses of Study Two questionnaire responses suggest the questionnaire used to collect data provided information which has allowed us to answer the research questions. From the data it would appear stigma by association is indeed a stressor present in the lives of NZ caregivers of children with ASDs, with a significant impact on wellbeing. Positively it seems that certain factors, including caregiver signature strengths can influence the relationship between stigma by association and wellbeing, and - when given the opportunity – caregivers can identify how they have grown through their experience. On the whole, results from the Study Two supported and extended on findings of Study One.

Chapter Twelve:

Study Two Discussion

"Most people find it easier to ignore us than to get involved. Of course there are some wonderful people who have helped us who are the exception." (Participant 115)

Study Two built upon findings of Study One and continued to examine stigma by association, wellbeing, and personal growth of caregivers of children with an ASD in the NZ context. In particular Study Two aimed to explore the experience of stigma by association, its' impact on caregiver wellbeing, whether caregivers possessed qualities (such as hope, gratitude or curiosity) which could serve to reduce the impact of stigma by association on wellbeing, and whether caregivers identified common forms of growth as a byproduct of raising their child. A summary of key findings from this study follows.

Study Two: Summary of Findings

In the current sample the majority of respondents were biological parents, female, and of NZ European/Pakeha ethnicity. Most were educated past high school level, owned their own home (suggesting high socioeconomic position) lived with a spouse or partner, and worked at least part-time. Ages of caregivers ranged from 26 to 69 years old. The majority of children referenced were males matching research findings of higher prevalence of ASDs in males compared to females (Attwood, 1998). Child ages ranged from three to 16 years old with an average of eight years old.

Do New Zealand Primary Caregivers of Children with ASD Experience Stigma by Association, and if so what are the Common Experiences?

Stigma By Association Measure Validity and Reliability

To enable assessment of caregiver stigma by association related to raising a child with an ASD a search was conducted of available measures. As no measures suitable to this sample were identified, a new measure was developed. Items were constructed based on a literature review and qualitative findings from interviews in Study One. An initial item pool was assessed by an expert panel to ensure content and face validity, breadth of coverage, and acceptability of items. The resulting items were piloted with a small representative sample leading to the final 20 item Caregiver Stigma by Association Measure (C-SAM). Results from both the pilot and questionnaire studies found the measure had good content and face validity, excellent internal consistency, negative correlations with measures of hope and wellbeing suggested discriminant validity, and factor analysis suggested one large factor, enabling the use of a total stigma by association score.

The Experience of Stigma by Association in NZ Caregivers of Children with ASDs

How the results from this study are interpreted in relation to the stigma by association experience depends on one's optimism and expectations. For example, positively - around one third of respondents had, over the past six months, *never* noticed feeling rejected, hopeless or embarrassed. Participant responses suggested that similarly, they at most *once in a while* experienced feeling angry or vulnerable and noticed other people seemed to pity them, didn't want to listen to them, didn't want to be around them, made rude comments, or avoided them when they were out in the community with their child. This suggests that for the majority these experiences were infrequent.

On the other hand, C-SAM item means suggested that for each stigma by association experience recorded, the majority of caregivers had encountered this experience at least once over the past six months. It is encouraging that for participants in this study overt discriminatory experiences such as being the target of rude comments were uncommon (rude comments were reported to be experienced by caregivers of children with ASDs in Australia [Gray, 2002] and Hong Kong [Mak & Kwok, 2010]); unfortunately more subtle forms of stigma were common. The fact that approximately one in three participants had recently experienced people staring or glaring at them or were led to doubt their abilities as a caregiver, while between one in four and one in five caregivers experienced people looking down on them, or feeling awkward or tense around them suggests that experienced stigma by association is a very real, and widespread experience in NZ. In this sense, experienced stigma examples encountered by this sample of caregivers of children with ASDs reflect those suggested by Bevan-Brown's (2004) NZ study, an Australian study by Farrugia (2009) and many of the experiences identified by Gill and Liamputtong (2011), Gray (2002), and Mak and Kwok (2010).

Qualitative responses from this study further reflected previous research findings on the prevalence of experienced stigma. Themes which arose indicated caregivers encountered stigma and discrimination in interactions with both individuals and institutions in their community. Noteworthy themes which compounded the perception caregivers had that *they* were 'bad' included experiences of others giving them unsolicited advice (akin to findings by Bevan-Brown, 2004), being blamed by others for their child's behaviour or struggles (similar to the experience of being perceived as a bad caregiver, i.e. Bevan-Brown [2004], Farrugia [2009], Gill & Liamputtong [2011], and Mak and Kwok [2010]), and having their knowledge and

experience disregarded (reflecting both being perceived as a bad caregiver themes and experiences of being ignored and dismissed noted in Bevan-Brown's study [2004]).

Supporting findings from Study One, and findings of Bevan-Brown (2004), qualitative responses also provided numerous examples of ways in which the health and education systems, which were expected to provide inclusive support, instead were some of the most significant perpetrators and perpetuators of stigma and discrimination. Bevan-Brown's study, which focussed primarily on interactions between caregivers and the education system, found caregivers experienced increased conflict with educational authorities (2004). Examples given by participants in this study of both education and health system stigma indicated this conflict still occurs over a decade later, and as a result caregivers felt they and their child were either excluded or neglected. As health and education systems are intended to support the development and wellbeing of the child and the parent, these findings are troubling.

In contrast to the quantitative responses, a key theme arising from the qualitative responses was the experience of being avoided. Quantitative results suggested the experience of avoidance may not be frequently encountered, yet the presence of this theme in qualitative findings suggests respondents felt it important to provide further comment on this experience. This study's divergence between quantitative and qualitative results for this theme should not be viewed as a contradiction, but rather, complimentary. These results indicate that while the C-SAM explores the frequency of caregiver experiences of stigma by association, the intensity of experiences such as being avoided is important to capture.

At least half of the questionnaire respondents reported regularly experiencing internalised stigma experiences of feeling stressed, tense and/ or frustrated when engaging in social interactions with their child. The majority of participants also indicated that over the past six months they had at least *sometimes* endured further internalised stigma responses of feeling self-conscious or worried. These internalised experiences reflect findings such as those by Gill and Liamputtong (2011), Gray (2002), and Mak and Kwok (2010) whose research also spoke to ways in which caregivers of children with ASDs experience stigma by association and subsequently internalise the experience. The qualitative responses to Study Two indicated that the main experience of internalised stigma identified was that of guilt that they should try to do more to support their child. This guilt experience was not captured by any items of the C-SAM, however is an experience similar to that identified by participants in the study by Mak and Kwok (2010) in which their participants reported experiencing both self-blame, and feeling

as though they should be more responsible. This finding suggests a potential gap in the C-SAM measure worth investigating in future revisions of this measure.

In regards to the experiences of stigma by association for this sample, results suggest that all caregivers had encountered stigma by association over the previous six months. The experienced stigma encountered by participants was usually covert, yet if Corrigan and Watson's (2002) theory that internalised stigma is a result of experienced stigma is correct, then the level of internalisation demonstrated by this sample implies stigma by association is a significant stressor. Therefore, if stigma by association is indeed a common stressor, what impact does it have on the caregiver's wellbeing?

Does Stigma by Association Negatively Affect Caregiver Wellbeing?
Mean comparison of results from the use of the WEMWBS to measure wellbeing in this study versus WEMWBS results from previous studies suggest this sample experienced significantly lower levels of wellbeing than average. The experiences discussed above suggest numerous ways in which stigma by association may undermine a caregiver's wellbeing, however does this translate to a statistically significant relationship? As expected correlational analysis did detect a large negative and significant relationship between total C-SAM and total WEMWBS scores. This suggests higher levels of stigma by association are correlated with lower levels of wellbeing.

Of interest, previous findings that higher socioeconomic position and lower levels of child difficulties may protect a caregiver from stigma were supported by findings in this study. The evidence from this research implies that both lower socioeconomic position and higher levels of child difficulties were associated with higher levels of stigma by association. Gill & Liamputtong's (2011) similar findings were theorised to be a result of the fact that caregivers with lower socio-economic position may experience greater difficulty accessing support and information for themselves and their child, leaving them more vulnerable to the impact of stigma experiences. Reflecting findings from Gray (2002,) the relationship between higher levels of child difficulties and higher social stigma by association could be interpreted in terms of Goffman's theories around discreditable stigmas. Using this theory, the more social and behavioural difficulties the child experiences, the more difficulty the child and family will have concealing these difficulties in order to pass as normal.

Unique to this study was the finding of a significant link between caregiver age and level of stigma by association experienced. More specifically, severity of stigma by association was found to decrease as caregiver age increased. The absence of a similar link between stigma by association and time since diagnosis or child age suggests that this difference is unlikely to be related to experience coping with ASD stigma by association. The age range of participants in this study covered broad life experiences (with Baby Boomer, Generation X and Generation Y cohorts represented) suggesting a broad range of ideals and values. Caregiver age differences in stigma by association severity could be a result of these cohort differences, i.e. the Baby Boomer generation is said to be more influenced by experts and evidence, while Generation Y is believed to be more influenced by experiences and peers (McCrindle, 2014). In this scenario, a respondent from Generation Y would be more attune to, and affected by social experiences of stigma by association than their older counterparts, thus reporting higher levels. The decrease in stigma by association as age increases could also be explained by the caregivers' stage of progression through psychosocial developmental stages (i.e. changes between Erikson's stages of intimacy vs. isolation and generativity vs. stagnation; Dacey & Travers, 2002). In this scenario, a younger person whose developmental concern is theorised to be focussed on avoiding isolation would find stigma by association much more threatening and be more attentive to these threats than a person who has successfully negotiated this life stage.

In contrast to previous studies, no significant relationship was found between social support and severity of stigma by association.   These findings regarding social support were unexpected; as previous research by Mak and Kwok (2010) suggested both spouse and friend support reduced the experience of stigma. There are two possible reasons for this contrast. Firstly, Mak and Kwok (2010) explored the specific experience of affiliate stigma (aka internalised stigma), while this study examined both experienced and internalised stigma together, meaning the inclusion of experienced stigma in this study could have diluted the strength of these relationships during analysis. Secondly, Mak and Kwok (2010) found no significant relationship between family support and stigma attributing this to the influence of stigma and discrimination within close relationships. In this study, family, spouse, and friend support were all found to have no significant relationship, which could lead us to infer that the impact of stigma within close relationships extends further in this sample than in the sample studied by Mak and Kwok.

To conclude, results of these analyses indicate that stigma by association does negatively affect the wellbeing of a caregiver raising a child with an ASD, however environmental and individual caregiver attributes can decrease the severity of stigma by association for some. Is it possible then that inner caregiver traits can serve to help reduce the impact of stigma by association on wellbeing?

Can Caregiver Signature Strengths of Hope, Gratitude or Curiosity Positively Influence Caregiver Wellbeing and Reduce the Impact of Stigma by Association on Wellbeing?

This is the first study we are aware of that has investigated internal caregiver qualities as possible intervening factors in the relationship between wellbeing and stigma by association. For this study signature strengths which had been previously shown to contribute to wellbeing were explored. The potential for three particular signature strengths to positively influence caregiver wellbeing when they experience stigma by association were investigated in this study, those being hope, gratitude and curiosity.

Relationship between Hope, Stigma By Association Experience and Wellbeing

Findings of moderation analysis showed that hope did not moderate the relationship between stigma by association and wellbeing. According to Baron and Kenny's (1986) definition of moderation, this implies that the relationship between stigma by association and wellbeing does not change as a function of hope. On the other hand, using mediation analysis results showed that for those caregivers who experienced stigma by association, less hopeful individuals reported experiencing lower wellbeing. These findings suggest that the presence of higher levels of hope can significantly influence the impact of stigma by association on wellbeing. Due to the cross-sectional nature of this study the findings do not allow conclusions about causality to be made, however results suggest that a caregiver who has high levels of self-reported hope is likely more resilient in the face of experienced stigma, and potentially more able to resist internalised stigma.

Relationship between Gratitude, Stigma By Association Experience and Wellbeing

Similar to results of moderation analysis using the hope variable, the findings of moderation analysis using gratitude as the moderating variable showed gratitude did not moderate the relationship between stigma by association and wellbeing. This indicated that the relationship between stigma by association and wellbeing did not change as a function of gratitude. Again similar to analysis of the hope variable, mediation analysis results using gratitude as an independent variable showed that for those caregivers who experienced stigma by association, individuals who reported themselves as less grateful experienced lower wellbeing. These

findings suggest that a caregiver with higher levels of gratitude will likely experience greater wellbeing, in spite of their experiences of stigma by association.

Relationship between Curiosity, Stigma By Association Experience and Wellbeing

An unexpected finding in this study was that, while self-reported curiosity was correlated with wellbeing, curiosity was not found to moderate the relationship between stigma by association and wellbeing. As curiosity also did not have a significant relationship with stigma by association for this sample, statistical mediation models were unable to be applied, suggesting curiosity was unlikely to mediate the relationship between stigma by association and wellbeing.

In summary, none of the signature strengths of hope, gratitude or curiosity were found to moderate the relationship between stigma by association and wellbeing for this sample. However, hope and gratitude were demonstrated to mediate the interaction between stigma by association and wellbeing. These findings suggest internal caregiver traits can influence how much the stressful experience of stigma by association affects wellbeing. With this knowledge, is it reasonable to assume caregivers could then in fact thrive through their experience?

Do Caregivers Identify Common Experiences of Growth as a Byproduct of Raising their Child?

While research on parenting a child with an ASD has referenced ad-hoc experiences of growth, we are unaware of any research to date specifically examining growth experiences using quantitative methodology.   In this study we wished to explore what positive changes caregivers had experienced in themselves through the experience of raising their child. Responses to this study suggest caregivers experience a range of positive changes. All respondents endorsed at least three positive changes which they attributed to the experience of raising their child, while on average respondents could identify approximately 11 different areas of personal growth. A discussion of the most commonly identified growth aspects follows.

Reflecting findings of the original LMS-PCS study of parents of children with disabilities (Scorgie, 1996), the growth experience given the highest ranking by participants was the item: *"I have learned to speak out for my family member."* This finding, which suggests development of courage was supported by a theme developed from qualitative responses to this study which indicated caregivers had grown in their understanding of the importance of

communication. This development in the caregiver's courage and perhaps even social intelligence is unsurprising given the discriminatory experiences noted by respondents, which almost make this development a necessity.

Similar to the development of the ability to speak out for their child noted above, another strength commonly reported to have developed was the capacity for more compassion toward others. This result supports findings from Scorgie's (1996) original Alberta study, and an Italian study of parents of children with disabilities (Wilgosh, Nota, Scorgie & Soresi, 2004). It is possible that this development is a result of caregivers witnessing the struggles their child endures in order to achieve what many of us take for granted. Or it is a result of the caregiver knowing firsthand the distress associated with being positioned as 'other.' Analyses of qualitative results indicated that for some this compassion created further growth, in the form of citizenship. Compassion through knowing and understanding their child's, and family's, struggles appeared to lead caregivers away from perpetuating prejudice and discrimination and toward efforts to develop a fairer and more accepting community.

The majority of caregivers endorsed items which reflected a change in their outlook on life. Two items in particular were endorsed by over three quarters of participants, those being the growth in the ability to see life from a different perspective, and learning what is important and valuable in life. Qualitative responses suggested that for this sample the difficulties they encountered while raising their child had required them to relax their expectations of life; to *"not to sweat the small stuff"* (Study One). These results reflect those of Wilgosh et. al. (2004). As there are no known studies using the LMS-PCS subscale for a population of typically developing children, this research is unable to establish whether this finding is part of the experience of raising a child, or unique to the experience of raising a child with an ASD. If a comparison could be made, and caregivers were found to experience more growth in these areas, one could suggest that the ability to see life from a different perspective may be linked to the experiences identified in Study One; where parents noted they must sacrifice their own dreams and wishes (therefore requiring the caregiver to adjust their life values to support this new perspective). Similarly, the shortage of resources and strain on wellbeing experienced by these caregivers may necessitate the adjustment and prioritising of life values in order to maintain wellbeing.

As was found in Scorgie's (1996) study, the other most commonly reported positive changes were developments in the individual's sense of their own abilities. Over three quarters of caregivers endorsed the statement that they felt stronger as a person, and just under three quarters reported they had learnt they could achieve rather than feel powerless. These changes could be attributed to the above noted examples of the caregiver having to take action and speak up for their child, perhaps something they had never felt compelled to do previously. They may have also resulted from the caregiver being confronted with challenges accompanying the experience of raising a child with an ASD they may never have imagined encountering, and surviving these in spite of their doubts.

While it is heart-warming to note that caregivers appear to experience personal growth through their difficult experiences, the positive changes subscale also provided further support for how difficult the experience of raising their child can be. Just under half of participants disagreed with the statement that their marriage/relationship had grown stronger, while a similar number disagreed with the idea that they now take better care of themselves. Supporting findings from Study One, (and perhaps attributable in part to the lack of time, energy and resources spoken of), most participants indicated they had not experienced growth in relationships or their ability to engage in self-care.

Additional qualitative responses relating to the positive changes theme gave examples not captured by the LMS-PCS scale of growth in self-regulation and self-acceptance. Supporting findings from Study One, caregivers in Study Two also noted the development of skills in self-regulation such as patience. This addition by caregivers may indicate an area for future development of the LMS-PCS subscale. The finding may also be unique to the experience of caregivers of children with ASDs (as the LMS-PCS subscale was developed based on a wider range of child disabilities), a consequence of the distinct social, communication, and behavioural difficulties this population experiences.

An unexpected finding in this study was the growth in self-acceptance reported to be experienced by a unique subset of this sample. More specifically, a group of caregivers reported that through their experience with their child's ASD, they had come to understand and accept their own ASD related difficulties. While this finding was not expected, similar experiences have been noted by researchers such as Erwin & Soodack (1995) who noted that parents who advocate for their children with intellectual disabilities experienced awareness of personal strengths and self-understanding. In a study of civil rights workers, survivors of

childhood cancer, and children of parents with affective disorders, Beardslee (1989) noted self-understanding was *"an essential dimension of their being able to function effectively"* (p 269) and was noted to be present in all of those participants who were coping well.

In summary, findings from Study Two provide further evidence that raising a child with an ASD in NZ is difficult and is made even more so by stigma by association. All questionnaire respondents had experienced stigma by association over the past months, and the majority had reported experiences suggesting they had internalised this stigma. Correlational analyses suggest that older caregivers with a higher socioeconomic position and children with less social difficulties are likely to experience less stigma by association. Important for future work supporting caregivers of children with ASDs, the presence of signature strengths of hope and gratitude were shown to decrease the interaction between stigma by association and wellbeing, suggesting these strengths can assist caregivers to maintain wellbeing. Lastly, results suggest that caregivers do experience positive changes as a by-product of raising their child. These positive changes include the development of new skills and new life meaning, support wellbeing, and suggest caregivers can thrive in spite of the challenges they face.

SECTION FOUR

Chapter Thirteen:

Overall Findings: Understanding Stigma by Association and the Exploration of Wellbeing and Growth in Caregivers of Children with ASDs

"You know it's not just the good stuff it's the tough stuff that makes us who we are." (Bridget, Study One)

Within New Zealand up to 116 in every 10,000 people may have an Autism Spectrum Disorder (ASD) which affects their ability to negotiate our social world due to social, behavioural, and communication difficulties. For children with ASDs, the support provided by their family, in particular primary caregiver/s, is known to be vital to the child's success in managing these difficulties. In recent years, interest in the experience of caregivers raising a child with an ASD has increased and more understanding sought, with particular emphasis on the stressors associated with this experience. One such stressor identified through studies such as those by Gray (1993, 2002) and Farrugia (2009) is the experience of stigma by association. While researchers have begun to identify common stigma by association experiences for caregivers of children with ASDs, research to date has been qualitative and mainly focused on the experience of mothers. In addition, while some researchers had begun to explore whether specific variables such as socioeconomic position or social support could influence the severity of stigma by association (i.e. Gill and Liamputtong, 2011; and Mak & Kwok, 2010), none of the identified research had examined whether a caregiver's personal traits could aid a decrease in the severity of stigma by association. Following a review of research on the experience of caregivers of children with ASDs it was also noted that the majority of this research was from a deficits perspective. This focus missed the opportunity to identify how and why caregivers of children with ASDs maintain wellbeing, and in some cases thrive; even in the face of the stigma and discrimination they experience.

Noting these research gaps, and with the aim of furthering our understanding of the challenges of caregivers of children with ASDs in NZ, this current research focused on documenting the experience of and providing information which may help improve the wellbeing of caregivers of children with ASDs. Four aims were proposed for this research and two studies were undertaken in order to achieve these. Study One was qualitative in nature, and interviewed six primary caregivers (two male and four female) of children with ASDs. The focus of this study was on establishing whether caregivers of ASD children in NZ experience

similar challenges to those identified in international research, exploring the stigma by association encountered by these caregivers, and also whether caregivers experienced growth in spite of the difficulties they encountered.

Study Two used quantitative research methodology to survey 100 NZ primary caregivers of children with ASDs in order to build on the understandings gained from Study One. In particular, Study Two aimed to provide an in-depth understanding of stigma by association and its impact on caregiver wellbeing, identify whether caregiver signature strengths such as hope, gratitude or curiosity could explain why some caregivers appear to cope better with the experience of stigma by association than others, and further explore ways in which caregivers had experienced personal growth as a byproduct of raising their child. This final chapter is a summary of findings from Studies One and Two as related to each study aim, followed by an overview of strengths and limitations of this research, suggestions for future research directions and concluding remarks.

Do Caregivers of Children with an ASD in NZ Experience Similar Challenges to Those Identified in Previous Research?

Existing literature indicates caregivers of children with ASDs encounter practical, personal and social challenges. From Study One, and supported by additional qualitative findings from Study Two a diverse range of experiences were identified by caregivers of children with ASDs. These were grouped by theme with challenges grouped under the main theme *"having a child with an ASD can be hard"* and positive and growth experiences under the other main theme *"having a child with an ASD is not all bad."* The challenges of the caregiving experience are covered here, with positive and growth experiences discussed later.

Practical Restrictions

Practical restrictions noted in previous research included limited resources, particularly time and money (Ministries of Health and Education 2008, and Sawyer et al., 2010). Consistent with previous findings, caregivers from Study One also reported that their inability to find or access enough time or money in order to support their child added to the complexity of raising their child. These restrictions were noted to be a source of frustration and stress for the majority of participants in Study One, and were further supported by qualitative findings of Study Two. These reduced resources were said to contribute to increased isolation, relationship strain and decreased physical and mental wellbeing of caregivers.

Caregivers in both studies spoke about how, in addition to limited resources, barriers to accessing available supports was a further source of stress. These barriers were often created by the very systems which were intended to support caregivers and their children ("*systemic"*), or were presented by other's lack of understanding of ASDs. Systemic barriers were noted when caregivers spoke of their difficulties accessing both health and education systems; common barriers included service wait lists, acceptance criteria, and processes. These barriers were a point of difference between this study and international studies. While caregivers in international studies spoke more about cost as a barrier to accessing services (i.e. Ganz, 2006), within this sample the focus was more on processes. This is likely due to the largely tax funded structure of the NZ health and education systems as opposed to user-pays systems of countries such as the U.S. which shifts the barrier locus.   The other commonly identified barrier noted to hinder caregiver's attempts to access support was the public's lack of knowledge about the reality of ASDs. Caregivers spoken to in this research were noted to be empathetic about the public's lack of understanding. Nevertheless, they appeared to feel burdened that this responsibility fell on them when they already felt so stretched for time and energy.

Potentially unique to the experience of raising a child with an ASD, caregivers in this study reported the practical restrictions of unexpected life obstacles which made it difficult for them to live life well. Reflecting previous studies (e.g. Ministries of Health and Education, 2008), caregivers noted they had to regularly re-organise their life (including employment, holidays and residences) in order to ensure their child's safety, manage behavioural problems, and negotiate around social and communication difficulties. These obstacles were accentuated when the family wished to leave the house as the child's difficulties were often exacerbated by unfamiliar places, people or situations.

Personal Costs

Previous research has noted that the experience of raising a child with an ASD has both social and psychological costs. Social costs previously noted include isolation from peers and community, and decreased marital satisfaction (i.e. Ministries of Health and Education, 2008; and Rodrigue et al., 1990). Caregivers in both Studies One and Two reported an increase in isolation from their peers and community. As already mentioned, this isolation was often noted as the result of decreased time and energy (and therefore reduced ability to engage socially), inability to find skilled childcare in order to have child-free time, a necessity in order to manage the child's behaviour, and safety, or due to social stigma. Two participants in Study One attributed the dissolution of their marriage at least in part to the stress associated with

raising their child. While respondents to the Study Two questionnaire indicated diverse opinions on the impact of raising their child on their marriage, more participants disagreed than agreed with the statement *"my marriage/ relationship has grown stronger."*

Research has shown caregivers have an increased incidence of stress, anxiety and depression, experience a loss of their own dreams and goals, and experience decreased physical health (i.e. Allik et al., 2006; Dunn et al., 2009; Montes & Halterman, 2007; and Weiss, 2002). Results of this research support previous findings of the high levels of stress and reduced wellbeing associated with raising a child with an ASD. Common experiences reported by caregivers in both Studies One and Two included constant worry about both their child's wellbeing and their future, ongoing stress – exacerbated by the above mentioned practical restrictions, the loss of their own dreams and goals, and decreased physical health. Participants of Study One also regularly referenced personal costs of reduced energy and increased fatigue, a state of perpetual mourning, and of concern, the majority of participants had encountered difficulties with low mood or depression.

Experiences reported by caregivers and discussed thus far grouped under the theme *"having a child with an ASD is hard"* are mostly consistent with previous research on the experience of parents of children with ASDs. The challenges of raising a child with an ASD are numerous, pervasive and can be the catalyst of significant change to the course of a caregiver's life. With this number and severity of stressors one would hope that the caregiver's community would provide support. Unfortunately this is often not the case, as this research revealed when exploring caregiver's experience of stigma by association.

Do New Zealand Caregivers of Children with ASD Experience Stigma by Association, and if so what are the Common Experiences?

While researchers such as Gray (2002), Farrugia (2009) and Mak & Kwok (2010) suggest stigma by association is a stressor encountered by caregivers of children with ASDs, this research topic has been largely neglected. Furthermore, while research by Bevan-Brown (2004) exploring Māori perspectives on ASD indicated stigma by association may be encountered by NZ caregivers of children with ASD, there was no information on the extent or prevalence of this issue for the NZ population. One of the aims of this research was to identify factors which may support caregivers in the face of stigma by association, but first it was necessary to establish whether this was indeed an issue for this population. Second, it was important to identify whether stigma by association as it was encountered in the NZ context reflected experiences

identified in previous research. To achieve these goals, both qualitative (Study One) and quantitative (Study Two) approaches were used. Results of both studies suggested all caregivers who participated in this research had experienced stigma by association. Stigma by association encounters talked about by caregivers in Study One were organised into subthemes under the theme *"stigma by association."* Results indicated that caregivers universally encountered both experienced and internalised stigma. Correlational analysis also suggested some caregivers were more susceptible to stigma by association than others. Findings from both studies are summarised next.

Experienced Stigma by Association

Commonly experienced stigma by association examples reported by previous researchers were, as a rule, fitting with results of this research. Experienced stigma by association examples from this research could be organised into the subthemes of "*interpersonal*," "*systemic*" and *"choose your stigma."* In regards to interpersonal stigma, Gray (2002) and Bevan-Brown (2004) previously identified that caregivers of children with ASDs are often avoided or ignored. These findings were supported by participant talk in Study One, with two key themes being the experience of being avoided by others, and of having their experience and knowledge disregarded. Similar to prior research conclusions that caregivers are treated as bad parents (i.e. Farrugia, 2009 and Gill & Liamputtong, 2011) – participants in this research also encountered this stigma. Caregivers in Study One reported experiences where they were blatantly blamed for their child's difficulties, or were given the message they were not parenting correctly by people who provided unsolicited advice.

The most common experience of stigma by association identified by caregivers in both Study One and Study Two was that of being stared or glared at. Unlike Mak and Kwok's (2010) study in China, caregivers did not report experiencing more aggressive verbal abuse; this contrast may point to a cultural difference between the two societies. Nevertheless, the high frequency with which staring and glaring was encountered by NZ caregivers (reported by 92% of Study Two participants to have occurred at least once in a while during the previous 6 months) suggests prejudicial attitudes persist in NZ communities. Rather than providing support, community members are often hostile towards and unsupportive of caregivers.

The Ministries of Health and Education's ASD guidelines published in 2008 reported that caregivers encounter difficulties accessing support and education services, a finding supported by the results discussed above. The guideline suggests that public workshops which include a focus on destigmatising ASDs could be of use to the Māori population, however the guideline

overlooks the stigma and discrimination enacted and perpetuated by the health and education systems themselves. Supporting findings from studies such as that by Woodgate et al. (2008), results from both Studies One and Two strongly suggest that both the child and their caregiver encounter stigma regularly in their interactions with both health and education systems. Reported experiences were represented by themes of exclusion, and neglect. Research participants often noted how they were excluded, usually through very covert means. Methods of exclusion spoken of included veiled messages suggesting that a child and their family cannot be catered for, or to do so would require extraordinary effort on the part of service provider. If a service was provided, caregivers often noted that their child's and their own needs were often neglected. Examples of this neglect included service providers or professionals not providing access to available services or resources which would help the child and family to achieve greater wellbeing and inclusion, delays in service provision, or biases towards other populations. One striking example of neglect through bias was the contrast in care received by one participants' children – one with autism who experienced both exclusion and neglect, the other with diabetes who experienced inclusion and accommodation. Overall, the message which appeared to be consistently received by caregivers in this research was that they should go away because they were being too demanding. This finding is troubling, not just because our health and education system should be the most open to supporting these hard working caregivers as they try their best to support their child. This finding is also upsetting because health and education providers have access to the most up to date research and education on how challenging ASD difficulties can be, and therefore should be leading the way in providing the best and most inclusive support, and breaking down barriers; not perpetuating stigma and discrimination.

A distinctive finding from this research which likely resulted from enacted stigma encountered by caregivers was the experience of caregivers feeling they had to choose a stigma.   This stigma was encountered while out in public with the child. Caregivers spoke about how they often found others would judge them as a bad parent no matter which choice they made. If a caregiver decided they would not disclose their child's ASD, then the child subsequently outed themselves or behaved in a socially un-condoned manner caregivers found they were judged as a bad parent.   Yet if they disclosed their child's ASD they were often labeled as exaggerating.   Even more problematic – therapeutic care advisors (i.e. Attwood, 2007) encourage caregivers to take their child out to experience and become accustomed to social experiences (if they do not they are seen as a bad parent), yet if they do, and their child reacts

with socially unacceptable behaviour, caregivers are judged as insensitive to others and as bad citizens. The caregiver is placed in an unwinnable situation; the consequences of which are that their own rights are often placed last (as participants noted first respecting either the rights of their child or the public) a likely stressful and demeaning experience.

Internalised Stigma By Association

With the above mentioned ways in which a caregiver is given the message that they and their child do not meet social expectations, it would be difficult for caregivers not to internalise at least some of the discriminatory messages. Corrigan and Watson (2002) argue that it is by encountering stigma, trying to make sense of stigma and then believing in the legitimacy of that stigma that people come to internalise stigma. Results of this study suggest that even those caregivers who appear to be coping well in spite of encountering stigma (with the highest reported wellbeing) internalise at least some stigma messages. Findings of Studies One and Two indicate that over the past six months caregivers were more likely to encounter internalised stigma than experienced stigma. Common internalised stigma experiences included caregivers feeling ashamed and embarrassed attributed to thoughts about how their child does not obey social norms, and guilty that they have in some way not done enough to meet society's standards of a good parent. When out in public with their child the majority of caregivers in the questionnaire study reported regularly feeling stressed, tense, frustrated, worried and self-conscious. While the nature of this questionnaire did not allow exploration of individual precipitants of these emotions, the qualitative study findings suggest these emotions are linked to the discreditability of ASDs. Study One participants spoke of the great effort they put into trying to shape their own, and their child's, behaviour towards the unwritten rule of socially acceptable behaviours (working hard to pass as normal). With the effort required to manage the child and themselves to ensure they do not discredit themselves (knowing that the consequences can include isolation, exclusion and being othered (along with additional burdens accompanying these experiences) it is no wonder caregivers report increased stress, tension, and anxiety in social situations.

Individual Caregiver Characteristics Associated with Decreased Stigma by Association Severity

Correlational analyses were used in Study Two to explore whether particular caregiver characteristics contributed to decreased severity of stigma by association. Consistent with prior research, higher levels of child pro-social behaviour, and higher socioeconomic position was associated with lower severity of caregiver stigma by association (i.e. Benson, 2010, and Gill & Liamputtong, 2011). As expected, higher levels of stigma by association were associated

with lower levels of wellbeing. Unique to this study, higher levels of caregiver hope, gratitude and positive changes were associated with lower reported levels of stigma by association (elaborated on in the following section). Unexpectedly, increases in caregiver age but not age of the child were found to correlate with decreases in stigma by association suggesting a potential caregiver cohort or developmental stage effect. In contrast to previous studies, social support from significant others, friends or family was not correlated with decreased stigma by association.

Overall, in regards to challenges faced by caregivers of children with ASDs in NZ, results from this research suggest that many of the experiences noted in existing literature are relevant to this population. Caregivers encounter restrictions which limit their ability to navigate the world in ways many of us could not normally tolerate. The experiences of these restrictions contribute to reduced social, emotional and physical wellbeing of caregivers. To top it off – instead of providing support – a caregiver's community often contributes (both actively and passively) to the stress through stigma by association, which is frequently internalised by caregivers contributing to further decreased wellbeing. As evidence suggested caregivers do experience stigma by association, and that stigma by association has a significant negative relationship with wellbeing this area of research is important to study further.

Can the Presence of Caregiver Signature Strengths of Hope, Gratitude, or Curiosity Explain why Some Caregivers Cope Better than Others with the Impact of Stigma by Association on Wellbeing?

Stemming from an initial interest in how some caregivers appeared more resilient to the stress of stigma by association than others, this research set out to explore whether certain caregiver signature strengths could explain variance in wellbeing. To investigate whether these strengths moderated the relationship between stigma by association and wellbeing, the relationship between each of the signature strengths hope, gratitude, curiosity and both stigma by association and wellbeing were explored using moderation analysis. Surprisingly results from moderation analyses for hope, gratitude and curiosity indicated that the interaction between each of these signature strengths and stigma by association did not significantly affect the caregiver's wellbeing. This meant that for this sample, signature strengths of hope, gratitude and curiosity did not function to change the relationship between stigma by association and wellbeing.

As moderation analysis suggested signature strengths did not buffer the stigma by association wellbeing relationship, a mediation model was tested to explore whether the presence of signature strengths may explain variation in caregiver wellbeing. As curiosity was not found to have a significant relationship with stigma by association, curiosity was found to be unable to mediate the relationship between stigma by association and wellbeing. These findings were surprising, especially as curiosity had previously been found to help people challenge stereotypes, tolerate uncertainty, and reframe experiences (Kashdan et al., 2004; Langer, 1992, and McCrae & Costa Jr., 1997).

In contrast to caregiver curiosity, the signature strengths of both hope and gratitude were found to mediate the relationship between stigma by association and wellbeing. Both hope and gratitude accounted for a significant and large amount of the basic relationship between stigma by association and wellbeing. Results for the hope variable showed that the effect of stigma by association on wellbeing is influenced by caregivers' personal levels of hope. One possible interpretation of these findings is that when caregivers experience stigma by association, hopefulness encourages the caregiver to maintain a future and action oriented approach to coping with experiences of stigma, which in turn supports greater wellbeing. Similarly, mediation analysis results showed that when a caregiver experiences stigma by association, the impact on wellbeing is influenced by caregiver levels of gratitude. This finding could be interpreted as suggesting that gratitude allows a caregiver to frame their situation in such a way that their outlooks encourages a solution focus and increased social support and resolve rather than accept the negative effects of stigma on wellbeing.

The present study provided unexpected results suggesting signature strengths of hope, gratitude and curiosity do not moderate the stigma by association and wellbeing relationship, however hope and gratitude do mediate the interaction between stigma by association and wellbeing. While these findings do not allow determination of whether hope or gratitude affect wellbeing through buffering the effects of stigma by association on wellbeing, or whether they do so directly, they are informative. Results of these analyses suggest that while curiosity was not found to influence caregiver wellbeing when facing stigma by association, the experience of both hope and gratitude can have significant and positive implications for caregivers who must face this stressor. These findings are important as they suggest that - rather than caregivers being helpless victims of stigma by association - through the development of signature strengths such as hope or gratitude a caregiver may have agency over the strength of the impact of a stressor such as stigma by association. As these findings

appear to suggest caregivers as individuals can influence and support their own wellbeing in spite of the challenges they face, then the next natural question is may they thrive?

In Spite of how Difficult the Experience of Raising a Child with an ASD can be, can Caregivers Experience Personal Growth as a Byproduct of this Experience?

Theorists now acknowledge that personal growth can result from stressful experiences. While there is research on the experience of caregivers of children with ASDs which notes a small number of findings related to growth, to date we are unaware of any research specifically exploring growth experiences. Results from Studies and One and Two provide insight into and evidence for ways in which caregivers do experience growth, and are discussed next.

Indicated as a possibility by previous studies, participants in Studies One and Two identified numerous ways in which they had experienced growth as a byproduct of (and in spite of the challenges of) raising their child. Encouragingly, all caregivers in both studies were able to identify positive changes. These included positive emotions, engagements and meaningful developments. Supporting findings by Myers and colleagues (2009) and Bayat (2007) caregivers who took part in Study One reported an increase in love and gratitude. Unique to this research, participants also noted an increase in pride. This pride was of their child's achievements in spite of odds which seemed to be against them. Interviewees also spoke of opportunities that had arisen through parenting their child. Participants noted that, while they had experienced relationship losses, they had also gained enriched relationships which they believed they would not have established if their child did not have an ASD. Some caregivers even reported that, in contrast to the experiences of the majority of participants in Studies One and Two, raising their child had strengthened their relationship with their spouse or significant other (also found by Myers et al., 2009, Zhang et al 2015). Supporting previous findings (i.e. Altiere and von Kluge, 2009; Bevan-Brown, 2004 and King et al 2006) caregivers also referenced career and interest developments. They spoke of the changes having a child with an ASD had necessitated (e.g. needing to work part time, or developing knowledge about ASDs) and reframed these as an advantage, for example obtaining a more rewarding career, or engaging with new interests (e.g. psychology or volunteer work).

Study One and Study Two results identified numerous areas in which caregivers commonly identified personal growth. The most common areas of growth identified across both studies could be encompassed by themes of wisdom, courage, and humility. Study One participants spoke of their growth in wisdom through the deepening and widening of their understanding

of what is important in their lives (perspective, also noted by Kayfitz et al 2010, King et al 2006, and Zhang et al, 2015) and their interest in alternate ways of seeing and approaching their world (curiosity). Perspective was also strongly supported as a growth area in Study Two with over two thirds of participants identifying that they experienced growth in their ability to see life from a different perspective, and learning what is important and valuable in life.

Courage was identified by research participants through growth in bravery, integrity and persistence. Bravery examples spoken about by participants in Study One encompassed the caregiver's development in their ability to advocate for their child's needs, in spite of their own apprehension.   This bravery was reflected by Study Two participants, with frequent endorsement of growth in their ability to speak up for their child. Integrity was demonstrated in Study One, often in reference to enacted stigma by association. This integrity was spoken about in the form of the caregiver's willingness to be as honest and genuine as possible in their interactions with others, in spite of the potential that this approach may create further work for them. Reflecting findings in previous research (i.e. King et al 2006, and Zhang et al, 2015) persistence was frequently identified by participants in both Study One and Study Two, and perhaps was best summed up by the positive changes scale item: *"I have learnt I can achieve rather than feel powerless."* Participants in Study One noted how persistence was crucial in order to overcome many of the encountered restrictions and barriers, especially through stigma by association.

Humility in this research represented both caregiver growth in their ability and desire to understand others (social intelligence) and support others (kindness). Both Studies One and Two supported previous research findings that caregivers reported increased kindness and social intelligence (i.e. Altiere & Von Kluge, 2009; Bayat, 2007; and Zhang et. al. 2015). Caregivers noted that because of their own difficulties engaging with their child, and the development of their understanding of how complex social interactions can be, their compassion for others had grown. This insight had also increased their willingness to try to understand others, in spite of the extra effort this may require of them.   It is also possible that, because caregivers have experienced being othered through stigma, this gave them insight into how aversive this experience can be which they then kindly wished to prevent others from experiencing.

Qualitative results from Studies One and Two also provided further examples of how caregivers attributed their personal growth to their experience of raising their child. Providing

support for previous research findings by Bayat (2007) and Altiere and Von Kluge (2009), caregivers regularly spoke of developments in skills of patience and self-regulation, noting the necessity of these skills for both their child's and their own development and wellbeing. A number of caregivers also reported that they had gained a new sense of loyalty to others in their situation, and a desire for others not to have to suffer the injustices they had encountered (likely from similar roots as the kindness noted above). An unpredicted additional finding of Study Two was the growth in self-acceptance experienced by caregivers who also identified as having ASD. This growth appeared to stem from both the opportunity to observe their child, and access to new information about ASDs via their child's support network.

Results of both Studies One and Two suggest that indeed, while caregivers do find having a child with an ASD challenging, the experience is also reported to be a catalyst for personal growth. Caregivers directly attributed increases in positive emotions, opportunities, and growth to their experience of raising their child. Caregiver attributions from the qualitative study, and the positive correlation between personal growth and wellbeing from the quantitative study suggests that for some caregivers, raising their child is a personally meaningful endeavour in its own right – leading to gains in personal strengths and skills. Utilizing Frederickson's broaden-and-build theory it is therefore reasonable to suggest that these experiences of positive emotions and purpose enable caregivers to utilise their available personal and environmental resources, therefore building and reinforcing their wellbeing over time (2001). These findings are important, not only because they speak to the strength of caregivers of children with ASDS in NZ, but also as this gives evidence to support further study into how positive psychology can be utilized to support and increase the wellbeing of this population.

Strengths and Limitations of this Research and Suggestions for Future Research

This is the first known research study to use quantitative methods to investigate the impact of stigma by association on the wellbeing of caregivers of children with ASDs, and their growth experiences. The findings of this research have contributed in depth qualitative and quantitative information for caregivers of children with a variety of ASDs in NZ on what the experience of stigma by association looks like, factors which may reduce the impact of stigma by association, and ways in which caregivers can and do experience growth in spite of the challenges they face.

Prior to this research there were no measures suitable for assessing both externalised and internalised stigma by association in caregivers of children with ASDs. This gap was addressed with the development in Study Two of an inventory of these experiences, named the Caregiver Stigma by Association Measure (C-SAM). This measure built on results of an in depth literature review, and interviews with caregivers of children with ASDs in Study One. In both a pilot study and the Study Two questionnaire study the C-SAM was found to have excellent internal reliability, construct and face validity, and provided insight into the variety of stigma by association experiences encountered by caregivers.

As indicated earlier, the potential protective influence of caregivers' inner characteristics on the relationship between stigma by association and wellbeing for caregivers of children with ASDs had not been previously examined. Similarly, there was no known research where positive psychological concepts such as signature strengths had been utilized to explore what differentiates a person who copes well with stigma versus a person who does not. Thus both the expected and unexpected findings of this study add to the knowledge of both the psychological mechanisms of stigma by association, and the role of signature strengths in the protection of wellbeing for this population.

In addition to this absence of research on caregivers of children with ASDs utilising positive psychological theory, it was also identified that the majority of research on their experiences was problem focussed. This bias meant available research on the caregiver experience portrayed a life of dysfunction and misfortune, neglecting to acknowledge the ways in which caregivers do lead a meaningful life, and can thrive. The findings of this research provide support for the numerous challenges caregivers face, and also recognizes and provides the initial foundations for understanding the ways in which caregivers maintain wellbeing, grow, and can thrive.

It is important to note that there are limitations to this study which restrict the generalisability of results and prevent definite conclusions from being made, but simultaneously suggest avenues for future research. Firstly, while efforts were made to ensure the Study Two questionnaire appealed to fathers and the ethnically diverse population within NZ, demographic analyses of respondents indicate the majority were female, of NZ Pakeha/European ethnicity, and of higher education and socio-economic position. Possible reasons for the demographic bias towards females could be that males may not identify with the term *caregiver* due to traditional NZ father roles as the "breadwinner;" or it could be that,

as mothers are more likely to take on the child caring role (McPherson, 2006) fathers in some way interpreted this research as less applicable to them. The limited response from Māori, Pacific and Asian populations could be explained by language barriers and the fact that Study Two was conducted in English, and accessible only to caregivers who had access to the internet. Data from Statistics New Zealand (2004) suggests that Māori, Pacific, and Asian peoples are more likely to speak English as a second language, and less likely to live in a household with internet access. Additionally, those with internet access are likely to be of higher education and socio-economic position (Statistics New Zealand, 2004). As the experience of fathers and those from ethnic minority groups therefore remains under represented in this research area, extra effort must be put into accessing these populations in future to better understand their experiences.

One way to combat the limited insight provided by this research into ethnic minorities would be to work alongside representatives of these communities to adapt the questionnaire language and explore the possibility of questionnaire translation. In New Zealand, as we have a responsibility to improve representation of Māori in all aspects of life, this is especially important. To negate the barrier of access to the internet, the researcher could personally visit ASD parent support groups to introduce the research, and provide paper-based versions of the questionnaire.

As previously noted, the cross-sectional nature of this research prevents firm conclusions about the direction and causality of the identified correlational and meditational relationships. In addition, Study Two relied on subjective self-report measures to explore the experiences of stigma by association and positive changes. While efforts were made to reduce the likelihood of this, self-report measures have been criticised as susceptible to social desirability bias (Bethlehem, 2009). It could be suggested that results from this study reflect the caregiver's desired image, however we would argue that the voluntary nature of participation in this research, along with anonymity would serve to decrease the likelihood of social desirability bias. As we were wishing to access participants' thoughts and feelings regarding stigma, wellbeing, and growth, the participants themselves are the only ones privy to the quantity and breadth of information required, and therefore self-report was regarded as the best method of accessing this information. To improve the ability of this research to provide firmer conclusions about causality, a longitudinal research design collecting questionnaire data at multiple time points is suggested. In this way natural variations in stigma by association, hope,

gratitude, wellbeing and growth can be monitored and further conclusions about relationship directions and the influence of signature strengths on the stigma by association and wellbeing interaction made.

While this study provided evidence for stigma by association and growth experienced by caregivers of children with ASDs, future research could extend on this knowledge. One avenue for further extension of the research could be to include caregivers of children with other known stigmatised difficulties (for example children with mental illness or epilepsy). To do so would allow further exploration of the role of signature strengths and growth associated with caring for a marginalised child without exhausting the community of caregivers with ASDs. This would also contribute to greater understanding of the extent and impact of stigma by association on caregivers in NZ and contribute to further understanding of the C-SAM measure.

In regards to the C-SAM measure, Study Two qualitative findings suggest the inclusion of a C-SAM item measuring guilt feelings could be trialled in future. Furthermore, this scale focussed on collection of data about the caregiver's perceived frequency of stigma by association experiences. As identified through qualitative feedback in Study Two, the perceived *impact* of individual stigma by association experiences may be as important to capture as the frequency of these experiences. Future adaptations of this scale may include an additional measure of the personal impact of each item. This added information could be used to help inform health and wellbeing support professionals of the most salient areas in which to support caregivers who experience stigma by association.

Unique findings from this study also suggest further areas of possible future research. Building on the findings on signature strengths of hope, gratitude and curiosity in this study, further research should be conducted to explore whether other signature strengths may also positively influence the negative impact of stigma by association on caregiver wellbeing. This research could also be extended to examine other caregiver populations.   Concerning the correlation between higher caregiver age and lower stigma by association frequency, it would be interesting to explore the reasons for this correlation further as this may provide further information on methods to combat stigma. Also of interest are this research's findings that caregivers often feel forced to 'choose their stigma.' Again in the interests of aiding caregivers to manage the challenges they face, further research exploration of this area and ways in

which caregivers navigate this difficulty (as well as the costs of attempting to pass as normal) would likely be fruitful.

Concluding Comments

In conclusion, the results of this study suggest that while a child's ASD may be largely invisible, the challenges they and their caregivers face are undeniable. Findings of this study suggest that alongside caring for their child, the caregiver must negotiate around practical complexities in day to day life, resource limitations, and barriers to supports. This effort comes at a cost; with caregivers experiencing decreased wellbeing and interpersonal loss. On top of these stressors, caregivers must cope with the stigma by association attributed by their community and the services they should be able to rely on for support. Stigma repeatedly leaves caregivers isolated, excluded and blamed, with caregivers regularly internalizing this stigma. In attempts to avoid these negative experiences, caregivers spoke of how they try to pass as normal, but subsequently experience heightened anxiety about the possibility of future and further stigma.

The experience of raising a child with an ASD in NZ is hard. Yet participants of this study also provide hope. Results imply that all caregivers can and do experience positive changes and can experience personal growth. Important to the development of future interventions for professionals working with these families is the suggestion from this study that facilitating caregivers' signature strengths such as hope and gratitude can positively influence caregiver wellbeing, even in the face of stressors such as stigma. This offers hope that, while public interventions to improve community attitudes towards caregivers of children with ASDs are unlikely to be available in the near future, in the interim we can support caregivers to not only survive, but thrive.

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Appendices

Appendix A
DSM-IV-TR Criteria for ASDs and related Pervasive Developmental Disorders

Diagnostic criteria for 299.00 Autistic Disorder

A. A total of six (or more) items from (1). (2). and (3). with at least two from (1). and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

(a) marked impairment in the use of multiple nonverbal behaviors such as eye to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
(b) failure to develop peer relationships appropriate to developmental level
(c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing. or pointing out objects of interest)
(d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

(a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
(b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
(c) stereotyped and repetitive use of language or idiosyncratic language
(d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior. interests, and activities, as manifested by at least one of the following:

(a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
(b) apparently inflexible adherence to specific, nonfunctional routines or ritual,
(c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
(d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (I) social inter action, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic criteria for 299.80 Rett's Disorder

A. All of the following:

(1) apparently normal prenatal and perinatal development
(2) apparently normal psychomotor development through the first 5 months after birth
(3) normal head circumference at birth

B. Onset of all of the following after the period of normal development:

(1) deceleration of head growth between ages 5 and 48 months
(2) loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)
(3) loss of social engagement early in the course (although often social interaction

develops later)
(4) appearance of poorly coordinated gait or trunk movements
(5) severely impaired expressive and receptive language development with severe psychomotor retardation

Diagnostic criteria for 299.10 Childhood Disintegrative Disorder

A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behaviour.
B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
    (1) expressive or receptive language
    (2) social skills or adaptive behaviour
    (3) bowel or bladder control
    (4) play
    (5) motor skills
C. Abnormalities of functioning in at least two of the following areas:
    (1) qualitative impairment in social interaction (e.g., impairment in nonverbal behaviours, failure to develop peer relationships, lack of social or emotional reciprocity)
    (2) qualitative impairments in communication (e.g., delay or lack of spoken language, inability to in initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
    (3) restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities, including motor stereotypies and mannerisms
D. The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

Diagnostic criteria for 299.80 Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:
    (1) marked impairment in the use of multiple nonverbal behaviours such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction
    (2) failure to develop peer relationships appropriate to developmental level
    (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
    (4) lack of social or emotional reciprocity
B. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
    (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
    (2) apparently inflexible adherence to specific, non-functional routines or rituals
    (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
    (4) persistent preoccupation with parts of objects
C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviour, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism"-presentations that do not meet the criteria for Autistic Disorder because of late age, late onset, atypical symptomatology, or sub-threshold symptomatology, or all of these.

Appendix B
The VIA Inventory of Strengths and Virtues

Six Virtues and their Contributing Twenty-Four Signature Strengths

Virtue	Signature Strengths Associated with Virtue
Wisdom and Knowledge	
	Creativity
	Curiosity
	Open-Mindedness
	Love of learning
	Perspective
Courage	
	Integrity
	Bravery
	Persistence
	Vitality
Humanity	
	Love
	Kindness
	Social Intelligence
Justice	
	Citizenship
	Fairness
	Leadership
Temperance	
	Forgiveness
	Humility
	Prudence
	Self-regulation
Transcendence	
	Appreciation of beauty and excellence
	Gratitude
	Hope
	Humour
	Religiousness

Adapted from Park, Peterson and Seligman, 2007.

Appendix C
Study One: Ethical Permission

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

10 June 2013

Katie Weastell
76 Waripori Street
Berhampore
WELLINGTON 6023

Dear Katie

Re: HEC: Southern A Application – 13/28
        Stigma by association in family/Whānau of children with an Autism Spectrum
        Diagnosis: Interview study

Thank you for your letter dated 5 June 2013.

On behalf of the Massey University Human Ethics Committee: Southern A I am pleased to
advise you that the ethics of your application are now approved. 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
Massey University Human Ethics Committee: Southern A

cc   Dr Ross Flett   Dr Natasha Tassell-Matamua
     School of Psychology   School of Psychology
     PN320   **PN320**

     Dr Paul Merrick   A/Prof Mandy Morgan
     School of Psychology   School of Psychology
     ALBANY   **PN320**

Appendix D
Study One: Semi Structured Interview Question Schedule

1. Can you tell me about why you decided to take part in this interview?

2. Can you tell me a little about the child in your family/ whānau who has an Autism Spectrum Disorder (ASD)?

3. Has your life changed since you found out (*insert child's name*) has an ASD? *If yes*, how?

4. Do you think this is different to how life may have been if (*insert child's name*) did not have an ASD?

5. How have other people treated you and your family/ whānau since you found out (*insert child's name*) has an ASD?

   (If people have reacted differently):

   a) What do they do (or not do) that is different?

   b) Can you tell me why you think they have changed how they treat you?

   c) Can you give me some examples of times or places when you notice this difference more?

6. Have *you* changed since you found out (*insert child's name*) has an ASD? *If yes,* how?

7. Do you think this is different to how you may have been if (*insert child's name*) did not have an ASD?

8. People sometimes say that challenges in life can be 'character building,' what do you think about this perspective?

9. Have you learned any new skills since you found out (*insert child's name*) has an ASD? *If yes*, what have you learned?

10. Have you learned any new things about yourself since you found out (*insert child's name*) has an ASD? *If yes*, what have you learned?

11. Is there anything else we haven't covered that you would like to add?

Appendix E
Study One: Information Sheet

Children with an Autism Spectrum Disorder:
The Family/ Whānau Experience

INFORMATION SHEET

Researcher Introduction:

My name is Katie Weastell and I am a Doctor of Clinical Psychology Candidate at the Massey University School of Psychology. I am interested in finding out about what life is like for family/ whānau living with a child with an Autism Spectrum Disorder (ASD), as I believe family/ whānau wellbeing is important.

Invitation:

You are invited to take part in a research study which aims to learn about experiences of being a parent/ caregiver of a child with an ASD in Aotearoa New Zealand. This research will look specifically at experiences when socializing with others outside the immediate family/ whānau, while also exploring whether experiences of personal change can be linked to having a child in the family with an ASD.

If you choose to take part I will interview you and ask about:
- your life with *a* child with an ASD,
- whether you have seen any differences in how other people treat you since your child was diagnosed with an ASD,
- whether you have noticed any changes in yourself since your child was diagnosed with an ASD,
- your thoughts on the idea that people have referred to the experience of having a child with a disability as 'character building' and what this might mean to you.

Why did I get this letter and who can take part?

You have received this letter because you have been identified through the researcher's acquaintance networks as a person with the experience of having a child with an Autism Spectrum Disorder. In total I am looking to interview between six and twelve parents/ mātua/ caregivers to get a good understanding of what it is like being a family/ whānau member of a child with an ASD.

To participate in this research you need to:
- be a parent/ caregiver of a child with an Autism Spectrum Disorder between ages three and 18 years old.
- consider yourself to be a family member of a child with an ASD,
- be living with the child for the majority of the year (e.g. at least 84 hours in a week)
- live in the Wellington Region,
- be able to understand and speak fluent English.

Recruitment of new participants will end once I have interviewed twelve parents/ matua /caregivers.

What will happen if I decide to take part?

If you wish to participate please contact me on the details at the end of this sheet. If you agree to an interview I will organise to meet with you at a location that is private and comfortable for you. No one will know about your participation unless you tell them. Because I am interested in what the experience was like for you, nothing you talk about in the interview will be judged, and all information will be kept private. I will use a digital voice-recorder to record the conversation and then type up the interview as a transcript. You will be offered the opportunity to view this transcript and withdraw your own statements at this stage if you wish. If you do choose to take part in this interview a $20 supermarket voucher will be given at the end of the interview to say thanks for the time and effort you have given to the research. You may also choose to have a support person with you during the interview.

Information Use and Security:

All information you give to this research is completely confidential. The consent forms will be kept in a locked cabinet and destroyed within five years of the research completion. Electronic recordings of the interviews will be stored as a password protected file. In written documentation and the final report all identifying features will be disguised using numbers or initials to ensure nobody but the interviewer will be able to link you with the information you provide.

I will use the information I receive as part of the thesis I am writing for my qualification to become a clinical psychologist. I plan to talk at conferences with other psychologists and health professionals about what I find through this research. The information will also help me with a questionnaire survey on the same topic I plan to complete later in the year.

Your Rights if You Decide to Take Part:

Please be aware that 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,
- ask for the digital voice-recorder to be turned off at any time during the interview,
- ask questions about the study at any time during the research,
- provide information on the understanding that your name, and your family members' names will not be used,
- withdraw from the study at any time,
- have access to a summary of the research findings when complete.

Please feel free to contact Katie Weastell if you would like to take part in this research or have any questions about the research.

Researcher:	Supervisor:
Katie Weastell	Dr Ross Flett
027 305 8719	School of Psychology
Katie.weastell@uni.massey.ac.nz	Massey University
	Palmerston North
	Email: r.a.flett@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/28. If you have any concerns about the conduct of this research, please contact Dr Brian Finch,Chair, Massey University Human Ethics Committee: Southern A, telephone 06 380 5799 xtn 84459, email humanethicsoutha@massey.ac.nz

Appendix F
Study One: Consent Form

Children with an Autism Spectrum Disorder:
The Family/ Whānau Experience

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 at any time.

- I consent to my interview being sound recorded: *Agree* ☐   *Do Not Agree* ☐
- I wish to receive a summary copy of the research: *Agree* ☐   *Do Not Agree* ☐

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

Full name - printed:

....

Please feel free to contact Katie Weastell if you have any questions about the research.

Researcher:	**Primary Supervisor:**
Katie Weastell	Dr Ross Flett
DClin Candidate	School of Psychology
Massey University	Massey University
Katie.weastell1@uni.massey.ac.nz	Palmerston North
027 305 8719	r.a.flett@massey.ac.nz

Appendix G
Study Two: Information Sheet

Children with an Autism Spectrum Disorder: The Family/ Whānau Experience

INFORMATION SHEET

Researcher Introduction:
I'm Katie Weastell and I am a Doctor of Clinical Psychology student at Massey University. I am interested in finding out about what life is like for Aotearoa/ New Zealand family/ whānau living with a child with an Autism Spectrum Disorder (ASD).

Invitation:
You are invited to take part in research looking at experiences of being a parent/ mātua/ caregiver of a child with an ASD in Aotearoa New Zealand.
During the survey you will be asked questions about:

- changes you have experienced since your child was diagnosed with an ASD,
- whether you have seen any differences in how other people treat you since your child was diagnosed with an ASD,
- your child's unique abilities and difficulties,
- your current thoughts, feelings and levels of support.

Who can participate?
To take part you will need to:
- be a parent/ mātua or related caregiver of a child aged between 3 and 18 years old who has a diagnosis of Autism Spectrum Disorder (e.g. Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder),
- be aged 16 years old or older,
- have lived with the child who has an Autism Spectrum Disorder in Aotearoa New Zealand for the majority of the past year,
- have access to the internet.
I am wanting to hear from people from across Aotearoa New Zealand, so at least 200 participants are being sought.

What will happen if I decide to take part?
Completing the survey will take about 15 to 25 minutes (if English is your second language this may take longer). Once you click on the next button at the bottom of this page you will be taken to the survey. Once you submit your answers to the survey your results will be sent through to a database automatically.

How will the information be stored and used?
All the information you give to this research is completely anonymous and confidential. Information from this research will be securely stored at Massey University for 5 years, after which it will be destroyed. The information you provide will be used in my doctoral thesis to be submitted for assessment, and the findings may be published in scientific journals or presented at scientific conferences in Aotearoa New Zealand and overseas.

Your rights:
- You are under no obligation to accept this invitation.
- If you decide to take part, completion and submission of the questionnaire implies that you have given us consent to use your answers.
- You have the right to decline to answer any particular question.

Project Contacts:
If you have any further questions please feel free to contact the researcher or supervisor.

Researcher	Primary Supervisor
Katie Weastell	Dr Ross Flett
School of Psychology	School of Psychology
Massey University	Massey University
c/o Dr R Flett	Private Bag 11-222
School of Psychology	Palmerston North 4442
Private Bag 11-222	New Zealand
Palmerston North 4442	Phone: (06) 356-9099, Ext 2051
New Zealand	r.a.flett@massey.ac.nz
katie.weastell1@uni.massey.ac.nz	

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/27. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 xtn: 84459 email humanethicsoutha@massey.ac.nz

Thank you for taking the time to complete this survey. Please click on the '**Next'** button below when you are ready to begin.

Appendix H
Study Two: Ethics Permission

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

21 June 2013

Katie Weastell
76 Waripori Street
Berhampore
WELLINGTON 6023

Dear Katie

Re: HEC: Southern A Application – 13/27
        **Stigma by association in family/Whānau of children with an Autism Spectrum
        Diagnosis: Questionnaire Study**

Thank you for your letter dated 20 June 2013.

On behalf of the Massey University Human Ethics Committee: Southern A I am pleased to
advise you that the ethics of your application are now approved. 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
Massey University Human Ethics Committee: Southern A

cc   Dr Ross Flett   Dr Natasha Tassell-Matamua
     School of Psychology   School of Psychology
     PN320   PN320

     Dr Paul Merrick   A/Prof Mandy Morgan
     School of Psychology   School of Psychology
     ALBANY   PN320

Massey University Human Ethics Committee
Accredited by the Health Research Council
Research Ethics Office
Massey University, Private Bag 11222, Palmerston North 4442, New Zealand   T +64 6 356 9099   +64 6 350 5573   F +64 6 350 5682
E humanethicsofthnorth@massey.ac.nz   zeizofafdan@massey.ac.nz   gro@massey.ac.nz   www.massey.ac.nz

Appendix I
C-SAM Pilot Information and Questions

  Page One:

Children with an Autism Spectrum Disorder: The Family/ Whānau Experience
Measure Feasibility

INFORMATION SHEET

Researcher introduction:
My name is Katie Weastell and I am a Doctor of Clinical Psychology Candidate at the Massey University School of Psychology. I am interested in finding out about what life is like for Aotearoa New Zealand family/ whānau living with a child with an Autism Spectrum Disorder (ASD).

Invitation:
You are invited to take part in research looking at experiences of being a parent/ mātua/ caregiver of a child with an ASD in Aotearoa New Zealand. We have discovered that there are no current measures which look at parent's experiences when out in the community with their child. Therefore we have designed a new measure for this purpose.

The measure we have developed is a scale which focuses on your negative feelings and experiences. This scale is based on literature on experiences and interviews with parents of children with Autism or Aspergers in Aotearoa New Zealand. We want your help because each parent has a unique experience, but we believe some parts of that experience may be similar across many parents.

Who can participate?
You will need to:
- be a parent/ mātua or related caregiver of a child aged between 3 and 18 years old who has a diagnosis of Autism Spectrum Disorder (e.g. Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder),
- be aged 16 years old or older,
- have lived with the child who has an Autism Spectrum Disorder in Aotearoa New Zealand for the majority of the past year,
- have access to the internet.

To get a good idea of how well our measure works we need to get around 30 participants.

What will happen if I decide to take part?
If you choose to take part, clicking on the next button at the bottom of this page will take you to the questionnaire. The questions take approximately 5-10 minutes to complete (if English is your second language this may take longer). When you submit your answers to the questionnaire your results will automatically be sent through to a database. Once we have tested this scale it will be assessed and we intend to include this in a larger questionnaire about parent experiences.

How will the information be stored and used?
All information you give to this questionnaire is anonymous and confidential. Information will be securely stored at Massey University for 5 years, after which it will be destroyed. The information you

provide will be used in my doctoral thesis to be submitted for assessment, and the findings may be published in scientific journals or presented at scientific conferences in Aotearoa New Zealand and overseas.

Your rights:
- You are under no obligation to accept this invitation.
- If you decide to take part, completion and submission of the questionnaire implies that you have given us consent to use your answers.
- You have the right to decline to answer any particular question.

Project contacts:
If you have any further questions please feel free to contact the researcher or supervisor.

Ready to begin?
Please click on the '**Next'** button below when you are ready to begin.

Many thanks
Katie Weastell

Contact information

Researcher	Supervisor
Katie Weastell C/o Dr R Flett School of Psychology Massey University Private Bag 11-222 Palmerston North 4442 New Zealand Email: katie.weastell.1@uni.massey.ac.nz	Dr Ross Flett School of Psychology Massey University Private Bag 11-222 Palmerston North 4442 New Zealand +64 6 3569-099 ext 2051 R.A.Flett@massey.ac.nz

This project has been reviewed and approved by the Massey University
Human Ethics Committee: Southern A, Application 13/27.
If you have any concerns about the conduct of the research, please contact
Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A,
telephone 06 350-5799 x 84459, Email: humanethicsoutha@massey.ac.nz

Page Two

Please note that providing answers to these questions implies consent.
You have the right to decline to answer any particular question.

I have read and understood the information sheet for this study and consent to collection of my responses
(Please click on the 'Yes' choice if you wish to proceed.)

- ○ Yes
- ○ No

Page Three

In this section we want to get a sense of unhappy experiences you may have had when out with your child in the community. These items are examples of what some people have experienced when they went out in the community with their child who has an ASD.

For the next items please choose the answer to fill in the gap of each statement by placing a tick in the appropriate box on the right-hand scale.

When it says 'child' please insert your child's name.

	When I'm out in the community with (child) I feel:	
1	Stressed	Always
2	Self-conscious	Frequently, if not always
3	Frustrated	Quite often
4	Embarrassed/	Sometimes
5	Rejected	Once in a while
6	Angry	Never
7	Vulnerable	
8	Tense	
9	Hopeless	
10	Helpless	
11	Worried	

	When I'm out in the community with (*child*) other people:	
12	Look down on me	Always
13	Seem to pity me	Frequently, if not always
14	Don't want to listen to what I have to say	Quite often
15	Seem tense around me	Sometimes
16	Don't want to be around me and my child	Once in a while
17	Make rude comments	Never
18	Seem awkward around me and my child	
19	Seem to think I'm a bad (mother/ parent/ caregiver etc)	
20	Stare or glare at me	
21	Avoid me	

Nearly there

Page Four

Now just a few quick questions about the survey:

How long did it take you to answer the questions?
…. minutes
Were there questions that didn't make sense/ were hard to understand? If yes – which question/s?
Are there any questions that didn't seem to fit?
Acknowledging that these questions repeat some uncomfortable experiences, are there any questions that felt too uncomfortable?
Are there a feeling/s or experience/s that we missed?
Other suggestions…

Many thanks for taking the time to review this survey. If you have any questions about my wider research focus, or in particular about this survey, then please don't hesitate to contact me (Katie) at:

k.weastell@gmail.com
027 305 8719
(04) 801 5799 xtn 62609

Appendix J
C-SAM Pilot Email

Hi there

We here at Massey University are wanting to increase the understanding within Aotearoa New Zealand of the experience of being a parent/ mātua or related caregiver of a child with an Autism Spectrum Disorder.

The research has three parts involving interviews, development of a scale and distribution of a nationwide questionnaire. Currently we are wishing to find up to 30 parents/ mātua or related caregivers who have a child with an ASD under the age of 18 who would be willing to complete a test version of our scale looking at social experiences.

If you are would like to participate in this stage of the study, please click on the link below, or copy and paste into your internet browser address bar for more information:

https://qasiasingleuser.asia.qualtrics.com/SE/?SID=SV_9yQpMq8cYcI4qiN

The test scale would take 5 - 10 minutes of your time.

Participation is anonymous and all information collected will be kept confidential.

Researcher:

Katie Weastell
Email: katie.weastell1@uni.massey.ac.nz

 Many thanks in advance, your participation is appreciated!

Appendix K
CSAM Pilot Statistical Supplements

Table K1

CSAM Pilot Item Correlation Analysis Results

	Stressed	Self-conscious	Frustrated	Embarrassed	Rejected	Angry	Vulnerable	Tense	Hopeless	Helpless	Worried	Look down on me	Seem to pity me	Don't want to listen to what I have to say	Seem tense around me	Don't want to be around me and my child	Make rude comments	Seem awkward around me and my child	Seem to think I'm a bad parent/(mother/)child	Stare or glare at me	Avoid me
Stressed	1.00																				
Self-conscious	.62	1.00																			
Frustrated	.67	.49	1.00																		
Embarrassed	.51	.58	.56	1.00																	
Rejected	.48	.55	.25	.42	1.00																
Angry	.46	.39	.50	.49	.60	1.00															
Vulnerable	.50	.52	.44	.59	.35	.33	1.00														
Tense	.73	.52	.77	.48	.33	.52	.59	1.00													
Hopeless	.50	.45	.47	.69	.64	.48	.31	.32	1.00												
Helpless	.50	.37	.41	.60	.59	.47	.43	.49	.84	1.00											
Worried	.49	.51	.55	.30	.33	.21	.52	.71	.27	.41	1.00										
Look down on me	.54	.41	.27	.39	.62	.39	.32	.35	.64	.64	.36	1.00									
Seem to pity me	.31	.28	.23	.26	.46	.38	.32	.37	.40	.60	.47	.62	1.00								
Don't want to listen to what I have to say	.11	.33	.24	.23	.47	.30	.13	.28	.32	.42	.53	.51	.49	1.00							
Seem tense around me	.32	.60	.12	.26	.40	.26	.27	.38	.25	.30	.56	.61	.47	.63	1.00						
Don't want to be around me and my child	.58	.54	.27	.44	.73	.43	.39	.46	.49	.58	.55	.74	.65	.58	.63	1.00					
Make rude comments	.37	.37	.19	.30	.40	.27	.30	.37	.30	.44	.48	.47	.35	.69	.56	.58	1.00				
Seem awkward around me and my child	.28	.40	.08	.13	.40	.22	.41	.34	.17	.34	.53	.50	.48	.57	.67	.59	.66	1.00			
Seem to think I'm a bad caregiver	.54	.41	.57	.55	.44	.37	.33	.58	.54	.55	.63	.65	.56	.60	.61	.69	.55	.38	1.00		
Stare or glare at me	.45	.51	.25	.13	.55	.21	.34	.37	.39	.48	.65	.70	.57	.61	.64	.71	.51	.69	.57	1.00	
Avoid me	.36	.40	.32	.27	.46	.28	.38	.48	.40	.60	.64	.58	.79	.63	.59	.63	.61	.73	.63	.77	1.00

Table K2

C-SAM Pilot Item-Total Correlations and Cronbach's Alpha if Item Deleted Results

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Stressed	57.36	269.49	.67	.87	.94
Self-conscious	57.76	268.63	.66	.90	.94
Frustrated	57.73	272.64	.55	.93	.95
Embarrassed	58.48	275.01	.59	.88	.95
Rejected	58.70	269.28	.67	.84	.94
Angry	58.67	275.42	.53	.75	.95
Vulnerable	58.45	267.63	.55	.75	.95
Tense	57.42	266.88	.68	.90	.94
Hopeless	58.91	268.77	.63	.92	.94
Helpless	58.94	265.56	.72	.90	.94
Worried	57.52	261.26	.70	.86	.94
Look down on me	58.15	269.76	.74	.89	.94
Seem to pity me	58.55	273.63	.65	.87	.94
Don't want to listen to what I have to say	58.48	267.20	.61	.85	.95
Seem tense around me	58.39	271.93	.65	.93	.94
Don't want to be around me and my child	58.12	259.86	.81	.88	.94
Make rude comments	58.55	272.94	.63	.79	.94
Seem awkward around me and my child	58.24	276.31	.61	.81	.95
Seem to think I'm a bad (mother/ parent/ caregiver etc)	57.88	261.11	.77	.89	.94
Stare or glare at me	57.73	260.89	.72	.92	.94
Avoid me	58.39	265.56	.76	.92	.94

Children with an Autism Spectrum Disorder: The Family/ Whānau Experience

INFORMATION SHEET

Researcher introduction:
My name is Katie Weastell and I am a Doctor of Clinical Psychology Candidate at the Massey University School of Psychology. I am interested in finding out about what life is like for Aotearoa New Zealand family/ whānau living with a child with an Autism Spectrum Disorder (ASD).

Invitation:
You are invited to take part in research looking at experiences of being a parent/ mātua/ caregiver of a child with an ASD in Aotearoa New Zealand.
If you choose to take part you can complete the following questionnaire which will ask questions about:
- your child's unique abilities and difficulties,
- whether you have seen any differences in how other people treat you since your child was diagnosed with an ASD,
- changes you have experienced since your child was diagnosed with an ASD ,
- your current thoughts, feelings and levels of support.

Who can participate?
You will need to:
- be a parent/ mātua or related caregiver of a child aged between 3 and 18 years old who has a diagnosis of Autism Spectrum Disorder (e.g. Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder),
- be aged 16 years old or older,
- have lived with the child who has an Autism Spectrum Disorder in Aotearoa New Zealand for the majority of the past year,
- have access to the internet.

To get a good idea of how most parents/ mātua/ caregivers experience life with a child with an ASD, we are looking to get at least 200 participants within Aotearoa New Zealand.

What will happen if I decide to take part?
If you choose to take part, clicking on the next button at the bottom of this page will take you to the questionnaire. The questions take approximately 20 to 30 minutes to complete (if English is your second language this may take longer). When you submit your answers to the questionnaires your results will automatically be sent through to a database.

How will the information be stored and used?
All information you give to this questionnaire is anonymous and confidential. Information will be securely stored at Massey University for 5 years, after which it will be destroyed. The information you provide will be used in my doctoral thesis to be submitted for assessment, and the findings may be published in scientific journals or presented at scientific conferences in Aotearoa New Zealand and overseas.

Your rights:

- You are under no obligation to accept this invitation.
- If you decide to take part, completion and submission of the questionnaire implies that you have given us consent to use your answers.
- You have the right to decline to answer any particular question.

Project contacts:

If you have any further questions please feel free to contact the researcher or supervisor.

Researcher	Primary Supervisor
Katie Weastell	Dr Ross Flett
School of Psychology	School of Psychology
Massey University	Massey University
c/o Dr R Flett	Private Bag 11-222
School of Psychology	Palmerston North 4442
Private Bag 11-222	New Zealand
Palmerston North 4442	Phone: (06) 356-9099, Ext 2051
New Zealand	r.a.flett@massey.ac.nz
katie.weastell.1@uni.massey.ac.nz	

> This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/27. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 xtn: 84459 email humanethicsoutha@massey.ac.nz

Copy of Electronic Questionnaire:

Instructions

Instructions

This questionnaire has eight parts. Each part has instructions on how to respond to each item. Please choose the answer that best matches your experience. There are no right or wrong answers!

To keep track of your progress check the progress bar at the bottom of each screen.

Consent

Respondent Consent

Many thanks for your help with this questionnaire.

Please note that providing answers to these questions implies consent.
You have the right to decline to answer any particular question.

I have read and understood the information sheet for this study and consent to collection of my responses
(Please click on the 'Yes' choice if you wish to proceed.)

    ○ Yes

    ○ No

Caregiver

Do you currently live in Aotearoa New Zealand AND consider yourself to be a parent/ matua/ or unpaid caregiver of a child with an Autism Spectrum Disorder?

    ○ Yes

    ○ No

Thank you for your interest.
This survey is limited to those who have lived with a child who has an Autism Spectrum Disorder in Aotearoa New Zealand for the majority of the past year.

The following page may be of interest if you wish to view the results when they are released or you are looking for other support options.

Part 1

Part 1: Questions About You

What is your gender?

    ○ Male

    ○ Female

    ○ Other

What is your age in years?

    [_____]

Which ethnic group do you belong to?
(You may select more than one)

    ☐ New Zealand European/ Pakeha

    ☐ Maori

    ☐ Samoan

☐ Cook Island Maori

☐ Tongan

☐ Niueaen

☐ Chinese

☐ Indian

☐ Other (Please tell us)

> [   ]

Right now are you....

○ Single

○ In a partnered/ de facto relationship

○ Married/ in a civil union

○ Widowed/ a widower

○ Divorced/ separated

What is the highest level of schooling you have finished?

○ No school qualification

○ Secondary school qualifications (e.g., School Certificate, University entrance, NCEA) Post-

○ secondary certificate, diploma, or trade diploma

○ University degree

○ Other (Please tell us)

> [   ]

Please tell us your CURRENT employment status:

○ Full-time paid employment including self employment (35 or more hours per week)

○ Part-time paid work including self employment (less than 35 hours per week)

○ Retired

○ Full-time homemaker/ caregiver Full-

○ time student

○ Unable to work due to health or disability issue

○ Unemployed and seeking work

○ Other: (Please tell us)

> [   ]

How many other adults (age 18+) usually live in the same household as you? (not including yourself)

0	1	2	3	4 or more
○	○	○	○	○

How many other people (of all ages) usually live in the same household as you? (not including yourself)

0	1	2	3	4	5	6 or more
○	○	○	○	○	○	○

Do you own your own home?

○ Yes

○ No, I rent or board

○ Other

Apart from your child, have you ever lived with other family/ whanau members who have an Autism Spectrum Diagnosis?

○ Yes

○ No

Part 2

Part 2: Questions About Your Child

The next questions help us understand your family/ whanau situation. The questions are about the child in your family/ whanau who has an Autism Spectrum Diagnosis.
Note: if there is more than one child in your family/ whanau with an Autism Spectrum Disorder, please complete this questionnaire based on details related to the oldest child.

What is your relationship to the child?

○ Biological Parent

○ Adoptive/ Whangai Parent

○ Unpaid Caregiver

○ Step Parent

○ Grandparent

○ Other (Please specify)

Does the child live with you___?

○ Full time

○ Part time

How old is the child?

[   ]

What gender is the child?

○ Male

○ Female

Would you describe the child as...
(You may select more than one response)

☐ New Zealand European/ Pakeha

☐ Maori

☐ Samoan

☐ Cook Island Maori

☐ Tongan

☐ Niueaen

☐ Chinese

☐ Indian

☐ Other (Please state)

[   ]

What formal diagnosis has the child received?

○ Autistic Disorder

○ Asperger's Disorder

○ Other

[   ]

About how old was the child when they received a diagnosis?

[   ]

What form/s of support or interventions does the child <u>currently receive</u>?
Indicate as many as are relevant.

☐ Support groups

- ☐ Respite care
- ☐ Financial assistance (eg. ORRs funding)
- ☐ Counselling services
- ☐ Case manager
- ☐ Autism Spectrum Disorder support organisations
- ☐ School support staff
- ☐ Primary care provider (GP, nurse etc)
- ☐ Specialised physicians (Pediatrician, Psychologist, etc)
- ☐ Therapy providers (Speech, Occupational, Behavioural etc.)
- ☐ Traditional healer (e.g. Tohunga, Rongoa or Fofo)
- ☐ None of the above
- ☐ Other

```
┌─────────────────────┐
│                     │
└─────────────────────┘
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What form/s of support or interventions has the child received <u>in the past</u>? Indicate as many as are relevant.

- ☐ Support groups
- ☐ Respite care
- ☐ Financial assistance (eg. ORRs funding)
- ☐ Counselling services
- ☐ Case manager
- ☐ Autism Spectrum Disorder support organisations
- ☐ School support staff
- ☐ Primary care provider (GP, nurse etc)
- ☐ Specialised physicians (Pediatrician, Psychologist, etc)
- ☐ Therapy providers (Speech, Occupational, Behavioural etc.)
- ☐ Traditional healer (e.g. Tohunga, Rongoa or Fofo)
- ☐ None of the above
- ☐ Other

```
┌─────────────────────┐
│                     │
└─────────────────────┘
```

Part 3

Part 3: Your Child's Skills and Difficulties

These next questions are about skills and difficulties which make your child different from other children of his/ her age.

For each statement below, please click the circle in that row that best describes your child's behaviour.
Over the last 6 months my child:

	None of the time	Rarely	Some of the time	Often	All of the time
Was aware of other people's feelings	O	O	O	O	O
Did not realise when others were upset or angry	O	O	O	O	O
Noticed the effect of his/her behaviour on other members of the family	O	O	O	O	O
Behaviour often disrupted family life	O	O	O	O	O

	None of the time	Rarely	Some of the time	Often	All of the time
Was very demanding of other people's time	O	O	O	O	O
Was difficult to reason with when upset	O	O	O	O	O
Understood social skills, e.g. did not interrupt conversations	O	O	O	O	O
Did not pick up on body language	O	O	O	O	O

	None of the time	Rarely	Some of the time	Often	All of the time
Understood how to behave when out (e.g. in shops, or other people's homes)	O	O	O	O	O
Realised if s/he offended people with her/ his behaviour	O	O	O	O	O
Responded when told to do something	O	O	O	O	O
Could not follow a command unless it is carefully worded	O	O	O	O	O

Part 4

Part 4: Your Personal Views

Your responses to the following statements in this section will help give us an idea of your approach to life.

Rate the statements below for how accurately they reflect the way you generally feel and behave.
Do not rate what you think you should do, or wish you do, or things you no longer do.

Please be as honest as possible.
For each statement below, please click the circle with your response in that row.

	Very Slightly or Not at All	A Little	Moderately	Quite a Bit	Extremely
I actively seek as much information as I can in new situations	O	O	O	O	O
I am the type of person who really enjoys the uncertainty of everyday life	O	O	O	O	O
I am at my best when doing something that is complex or challenging	O	O	O	O	O
Everywhere I go, I am out looking for new things or experiences	O	O	O	O	O
I view challenging situations as an opportunity to grow and learn	O	O	O	O	O

	Very Slightly or Not at All	A Little	Moderately	Quite a Bit	Extremely
I like to do things that are a little frightening	O	O	O	O	O
I am always looking for experiences that challenge how I think about myself and the world	O	O	O	O	O
I prefer jobs that are excitingly unpredictable	O	O	O	O	O
I frequently seek out opportunities to challenge myself and grow as a person	O	O	O	O	O
I am the kind of person who embraces unfamiliar people, events and places	O	O	O	O	O

These questions continue to look at your approach to life.
Rate each statement below to indicate how much you agree with it.
For each statement below, please click the circle with your response in that row.

	Strongly disagree	Disagree	Slightly disagree	Neutral	Slightly agree	Agree	Strongly agree
I have so much in life to be thankful for	O	O	O	O	O	O	O
If I had to list everything that I felt grateful for, it would be a very long list	O	O	O	O	O	O	O
When I look at the world, I don't see much to be	O	O	O	O	O	O	O

	Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True
grateful for								
I am grateful to a wide variety of people	O	O	O	O	O	O	O	
As I get older I find myself more able to appreciate the people, events, and situations that have been part of my life history	O	O	O	O	O	O	O	
Long amounts of time can go by before I feel grateful to something or someone	O	O	O	O	O	O	O	

The following questions are the final set looking at your approach to life.
Read each item carefully. Please select the option in the row for each statement that best describes YOU.

	Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True
I can think of many ways to get out of a jam	O	O	O	O	O	O	O	O
I energetically pursue my goals	O	O	O	O	O	O	O	O
I feel tired most of the time	O	O	O	O	O	O	O	O
There are lots of ways around any problem	O	O	O	O	O	O	O	O
	Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True
I am easily defeated in an argument	O	O	O	O	O	O	O	O
I can think of many ways to get the things in life that are important to me	O	O	O	O	O	O	O	O
I worry about my health	O	O	O	O	O	O	O	O
Even when others get discouraged, I know I can find a way to solve the problem	O	O	O	O	O	O	O	O
	Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

My past experiences have prepared me well for my future	O	O	O	O	O	O	O	O
I've been pretty successful in life	O	O	O	O	O	O	O	O
I usually find myself worrying about something	O	O	O	O	O	O	O	O
I meet the goals that I set for myself	O	O	O	O	O	O	O	O

Part 5

Part 5: Your Personal Wellbeing

For this section We want to know about to your overall wellbeing.

Below are some statements about feelings and thoughts. Please select the answer that best shows your experience of each statement over the last TWO WEEKS.

	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	O	O	O	O	O
I've been feeling useful	O	O	O	O	O
I've been feeling relaxed	O	O	O	O	O
I've been feeling interested in other people	O	O	O	O	O
I've had energy to spare	O	O	O	O	O

	None of the time	Rarely	Some of the time	Often	All of the time
I've been dealing with problems well	O	O	O	O	O
I've been thinking clearly	O	O	O	O	O
I've been feeling good about myself	O	O	O	O	O
I've been feeling close to other people	O	O	O	O	O
I've been feeling confident	O	O	O	O	O

	None of the time	Rarely	Some of the time	Often	All of the time
I've been able to make up my own mind about things	O	O	O	O	O
I've been feeling loved	O	O	O	O	O
I've been interested in new things	O	O	O	O	O
I've been feeling cheerful	O	O	O	O	O

Slide the bar to rate your satisfaction according to the statement below.

	Not at all satisfied									Completely satisfied	
	0	1	2	3	4	5	6	7	8	9	10
Overall, how satisfied are you with your current level of physical health?											

Part 6

Part 6: Social Experiences

Research tells us that there are many areas of life that parents/ matua/ caregivers of children with an ASD find challenging (e.g. finance or time limitations). In this section we want to get a sense of challenging experiences you may have had when out with your child in the community. The following items are examples of what some people have experienced when they go out in the community with their child who has an ASD.

For the next items please indicate how often over the past 6 months you have felt this way by choosing a response which most accurately reflects your experience.

Where it says '(child)' please insert your child's name.

When I'm out in the community with (child) I feel ...

	Always	Frequently, if not always	Quite often	Sometimes	Once in a while	Never
Stressed	O	O	O	O	O	O
Self-conscious	O	O	O	O	O	O
Frustrated	O	O	O	O	O	O
Embarrassed	O	O	O	O	O	O
Rejected	O	O	O	O	O	O
	Always	Frequently, if not always	Quite often	Sometimes	Once in a while	Never
Angry	O	O	O	O	O	O
Vulnerable	O	O	O	O	O	O
Tense	O	O	O	O	O	O
Hopeless	O	O	O	O	O	O
Worried	O	O	O	O	O	O

When I'm out in the community with (*child*) other people ...

	Always	Frequently, if not always	Quite often	Sometimes	Once in a while	Never
Look down on me	O	O	O	O	O	O
Seem to pity me	O	O	O	O	O	O
Don't want to listen to what I have to say	O	O	O	O	O	O
Seem tense around me	O	O	O	O	O	O
Don't want to be around me and my child	O	O	O	O	O	O
	Always	Frequently, if not always	Quite often	Sometimes	Once in a while	Never
Make rude comments	O	O	O	O	O	O

Seem awkward around me and my child	○	○	○	○	○	○
Seem to think I'm a bad (mother/ parent/ caregiver etc)	○	○	○	○	○	○
Stare or glare at me	○	○	○	○	○	○
Avoid me	○	○	○	○	○	○

Part 7

Part 7: Changes To Your Life

The following statements show how some people feel they have been changed through the experience of caring for a child with special needs.

As you read each statement, decide how much you agree, and select one answer to show your decision.

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
I have learned to speak out for my family member	○	○	○	○	○
I have learned that I can achieve rather than feel powerless	○	○	○	○	○
I am more compassionate toward others	○	○	○	○	○
I have made a career change, which has lead to greater vocational satisfaction	○	○	○	○	○
I am stronger as a person	○	○	○	○	○

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
I am more confident	O	O	O	O	O

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
I take better care of myself	O	O	O	O	O
I have stronger spiritual convictions now (e.g., personal spirituality, faith in god)	O	O	O	O	O
I have made many close friends with people I would have never met otherwise	O	O	O	O	O
I have learned to see life from a different perspective (learned what it is like to live in someone else's shoes)	O	O	O	O	O
I have made a difference in the lives of other people (through advocacy/promoting changes)	O	O	O	O	O
I make the most out of each day rather than living for the future	O	O	O	O	O

	Strongly Agree	Agree	Not Sure	Disagree	Strongly Disagree
I celebrate life more now (rather than just merely surviving day to day)	O	O	O	O	O
I have a different and more genuine view of what it means to be successful in life	O	O	O	O	O
I have learned what is really important and valuable in life	O	O	O	O	O
I have developed new skills that have helped me to do a better job in my career/vocation	O	O	O	O	O
I have developed attitudes that have helped me to do a better job in my chosen career/vocation	O	O	O	O	O
My marriage/ relationship has emerged stronger	O	O	O	O	O

Are there any other experiences or changes in your life you would like us to know about which have not been mentioned?

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Part 8

Part 8: Your Current Social Support

This last section helps us understand how well you feel your current support networks are working.

We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
I get the emotional help and support I need from a spouse/ partner/ significant other	O	O	O	O	O	O	O
I get the emotional help and support I need from my family	O	O	O	O	O	O	O
I get the emotional help and support I need from my friends	O	O	O	O	O	O	O

Part 9

Are there any other situations, thoughts, experiences or feelings you would like to add we haven't covered?

The End

You are near the end of this questionnaire.

Please click on 'Next' to submit your responses and access a page with further support information.

Thank you for taking part in this research study.

A summary of this research will be available on the Massey University School of Psychology research web page once all results have been collected and analysed.
Please note the following website for future reference if you wish to access the summary: http://psych-research.massey.ac.nz

Children with an Autism Spectrum Disorder: The Family/ Whānau Experience

Debrief Information

Thank you for completing this questionnaire. In this study, we were interested in finding out your experience of having a child with an Autism Spectrum Disorder (ASD). Very little research has been done in Aotearoa New Zealand to explore this experience. This research will help us to learn more about in what ways we can support family/ whānau who have a child with an ASD.

Thank you once again for taking the time to participate in this study.

Need to talk to someone?

If you have found completing this questionnaire distressing in any way, it may be helpful for you to talk to a friend, relative, or other support person (e.g. minister, counselor, GP) about how you are feeling. You could also call, or check out the websites of one of the following support organizations:

LifeLine
> Free telephone counseling available 24 hours a day, 7 days a week
>> *Ph*: 0800 111 777
>> *Website*: http://www.lifeline.org.nz

Parent Help
> Free telephone helpline available 24 hours a day, 7 days a week
>> *Ph*: 0800 568 856
>> *Website*: http://www.parenthelp.org.nz/

Parent to Parent
> A coordinating agency who believe in the value of supporting parents.
>> *Website*: http://www.parent2parent.org.nz/

`

Appendix M
Study Two: Poster Advertisement

Appendix   N
Study Two: Facebook Advertisement

Advert preview:

Autism and the Family

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Your child has an Autism Spectrum Disorder? Please click here to find out about our survey

Advert name: http://www.massey.ac.nz/mass

Audience: This advert targets users:

- who live in New Zealand
- age 16 and older

Campaign: Autism Research (new campaign)

Bid type: CPC

Bid: $0.60 NZD per click

Lifetime budget: $120.00 NZD

Facebook Advertising Limitations:

1. **Heading**: 25 characters (including spacing and punctuation)
2. **Body**: 90 characters (including spacing and punctuation)
3. **Link:** to the Massey Website page:
   http://www.massey.ac.nz/massey/learning/departments/school-of-psychology/research/online-surveys-and-results.cfm
4. Can have one image.

Appendix O
Study Two: Email Advertisement

To Whom it May Concern

Are You a Parent or Caregiver of a Child with an Autism Spectrum Disorder?

If so, can you help researchers at Massey University learn more about the experience of being a parent/ mātua or caregiver of a child with an Autism Spectrum Disorder?

Who can Participate?

To assist with this research we need people who consider themselves family/ whānau of a child with an Autism Spectrum Disorder (ASD) to complete an internet based questionnaire.

You will need to:

- be a parent/ mātua or caregiver of a child aged between 3 and 18 years old who has a diagnosis of Autism Spectrum Disorder (Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder),
- be aged 16 years old or older,
- have lived with the child who has an Autism Spectrum Disorder in Aotearoa New Zealand for the majority of the past year,
- have access to the internet.

To Participate:

As of the 26.08.13 the questionnaire will be available at:
http://psych-research.massey.ac.nz/

The research will take approximately 20 minutes. Participation is anonymous and all information collected will be kept confidential.

For more information contact:
Researcher:
Katie Weastell
Email: katie.weastell.1@uni.massey.ac.nz
Phone/text: 027 305 8719

Primary Supervisor:
Ross Flett
Email: r.a.flett@massey.ac.nz
Phone: (06) 356-9099, Ext 2051

Many thanks in advance, your participation is appreciated!

Appendix P
Study Two: Data Analysis Supplementary Tables

Table P1

SCDC Number of Responses Per Item, Rating Frequencies and Item Means

SCDC Item	n responses	n endorsement of response categories*					Item m (SD)
		1	2	3	4	5	
Was not aware of other people's feelings	100	2	13	54	28	3	3.17 (.77)
Did not realise when others were upset or angry	100	5	16	52	24	3	3.04 (.85)
Did not notice the effect of his/her behaviour on other members of the family	99	1	4	29	51	14	3.74 (.79)
Behaviour often disrupted family life	98	4	10	23	50	11	3.55 (.97)
Was very demanding of other people's time	100	1	7	22	55	15	3.76 (.83)
Was difficult to reason with when upset	99	1	3	20	46	29	4.00 (.85)
Did not understand social skills	100	1	7	22	45	25	3.86 (.91)
Did not pick up on body language	99	7	21	22	34	15	3.29 (1.17)
Did not understand how to behave when out	100	7	22	41	24	6	3.00 (.99)
Did not realise if s/he offended people with her/his behaviour	100	1	6	21	48	24	3.88 (.88)
Did not respond when told to do something	100	3	30	54	12	1	2.78 (.73)
Could not follow a command unless it is carefully worded	100	1	9	41	40	9	3.47 (.82)

*1 = 'none of the time,' 2 = 'rarely,' 3 = 'some of the time,' 4 = 'often,' 5 = 'all of the time.'

Table P2

Wellbeing Scale Item Frequency Analysis

WEMWBS Item	n responses	n endorsement of response categories*					Item m
		1	2	3	4	5	
I've been feeling optimistic about the future	99	2	14	32	42	9	3.42
I've been feeling useful	100	3	11	22	50	14	3.61
I've been feeling relaxed	100	6	42	36	13	3	2.65
I've been feeling interested in other people	100	4	10	37	37	12	3.43
I've had energy to spare	100	17	46	29	7	1	2.29
I've been dealing with problems well	100	0	8	48	38	6	3.42
I've been thinking clearly	98	0	9	45	40	4	3.40
I've been feeling good about myself	100	1	19	49	26	5	3.15
I've been feeling close to other people	100	3	20	34	34	9	3.26
I've been feeling confident	100	1	14	43	37	5	3.31
I've been able to make up my own mind about things	100	0	2	26	51	21	3.91
I've been feeling loved	99	2	7	27	36	27	3.80
I've been interested in new things	99	2	12	37	37	11	3.43
I've been feeling cheerful	99	1	14	38	39	7	3.37

*1 = *None of the time*, 2 = *Rarely*, 3 = *Some of the time*, 4 = *Often*, 5 = *All of the time*

Table P3

Comparison of Study Variable Means to Previous Research

| Scale (n items) and Data Source	Variable	Literature Mean (SD, *n*)	Study Two Mean (SD, *n*)	*d*
WEMWBS (14), University College of London, 2011	Wellbeing	51.6 (8.7, 7020)	46.5 (9.25, 94)	t(7112) = 5.64, p = <.001, d = 0-0.586
CEI-II (10), Kashdan et al, 2009	Curiosity	33.2 (6.78, 311)	29.83 (7.55, 95)	t(404) = 4.13, p = <.001, d = -.484
GQ-6 (6), McCullough et al. 2002	Hope	36.9 (4.92, 1228)	34.51 (5.42, 99)	t(1325) = 4.61, p = <.001, d = -0.482
ADHS (8), Lopez, Ciarlelli, Coffman, Stone, & Wyatt, 2000	Gratitude	48 (7, 3920)	48.75 (7.77, 97)	t(4015) = 1.04, p = .30, d = 0.107
Physical Health (1) Developed for study	Physical Health	n/a	5.3 (2.26, 94)	No previous data available.
C-SAM (20) Developed for study	Stigma By Association	Pilot Study: 58.94 (16.30, 33)	54.75 (19.38, 96)	t(127) = 1.12, p = .26, d = -0.23
LMS-PCS (18), Scorgie, 1996	Positive Changes	63.72 (?, 80)	66.09 (9.98, 94)	Unable to be calculated
SCDC (12) Skuse & Scourfield 2005	Child's Difficulties	n/a	41.44 (5.97, 96)	Means not comparable
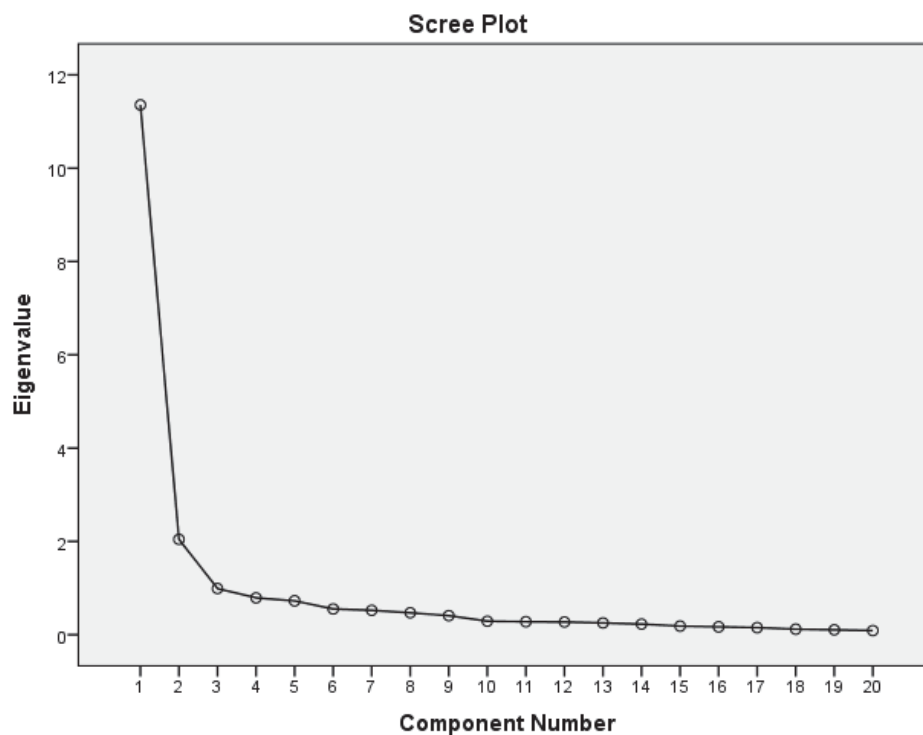
Figure P1: Scree plot analysis of C-SAM factors.

Table P4

Descriptive Statistics and Internal Reliability of the questionnaire variables

Variable (Scale, items)	N	M (SD)	95% CI	α	α reported in previous studies
Wellbeing (WEMWBS, 14)	94	46.50 (9.25)	[44.61, 48.39]	.94	.91 – 93[*]
Curiosity (CEI-II, 10)	95	29.83 (7.55)	[28.29, 31.37]	.89	.85 - .86[**]
Gratitude (GQ-6, 6)	99	34.52 (5.40)	[33.43, 35.60]	.80	.82 - .87[***]
Hope (ADHS, 8)	97	48.70 (7.77)	[47.19, 50.32]	.87	.74 - .88[****]
Physical Health (1)	94	5.30 (2.26)	[4.85, 5.77]	-	-
Stigma by Association (C-SAM, 20)	96	54.75 (19.38)	[50.82, 58.68]	.96	.94[*****]
Positive Changes (LMS-PCS, 18)	94	66.08 (9.98)	[64.04, 68.13]	.87	.81 to .86[******]
Social Support					
- Spouse/ significant other (1)	97	4.26 (2.04)	[3.85, 4.67]	-	-
- Family (1)	96	3.76 (1.80)	[3.40, 4.12]	-	-
- Friends (1)	97	4.6 (1.40)	[4.31, 4.89]	-	-
Child's Difficulties (SCDC, 12)	96	41.4 (5.97)	[40.23, 42.63]	.80	.93[*******]
Total number of Current Supports (1)	100	2.95 (2.07)	[2.54, 3.36]	-	-
Total number of Past Supports (1)	100	4.12 (2.45)	[3.63, 4.61]	-	-
Number of other Adults Available (1)	100	1.00 (0.73)	[0.86, 1.14]	-	-
Child Age at Diagnosis (years, 1)	92	3.45 (3.14)	[2.80, 4.09]	-	-
Time since Diagnosis (years, 1)	92	5.02 (3.61)	[4.27, 5.77]	-	-

*Tennant et al., 2007, and Lloyd & Devine, 2012. ** Kashdan et al., 2009; and Kashdan et al., 2011 *** Froh et al. 2011; Jarden, 2011; and McCullough et al. 2002, **** Snyder et al., 1991; and Sumerlin, 1997, ***** C-SAM Pilot, ****** Diamond, 2005, ******* Skuse, Mandy & Scourfield, 2005).

Appendix Q
Additional Subthemes Identified During Analysis of Study Two Open Ended Questions

Having a Child with an ASD is Hard

   Practical Restrictions

Practical restrictions documented by Study Two participants included a new theme *a complex life* replacing Study One's theme *unexpected obstacles*, however both themes of *barriers to support* and *resource limitations* were found to be similar in Study Two to Study One. Similar to findings under *unexpected obstacles* in Study One, three participants in this study referenced how their life had become more complicated (hence the altered theme name). For example:

> *I feel like everything has changed! A big thing for me is how rigid and predictable everything is, always planning ahead to avoid meltdowns and make things easier on them (I have 2 with ASD). I used to be a very "go with the flow, live for the moment" kind of person. Now that is not an option. I also don't have the luxury of leaving my kids with just anyone …there are only a few that understand them well enough and that can cope with them.* (Participant 44)

As in Study One, Study Two respondents identified how they experienced frustration associated with their attempts to access support. These *barriers to support* included systemic barriers referenced by fifteen respondents, for example:

> *Frustration with the difficulty of accessing support. As parents, we have to deal with so many different agencies, each having their own systems and criteria. We also are expected to know what is available and to ask for it. If we don't know, or don't ask, we don't get.* (Participant 108)

Caregivers also spoke about the lack of understanding they experienced from family, friends, and professionals, for instance:

> *Difficulty within the health system/ hospital when a child on the spectrum is sick and needing care/ often misunderstood and makes for a more stressful situation.* (Participant 70)

The *resource limitations* noted by respondents in Study Two included time and financial constraints. Examples of time stressors included illustrations such as:

> *We don't have babysitters or time off and my son is a 24/7 job as I'm always trying new things/ways to help him, lessen his load.* (Participant 5)

Financial stressors raised were also similar to those in Study One, such as the inability to work such as is possible when raising a 'typical' child, and the costs of accessing evidence based supports:

> *There should be more financial help - I took a part time job earning less to care for my son and the financial stress is difficult on top of the other everyday stressors one has to face.* (Participant 144)

> *ABA [Applied Behaviour Analysis Therapy] is too expensive and not available in our area - but that is without a doubt the one we have heard the best things about, and would like to have undertaken.* (Participant 68)

Personal Costs

Also reflecting findings of Study One, common 'personal costs' identified by respondents could be summarised under themes of 'reduced wellbeing' and 'interpersonal loss.'

Reduced Wellbeing

The theme 'reduced wellbeing,' represented the same subthemes as this theme in Study One of 'loss of own goals,' 'limited energy,' 'stress,' 'constant worry,' and 'decreased physical health' plus a new theme 'sleep deprivation.' Ten participants spoke of ways in which they felt their life goals had been overshadowed by needs created by the ASD, for example:

> *We choose to Homeschool [sic] our 2 ASD children rather than for me to continue with my career. A decision that is hard financially but the right one for our family as the kids are thriving and growing in this environment.* (Participant 38)

Connected to this loss of own goals was the limit described by participants to the amount of energy they had, and the priority they had to give to extra care needs associated with caring for a child with an ASD:

> *… a lot of the time I am just making it through the day with the day to day challenges of dealing with autism, and I don't have the time or energy to pursue a career, as the most important thing I have to do is look after myself, as I am raising my kids on my own with not much outside help.* (Participant 115)

Stress associated with caring for their child was also raised by a substantial number of respondents in the Study Two questionnaire:

The stress involved with caring for an intellectually disabled child is second to

none, this pressure on top of it is inhumane. (Participant 36)

Adding to the stress of daily changes raising a child with an ASD, five participants felt it was important to share their experience of constant worry, which most frequently was presented as worry about the future:

Rarely do a couple of days go by without thinking about the future. What will

happen to him? Where will he go? Who is there looking out for him? As he is so

vulnerable is he liable to be the subject of abuse? It seems ludicrous at 6 years of

age to worry about such things but it's a part of life you take on board when you

have an autistic child. (Participant 68)

Not surprising considering the considerable stress caregivers report they experience, respondents conveyed that they had experienced detrimental effects on their physical health which they attributed to their experience raising their child, for example:

Having an internationally adopted child…, with the likelihood of FASD… placed

exponential stress on my marriage, my health and my wellbeing, it fractured my

family and marginalised me to the extent that I lost practically everything I had

ever worked for prior to this. (Participant 109)

Interpersonal Loss

The theme 'interpersonal loss' represented respondent experiences of both 'isolation' and 'relationship loss and strain.' Isolation was directly referenced as an important area to explore by five participants, for instance:

Perhaps a section on how isolated you feel as parents with autistic kids. Since my

son's diagnosis I have lost three of my closest friends. My son has bad anxiety so

we don't go out much now. A section on that would be interesting. (Participant

23)

The above quote also provides an example of relationship loss reported by Study Two respondents, with many respondents referencing loss of friendships and strained family relationships. The following is an example of how one respondent framed the strain on their relationships:

… its hard on a marriage/relationship though. For us not necessarily because we fight about our child but because it adds to the already hectic and often demanding characteristics that make up a family living in NZ today. (Participant 110)

Having a Child with an ASD is Not all Bad

Positive Emotions

As was found in Study One, positive emotions were often not explicitly referenced, however could be identified threaded through the information respondents shared. Positive emotions identified, again reflecting the findings from Study One, were 'love,' 'pride' and 'gratitude.' Love was frequently noted by respondents within the open-ended questions, often communicated intensely, for example it is difficult to miss the love conveyed in the following passage:

I find that many people cannot look past that diagnosis and do not see my son for who he is. It is their loss, as he is the light of my life and is a very precious boy. (Participant 57)

Pride was also common in participant quotes. Often statements conveying pride followed illustrations of how difficult life could feel at times, and then in contrast at times it was the first thing the caregiver wished to communicate, for instance:

…just that having a child with an ASD is an amazing blessing in my life. He is touching peoples [sic] lives in such a profound way it often leaves me speechless. (Participant 110)

The above example also demonstrates gratitude, the mostly commonly identified positive emotion in participant responses. This gratitude extended from gratitude for the presence of the child, to gratitude for what the caregiver has gained:

I have definitely learned so much about what is really important in life. *(Participant 115)*

Positive Experiences

'Positive experiences' were often shared by caregivers alongside difficult experiences. The main subtheme reported by respondents to Study Two was the experience of gaining Subthemes encompassed by the theme positive experiences included 'quality friendships' and 'career development.'

Quality Friendships

Quality friendships was a theme representing responses from four who participants wrote about how, in spite of losing some friendships, those friendships that had endured were of greater quality. For example:

> *You go through the worst of times and find out how strong you are. You end up with the best people in your life because others who don't 'get it' fade away.* (Participant 144)

Career Development

Study One found that some caregivers were able to reframe the difficult lessons they had learnt through the process of caring for their child into benefits for themselves, often in the domain of work life. Five participants noted that their experiences had simulated positive growth for their career, for instance:

> *As a newly trained teacher I feel I have gained 'inside' understanding that will help me to support special needs students and their families in the process of raising my daughter.* (Participant 59)