Parent experiences and coping processes when raising children with Asperger syndrome: Challenges, turning points and building resilience

By

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Abstract

This study explored parent experiences and their coping responses raising a child or children with Asperger syndrome, an autism spectrum disorder. A family resilience framework was used to interpret the process of positive adaptations that led to resilience. A disability studies perspective considered how parents reconceptualised what was 'normal' as they managed the friction between societal views of difference and their child's strengths. The chosen methodology was narrative inquiry with a thematic approach to the narrative analysis. Semi-structured interviews were conducted with 25 parents and 1 grandparent of children with Asperger syndrome in New Zealand. This study found families experienced significant stress when raising a child or children with Asperger syndrome and considerable adaptations over the course of their child's growing up years were made.

Four key themes around challenges were identified: the *challenges associated with Asperger syndrome*, such as their child's difficult behaviour, social skill difficulties and high sensory sensitivities; *challenges arising from a lack of understanding and acceptance* in the community that led to stigma and social withdrawal; *challenges interacting with health and education services*, such as a long medical diagnostic process and inadequate support at school; and *challenges to family dynamics* that resulted in increased tension between family members. Turning points were identified as part of the process of building resilience as parents successfully managed difficult circumstances at critical junctures in their lives. Positive coping strategies included *meaning making*, *developing resources*, *planning ahead and solving problems*; and *strengthening intrapersonal assets*.

The findings from this study contribute to the theoretical construct of resilience and to the emerging literature on positive adaptations. Implications for practice include encouraging respectful parent and professional relationships; strengthening social support, especially through parent groups; raising parents' self-efficacy through tailored behavioural strategies for their child; early intervention and targeted school resources; and support at critical times.

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Chapter 1

Introduction

The autism spectrum describes a range of neurological disorders that centres on social, communication and behavioural difficulties. There is a wide range of ability levels within the autism spectrum, with Asperger syndrome (AS) considered to be on the high functioning end of the autism spectrum. The diagnoses of children with an autism spectrum disorder (ASD) are rapidly rising, with an estimated incidence of one in 68 children currently being diagnosed in the United States (Centers for Disease Control and Prevention, 2014) and one in 100 identified with an autism spectrum disorder in New Zealand (Autism New Zealand, 2011). In fact, autism spectrum disorder is growing faster than any other developmental disability (Twoy, Connolly, & Novak, 2007). A wider definition of pervasive developmental disorders and an increased awareness influences this higher rate of diagnosis, with genetic and environmental elements acknowledged as contributing factors.

Background on Asperger Syndrome

Hans Asperger, an Austrian paediatrician, published a paper in 1944 (cited Frith, 2004) on autistic psychopathy that featured case descriptions of children with high intellectual functioning, precocious language, social awkwardness, intense absorption in a special interest, and clumsy movements. Asperger coined the expression 'little professors' as a result of the children's ability to speak at length regarding their area of special interest. Lorna Wing (1981) a British psychiatrist, introduced the term 'Asperger's syndrome' in 1981 in relation to the aspects Asperger had described in these case descriptions. The translation of Asperger's papers from German to English and the publication of Wing's paper reignited interest in Asperger's work and raised awareness regarding a fuller spectrum of autism disorders.

Fifty years after first being described, Asperger syndrome was made an official diagnostic category in the Diagnostic and Statistical Manual of Mental Disorders or DSM-IV (American Psychiatric Association, 2010). In May 2013, the DSM-V reclassified Asperger syndrome as part of autism spectrum disorders instead of AS

being considered a separate condition (American Psychiatric Association, 2013). This was a result of extensive reviews that demonstrated different quantitative manifestations due to individual variability within Asperger syndrome and autism spectrum disorders rather than evidence to support two qualitatively distinct disorders (Broadstock, 2014; Frith, 2004; Sanders, 2009). It was determined that different sub-groups along the spectrum shared a mixture of features, from classic autism with intellectual impairment through to high functioning autism and Asperger syndrome (Wing, Gould, & Gillberg, 2011). High functioning autism and Asperger syndrome are also very similar in their presentations without clear evidence in research or clinical practice that they are different disorders (Attwood, 2013). However, Asperger syndrome remains a separate classification in the World Health Organisation's (WHO) International Classification of Diseases – ICD-10 (World Health Organisation, 2010). Other diagnostic tools designed by Szatmari (Szatmari, Brenner, & Nagy, 1989); Gillberg and Gillberg (1989); and Atwood (2008) are used on a lesser scale to identify AS.

Asperger syndrome is a pervasive developmental disorder that shares the triad of difficulties in reciprocal communication, social interaction and social imagination within the wider autism spectrum disorders (Gillberg, Nordin & Ehlers, 1996). AS has a salient feature in common with more severe levels of the disorder known as 'theory of mind' or mind-blindness, that is, a person having great difficulty recognising other people's feelings and thoughts (Frith & Happé, 2005). People with Asperger syndrome have average to above average intelligence and may have intense interests in a particular subject area or topic; strong desires for predictability and routine; formal language choice and patterns; odd voice tonality; non-verbal communication difficulties; and motor clumsiness (Atwood, 2008; Gillberg & Gillberg, 1989). Repetitive mannerisms and sensory sensitivities are common, and obsessions and compulsions may emerge (Atwood, 2008). Children with AS experience great difficulties reading the social cues of their peers which leads to poor success in initiating and maintaining social relationships (Church, Alisanski, & Amanullah, 2000). Depression and ADHD have been found to have high comorbidity rates with AS (Atwood, 2008; Ghaziuddin, Weidmer-Mikhail & Ghaziuddin, 1998). Strengths observed regarding AS include "remarkable memory, superior academic skills, visual thinking, recognizing order, passion and conviction, and comfort with adults" (Lasser & Corley, 2008, p. 338). Atwood (2008) describes people with Asperger syndrome as

attending to fine detail, being honest and possessing a strong sense of social justice. Lastly, Frith and Happé (2005) note a "strikingly uneven profile of abilities and difficulties" (p. 789) with a general consensus around a diverse range of functioning (Atwood, 2008; Moloney, 2010).

A search for a diagnosis can span several years, resulting in considerable stress for families (Calzada, Pistrang, & Mandy, 2011; Dale, Jahoda, & Knott, 2006; Fleischmann, 2004). Prolonged waiting periods for referrals, assessments, and specialists' reports contribute to this stress (Hutton & Caron, 2005). Comorbid diagnoses, misdiagnoses and/or overly general conclusions are often made before an official diagnosis is obtained (Hutton & Caron, 2005). Asperger syndrome is rarely brought to the attention of clinicians before the ages of 5–6 years, with the average age for diagnosis at 11 years, though in retrospect, abnormalities of communication, social interaction and behaviour were considered to be present much earlier (Ghaziuddin, 2010; Gillberg et al., 1996; Howlin & Asgharian, 1999). Boys are three to four times more likely than girls to be diagnosed with AS (National Institute of Neurological Disorders and Stroke, [NINDS], 2012). There is recognition that girls miss being identified due to their behaviour and interaction presenting differently, including varied coping and camouflaging mechanisms (Attwood, 2008; Wing et al., 2011).

Parent Experiences

Parents experience a long and difficult search for answers about their child's odd behaviours and atypical development, such as inflexibility towards changes in routines, pervasive anxiety and hyper-sensory sensitivities. Parents of children with AS experience significantly longer delays and greater frustration searching for a diagnosis than parents of a child with classic autism (Howlin & Asgharian, 1999). The following factors can contribute to these prolonged delays: a lack of professional awareness, knowledge and training; a 'wait and see' attitude; misdiagnoses; excessive financial costs; and the length of time for the majority of the child's difficulties to become apparent (Inglis, 2006; Shacar, 2006). Partners or spouses may have conflicting views on pursing a diagnosis (Murray, 2006) and not all parents agree with the clinical diagnosis specifications and its relation to their own child's behaviours (Calzada et al., 2011; Russell & Norwich, 2012).

Parents can experience a sense of relief and enlightened understanding after a diagnosis, especially after years of confusion regarding their child's development and behaviour (Calzada et al., 2011; Gill & Liamputtong, 2013; Gray, 1994; Hutton & Caron, 2005; Midence & O'neill, 1999; Russell & Norwich, 2012). When Willey (1999) received an AS diagnosis for both herself and her daughter she wrote in her autobiography: "The storm lifted and the answers that explained who my daughter and I were swirled around us like precious gemstones safely washed in with the tide. At last, I had reasons and explanations so rich and real I could almost touch them" (p. 110-111). A diagnosis can combat judgment about parenting skills and attribute their child's troublesome behaviour to an innate neurological condition. Thompson-Kroon (2012) found that parents sought a diagnosis to secure services, provide legitimate answers about their child's behaviour, and help "redefine themselves as no longer a 'bad' parent, but a parent who has a child for whom help is required" (p. 109). However, after a diagnosis, parents can be left without clear information, relevant advice or support which presents additional hurdles (Hutton & Caron, 2005; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010; Whitaker, 2002). In her memoir, Fling (2000) described this as a "diagnosis and a handshake" (p. 131).

> As quickly as the diagnosis of Asperger syndrome had given me happiness and hope, the enormity of [my son's] situation was beginning to dawn on me. Now that I had the knowledge of this new mysterious disorder, things had not suddenly changed for the better, the only thing different was that I knew why [my son] behaved the way he did. (p. 131)

A diagnosis of AS can confirm and validate parents' worries and suspicions but also cause disequilibrium within their family life (Abbott, Bernard & Forge, 2013; Bayat & Schuntermann, 2013; Seligman & Darling, 2007). Parents can experience a major emotional impact that continues long afterwards (Abbott et al., 2013). Fear and shock can predominate with a sense of isolation and uncertainty (Whitaker, 2002), as well as grief, loss, hope and acceptance (Inglis, 2006). O'Brien (2007) found mothers experiencing 'ambiguous losses' in response to their child's autism diagnosis. Emotions of ambivalence and hopelessness alternated with hope and doubt about their identity, role or relationship with their child. Anxiety may arise regarding stigmatisation, along with worries about their child's future (Calzada et al., 2011; O'Brien, 2007). The parents in Huws, Jones and Ingledew's research (2001) wrote about "the ceaseless uncertainties and feelings of anxiety associated with autism" (p.

577). Moyes (1993) explains that since the official diagnosis is usually received in late childhood, parents "may have to develop a completely different 'game plan' than the one they originally had in mind when they thought their child was 'typical'" (p. 196).

A diagnosis can signal "an official loss of normality" and the expectations that accompany it (Russell & Norwich, 2012, p. 237). Parents might withdraw from situations that have the potential to cause embarrassment (Gray, 2002a), as they strive to restore stability, security and predictability (Walsh, 2003c). As families make adjustments to the challenges they might construct a 'new' normalcy (Lasser and Corley, 2008). A diagnosis can also create a *turning point* that prompts parents into action after prolonged distress (Fleischmann, 2004; Inglis, 2006). This climatic event in the course of a parent's life can result in a new direction with increased self-efficacy (Bandura, 1978). Green (2007) found that after the initial shock of receiving a diagnosis, mothers described "a conscious and decisive moment" to carry on loving and caring for their child (p. 155). Sousa (2011) discovered in mothers' memoirs that a diagnosis can result in understanding and acceptance after a long and arduous process, and "through the process of diagnosis, mothers begin the journey as protagonists in the quest to access service and solutions" (p. 227).

Stress and coping. The unique and pervasive presentation of higher functioning autism creates significant stress for parents and caregivers with repercussions for healthy family functioning (Rao & Beidel, 2009). Autism could be viewed as the centre of a constellation of stressors that build up and interact over time, taxing families' resources (Marshall, 2004; Marshall & Long, 2010). Parents of children with autism spectrum disorders, including Asperger syndrome, are more likely to experience poorer physical health compared to parents of typically developing children (Allik, Larsson, & Smedje, 2006) and serious psychological distress compared with parents of children with other disabilities (Abbeduto, Seltzer, Shattuck, & Krauss, 2004; Bromley, Hare, Davison, & Emerson, 2004; Luther, Canham, & Young Cureton, 2005; Meadan, Halle, & Ebata, 2010; Rao & Beidel, 2009; Sivberg, 2002). A child with Asperger syndrome contributes to parents' life stress through its intensity, unpredictability and continued duration (Wolf, Noh, Fisman, & Speechly, 1989). The challenging aspects directly associated with AS and autism spectrum disorders, such as their child's difficulty in regulating their emotions

and behaviour, aggressiveness, and misbehaviour in public strains a family's stamina, problem solving abilities, and well-being (Davis & Carter, 2008; Higgins, Bailey, & Pearce, 2005; Lecavalier, Leone, & Wiltz, 2006; Rao & Beidel, 2009; Ryan, 2005). The deficits and delays in the child's social skills (Davis & Carter, 2008; Gray, 1994; Montes & Halterman, 2007) can also cause great consternation for parents.

Engagement with health professionals becomes problematic when inappropriate and inadequate information and resources are given, inhibiting parents' efforts to manage the complex nature of an autism spectrum disorder (Huws et al., 2001). Additional stress can occur when health and education professionals disregard parent experiences and their personal views regarding their child (Huws et al. 2001; Schall, 2000). A lack of respect for parents' own expertise can lead to "feelings of distress, frustration, confusion and hopelessness" (Huws et al. 2001, p. 578). Limited access to services and professional support can lead to feelings of helplessness (Pisula & Kossakowska, 2010). Moreover, poor awareness, understanding and support in schools present on-going challenges for parents (Brewin, Renwicks, & Fudge Schormans, 2008). Lastly, an overall lack of understanding and acceptance from the community (Oprea & Stan, 2012; Ryan, 2005) contributes to parents' stress levels.

The significant disruption and stress associated with raising a child with ASD prompts parents to make substantial adjustments in their efforts to function adequately (Altiere & von Kluge, 2009b; Huws et al., 2001; Lasser & Corley, 2008). Parents must continuously plan ahead to help their child cope with an unpredictable and overstimulating environment, resulting in little or no relief from stress (Hutton & Caron, 2005). Huws et al. (2001) state that the "adaptation process involves regaining coherence and taking control over events, and involves restructuring of their lives" (p. 576). A family's ability to recover and gain proficiency has implications for their general well-being (McCubbin, McCubbin, Thompson, Han, & Allen, 1997; Patterson, 1991; Walsh, 2003c). Part of the adaptation process to the diagnosis of ASD can include parents utilising their strengths to mediate stress (Davis & Carter, 2008; Hutton & Caron, 2005) or the manner in which they conceptualise their situation and coping abilities (Altiere & von Kluge, 2009a; Marshall, 2004). A positive reinterpretation can subsequently contribute towards building resilience (Bayat, 2007; Luthar, Cicchetti, & Becker, 2000; Summers, Behr, & Turnbull, 1989; Tedeschi & Calhoun, 2004).

New Zealand Context

In New Zealand there are a variety of national and regional groups that offer information, support and advisory services for families raising a child on the autism spectrum that are funded through ministerial and charitable funds. These organisations provide training programmes and seminars that introduce family and professionals to basic information on autism and targeted training on early play skills, behavioural modification strategies, adaptations and modifications for learning environments, and communication development (Altogether Autism, 2015). Other outreach includes parent support, specialised libraries, peer mentoring for those diagnosed with AS, advocacy assistance, employment advice, web communities and private consultation services (Autism New Zealand, 2015). In addition, Cloud 9 Children's Foundation is a non-profit organisation that offers information and support throughout New Zealand on Asperger syndrome (Cloud 9, n.d.). Their aim is to increase Asperger syndrome awareness in the community, help children gain needed skills, and assist families, teachers and professionals in regards to AS issues. Examples include social skill programmes for teens, discussion forums, library loans, legal advice, web page resources and parent support groups. Furthermore, there are general programmes available on parenting issues and counselling offered through the public health system. The Ministries of Health and Education prepared a comprehensive Autism Spectrum Disorder Guideline (2008) with an extensive evidence-based literature review. This guideline provided a summary of best practice for health and education practitioners to raise the standard of care for children and adults with ASD in New Zealand, as well as presenting current information for parents and caregivers, policy makers, funding managers and community workers. The Living Guideline Group, a small group of specialists from allied sectors, choose a topic yearly, reviewing and updating the ASD guideline in light of new evidence (Ministry of Health, 2014). Supplementary papers are then published based on these particular topics, thus keeping the evidence-base up to date. The Ministry of Education also provides an online resource that includes informative guides on ASD and strategies for inclusive learning (Ministry of Education, 2015a).

Special education policy, funding framework and services in New Zealand are informed by the United Nations Convention on the Rights of Persons with Disabilities and strive to establish an inclusive education system by supporting special needs

students through a range of funds and schemes (Daubé et al., 2013). However, ongoing specialist support for children in New Zealand's school systems services a very small population of children and is primarily based on the severity of the child's learning needs (Ministry of Education, 2015b). It is very rare for children with AS to qualify for ongoing specialist support due to their average to above average intelligence and overall capabilities, and if they do qualify, other comorbidity diagnoses and/or health concerns most likely would have contributed to their full assessment of need. Students with learning and behavioural needs in mainstream schools can qualify for short term support when difficulties arise, but must reapply for help after short term goals are met (Ministry of Education, 2015c). Extra funding has been allocated in the latest 2015 budget for those students on the autism spectrum who previously did not qualify for specialist support; though there is concern unmet needs will continue (Jones, 2015). After lengthy public consultation, an educational programme is currently being designed that better meets students' ongoing special needs within the classroom environment (Hughes, 2015). A critical examination of inclusionary practices in New Zealand schools regarding policy, curriculum, teaching practices and funding allocation for services and advocacy (Macartney, 2011) including culturally appropriate ASD-related services is warranted (Bevan-Brown, 2004).

Eremin (2011) conducted a qualitative doctoral study in New Zealand on parental constructions of autism and the impact of autism on family life and found that after a diagnosis parents felt clinicians only communicated general information on ASD; follow-up appointments were not scheduled to discuss concerns; comprehensive assessments of their child's capabilities were not provided; and no specific interventions for their child were recommended. Birch (2003) wrote in her memoir about growing up with Asperger syndrome in New Zealand of professionals' unfamiliarity with autism spectrum disorders, particularly when individuals presented with 'mild' symptoms. This lack of awareness substantially delays the correct diagnosis and contributes to misdiagnoses. When interviewing New Zealand Māori[1] parents and whānau raising children with autism spectrum disorders, Bevan-Brown (2004) found several stressful aspects. Though helpful people and services were acknowledged, numerous barriers were described that included "delays in diagnosis;

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[1] Indigenous people of New Zealand

disbelief and detrimental attitudes; lack of information, services, funding and qualified personnel; difficulty accessing services; assessment, organisational, system and procedural hassles; and financial strain" (p. vii). Parents had to cope with their children's challenging behaviours while simultaneously advocating for services.

As part of a joint programme with the Ministry of Social Development and the Ministry of Research, Science and Technology, a report was commissioned on the issue of family resilience (Kalil, 2003). The aim was to increase understanding of the family processes that contribute to positive child outcomes and explore why some families cope better with stress than others. This review largely drew on the results of overseas studies as there is little empirical evidence on family resilience in New Zealand. Results revealed that family level processes, such as connectedness and cohesion, communication patterns, problem-solving techniques and family belief systems were important to families' abilities to master challenges and reduce ecological stresses.

There is very little research on parent experiences raising children with AS in New Zealand. Parent perspectives are needed to gain an informed understanding of their lives as they navigate local environments and systems. Their perspectives are especially valuable for health and education services and can be used to enlighten government policy (Stace, 2011). It is vital to understand how parents maintain positive mental health as they adapt to their child's challenges (Baker, Seltzer, & Greenberg, 2011). There is a pressing need to explore parental coping processes and adaptation within socioecological contexts to better understand variations and how these processes can lead to long-term positive outcomes (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). The identification and linking of positive developments and adaptations can add to our understanding of how stress can be mediated or moderated, and how positive family functioning can be facilitated and fortified (Gerstein, Crnic, Blacher, & Baker, 2009; Hayes & Watson, 2013).

An exploration of parental coping responses when raising a child with AS could reveal opportunities for future targeted support in New Zealand and contribute to a fuller understanding of how parents with children with autism spectrum disorders develop resilience. This research contributes to the critical gap in knowledge about parent experiences and their coping responses in New Zealand.

Research Questions

Although there is a large base of quantitative studies on the stressors parents face when raising a child on the autism spectrum, there are very few qualitative studies that examine experiences of parents raising a child with Asperger syndrome; the aspects they view as stressful; and their productive coping processes. A better understanding of the *complexity* of parental experiences raising a child on the autism spectrum is deemed as warranted (Ludlow, Skelly, & Rohleder, 2012; Woodgate, Ateah, & Secco, 2008). A qualitative study that uses in depth interviews can contribute rich details about parent experiences, reveal parent perspectives, and illustrate adaptations made over the course of their child's growing up years. Most important is understanding the specific challenges associated with raising a child with AS, the impact on families' daily lives and the parental coping responses that manage stress productively. This study examined parent experiences of raising a child with Asperger syndrome, their positive coping responses, and the process of building resilience. The two central research questions were:

1) What are parents' experiences raising a child or children with Asperger syndrome, an autism spectrum disorder?
2) How do parents respond to and cope with the particular challenges raising a child or children with Asperger syndrome, an autism spectrum disorder?

Theoretical Framework

This research is based on the premise that parents know their children best and are intrinsically motivated to help their children reach their full potential. Parents learn valuable strategies for managing the effects of AS through trial and error and become adept at maximising their strengths, thus a strengths-based approach captures the productive and positive aspects of family experience rather than the traditional pathological view of families as 'damaged' or 'deficient' (Altiere & von Kluge, 2009b; Munford & Sullivan, 1994; Munford & Sanders, 2010; Tedeschi & Kilmer, 2005; Walsh, 2003c, 2006). A focus on parents' and families' "talents, skills, resources, life experiences, and unmet needs" is gaining more attention for assessing strengths and resilience to guide interventions (Tedeschi & Kilmer, 2005, p. 230). Parents' expertise and experience raising a child or children with AS can

subsequently be used as a foundation for support (Altiere & von Kluge, 2009a; Bevan-Brown, 2004; Bromfield, 2011; Knafl & Deatrick, 1987; Oprea & Stan, 2012; Summers et al., 1989). Boss (2002) asserts that "only after we see through a family's eyes (and each member's eyes) can we learn how to assess, support, and intervene without prejudice" (p. 26).

In this study, positive coping efforts were considered within a family resilience framework (Walsh, 2006). A resilience framework illuminates how parents cope, adapt and gain competency against significant adversity (Blacher & Hatton, 2007). A focus on positive adaptation "engages distressed families with respect and compassion for their struggles, affirms their reparative potential, and seeks to bring out their best qualities" (Walsh, 2003c, p. 14). Furthermore, a resilience perspective provides opportunities to acknowledge family strengths and is respectful of parent perceptions and knowledge (Bayat, 2007; Summers et al., 1989).

Research has been found to be inadequate in assessing family well-being when raising a child with autism (Altiere and von Kluge, 2009a; Myers, Mackintosh, & Goin-Kochel, 2009). A clearer picture of the difficulties that contributes to parental stress, along with their efforts to manage is urgently needed to support healthy family functioning (Hayes & Watson, 2013; Meadan et al., 2010; Rao & Beidel, 2009; Summers et al., 1989). Studies of families of children with ASD building resilience is a relatively new focus (Bayat & Schuntermann, 2013) and the field of family–focused autism spectrum disorder research, which includes resilience growth, is still in the early stages of theoretical development (Cridland, Jones, Magee & Caputi, 2014). There is a gap in empirical investigation regarding how parents of children with AS meet their challenges over time (Gray, 2006; Phelps, McCammon, Wuensch, & Golden, 2009) and exploration expands our understanding of how resilience develops in this group at risk of high stress (DeHaan, Hawley, & Deal, 2013).

An examination of significant events that occur as parents raise their child or children with AS could lead to an improved understanding of developmental processes (Patterson, 2002; Rutter, 1996) and illuminate how families build resilience in the face of stress (Walsh, 1996, 2006). Part of parents' coping processes could include key factors that alter their life trajectory such as significant turning points that improve their well-being and family functioning. These turning points offer opportunities to examine the effect of stressors and parents' subsequent responses to manage that stress. Identifying productive coping processes over time has crucial

implications for timely and effective support (Walsh, 2006). The study of resilience development is instrumental to understanding how adaptation evolves in daily life, and how healthy family functioning can be best supported long term (Luthar et al., 2000; Walsh, 2013). There is very limited knowledge of the occurrence and effects of turning points in parents' lives raising a child with AS.

Since coping is a dynamic contextual process (Folkman et al., 1986), it is vital that the context in which parents are raising children with AS is considered to better understand coping processes and the emotional impact of associated stressors (Bronfenbrenner, 1979; Pearlin & Schooler, 1978). Resilience research is beginning to understand these processes and consider the systems in which an individual is embedded (Masten, 2001). The awareness of the factors associated with protective processes that take into account the family's distinctive ecological and developmental contexts and their particular challenges, constraints, and resources, will contribute to a more robust theoretical framework and systematic understanding of resilience (Cridland et al., 2014; Gerstein et al., 2009; Luthar, Sawyer, & Brown, 2006; Ungar, 2011; Walsh, 1996, 2013). Furthermore, research in positive adaptations and building resilience can contribute to programmes that foster competence (Masten, 2001). There is a large gap in the research in how resilience builds for parents raising a child with AS with a socioecological perspective.

Lastly, a disability studies' perspective acknowledges the environmental influences and interactions on coping processes while considering diverse interpretations of disability and resilience. In environments that provide scarce resources and limited support then "the illumination of lived realities, everyday practices, and performed identities of individuals and groups as they preserve self, relationship, and community" must be acknowledged and explored (Hutcheon & Lashewicz, 2014, p. 1385).

Methodological Approach

For this study, narrative inquiry was the methodological approach chosen. Narratives represent parents' perceptions of their lives and interactions with others (Pinnegar & Daynes, 2007) and can be used to interpret conceptualisation and adaptation to adversity (Plummer & Knudson-Martin, 1996). Qualitative research on parents raising children with an autism spectrum disorder is critically needed to

provide a more holistic and clearer picture of the stressors within the social environments of their daily lives and how stress is productively managed (Ferguson, 2002). Preliminary research suggests that parents' perspectives and belief systems change over time when raising a child with an autism spectrum disorder, though the nature of this development and the interactional processes and influences remain unclear (Cridland et al., 2014). Narrative inquiry is an appropriate qualitative methodology to explore positive adaptations and developmental changes. Narratives can provide a rich history of parents' challenges over time and reveal their perspectives, turning points, and adaptation within the context of their experiences (Clandinin, 2007; Elliott, 2005; Riessman, 2002a). The bulk of the empirical research on parent stress comes from quantitative measurements that lack the depth, complexity and perspectives of those directly living with stressful circumstances. Although narrative inquiry is being used to study a range of family experiences, narrative inquiry in parent experiences and positive coping processes while raising a child with AS is scarce.

Researcher Stance

My perspective is influenced by my work as a teacher in the early childhood, primary, secondary and tertiary levels and as a special educator working with families. Furthermore, my background in teaching literacy, English as a second language, and human rights education has informed my point of view. In my work with families, I have noted significant stressors on parents' time, resources and coping abilities. These stressors included families searching for and adjusting to a diagnosis; managing their child's challenging behaviours; meeting with numerous specialists as they incorporated therapies into daily routines; and coping with social stigma and school inclusion issues. I have learned from parents as they rallied and created workable routines for their families and acquired valuable experiential knowledge. Family experiences with difficult circumstances and their tenacious efforts to adapt left a long lasting impression on me. I recognised the importance of interventions sensitive to parental interpretations of disability. Moreover, my training and experience has led me to the belief that supporting parents in their roles as first teachers and utilising their strengths and capabilities results in the best outcomes for

their children and families. These personal insights have strongly orientated me to this research.

As a literacy teacher, I found stories a powerful medium for understanding different perspectives and character transformation. Stories can provide valuable insight into internal and external struggles with potential applications to the reader's life. In my experience, the process of narrative inquiry can lead to an increased understanding of people's responses to the conflict or challenges they met.

A review of the literature will follow in the next two chapters, Chapter 2 and Chapter 3. Chapter 2 addresses parent experiences raising a child with ASD, notably the stressors and high demands associated with raising a child on the autism spectrum; parental responses to those stressors and their coping processes; and beginning empirical evidence of parents building resilience raising children with ASD. Chapter 3 presents the theoretical framework that includes an overview of the development of stress and coping theory, a family resilience framework that includes socioecological systems and a disability studies perspective, and the prospect of turning points for understanding the process of building resilience.

Chapter 4 covers social constructionism, narrative inquiry methodology, an overview of the study's method, and issues regarding the researcher's role, validity, and ethics.

Chapters 5–7 present the study's findings. Chapter 5 presents the key four themes regarding challenges: challenges associated with Asperger syndrome, challenges to understanding and acceptance, challenges interacting with health and education services and challenges to family dynamics. Chapter 6 features four turning points areas: finding a diagnosis, coming to terms, school breakthroughs, and gaining independence. Chapter 7 reports on parents' coping responses and their resilience building processes: meaning making, developing resources, planning ahead and solving problems, and strengthening intrapersonal assets. Chapter 8 includes discussion on the study's two research questions, turning points contributing to resilience and resilience within social systems. Implications cover respectful parent and professional relationships, social support needs, raising parents' self-efficacy, early intervention, targeted school resourcing and support at critical times. Limitations, future research and conclusion follow, ending with references and appendices.

Chapter 2

Literature Review

The purpose of this study was to explore parent experiences of raising a child with Asperger syndrome, their productive responses to parenting challenges, and the process of building resilience; hence this literature review examined studies of parents raising children on the autism spectrum, the stressors encountered and their coping processes. This examination primarily covers relevant empirical research and also includes memoirs and theoretical writings.

Parental Stress Raising a Child with ASD

Research on parent perceptions of the impact of raising children with disabilities reveals historical sociocultural interpretations of disability (Ferguson, 2002; Oliver, 1990; Woolfson, 2004). In the early history of autism, Kanner (1943, 1949) described the extreme aloneness that children with autism exhibited and wrote of parents' interaction with their child as being cold and distant. This Austrian-American psychologist who first identified autism initially thought that this interaction could be a contributing factor towards to their child's autistic symptoms. The unjust term 'refrigerator mothers' emerged and persisted long afterwards, creating stigma, guilt and blame for parents of children on the autism spectrum (Boucher, 2009; Sousa, 2011). Ferguson (2002) wrote in a review of historical perspectives of families raising children with disabilities that medical and educational professionals in the 19th century assigned moral blame to parents for their child's disability and the removal of their children into state care was deemed necessary. A shift from blame to viewing children with disabilities as a source of 'damage' and a burden for families occurred from 1920–1980, and the medical model shifted from interpreting disability to include how families functioned. During the last forty years, research has focused on parental adjustment to their child's disability, and a range of emotions such as grief, guilt, denial, anger, sorrow, and fear have been explored (Ferguson, 2002; Kearney, & Griffin, 2001).

A recent review of literature studies investigating parent experiences reveals that raising a child with an autism spectrum disorder is exceptionally stressful

(Hastings, 2003; Higgins et al., 2005; Hutton & Caron, 2005; Plumb, 2011; Smith, Seltzer, Tager-Flusberg, Greenberg & Carter, 2008). Parenting stress is found to be significantly higher for parents of children with ASD than for parents of children with neurotypical development or children with mental retardation (Dąbrowska & Pisula, 2010; Dale et al., 2006; Kasari & Sigman, 1997; Lee et al., 2009; Montes & Halterman, 2007; Rao & Beidel, 2009; Sivberg, 2002; Weiss, 2002; Wolf et al., 1989). A meta-analysis of 15 quantitative studies investigating parenting stress of children with ASD compared to families of typically developing children or those diagnosed with other disabilities found a large effect size (Hayes & Watson, 2013). This suggests that "parenting stress in families with a child diagnosed with ASD is a significant experience that warrants attention and intervention" (p. 638). Stress results when a person perceives their environment as threatening and personal and social resources at hand are not sufficient enough to cope with that stress (Lazarus, 1966; Lazarus & Folkman, 1984). Life stressors distinguished by their magnitude, intensity (or rate of change), duration, unpredictability, or unusual nature will have detrimental effects on a person's well-being (Rabkin & Struening, 1976).

The studies on parental stress when raising a child with an autism spectrum disorder are predominantly quantitative in nature and utilise measures such as parenting stress indexes, questionnaires and quality of life surveys. Indicators of stressful experiences that are most frequently reported are depression, anxiety, compromised physical health and threats to healthy family functioning, such as endangered relationships and the inability to socialise (Benson & Karloff, 2009; Bitsika, Sharpley, & Bell, 2013; Davis & Carter, 2008; Ekas & Whitman, 2010). The rates of divorce have been reported to be nearly twice the rate of a comparison group of parents raising neurotypical children (Hartley et al., 2010). The stress of caregiving can exert a considerable psychophysiological toll (Lovell, Moss, & Wetherell, 2012).

Koegel et al. (1992) administered an 11-scale 66-item questionnaire on resources and stress to 50 families with a child with autism representing a range of socioeconomic statuses, child ages and functioning levels from four different geographical and cultural locales in the United States and Germany. The results suggested there may be a constant characteristic stress profile in parents raising a child with autism. A quantitative study utilising surveys conducted by Lee et al. (2009) found that parents raising children with high-functioning autism reported a lower physical and mental health-related quality of life compared to parents of children

without disabilities. These researchers assessed parenting stress, coping, resources and quality of life variables from 89 parents of children with high-functioning autism and compared them to 46 parents of neurotypical children. Significant differences were found for all factors, with higher stress, lower adaptive coping and resources, higher negative experiences and substantially reduced quality of life noted for the parents of children with high functioning autism. In a quantitative study, Aliik et al. (2006) compared 31 mothers and 30 fathers of children with AS/High Functioning Autism with a control group on their health-related quality of life. Mothers of children with AS/HFA reported poorer physical health compared to fathers from both groups, and a relationship found between the child's hyperactivity and conduct problems and maternal well-being. These studies reveal the physical and mental toll that parents experience when raising a child with high functioning autism.

Rao and Beidel (2009) found through examining the results of quantitative questionnaires given to 15 parents of children with high functioning autism and 15 control families that the higher intellectual functioning associated with AS does not help alleviate parental stress levels. As Lee et al. (2009) explain, the higher functioning descriptor is deceptive as 'high functioning' does not equal adaptive function; the pervasive nature of the deficits are not diminished; and there are often unique and significant challenges for parents and caregivers. O'Brien (2007) conducted a mixed methods investigation through semi-structured interviews via telephone and quantitative measures with 63 US mothers of children with ASD. This researcher concluded that the severity of the child's ASD was not related to stress or depressive symptoms in the mothers, rather identity ambiguity, or the blurred roles and responsibilities between mother and child, was more strongly linked to maternal distress. O'Brien explains that the unknown variables around autism spectrum disorders, such as aetiology, range of symptoms, recommended interventions and possible outcomes means families experience "conflicting realities and emotion" (p. 142). Mothers' narratives revealed ambivalence as expectations were adjusted regarding their child's abilities and the inconsistent manner in which their child functioned. The inclusion of narratives from fathers would give a more holistic exploration of the factors that can lead to stressful parental experiences.

The later timing of the diagnosis can result in a culmination of stress over their child's atypical development. There are significant delays finding a diagnosis and appropriate support (Bevan-Brown, 2015; Keenan et al., 2010; Midence & O'neill,

1999; Wiggins, Baio, & Rice, 2006). Bevan-Brown (2015) noted several factors through parent and caregiver interviews that contributed to delays in obtaining a timely diagnosis in New Zealand, such as "difficulty identifying ASD in young children; a cautious wait-and-see attitude among medical personnel; long waiting lists; parents' concerns not being taken seriously; the existence of other confounding disabilities or medical conditions; an initial, inaccurate diagnosis; [and] delays caused by red tape and rural location" (p. 178). Bevan-Brown (2004) found numerous other stress factors for parents of children with AS and autism spectrum disorder, such as managing the high level of daily demands, the challenging behaviours of their children, and a lack of adequate and culturally appropriate services. In Northern Ireland and the Republic of Ireland, Keenan et al. (2010) surveyed 95 parents and carers of children diagnosed with an ASD along with 67 multi-disciplinary professionals to elicit information on the diagnostic process and forward planning. Ten parents also participated in a focus group discussion. In the focus group one parent expressed great frustration about finding a diagnosis:

> I knew from 18 months that something was wrong, but the health visitor put me off. She said I was labelling my child. Terrible ADHD until he was 16 years of age. Then the teacher in a special school woke up. The teachers should know what to look out for and inform the parent. Consultant gave written diagnoses of ADHD ⁄ Dyspraxia. Then rang me at work to say she forgot to put down Asperger's, but sure I knew anyway. I didn't and was left devastated at work. (p. 393)

Almost half of the parents in the above study felt that the process of receiving a diagnosis was not completed in a timely and professional manner or clear information given afterwards. Overall, the parents viewed the diagnostic process as an extremely stressful experience. In addition, these researchers gathered parent and professional feedback on educational planning. One of the barriers identified were parent and professional partnerships, with parents stating that professionals needed to be more respectful and accommodating. This feedback is especially informative as it brings to light the additional burdens families deal with as they attempt to navigate health and education systems.

Although the bulk of the studies over the past two decades have been quantitative in nature, Gray (1993–2006) has conducted several insightful qualitative studies on autism spectrum disorders and Asperger syndrome in Australia. Gray

(2002a) explains that "high functioning autism or Asperger's syndrome is a condition that often presents severe problems for parents, as they try to cope with the demands produced by their child's disability and the social consequences that flow from it" (p. 734). Parents socially withdraw to avoid repeated public embarrassment and stigmatisation (Gray, 1993, 2002a). Gray (1997) determined that families with children with AS measured their ability to lead a 'normal' life on how well they were able to socialise; the intensity of their emotional bonds with each other; and their ability to carry out the rituals and routines that comprised their daily lives. A child with aggressive behaviours was seen as causing extensive disruption in these areas. Families were not able to participate in regular social outings and activities, such as eating out, shopping or visiting friends. The potential for disruption and the restriction on spontaneity was viewed as significant, and the resulting conflict jeopardised the quality of the relationships in the family.

Furthermore, in an ongoing study of the social experiences of 33 families of children with autism from the Brisbane region, Gray (2002a) conducted in depth semi structured interviews with parents of children ages five to 26 years old, with the majority of the children aged nine to 14. Gray found that mothers who were raising a child with AS experienced "enacted stigma" more often than fathers, such as enduring hostile staring, rude comments and avoidance from outsiders. Both mothers and fathers reported "felt stigma" or feeling that their parenting skills were being called into question. To lessen the effects of stigma, parents withdrew to prevent embarrassment and potential confrontations. Gray states that the experience of stigma "reflects the essential precariousness of maintaining a normal identity in the face of a possible failure of interaction" (p. 737). The findings from Gray's studies present a beginning awareness of the negative social repercussions that parents encounter when raising a child with AS. Additional exploration is needed to explore these effects on the process of positive adaptation.

There are high demands associated with parenting a child with Asperger syndrome. Parents can be overwhelmed and endure chronic levels of stress. This was evident in Gill and Liamputtong's (2013) qualitative study utilising thematic analysis of interviews and diary entries from 15 mothers raising children with AS in Australia. Mothers were found to be at risk of outsider's judgement when their children misbehaved in public and did not conform to societal norms. Mothers subsequently experienced guilt and self-blame. Furthermore, Gill and Liamputtong

noted mothers being extremely tired, with little time to participate in activities that might enhance their well-being. Some mothers wondered if they were too involved or too strict, though on the positive side, they discussed their advocacy and good relationship with their child. By using a qualitative approach, this study produced valuable and insightful information regarding the lives of mothers parenting a child with AS, which also could be enhanced if fathers were included.

The pervasive nature of an autism spectrum disorder creates strain for parents and their families. Meirsschaut, Roeyers, and Warreyn (2010) conducted a mixed methods study, interviewing 17 mothers who had one child with ASD and one typically developing, both under the age of 7. They asked mothers two open-ended questions regarding the impact of the child with ASD on their family and on their personal life. Mothers reported that having a child with ASD affected their *whole* life. Aspects reported as stressful included an inaccessible care giving system; the necessity to plan for each outing; job and career adjustments; worries about their child's future; impact on the other siblings; and a lack of understanding of ASD that had consequences on their family life. Merisschaut et al. found that mothers showed a determination to do everything they could for their child with ASD and mothers developing several coping strategies. This data gives an indication of the enormity and complexity of stressors mothers face.

Several studies revealed the multifaceted stressors that parents face on a daily and ongoing basis, leaving little time to recoup (Cashin, 2004; Ekas & Whitman, 2010; Hutton & Caron, 2005; Ludlow et al., 2012). In Hutton and Caron's (2005) qualitative study, the researchers found a substantial need for respite care to mediate the stress on parent relationships and the repercussions associated with little or no free time and limited opportunities for time away. Though families had adapted to the challenges, specific support such as respite care was recommended for reducing stress. Moreover, these researchers discovered that more than half of the 21 families interviewed had experienced difficulties with services, and nearly half did not feel respected by health professionals, namely doctors and therapists. Ludlow et al. (2012) interviewed 20 UK parents (14 mothers and six fathers) of children with autism and AS to explore parenting challenges and coping responses. The findings revealed parents dealing with the following: their child's challenging behaviours along with judgements from others; the emotional impact on the family; lack of understanding, information, support and resources from extended family, community

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and external organisations; and little time to recoup from daily stressors. Ludlow et al. reported that parents' experiences entailed "never-ending" stress (p. 706). Furthermore, there were indications that children diagnosed with Asperger syndrome had less resources and support available to them than the children in the study that presented with more severe autistic symptoms.

In a hermeneutic phenomenological study of nine parents of children ages four to 10 in Australia diagnosed with autism and AS, Cashin (2004) found that the pervasive nature of autism had created profound changes to the self of the parent. Cashin compared their parenting experience as being "sucked into a vortex" and "subjected to a restricted and repetitive way of being-in-the-world" (p. 166). Themes revealed less spontaneity, less social contact, less things due to financial costs, and less self as autism dominated their lives.

> The parent's self is transformed. All other roles of self are impacted upon. The parent's sense of ease or personal comfort is eroded; there remains a constant sense of anxiety and exhaustion that arises from the act of care, frustration, hyper vigilance (including monitoring others in their relationship with the child) and communication effort. (p. 168)

Two positive developments noted by Cashin included patience and the triumph of connection.

In summary, the studies on parenting a child on the autism spectrum point to particularly stressful experiences. These parents are at a higher risk of depression and anxiety and report a lower quality of physical health. The higher intellectual functioning of AS does not lessen the stressors associated with parenting children on the autism spectrum. There are significant delays finding a diagnosis that result in pronounced frustration and these delays add additional emotional and financial burdens to parents' caregiving responsibilities. Tenuous parent and professional relationships create barriers to garner support and needed information. Children's aggressive behaviours cause parents to withdraw socially and the experience of stigma endangers relationships outside of the family. Several studies focused on the experiences of mothers, with findings revealing significant maternal distress and a gap regarding fathers' perspectives. The studies utilising a qualitative approach were better able to capture the pervasive nature of autism in parents' lives and provided an emerging picture of the impact of these stressors (Cashin, 2004; Gray 2002a; Ludlow et al., 2012).

Parental Coping Responses

When parenting a child with ASD, families make considerable adjustments in their lives to cope and function adequately and to regain control and coherence (Altiere & von Kluge, 2009b; Huws, et al., 2001). Building adaptive coping skills manages the frustration, stress, and "ceaseless uncertainties and feelings of anxiety" that can result from parenting a child with ASD (Huws et al., 2001, p. 577). The ability of families to adapt can have a positive influence on maternal depression and challenging child behaviour (Baker et al., 2011). Coping involves a multifaceted approach that weighs the effectiveness of possible coping options and their potential to mediate stress. The success of a coping response is influenced by the context in which it is used and can signal the changes of the person within that environment (Compas, 1998). Coping responses for parents of a child on the autism spectrum can include improved family cohesion; positive reappraisal or reframing of their stressful situations; creating and establishing a 'new normal'; making sense and finding benefit; and promoting strengths. This section of the literature review focuses on the positive changes parents make to manage the effects of autism in their lives.

Oprea and Stan (2012) noted from 22 mothers of children with autism in Romania that though there were mostly negative aspects in regards to parenting a child with ASD, there were a small number of positive gains identified, such as increased family cohesiveness and an improved understanding of the syndrome. The importance of hope and trust in God was reported on a questionnaire based survey that included open questions, and mothers determined that "patience, perseverance in making efforts to help their child, optimism, commitment, [and] understanding to overcome the critical moments" were necessary parental qualities (p. 4193). Analysing daily diary entries from 46 mothers of children with autism over 30 consecutive days, Ekas and Whitman (2010) found that positive affect can protect mothers against the acute and long-term stress in the low to medium stress range, but the benefits disappeared when stress levels were extremely high. Ekas and Whitman hypothesised that mothers were trying everything to cope and that "days of extreme stress…are so psychologically taxing that mothers are not able to recover even when positive affect is elevated" (p. 1211). Coping then was jeopardised when

the heightened strains associated with the job of parenting a child on the spectrum became overwhelming.

In a US study, Lutz, Patterson and Klein (2012) conducted personal interviews with 16 mothers of children and adults diagnosed with classic autism ranging in ages from 2 to 31 years old. The researchers used a narrative research methodology (Riessman, 1993) with a constructivist lens (Munhall & Fitzsimmons, 2001) to analyse themes and patterns in the data. The research questions explored the impact of autism on the family unit from the mother's perspective and considered how the family unit changed as the child matured from childhood to adulthood. Nearly every mother's narratives described the pervasive effects of autism on their family life, saying "the whole family had autism, not just the child" (p. 210). Lutz et al. created a preliminary model titled *Journey Towards Adaptation* that captured the impact of the child's diagnosis – likened to facing a 'curve ball' – and the coping strategies mothers used in response to the stressors associated with parenting a child with autism. The narratives collected revealed a trajectory of adaptation that began with seeking answers after the diagnosis through to seeking support, socialisation and spirituality; appreciating life and fulfilling the multiple roles of caretaker, teacher and advocate; and revising dreams and future planning. Mothers experienced a range of emotions over time, such as grief, anger, guilt, doubt and disappointment, along with relationship strain, dis-ease, and sacrifice. Dis-ease included psychological stressors such as fear and anxiety; physiologic strains from the physical symptoms of stress and caregiving duties; and social repercussions from stigmatisation, social isolation and financial burdens. The stressors and subsequent coping strategies did not necessarily emerge in a predictable manner, for example, though grief and anger were the prominent feelings around the diagnosis, they could resurface when the child reached, or did not reach, expected developmental milestones.

Woodgate et al. (2008) conducted a hermeneutic phenomenological study of 16 families raising children with autism in Canada. Parents found themselves "living in a world of our own" as they attempted to manage the daily challenges of parenting a child with autism (p. 1075). Parent narratives revealed a strong sense of isolation due to outsiders' lack of understanding; a disconnection from their child, spouse and extended family; a 'normal' way life missed; and an unsupportive health and education system with led to a diminished sense of hope. In response to

experiencing this isolation, the researchers found vigilant parenting, sustaining self and family, and fighting all the way as the dominant themes. Vigilant parenting described parents intensely focusing on their child and a "heightened watchfulness and preparation for action" (p. 1079). Parents learned to sustain their self and family by working toward a healthy balance, cherishing different milestones, and learning to let go. Fighting all the way entailed becoming more direct with securing services, learning as much as they could, and educating others.

Studies have found that a balance of cohesion and adaptability can result in favorable outcomes, though the high demands and unique nature of ASD may result in parents being overly involved and protective. This extreme level of cohesion and adaptability or "enmeshed style" can then result in the higher use of positive coping mechanisms (Altiere & von Kluge, 2009a). In an ethnographical longitudinal study that Gray (2002b) conducted 10 years after his original study on the social experiences of parents of children with autism, parents were found to demonstrate increased manageability and improvement. These findings were encouraging, taking into consideration several complicating factors: many of the parents in the study were dealing with the demands of adolescence and the probability of increased seizures; the difficulties of special needs coordination in secondary schools; the challenges for independent living and job procurement; and the closures of residential care facilities. There are few longitudinal studies in this area, and according to Gray, the tendency for these studies to be cross-sectional by design makes it difficult to know how families change over time. Gray (2002b) found that coping and stigmatisation challenges identified in the original study continued to be problematic 10 years hence, such as coping with their child's inappropriate behaviour in public. However, parents reported in the second study that they were less sensitive to public opinion. Of note was the decline after 10 years in the total number of reported coping strategies (Gray, 2006). Gray speculated that family life might have become more routine, leading parents to the perception that they were using less coping strategies. Parents had shifted from problem-focused to emotion-focused strategies, and utilised other coping responses such as appreciating their child's good qualities. In a study conducted by Smith et al. (2008), emotion-focused coping strategies were found to be used by mothers of adolescents with ASD more often compared to mothers of toddlers with ASD. Smith et al. conducted in home interviews lasting 2–4 hours and collected data from questionnaires measuring maternal well-being and coping

strategies. The participants included 153 mothers of toddlers and 201 mothers of adolescents drawn from two ongoing longitudinal studies of families raising children with ASD. Higher levels of problem-focused coping and lower levels of emotion-focused coping were associated with better maternal well-being in both the toddler and adolescent groups. Positive reinterpretation was found to strongly predict positive well-being in both groups. The strength of the main effects of coping responses were strong for both groups and the presence of more buffering effects in the adolescent group may reflect the effectiveness of parental coping responses.

Problem-focused responses have been found when there is an expectation that the situation is malleable, and emotion-focused forms of coping when there is a perception that there are few or no options for altering the outcome (Folkman et al., 1986). However, Benson (2010) argues that the dichotomisation of problem or emotion-focused responses is an oversimplification. Benson proposed after examining results reported by 113 mothers on a coping scale that four different coping dimensions could be considered: engagement and disengagement, distraction and cognitive reframing. The use of cognitive reframing was associated with higher levels of maternal well-being. These studies reveal the value of exploring the variety and complexity of coping responses and their productive effects on parents' well-being.

Pisula and Kossakowska (2010) compared 26 parents of children with autism in Poland with a control group of parents of typically developing children using the Antonovsky's Sense of Coherence (SOC) scale. Antonovsky (1987) defines coherence as confidence in a person's living circumstances being comprehensible, that is, structured and predictable; manageable or the perception that adequate resources are at hand; and meaningful, for example, the stressors are viewed as challenges worthy of time and energy. These researchers found that the parents of young children (4–7 years old) with autism in their study showed weaker SOC than the control group of parents with typically developing children. In Dale et al.'s (2006) study of 16 mothers raising children on the autism spectrum including five with AS, mothers shared a range of views regarding their efforts to manage and exert control. A semi-structured group interview was conducted along with three formal measures that examined links between attributions and parents' sense of efficacy, emotional well-being and beliefs about their child's future. Mothers who reported higher levels of personal control were assessed with higher levels of depressed affect. The

authors interpreted their findings to mean mothers were shouldering too much of the responsibilities themselves, combined with the challenges and the social isolation associated with raising a child on the autism spectrum.

Parents' socioecological adaptations reveal a variety of responses. Twoy et al. (2007) gave 55 parents of children with ASD a coping scale that evaluated the interaction of the individual to family systems and family to social environment. They found parents using coping strategies such as seeking support to alleviate stress: informal social support from extended family members and close friends; information and advice from other families facing similar challenges; and help from community agencies. Reframing through defining the stressor in a more positive light was used as well. Conversely, passive behaviour and appraisals were noted in parents' responses to questions that appraise agency, such as waiting for behaviours to subside; believing they did not hold sway over the outcomes of the child's disorder; or regardless of their efforts to prepare, believing they would still struggle to handle problems. The belief systems of 16 families of children with ASD or Down syndrome were examined through interviewing by King, Baxter, Rosenbaum, Zwaigenbaum, and Bates (2009) who found that parent experiences encompassed optimism, acceptance or appreciation, and striving to bring about change. Warter (2009) also examined parental belief systems and a family's adaptation to a family member's ASD. This doctoral study evaluated questionnaires measuring risk and protective factors on family adaptation from 207 parents and primary caregivers in the US. Optimism and mastery beliefs were found to play a positive role in a family's ability to adapt to a family member's ASD. A further exploration of these beneficial aspects and other contributions to positive adaptation would be valuable.

A number of studies using both quantitative and qualitative methods have found that the biggest influence on parents' perceptions of challenges and their coping processes is the manner in which the adverse situation is appraised (Altiere & von Kluge, 2009b; Gerstein et al., 2009; Gill & Harris, 1991; Milgram & Atzil, 1988; Rabkin & Struening, 1976; Tunali & Power, 2002). Lazarus and Folkman (1984) interpret cognitive appraisal as a dynamic relationship between a person and their environment. During primary appraisal, a parent determines what is at stake in respect to their commitments, goals and values, such as the well-being of their child, and in secondary appraisal, the parent evaluates what can be done to manage risk or harm, or determine the possibilities for benefit.

Folkman and Moskowitz (2000) put forth that positive reappraisal helps one reframe difficulties in a favourable light. Positive reappraisal and finding positive meaning in parenting a child with ASD helps to process and protect against negative effect and stress (Folkman & Moskowitz, 2000; Hastings & Taunt, 2002; Kayfitz, Gragg, & Orr, 2010; McCubbin, Thompson, Thompson, & McCubbin, 1993; Taylor, 1983). A change in one's perspective and positive reinterpretation of a stressor is a component of the coping process that can lead to a more optimistic view and increased life satisfaction (Fleischman, 2004; Tunali & Power, 2002), less social isolation, and fewer spousal relationship problems (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Lazarus (1991) said "emotion is a reaction to meaning, and if the meaning is changed there will be also be a change in the subsequent emotion" (p. 830). This finding is congruent with coping themes identified in a review of sixty books authored by parents of children with disabilities, such as reappraisal, managing the extraordinary demands and stress, resolution and growth (Mullins, 1987). Luther et al. (2005) found after analysing 18 questionnaires from parents raising children with autism ages 5 to 13, that parents' perception of stressful events contributed to their ability to manage stress. However, parents in this study were also found to use inactive or passive behaviours, such as avoidance, which may be related to parents' extreme stress levels. The researchers found parents struggling to balance multiple role responsibilities and parents highlighted formal and informal social support as beneficial, such as parent support groups. These support groups provided opportunities to freely discuss troubles and share coping strategies, though there were variable responses to the availability of support in the community.

Parents' perspectives on their situation can influence their perceptions of stress and the resources available to them. For example, concentrating on the uniqueness of AS rather than the drawbacks helps parents actively problem solve and manage challenges (Lasser & Corley, 2008). Hastings and Taunt (2002) found in their literature review on positive perceptions of families of children with developmental disabilities that family members report a range of positive perceptions in conjunction with negative and stressful experiences. Bayat (2007) collected qualitative and quantitative data through surveys, rating scales and three open-ended questions from 175 mothers and fathers raising a child with ASD and found:

The way that a [parent] perceives, appraises and makes meaning of the disability of his/her child determines whether the parent is able to utilize family's resources, arrange its structure, and ultimately balance – or fail to balance – the family's resources against the demands and stressors of having a child with a disability. (p. 704)

This perception and interpretation of the stressors experienced contributes to parents' overall wellbeing (Woolfson, 2004). Reframing helps parents see stressful situations in a positive manner (Altiere & von Kluge, 2009a; Luther et al., 2005) and reconstructing an alternate view of their child's future can lead to renewed family cohesiveness and stability. Family belief systems can "powerfully influence how we view a crisis, our suffering, and our options" (Walsh, 2006, p. 6).

In an online study of parents of children with autism, Huws et al. (2001) found that parents of children with autism reappraised their situations with other parents as they shared their stories and supported each other. This qualitative study gathered messages posted over a three month period to an international email discussion board. A total of 6142 messages were posted from 374 email addresses. Using a grounded theory approach to determine the underlying concepts within the messages, the researchers observed parents searching for meaning and adjusting to changes, such as working to establish a sense of normality, dealing with uncertainties and solving problems. The online community created supportive relationships and helped parents gain perspective: "By comparing their situations with those of others, parents develop a focus on the unique qualities of the child, and this helps them develop a renewed coherence in their lives" (p. 574). Validating concerns and the narrative sharing of experiences provided the needed emotional support and encouragement. Here is an excerpt under "surviving autism":

There's nothing easy about having autistic children. It's not fun. It's not glamorous. The money stinks. The hours are long. There's frequently few, if any, to say 'well done' after you've accomplished a minor miracle. Yet, after nearly 30 years of living, and for lack of a better word, 'surviving' autism, you honestly do get stronger. The impossibly difficult becomes acceptable and doable. Life for us has become more than acceptable. It actually has become quite wonderful at times. (R82) (p. 580)

The qualitative nature of this study enabled readers to better understand the realities of raising children on the autism spectrum and the benefits of reciprocal support to mediate stress.

Pakenham, Sofronoff, and Samios (2004) analysed questionnaires developed and validated through the study for 220 parents of children with AS, examining the relations between sense making and benefit finding, and the variables from the Double ABCX family stress model (initial stressor and pile-up of demands, appraisal, social support, coping strategies and adjustment). Statistical analysis was used to examine the variables, and content analysis was used for the two open-ended meaning questions. Parents stated they had more "patience, compassion, empathy, open-mindedness, independence and self-control" due to having a child on the spectrum (p. 254). Their perspectives had changed through seeing the world through their child's eyes and making the necessary accommodations. As part of parents' coping processes, ASD was reframed in terms of differences and strengths, rather than viewing it as a disorder. In addition, finding benefit and making sense was found to be associated with greater self-efficacy. From this same study, Samios, Pakenham, and Sofronoff (2009) examined the relationships of benefit finding dimensions with positive and negative indicators of adjustment. Exploratory factor analysis found the following six benefit finding factors: new possibilities, personal growth, appreciation, spiritual growth, positive effects of the child, and greater understanding. Examples of questions that factored highly included: "I have become involved in helping other parents", I have improved my coping skills", and "I am more aware of problems people with disabilities face" (p. 365–366). McConnell, Savage, Sobsey, and Uditsky (2015) concluded after surveying 538 parents and caregivers raising children with disabilities that benefit finding reported by most parents had moved beyond cognitive coping to transformational outcomes. From that same three year study, McConnell, Savage, and Breitkreuz (2014) investigated the relationship between child behavioural problems, social-ecological resource fit and positive family adaptation. The researchers maintain positive adaptation occurs when family routines are both meaningful or in line with their values and aspirations, and balanced between the needs and interests of family members. They found families' resilience was strongly associated with the availability and accessibility of culturally relevant resources versus intrinsic individual or family attributes. Furthermore, the researchers concluded that families raising children with disabilities struggle even

when the number and intensity of the child's behavioural problems are low if there are corresponding low levels of social support and high levels of financial hardship. Likewise, Ryan and Cole (2009) found in their qualitative study of mothers raising children with ASD that advocating for increased awareness and support can contribute to a sense of empowerment and concentrate efforts on a positive versus negative outcome.

Parents striving to normalise family functioning when raising a child with a disability engage in a "negotiated readjustment" (Patterson, 1991, p. 494). Thompson-Kroon (2012) conducted a phenomenological doctoral study using observation and one-on-one interviews of ten families with a child diagnosed with AS. It was found that parents created a reality for their family that became 'normal' for them: "In other words, when a child with Asperger syndrome is in their own home, in their own world, they are a 'normal' child. Outside that home or family based reality, they are a child with Asperger syndrome" (p. 109). Parents made adjustments in their home to mitigate the challenges associated with AS, such as controlling sensory overstimulation, that become part of their normal routine and practices. The narratives published on the internet from Fleischmann's (2004) study showed that "parents constructed a new story in which they have undergone a metamorphosis that allows them to approach their child and his or her life in a new, more positive light, enhancing their own coping skills for the future" (p. 42). Fling (2000), recounted in her personal account of being a parent of a child with AS, a notion of a "new version of normalcy" that came with the realisation that her son's odd behaviours were not congruous with her idea of a "just right" family (p. 20). To better understand the experiences of parents raising children with AS, Lasser and Corley (2008) interviewed 20 parents using a grounded theoretical approach to identify outstanding themes. Parents were found to construct normalcy through meaning-making and their efforts to create adaptive outcomes, though this was complicated by their child looking normal to outsiders when their unusual behaviour in public drew attention.

Sousa (2011) found commonalities in 33 published memoirs from mothers raising children with intellectual disabilities that included the following: challenged expectations; the diagnostic process; a quest for a better life for their child; battling social systems; and acceptance of a new parenting conception. Mothers first experienced atypical development and behaviour and then sought medical explanations with a diagnosis. During the quest and battle, mothers became "warrior-

heroes" as "first responders for their children" as they developed expertise and negotiated support (p. 227). After acceptance, a transformation occurred as a new conception of mothering arose while reappraising normalcy. In Maul and Singer's (2009) qualitative study in the US that included 15 parents and 2 grandparents of children with developmental disabilities and autism, families worked to normalise their lives. Families rejected the view that they were damaged and confronted the stigma attached to parenting a child with disability. This was accomplished by accepting accommodations as normal for any child and incorporating advanced planning to achieve the best result.

There can be a shift in a parent's world views after the ASD diagnosis, moving from shock and grief to one that values their child's inherent strengths. This perspective becomes a cyclical process "in which preexisting interpretive frameworks shape how people make sense of their experiences, and these experiences, in turn, shape the development of new interpretive frameworks" (Ezzy, 2002, p. 6). In a mixed methods study of 81 mothers raising children with disabilities (including autism), Green (2007) found mothers loved and valued their child for who they were, and communicated their "love, pride and appreciation for their intrinsic worth" (p. 157). In a small qualitative study by Midence and O'neill (1999) of four parents' experiences seeking a diagnosis in North Wales, a parent explained the intrinsic nature of their son's personality:

> I cannot imagine him without autism. Without autism he would still love his food, he would have a real sense of humour. We have always known him with autism. He is a loving person, and he was a loving child, he is very loveable. My son is my son. I would never change him, not his personality. (p. 281)

Midence and O'neill noted parents utilising coping strategies such as acceptance and concentrating on the positive aspects of their children.

Markoulakis, Fletcher and Bryden (2012) conducted a phenomenological study interviewing eight female primary caregivers of children with autism in Canada. These researchers found families becoming more unified and sensitive in their interactions as they worked towards common goals and an increased commitment to the marriage. One participant told of the benefits from her advocacy work:

Autism takes control of your family and your life. You have to sort of get control back somehow. So my advocacy, I find, gives me something about autism that I can control or can try to find control in. Advocacy has given me a feeling of being able to make a difference in a world that is sadly lacking for my son and others affected by autism. That gives you a feeling of contributing to society for the better. (p. 52)

Increased involvement in the autism community and sharing their knowledge had a reciprocal effect and the inherent process of experiential learning had a positive influence on other aspects of their lives, for example, increased patience and appreciation of life, and improved outlook. This qualitative study was able to present an alternate view of caregivers' experiences as the women in the study shared how they had become better people as a result of raising a child with ASD and 'seeing the glass half-full'.

To review, parental responses to the stressors associated with raising a child on the autism spectrum were varied and multi-faceted, such as seeking support and information through to increased family cohesion. Many studies noted parents' belief systems, particularly their appraisal and positive reinterpretations of their stressful situation. Researchers found families establishing a 'new normal' and finding benefit and meaning in their experiences. Researchers noted parents' focusing on the strengths of their child, and utilising patience, optimism, and acceptance. Mothers and fathers were found to be struggling with the demands, limited resources and multiple role responsibilities; however, longitudinal studies found parents adapting over time and moving from problem focused strategies to emotion focused approaches. Qualitative studies, especially those that utilised interviews, produced favourable opportunities to capture parents' perspectives. This has important implications to improve understanding of parents' experiences and their subsequent coping responses.

Resilience in Families

The study of resilience in families parenting children with ASD is in its embryonic stages with early results showing indicators of resilience (Bayat, 2007; Bekhet, Johnson, & Zauszniewski, 2012; King, et al., 2009; Levine, 2009; Luther et al., 2005; Twoy et al., 2007) and the positive effects of psychological resilience on stress (Bitsika et al., 2013; Cripe, 2013). These studies are primarily quantitative in

nature with a few utilising mixed methods or a qualitative approach. Bekhet et al. (2012) reviewed 58 research articles on raising a child with ASD and found 22 of the articles included indicators of resilience. Examples of these indicators include self-efficacy, acceptance, sense of coherence, optimism and positive family functioning, such as commitment to sharing responsibilities, communicating, having a positive outlook and relationships, and exercising spirituality. Those parents who possess indicators of resilience were better able to manage the stressors associated with raising a child on the autism spectrum. There was a significant relationship between resilience and parental stress found in a quantitative study conducted in Spain by Pastor-Cerezuela, Fernández-Andrés, Tárraga-Mínguez, & Navarro-Peña (2015). Twenty-four parents of primary age children with ASD who perceived themselves as more resilient reported less stress associated with symptoms of depression and with their feelings of competence regarding their parental roles. Indicators of resilience, such as optimism and self-efficacy, were found to predict a greater ability to cope with the challenges of raising a child with ASD. Plumb (2011) found lower levels of stress were associated with greater family resilience in a US quantitative doctoral study that assessed social support levels, parental stress and family resilience in 50 primary caregivers of children 6–12 years old with ASD. In another quantitative study from the US of 170 mothers of children under 11 years old with autism and AS, Kuhn and Carter (2006) found that agency was positively correlated to maternal self-efficacy, while guilt, depression and parenting stress were negatively correlated.

Building resilience illustrates a parent's positive adaptation and evolution over time in response to stressors in their environment. Altiere and von Kluge (2009b) utilised grounded theory to analyse emergent themes from semi-structured interviews of 52 US parents (26 mothers and 26 fathers) of children with autism and AS.The researchers explored these parents' struggles and successes and found parent experiences falling into five progressive areas: 1) noticing their child's atypical development; 2) questioning why their child was different; 3) devastation when a diagnosis was received and struggling with a lack of support; 4) looking for solutions such as turning to other parents of children with ASD; and then 5) finding increased support from extended family and experiencing growth, such as increased patience, acceptance of other people with disabilities, and compassion. Many of the families reported that their coping abilities had improved because of their experiences and more meaningful relationships established with others. This research provided an

increased understanding of the developmental process that parents experience over time as they cope with their child's challenges and build resilience. DuPont (2009) conducted a US phenomenological doctoral study exploring the characteristics of family resilience from 14 parents of children with ASD. DuPont explored parents' experiences raising a child or children with ASD within a family resilience framework (Walsh, 2006) and found parents doing the following: 1) balancing life around the child, 2) remaining watchful and alert, 3) reaching a point of acceptance, 4) dealing with judgement, 5) gaining support, 6) relying on spirituality and faith, 7) learning to laugh, and 8) celebrating small successes. Further research on the experiences unique to parents of children with AS was recommended.

In 20 narratives published online by parents of children with autism, Fleischmann (2004) utilised Labov's (1972) textual analysis and found parents writing about a growing sense of empowerment and acceptance of their child; a heightened sense of patience, love and appreciation for any achievement; the advantages of a new perspective gained from their child's diagnosis and seeing life as half-full; and the ability of their child to be a teacher for other adults regarding autism. Parents regained control after the diagnosis and rose to meet the challenges associated with autism, seeing themselves as "daring mountain climbers" (p. 41). The researcher concluded that parents go through a transformation following the diagnosis that allowed for a more positive view of their child and a subsequent increase in their coping skills, capturing a significant turning point in their parenting experience. These findings indicate the development of coping processes over time for parents raising a child on the autism spectrum and the possible contribution of turning points to this transformation.

Through narrative analysis of five mothers of children with ASD of primary age, including Asperger syndrome, Marshall (2004) found cognitive and behavioural coping strategies in response to significant stress, with mothers adjusting over time to reconcile what autism meant in their lives. Mothers' coping strategies included comparison; a "resetting" or conscious decision to redirect a troublesome life trajectory; negotiated understandings of what autism meant in their lives; engagement and separation to manage the repercussions of their child's behaviour and sensitivities; anticipatory coping to deal with the unpredictable nature of autism; and creating communities, such as support from the autism community. Through these narratives, Marshall was able to explore the active roles mothers took to cope

with the pervasive stressors in their lives and consider the dynamic interaction across time and contexts.

Parents' become researchers and advocates, improving their coping abilities strategies and building up a valuable knowledge base as they begin to 'specialise' in their child's condition (Altiere & von Kluge, 2009b; Schall, 2000). Levine (2009) conducted a longitudinal qualitative study to identify the factors that contribute toward resilience in single mothers raising children with disabilities which included AS. The findings challenged established deficit views of single parenting, disability and family knowledge. Levine used an integrative theoretical framework to analysis the data from interviews and found the core theme to be the expression of personal agency, such as responsibility and choice. Mothers identified a turning point when they realised they were the sole responsible parent, and to combat negative perceptions, they reframed single parenthood as a superior and empowered choice. They also transformed their personal definition of disability to one where their child had the capacity to change, grow and develop. Mothers in the study drew upon family support and moved from receiving knowledge to gaining, valuing and capitalising on their own experiential knowledge. This qualitative study exploring single mothers' experiences over time discovered important markers, such as turning points, and the evolution of adaptation as they dealt with negative perceptions of their parenting abilities and their child's disability.

Bayat (2007) surveyed 175 parents of children with autism and asked parents to describe their child, their personal life, and the positive and/or negative effects of autism on their family life. Thematic analysis guided by a family resilience framework (Walsh, 1998, 2003) revealed the majority of the themes showed a positive orientation. There were indicators of resilience as parents' worldviews, values and priorities demonstrated a sense of hope, meaning and control. The five themes relating to resilience in the study included the following: 1) pulling resources together and being connected; 2) making meaning out of adversity; 3) a change of world view; 4) becoming more compassionate and strength affirming; and 5) having a spiritual belief system. Furthermore, Bayat noted that families' connection improved as they collectively worked to manage the effects of autism in their daily lives.

A search for support can be an indicator of resilience with wide ranging benefits (Walsh, 2003c, 2006). In a qualitative study of 63 children born with a congenital disability, Kerr and McIntosh (2000) found that parent-to-parent support

exerted a powerful influence on combating stress. This was accomplished by meeting the emotional and social needs of the parents as well as providing practical support. A critical turning point occurred for parents when they realised they were not alone and other families were there that understood and could help. Mackintosh, Goin-Kochel, and Myers (2005) found in an online survey of parents of 498 children on the autism spectrum from the United States, Canada, Australia, New Zealand, England and Ireland, that parents ranked other parents of children with ASD as their highest source of support. Furthermore, in a quantitative longitudinal replication of 84 mothers and six fathers of children ages 3–7 diagnosed with ASD, Benson and Karlof (2009) found informal social support decreased parent depressed mood over time. Ekas, Lickenbrock, and Whitman (2010) found from several measures completed by 119 mothers of a child diagnosed with ASD that those who reported higher levels of informal social support also reported lower levels of parenting stress, negative emotions, and depression. Compared with partners or other family members, social support from friends offered the most benefits, such as increased life satisfaction, positive affect, and psychological well-being.

In a qualitative, phenomenology doctoral study of mothers of high school students with ASD, Plant (2011) explored maternal experiences with social support, both formal and informal. Mothers shared that as a result of support, they were able to resolve problems better and function on a higher level. In an ethnographic doctoral study of 20 parents in an autism support group in Queens, New York, de Wolfe (2013) conducted participant observation and interviews over an 18-month period. She found that parents "constructed, revised, presented and reflected upon personal narratives by describing their personal situations, asking for help, and giving help; through this process, they wove together their stories to create a group narrative of sharing and educating" (p. 189). These studies illustrate the significance of support in parents' lives to counter the demands associated with challenging circumstances.

The buffering effect of resilience for 108 parents who had a child with ASD was investigated by Bitsika et al. (2013). The rate of clinically significant anxiety and depression was found to be three to five times higher than the normal adult population, with mothers significantly more anxious and depressed than fathers. Almost all of the parents identified the specific characteristics of ASD as their main challenge, that is, behavioural, communication and social skill difficulties, and these were perceived to be a daily source of stress. The Connor-Davidson Resilience

Scale (Connor and Davidson, 2003) was used to measure the following five factors contributing to resilience: 1) personal competence, high standards and tenacity; 2) trusting in one's instincts, tolerance of negative affect, and strengthening effects of stress; 3) positive acceptance of change and secure relationships with others; 4) control; and 5) spiritual influences. Resilience appeared to be lower in the parents of a child with ASD, though it was found to buffer against anxiety and depression, even when present in relatively low levels. In the face of pervasive stress, families' abilities to build and maintain resilience were jeopardised. Parental resilience was found to have a strong positive correlation to stress in Cripe's (2013) dissertation investigating 206 parents (103 families) with ASD children ages two to 18. Increased stress was found to be linked in this quantitative study to lower family resilience. Cripe concluded that the results demonstrate that families raising children with ASD follow Walsh's (2003c) resiliency model; that is, the more the father and mother's resilience rises, the more resilient the entire family unit becomes.

Resilience appears to be a complex phenomenon. In the narratives of three families with a disabled family member, Hutcheon and Lashewicz (2015) found "unevenness, paradox, and contradiction" in regards to their family connections, perspective of challenges, and mobilisation of support (p. 56). The notion of resilience can contain uneven and divergent aspects, and reflect the diversity of the people navigating life's ups and downs. These researchers encourage a more nuanced conceptualisation of what it means to be resilient that captures fluid and localised perspectives. This dialectical view was also found in online responses from 493 parents of children with ASD (primarily between the ages of 3–11) representing six different countries, including New Zealand. Myers et al. (2009) asked how their child with ASD had affected their life and their family's life. Both negative and positive themes were found. Examples of the 15 negative themes included the following: stress; difficulty with the child's behaviour and care demands; strain on their personal well-being, relationships and work commitments; impact on the family as a whole; and social isolation. Autism was noted as becoming the centre of their lives with stress being the most frequent theme. The nine positive themes included a new understanding of the world of disabilities; enriched lives; and positive family adaptation. Almost half of the responses were negative throughout and highlighted parents' pain and distress; about a third contained both positive and negative comments; and one in ten was positive throughout. The researchers concluded that

parents appraise a positive meaning to their lives while simultaneously facing difficult challenges. One father commented in the study, "Autism does one of two things: it drives families apart, or makes them stronger" (p. 682).

It can be concluded that the current studies show parents experiencing pronounced stress when raising a child or children with an autism spectrum disorder, significantly endangering parents' well-being and healthy family functioning (Hayes & Watson, 2013). Characteristics associated with AS, such as aggressive behaviour, cause parents great consternation (Aliik et al., 2006), as well as delays in the diagnostic process (Keenan et al., 2010), critical public judgement of their parenting abilities (Ludlow et al., 2012), and a lack of respect for their parental expertise (Huws et al., 2001). Recent studies find parents' coping responses include a variety of positive adaptations to counter the challenges associated with parenting a child on the spectrum, such as reframing adversity (Bayat, 2007); working to establish normalcy in their families (Huws et al., 2001); making sense of the challenges in their lives, finding benefit and focusing on strengths (Pakenham et al., 2004); working to achieve family cohesion (Woodgate et al., 2008); and seeking support (Twoy et al., 2007). The current research on resilience in parents raising children with disabilities shows indicators of resilience, such as self-efficacy, sense of coherence, optimism and acceptance that contributes to parents' ability to cope with the increased stress (Bekhet et al., 2012). The buffering effects of these indicators were noted against depression and anxiety (Bitsika et al., 2013). The studies that utilised a qualitative approach revealed a progression or adaptive process that could include turning points and transformation (Fleischmann, 2004; Levine, 2009; Walsh, 2006), and revealed divergent views regarding their experiences (Hutcheon & Lashewicz, 2015; Myers et al., 2009).

The following chapter will review the development of stress and coping theory, the prospect of turning points for resilience and present a family resilience framework that includes socioecological systems and a disability studies perspective.

Chapter 3

Theoretical Perspectives

The second section of this literature review will focus on the theoretical development of stress and coping theory, its progression to family resilience theory, and the socioecological and disability studies perspectives that are included in this study's framework. In addition, the prospect of turning points for understanding the process of building resilience is introduced.

Resilience can be described as a dynamic process of working through adversity and persistent stressors while gaining the aptitude, resourcefulness and coping skills needed for future challenges (Luthar, et al., 2000; Ungar, 2011; Walsh, 2006). Resilience research initially focused on individuals that demonstrated positive outcomes after exposure to significant stress. Early examples included studies on children growing up in adverse environments and the examination of the protective factors that contributed to resilience (Masten & Garmezy, 1985; Rutter, 1987; Werner, 1995). A significant contribution to resilience research was the longitudinal study conducted by Werner (1995) of 698 children born in 1955 in Hawaii, US. Werner examined the psychosocial risk and protective factors of the children at the ages of 1, 2, 10, 18, 32 and 40. Werner determined that one third of the children who had experienced significant stress growing up in high-risk environments on the Kauai plantations went on to develop into "competent, confident, and caring adults" (p. 82). Self-efficacy, cognitive appraisal of stressful circumstances and supportive relationships were determined to be protective factors. Werner surmised that in adverse circumstances, resilient individuals are prompted to actively choose or create environments that complement their approach to life and promote their strengths. They also demonstrate the ability to be both autonomous and mobilise help when needed that can lead to successful coping and resilience later in life. Moreover, Werner (2005) found that during adulthood, several turning points were noted that resulted in a positive shift in their life trajectories.

Over the last three decades, research on resilience has moved from focusing on individuals to family, and on to community levels, with an acknowledgement that there are multiple pathways to resilience (Berger & Weiss, 2009; Masten & Obradović, 2006; Walsh, 2006). Family resilience considers coping processes from a

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systems perspective as parents manage stress both short and long term within their families (Walsh, 2006). Walsh states:

> How a family confronts and manages a disruptive experience, buffers stress, effectively reorganizes, and moves forward with life will influence immediate and long-term adaptation for every family member and for the very survival and well-being of the family unit. (p. 15)

For this study, parent experiences raising a child or children on the autism spectrum and their positive adaptation were informed by a family resilience framework. A resilience framework takes into consideration how parents respond to stressors and how they manage the challenging aspects within their family life with positive outcomes (Rutter, 2006; Walsh, 2006). The coping responses people choose depend on assessments of the psychological and environmental demands and resources that are available (Folkman et al., 1986). Resilience is not a reflection of a particular personality trait, attribute or single coping mechanism, rather it is a varied, adaptive process to adversity over time that draws on psychological, social, cultural and physical resources, fostered by the relationships with others (Luthar et al., 2000; Ungar, 2011; Walsh, 1996, 2006). Masten (2001) reasons that "resilience does not come from rare and special qualities, but from the everyday magic of ordinary, normative human resources in the minds, brains, and bodies of children, in their families and relationships, and in their communities" (p. 235). Family resilience theory has evolved and been influenced from numerous theories on stress and coping, and an abbreviated overview of those theories and concepts follows. Resilience processes have traditionally focused on child development; hence more investigation is needed to understand how parents cope with formidable challenges (Luthar et al., 2006).

Stress and Coping Theory

Pearlin and Schooler (1978) define coping in their influential article *The Structure of Coping* as "any response to external life strains that serves to prevent, avoid, or control emotional distress" (p. 3). They describe three possible avenues that protect against life stressors: 1) eliminate or modify the situation to prevent the rise of the problem; 2) perceive or interpret the situation in a way that neutralises its negative characteristics; or 3) work to manage the emotional consequences to

prevent being overwhelmed. Pearlin and Schooler further state that a person's coping repertoire can include psychological resources, social resources, or specific coping responses such as behaviours, cognitions, and perceptions. Psychological resources are the personality traits that enable people to mediate or endure stress, such as positive effect; social resources are those found from family, friends, neighbours, and parent groups that support and guide; and specific coping responses are "the things that people *do*" (p. 5). Stress theory has contributed to conceptual models that describe the active processes and adaptation that builds resilience.

Family stress theory was originally developed by Hill (1949) in his seminal book *Families Under Stress* and is known as the *ABCX model of stress*. Hill examined the impact of a father's or husband's conscription into armed service during war: the hardships on families, such as a sharp drop in family income; women needing to enter the work force and assuming dual roles with their husbands absent; a change in living arrangements if the family moved in with relatives; resultant discipline problems with the children; and family reunification after the war. Hill hypothesises that a family's stress is determined by the event (A); their resources (B); their perceptions of the event's significance (C); and then their reaction to it (X). The ABCX model identifies the components that can mediate stress and promote resilience, such as family definitions of the situation and their personal resources that lie within family control (Nichols, 2013).

McCubbin and Patterson (1983) developed their family crisis framework grounded on Hill's work on family coping. They examined how family members work to fit demands and resources into family life. McCubbin and Patterson proposed a *Double ABCX model* that incorporates multiple events (Aa); additional resources (Bb); altered perceived contributions (Cc); as a result of the family's reactions (X). Parent appraisal of family stress and coping processes are emphasised in this model to ascertain how to rebalance the family while dealing with co-occurring and accumulative normative stressors that pile up over time. According to McCubbin and Patterson, a family's adaptation to stress can include positive outcomes (termed *bonadaptation*) versus maladaptation. This translates into strengthened family integrity; individual and family development; maintenance of family independence; and a sense of control over environmental influences.

Lazarus (1966, 1991) states that appraisal occurs when a person evaluates what is at stake and determines its significance for their (or a loved ones') well-being. After appraisal, potential responses are considered and coping processes follow. Problem-focused coping includes planning, taking active steps, seeking assistance, suppressing competing activities and exercising restraint; and emotion-focused coping includes acceptance, positive reappraisal and seeking social support (Carver, Scheier, & Weintraub, 1989; Folkman et al., 1986; Gill & Harris, 1991). Problem and emotion focused coping can be implemented concurrently. A cognitive-motivational-relational theory of emotion was forwarded by Lazarus in 1991 that further explored coping and emotion. Lazarus explained that not only does coping follow emotion; it also shapes subsequent emotion, as changes in the person-environment relationship occur or meanings are reappraised. Park and Folkman (1997) explain that meaning making is part of a person's coping when they either change the appraised meaning of a particular situation so it is congruent with their global beliefs or they change their beliefs or goals to accommodate the situation.

Bandura (1978) explains that a developed *sense of efficacy* contributes to the ability to solve problems creatively and utilise strengths effectively, which in turn influences coping behaviour. In the face of obstacles, a person's self-efficacy affects when a person begins a coping response, how much energy they invest, and the length of time they persevere. There are resultant gains to self-efficacy during mastery of the challenging experience. Moreover, there is an interdependent design of family interactions where a "collective efficacy" is formed, and the family members "pool their knowledge, skills and resources, provide mutual support, form alliances, and work together to secure what they cannot accomplish on their own" (Bandura, Caprara, Barbaranelli, Regalia, & Scabini, 2011, p. 422). Other family members and extended family can provide parents a broader base of collective abilities and experience to draw from. Antonovsky (1987) developed a similar concept to explain how stress is perceived and managed. He proposed that the strength of a families' *sense of coherence* (comprehensibility, manageability and meaningfulness) can be used to gauge their ability to successfully cope and adapt to family stressors, opening up collaborative solutions across social structures. A family's sense of coherence is not a specific coping style per se, rather it captures how a family judges which coping responses are the most appropriate and relevant to their situation as a family (Antonovksy & Tourani, 1988). Furthermore, Antonovsky (1987) describes a

salutogenic orientation for well-being where energy is focused on "active adaptation to an inevitable stressor-rich environment" (p. 9).

Taylor (1983) proposed a *theory of cognitive adaptation* to threatening events that revolved around three themes: searching for meaning, trying to regain mastery and restoring self-esteem. This perspective is analogous to Bandura's work on self-efficacy and Antonovsy's sense of coherence concept. Taylor explained that a search for meaning encompasses putting the experience into perspective, or understanding why it happened and what it means for the future. Mastery entails gaining control over the event in particular and believing in control over one's life in general. Self-esteem can be restored through social comparison and finding benefit. Taylor argues that meaning, mastery and self-enhancement rest on cognitive 'illusions' that contribute to psychological adaptation. Making meaning is also a central component of well-being theory and the positive psychology movement (Seligman, 2012; Seligman & Csikszentmihalyi, 2000).

The *Family Adjustment and Adaptation Response* (*FAAR) model* interpreted families' efforts to balance stressor demands with their resources (Patterson, 1988). Integral to this model is the family's process of developing meaning and its relationship to their coping ability. The manner in which families conceptualise disability directly influences how the family balances their resources against the demands and associated stressors from parenting a child with a disorder. This model integrated concepts across multi system levels. Patterson introduced resistance, restructuring and consolidation adaptation phases to capture how family members work to restore balance within the family, and between the family unit and the community. In 2002, Patterson incorporated family stress and family resilience theory by further clarifying family resilience constructs, and emphasising protective factors and adaptation processes that occur as families cope with significant risk. Transactions between multiple protective sources in a family's ecosystem (individual, family and community) are highlighted (Nichols, 2013; Patterson, 2002).

The FAAR model evolved into *T-Double ABCX model* that incorporated family typologies, schema, life cycle, and additional appraisal considerations (McCubbin, Thompson, & McCubbin, 1996). McCubbin et al. (1996) then conceptualised the *Resiliency Model of Family Stress, Adjustment and Adaptation*. This model advanced adjustment and adaptation phases and included five levels of appraisal related to

problem solving and coping*:* schema, coherence, paradigms, situational and stress appraisal.

A concept of healthy adaptation was advanced by Tedeschi and Calhoun (2004) that explains positive psychological maturation to highly stressful and challenging conditions. Tedeschi and Calhoun noted that reports of growth experiences from significant adversity far outnumbered the reports of psychiatric disorders. They recognised that the same psychological processes involved in managing stress can be those that produce positive changes and that "continuing personal distress and growth often coexist" (p. 2). Berger and Weiss (2009) expanded Tedeschi and Calhoun's model of posttraumatic growth (PTG) to include family systems. This model acknowledged individual as well as family and community growth, and shifted the paradigm away from seeing families as deficit based to a strengths-based view of family functioning. Furthermore, Berger and Weiss saw adversity as strengthening a family's identity and relationships with others and contributing to a realignment of priorities and beliefs.

These stress and coping models consider the process of how stressful events and resources are perceived and utilised. The appraisal of the significance of the event has been determined to be instrumental to coping (Lazarus, 1966; McCubbin & Patterson, 1983). A family's sense of coherence can be used to explain how families navigate stress successfully (Antonovsky, 1987). Self-efficacy gains can follow (Bandura, 1978) as they search for meaning (Taylor, 1983). Family stress theory progressed to family resilience theory as the adaptation process was better conceptualised to consider families' efforts to restore balance within different ecosystem contexts (Patterson, 2002). A posttraumatic growth model has evolved from coping theory to support the positive changes that were noted as families dealt with significant stressors (Berger & Weiss, 2009; Tedeschi & Calhoun, 2004). Stress and coping theory illustrates how a family dealing with challenges will "marshall its resources and focus its perceptions on positive aspects of its life" and become a catalyst for improved family functioning (Summers et al., 1989, p. 30).

Family Resilience Theory

Family resilience theory captures the constructs of stress, coping and adaptation within the family unit while considering the social, relational and

developmental contexts that eventuate within families during the resilience process (Patterson, 2002). Walsh (2003c) contests the deficit based approach to families as damaged or broken when faced with adversity to one that acknowledges parental *strengths*. The family's experience can contain common and unique features, and since families are complex, different strategies and approaches are needed to meet future challenges.

Family resilience considers the systems that give families the capacity to counter the negative and destabilising effects of risk. Luthar et al. (2000) discuss resilience in family systems in terms of *risk factors, protective factors, indicators of resilience* and *resilience outcomes*. Examples of risk factors in parents of children with autism include anger or depression (Bekhet et al., 2012). Protective factors can include social support, locus of control and cognitive appraisal (Bekhet et al., 2012). Social support mitigates the challenges associated with raising a child on the autism spectrum (Henderson & Vandenberg, 1992) and has been found to be inversely related to depression, anxiety and anger (Gray & Holden, 1992). The advice and information offered through social networks helps parents to problem solve, bolster their self-confidence, or reappraise their situation with positive effect. When parents appraise difficult experiences as challenging they take control, even transcending adversity (Lazarus & Folkman, 1984). A supportive partner, a positive parent-child relationship, and personal well-being are additional compensatory factors for positive adaptation (Gerstein et al., 2009). Indicators of resilience can include acceptance, optimism, self-efficacy, a sense of coherence, positive family functioning and enrichment (Bekhet et al., 2012). Positive emotions and meaning making help people rebound from stressful experiences and can be used to appraise resilience (Tugade & Fredrickson, 2004). Resilience outcomes can point to improved parental mental health and well-being, better marital quality, and greater life satisfaction (Bekhet et al., 2012).

The family resilience framework developed by Walsh (2003c, 2006) improves our conceptual understanding of the key family processes that can manage current and future environmental stressors. This framework contains three key themes, each with three sub themes (See Table 1). Family belief systems encompass how a family makes meaning of adversity, their positive outlook, and transcendence and spirituality. Organisational patterns include a family's flexibility, connectedness, and

social and economic resources. Communication processes cover clarity, open emotional express, and collaborative problem solving.

A family resilience framework explores the elements that protect and moderate families' experiences with stress, and the dynamic processes of overcoming adversity within a life course context. Resilience is an interactive concept that encompasses positive adaptation to risk experiences over a life-span trajectory and the effects of the turning points within it (Rutter, 2006). For this study, a family resilience approach is appropriate to understand the complexity of coping for parents raising children with AS and the instrumental processes of adaption to challenging circumstances. With a socioecological perspective, a resilience framework considers the wide variety of protective factors that can mediate stress and the development of subsequent competence:

> [The] key element is some form of successful coping with the challenge or stress or hazard. This is likely to involve physiological adaptation, psychological habituation, a sense of self-efficacy, the acquisition of effective coping strategies, and/or a cognitive redefinition of the experience (Rutter, 2006).

Developing coping skills to counter adverse conditions and reduce the negative impact of stress improves capabilities for subsequent challenges (Cowan, Cowan, & Schulz, 1996). A resilience framework emphasises strengths, positive adaptations, and competence (Luthar & Cicchetti, 2000; Walsh, 2006).

A systems approach to family functioning takes both an ecological and developmental perspective to better understand coping and adaptation in stressful contexts, and situates this within a family and social context (Walsh, 2006). This resilience framework also takes into account the myriad of dynamic interactional systems that influence an individual's development over a course of their lifetime, along with the differing skill set and resources needed for either a sudden crisis, a pileup of stressors, or a persistent challenge (Masten & Obradović, 2006; Walsh, 2006; Wright, Masten, & Narayan, 2013). A family resilience approach considers ecological systems as it "links symptoms of distress with distressful events and contexts" (Walsh, 2006, p. 138). A review of ecological systems follows to explain these contextual relationships.

Table 1

Walsh's (2003c, 2006) Key Processes in Family Resilience

<u>Family belief systems</u>

Making meaning of adversity, such as viewing resilience as relational and a shared challenge versus particular individual traits; contextualising or normalising adversity, having a family life cycle orientation, and viewing vulnerability and distress as natural, common and understandable; developing a sense of coherence – crisis as meaningful, comprehensible and manageable challenge; appraising adverse situations and settling issues of control, responsibility, or blame, attributing cause and explaining – 'How could this happen?' and exploring and managing future expectations and fears, such as 'What will happen' and 'What can be done?'

Positive outlook, such as having hope, optimism and confidence in overcoming odds; affirming strengths and building on potential; capitalising on opportunities, exercising active initiative, and demonstrating perseverance; showing courage; mastering the possible and accepting what cannot be changed.

Transcendence and spirituality, such as having larger values and purpose; practicing a faith and having congregational support; inspired by new possibilities, trialling innovative solutions, having role models, life dreams, and creative outlets; experiencing transformation through learning, changing and growing from adversity – seeing crisis as a challenge with potential benefits and reassessing, reaffirming or redirecting life priorities, and taking social responsibility through concern for others.

<u>Organisation patterns</u>

Flexibility, such as being open and adapting to change, rebounding, reorganising, and adapting to fit new challenges; stability through disruption, showing continuity and dependability, incorporating routines and rituals; varied family forms present such as strong authoritative leadership demonstrating nurturance, guidance, and

protection of children and vulnerable family members, co-parenting with mutual respect, and cooperative parent/caregiving teams.

Connectedness, or seeking mutual support, collaboration and commitment; respecting individual needs, differences and boundaries; seeking reconciliation and reconnection of damaged relationships.

Social, economic and knowledge resources, such as mobilising family, social and community networks; seeking models and mentors; building financial security; and balancing work/family demands; accessing larger system support.

Communication processes

Clarity, using clear and consistent messages through word and action; clarifying ambiguous information; seeking and speaking the truth.

Open emotional expression, or sharing a range of both positive and negative feelings, showing mutual empathy and tolerance for differences; taking responsibility for own feelings and behaviour and avoiding blame; and having pleasurable interactions, a sense of humour and respite.

Collaborative *problem solving,* identifying problems, stressors, constraints and options; utilising creative brainstorming, resourcefulness and capitalising on opportunities; sharing decision making, negotiating, resolving conflicts and working to repair misunderstandings, being fair and reciprocal; focusing on goals, taking concrete steps, building on success and learning from failure; and taking a proactive stance by planning to prevent problems, avert crises, preparing for future challenges, having a 'Plan B'.

Ecological Systems

A socioecological perspective considers how stressors are social in origin (Pearlin & Schooler, 1978) and how systems can mediate a family's coping ability in a social context and over time (Fernandez, Schwartz, Chun, & Dickson, 2013; Walsh, 1996). Lives are embedded within social relationships spanning generations (Elder, 1994). Furthermore, a sociocultural context is integral to a family resilience framework (Walsh, 2013) and captures the central premise of narrative inquiry, namely that of "human interaction in relationships" in and across dynamic social contexts (Riessman & Quinney, 2005, p. 392).

The nested ecological systems model that Bronfenbrenner first introduced in 1979 can be used to understand the contextual influences on stress and coping. The first domain starts with the *microsystem*, such as the parent's home, neighbourhood, or workplace environment, and might feature supportive relationships from their partner, family, friends and professionals. The following level is the *mesosystem* which describes the intersection of those microsystems and captures the interrelationships between two or more systems in which the child, parent or family works and lives. Next, the *exosystem* includes social structures, such as the availability of health and social services and the responsiveness of schools to their child's needs. Radiating out farther is the *macrosystem*. The macrosystem encompasses ideologies that influence how people treat and interact with other in different types of settings, such as societal views on disability, health diagnostic practices or a government's policies.

Lastly, the *chronosystem* explains the dynamic relationship between a person's role, activity and environment within their daily life and across historical time. A chronosystem view examines cumulative effects or specific life transitions or events, such as turning points, that are significant during a person's life course. After major transitions, "the family must readjust and recalibrate" (Walsh 1996, p. 7). The changes over time not only encompass personal changes, but also can be studied in the environment, and more importantly, the dynamics between the two analysed (Bronfenbrenner, 1986). For example, a parent's turning point could alter altitudes about self-belief, and subsequently have positive repercussions for patterns of interaction within and outside of the family unit.

Bronfenbrenner later developed a *Process-Person-Context-Time* bioecological model that more strongly permitted these changes in developmental processes and outcomes to be analysed, as the joint function of the characteristics of both the environment *and* the person were recognised (Bronfenbrenner, 2005). In this model, proximal processes were identified as crucial components in a person's development. For example, the process of parents striving to make meaning of their stressful circumstances and their role in it exerts changes within family dynamics and relationships outside of the family. Personal characteristics were viewed as having a clearer role in influencing changes in the environment, and the effect of time was considered within the subsets labelled micro, meso and macrochronological systems (Bronfenbrenner & Morris, 1998). Within family resilience theory, familial developmental processes and contextual influences are vital components to understanding how families "meet emerging psychosocial challenges over time" (Walsh, 2006, p. 20). The concept of resilience considers relational resilience processes that vary over different phases of adaptation and transitions in a life cycle (Walsh, 1996, 2006).

An ecological systems view takes into account both the stressors associated with parenting a child with ASD and the possible accommodations and supports available to successfully mediate those stressors. For example, societal views that consider disability as a medical problem or a tragedy influences parental beliefs and behaviour (Phillips, 1990; Woolfson, 2004) and a social support intervention model that incorporates the multiplicity and strengths of networks can bolster hardiness (Weiss, 2002). Ravindran and Myers (2012) explain that an ecological system model is useful for examining cultural beliefs on disability because it considers how influences flow between interconnected systems. For example, when a culture becomes more accepting of children with challenges and government policies encourage early intervention on the macro level; school systems then cater for the full range of students' needs in the exosystem level; and relationships improve between parents and professionals as they develop mutual respect. These contextual domains and transactional interchanges form the conceptual foundation for resilience research (Luthar et al., 2000).

Ungar (2011) argues that social and physical ecologies affect positive developmental processes when people are faced with significant stressors. The parent's capacity to develop resilience needs to be considered through their

interaction with their mesosystem, exosystem and macrosystem and a shift is warranted that focuses more on how the environment can facilitate positive development. Ungar proposed that the construct of resilience will be advanced when considering the interactive processes between environments and individuals with resilience dependent on available resources rather than individual factors.

Prospect of Turning Points

Patterson (2002) explains that a response to a crisis can present a *turning point*. The discontinuity that is created can either lead to poorer or improved functioning. When the latter occurs, regenerative power occurs when families restore balance by "reducing demands, increasing capabilities and/or changing meanings" (Patterson, 2002, p. 351). A turning point is a disturbance along a life course trajectory, becoming consequential "because they give rise to changes in overall direction or regime, and do so in a determining fashion" (Abbott, 2001, p. 249). There is potential for a person to experience transformation as a new identity emerges from a new trajectory and a commitment to the new direction (Wheaton & Gotlib, 1997). Wheaton and Gotlib (1997) characterise turning points as follows:

> But turning points need not be dramatic events, or unusual events, or even a single discrete event. Turning points may be difficult to see as they are occurring because they are only recognized to be turning points as time passes and as it becomes clear that there has been a change in direction.

Marshall (2004) speaks of "reset points" in his research of mothers raising children with ASD. This resetting required problem-focused coping from mothers to relieve accumulated stress with a substantial alteration of the status quo. In this way, turning points offer opportunities to increase stability (Rutter, 1996). The prospect of turning points can be used as a focal point to better understand how coping and adaptation develops. Turning points can provide opportunities to explore how parents regain stability and confidence in the face of ongoing and pervasive stress.

Boss (2002) explains that turning points develop from a change in the stressor(s), a change in available resources needed for coping, or a change in the family's perception of both of those factors. Rutter (1996) differentiates turning points from life transitions and sets out two features that underlie them: firstly, within a

person's realm, there is a marked discontinuity or change that in turn influences new development, and secondly, the experience has the potential for meaningful, lasting effects over time. Rutter categorised turning points into three types of life experiences: 1) a turning point that opens or closes opportunities for a person; 2) produces a lasting change in the person's environment; or 3) changes a person's self-concept, views or expectations. There can be a "radical alteration in life circumstances", altering a life trajectory (p. 621) and the potential to determine the "overall structure of a life course" (Abbott, 2001, p. 249). Turning points present opportunities in people's lives to make changes with positive effects (Rutter, 1996; Walsh, 2006; Werner & Smith, 2001).

Exploring turning points for parents and families presents an opportunity to examine contributing contextual factors as well as the internal struggle necessary to surmount the challenges. Careful analysis can lead to the development of more empirically and comprehensive theories about social influences (Mishler, 1986) and developmental processes (Walsh, 2006). Moreover, turning points can reveal progress towards building resilience. They can have a significant influence on the outlook, expectations and patterns of interaction within the family after the transition. Bronfenbrenner (1979) explains that "if it is true that ecological transitions and interconnections between settings play a major role in affecting the direction and rate of development, then adulthood should be a period of dramatic shifts, spurts, and slumps in psychological growth" (p. 232). A retrospective view across time can focus on life alterations that "serve as a direct impetus for developmental change" which in turn, has an effect on family processes (Bronfenbrenner, 1986, p. 724). Turning points are opportune events that can reveal the dynamic systems involved in personal growth, especially when individuals enter new roles and settings (Clausen, 1995). A major life change presents an opportunity for self-reflection and the recognition of the ensuing benefits, which is an effective coping strategy for managing difficult experiences (Folkman, 2008). In the *sense of coherence* concept, a personal assessment around a turning point has implications for the meaningfulness component, that is, when a person feels that life makes sense emotionally and the difficulties faced are worthy of their energy, commitment and engagement; consequently the challenges are seen as acceptable rather than burdens (Antonovsky, 1987). A challenge is willingly taken up, meaning created, and the person "will do his or her best to overcome it with dignity" (p. 19).

Disability Studies Perspective

A disability studies perspective examines how disability itself is interpreted; how environments handicap people over and beyond the characteristics of their impairment; and how the viewpoints of those directly affected can be incorporated into the dialogue. The concept of disability is a "social phenomenon storied, negotiated, and constructed in different ways" (Goodley & Tregaskis, 2006, p. 644), reinforced by current cultural ideologies (Phillips, 1990). Linton (1998) contends that a psychological explanation for disability pervades societal perceptions:

> [The] meaning most often accorded to disability is that it is a personal condition, rather than a social issue; an individual plight, rather than a political one. When individuals with disabilities fail in education, employment or in love, the failure is attributed either to the disability, itself considered an obstacle to achievement, or to the individual's psychological weaknesses or lack of resilience, their inability to 'overcome' their misfortune. (p. 4)

Oliver (1990) reasons that as humans we assign meaning and then orientate our behaviour accordingly; seeing disability as a tragedy translates into society treating disabled people as victims of some tragic circumstance. Stigma and prejudice arise from viewing people with disabilities as not 'normal'. Sociologists and disability rights activists challenge the perception that people with disabilities lack wholeness or that they deviate from an entrenched norm. For example, diagnostic tools, such as the DSM, frame disability as one of deficit and dysfunction (Connor, 2013). Underlying a diagnosis is the assumption that there are material entities that people permanently possess, rather than recognising the abstract, conceptual nature of psychiatric diagnoses and considering alternative ways of thinking about behaviour and experience (Boyle, 1999).

Moloney (2010) puts forth that "the distressing experience and conduct upon which the diagnosis is based…are likely to be found as much if not more outside the labelled person as within their supposedly internal psychobiological world" (p. 139). Phillips (1990) explains that "the basic flaw in the medical model is the presumption of normality" and anything that deviates from that is damaged and defective (p. 851). A pathological view of disability then leads to the 'necessity' for specialised knowledge to address the person's perceived limitations, and the medical discourse

of disease creates a doctor/patient dependency where expertise is held and protected (Moloney, 2010; Phillips, 1990). Historically mothers have shouldered blame for their child's autism and been labelled as 'refrigerator mothers'; they have negotiated societal norms regarding their child's behaviour and development; and have been pressed to engage with medical, health, social work, psychological and educational professionals within their family life (Sousa, 2011). Sousa (2011) discovered in mothers' memoirs an attempt to "wrest control away from dominant medical discourses about disability and redefine a public identity in relationship to their children" with a call to action and a strong desire to raise awareness (p. 230). Levine (2009) found from interviewing single mothers a process of self-empowerment as they discarded deficit views of disability and trusted their parenting choices.

A disability studies perspective rejects a pathological description of people with disabilities and works to redefine what difference means within a person's inherent worth. Baron-Cohen (2000) proposes that AS be viewed as 'different' versus 'disabled' which is a more "neutral, value-free, and fairer description" (p. 489). Connor (2013) enlightens: "As ontological outlaws, aspies therefore provide alternative ways of understanding what society perceives as disability, normality and reality, troubling the truth about human difference" (p. 124). Baron-Cohen (2000) describes children with AS or high functioning autism as tuned into objects, information, details, patterns and systems versus being socially driven, and this should not be considered 'abnormal'. Moreover, these preferences only become a disability when the environments that children learn and grow in are predominantly social. Hence, when societal expectations of what constitutes 'normal' behaviour changes, the child ceases to be disabled. A socioecological perspective notes that beliefs and assumptions about difference arise from the "overarching beliefs and values of the society, including macro elements that are economic, political, social, and spiritual" (Ravindran & Myers, 2012, p. 313).

Disability studies turns the focus from people with disabilities to societal constraints, and positions the argument for full participation not with remedial efforts aimed at individuals, but against the barriers that prohibit full participation (Connor, Gabel, Gallagher, & Morton, 2008; Goodley, 2011; Goodley & Tregaskis, 2006; Linton, 2005). A disability studies perspective examines the social and cultural overtones that prescribe acceptable behaviour against the political backdrop of who gets to participate and their entitlements. This shift to address the tension between

full integration and social oppression crosses several disciplines, and draws on the movements of other disenfranchised groups that opened discourse around race, gender, sexual orientation and class (Goodley, 2013; Thomas, 2004). The social model of disability holds that societal views and structures disable a person on top of their actual impairment, and that economic, environmental and cultural barriers must be challenged, such as inaccessible education systems, inadequate social support services, and the disempowering view of impairment as personal tragedy (Oliver, 1990, 2004). In addition, how disability is conceptualised influences who wields influence and power (Goodley, 2011).

The opportunity for people with disabilities to be heard and their perspectives considered is a fundamental part of disability studies, especially as it considers the government policies, health interventions and educational support directly affecting them. Examining the barriers and exclusionary practices, the motivations and reasoning for implementing them, and the consequences for maintaining this structure are all integral facets of disability studies and contributes authentic perspectives through personal narratives of lived experience. People with disabilities do not stand *outside* the majority, but claim the right to exist *within* a diverse society as a minority group with accompanying rights and recognition.

A disability studies approach can also be used to broaden the concept of resilience. Recognition of family strengths challenges the historic view of family dysfunction (Walsh, 2002). Theories that accentuate personal traits ignore person-environment interactions and the constraints of under resourced settings; societal interpretations of family competence must be challenged and diverse interpretations of coping embraced; understandings seen as socially constructed and acknowledged as subjective; and an emphasis placed on the varied dynamic processes over stable measurable outcomes (Hutcheon & Lashewicz, 2014, 2015). Research on family experiences with disability can reinterpret what constitutes adversity, challenge and success, moving away from an overly prescriptive definition constrained by hegemony and ability-centrism (Hutcheon & Lashewicz, 2014).

A disability studies perspective is an important component of a family resilience framework when exploring the experiences of parents raising children on the autism spectrum. The voices of parents of children with Asperger syndrome add a valuable contribution to understanding the unique stressors they face. Their experiences shed light on their struggles for their children to reach their best potential

in a society that views them as 'bad' parents and their children as 'misfits'. Woolfson (2004) explains how societal views of disability – disability as a medical problem, as a tragedy, or disabled people are dependent and needing help from others – influences coping processes for parents. The social experience of disability has a significant impact on parents, with perceived stigma creating additional emotional distress and increasing maternal perceptions of caregiving burdens (Green, 2007). There are "profound pressures" to conform to societal standards (Sousa, 2011, p. 221). Parent narratives reveal the realities of stressful journeys as they struggle to gain acceptance as capable parents and a sense of belonging and value for their children. Parents' voices are especially valuable in research as their experiences expose the barriers, judgment, and limited support they grapple with on a daily basis (Connor et al., 2008; Linton, 1998). A disability studies perspective respectfully acknowledges the challenges parents face within the social and cultural forces surrounding them.

The theoretical framework of family resilience that has evolved from stress and coping theory and shifted from individual processes to family and community systems is an appropriate and relevant framework to explore how parents respond to the stressors associated with raising a child on the autism spectrum. Walsh (1996) states "a resiliency-based approach aims to identify and fortify key interactional processes that enable families to withstand and rebound from the disruptive challenges they face" (p. 1). A socioecological perspective, recognised as an important component of a family resilience framework, provides an awareness of the social contexts and transactional processes of parents' experiences and their attempts to adapt within the different systems they live and interact. This perspective accounts for the "many spheres of influence in risk and resilience over the life course" (Walsh, 2006, p. 12). Lastly, a disability studies perspective acknowledges divergent views on what is considered 'normal' and the additional pressures parents face. This overall approach to exploring parent experiences when raising a child with Asperger syndrome accentuates parental strengths and their positive adaptations; considers the societal contexts and influences embedded into parents' lives; and challenges what is considered 'normal'.

Chapter 4

Methodology

A major portion of the literature on parental stressors and coping with a child with AS draws from quantitative research methods. These findings have provided an increased awareness of the challenges parents face when raising children on the autism spectrum (Hastings, 2003; Montes & Halterman, 2007; Rao & Beidel, 2009; Smith et al., 2008), as well as the process of building resilience (Bitsika et al., 2013). On the other hand, quantitative tools are limited in their scope when examining the *complexity* of parent experiences and the development of resilience over time. Qualitative findings produce rich, detailed descriptions leading to a more comprehensive understanding of challenging experiences and positive adaptation. Qualitative research explores processes and meanings with an interpretive naturalistic approach and is well suited to describing how social experience is influenced and understood (Denzin & Lincoln, 1994; Hastings & Taunt, 2002; Liamputtong, 2009). A qualitative methodology is better suited for interpreting "routine and problematic moments and meaning in individuals' lives" and is more apt to capture parents' perspectives within the *context* of their lives (Denzin & Lincoln, 1994, p. 2). Furthermore, it is instrumental for exploring parental coping and adaptation (McCubbin et al., 1996). This is especially pertinent when raising a child that does not readily fit societal norms and revealing the constraints and pressures of parents' everyday social world. Therefore, a qualitative approach was taken in this study to better understand parents' lived experiences and coping processes while raising a child with an autism spectrum disorder.

Social Constructionism

Using an epistemology of social constructionism, this research is based on the assumption that meaning is created when people interact with the world they are interpreting (Crotty, 1998). Constructivists acknowledge multiple realities, and that knowledge is constructed through discourse in the context of individual histories and social interaction (Schwandt, 2000). This ontological stance contends that the narratives told by the parents will reveal numerous subjective positions that reflect

their world views, social environment, and their relationship with me as a researcher (Clandinin & Connelly, 2000; Ponterotto, 2005). As a consequence of multiple interpretations of reality, there is no one central meaning to be discovered, but rather, there are diverse possibilities to be constructed (Crotty, 1998). Social constructionism pertains to how parents make sense of the challenges within the context of their daily lives, as well as how I, as a researcher, interpret these meanings through my connection with the participants and their stories.

This research is based on the premise that people's stories are a fundamental representation of human understanding (Pinnegar & Daynes, 2007). Words are the manner in which we come to understand and explain our worlds and ourselves and can be used as tools to interpret stressful situations and the meaning attributed to them (Maykut & Morehouse, 1994; Plummer & Knudson-Martin, 1996). Narratives can be considered external expressions of internal experiences (Squire, Andrews & Tamboukou, 2008) or "retrospective meaning making" (Chase, 2005, p. 656). Polkinghorne (2007) asserts that "the storied descriptions people give about the meaning they attribute to life events is, I believe, the best evidence available to researchers about the realm of people's experiences" (p. 479). Narratives are a manner in which we can understand experience, both in the story and in the telling, with narrative inquiry a compelling method to explore perception and meaning-making from the perspective of the study participant.

Narrative Inquiry

Narrative inquiry embraces how people make sense of their world and is instrumental to understanding meaning-making processes when used as a methodology (Clandinin & Connelly, 2000). Within narrative research there is an increased theoretical interest in how peoples' perspectives are revealed through the process of storytelling (Elliott, 2005; Ricoeur, 1991a, 1991b). Clandinin (2007) clarifies:

> Personal stories can be examined...to experience how subjective accounts of one's life often contain a personal worldview, a personal philosophy, a personal value system, a personal ideology, and a view of what is morally, if not politically, correct. (p. 229)

According to Goodley (2011), "narratives mould a sense of self" which allows that self to be presented (p. 129). We think and act as narrators and protagonists as we shape our daily lives by stories of who we and others are, and interpret our past through these stories (Connelly & Clandinin, 2006). We must closely examine how we "construct ourselves autobiographically" (Bruner, 2004, p. 692).

Narratives also represent a means to holistically examine parents' efforts to negotiate within the sociocultural contexts in which they live (Lalvani & Polvere, 2013). The narrative form is a reflection of the world in which the participants exist, and reveals "larger cultural, social, familial, and institutional narratives" (Caine, Estefan, & Clandinin, 2013, p. 577). Our ideas about ourselves are created through our social interaction and reflect societal values, or as Bruner (1995) proclaims "there is no escaping the culture: it is us" (p. 176). The stories we tell reflect the meaning, purpose and the construction of our identity in our world (Berger & Quinney, 2004). Social conditions are brought out within narratives as the narrator transitions through their past, present and possible futures influenced by the boundaries of place (Connelly & Clandinin, 2006).

Bruner (2004) asserts that narratives excel at "capturing the sense of *lived* time" (p. 692). A narrative is the principal mode to communicate connections between actions, events and contexts (Ricoeur, 1984). Mishler (1986) discusses the distinctive features of narratives with their dynamic ordering of events – their "meaningful and coherent courses of action, with beginnings, middles and ends" (p. 248). The narrative design then produces a framework for understanding the events and phenomenon of change in one's life. According to Bruner (1994), our lives are "storied" and resemble a narrative structure: 'there is an *agent* engaged in *action* deploying certain *instruments* for achieving a *goal* in a particular *scene*, and somehow things have gone awry between these elements to produce *trouble*" (p. 43, emphasis in original). Narratives reveal people striving "to configure space and time, deploy cohesive devices, reveal identity of actors and relatedness of actions across scenes. They create themes, plots, and drama. In so doing, narrators make sense of themselves, social situations, and history" (Bamberg and McCabe 1998, p. iii). The temporal aspects of parents' narratives make known the *evolution* of coping processes – their past journeys searching for a diagnosis; coping with a lack of acceptance in the present; and planning for an uncertain future.

The narrative structure can include turning points in a person's journey. In personal narratives, a turning point signals a new order as conflict and trouble are remedied with potential for transformation. During reflection, a retrospective appraisal is made of this change of direction that is subsequently imbued with meaning (Abbott, 2001; Clausen, 1995). Nünning (2012) states that these "turning points, in a word, construct emblems of narrative clarity in the teller's history of self" (p. 50). Personal narratives illustrate the efforts of the narrator to portray their life in a coherent fashion, and "perceived turning points become a means of bridging the continuities and discontinuities in a way that makes sense to the individual" (Clausen, 1995, p. 370). Riessman (2002a) explains that turning points are useful for exploring how personal identities have shifted over time and a recognition that a new identity has been constructed. Narrative inquiry therefore, is an appropriate methodology to explore turning points in relation to parent experiences and their coping processes over time.

Narratives are a means to impose order on a disordered and unpredictable world and hence offer possibilities for understanding stressful experiences such as those associated with parenting of a child with AS. Walsh (2003b) establishes that major stressors "involve not simply a short-term event, but a complex set of changing conditions with a past history" (p. 56). Participants share stories about particular points in their lives "where there has been a breach between ideal and real, self and society" (Riesmann, 1993, p. 3). Hence, narrative inquiry provides opportunities to explore and interpret these experiences, and the significant aspects that are communicated within a story's arc (Clandinin and Connelly, 2000; Creswell, Hanson, Plano Clark, & Morales, 2007; Labov, 2006). For example, turning points are an opportune time to learn how parents cope and overcome the challenges in their lives.

Narratives are a medium to explore what is atypical: "[W]hen you encounter an exception to the ordinary, and ask somebody what is happening, the person you ask will virtually always tell a story that contains reasons" (Bruner, 1990, p. 49). When we document the perspective of the participant, we are better able to understand the unique stressors associated with raising a child with AS, parents' atypical approaches to coping, and their interactions with social environments (Ungar, 2011). As a qualitative approach, narrative inquiry provides opportunities for new insights into parent experiences and their responses to their challenges – the conditions and impact are revealed within the context and structure of the stories they share.

Riessman (2002a) writes "personal narratives provide windows into lives that confront the constraints of circumstances" (p. 707).

Narrative inquiry captures both the process and the product of making meaning. Parents' stories bring to light the positive and negative influences in their lives, their responses to stress, their meaning making, and the lessons learned. Linde (1993) explains that the narrator creates coherence within the narrative when causal connections between life events are interpreted. This can eventuate during the interview process as the story is told and understood between the parent and myself – as omniscient narrators, parents are able to communicate to the listener their own understanding and insight as they interpret the events in their lives. As Trees and Kellas (2009) express, storytelling helps people make sense of trying times and provides insight into how they make sense of their world. Gray (2001) argues that narrative reconstruction reveals efforts of an individual to reconcile their experience with disorder as "a morally adequate person who attempts to lead a normal life under difficult circumstances" (p. 1248). A story shares not only the events and circumstances surrounding them, but also the deliberation and contemplation of the story teller to recount them.

A narrative approach enables parents raising children with AS to share stories on their terms, defining their own reality while protecting the integrity of their experience (Plummer & Knudson-Martin, 1996). This methodological tool has the potential to create an enlightened understanding of the challenges parents' face in their lives related to AS. Elliot (2005) explains:

> There is an important link between an interest in these evaluative elements of narratives and a commitment to a humanist sociology which prioritizes 'understanding' or Verstehen…an hermeneutic approach to the social sciences emphasizes the importance of empathizing with the subjects of research and developing a detailed understanding and appreciation of how they make sense of the social world. (p. 43)

Narrative inquiry situates parents of children and young persons with Asperger syndrome in the forefront of this study with a desire to best understand how they interpret and navigate their daily lives.

There are a multitude of approaches to conduct narrative inquiry with no best single approach (Elliot, 2005). The emphasis for this narrative inquiry examined the *content* of the stories shared versus the language choice, structure, context, intended

audience, or units of analysis (Riessman, 2008). The content includes descriptions of past events within a chronological account and the meanings the participants ascribed to those experiences (Elliot, 2005). As Riessman (1993, 2002a, 2002b, 2008, 2015) embraces the social and cultural processes that intersect personal experiences while interpreting personal understandings and meaning making, Riessman's philosophy and approach to narrative analysis was preferred as a guide for collecting and analysing the data. Riessman's approach more closely matches the research questions that explored aspects of parents' experiences with raising a child that encompass particular perspectives, beliefs and their process of meaning making as a coping response. Riessman's (1990a, 1990b, 2000) approach in narrative research portrays the events and situations that disrupt an expected life course with sensitivity and insight, which this study hoped to achieve.

Riessman (2008) calls interviews "narrative occasions" where discrete stories are produced in response to an interviewer's single questions and extend over a course of interviews (p. 23). There are allowances for the narrators to tell the story in their own ways and power shared as the script is co-created (Riessman, 2008). This study aimed to gather semi-structured narratives within and across two interview sessions; acknowledge the theoretical and epistemological perspectives of the researcher; and allow the narrator's stories to unfold naturally.

Though the intention was to also present narratives in the findings, the large number of respondents who wished to participate in this study shifted the analysis and presentation to a thematic approach. When used within the family resilience theoretical framework, thematic narrative analysis can generate significant findings, with new insights drawn from the data as common themes are identified across study participants, their environments, and their coping responses (Riessman, 2008). Thematic analysis allowed for social and psychological interpretations of the data and the flexibility to interpret semantic and latent themes (Braun & Clark, 2006). Moreover, Riessman (2008) asserts that within narrative inquiry, thematic analysis is well suited for examining and interpreting parents' everyday experiences. Analysing themes captured both the substance of parents' daily lives as well as the societal discourses on parenting and disability: "Thematic analysis can be a method that works both to reflect reality and to unpick or unravel the surface of 'reality'" (Braun & Clark, 2006, p. 81).

In summary, narratives enable researchers to understand people's lives through the stories they tell and present an authentic voice currently missing in quantitative studies. Chase (2005) states that "the stories people tell constitute the empirical material that interviewers need if they are to understand how people create meanings out of events in their lives" (p. 660). They offer rich, multi-layered descriptions of psychological and social phenomena that contextualise how the parent, as a narrator, is experiencing the stressors within their family life (Jossleson, 2006). Bruner (1990) asserts that a narrative is "one of the most ubiquitous and powerful discourse forms in human communication" (p. 77). As a researcher "being in the field, that is, engaging with participants, is walking into the midst of stories" (Clandinin, 2006, p. 47). Narrative inquiry with thematic analysis presented a method that was appropriate for understanding a population that deals with exceptional stressors on a daily basis; the barriers and constraints parents faced while managing difficult situations; and the positive adaptations they have implemented in the process of building resilience.

Recruitment and Participant Selection

A description of the study's research parameters was provided to the organisations that served parents of children with AS in the wider Wellington region of New Zealand and adverts were placed in online support group newsletters through Altogether Autism, Autism NZ, Cloud 9 and Parent-to-Parent (See Appendix B and C). The majority of the parents answered the online advert posted by Cloud 9 and a few responded to the Parent to Parent advert. I had originally planned for 8–12 families to participate and after the first day of the adverts being posted, 18 families expressed their interest to participate. I withdrew the adverts one week later after 27 families had responded directly to me by email or phone, and interviews were scheduled with those who met the inclusion criteria. Volunteers who met the following criteria were asked to participate in the study: 1) they were parents or caregivers of a child 5–21 years of age; 2) the child had a medical diagnosis of Asperger syndrome; and 3) the child was living at home. The age of five was chosen as the beginning of the age range as a diagnosis of AS is uncommon before a child starts school (Howlin & Asgharian, 1999), continuing up to the age parents are legally responsible for and under the guardianship of their child's care, that is 21 years of age. One family whose

child had recently turned 22 was included as he was still living at home and dependent on his parents. Parents needed to be available for two interviews lasting 1–2 hours each, with the follow-up interview occurring approximately 3–6 months after the initial interview. At the initial interview, an introduction letter was reviewed with each participant that described the research aims and procedures. Confidentiality and the right to withdraw from the study were discussed and a consent form signed (See Appendix D).

Sample

The sample included 19 mothers, 6 fathers (including two step dads) and 1 grandmother, who were parenting 16 boys and four girls diagnosed with AS, totaling 19 families. The ages of the children at the initial interview were evenly spread from five years old through to 22 years old. The children were diagnosed between 3 1/2 years old and just before 15 years of age. Other comorbid diagnoses noted in the study included ADD/ADHD, dyslexia, oppositional defiance disorder, epilepsy, anxiety disorder, sensory disorder and depression. There was a set of siblings both diagnosed with AS and another set where only one had a formal diagnosis; a set of siblings diagnosed with AS and the other autism, and one with AS and the other diagnosed with PDD-NOS; and one set of twins with one sibling diagnosed with AS. Four of the mothers were divorced and 16 were living with spouses or partners, and three of those mothers were in relationships where the father traveled extensively. Nine parents were born overseas and one parent and two children had iwi affiliations. The participating families represented a diverse range of socio-economic levels.

Parents in this study were eager to participate and shared their experiences openly. A few commented on how cathartic it was to share their stories and several hoped that participating in the study would improve the experiences of other families raising children with AS.

Data Collection

Interviews. The majority of the interviews took place in the parents' home. For reasons of privacy or ease, three parents chose to meet at my home and one parent chose to meet at the university. There was recognition of the home environment as a representation of personal space that functioned as a valuable place to experience

their lives. This approach helped me as a researcher to "think and observe narratively" (Polkinghorne, 2010, p. 396). Care was exercised to schedule interviews at a time that was convenient for the participant and interviews were rescheduled if the participant had a conflicting commitment arise.

Two in depth, semi-structured interviews were conducted. The initial interview lasted approximately one to two hours and the follow-up interview covered 30 minutes to 1.5 hours. The semi-structured format enabled participants to choose what was significant to share and to elaborate within the parameters of the suggested topics. This qualitative approach has the potential to capture the multidimensional and idiosyncratic nature of families (Cridland et al., 2014). Interview questions were chosen to align with the primary research questions investigating parent experiences, coping responses and resilience building. The questions were generally open-ended, such as "Tell me about your child" or "Are there any particular times that stand out for you as a parent?" (see Appendix A for a complete list of the questions). I studied the questions, study rationale and objectives before each interview to allow for a more natural exchange and improvisation during the interview process (Wengraf, 2001). Not all of the questions were asked of all of the participants, nor were they asked in exact order, making allowances for the participants' narratives and responses to develop spontaneously. When needed, I followed Riessman's (1993) approach by asking if the participant could tell me more or provide a specific example.

The follow-up interview was conducted approximately five to six months later to allow time for the first interview transcripts to be transcribed and analysed. This analysis provided a framework for the follow-up interview. The follow-up interview helped to clarify initial interpretations and gain a fuller understanding of the experiences parents shared. After the preliminary analysis of the initial interview, a list of potential questions was generated to explore the challenges parents had identified; the phenomenon of turning points; and parents' coping processes. Parents were encouraged to share any additional reflections and new stories as appropriate. Three participants (one couple and the grandmother) who had participated in the initial interview did not take part in the follow-up interview, and one participant withdrew citing confidentiality issues.

A concerted effort was made to build rapport during the interviews so the participants felt comfortable sharing their personal experiences. It was critical to

listen attentively and without judgement, along with a sensitivity and awareness for the challenges and difficulties being described (Polkinghorne, 2007). Allowance was made for the story to unfold according to the narrator's intent and there was freedom for the participants to choose which events and situations were memorable to them. All meetings with the participants were audio recorded.

Field notes and transcripts. Field notes were written immediately after each interview concluded. This would contribute to the "fullest possible record of what happened" and become an integral component alongside the transcripts during the data analysis (Wengraf, 2001, p. 142). Writing field notes directly after each interview captured impressions of our interaction, descriptions of the surrounding environment, and my initial observations of the interview process before they were lost. The field notes were also a means to note down comments participants made after the audio recording had finished that were pertinent to the study. In addition, I kept a reflective researcher journal throughout the interview and data analysis process.

The audio tapes of the interviews were transcribed verbatim and pseudonyms assigned. All transcribers signed a confidentiality statement (see Appendix E). The participant's transcripts were then entered into NVivo® 10, a software programme chosen to assist with the quick retrieval of data, link field notes, marginal notes and interview summaries to the transcripts, organise thematic groups, and create tree diagrams for further analysis. As an organisational tool, NVivo® 10 provided a means to code and categorise data in an efficient and consistent manner. It allowed me to effectively manage the volume and density of narrative transcripts for the reading, coding, analysing, summarisation and writing up stages in a more methodical and thorough manner (Bazeley & Jackson, 2013).

Data Analysis

The data analysis began with the belief that the parents' stories reflected a genuine interpretation of their experiences and contained valid points of view for the situations they described. For the first phase of analysis, I read the parents' accounts and noted the circumstances surrounding them, developing a general impression of the narration and the significant aspects of the stories (Braun & Clark, 2006). This helped me become familiar with the data. After this initial immersion, I wrote summaries of my impressions and linked these to the pertinent transcripts using

NVivo® 10's cross-referencing capability. For the second phase, I read systematically through all of the data again, using an inductive approach to identify significant themes and multiple meanings and concurrently recorded my notes and questions (Braun & Clark, 2006, 2012; Charmaz, 2006; Thomas, 2006). Codes that described a singular aspect were assigned to each pertinent segment. Numerous codes were generated from the interview data during this phase. Data segments often contained more than one code; a few segments did not have codes assigned if that segment did not directly relate to the research questions. A successive reading in the third phase refined and consolidated the codes as similarities and counter-examples were noted. As I identified patterns and recognised relationships between the codes and themes, I designated themes and sub-themes. This stage of analysis centred on semantic themes and progressed to a detailed theme description for the fourth phase. I wrote clear definitions and selected appropriate examples to represent these themes (see Appendix F for a sample of initial code definitions). I systematically reviewed these as additions and deletions were made, fitting the codes into an evolving conceptual structure and then finally into a tree diagram to show hierarchal relationships (Miles & Huberman, 1994).

After identifying all possible semantic themes, I looked for latent themes to "examine the *underlying* ideas, assumptions, and conceptualizations – and ideologies that are theorized as shaping or informing the semantic content of the data" (Braun & Clark, 2006, p. 84). I searched for what the story was *about* and the meaning the narrator intended to communicate, which was or was not explicitly stated (Mishler, 1986). I practiced a constant comparison and recursive process that entailed moving back and forth between the two interviews, and then throughout all the interviews, continually adding and refining codes, themes and concepts with detailed memo writing (Lincoln & Guba, 1985). Coding stopped when saturation was reached and subsequent readings did not reveal any new conclusions. In phase five during subsequent readings and rechecking, themes were collapsed, definitions further refined, and examples re-evaluated, with sub-themes integrated into a main theme when appropriate (see Appendix F for an example related to the development and integration of the code for *belonging*). If a sub-theme did not pertain to the research aims or questions, it was set aside at this time.

It was clear after the data analysis that the overarching theme of parents' experiences related to the *challenges* they faced with four categories of challenges

noted. Parent response and adaptation to those challenges included five categories under *building resilience* (see Appendix G for an example of thematic narrative analysis for one couple's narratives). Within each final thematic category there was both internal homogeneity and external heterogeneity, that is, the data within the themes shared meaningful and sound features, and the themes were clearly distinguishable from each other (Patton, 1990). These final themes present a comprehensive, robust and detailed picture of parent experiences raising a child with AS in New Zealand. Parent experiences were characterised by the following: challenging aspects associated with Asperger syndrome, challenges to understanding and acceptance, challenging interaction with education staff and health services, and challenges to family dynamics and work responsibilities. Parental coping responses included turning points, meaning making, developing resources, planning ahead and solving problems, and strengthening intrapersonal assets (see Table 2 for theme summary).

Table 2

Theme Summary

What are parents' experiences raising a child or children with Asperger syndrome, an autism spectrum disorder?

Challenges

1) Challenges associated with Asperger syndrome
    a) Self-regulation problems – child became upset quickly and/or demonstrated angry and violent behaviour
    b) Obsessions and compulsions inhibited interaction
        a. Special interest intensity
    c) Social skill challenges
        a. Difficulties understanding emotions in themselves and others
        b. Theory of Mind impediment
    d) High rates of anxiety, fear, worry, and depression for children with AS
    e) High sensory sensitivities
    f) Child's world perception unexpected
    g) Development did not fit a 'norm' for neurotypical or children with AS
    h) Inflexible, unreasonable and unpredictable behaviour
    i) Executive functioning difficulties – starting and completing tasks, remembering and following multi-step directions, planning and organising, and self-monitoring
    j) Comorbidity diagnoses complicating AS presentation
    k) Longer time necessary for all school transitions
    l) Intensive demand on time and effort needed by parents to teach skills, such as social nuances; preparation for new situations; prevention of sensory overload
    m) Difficulties with coordination influenced ability to dress and eat independently, manage handwriting tasks at home and school, and participate in sporting activities
    n) Desire to adhere to routine for child with AS which in turn influenced family routine
    o) 'Invisible' aspect of AS in public; duality between child's behaviour at school and at home

2) Challenges to understanding and acceptance
    a) Lack of awareness, knowledge or familiarity about AS
        a. Public embarrassment and withdrawal
    b) Lack of acceptance
        a. Bullying at school
        b. Child has no or few friends

   c. Parents worried about child's future regarding employability, independence and relationships
  c) Lack of tolerance and empathy
   a. Judgment
   b. Decisions regarding disclosure – potential for stigma and privacy issues

3) Challenges interacting with health and education services
  a) Large number of specialists and medical professionals involved
  b) Tenuous partnerships
   a. Lack of respect or acknowledgement for parents' expertise or consultation
  c) Health and education systems not delivering appropriate and timely support
   a. Family financial costs associated with raising a child with AS
  d) Long medical diagnostic process

4) Challenges to family dynamics and work responsibilities
  a) Conflict with siblings
   a. Expectations regarding fair discipline
  b) Conflict with partner
   a. Single parenting challenges
  c) Conflict with outside work

How do parents respond to and cope with the particular challenges raising a child or children with Asperger syndrome, an autism spectrum disorder?

Building Resilience

1) Turning point experiences
  a) Finding a diagnosis
  b) Coming to terms
  c) School breakthroughs
  d) Gaining independence

2) Meaning making
  a) Acceptance
  b) Positive reinterpretation
  c) Making sense of the origins of AS
  d) Comparison
  e) Reconceptualising 'normal'

3) Developing resources
  a) Researching information and securing help

b) Seeking social support from family, friends, and other parents of children with ASD

c) Advocacy

4) Planning ahead and solving problems
   a) Stepping back

5) Strengthening intrapersonal assets
   a) Self-efficacy
   b) Positive outlook
   c) Sense of humour
   d) Patience
   e) Perseverance

Presentation of Findings

The themes that appeared repeatedly in an individual's interview and also across several participants were noted, alongside the intensity that it carried for families. Riessman (2002b) calls this themal coherence, or when "particular themes figure importantly and repeatedly", contributing to the validity of the narrative data (p. 260). For example, most of the families spoke of their child's characteristics that inhibited social interaction, such as being quick to anger, their obsessions, and their poor social skills; a few families related strong emotional experiences of the adverse effects of stigma and outside judgement. The final arrangement of themes reflects this consideration of frequency and intensity. As a predominant feature in parent experiences that captures both frequency and intensity, the challenging aspects associated with AS are listed first, with their child's self-regulation being the most problematic down through to the 'invisible' nature of AS, followed by challenges to understanding and acceptance and so on.

An effort to present quotes and excerpts within the appropriate context and in large enough detail to prevent misinterpretation was made. The majority of the quotes are presented verbatim, unless there were excessive utterances that could overly distract the reader from the core meaning and the flow of the excerpt, such as "you know", "like", "yeah", and "ummm". My intermittent responses of "okay" and "yeah" were also removed to avoid interruption.

Acknowledging Researcher's Role

Reflexivity, or a thoughtful consideration of the impact of my beliefs, background, social class, age, ethnicity, cultural orientation, education, and status as researcher was critical throughout the study (Bold, 2012; Etherington, 2007; Gilgun, 2012). I needed to actively reflect on the "intertwining" of myself with the participants and their stories as they unfolded; how it shaped my interpretations; and how it changed over the course of the study (Peshkin, 2000). During the narrative inquiry process, it was imperative that I acknowledge the "inherent subjectivity of accounts, recognizing the positionality and personal characteristics of the researcher" (Josselson, 2006, p. 6). Yow (1997) describes the possible intersections of interviewer effects:

[These] include motives for doing the project, feelings about the narrator, interviewer's reaction to the narrator's testimony, and intrusion of the interviewer's assumption and of the interviewer's self-schema into the interviewing and interpretive processes. (p. 56)

Thomas (2006) states that when determining what is or is not important, the researcher's assumptions and experiences shape the findings. I actively questioned my intentions, interpretations, and decisions throughout the study to weigh their influence during the process (see page 163 in Chapter 8 for journal excerpt).

The method of thematic analysis I used entailed a reflexive and organic evolving process as detailed by Braun and Clark (2006, 2012). This was particularly true during phase four when themes were moving into conceptual categories, and latent themes and meaning were explored. Peshkin (2000) iterates that "interpretation is an act of imagination and logic. It entails perceiving importance, order, and form in what one is learning that relates to the argument, story, narrative that is continually undergoing creation" (p. 9). Keeping an open and reflective mind, writing rationales for my decisions and discussing my point of view with my supervisors were methods I used to recognise my role in the process.

Clandinin (2006) speaks of narrative inquirers shaping and being shaped by the landscape. I needed to contemplate my own stories and how it enabled and constrained my ability to understand what the participants were saying (Sparkes & Smith, 2012). Ezzy (2010) cautions that as a researcher I must "explicitly acknowledge that embodied emotional orientations always and inevitably influence the research process and to engage these in dialogue" (p. 169). I kept a reflective journal to document theoretical assumptions, perspectives and interpretations throughout the research process (Cathro, 1995). A transparent reflection helps to identify my own values and beliefs and recognise the multiple layers of interpretations and perspective in the text between myself and the research participants (Morton, 2006; Ponterotto, 2013; Trahar, 2009). Furthermore, I recognise that in undertaking narrative inquiry, I have changed as a result of the relationship between myself and the parents that participated, during the interviews and after as I read the transcripts, analysed the data and wrote the findings. Therefore, meaning has developed collectively (Pinnegar & Daynes, 2007).

Validity

The telling of a story is an interpretive process where one's life is reconstructed for the listener (Bruner, 1995). The story is not a recount of life as lived, but captures instead the vividness of lived experience (Berger & Quinney, 2004). This research takes a subjectivist stance where reality is socially constructed and where there are "multiple meanings of a phenomenon in the minds of people who experience it as well as multiple interpretations of the data" (Ponterotto, 2005, p. 9). According to the social constructivist perspective, meanings are not implicit in the data, but rather are constructed through the values, philosophies and ideas that the researcher brings to the data (Crotty, 1998).

Riessman (2002b) suggests there are at least four ways to consider validity in narrative accounts: persuasiveness or plausibility, correspondence or member checking, coherence, and pragmatic use. I endeavoured to select descriptive and compelling examples from the parents' narratives to create a comprehensive picture for the reader and make robust connections between these examples and the theoretical framework. Polkinghorne (2007) contends that since storied descriptions are not a mirrored reflection of their meaning, there are four challenges to their validity during the research process:

> (a) the limits of language to capture the complexity and depth of experienced meaning, (b) the limits of reflection to bring notice to the layers of meaning that are present outside of awareness, (c) the resistance of people because of social desirability to reveal fully the entire complexities of the felt meanings of which they are aware, and (d) the complexity caused by the fact that texts are often a co-creation of the interviewer and participant. (p. 480)

As Polkinghorne succinctly addresses the factors that can influence the soundness of personal narratives, I endeavoured to do the following in regards to the four challenges stated above: a) listened attentively and asked further questions when appropriate to explore and expand a layer of meaning, and looked for recurring themes within the same interview to capture the complexity and depth of experienced meaning; b) allowed adequate time for reflection during the interview, submitted questions to the participants by email a week before the follow-up interview, and scheduled the follow-up interview an adequate time after the first interview to allow a

longer time for reflection to "deepen their subsequent responses" (Polkinghorne, 2007, p. 482); c) met the participants where they were most comfortable, such as in their own homes or in another location if they desired, explained the aims and objectives of the study to the participants, strove to establish a comfortable rapport during the interviews by interacting in a genuine and sincere manner, and listened to and studied the stories without judgment and an awareness of the difficult nature of parenting a child with AS; and d) identified my values, motivations and biases regarding the study and kept my responses brief during the interviews so that the story was primarily the participant's creation. I acknowledged that stories are socially created and that a "greater recognition of the importance of the relationship between the storyteller and the audience, and between the knower and what is known" is necessary (Etherington, 2007, p. 600).

Clarification and feedback was sought with the participants during the follow-up interview for descriptive and interpretive validity. This verification helped to serve as a member check, improving credibility (Leech & Onwuegbuzie, 2007; Polkinghorne, 2007; Thomas, 2006). Clarifying whether the initial interpretations reflected an accurate picture of their experience contributed to the trustworthiness and validity of the data (Lincoln & Guba, 1985). Opportunities for parents to elaborate throughout both interviews was given and parents were asked at the completion of each interview if there were any additional comments they wished to make regarding parenting a child or children with AS. Transcripts were available for input if desired and participants were invited to send additional feedback via email during the data collection phase. A few participants sent additional information via email after their interviews which were linked to their transcripts.

Braun and Clark (2006) measure validity by how well the individual themes relate to the data set and how the meanings of the entire data set are reflected in the overall thematic categories. This was accomplished through careful re-reading of the transcripts, refinement of thematic categories, studying field and summary notes and reviewing my journal. I met regularly with my supervisors during the analytical phases to discuss several aspects of the data and procedures such as coding, theme development, and writing concise definitions. Transcripts and examples from the interviews were analysed together to ensure that the conclusions being reached were consistent, sound and thorough. Lastly, inclusion of extensive excerpts and quotes

from the participants provides opportunities for readers to analyse and assess the interpretations independently (Polkinghorne, 2007).

Ethical Issues

Ethical issues were considered throughout the study. I made the decision to schedule interviews with all of the parents who had responded to my advert in good faith, though this number was approximately twice what I had initially planned. An acknowledgement of parents' limited time for outside commitments meant limiting the interviews to two sessions and the interview sessions to 1–2 hours, plus travelling to their homes unless they desired otherwise. If a topic being discussed caused a strong emotion then I took extra care to listen thoughtfully and empathetically; slowed the interview's pace; and rearranged or put aside certain questions. The majority of the interviews involved reliving difficult and frustrating experiences from their past, stressful circumstances in their present, and anxiety regarding their child's future. Parents shared several stories that were of an intimate and sensitive nature, and many mothers and I were moved to tears during the interviews. I made a conscious choice to end the interviews when the parent became weary or when our conversation reached a natural conclusion, and after the interviews ended we conversed in a more relaxed and casual manner for a short period of time. There was an open invitation for parents to send any additional thoughts by email if they desired, which a few chose to do so. Parents' openness and strong desire to help other families by participating in this study meant additional care needed to be exercised to protect their trust in the research process. Excerpts quoted throughout the thesis were carefully chosen so they did not reveal anything of an especially private nature. I strove to be respectful towards the participants' culture, religion and social status. For example, I asked participants to clarify or elaborate on their perspectives of raising a child with AS to provide a fuller meaning and understanding of their beliefs, and strove to include a diverse representation of these experiences and perspectives in the presentation of the findings.

University procedures were followed for full approval by the Victoria University of Wellington Faculty of Education Ethics Committee. The research's purpose was posted through the online adverts and explained in detail before the interviews began. Voluntary written consent was obtained for all participants in the study and all

participants had the right to withdraw through to the completion of data collection. When one participant withdrew after the initial interview, all identifying information was removed as requested. Participants were encouraged to have a support person present if desired and contact information was given for the chair of the human ethics committee if ethical concerns arose for the participants. Interviews were audio recorded and stored in a secure place without direct identifying information. Pseudonyms (see Table 3) were given to all the participants and all transcribers signed confidentiality agreements.

Table 3

Participants' Pseudonyms with Children's Gender and Ages

Abbie, 15-year-old son

Allison and Jeffrey, 14-year-old son

Anne and Evan, 7-year-old daughter

Camille, 17-year-old daughter and 13-year-old son

Erin and grandmother Neva, 5-year-old son

Eve, 16-year-old son

Gayle, 17-year-old son

Grace, 22-year-old son

Juliana, 11-year-old son

Kathryn and John, 22-year-old son

Leah and Brett, 10-year-old son

Liz, 19-year-old son

Natalie and Leo, 17-year-old son

Rita, 9-year-old daughter

Sandy and Ian, 12-year-old son

Susan, 10-year-old son

Tanya, 13-year-old daughter

Tessa, 13-year-old son

Yvonne, 14-year-old son

Chapter 5

Findings: Challenges

"…you don't know until you live it; *thinking* you know is different to knowing". (Tessa, 13-year-old son)

The next three chapters detail the findings from this study and cover challenges, turning points and building resilience. The headings in these chapters will align with the themes noted in the thematic summary (see Table 2). As mentioned previously, the arrangement of these themes reflects the frequency and intensity these challenges had for parents, starting with the themes mentioned most frequently; it also influenced the depth of material under each heading, for example, it could reflect an intense experience for a few parents.

In this study, narratives of parents raising a child or children with Asperger syndrome revealed stories primarily consisting of challenges: the challenges associated with Asperger syndrome; challenges arising from a lack of understanding and acceptance of AS; challenges interacting with health and education services; and challenges to family dynamics.

Parents identified numerous challenges in the first interview, hence in the follow-up interview they were asked to identify what they considered to be their *main* challenge parenting a child or children with AS. In many cases, the challenging aspects identified by parents were interconnected. For example, at home and in the community, a lack of awareness about AS compounded the behavioural aspects that were challenging, such as the child's high sensory sensitivities, strong desire for routine and/or angry behaviour. At school, social skill challenges led to a child's vulnerability to bullying that then created tenuous relationships between home and school. Furthermore, a lack of understanding, tolerance and acceptance of children with AS permeated throughout the stories shared.

> I think the main challenge, I had a long think about that because there's lots of different challenges, but I think one of the main challenges I found is getting other people to *understand* it…I always thought that, that above all things…especially getting other people's children to understand it, because they would just see a weird child who's good at being teased,

and good for a target, he might as well have had a target painted on his back, and getting other people's parents to understand that he wasn't trying to be mean…he didn't have this nasty streak, that he wasn't out to target their child or whatever, that kind of getting acceptance from other people, and we've had a few people in our lives who have been accepting of him, and they've stayed our friends, and other people will come through and find he has a wobbly one day in front of them and they can't cope with it at all…and also one of the main things that's tied into that is getting the right school teachers, because if you get the right school teacher the year is fantastic; if you get the wrong school teacher and *boy*… (Allison, 14-year-old son)

Three quarters of the families stated that the characteristics directly associated with AS contributed to the main challenges they faced daily, followed by the majority declaring a lack of understanding and acceptance as a major concern. Almost half of the parents identified the interaction with health and education services as the most challenging for them, and lastly, a few of the families said their primary challenge was striving to maintain healthy family functioning.

Challenges Associated with Asperger Syndrome

The challenges most often identified in the narratives were those directly connected with Asperger syndrome. The most troublesome challenges were those that revolved around the child's behaviours. For example, the child became upset quickly, or was anxious, angry, or violent; exhibited obsessions and compulsions inhibiting interaction with others; or showed inflexible, unreasonable and/or unpredictable thinking. High anxiety and depression, along with sensory sensitivities, such as aversions to certain foods, light, clothing, and loud sounds were problematic. Social skill challenges caused considerable difficulty, such as the child not predicting another person's thoughts or intentions, as well as their self-centredness and a lack of reciprocity. The invisible aspect of AS created problems in public when inappropriate behaviour occurred, and the child's unusual and unexpected perception of the world was confounding. Lastly, parents needed additional time and effort to parent their child with AS, for example to teach the needed social skills and to prepare for outings.

Self-regulation problems. The most challenging aspect associated with AS was when their child became upset quickly, sometimes leading to angry and violent

behaviour. Erin said her five-year-old son was aggressive, lashed out, and did not understand consequences or emotions. Sandy, a mother of a 12-year-old son, related a similar story:

> That was really difficult, those probably from age of two and a half to five, six when he was so physical, he didn't know where to exert that energy and it wasn't okay to pick up furniture and throw it at people, or to belt the hell out of your brother and bite him, all those other things.

Sandy said her son would get exceedingly frustrated:

> …he'd get very angry, he'd know where a piece of puzzle would fit and he knew it went in there, great big chubby hands and a small puzzle piece, you could see him and then he would scream and the puzzle would go flying, and all hell would break loose.

Sandy was perplexed about her son's behaviour as it was so different from the other family members and it took a toll on the family dynamics. She said, "Everyone is like walking on egg shells around [him], tread carefully". The strife in the home affected her husband's mood when he returned home from work and relationships between the other children. In another part of Sandy's story, she recounted how her son came home from school one day "like a soda bottle and exploding" and "he was coming in and banging his head, all the head banging started again against the walls, the whole hate me, hurting his arms, biting himself".

This story of her child's afterschool behaviour is indicative of several other families' experiences as their children tried to physically relieve the pressure built up from the school day. Or the child might relate his or her day in its entire length, with Leo stating for their family "this is not a 10-minute talk, this is six or seven-hour talk". When Leo and his wife tried to shorten this or stop it from going into the late hours of the night "it caused a lot of anger and screaming and shouting, doors slamming". Often the mother was on the receiving end of the child's frustration and confusion. Ian explained that Sandy was on the 'front line':

> …the first port of call for all you know, everything he wants to tell from the day…he'd remembered everything in sequence, so he, if an incident had happened he will remember it, he'll store it in his memory, but has no one to tell, so he waits to get home and tell his mother exactly, from the whole day, no interruptions, it has to be, has to all get out in one go, so this is

how I would learn, oh, little by little I'd understand how her day would go, because I'd just come home from work.

Tanya, mother of a 13-year-old daughter, recounted her daughter's violence after returning home from school:

…when she was going through all this stress at school, all the stress of having to go to school and not wanting to and she became very aggressive, very aggressive. Like she would be kicking me, punching me, kicking and bailing me up screaming. It was a nightmare. Well, it was living in an abusive relationship...

Some families recounted hurtful statements their child said to them, such as "'I don't love you', that was the latest thing the last couple of days" and "if she thinks it, she'll say it" (Rita, 9-year-old daughter). Tanya related the following observation about her daughter's self-regulation challenges:

I've definitely learned not to take it personally, I've just learned that it's, I guess it's her behaviour, the way she deals with the feelings, yeah, of being angry or anxious, being able to come out…that has actually been a challenge, because it used to get, especially if she chose 'I hate you Mum' and I guess most children say it and you think ah, but when she keeps saying it you go, I used to get upset and now it's like, no that's just her you know…it's funny you can watch her, like it certainly is like a light switch, when you turn on the light, well, it's just an instant anger that will come over her, and her whole face changes and stuff and it's just like, 'Hello, are you in there?' sort of thing, and once she's got all of that out then she'll usually – like the light switch – *gone*, anger's gone and it's 'oh, yeah'.

At the follow-up interview, Tanya added:

…her tantrums that she was having, definitely aren't anywhere like, it's been a long time since she's hit me or pushed me, or barrelled me up and I'll just get the swearing really, I'll just get the swearing and name calling.

Dealing with angry children was stressful for families and challenged their patience, health and relationships.

Yeah big meltdowns, slamming of doors and screaming and shouting, blood pressure going up. It can get quite out of hand, which is not enjoyable. As he's getting larger, he's very strong, very physical and he

says things, whether he means them or not, they're extremely hurtful…
(Jeffrey, 14-year-old son)

Parents explained that their children almost have dual natures. They can be "a little angel at school and a devil at home" (Sandy) or easily upset after a long calm spell. Eve said her 16-year-old son has "quite a soft nature, but when he has a meltdown it's overwhelming for him as well as for me", and he can become "almost frighteningly angry" very quickly. Camille described her 13-year-old:

> …he is a smart kid, he is quite polite, he's got quite an endearing and engaging personality but if he gets wound up or upset, feels threatened in any way and starts to have a meltdown he will lash out.

She continued:

> [He] has had a lot of behavioural issues at school with hitting other kids and so some of that is dealing with that and the disappointment that goes with that, the emotion that goes with that, that your child is doing these things and that you've got to kept fronting up, supporting them, but explaining and not humiliating, but it's hard.

Allison related this story about her son's quick temper:

> He would break things, throw things, hit, punch, kick other children if he was aroused and it was discovered quite early on that he had this volatile temper and I think children as young as about four had discovered that if they pushed his buttons they would get this amazing volcanic reaction which was very gratifying for other children but appalling for us.

There are stories of their children hitting or lashing out at school staff when the child felt threatened and then being stood down from attending school for an extended time period. This resulted in parents being called to school for repeated meetings and rearranging work schedules to accommodate a child out of school. Mothers also had to monitor sibling interaction at home if there was the possibility their other children or their children's friends would be hurt. One mother reported an episode when police were called to protect other family members from her child.

Many parents spoke of their child's other diagnoses that presented additional behavioural and emotional challenges. These might have been given before and/or after the AS diagnosis. The comorbidity diagnoses specified included oppositional defiance disorder, attention deficit disorder, attention hyperactivity deficit disorder,

anxiety disorder, and depression. Yvonne, mother of a 14-year-old son who had been diagnosed with AS, ADHD and oppositional defiance disorder, had recounted times when he had hurt animals, his siblings, cousins, other children, teachers and himself. She thought her main challenge was "the amount of apologies I have to make…there's damage control, risk mitigation and mitigating *all* the risks…"

It was clear after analysing the narratives that their child's self-regulation problems, both inside and outside of the home, had caused considerable stress and worry for families in conjunction with significant management challenges for parents during and after disturbing events.

Inflexible, unreasonable and unpredictable behaviour. Camille shared that unpredictable behaviour meant "the next one is probably not far away; the only unknown is how long it's going to take before it surfaces". Kathryn and John's experience was similar: "It's very hard to be ahead of the ball, isn't it? It really catches us every time". Unpredictable behaviour is especially challenging for families and threatens their ability to function well in a consistent fashion. Brett elaborated about his 10-year-old son's changeable nature:

> …he would have days where he'd just go, everything would go balls up and on those days where everything would go balls up, his mum had enough of him, and it's just all the pressure from being, from being exasperated about his behaviour and that sort of thing, cause it had all been boiling up to that point.

Behaviour that parents viewed as unreasonable was particularly difficult for parents as well. Rita shared her main challenge parenting two daughters on the spectrum:

> Their behaviour really…and not really understanding…like just trying to get her into the bath and then trying to get her out of the bath, it was a fight to get her in there and she loved being in there but then it was a fight to get her back out again… the normal things that should be easy are not easy.

> … they're the things that sort of trip me over cause I would not anticipate them being a problem, they would be a problem and then I'd get really frustrated. It was like 'What's the matter with you?' It's like, I mean, what's the matter with *me*, you know, this should be simple.

She said her daughters' behaviour was continuously capricious – they would be playing and "then all of a sudden it's just disintegrated and then they're screaming in tears at each other. And you can't stop it, it happens every day".

The teen years amplified the difficult behaviours of unreasonableness and inflexibility. Tanya explained: "the stubbornness, the anxiety…that's a major one, and the whole not being able to reason with them, no reasoning with her". Jeffrey, father of a 14-year-old, shared a similar sentiment:

> …the biggest difficulty that we're having is him not wanting to follow instructions, if he doesn't think they apply to him or if he thinks that he's better than them, or if he can't see a reason for them, the fact that we've got reasons that he doesn't agree with well, 'I'm not going to do it', that's very difficult, and also him trying to be the parent, he isn't and we don't want him to be, but he tries to take that role, and no matter what we say, he doesn't agree with it.

Brett recounted the difficulties with his son's headstrong, inflexible behaviour:

> …he always wants to finish what he started, like if he's got a sentence or he's saying something particularly ridiculous, and we tell him to stop, he's got the compulsion to finish that sentence even though we've told him that it's totally wrong, and he's just making up stuff right now…he's got in his head that something is this way, and that's his little world, and he's very intractable.

Obsessions and compulsions. Obsessions and compulsions, coupled with a child's intense interest in a particular subject made life particularly difficult for parents. Tessa affirmed that her 13-year-old son's obsessions "can dominate the whole family":

> …his mind races, is how he explains it, and then whatever obsession is on the mind, you know, thinks about how he can get it, how he can do it, 'Ah mum, if I be good at school can I get such and such?'…it just jumps from one thing to the other and he'll come up and wake you up at midnight, 'I just wanted to tell you…'

Some of the families related stories of their child asking questions relentlessly throughout the day, taxing their patience with their sheer number; asking the *same* question repeatedly; or asking questions during a television programme or movie when other family members wanted to watch:

> …it used to be really hard when…he always asks questions that he knows the answers to, he…throws things into a question instead of a statement and so I would be asked 200 – 300 questions an hour it would feel like, and you couldn't, you couldn't short change him with the answers, he just wanted it again and again and again. So I found it really demanding, it's got easier just as he's got older and we, well I suppose what we did was work out routines so we, we could agree that he would ask, he could ask me the questions, say at bedtime or where he wouldn't ask it for another half an hour. So he got on to, he got on to clock watching a lot…so it was that incessant need for the whole verbal thing from me that is the most exhausting. (Juliana, 11-year-old son)

Parents reported that their child's obsessions or preoccupation with their special interests could be short-lived or be stretched over long time periods. Regarding her 10-year-old son, Leah said "you've got to keep on your toes because you don't know what he's obsessing about this week…he's very changeable and it's really hard to keep your finger on what he is [into] this week". The mercurial aspect of their child's obsessions perplexed many of the parents in this study.

High rates of anxiety, fear, worry and depression. Parents reported struggling with their child's high anxiety and irrational fears:

> …he went through an intense weather thing, he'd get concerned if there was a lot of heavy rain that it would flood in the night when he was asleep. So before he went to bed we'd be out in the dark with the torch and we'd be saying, 'See the water's not pooling, [it's] draining into the soil. And if it did pool and start lapping up against the door we would know that and what we would do then'. And then he was okay. (Susan, 10-year-old son)

This mother, as well as others, reported that science discussions at school, such as ones on volcanoes, earthquakes or germs, could heighten their child's fears. Worries would then dominate their child's thoughts and influence their ability to function well at home and at school. Sometimes the anxiety would not manifest itself outwardly until four to six weeks after the lesson. Susan said when her son "started learning about super volcanoes…and all those things, [now] he's *never* going there, he would like to go there, but he's too scared to go there". Parents shared stories of their child's anxiety steadily increasing as they advanced in school, until it became very difficult to convince them to attend.

Many of the families shared personal stories of their child's depression.

> From about the age of four he started verbalising that it was too difficult to be alive, he would rather be dead, and when things went wrong he would go off wailing that he would like to kill himself and be dead; at the age of four, it was heart-breaking. (Allison)

There were numerous examples in parents' narratives of their child's depressive behaviours, for example self-harming at a young age, threatening and attempting suicide, withdrawing from daily family activities and dropping out of school. These episodes sent families into crisis mode and mental health agencies often became involved for a short term. Their child's depression and behaviour added enormous stress as parents tried to manage its effects and prevent reoccurrences.

Social skill challenges. The difficulty of their children trying to make sense of seemingly random, confusing and illogical social rules caused great consternation for parents, especially regarding their child's attempts to make friends.

> …she doesn't like change very much, but she finds it really hard to make friendships, like she really wants to make friendships but she just struggles to go through the process of making them…she's unhappy because she's got no friends and everyone's mean to her…but if she could be at school with a little friend and actually feel like there's somebody loves me at school and I've got a friend, it would make her happy…whatever makes her happy makes me happy. (Rita)

Mothers expressed frustration when their child did not recognise emotions in other people, especially them.

> I have to make it very clear to him how I am feeling, he doesn't understand sometimes, he'll just do something or say something and I have to say to him…sorry I don't like that, I find that insulting or I find that – without turning him off… (Grace, 22-year-old son)

Embarrassment occurred when their child expressed outright what they were thinking without tempering it for the listener's sake, such as commenting on a grandparent's weight or age in front of them. Taking conversation literally also created problems:

> [The teacher] went into the class and [said] 'Turn to page 42'. So [my son] does and then he starts talking. 'Have you done what I've told you to do?' 'Yes'. 'Well, why aren't you reading the page?' 'You haven't told me

to'. 'Don't be cheeky'. 'I'm not being cheeky'. 'You really do need to pull your socks up'. So he bends down and pulls his socks up. 'Get out!' …so he's gone, and he's upset, he slams the door because this [teacher] has just gone at him, then another phone call, 'Come and get him'. So those were the sorts of things we were getting… (Abbie, 15-year-old son)

A few parents stated that a "lack of reciprocity" was their main challenge. Eve said, "I can go to the end of the world to give out and then there's nothing coming back". Her children's lack of sensitivity or acknowledgement about her needs troubled her. Sandy said "it's just exasperating sometimes because I see him improving in so many ways, but it's still a me, me, me world; it's all about me". Brett shared his frustration around reciprocity:

It's very, it's very, it can be very easy to get disheartened because he can be a lot harder to, he can be a lot harder to love than the other children, particularly because he does seem to come off as very self-centred. But then again he is, he is kind of an ambassador, so he can go up to a perfect stranger and expect them to interact as somebody you'd known for a long time.

The challenge for children with AS to interpret people's emotions or anticipate the perspectives and needs of others created additional tension in the home. Leah said "he doesn't pick up when people are really pissed off or whatever, he just kind of goes on like normal and takes things so literally".

High sensory sensitivities. Parents shared several stories that dealt with the challenges surrounding their child's sensory sensitivities. Consequently, parents strove to prepare for any circumstance that might trigger an episode. High sensory sensitivities made eating a range of foods, wearing certain clothes or going out in public problematic, so planning ahead was imperative to prevent a "tantrum or an explosion" (Susan). Rita, trying to manage two children on the spectrum, said "we just finally, just stayed home because it was so hard". Meltdowns would result after their child reached sensory overload. Susan shared this story of a public meltdown due to sensitivities to sound and crowded spaces:

…there was one at soccer practice that they, the weather wasn't a go so they had it in a hall and it had an incredible echo in this place and because the kids were excited and shrieking there actually. And [my husband] took him and I think if I'd taken him I would have seen he was

getting to that point and just taken him out, but he'd got talking and didn't notice and [our son] became very, very upset and almost hysterical I gather, and crying and 'I can't do this and I hate this and get me out of here'. And then he's horribly embarrassed afterwards because he's quite aware that, as he says, 'I've made a fool of myself, haven't I?'

Susan said when situations did not go well for her son he would avoid it afterwards – "we're starting to notice around the food issues that he will say 'I'm not hungry' and things like that". Her son told her, "I don't like eggs because they smell rotten to me, it smells wrong, I think something bad will happen if I eat them". Getting a haircut, shopping in malls, going to school camp, or needing a dark room to sleep presented complications for families. Juliana said it was a challenge "continuing with his confidence…being able to give him enough opportunity to develop...without him having a bad first experience".

Development does not fit a 'norm'. Physical, emotional and social development generally did not follow a normal trajectory. Susan's experience was fairly typical of the families interviewed:

> …he was colicky baby, very active, he's always been very thin. He walked at 10 months then ran shortly thereafter. And then enjoyed climbing everything…Like the top of that bookcase there, he'd be up there sitting on the top and trees, he'd be right up the top of them…no fear at that point. Where other kids were like kindergarten age and they're doing sort of role play playing and getting to that point where they would chat and play with each other, he was very solitary and it was all about constructing things…and now that the kids have stopped as they got older sort of 6–7–8 they stopped doing that kind of play, but just walking around and chatting sort of thing, he's wanting to do that kind of 'acting out things' play.

Some developmental areas lagged while other milestones were reached quicker. For some families, their child's accelerated intellectual development became financially challenging as they bought books, computer programmes, and extra tuition to hold their child's interest.

Leah said her main challenge was "there is no one way the Asperger's comes out". Her son's unique characteristics and the largess of the spectrum made parenting difficult for her. She expanded: "just trying to explain to someone how his brain works is probably the hardest and then you'll talk to someone else whose kids

got Asperger's and their kid's completely different". Camille had a similar sentiment: "One size does not fit all and all kids with Asperger's syndrome are not the same".

Intensive demands on time and effort teaching skills. There are several examples of parents investing extensive time in teaching skills to their children with AS. Additional time and effort was needed to teach their child self-regulation, to explain social nuances and to prepare for new situations. Some parents used bedtime to debrief the day's events with their child and give their child some insight into the social world they struggled in. Brett explained his process:

> And so we'd have talks late at night, well, when he'd be going to bed about why, about how his Asperger's had been causing problems. And I'd explain to him that it's not just the Asperger's, it's just the way that you're always going to have Asperger's. It's just *you*, you need to actually deal with that like an actor would. Like some of the time you wouldn't necessarily feel the emotions that you're supposed to feel and you'd have to sort of like fake it to just get along a bit better. I mean we all kind of fake it a little bit just so that we can be sociable with each other. And then he'd say, 'But I can't do it because I've got Asperger's' and you'd say, 'Yeah, but that's not an excuse, that's just what you've got, you've just got to live with that and, and deal with it differently than anybody else has to'.

His wife also spoke of the time investment it took to teach their son the social skills that came naturally to others so he "can to try and navigate the way the world is" (Leah). After their son acted in an inappropriate manner in public, she explained how difficult it was for him to draw on his past experience for insight:

> It's almost like every time that happens it's a completely new situation for him, so if you say to him it's bad for having done that then he'll think that it's different when he's in a different room with different people and a different food or whatever, it's completely different so it's not the same rule as before. And trying to get him to transfer things from one to the other isn't easy.

Other parents also mentioned the difficulty their child had transferring skills from one context to another. Parents invested intensive effort to teach their child the necessary skills their child needed to interact successfully in the world. As a result, Tanya replied that "definitely being able to have time out for yourself" was one of the main challenges for her. The additional time and energy needed to manage the aspects

associated with AS contributed to her weariness, a similar refrain found in several other narratives.

Challenges to Understanding and Acceptance

    Lack of awareness. More than half of the families explained that their main challenge was a direct result of people being unaware, uninformed, and/or unfamiliar regarding AS. This included themselves, direct and extended family members, neighbours, people in the community and professionals. Parents were candid about their own journey trying to make sense of their child's reactions, behaviours and decisions as they grew. This was especially true before a diagnosis was found. Kathryn and John, parents of a 22-year-old, explained that it was difficult "not understanding why he is the way he is, not understanding why he won't do things, won't perform to expectations" and "dealing with how [he] felt and viewed the world". Gayle, mother of a 17-year-old son, shared her frustration trying to make sense of her son's behaviour before he was diagnosed at age 13:

> I think for us probably the main challenge was the lack of diagnosis, like we didn't know and so it was hard to decide whether…he was being naughty all the time and [we] didn't understand that [though] some of it was deliberate, a lot of it wasn't, a lot of the behaviour…I remember saying to him so many times, 'I know where you got your stubbornness from' and 'I've got 39 years more experience on you' but, but it seemed, and I'd say to him, 'I don't understand why you just don't seem to get it'.

A lack of awareness and familiarity with AS for families and professionals contributed to a late diagnosis. Gayle said it was frustrating and challenging not knowing early enough that her son had AS. From her perspective, "most of his growing up" was already done by the time he was finally diagnosed. She was perplexed as to "why this child is so different, because he seemed and looked so normal" and why traditional parenting was not working. When a family member first suggested her son might be autistic she was "horrified" and thought that people with autism "wander around almost mute, just making noises". Her unfamiliarity with the higher range of the autism spectrum postponed her decision to pursue a diagnosis.

    After a diagnosis, reactions, comments and attitudes from extended family, acquaintances, friends, health and education staff, and the general community, made situations stressful for families and endangered important relationships. Leah

remarked emphatically "it's the *outside* that's harder". Kathryn and John related stories about misinformed attitudes from extended family members, friends or other parents – "we found it incredibly hard, people would either see [our son] as severely deformed and disabled, or they would see him as totally just like anybody else, and not give any thought for that". Stories included examples of people outside of the family not taking the stress of raising a child with AS seriously:

> …I often do feel very alone with my children being diagnosed…because it's not something that's easily understood, and people looking from the outside in see my kids and see…amazing, creative, articulate, gifted kids and how lucky am I, and okay, I'm very proud of their achievements and successes and things like that, but there really is another side to it that's very difficult, and people don't see that and don't understand it, and I think they think I am insane when I try and talk to them about it, because they think how can it be like that, it can't be like that, it doesn't look like that to us, so I do feel like I'm a little bit alone with it… (Eve)

Eve said she felt like a "minnow among the sharks" dealing with her family members on the spectrum and she struggled to find people that understood AS and her situation. Camille said, "What would have been most helpful to us? Acceptance and understanding…"

Lack of acceptance. A lack of acceptance was noted through the narratives, for both the parent and their child with AS. Due to their child's challenges building and maintaining friendships, a foremost concern for parents was their child's lack of friends. They also shared their frustration and sorrow over their children being bullied. Rita described how her nine-year-old daughter told her "I don't want to live my life being bullied".

> …she didn't have any friends and so she often wanders around the school by herself kind of like a lost sheep around the school, the teachers sort of commented on it. And then if somebody sort of came near her she had trouble relating, because her, her social skills are lagging. And so when she is trying to make friends it's clumsy and so they give up and move on because that's hard work and so she ends up being on her own.

> But sometimes they end up, you know these kids can seem so vulnerable, they can niggle and so that's what they started doing. And so they would niggle her and then they'd get a reaction and then once that happened it just was constant. And so, and she would scream for like two

hours solid and they'd have to literally drag her to the principal's office to try and calm her down and she would scream there for two hours. And like they'd ring up and say 'Please could you come get her'…

Most of the parents shared stories about their child being bullied physically and emotionally. Natalie said her 17-year-old son "pretty much stopped smiling" when he started primary school. Later, he "would say absolutely convinced, he was ugly, jinxed" and it was not until secondary school that they realised the severity of the bullying at school. The particulars in her story paralleled many others: her son showed anxiety and depression at home related to the bullying, he perceived teasing or small slights as aggressive, and she was unaware of the particular episodes or its pervasive nature. She was dismayed to find out how distressing it had been, such as "having a knife pulled on you…being hit on the head with a chair, slammed into a door", bullying on Facebook, and her son's school not taking the situation seriously:

> Part of it was, I think, also to get the school to really take notice that if there's some sort of harassment going on that it really impacted on [my son], other kids would just go 'oh', but for him it was, I guess, a lot around his perception and some of it was quite serious, if there was going to be a bicycle targeted in the bicycle area it was [his] and I do sometimes wonder whether even when he was at primary school whether he had this label on top of his head which I just couldn't get, but I think on reflection kids can tell when someone is a little bit different.

Camille said "the bullying, the baiting, the isolation, the ostracism" contributed to the main challenges for her and her children. She spoke of her daughter being marginalised because she did not "fit so easily into the norm" and she herself was never invited to neighbourhood coffee get-togethers. She hoped that her children would be able to belong eventually:

> …for them to find their place in society and [for] me that means finding a job that has a financial security, being able to live independently of us if they want to, having friends and a support network, having a sense of purpose and being able to make a contribution to society that's meaningful to them. So I guess it's what every parent wants for their child but it's just a bit more challenging.

She continued:

> …if they could just find one person that got them and, and in return so it was that companionship, that sense of somebody by your side,

somebody who wants to be with you because they like you, cause you're you, it's that kind of thing.

Describing her adult son, Grace said "what worries me is that because he has such a different personality, he's going to be treated differently". His lack of acceptance at school still affected his confidence years later:

> ...quite often he has been in a situation where he has been knocked back from doing something, simply because of how he is, how he presented as a person, and I think deep down that has had quite an impact on him, although he's not one for projecting his feelings, I think deep down doesn't mean to say he hasn't got them, and I can think of little things that have happened, although they were little things they've actually been quite hurtful to him, and I think that had built up a sort of, that would have probably had a big impact on how he felt about going to school, especially as he got older…that basically said to him 'You're different, I don't want you'.

Most of the parents expressed worry about their child's future, especially their employability, independence and ability to find and maintain meaningful relationships. Many parents commented on the possibility of their children living at home longer than usual and their children voicing a desire to live at home indefinitely. Leah remarked, "Planning to be at home forever when you're 10 is just a little bit much".

Lack of tolerance and empathy. Six of the nineteen families stated that other people's attitudes were their main challenge, especially hearing judgemental remarks regarding their parenting. Hurtful comments came from extended family, neighbours, work colleagues, or strangers. Liz, a mother of a 19-year-old son, shared this story:

> …other people's perception of the child, that's the worst thing, I don't know if I told you about that, but because they look really normal, even my neighbour said to me one day…he'd just been diagnosed with Asperger's, and she said, 'Well, we just think it's bad parenting' and I was like, you know *nothing*. I get on well with her, but I was so angry, I said 'You don't know what it's like at all, it's not bad parenting'. And that's another thing, like [my son] having meltdowns, he doesn't do that now and people just think what a brat or I'm a bad parent, that's one of the biggest challenges that people don't understand about.

Susan said that other people were "fairly judgemental we found, and so questioning your own parenting skills, which you do yourself, like wow, where have we gone

wrong here, sort of thing". Misunderstandings around the child's behaviour were commonplace:

> …I think everyone thinks he's older than he is, he's very tall for his age so when he was 3–4 and stripping off clothes, people thought he was a 6–7-year-old, and were thinking, 'Why is he doing that?' I'm like, because he's 3, and that's what 3-year-olds do. I became really defensive. I got a harder shell on me than I first did years ago. (Sandy)

Allison, who had moved here from overseas said, "I do notice we are considered to be quite hard here because we use the word 'No' and the word 'No' will get us spectacular meltdowns, he is allergic to the word 'No'". Outsider criticism was especially difficult when their parenting skills were questioned. Tessa remonstrated about "other people who don't know nothing about it, they go 'there's that weird child or that annoying child'". Grace shared these two reflections:

> …especially sometimes if his behaviour was such and people would look at me as if to say 'What sort of mother are you?' and I am thinking, 'Hey, you are not coping with it, I am, you really don't understand'. People don't, they look at what's there in front of them.

> …because your child perhaps behaves a bit differently, you know, people can write you off, we don't want to have anything to do with her, her kid's funny, that sort of thing and that does happen you know, so those are the sort of challenges that you're faced with…

Parents were at risk for public censorship when outsiders did not have a clear understanding and acceptance of AS.

Susan talked about the importance of open-mindedness when her son was not coping well in public:

> I think it's probably about tolerance, we run into a couple of times where, because these other parents know he's as clever as he is, because he's in all these extension classes, or they've talked to him and that, and then when they see him, if he's having a meltdown and not coping well, there's almost a smug kind of like 'oh' verging on nasty kind of 'yeah, look at you, you might be bright, but you don't cope' with that kind of attitude, which has surprised me because you are talking about a child, but there is that sort of, it is out there.

Grace had a similar experience with her teenaged son:

People expect a certain standard of behaviour from that age group which in certain circumstances he wasn't able to live up to and to try and get that through to people without making the Asperger's an excuse was very difficult.

She hoped in the future there would be more understanding about where her son "was coming from because he's coming from a completely different viewpoint". According to the situation, attempting to explain their children's behaviour to outsiders could be problematic. Some parents were concerned about protecting their child's privacy rather than disclosing their diagnosis and risking any stigma attached to it. On the other hand, Allison said even though other people were her biggest challenge she would "rather people knew, you know, I'm not hiding it under a rug, I'm honest about what he's got". Parents also shared stories of when they stopped trusting professionals after encountering judgemental attitudes and receiving uninformed comments from them.

A few parents pointed out that they did not have problems parenting their other children: "It was like a judgement that you were a bad parent, we didn't understand it really because we had two that we didn't have this problem [with], we weren't bad parents" (Abbie). Outside perceptions of their parenting skills were frustrating when their other children behaved in a more typical fashion:

…when they're not coping, well, they see that as being spoilt, 'oh that kid's spoilt, she's never told them no, they've not taught them how to be a good sport' and they start looking at you funny as a parent thinking you're not as good a parent as them, and I have to say my other child is completely not on the spectrum, and is quite, she goes with the flow, everything is easy for her socially, and really, we haven't done a lot to teach her that, that's actually just how she popped out into the world. (Susan)

A few parents commented on the invisible nature of AS. Without an outward sign of disability, Camille said "there is no clue to people and so people's expectations – that's the hard thing managing people's expectations".

Challenges Interacting with Health and Education Services

Almost half of the parents considered their interaction with education and health services to be their main challenge. The attitude or the "arrogance" of the schooling

system was specifically named as the primary challenge by two families. Subsequently, this had a negative influence on their relationships with school staff.

Tenuous partnerships: Parents' narratives contained recurrent examples of health and education professionals demonstrating a lack of respect for parents' collective knowledge about AS, their child's needs, and the strategies that they had trialled. Parents' concerns, desire for support and decision to pursue a diagnosis were often disregarded:

> [Our daughter] was just not coping in the classroom setting. I said [she's] been diagnosed with Asperger's, and the principal said, 'Are you sure? Girls don't get Asperger's. I think it's your personal anxiety that's traumatising your child'. The principal said this and I just stopped. I don't remember the rest of the meeting, I was just so hurt. Here I had opened up this tremendously vulnerable side of our life, and she completely dismissed it. (Anne, 7-year-old daughter)

Sandy related a conversation with her son's teacher about her son's difficulties in class:

> 'I think he's on the spectrum.' 'No he's not', I hadn't even finished my sentence and she said, 'No he's not'. I said, 'Well, he's in the middle of being diagnosed at the moment'. It was a long process, it took forever…I didn't say it out loud, but you've only been teaching him for a couple of months, I've been his mother for eight years.

Sandy remarked her son's teacher "was just straight, like slam the door in your face, she didn't even want to know about it". She also noted, "teachers really don't like parents telling them what their child is or isn't".

After families finally obtained an official diagnosis, they endeavoured to negotiate accommodations and support.

> …we had these meetings, it was almost like Groundhog Day year in year out, so we would get the psychiatrist along, we would have a meeting with the teachers, the teachers would either pat us on the back and sort of go, 'Oh yes, yes, we understand' or whatever or they'd go, 'No, he's got nothing wrong with him' and do nothing, but year after year nobody really got what we were trying to say. (Kathryn and John)

The lack of respect from school staff regarding their children's needs contributed to strained relationships between school and home, lasting until the child transitioned to the next level or the parents moved their child to a different school.

Many parents reported that their children were called "naughty" and "lazy" by teachers, notably in regards to their difficulties with handwriting and starting and finishing tasks: "the teacher's saying, 'Oh, you know, look at this page, it looks like a spider has written over it, and your daughter's really hard work, your daughter is lazy, she needs to concentrate and she's naughty'" (Tanya). Parents' narratives revealed teachers' misconceptions about the reasons behind their children's behaviour, which in turn impeded on respectful interactions with parents.

> A [special education teacher]…indicated that 'You must smack him or you must be violent to him, why he is like that?' I said, 'Do you know that [an AS specialist] is his paediatrician?' and she goes 'But that's only a medical opinion'. I've been through the wringers…I said, 'Well, I'm telling you, you are wrong, but I do have another child at school who does not act like that so feel free to go and talk to him, completely different children, otherwise they would have the same if I was abusing them'. And then she conceded that he is not physically abused. (Yvonne)

Long medical diagnostic process. The long diagnostic process took its toll on many parents. Most often, parents' first enquiries were assuaged or downplayed. This left parents to puzzle over their child's behaviour and development as they tried to manage the more difficult behaviours. There were examples of teachers noticing unusual behaviour, such as playing alone or showing unease when routines were disrupted, but most often it took cumulative reports to build up a combination of identifying features of AS. Gayle shared her frustrations of waiting 13 years for a diagnosis:

> I kind of look and think well, you know, right from kindy through most of [school] his teachers would say things to us that sort of suggested that they were aware there was something not right but it wasn't strong enough for them to realise or [do something]. His new entrants teacher was probably the closest because she put us on to that, I think I told you, the special education services and they said then that he had some autistic tendencies. So I think she had picked up on that from the behaviours that he was doing.

But nobody followed it through to say well, okay, if he's got those things, if he's showing those tendencies, what should we do about it? You know, they kind of just swept it under the carpet when I brought it up with him a year or so later.

…I think that's probably been the most frustrating thing for me is just not knowing early enough, sort of, you know, like in some ways it's been more of a struggle to deal with because we found out so much later. But then on the other hand it's just been ah, oh, okay, so *that's* what the problem has been, it's that, so we just carry on as normal. We just, now we understand why.

When parents were directed in the right direction, there could be several months between specialists' appointments, periods of long observation, different agency involvement and mounting financial costs before a diagnosis was given.

…they handed me the report after a year, took a whole year and it shouldn't have taken that long, and I mean the report wasn't even finished and she said 'Good luck with trying to find something that will help you', and I just took it and I left…then I was angry that they'd just given me the report and this magic report that was supposed to open the doors to all access that we can get you know, it was just, no, the door was slammed shut, that's it. (Tanya)

The long process to secure a diagnosis prevented families from accessing the relevant and needed support.

Large number of specialists. A large number of specialists and staff were involved in families' lives before, during and after the diagnosis, such as paediatricians, speech language therapists, occupational therapists, behavioural therapists, specialists for anxiety/food issues/bowel control, psychologists, counsellors, social workers, pharmacists, special education teachers, staff from parenting programmes, respite care, disability funding personnel, and so on. The time and energy it took to interact with such a diverse group was challenging and tiring. Rita commented that her daughter's diagnosis "brought us out of the realm of home and into the realm of medical intervention". This suggested that a balance of power shifted from her to the health system and decisions were now made for her.

Lack of support. Four of the families identified lack of support, either from school or health as their main challenge. There are several stories that illustrated the

lack of support for families throughout the diagnostic process. A lack of support was especially trying before the diagnosis:

> …not really understanding what was wrong with him, why was he so difficult and no help, there was no help about that, the Plunket nurse was 'Well, some babies cry, wait till he's three months', then 'Wait till he's six months he'll be fine', 'Wait till he starts talking', which he didn't, it's always just they've got to hit the milestones and then they're okay, but he wasn't hitting any of them and nobody was really listening. (Erin)

Eve recounted her difficulties before her son's diagnosis:

> I think that there were times I definitely needed [support] before the diagnosis, but I didn't have it. There were a lot of times where I felt like I was bashing my head against a brick wall trying to get people to understand that [my son] wasn't just a teenager with a bit of depression, there was something different going on, but they just didn't get it and that was a bit frustrating. So once the diagnosis came through and I was able to speak to the doctor and relate to him on a level which he totally understood and got with what I was saying, it was such a sense of relief.

Sandy said we "were at the point of pulling our hair out" dealing with the tension mounting at home around their son's difficult behaviour, "but there was no help there".

> ...the years leading up it took so long to have him diagnosed, it took about two years to have him fully diagnosed but we had thought for about two or three years before that that he was Asperger's so that's five years we were sitting there going who can we call, what do we do, who do we talk to? (Sandy)

This lack of support contributed to conflict in Sandy's family. Leah revealed, "It's really, really hard to deal with, what do I do?" Some families sought advice through community parenting programmes though they reported that the programmes were aimed at a general population. These programmes did not take into account the behavioural aspects of children on the autism spectrum; were usually geared to younger, primary aged children; and were missing tailored or specific family counselling aspects, even during or shortly after crisis periods. Brett said the programmes were about "traditional parenting", such as learning consequences for their actions:

…it doesn't really work with [my son], he'll just keep on doing the same thing, he has no connection between that, they're like two totally separate things…it's almost like you've got to teach them these things by rote, rather than 'This is what's happened, this is a consequence of it'. You've just got to go, 'Okay, this is what's happened, this is the tenth time it's happened, and this is what's going to happen because of that'. This is a, I don't know, a logical event rather than an emotional consequence or something like that.

Tessa spoke of the challenges finding counselling for their family:

…if you're not a solo parent, if you earn over a certain amount, we can't get any access to free counselling anywhere, not even with [local mental health services], not even when he was suicidal…I just can't take it…

After the diagnosis, parents commented on the lack of communication between agencies, the bewildering requirements and forms from varied government departments on resource allocation, and the complicated system requirements for support, such as repeated costly and time intensive doctor visits. One family was asked to go through the diagnostic process twice to obtain services because different government agencies did not share information. Some parents told stories of specialists "treating symptoms" of anxiety, depression, and anger, or passing the family onto another specialist instead of directly addressing the aspects of AS.

…they are specialists and I found them very frustrating, you know, we'd go there, but I wanted to say 'this is the current issue', the rest of it, I mean, I need your expertise, I need the experience of working with these kids, I actually want you to give me 'this works, this is a good strategy' dah to dah, I want a 'How to Guide' or a 'Dummy's Guide for Kids with Asperger's' would be great. That's all I want. (Yvonne)

Considerable stress resulted in not finding the appropriate help to manage the challenging aspects of AS. This stress intensified for families as the children grew. Parents reported increased anxiety, depression and eventual school dropout for their children as a consequence, with flow on effects to the family.

Juliana described the challenges that parents of children with AS faced in her local support group:

And there certainly doesn't seem to be any uniform kind of policy about getting a child diagnosed and then what to do about it and what they're offered. And it seemed to involve a great deal of effort and stress for

parents, huge amounts of stress and too much time waiting. And I feel very sure that the children who are diagnosed *after* age 5 have a much harder time with the school than if they go into a school with the diagnosis. I don't know whether the school sort of thinks that because they haven't picked it up or whether they've sort of, I think it probably is that, that they haven't really been able to do the right thing by the child in the first instance.

Families frequently stated that the lack of awareness, understanding and formal training hampered proper support for their children's needs. Grace shared this example from her initial interview:

He would skip school and I would get a call from the school and say 'Where's [your son]?' and I would say 'As far as I know I dropped him off' and I would go home and he would be hiding in the wardrobe and I realised that he was struggling. He was difficult to communicate with, he would totally shut down, close the door, didn't want to know, just went to his room and that was it was it. That would have been half way through the year and I thought, do I take him out of school now or do I get him to see the year out or what do I do. We tried talking. I went as far as the headmaster and said 'Help'. But looking back I think they did not know how to cope with his Asperger's and I think that they simply didn't know what it was and you can put as much, they said they got someone in from the Autism Foundation, but to me that's not the same as teachers have an understanding. To me it's something that's got to be taught. They've got to know about it right from when they are training, that's where I believe.

Grace elaborated on the importance of support in her follow-up interview:

…school support I think is vital, does the school really understand and support the child, and it could be that they're struggling with understanding the syndrome and how to deal with it in the classroom, and very often they don't. And you sort of feel as if your child is in a limbo because he's not learning under the norm, but you know that he's intelligent, you know that he can, that's the thing…I've had a teacher say 'I don't have time, I've got 20 other kids in the class, I don't have the time or the resources to help your child'.

The majority of the participating parents that had older teenaged children had withdrawn their children from public school before they finished as a consequence of inadequate support and difficult relationships with school staff, and had expressed great frustration with school professionals surrounding this time.

Challenges to Family Dynamics and Work Responsibilities

Several families identified family conflicts that arose in relation to parenting a child with AS, and three families disclosed that maintaining family equilibrium was their main challenge. Parents said it was a struggle to manage the family dynamics between their spouse and children; juggle time between their child with AS and their other children; and protect their family from potentially breaking apart.

Conflict with siblings. Abbie explained how outside judgement affected her other children:

> I think the main challenges are maintaining a family actually, I think every person who has connection, close connection to the child in a family unit has to have a certain inner strength, because it's a challenge and it's not a challenge that everybody can see…when you're a sibling of a child with Asperger's you, people don't see it, but you know it and the child knows it, and the behaviours are explicit so I think it takes an inner strength to maintain a family unit…probably the *most* challenging is maintaining a cohesive family unit.

This example illustrated the interplay of concurrent challenges for families, for example, the child's limited social skills or meltdowns in public caused embarrassment for siblings, which in turn hindered strong familial relationships. There was a direct and constant challenge for parents to maintain "a cohesive family unit". Abbie elaborated on the impact on the family when they withdrew socially:

> …and us maintaining social relationships as well is quite difficult, because you have connections with people because you have children, that's where you tend to make most of your social friendships, and you can't maintain them because they judge you as a bad parent because you have a child that displays things, that are outside the norm and not always terrible behaviours, but when it comes to rude behaviours and so they judge you and it's really difficult sometimes to maintain those friendships because of it, and therefore maintaining your family, just normal family life I would suggest is almost impossible.

This withdrawal means reduced interaction with the parents of their children's friends, resulting in further dissonance.

Tessa spoke of trying to balance time and attention between her children as her biggest challenge:

> My biggest one, well, one thing is trying to be fair to the other sibling. I find that quite hard trying to spread yourself when his needs are so great, and it always seems to be, and it's *him* again in a meeting or whatever and trying to, you know, get the younger one to understand.

Leah also told of having to "restrict stuff for the whole family" because of her son's food obsessions, which caused sibling resentment.

Brett explained the difficulties of trying to hold steady two different parenting approaches in their blended family of five children:

> I think mainly it's just thinking differently with him, like if I just had an Asperger's child then it may have been easier, because then you just work your parenting style to a child, but since we've got another four children who don't have Asperger's, you deal with them one way and then you've got to deal with him another way.

Leah elaborated:

> …standard parenting stuff just doesn't work for him…so trying to adapt the family to the fact that you can't discipline him the same way…so he'll be seen to be getting away lightly on some things when the punishment for him might seem really light to the other kids but to him it's almost the end of the world.

Striving to manage their child with AS "with him being so different to normal" put pressure on families, especially when outside opinion of their parenting from extended family was also called into question.

Conflict with partner. Some parents spoke of conflict between their spouses when stress levels rose too high. Describing her son's anxiety at school during a particular challenging school term, Tessa said, "We almost split up over it because it was just so horrendous". Camille shared how the strain of parenting two children with AS, now in their teens, affected her marriage:

> …it's very stressful on our relationship because we don't know how long our children will be with us, because they're not following the normal path, nothing has been straightforward with them…we sacrifice a lot of couple time, I mean like life is never the same when you have children, but normally there comes a time where they do attain their independence and you can start to withdraw, and that has happened to a degree but they still need a lot of our time and a lot of our support…it's a struggle, I can see why a lot of marriages don't survive, just the stress is dreadful…

Camille elaborated later in her narrative:

> …you get so involved in the day to day dramas you tend, being a mother I think, you just tend to put everybody else first and end up in a mess and then of course the family doesn't function and you don't function.

Single parenting, either through divorce or when their partner travelled extensively as part of their jobs, meant coping alone with intensive time and energy demands. According to parents' reports, the additional time needed to teach skills and manage the challenging aspects of AS placed extra strain on their patience and ability to manage. Liz explained, "You do need two parents…it's really hard just with one person. *Really* hard". Lastly, some of the parents commented on their partner's characteristics on the autism spectrum and the additional complexity this brought to the family routine and patience.

Conflict with outside work. There were examples of parents struggling to manage their work responsibilities with the additional demands of raising their child or children with AS. Some parents chose night shifts or jobs that allowed a bit more flexibility to go to meetings and appointments, or to care for their child when they were not allowed at school. Parents spoke frequently of leaving work to collect their child at school's request. Yvonne spoke of having to take her son to her workplace when her son was stood down for a month: "He was miserable, he had to come to work with me. Absolutely miserable, it was the worst four weeks of his life and he cried and he does not cry, because he was so upset". When Tanya's daughter had severe anxiety, she said, "I had to end up taking her to work with me and of course that was interfering with my work so I handed in my notice".

The number of specialists involved also created time management challenges. Tessa said, "You've got all these agencies, for me, like, when school's bad, I had to drop my hours, just about had to give up the job I loved", and some parents took jobs in education specifically to have similar hours and more flexibility.

In summary, parent narratives were heavily centred towards the challenging nature of raising a child or children with AS, from the aspects associated with the syndrome itself through to their interaction with others. The stress of managing the challenges placed additional burdens on their family life and their ability to function

well. A child with AS can exert a formidable toil on a parent's energy levels. For example, Brett described his son this way:

> He's very, very, he's very intense, like he can be intense and he doesn't switch off, like he doesn't like, go into like a resting mode or anything like that. He generally only has one, one, one volume setting.

The cumulative effects experienced from the challenges raising a child with AS were exhausting for parents. Descriptions such as "it is a constant battle" and "it's really hard" were used throughout their stories. Camille summarised her personal experience: "Just that it's hard and it's stressful, be prepared to suffer for, if you haven't got depression be prepared that you might end up with it because it is so relentless, nothing is ever easy, nothing's ever straightforward". These narratives revealed the pervasive and ongoing challenges parents faced in their day-to-day lives.

Chapter 6

Findings: Turning Points

"I think the turning point was when [our son] turned around nine…and I realised Asperger's was actually something they never get over". (Sandy, 12-year-old son)

Since several parents spoke of turning points during their initial interviews, all parents were asked in the follow-up interview, "On reflection, has there been a turning point(s) raising your child and why?" The majority of parents readily spoke of one or more times that stood out for them. Turning points revealed how parents made sense and coped with the challenges they faced. Not only do the stories unfold across physical settings, they are internal landscapes revealing the parents' inner worlds (Bruner, 2004), which in turn can be useful in understanding personal development (Rutter, 1996). On the whole, the turning points identified by the parents in this study were seen from the perspective of *overcoming* difficult circumstances, with positive resolutions for themselves and their families. Turning point experiences revolved around finding and coming to terms with a diagnosis, school breakthroughs and their child gaining independence and maturity.

Finding a Diagnosis

In their narratives, parents showed a strong drive to find answers for their child's troublesome behaviours and unusual development, along with effective solutions to address it. This journey was often a long and challenging one. Finally finding a diagnosis gave parents valuable insight into their child's behaviour; cleared the confusion and frustration around the strategies that they had unsuccessfully trialled over the years; and opened doors to resources and support that were greatly needed.

When her son was 12 years old, Gayle was prompted to actively pursue a diagnosis when an acquaintance recommended she watch a video posted online by a teen with AS:

…a little video clip from YouTube of a boy in America, a 16-year-old, very

unusual, he had done a little video of how he saw the world and how different he was from the others. I sat there and watched it and the funny thing was he looked a bit like our [son] as well, so as soon as I saw it I thought '*oh*'…

…I left [my son] to watch it…when he finished watching it and he came out to the kitchen, tears in his eyes, but a huge smile on his face, and he said, 'He's a lot like me isn't he?' And I thought 'wow'. Later in the day he came back to me and he said, 'I'm not the only one, am I Mum?' and that really broke my heart because I thought, all this time he was getting bullied at school, on the school bus, and I didn't understand how isolated he felt. It was quite a moving experience, but also a turning point for us that I knew I was doing the right thing. If I had had any doubts that cancelled them, okay we have got to go through with this. It was about that September I started that process…

Gayle's turning point revolved around her newfound courage and determination to find an explanation for her son's challenges. She explained what it was like after being told her son had Asperger syndrome the next year:

I kept harping back to the diagnosis thing but I think because we didn't find out till so much later, like he was right through intermediate by the time we, he was just starting high school…about 13 when we actually got the diagnosis, so kind of most of those growing up years have been done. And actually I found for me getting the diagnosis just made me relax and thought, okay, all those things I've been battling with for all these years, give up. Stop battling to try and make him act like a normal kid because he's not, you know. I know it's not, it doesn't sound nice, but I had to realise that he wasn't who I thought he was and so therefore I could treat him in a different way and feel okay about it…

Like Gayle, several parents in the study did not receive a diagnosis until their child was approaching or already in their teen years. This protracted journey and subsequent relief might be one of the reasons why the diagnosis featured so highly in parents' turning points.

For Leah, the diagnosis gave her a logical explanation for her son's difficult behaviours and the resultant peace of mind that she was a good mother:

But you know it was, it's nice having an explanation even if you don't have to give it to other people, you at least know that it's not because you're some terrible person or whatever, which is a lot how I felt at times, especially when we had [child family services] and people talking to us…I

sort of remember the social worker turning around and saying now, 'Yelling's a form of child abuse, do you yell at your children?' And I was like, if you're going to word it like that, no I've never ever even raised my voice above a whisper. And you start thinking, 'Oh man, I yelled last week, did I really damage him?' And just on really little things that they said you start thinking that you were the worst person in the world so actually to hear that you weren't the worst person and that obviously whatever you were doing was, you know, the right motives, but not working.

Parents shared several stories of combating public misconception regarding their child's misbehaviours. They had endured judgment about their parenting skills after several instances of their child's embarrassing behaviours in public, such as tantrums, running away, disrobing, shutting down, and so on. Several parents spoke of having to develop a 'thick skin'. Leah's turning point captures her moving from self-doubt to self-belief and forgiving herself for all of the strategies that did *not* work; she said the diagnosis "lifted a huge weight". Other parents in this study grappled with their beliefs on their parenting competence, often exacerbated by misunderstandings from extended family, professionals and outsiders. The diagnosis of an autism spectrum disorder validated parents' difficulties managing their child's troublesome behaviours and verified they were unequivocally not 'bad' parents. These turning points are ones of redemption, and demonstrate parents being able to move in a more positive and productive direction.

Brett spoke of how the diagnosis shaped his parenting approach:

…both of us we were pulling out our hair not knowing what was wrong with him, before he was being such a pain basically, just being a pain and 'why can't you act like the other ones?' We know there's something wrong with you but what is it, so…it's knowing that, I mean sometimes people say like you don't want to label a child, I think it can be very helpful to label it, then you know the structure or the framework that you can work in with him…there's more tools to deal with him, those different ways of dealing with him.

The diagnosis or 'label' gave Brett the structure or the framework and tools to improve coping efforts in the future.

Erin described the impact the diagnosis had for her:

The turning point would definitely be the diagnosis, just the help and it's a big relief you're not just, he's not just a strange child that you can't

understand and no one else understands, there's something he needs help with and now I can help him, I can go and talk to people about it.

The reprieve from uncertainty – "it's a big relief" – featured across several turning points. Furthermore, parents' stories reflected a surge in energy as they gained an enlightened understanding of their child's behaviours and a renewed hope for the future.

Coming to Terms

Coming to terms with the diagnosis featured prominently in family's turning points as well. Some parents spoke of the process of resolving what the diagnosis meant for them and then deciding on a plan of action. Gayle said, " I think for me too though, the biggest thing with having come to grips with it myself was then to get other people to understand that this boy is not going to act in the way you expect him to all the time". Other parents' turning points featured the different processes between themselves and their partners, and in some instances, the discord between partners when one did not agree with the diagnosis or think their child was on the autism spectrum. Some fathers and mothers shared that they felt guilty or responsible for the AS characteristics in their children, which in turn impeded on the time to process this new information about the autism spectrum. Abbie explained that allowing her husband to take time to accept the diagnosis came as the major turning point for their family of five:

> I think the main one for us as a family was…where the barrier came down, was that my husband, when [our son]…was about 11, and he was diagnosed about 10–11, his behaviours were there prior to that which were causing stress, and my husband couldn't cope with it at all, he really couldn't cope and he put up great barriers to it. He wouldn't accept anything and he found it really challenging, which made it in a way more difficult. And at that point he got an opportunity to have a job [in a different city]. I said to him 'I think for the sake of the family, I think you need to take that job, and do weekends so that he's not in your face all the time, and you're not dealing with him all the time. I'll deal with the day to day' because, and I think if we hadn't have done that, our marriage wouldn't have survived. I don't think as a family unit we would have survived. So that was a big decision, and not one that you take lightly, or without some emotional rollercoaster around it. But subsequently I think that when my husband accepted there was this thing, and he understood

it and he began to get it, and he came out the other side, it was quite almost enlightening you know. It was almost like alright, now we can rebuild, and now we can work through the rest of his childhood, as a team working for him. So and that's when we came, we decided we would come back and live together as a family here…

She went on to say:

...the low turning point when you realise one person in the family really isn't coping with it, and then there's the point where you realise people get it, and that means your job is easier…

For this family, there was more than one turning point. The first was recognising and allowing time and space to manage the complexity in their lives and the second was when they were able to move forward as a cohesive family unit.

Susan described how the diagnosis was troubling for her and her husband and how it still presented a challenge for them:

Certainly the diagnosis was a turning point, I think we were both as parents upset about that, it's not what you want to hear about your child really that they're autistic, and it's quite hard to get our heads around the fact that he has special needs, because he does really well in his school work, not generally a behavioural problem in class, aside from 10-year-old-smarty-pants-I-know-everything, and okay, his coordination has never been that great, but he can certainly run and ride a bike, do all the normal sorts of things, but we have been noticing the social thing was difficult and not going that well, coping skills where they should be, so the challenge was to think of him as a special needs kid, and even his teachers this year said he's down as a special needs kid, and I'm just having trouble thinking of him as one, what is it, what's going to be the special need…?

This turning point highlighted the conflicting emotions the diagnosis brought for these parents and the unsettling concept of 'special needs'. There was a clash between her perception of her son and his ability to "do all the normal sorts of things" and what it meant for him to have needs outside of the perception of 'normal'. Susan considered the resolution of this tension as her second turning point:

…the other turning point for me was when I was probably upset about it, was when a good friend said to me, 'Actually he's the same kid that he's always been, he's not a different kid now, he's always been that, he's the same beautiful kid that he's always been, he's not another species of kid

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now, he's still your kid and he's that kid you've always had'. And she said, 'I think you have to look at this as how you can help him now, because now you know, this is going to help you help him, try not to think of all this negative stuff'. Because when you read the report that you get with the diagnosis, it's pretty sobering, and then when you start reading other things, I was reading things like five or six times more likely to commit suicide, the bullying and the effect that has, you know, it's all very negative, and you need to know about it, but it's a bit scary at the same time, I think I was focussing on that…

The internal struggle and resolution was the strongest feature of this turning point. There was Susan's perception of "a special needs kid" coming up against the son she cherished, the diagnostic information that focused on the negative, pathological aspects, and the implications for his future. This struggle and the ramifications for her as a parent were resolved when she came to the core realisation that her son "was the same kid that he's always been". Her friend's help was especially beneficial at this time as well.

Sandy spoke about her turning point as she came to terms with AS: "I think the turning point was when [my son] turned around nine… and I realised Asperger's was actually something they never get over". Sandy said she turned a corner when she realised the full impact that her son with AS was having on the family:

We had spent years treading on eggshells around [him], including our other two children, and I realised that our best medicine was humour… [our son's] got a great sense of humour and he could and still can be brought out of a funk as long as we use the humour correctly…when we really noticed we could use the humour to our advantage, and that's when I was able to turn it around and start joking with him instead of mollycoddling him…

In this turning point there was an evaluation of what was at stake and an unwillingness to tolerate the pressure any longer. It also features acceptance of the innate nature of AS, an assessment of the implications of their child's behaviour within the family and a determination to address the problem while capitalising on a shared strength. Tension was released and family dynamics shifted in a more positive direction when they made a conscious decision to use humour judiciously: humour was their best "medicine".

School Breakthroughs

Rita, raising two children on the autism spectrum just one year apart in age, identified their school start as her turning point. It gave her the relief from the insistent daily routine that she so sorely needed:

> …it was really difficult for those first five years when they were both home and try and get them to go to kindy and though we had lots of support at kindy, and I was frazzled. So when [one daughter] went to school it was like good, you know what I mean, it's like I've survived, especially when [my next daughter] went to school as well, like the two were at school, it was like, 'oh I've survived'.

She said, "I felt able to cope better" when her first daughter with ASD went to school, giving her the necessary respite from "all day, all evening" that she had been handling for the previous years. Her description, such as "frazzled" and "survived" sheds light on her state of mind both before and after this significant turning point.

Juliana also identified her son's start in school as a turning point, both for him and her. She was especially worried about the school transition and whether he would cope with the new environment, but she was pleased all went well: "Starting school was one [turning point] in a good way as well, because he had a very structured classroom in Year 1, and it was perfect for him and what he needed". These turning points featuring school transitions also aligned with significant milestones, and parents' relief, though for different reasons, is apparent when they are reached.

Allison's turning point included school transitions as well:

> …there's been almost like two turning points, both educational, because the one [overseas] was getting him into the right school and the right system, going from the big huge government class where he couldn't deal with anything, to the small class where there was a lot less sensory overload and he suddenly started to blossom, that was a huge big turning point, school became a joy not a disaster, and the second one was getting here and finding that the school system suited him even better in this country than it had done [overseas]…

This example captures the contrast between before and after: before there was "disaster" and after there is "joy". These positive resolutions were a substantial feature in parents' turning points.

Leah enrolled her son in a different school with the hope it would be a turning point for him (and consequently, for her as well) and Camille said removing her daughter from school was her daughter's turning point because "it just was not going to work" as it currently stood. The prospect for improvement for their children moderated the extra stress and instability created by these decisions. Both parents shared positive outcomes: the home schooling tutors Camille put into place made a significant difference in her daughter's ability to learn and progress, and the teachers at the school Leah chose for her son were empathetic and readily put the appropriate supports in place. Several challenging situations at previous schools had preceded both of their decisions and after battling several years of unproductive and unsettling experiences, these mothers decided to choose a different path for their children. Finally finding the right environment and people became a noteworthy turning point for both of them. Here Camille describes the tutor she credited as her turning point:

> …so she starts to come up with the master plan, but she's been a fantastic role model, mentor, friend, all sorts of things to [my daughter] plus a great stress relief to me because I've just stepped back and I reinforce what she says and everything that gets done is discussed with [my husband] and I, but it's left to her…we knew that if we could get [my daughter] to that point that we would see a change in her, but it was just getting her to that point and I couldn't get her to that point. So for us the turning point was finding [this tutor] and we were just so fortunate that we found the right person…

Camille concluded her daughter "has turned around and she's on the way, every now and then we have a hiccup, but she's working pretty well". A breakthrough and positive results were welcome relief and outside help came at an opportune time.

Gaining support at school for their children, such as extra teacher aide hours or accommodations for school work were also mentioned as turning points. Tessa's narrative included lengthy examples of unsuccessful attempts to gain specialist intervention support at her son's school since he began at Year 1. After three separate applications were previously denied, specialist and teacher aide support was finally granted on her son's last year before attending college. She said it was a turning point "because now I feel like he has a chance, where I didn't feel like he had much of a chance beforehand".

Sandy and Ian also shared a defining time in their school struggles:

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> *Sandy*: …definitely that was one of the major turning points was when we had [a behavioural specialist] on board…And that was, that was a big thing for us.
>
> *Ian*:   Was a big thing.
>
> *Sandy*: Because he was able…
>
> *Ian*:   It got the teacher on board.
>
> *Sandy*: Yeah he was able to influence things at school that over the course of four or five years we couldn't do, it's getting someone in with an official title.

The pressure for Sandy and Ian to advocate for their son at school lessened when the specialist intervened on their behalf. He helped to raise awareness about AS and implement effective strategies in the classroom, freeing Sandy and Ian to work as partners with the school. This turning point captured the positive effect an ally can bring, a coming "on board". He helped break down barriers and clear a path for these parents. In Sandy and Ian's example, the teacher was now understanding and cooperative. When everyone began working as a team – parents, school and specialists – a significant breakthrough occurred:

> *Ian*: [The teacher] didn't want to come [on board], but once I think she realised that there was a point to all this, it wasn't just mumbo jumbo, it was actually true, or it helped…And then get the principal on line, he's an old school…but once he agreed, that was, I think one of the major turning points.
>
> *Sandy:*…because we were against each other, it was us against the school.
>
> *Ian*: Yeah, we felt we had someone to help us with actual, you know, we believe you.

These parents felt validated and were able to regain their relationship with the school staff.

The ability to access support in the health system was also mentioned as a turning point for one couple. Natalie said, "I think the fact that in the hospital system people were willing to listen to [my son] and work with him" during a crucial time was important to her and her husband. This is reminiscent of Sandy's example of an outside professional who provided the needed expertise and connection. Overall, the

weariness in parents' narratives was evident, so when timely support came into their lives, such as appropriate and practical information, a knowledgeable specialist, or an understanding friend, it tipped the scales towards a positive outcome.

Gaining Independence

Some parents' turning points featured stories of their grown children beginning to demonstrate independence. Grace described the time her son started taking his own medication, secured a loan for his car and planned a road trip. She said, "I'm thinking hey, this is the turning point, this is it, but he's done it on his own back". She also spoke of her son's friend that had had a positive influence at his time. Kathryn and John credited their 22-year-old son's success in an outdoor programme as his turning point, which was followed by finding and landing a job. Kathryn said "he has stuck with it and we're all so chuffed". They credited the good match between the programme and their son's need for routine and structure. For the first time he gained a boost in his confidence as he tackled the more difficult portions of the course. There had been many starts and stops for their son before this turning point and now these emerging successes provided hope for his future prospects. Liz said a "huge turning point" for her was when her 19-year-old son began showing independence, such as going into shops for himself, buying movie tickets and drinks, and finally making the transition into adulthood. She said, "He's way more confident and more mature, he doesn't have big meltdowns thank goodness, he's really sensible now". Juliana also spoke of a turning point that involved a gain in her son's self-confidence: "he thought he was useless and couldn't do maths, just really low confidence, lonely and then all of a sudden abrupt change, and he realised he could actually do as well as other kids, so he stopped comparing himself quite so much I think, the confidence started to grow". An improvement in the child's ability to successfully tackle challenges had a direct impact on their parents' well-being. A renewed sense of hope in their child's possible futures was seen as integral to these turning points.

In a few instances, a turning point did not have a satisfactory resolution or a clear respite from the stresses that led up to it:

> I think there has been a turning point, I mean [my son's] moved out so I suppose, I wouldn't really call that a turning point because things were still quite bad even after he moved out, but a turning point I think may be because I've learnt to pull right back, and think to myself,

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okay, well then, you're 16, you think you know everything, go and do it. (Eve)

Nevertheless, this mother's decision to step back shows her active involvement in a situation she did not initially have control over, helping her cope and gain perspective on a troubling development. One father did not find any particular turning points on his reflection, but described instead regular confrontations and difficulties parenting his teenaged son.

To weather the storm that leads up to turning points and cope with the aftermath directly afterwards, Yvonne said "you have to be so flexible…you can't set things in concrete, like you might have an overall picture but it can't be so detailed that your whole world just smashes apart, you know, that's the danger of having such a concrete look on things, that when something contrary to that happens" you are not prepared. She likened her journey to a "house of cards" or a "carousel" because "it's always moving". This mother spoke of how important this perspective was when appraising adversity and then being able to direct her energy in a more positive direction.

To review, turning points included finding and coming to terms with a diagnosis of AS, experiences related to school, such as their child starting school or their child receiving needed learning support, and lastly, their older child demonstrating the beginnings of independence. These critical times were characterised by release from significant stress and a change towards a more positive direction. In addition, some examples featured the opportune support of an outside person, resource, or programme. Parents' perceptions of the turning points in their lives revealed inner conflict and candid self-reflection, along with a renewed determination to do the best for their children. The process of building resilience is seen through turning points as parents make sense of difficult circumstances and gain perspective, such as after finding a diagnosis or working on family unification. There are examples of parents incorporating both a realistic appraisal of the situation with a hopeful outlook. Turning points are examples of transformative experiences that show parents learning and growing stronger and attaining a more positive and beneficial life direction.

Chapter 7

Findings: Building Resilience

"…we kind of just dealt with it the best way we knew how". (Gayle, 17-year-old son)

Parents' efforts to manage and overcome difficult problems were substantial. Overall, five key processes were identified regarding parents' coping responses under the overarching theme of building resilience. These are: turning points, meaning making, developing resources, planning ahead and solving problems, and strengthening intrapersonal assets. The previous chapter presented findings related to parents' turning points, and this chapter will cover parents' coping responses in relation to the other four processes. Within a family resilience framework, these coping responses indicate the process of building resilience (Walsh, 2003c, 2006). There were extended examples of coping responses throughout each of the parents' narratives as they built resilience to daily and long-term challenges. Moreover, parents were asked in the follow-up interview to share their personal *strengths* for managing their challenges and the helpful strategies they used. Positive coping responses and adaptation to adversity utilising strengths contributes to the process of building resilience (Walsh, 2003c, 2006). Lastly, parents shared several concrete examples of attempting to change or modify their circumstances, such as planning or limiting public outings or altering their child's room to curb sensory stimulation. Their ability to creatively problem solve and prepare were apparent.

Meaning Making

Pearlin and Schooler (1978) state that there are three major types of coping: 1) ones that change the situation before stress can arise, 2) ones that interpret the meaning of the experience before the emergence of stress, and 3) ones that help control the stress after it has emerged. The findings from this study point to the fluid connection between these three coping responses. For example, parents' positive reinterpretation of a challenging situation had an influence on their abilities to manage concurrent stressors in their environment as well as subsequent stress. This constructive perspective was seen as parents accepted and then made sense of their

challenges, determined what it meant to parent a child with a 'disorder' and then educating others about their child's differences. Acceptance and a positive reinterpretation helped parents manage the subsequent challenges in their lives. Other productive coping strategies under meaning making included making sense of the origins to AS, comparison and reconceptualising what 'normal' meant to them and their families.

The narratives collected demonstrate that coping over time with the challenging aspects of AS shaped parent perspectives and beliefs:

> There were a lot of difficulties when he was younger…after you get through each hurdle you think this is a clear run now, but no, we used to think there was a path, now we realise it's just a whole bunch of hurdles. (Sandy)

The expectation that there would be new challenges behind the old ones prepared and insulated parents from additional surprises. Yvonne's analogy of a moving carousel reflected this interpretation of challenges too. These parents were *expecting* their lives to be hard. Susan reflected, "I think what you've got to do is develop a thick skin about it, and accept that there will be days when they just won't go well, you'll just have days where it's not going 100%".

Acceptance. As was noted in Chapter 5 on challenges, the process of finding a diagnosis was a long and complicated process. Finally receiving the diagnosis had a powerful effect on parents. Some experienced shock and others a profound relief. Their reaction reflected what they knew about autism at the time and their appraisal of what this new label meant for them and their child. Some parents spoke of their limited understanding of autism at the onset of the diagnosis. They thought of someone with autism as being mute or similar to *Rain Man,* and this perception created fear and worry. Anne talked about her initial reaction to the diagnosis:

> I'm in this panic of, oh my God, my child has autism, what does this mean? I was so paranoid about autism, it's what you don't want your child to get, we delayed vacs, we avoided chemicals, we did not want this autism for our child, epidemic of autism, and so I had failed my child, somehow she had developed this autism…

However, due to the length of time it took to receive an official diagnosis, many parents had increased their knowledge about autism. Natalie and Leo explained that

the diagnosis gave "us enough of a direction to perhaps go, well, actually some of these things may never change, and he may always struggle, but he may be able to work with it". This point of view combined acceptance with hopeful possibility.

A few parents saw acceptance of the ramifications of the diagnosis as their particular strength for coping. Jeffrey spoke about talking to his teenaged son about AS: "we just accept that it's there and generally ignore it" and "just try and treat him as normal". However, his wife said that when other mothers asked her if raising a son on the autism spectrum gets better, she replied:

> …I think of my son and I think, 'God no, it doesn't get better, it just changes or it improves or you learn to adapt to it'. I don't think you ever really accept it, I think I still go through the 'why me, why him, why did I have to deal with it?' (Allison)

Parents mentioned that acceptance can come at different times for their spouse or ex-partners, and a few mothers spoke of a grieving period regarding their expectations and hopes for their child, for themselves and for their family.

> Your life is not, like I was saying to you before that grieving thing, your life is not what you necessarily anticipated or planned it to be, but in the same instance you have to then realise it's not awful either, you're sitting in a house in New Zealand with sunshine, so it's not as bad as all that. There's pictures of them up here, and I always say that's what they're like, the all American boy look, your dream for them then is they're going to be academically capable, socially able and what you call the normal things of life, and when you really realise that's not going to be and you accept that's not going to be, it is a big acceptance. It took my husband a long time to get there. He took a good 2–3 years to get there. (Abbie)

Abbie said that it was dangerous for her to wish for something different and that "you have to rise above it really". For this mother, acceptance created a more positive climate for her family and enabled her to better overcome the difficulties parenting a child with AS.

Brett spoke about accepting the bewildering aspects of his son's behaviour:

> Sometimes it feels like you try and break down a really solid wall just to get in to it, just to try and think like him so you can understand what's going on in there. Other times you just throw your hands up in the air and think that's just [him]. So just got to accept that he's going to do some peculiar stuff occasionally.

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Allison offered this advice in her narrative: "just accept it, learn to live with it because you go through the phases of '*grrrrr*', doubting this disorder or whatever, but it's not going to go away". Acceptance of the integral nature of AS helped her.

Other parents spoke of the tension in accepting and adapting to the diagnosis:

> But then I still went through a bit of a grieving process, even though I was relieved that that's what it was, I could learn to understand it and accept it, but I kind of had the thought process where, okay, my perfect little boy isn't perfect anymore, he never has been, but I didn't see that. It stirs up the emotions even though I've worked through them. At the time it was really a kind of weighing up between okay, this is who he has always been, but who he has always been wasn't who I thought he was… (Gayle)

This struggle to reconcile perceptions about the diagnosis came through in many of the parents' narratives. They also worried how the stigma would impair their children's future prospects, although Leah said, "I don't exactly want him to hide it, it's been such an awesome part of him as well".

The majority of parents found receiving a diagnosis alleviated their confusion around the reasons for their child's behaviour as *knowing* improved their ability to accept and cope: "I think if you have a diagnosis you're better able to cope with it, you're better able to understand it" (Grace). A diagnostic label also helped parents procure support at school, such as teacher aide time, accommodations for sensory sensitivities or permission to use a computer instead of writing by hand.

> Yeah, being able to say to the teacher, 'This child actually is different', you know, I'm not just the mum going 'my little darling's a genius' or 'he's just overly sensitive' or whatever; my kid actually has something that you guys now have to work around. You know that definitely made some difference. (Leah)

Parents agreed that an 'official' diagnosis helped outsiders, especially school staff, formerly recognise their child's needs. The diagnosis focused parents' energies on targeted interventions as well:

> I got very involved – I guess people say you are labelling your child – I don't believe you are labelling your child, what I really wanted was a diagnosis of what I was dealing with and from that point on I could say right, what resources do I need, how can I help him? So I guess it was in some respects it was labelling him, but it was aimed at helping, it wasn't

aimed at, 'Oh well, here's a label put him in the corner that's his little place'. It was a diagnosis, I don't call it a label, I call it a diagnosis. So it was a starting point for me, what can I do next, what tools can I put in place, strategies to help him, what sort of physical things does he need in the way of workbooks or special clocks, whatever he needed. (Grace)

For this mother, a diagnosis or label increased her knowledge and equipped her with the strategies and tools that helped her cope better. Sandy said that a label was beneficial "because people understand him, they've got more patience".

Not all parents embraced a diagnosis. Susan said that she "was surprised to have him labelled as autistic because he's very clever" and she felt the diagnosis did not relate entirely to her son, saying "that's the problem with a label I guess". Even though the 'label' had a negative connotation for some parents, it still improved their understanding of their child and provided a platform for information and support.

For a small number of parents and their children, acceptance was not a particular aspect of their coping responses. Moreover, there were heightened tensions noted for parents and their child if a diagnosis occurred when their child was already in their teens. Negative attributions and interactions had become entrenched for some. In addition, parents of the older children reported that their child resisted the notion of having a disorder or 'special needs'. A few parents said it disadvantaged their children to have this label, and reported their children avoided rooms at school set aside for them if they were specifically for 'children with special needs'. John said his son had "two labels floating on top of him, 'Asperger's' [and] 'special needs', and they float around with him, and he can see them because everybody reacts to them". He said his son "never sees himself as any different to this peers" so he disliked going to a 'special needs' room. Susan said, "It's really challenging normal perception of it, because when I think of special needs kids I think of kids who either have physical disabilities that prevent them from walking or doing things, or have real learning difficulties", as compared with her son who attended extension classes and was a gifted reader.

Positive reinterpretation. Parents' narratives revealed attempts to balance their perception of their child with the negative information they encountered about autism. This information might have come from the internet, doctors, friends or family. As a coping strategy, parents formed an identity that more closely matched

their beliefs about the unique and positive characteristics of their child. Evan explained how his personal journey researching autism shaped his perspective on this new identity for his young daughter:

> …before we had the diagnosis I'd kind of been reading quite a bit about the feelings of autistic people, in relation to how the world sees them, and some of these people, I'd guess you'd call them autism activists in a way, because they talk a lot about how campaigns to eradicate autism make them feel. They feel differently about it than you may expect, because to them the way they perceive the world is a really positive thing for them, and it's almost akin to a genocide to say that the way that they feel is wrong, and it should be eradicated…but I guess it led me to when we had the diagnosis, I saw it as oh, that's really awesome that [our daughter] can experience the world in a particular way, that might enhance her experience in some direction…

Evan shared how he thought the clinical descriptions of AS did not accurately describe his daughter:

> …something about not being able to read emotions…it makes you assume that the child is cold and clinical, and not empathetic, whereas we found [our daughter] was overly empathetic in some cases, really thinking about other people's feelings and stuff. When we got some information, I think from [the local support group] or read another book they provided us, it kind of put some of that stuff into context, and it had an alternative way of describing it, so some of the things were about being very honest, being very loyal, being able to focus intensely on something…

Evan focused on the more positive aspects of the diagnosis and its relation to how he saw her. This father had a constructive and optimistic interpretation of his daughter's diagnosis. This contrasts with medical descriptions focusing on deficits. Another father expressed a similar perspective, "As I say, in my view, it has to move off this diagnosis of an *illness* thing" (John). He and his wife felt that people had the perception of "you poor thing, you've got an Asperger's child" (Kathryn). This couple felt that looking at what was wrong or missing from a 'diseased' point of view prevented others from accepting the reality of a full *human* spectrum and making the necessary accommodations for learning and living. Yvonne also spoke of disagreeing with the medical point of view of AS: "All the things that I've found is that the medical profession, they have a different view from the *real* world that you live in". When

asked about the qualities of AS in her son, she said, "Positives, so intelligent and quirky, they have got an interesting perspective on life". This mother separated the diagnosis from her son:

> I know there's still, regardless of what diagnosis he has, he's still that person, like from our family they don't look at his diagnosis, that's just his behaviour and they work around his quirkiness. I guess they are working around they just need to be mindful. We always have, and we do get those niggles, and just let him go, he will be fine.

Grace said she hoped her older son, who was struggling with his own ideas regarding the diagnosis, would "realise that it's not such a bad thing, he's actually got gifts".

Across several of the interviews, parents described their children as "different", having "quirks" or "funny little ways". Parents commented, "They think differently than we do" (Eve) or he "does come from a very different sort of point of view" (Grace). Brett's narratives contained a variety of descriptions: "His *term of reference* is so very different to everyone else's; they don't have the same *motors* as the other ones"; and his son would be "just moseying along trying to do *his* thing in *his* world".

> Okay, [my son] is a very unique individual, he is, it's like he's on a, a slightly different…like this kind of, sort of wave and it's like he's on a totally different pitch and amplitude basically. So…he's totally different from the other four children, like very strongly different.

Characterising his son's behaviour as "different" framed his challenges and parenting approach. Brett explained: "I think mainly it's just thinking differently *with* him". The key for this father was to make that connection, to see the world from his son's point of view and work within that framework. There was a clear commitment in the narratives of parents to see the world from their *child's* perspective. Their child's behaviour had perplexed and challenged them, and part of parents' coping process was to try and make sense of their child's reasoning and odd behaviour. A conscious decision to gain insight contributed to patience and acceptance. Yvonne said, "I guess we learned to cope and we know the triggers…but it's [my son's] world view of things". Grace succinctly said her son is "entitled to his point of view". She hoped other people would understand him. This perspective was noted throughout parents' narratives. Parent's perspectives of their child had evolved over time to recognise

and accept their child's point of view, and presently they hoped others would see their children as unique and extraordinary in their own right. Sandy talked about her view on difference:

> I just have to remind myself every now and again that life can be really difficult for him…he just sees the world in a different way than other people do. He would often say to me after we'd explain to him, he would say, 'Is that because I see the world in a different way?' I'd say yeah it is. Sometimes it's a wonder, sometimes it's a blessing…you look at the world a different way and you notice things that other people don't notice. It's all good, good stuff, but when you get angry and anxious we have to now work out how to manage that, and we have over the years. Because each child is so different, and obviously each parent is so different, we all have to come together first, and it's like feeling each other out…

Sandy framed her view to "sometimes it's a wonder, sometimes it's a blessing" and she brought a constructive interpretation of the difficult aspects to her coping repertoire, such as his anger and anxiousness to "we have to now work out how to manage that".

Susan's perspective was seen in how she helped her son manage his challenges: "But I do try and explain to him that there are *big* problems and there are *little* problems and try and get that concept across". Tessa, who worked in education, articulated how she approached difficult behaviour:

> …you go to other people who don't know nothing about it, they go 'There's that weird child or that annoying child' and I've learnt one thing in my job there are no naughty children, honestly, children are not born naughty, there is an *issue* and that's what I've learnt.

Her perspective had developed through her parenting and work experiences to separate out "naughty" behaviour from the child's nature. A conversation between Susan and her young son reflected this more positive reinterpretation of difficulties: "Because of that Asperger's, Mum, you know, what's wrong in my head? And I sort of correct him saying, like, it's not *wrong*, it's just different, it's different in your head".

Parents' sense-making showed acceptance, openness and insight regarding AS: "He's still our [our son] and he still has his funny little ways" (Grace) and "Good and bad you accept that, that's just the way he is, good or bad" (Yvonne). Their perspectives embraced difference and a positive reinterpretation: "I told him

everyone has something" (Liz) and "That's right, everybody's got different needs" (Kathryn and John).

Making sense of the origins of AS. The majority of parents interviewed spoke of recognising the characteristics of AS in themselves, their spouses, siblings, parents, grandparents, uncles and aunts, and cousins. Susan said her family referred to extended family members who were possibly on the spectrum as "oh those ones" and Rita offered, "the apple doesn't drop far from the tree". Juliana shared, "my family's riddled with it basically, and so I've got the experiences of my great grandfather, my grandmother, my father and my brother" to draw on, and that she already "had a whole apprenticeship with it". Parents' ability to recognise similarities between their children with AS, themselves and other family supported their coping through familiarity and making sense of its origins.

Some mothers said they had worried their prenatal stress or postnatal depression had resulted in their child's autism. They spoke of trying to pinpoint events or circumstances that might have had a negative impact on their child's early development. They expressed relief when they learnt from their personal research and through consulting with medical professionals that they did not cause their child's condition.

The narratives included examples of parents attributing their child's challenging characteristics and behaviour to autism. Allison's perspective was reflected in how she referred to her son's "wiring":

> …I've always thought he is what he is, I'm honest about it and I tell people he's autistic, because Asperger's autism, they don't always understand the subtle differences, I say he's got autism, he's very high functioning, everything looks normal, but then there'll be a time when the wheels will fall off and you'll see just how *not* normal. And then there are some days when I look at him and think, wow, you're really being autistic today, and there are other days when I think you look pretty normal. Yeah, you have to just remember to take him as he is, you're not going to change things, you can help and you can guide, and you can mould and you know, but you aren't actually going to change the internal way his brain is wired, nothing I can do, the wiring is all crossed. I say to people it's like having cross wires and you're not wired right, he overreacts to things we wouldn't react to. I say to people, you know, he's just made differently…

She continued to elaborate:

> You can say to people, 'Look, he's got this, this is why he behaves like this' and it's not an excuse and I know he shouldn't hit your child or whatever, but unfortunately that's how he's made, okay, and we're working on it and we're making sure that he knows it's not the right thing to do. And you know we're doing our level best, but the aggression is hard wired in. I haven't actually said that to anybody because we've never been brave enough to have that when we've had those conflicts…

The perception of the intractable nature of AS relieved pressure, since "you're not going to change things" and there is "nothing I can do". For this mother, this approach allowed her to cope with her son's violent and fractious behaviour. Other parents spoke of the integral aspect of AS, stating "it's a lifelong condition" and "I realised Asperger's was actually something they never get over". Erin shared her view on the ubiquitous nature of AS:

> …you know he's lost a lot of his early-on symptoms with his flapping, it's not so noticeable and now I don't really announce it, because I don't have to explain it, because it's under the surface and people aren't aware of it as much anymore. I don't know, it's almost like you never quite get over it, you know what I mean? It's always there and they're always not quite, you know, yeah.

The recognition that AS was not a condition that could be readily 'fixed' facilitated acceptance and directed focus to manage the more challenging aspects of it.

Comparison. Parents used comparison to appraise and gauge the severity of their child's condition, as well as their difficulties in relation to other families' challenges. Parents often commented that their child was on the *less* severe part of the spectrum:

> I know that [my son's] Asperger's is on the low end of the scale, there would be other families whose children would be far worse, so I think I'm probably lucky in that what I've had to cope with is nothing compared to what other families have to cope with… (Grace)

This appraisal reassured parents that *at least* it was not worse, and that in minimising the severity they also might also diminish the difficulty. Ian shared his perspective of how difficult it was (or could be) parenting his son:

It does get easier as they get older, now again I'm lucky, we found out what [it] was to help him, and because it's a mild thing I still think we're way luckier than most, I think, if it's on this autism scale, you know, you have children that can't talk at all, can't, at least he can function, he is a funny kid…

Ian compared parenting his child with "mild" characteristics with those with more severe manifestations and found he was "way luckier than most". Juliana, who was coping with high health challenges in her family, said in her narrative "it could be a whole lot worse" and "in terms of coping with the Asperger's it's been relatively easy compared to other things". Comparisons helped parents cope with challenging behaviours as from their perspective and appraisal, their problems were manageable.

Reconceptualising 'normal'. Part of parents' coping processes included reconceptualising what 'normal' was for themselves and for their family. As part of the coping process there was a concerted effort to adjust routines, restore stability, maintain continuity, security and predictability and view this readjustment as the new 'normal'.

Parents were also acutely aware of societal expectations of a 'good' parent, 'typical' child development, and a 'conventional' family. Since raising a child with AS challenged all of those notions, parents endeavoured to cope:

> …so some of the ideals what we want [for] them, are they *that* important or are we just making life miserable for everybody trying to make them conform to those things. I probably had to let go of a lot of the ideas that I had when I became a parent that my children were going to do this and eat that, it didn't quite happen like that and the faster I let go of it the easier it was for me and probably for them as well. (Camille)

Societal perceptions of what is 'normal' caused conflict for these families. Some parents talked about changing their expectations, or not expecting a specific outcome to prevent disappointment:

> You just have to be so patient, and I've realised that to have expectation is really not good for me, because it just, I just end up feeling disappointed, hurt, let down, deceived and I don't want to feel all those things. (Eve)

Gayle said after receiving her son's diagnosis that she could "stop battling to try and make him act like a normal kid because he's not, you know". She acknowledged societal perceptions of what 'normal' expectations were for her child's behaviour and felt under pressure to function within those parameters. Later in her narrative she said that meeting the extra challenges had become routine for her family: "This is normal for us". Parents spoke of how difficult it was for their child to fit in according to societal expectations: "One of the hardest things is – it doesn't even occur to me sometimes how hard they work to appear normal and fit in and what an effort that is and how draining that is to socialise" (Camille). To cope with outsiders' expectations of 'normal', parents either counselled their children to embrace their uniqueness or work to fit in.

Many parents expressed their worries about their child's future, and a few parents coped through focusing on preparing their child adequately. Jeffrey said: "It's not easy, it's not easy, I'd much rather leave him in cotton wool and have an easy life, but no, you've got to push them". He continued, "We've always been quite hard on him because he has to conform to life, he has to conform to what goes on, he has to have a future". From his point of view, society's expectations created an additional challenge that moved him to action. Tessa had the same opinion: "How do I get him there, even if it's going to be hard, what real hard work do I have to put in now?"

Liz said to help her son, she tried to point out how people with AS are gifted and clever:

> I said sometimes people are so clever they just seem odd to so-called ordinary people, the ordinary people that think they're normal, but I said… you've got some special gift, cleverer than other people, but I just try and make it like that.

A few parents spoke of broader interpretations and applications of what 'normal' could be. John talked in length about the importance of education reconceptualising 'normal':

> … this whole idea of separating kids out into little groups, in my view is just fundamentally wrong, I mean I see how we need to do it because we look at all the kids and go well this is normal and if you're outside that box then you're abnormal…if you went, just took the mind-set of going *everybody* every year we're going to have people that are from this end to this end, and *that's* normal, we're just going to teach these kids

appropriately for where they fit on this normal scale. I mean it's a huge different jump to the way we look at life at the moment and that would make a huge difference. It would have made a huge difference to [our son], just that alone...

John stated it did not help that educators and policy makers amplified "the fact that they are different" without accommodating for difference. John and Kathryn strove to reconceptualise 'normal' to *include* differences and challenged the notion of 'special needs' to embrace an inclusive and holistic perspective. Sandy shared a similar view regarding school's perspective of 'normal', saying "No one's the same, so whether he was going to be diagnosed Asperger's or not it shouldn't have mattered, it should have been 'Look, what can I do for your child that you think would be helpful?'"

Developing Resources

Parents sought out information and support before, during and after the diagnostic process. They turned to the internet, their child's teachers, trusted friends, and other parents who had experienced similar trials. If there was a persistent gap in services to address practical and emotional needs, parents moved to advocacy roles to secure appropriate support.

Researching and securing help. Seeking help was a vital coping strategy for parents as they attempted to manage the difficulties raising a child or children with AS. Parents researched online before finding a diagnosis, seeking advice and strategies for their child's challenging behaviours. Sandy stated, "[We were] definitely more on edge, especially those toddler years. That's why we went to get help, I can't live like this". After the diagnosis, parents' searches became more focussed. Eve said, "I think my strengths are seeking help and taking on board how things can be better".

For most parents, the realisation that they and their families could benefit from outside help became a saving grace. Leah shared how her extended family frowned on her efforts to secure help outside of her family:

And I'm not too afraid of actually turning around and saying I need help... but you know that's another one of those things that comes to the external people sometimes, I mean that is something I fight with, with my family, because my family's very much you keep it under your roof and

you don't talk to anybody else and it's all reputation and you know, what's going happen if, I don't know, you call [child family services] for help and they decide to send a social worker round. And I said to my mum before, mostly jokingly, well the social worker could take all the f'ing kids with them and when they've worked out what's wrong they can bring them back and tell me what they need to do.

She added that she considered her strength to be resourcefulness since it was quite difficult to find appropriate parenting help: "We pretty much had to look up in books and on the internet the things that we ended up putting in place at home and at school". Her husband agreed: "Generally it's been us being proactive about reading about it, and trying things that have been online, rather than anything else…lots of blogs, I think the main ones are people's experiences" (Brett). This couple became adept at gathering information and building their knowledge base. They bolstered their problem-solving skills through research and demonstrated an open attitude to asking for help.

Parents sought support to alleviate daily pressures; to recover and prevent subsequent crises; and to address the weaker areas of their child's development. Overall, parents noted the lack of appropriate and timely support from education and health organisations, but also spoke of specific instances when the support they sought was especially useful. Regarding friendship building, Rita said her daughter needed "someone that's a bit gentle that will let her practice her clumsy way of being in the world" and she was grateful for the support from her daughter's school and a specialised behavioural service, stating "I just couldn't have done it independently". Jeffrey said he advised other parents to "find all the help you can get". Parents' continued willingness to ask for help reflected their great need and demonstrated continued perseverance. Camille had built up an impressive support network that spanned education, health services and home to help manage her two children with AS. She sought help from a counsellor at one stage:

> …it was quite a good experience cause sometimes you start to second guess yourself and think do I have a realistic view of my life, are my expectations realistic or have I completely lost the plot, am I unrealistic? And so it was actually good to speak to someone who had never met me before and just give her a one-hour snapshot of my life and at the end she said, 'Oh yeah, no, that's fair enough that you should be feeling the way you are'. And, and then to get, yeah also like to thank God for that. And then just two quick observations that she made were that you're

quite isolated because of your children, because it's difficult to do things, it's difficult to find time to do things, it's difficult to do things with them because it's stressful. And then she said you need to find time for yourself to fill up that well because it's emotionally you have been giving, giving, giving and if you're not doing anything for you to replenish that you're going to run out all the time.

Through seeking help, Camille gained a healthier perspective on the demands she faced each day and the emotional repercussions the constant stress had for her and her family.

Seeking social support from family, friends and other parents. Many parents in the study cited the support they received from their spouse, extended family, close friends, and other parents of children with ASD as particularly valuable. Tanya said "definitely having my sister on the other end of the phone" was one of her salvations. Some mothers highlighted how their partner's calmness contributed to their ability to recover from stressful episodes and others spoke of making concerted efforts to connect with their other children to maintain equilibrium in the family. A few couples communicated that their strength was working together as a team. The parents who were single spoke of the difficulties of parenting solo and sought out the support from extended family or close friends when possible. Many parents said the support from extended family for respite care gave them precious time to recoup.

Evan shared that having a connection with other parents was beneficial to his family:

…it felt like we were part of a community that has also experienced issues, and we weren't some sort of outlying group that didn't really have any peers who had experienced similar problems. Then it led us to [local parent support group] and other groups and stuff, which have been helpful in connecting with other people that have had similar issues…

This feeling of community helped to combat the social isolation that occurred when parents withdrew to manage their child's behaviours and limit their exposure to outside judgement. Leaning on others who understood had favourable results:

…we're managing okay within the family and with our friends that are our network, just talking to them is so helpful…if I've had a bad day I can talk to someone. And I mean most of the time I don't need to, I talk to [my husband] about it and it just comes up, like if I meet someone, meet a

friend for a coffee or for lunch or something or I go to someone's house and it's wonderful to talk about it with someone else, you know…talking about our children's days and just see what they're doing and seeing what works. (Sandy)

Leah found she could experience a sense of belonging after she received the diagnosis for her son, strengthening connections with others in her community:

…knowing that you could now go and type something in to Google or look for a book in the library or ring and ask for a support group, you know just made it not quite so alone, now it was actually something that more than one person had to deal with…

The beneficial effects of connecting with others, within and outside of the family were apparent in parents' narratives. Mothers benefited from sharing their troubles with a trusted family member such as their partner, mother or sister, and fathers and gained a sense of community through online and face to face support groups.

Advocacy. The high level of interaction with health and education professionals and the need to negotiate support and services propelled parents into advocacy. Furthermore, when parents consistently encountered inadequate support, they took a stand.

Particularly when he was very small, I was on my own and I would have got nowhere if I hadn't fought for it, I really wouldn't, I just knew there was something, where do I go, what do I do and did it, took him to the early intervention centre and then carried on taking him out there for God knows how long, it's such a long way, and then both of us advocating through school and all the rest of it, and with the sensory integration therapy you know I realised he needed it when I'd done my research, and where do I get it, no one was going to give it to me in the system… (Kathryn)

Speaking out on behalf of their child was a coping strategy that helped channel frustration and address gaps in the system. Tessa said "I know how hard it is, my strength is fighting for that for him…because I don't want him stuck and this is why I fought so bad". She also channelled her energies into advocating for other parents' behalf:

…autism's sort of become my strength now, I really want to fight for them because there's so many families that are just left where we were and

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don't know, and put up with so much rubbish and just left to deal with it. You get this diagnosis and then you're just left, you know, trying to struggle your way…sometimes it's about other people, not us, it's too late for us in some ways, like if we'd known about these things earlier, if we had known, you know, so I just help other people now. It's just become a knowledge thing for me, I want the best for them because they're just like everybody else and they're entitled to be like everybody else, especially the ones that are struggling through the school system. And they just get stood down and expelled, and the parents don't know any better so they just accept it…

Abbie outlined why she advocated for her son at school:

I think you're the only one that's going to advocate for that child. With all the knowledge of that child, there's no one else in the world that's going to advocate for your child like you are, but it's about building relationships that are supportive…

Abbie elaborated in her follow-up interview:

I've definitely had to be his advocate in a lot of ways, sometimes where I've maybe been a bit vehement, but on those occasions I think there's been a real necessity for it, it's not necessarily the way I like to do it, I'd rather do it alongside, but there's some times when you do have to actually fight your ground.

Parents stated that the gap in services and lack of relevant information pushed them into advocacy. One mother had started a parent support group in her rural area to address local needs. Many parents had attended regional meetings to advocate for improved educational support and had helped other parents navigate through bureaucratic hurdles. As a coping process, parents usually used advocacy when other means had not adequately produced satisfactory results.

Planning Ahead and Solving Problems

There were multiple examples of parents using their problem-solving skills and resourcefulness on a daily basis. Parents demonstrated a determined effort to circumvent and modify troublesome behaviour and to limit overexposure to triggering events. Some parents spoke of taking out sugary food and/or food with additives/colouring to try and control their child's behaviour, particularly if there was a comorbidity diagnosis of ADD/ADHD. To prevent anxiety or meltdowns, an important

part of planning ahead revolved around preparing their child for new or potentially unpleasant situations:

> [We] try to circumvent, problem solve I guess, you can be in situations that will be a problem for him, because often what we've found with [our son] is it's the *unknown* that's a problem for him, if he knows what's expected of him, you know who's going to be there, what it's going to be like, what they'll have to do there, he goes much better. So, first times with things can be quite stressful. (Susan).

Allison described how her family coped through problem solving:

> …it does affect the whole family. I think Asperger's is quite a weighty thing, it's there with you all the time, you are always thinking ahead, especially when they are young I found myself always planning ahead, shall we let him know, shall we not let him know, how do we keep this routine but not yet get over the top. How can we keep our family lifestyle of going out and doing adventures, exciting things without overloading him?

Mothers spoke of travelling to new locations with their child before they needed to venture there independently, such as to camp or a new school campus. If their child was young, they took pictures of the new place and reviewed them at home in a storybook format. On excursions, parents were prepared with books for their child to read or headphones with music to help calm. Parents shared several examples of trialling a wide variety of techniques and strategies that might only be effective for a short time. Other approaches were found to be successful over the course of their child's growing up years. This included parents learning to "listen, suggest, rather than demand, and clarify" (Grace) and using 'I' statements when they were communicating with their child. Clear and succinct directions were mentioned as particularly important. Parents' coping responses helped their child understand directions clearly, acclimate to new situations, and avoid triggering events, which improved family functioning.

Stepping back. Taking a step back helped many parents regroup, gave time for their child to process information and prevented the situation from escalating. Sandy and Ian explained how they tried not to "inflame" difficult interactions with their son:

> Now we know to take a breath and you know wait a bit, yeah, not just
> jump right at it, whatever situation has improved or come about, because
> usually we…come at it real quick, now you sit back and you wait, see
> what happens, come up with an alternative.

One mother had found walking away when her daughter was angry effectively stopped the situation from escalating. Other parents mentioned the skill and persistence of their children to argue, and said "don't fall into his trap" (Yvonne) or "he just [finally] realises you're not going to bite" (Natalie and Leo).

Stepping back was used as a conscious strategy to manage particular challenges, but it also was done when parents had reached the end of their patience. Gayle shared that she "got to the point where I didn't know how to handle it so I just gave up, he could do what he wanted to do" and Eve shared a similar frustration raising her two young adults with AS:

> I've almost given up trying to say no. I mean, if it's life threatening of
> course I put my foot down or something, but I realise that if I say no then
> I'm gonna find out sooner or later that they've gone and done it anyway.

Though this was not necessarily a productive strategy, it did give parents temporary relief and an opportunity to regroup.

Abbie said she and her husband purposefully waited if their son did not follow through on directions to give him adequate time to process the information rather than jumping in to nag.

> …other strategies have been visual guides, reminders of things, being
> patient, being repetitive, not nagging repetitive, but accepting that [her
> son's] initial 'No' doesn't mean no, it's the processing, I've had to teach
> my husband that one, so [my husband] will say 'Can you bring the bins
> up'. 'No'. And then [my husband's] like 'Grrr' and I'm like 'No, sit back,
> take five, wait and if he then doesn't do it go and ask him again'. What
> you'll normally find that giving him 10 minutes to process and then do it,
> he'll have done it, and lots of teenagers can be like that, but with aspie
> teenagers they tend to need even more of that processing time, so we
> might say 'Can you do it in the next hour?' then if they haven't we'll go
> back to him, your 'now' expectation just can't be there. (Abbie)

If past relationships had been tenuous with their child's school, either from attempts at resolving conflict over inadequate support or from their child's troublesome behaviour, a few parents shared they pulled back at the start of a new

year or when their child enrolled at a new school with the hope all would go well: "So this year I have kind of taken it a bit slow, just a back step" (Yvonne). Even though they told their child's new teachers that they were "available at any time should you need me" parents chose to step back even though they were frightened it would all "blow up" again (Leah).

The parents of the older children in the study spoke of taking a step back to give their children opportunities to practice independence.

> I think we've actually got to a point now where he's now 22, so he's starting to make decisions about what he wants to do, and yeah we're just sort of hopeful that, we will support him and we'll point out, I think it's how you approach him, instead of going in there and saying 'No, I don't think you should do that', it's a case of 'Okay, well, tell me a bit more about it', you know, and do it that way. (Grace)

The strategy of stepping back gave their children room to grow and provided relief from constant interaction.

Strengthening Intrapersonal Assets

Five intrapersonal assets were identified in parents' narratives that contributed to building productive processes. These included self-efficacy, positive outlook, sense of humour, patience and perseverance. Parents noted that all of these qualities were put to the test in their daily lives and over time, and consciously strengthening them produced positive results for everyone involved.

Self-efficacy. The efforts to manage the persistent and ongoing challenges, both inside and outside of their homes, resulted in parents gaining extensive experiential knowledge. Out of necessity, parents became very resourceful and spoke of their improved ability to handle difficult situations over time. Camille had learned through her personal experience that the following traits were crucial to parenting her children with AS:

> … self-belief, self-awareness, knowing your rights, not being intimidated by so-called experts, taking the initiative and retaining it, sticking together and being open and honest…

Jeffrey said it was important to be strong and confident to deal with the challenges

and prepare his son for the future and Abbie reflected that she must manage her challenges well because her family's well-being and marriage were at stake. In Juliana's narrative, she explained how her self-efficacy developed:

> I think it's really important just to remember don't try and make the child or the family fit in, the social pressures, and I think you've got to sit back and take your own time, and don't worry about what other people think, and also don't take the advice of mothers at the school gates, you know, just to be confident that you've got the answers really. I suppose, you know, there's not another mother that's going to have a better solution, because that can be quite hurtful sometimes, and you feel it's me. So that would be the main thing just to stay confident, and you know, don't worry what other people say or think. (Juliana)

Juliana's confidence contributed to an affirmative, supportive relationship with her son:

> I think that I don't feel the why me thing. I don't have any bitterness and I think that what I need to give him is confidence, and that he's equally able and deserving. I tell him I love him a lot and I think, you know, this isn't his fault. And I've always been very sure that there's no sense that he thinks that it is, you know. So I think I'm very kind of open and expressive around that.

Over time, parents had become self-reliant managing their child's difficult behaviours and more self-assured dealing with outside judgement.

Positive outlook. A positive outlook helped parents counter other people's negative feedback and created a climate more conducive to problem solving.

> …I think we've just learnt to sort of work around his quirks. It's more the outside world that's a challenge for him. So at the moment we just, as a parent, I'm just sort of feeling my way through things that work for him and things that don't and trying to accentuate the positive. (Susan)

Abbie said her family could be negative just by their "nature" so she helped balance it with a positive approach "otherwise it would be pretty awful". She added, **"**I always try and see a positive in something, I don't tend to get bogged down in deficit theorising". Brett's positive views on parenting a child with AS focused on the benefits:

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It's very intense sometimes and it can be very trying, but [my son] will reward you in different ways than the other children will, I think that's the real main thing about it…he'll respond in a unique – yeah it can be quite charming – way to a situation, one that you wouldn't ever expect a normal child to do…

For many parents, a positive belief in their child's ability to succeed motivated and sustained them through the multitude of challenges they encountered.

…you can do it, you can, you're perfectly capable, don't say 'can't', it's not a word we use, we don't use 'can't' we say 'we can'. We go out there and we give it a try. And a lot of it I think, that was one of the things that I did a lot of, was whole positive talking…and sometimes I would be quite impatient about it, I must be honest, I'm not the most patient person, I don't mollycoddle particularly, I encourage, 'Come on, you can do it, yeah, get going'. I'm not one of these 'Oh shame, you've got Asperger's, you can't do it'. You know I would never, I'm a bit like that…it's like you've got a special need, so what? Get on with it, you know…life is hard and mean and tough, you've got to get out there and do it. (Allison)

Having a positive perception of their child and hope for their future contributed to a better relationship and decreased stress. In addition, several parents capitalised on their child's strengths and interests and commented that positive reinforcement worked better than a punitive approach. Camille's maxims revealed her positive perspective and openness to try new strategies, such as there are "lots of ways to skin a cat", "nothing's ever set in concrete", and "if you don't try, then you don't know".

Sense of humour. Several of the parents' narratives revealed a strong sense of humour. They were witty, clever and quick to find the humour in difficult situations. Tessa said, "if I don't laugh I'll cry, we've had our very tough times too, so I think that's definitely [one of] my strengths". Sandy and Ian said they were using their sense of humour as a targeted strategy to manage their son's behaviour. It was a way to stop his repeated questioning or negative self-talk as he did not expect a humorous reply, and this approach helped to relieve built up tension. Humour worked for Allison as well:

But there are days when you get 'I hate you and you are horrible' and at one stage it was a standing joke with my entire department that I was 'Evil Mum'. He used to look at me and go *'Evil'*. So they said to me,

'Seeing it's worrying you so much, give it an acronym, change it into something funny'. So I went home and said [to my son] 'I've decided evil stands for extra vivacious, incredibly lovely, and every time you call me that I'm going to go *thank you'* and he couldn't bear it and it wore off very quickly, but I got the award at the end of the year for being the most evil mum from my department…I got these little sticking plasters with devil ducks all over them.

In this example Allison used humour successfully to diffuse a situation that was causing her stress and heartache.

Patience*.* Patience was the hallmark of coping processes in the parents' narratives. Camille stated "your patience is sorely tested on all levels". Liz, a solo mother said, "I'm patient now I suppose, never used to be patient, I'm patient even though I feel like I'm going crazy sometimes, being extremely patient and understanding Asperger's, thinking like he does…I can see how he sees things". Erin, a mother of a young child, offered this example:

…just a lot of patience I think, it took me a long time to get it because I thought it was my fault, and I used to get very frustrated, but it's just a lot of patience and taking it day by day, minute by minute…a lot of preparing him, any situation, anything we were doing in the day, it's just all about preparing, a lot of explaining, break it all down and sometimes that wouldn't work and he still wouldn't want to go somewhere, and he'd still have a meltdown, you know, he knew what was coming. And then a lot of it was reading the signs before the meltdown would happen, getting to know him really intensely like I said before, being able to know right, this is not going to work, there's going to be issues…

Patience evolved from acceptance, understanding and experience. Parents viewed their coping as an ongoing process.

I think one of my strengths, I think I'm quite, quite patient, I'm not, I could still work on it, but I think I have a really good amount of patience and I think in situations that [our son] seems to bring to us is a great thing. (Sandy)

Sandy said that forgiveness also was a key to her coping well: "You have to put it behind you" so you don't dredge up the past and "to me it's done and dusted and it's water under the bridge now".

Perseverance. Parents used words like "battle" and "fight" to describe the challenges they faced. They needed to keep their chins up and "ride it out". Tessa said "try, and if that fails, I'll try again" and to "*really* work on it". Kathryn put it succinctly: "Persistence, yeah, absolute dogged persistence". Neva, the one grandmother in the study who participated in the initial interview with her daughter, described the challenges of dealing with Asperger syndrome as: "Two steps forward, three steps back". Neva spoke of her determination to find support for her grandson when he first began showing some of the same troubling behaviours her own daughter did when she was young. Perseverance was a critical component observed in all of the narratives. This persistence is a key component to resilience building. Juliana ventured to say "you will probably actually end up feeling more fulfilled as a parent because it's that much more, it demands that much more of you". When parents encountered difficulties in several areas simultaneously and repeatedly, they showed renewed determination to secure help. Anne said "we moved hell and earth" to get to a specialist that could help with her daughter's extreme behavioural challenges at home, such as violence, self-harm, sleeplessness, and toileting issues. This mother's perseverance then led to a behavioural psychologist who put a successful programme in place.

Allison explained: "You pull yourself out the other side and you think, 'It's okay, we can deal with it, done it this far'". For example, Abbie described her journey this way:

> Parenting in itself is challenging, I think parenting a child with Asperger's is *highly* challenging. There are days where we feel we failed dismally, then there are other days we feel actually we've not done too bad…we're still hanging in there so we feel quite pleased that we're just maintaining some sort of normality for the children.

There was a strong commitment from this family to stay together and address the challenges of raising a child with AS. She said later in her narrative, "We're strong enough to ride the wave".

Camille shared her determination over the years raising two children with AS:

> I know a lot of my friends say to me they couldn't cope and how do I do it, and life has never been any different. It's always been this way and it's just evolved over the years as the kids have grown up and their needs have changed. I just kept on doing what I have been doing…

A resolve to persevere especially came through in the coping processes of parents that had faced significant challenges, such as raising two children on the spectrum, battling education or social services, or coping with additional family stressors.

In conclusion, parents were responding and coping with the particular challenges in raising their child or children with AS through five areas of building resilience: turning point experiences, meaning making, developing resources, planning ahead and solving problems and strengthening personal qualities. Parents demonstrated concerted efforts to manage stress successfully and adapt long term. After a difficult morning on the day of the follow-up interview, Leah shared her own story of being able to cope and recover:

> And four years ago I never, ever would have been able to cope with a day like I've had today, would have had me just a complete puddle of tears and you would have arrived to find me eating chocolate and ice cream, cuddled in front of a movie with a huge box of tissues hating the whole world. As it was I had a wee cry, bitched to my mate and then talked about the whole thing with my husband and calmed myself down and him down, and it was kind of I haven't done much more than that, but I'm not just a complete wreck on the couch.

Chapter 8

Discussion

The previous three chapters presented the findings from the participants' narratives in response to the study's two principal research questions: What are parents' experiences raising a child or children with Asperger syndrome, an autism spectrum disorder; and how do parents respond to and cope with the particular challenges associated with parenting a child or children with AS? The findings demonstrate that parents are faced with *exceptional* stress and challenges while raising a child with Asperger syndrome. The rich, qualitative data collected show families dealing with substantial stress within the context of their daily lives and throughout their child's growing up years. The challenges noted were persistent, pervasive, cumulative and unpredictable. As noted by Boss (2002), this will result in parents experiencing a higher level of stress. Walsh (2006) counsels that if stress is intense, unpredictable and prolonged, mothers and fathers are at risk of breaking down. The stressors parents cope with confirm findings from international studies while contributing valuable New Zealand data to this topic (Gray, 1997; Lasser & Corley, 2008; Rao & Beidel, 2009). The findings from this study provide a vivid and detailed account of the magnitude of the challenges for parents face raising a child or children with AS in New Zealand.

As parents worked to cope with the stressors in their environment, their personal turning points revealed self-efficacy and resilience developing, and their sense of coherence improving (Rutter, 1996; Walsh, 2006). These turning points demonstrate parents' positive transformation in response to stressful circumstances that have built up over time, contributing to the theoretical framework of family resilience (Walsh, 2006; Wheaton & Gotlib, 1997). Furthermore, turning points illustrate the contexts, settings and factors that play a critical role in positive adaptation along with the pertinent issues that need to be addressed (Liamputtong, 2009). In many of the parents' turning points, timely help, such as specialist support or a community programme, had a significant impact on their ability to regain control and confidence. This has significant implications for family support. Through the consideration of turning points, this narrative study makes an important contribution

to our understanding of the processes of building resilience when managing adversity over the long term.

The stories shared revealed parents employing numerous productive strategies in response to the stressors and heightened demands in their environment. Parents' coping responses demonstrated great tenacity and strength of purpose. They struggled over the course of their child's unusual development to manage difficult behaviours and cope with a community unfamiliar with, or resistant to, parents' challenges and experiential knowledge. Parents were persistent in their efforts to make sense of their situation, seek out resources, anticipate problems, and work actively to become stronger.

This discussion chapter will address the challenging aspects noted for parents and their impact on family functioning. Next, the indicators of resilience found in the parents' coping responses and key processes are considered. Following that, the complex nature of coping and building resilience within social systems are explored. The findings are compared with relevant studies covered in the literature review and considered within a family resilience framework (Walsh, 2003c, 2006). The implications for practice for the New Zealand context include early identification and intervention, raising parents' capabilities and self-efficacy through behavioural intervention strategies for their child, meeting parents' social support needs, the importance of respectful relationships between parents and professionals, targeting school support and resource allocation, and considering support at critical times, such as turning points. Closing this chapter are the study's limitations, future research directions and conclusion.

What Are Parents' Experiences Raising a Child or Children with Asperger Syndrome, an Autism Spectrum Disorder?

In this study, the distinct difficulties directly associated with Asperger syndrome and high functioning autism were identified as especially challenging for parents. The child's self-regulation problems impacted on relationships within the family and their ability to socialise outside of the family, which resulted in significant stress for the family. Outside excursions and transitions needed to be carefully planned due to their child's resistance to change, their high sensory sensitivities to crowds, noise, and smells and their predisposition to becoming unsettled. A child's meltdowns in public

combined with the 'invisible' aspect of AS put parents at risk of public censure. Consequently, families were affected by reduced social interaction on family functioning. The challenges mentioned across all the parents' narratives included their child's anger, anxiety, fear, worry, depression, as well as their inflexible, unreasonable and unpredictable behaviour. The child's obsessions and compulsions and strong desire to adhere to routines severely taxed parents' patience. Parents were also particularly distressed about their child's negative school experiences. School personnel's interpretation of 'mild' or higher functioning resulted in inadequate or no support for their child's difficulties with executive functioning, such as planning, organising, remembering and following through, nor with their social skills, resulting in the child having few or no friends and being bullied. Moreover, parents expressed serious concern about their child's future relationships, employability, and independence.

These challenges were combined with a pronounced lack of community awareness, knowledge and accommodation regarding the needs of their children. This lack of familiarity, understanding and sensitivity magnified *all* the challenges associated with parenting a child with AS. Parents were extraordinarily weary dealing with health and education systems in their search for answers and assistance, and had been adversely affected by stigma in their community. The prolonged search for a medical diagnosis created a financial and emotional burden for families that stretched over several years. Families faced additional challenges as they sought support after the diagnosis was found. A new layer of bureaucracy had to be dealt with that moved the locus of power from parents to health and education specialists. These stressors create considerable psychological distress and poorer physical health for parents (Allik et al., 2006; Rao & Beidel, 2009).

Many issues regarding the challenges associated with parenting children on the autism spectrum were corroborated in this present study (Gill & Liamputtong, 2013; Myers et al., 2009). Parents identified similar challenges found in Myers et al.'s (2009) study of almost 500 online parent responses of how their child with ASD affected their life and their family's life. These included difficulties dealing with the child's aggressive behaviour and managing on little sleep; struggles with schools and services; concerns about the impact on siblings; social isolation and stigma; and experiencing difficult emotions like depression and guilt alongside positive ones, such as patience and compassion. These findings were congruent with this study's

findings, however, the longer narratives from this study provide a clearer and more holistic view of these challenges within the social environments parents live in, and provide a clearer perspective across a period of time. The findings from this study also support those noted in Gill and Liamputtong's (2013) study of 15 mothers raising children with AS in Australia. Parents in both studies experienced mental and physical exhaustion coping with their child's uneven development, odd behaviour, disturbed sleep, lack of reciprocity, and poor response to typical parenting measures and discipline. In both studies, parents' detailed significant delays between their first concerns and the eventual diagnosis, and the repercussions of stigma. In this study, the perspectives and experiences of fathers and stepfathers provide more balance and depth to the findings, an aspect missing from current studies that predominantly focus on maternal stress levels (Baker et al., 2011; Kuhn & Carter, 2006).

Additional similarities were found in the studies that explored challenges encountered outside of the family (Gray, 2002a; Ludlow et al., 2012; Ryan, 2005). The findings in Ludlow et al.'s (2012) qualitative study of parent experiences raising children on the autism spectrum in the UK were also substantiated in this study, specifically the social implications of challenging behaviours that result in judgement, stigma and isolation. Parents in this study were highly committed to their child's success, so conduct challenges associated with AS, combined with a lack of understanding from people in the community caused considerable stress. Gray (2002a) found that in parents' efforts to negate the effects of stigma, mothers tried a variety of strategies, such as ignoring comments, lessening contact with others, avoiding situations where problem behaviour could occur, explaining the nature of the syndrome, or using humour to diffuse the situation. Similar strategies were reported by parents participating in this study.

The difficulty socialising was acutely felt by parents in this study. The 'invisible' nature of AS led to "those present judging the children by inappropriate standards and, therefore, questioning the competency of their caretakers" (Ryan, 2005, p. 294). As parents experienced stigma, they withdrew to combat judgement and potentially embarrassing situations, which in turn limited social interaction for themselves and their other children. Parents were also affected by the stigma their children encountered at schools when their children were bullied and rejected, and subsequent opportunities lost to socialise with other students' parents. Parent experiences in this study revealed a pronounced lack of understanding from

extended family, friends, teachers, social services and the general public about the behaviour of their children.

Furthermore, a range of negative emotions were experienced when their parenting skills and competence were called into question as they interacted with health professionals and their child's teachers. Parents' narratives contained several examples of interactions that contained judgemental and dismissive comments. In the New Zealand context, professionals' unfamiliarity with the dimensions of the autism spectrum, the perception of the disorder being less severe, and a lack of respect for parental expertise caused continual frustration for parents. Moreover, a lack of support and resources for children with AS was found when parents attempted to access help through the health and education systems. Parents' coping abilities were pushed to their limits due to the lack of appropriate resources for their child, themselves and their family, such as speech and occupational therapy, educational support, family counselling, and respite care. Families made adjustments to manage, such as investing their own funds, seeking out advice from other parents raising children with AS, and advocating for better services. Negative school experiences featured prominently in parents' narratives, and the effect of their child's inability to function well at school was a source of great distress. School-related stress also featured prominently in the narratives from Marshall's (2004) doctoral study. The parents of the older children in this study (17-years-old to 22-years-old) were relieved their battles with school services were in the past though the impact of opportunities lost was still keenly felt. Their present concerns centred on their child being able to find and keep productive work and gain independent living skills.

The *pervasive* nature of an autism spectrum disorder presented significant stress for parents; Camille conveyed "it is so relentless, nothing is ever easy, nothing's ever straightforward". These narrative thematic findings substantiate the results from other qualitative studies regarding the stressful experiences in parents' lives and contribute vivid accounts of the contextual factors that contribute to that stress. The findings demonstrate that raising children with Asperger syndrome is extraordinarily challenging and stressful.

The discussion that follows addresses the second research question: How do parents respond to and cope with the particular challenges associated with parenting a child or children with AS?

How Do Parents Respond to and Cope with the Particular Challenges Raising a Child or Children with Asperger Syndrome, an Autism Spectrum Disorder?

As previously discussed, parents must cope with significant stress when parenting a child or children with AS. Pearlin and Schooler (1978) surmise that the efficacy of coping "cannot be judged solely on how well it purges problems and hardships from our lives. Instead, it must be judged on how well it prevents these hardships from resulting in emotional stress" (p. 8). Raising a child with AS complicates parents' lives and family functioning in several ways (Rao & Beidel, 2009; Wolf et al., 1989). Lazarus (1991) explains that "we don't become emotional about unimportant things, but about values and goals to which we have made a strong commitment" (p. 819). The parents in this study are indeed committed to their child's development and future prospects, as well as the healthy functioning of their families. There was a strong sense of coherence evident as well, that is, challenges were seen as meaningful, comprehensible and for the most part, manageable (Antonovsky, 1987). There was a determined effort to cope successfully with the stressors they encountered on a daily basis.

In Ludlow et al.'s study (2012) parents expressed that challenges became easier to deal with over time and Gray (2006) found in his longitudinal study that parents used less coping strategies overall, relied less on support from outside of the family, and shifted from problem-focused to emotion-focused strategies, such as philosophical perspectives and finding benefit (Gray, 2006). In this study, the mothers and fathers of the older children noted many challenges over time and trialled a wide variety of strategies. Their narratives were introspective and contained examples of coping strategies that were emotion-focused as well, such as utilising positive reinterpretation for challenging circumstances. Perceptions of stressful situations are instrumental to how families appraise and manage successfully (Boss, 2002; Summers et al., 1989). Parents' perspectives in this study developed in response to significant stressors in their environment, the limited resources at hand, and their consideration of what a 'disability' meant alongside their feelings for their child. Their perspectives revealed how coping strategies and perspectives develop over time when raising a child with ASD in response to the "enduring circumstance of autism" (Marshall, 2004, p. 162).

Parents' meaning making, resource development and strengthened intrapersonal qualities were all noted as productive adaptation to the challenges raising a child with AS. Parents reconceptualised what was 'normal' for their child and for their family routines and capitalised on their own and their child's strengths. As parents connected with extended family and other parents raising children on the spectrum they built avenues of support and benefited from their guidance. Forward planning was noted as parents worked to curtail potential upsets. Patience and a sense of humour helped parents persevere through difficult patches. Parents developed expertise on effective strategies through problem solving and personal research, moving to advocacy when there were persistent gaps in services. Turning points highlighted parents' efforts to gain control, build self-efficacy and foster resilience. The narratives in this study reveal the complexity of the demands associated with raising a child diagnosed with AS and the perseverance needed to manage them.

The narratives collected in this study contained several indicators of resilience. The parents' perspectives, world views and personal values were revealed through the stories they told (Clandinin, 2007; Elliott, 2005). In addition to introducing turning points, four key processes demonstrate resilience building in parents' coping responses that parallel Walsh's (2003c, 2006) family resilience framework. In this study, these key processes are identified as: making meaning, developing resources, planning ahead and solving problems, and strengthening intrapersonal assets.

Meaning making. The findings show parents making meaning of their child's diagnosis and what it means to parent a child with challenging differences. Taylor (1983) proposed that people adapt to threatening events by making meaning of the experience, working to regain mastery and bolstering self-esteem. Adversity has the potential to disrupt personal and family integrity and create a crisis of meaning for those involved (Walsh, 1996). Meaning making continues *throughout* the coping process, from the initial appraisal through to subsequent reappraisals (Lazarus & Folkman, 1984; Park & Folkman, 1997). Efforts to make meaning of stressful circumstances and gain coherence contributes to building competence and confidence during the coping process (Walsh, 1996). Positive reappraisal can also facilitate purposeful planning (Folkman et al., 1986) and lead to personal transformation over time (Lutz et al., 2012; Marshall, 2004).

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Pearlin and Schooler (1978) state that the manner in which we perceive or interpret the situation can neutralise its negative characteristics. A positive appraisal and reconceptualisation of what is 'normal' can be a powerful tool that families use to minimise the effects of stress in their daily lives (Gill & Harris, 1991). In this study, a positive reinterpretation helped parents to restore the disequilibrium created by the diagnosis and by outsiders' judgement of their child's behaviour. When personal beliefs were challenged, parents' perspectives focused on their child's strengths and unique gifts. A positive reinterpretation of stressors allows parents to exert control over their situation in their attempt to master it (Carver et al., 1989; Folkman & Moskowitz, 2000).

The meanings parents give to the experience of raising a child with challenges illuminate societal interpretations of difference and efforts to reconcile these differences. Parent perspectives revealed their efforts to cope with the challenges associated with parenting a child with a 'disorder'. A few of the parents rejected a medical interpretation of their child and 'disability as tragedy' (Oliver, 1986) and most commented on their child's great potential. Their outlook embraced the constructive aspects of their child's strengths and attributes and challenged the deficit view present in society. Inglis (2006) found in a doctoral study of parent experiences that parents described their child's strengths as being loving and affectionate, funny and engaging, with amazing minds and Woolfson (2004) found that when a parent reappraises their view of disability to one that promotes a positive identity, their self-efficacy improves. For the parents in this study, their child was first and foremost always their *child* and being different was not wrong or lesser than.

There were several examples of parents highlighting the rewards and value of their child or children. Parents' viewed their child as someone who had a unique and valuable interpretation of the world. Evan remarked that the characteristics of autism spectrum contain "some really positive things about it that you can harness" and after his daughter received the diagnosis he realised she "can experience the world in a particular way". After he read the writings of people with autism who reject the notion that autism should be eradicated, this father saw autism as a gift that could enhance his daughter's life.

Parents' narratives contained many examples of working to see the world from their child's point of view. For example, the stories from Brett, Eve and Grace illustrated their efforts for developing an increased sensitivity and appreciation for

what their children are experiencing (Billington, 2006). This was congruent with the findings from Dale et al.'s (2006) study, where the researchers found that the "parents' ability to perceive and value their child's personality" showed acceptance and a recognition that autism is an integral part of their child (p. 281). A fundamental consideration is called for regarding *all* of the ways we interpret our world, and "autism somehow seems to demand that we consider the boundaries of our physiological and psychological experiences" (Billington, 2006, p.11).

Redefining 'normal'. The narratives collected in this study reveal the larger cultural, social and institutional narratives parents must confront when raising a child with a disability as detailed by Caine, Estefan, and Clandinin (2013). Society defines abnormality through the diagnostic instruments such as the DSM, and the idea of normalcy is influenced through social transaction and ideals (Moloney, 2010). Many of the parental perspectives on disability mirror the narratives from Connor's (2013) research that challenge societal perceptions of disability and instead frame difference as a new construction of normal. John had remarked about his son having two labels attached to him (Asperger's and 'special needs') that influenced his son "because everybody reacts to them"*.*

When the autism spectrum is viewed as a deviation from a 'norm' then a person with AS is seen as damaged and defective. This prompts parents to reconsider what normal means to them when their child has been diagnosed with a 'disorder'. John spoke at length of the importance of education systems widening the idea of what 'normal' is to include *all* children, each who have special needs in one form or another, rather than separating out those who are different or deviant and then assigned specialists. Baron-Cohen (2000) reasons that instead of a deficiency, "autism might be better characterized as a *different* cognitive style" (p. 489) and "the notion of a continuum assumes that there is an underlying dimension or set of dimensions along which all people vary" (p. 492).

In the novel *The Rosie Project*, the main character proclaims that the characteristics of AS are "simply variations in human brain function that had been inappropriately medicalised because they did not fit social norms – *constructed* social norms – that reflected the most common human configurations rather than the full range" (Simsion, 2013, p. 12). A neurodiversity perspective accepts and values different cognitive styles. One mother in Dale et al.'s (2006) study said, "I mean it's

really all down to what's socially accepted you know, there's actually nothing wrong with her as I see it, but it's what society's expecting of her…she's not fitting into what society wants her to be" (p. 474).

John also advocated for the medical establishment to move away from a pathological model, stating his son was not sick or diseased with all of the negative connotations that follow from that particular perspective. The conventional models of deficit and impairment that professional practices are based on poorly represent the full spectrum of human experience and consciousness, and disregard the variety of ways we feel, think and find meaning (Billington, 2006). A mother in Myers et al.'s (2009) wrote: I admire the way my daughter gets up in the morning and faces a world that often mocks her, rejects her, belittles her but I also wish we could celebrate excellence instead of just striving for normalcy" (p. 681). Summers et al. (1989) explain, "It is the attitude of society, rather than the families and/or the people with disabilities that needs to be addressed" (p. 37).

In this study, Eve reflected: "It's impossible to get inside their heads and it's impossible for them to get inside ours. The unfortunate thing for them is that we're the majority and that's what makes it so difficult for them. They have to come into our world; we don't have to go into theirs". Linton (1998) recommends an 'epistemology of inclusion'; that is, a thoughtful, analytical philosophical foundation for full participation. This extends to families of children with disabilities, and the social environments they participate in. To protect families' ability to build resilience, there needs to be an enlightened understanding of the relationship between family functioning and societal, political, economic and racial milieus (Rutter, 1987; Walsh, 2006).

Parents reframed their perspective to one of possibilities and what 'normal' was for their child and their families. For example, parents valued their child's differences and adjusted their approach to alleviate pressure from trying to conform to societal standards that was at odds with their child. This finding agrees with Levine's (2009) study of single mothers and how they transformed their positions from their child being 'disabled' to 'different' or 'normal'. Families formed a new concept of normality as they adjusted the fit between their environments (Walsh, 2003) and tempered the dissonance between other people's perceptions of normal and their child's differences (Huws et al., 2001). They capitalised on their own and

their child's strengths. Parents in this study accept their children for who they are and champion what they can be.

Developing resources and moving to advocacy. The appropriate resources help parents manage the demands in their environments, strengthening their sense of coherence and promoting health (Antonovsky, 1987; Antonovsky & Sourani, 1988). In this study, parents spent considerable amounts of time researching information; sought support for their child's learning and social needs at school; pursued advice and intervention from specialists in the health systems, such as for their child's behavioural challenges or sensory sensitivities or for family counselling; and connected with other parents of children with AS for practical and emotional support. Seeking social support can be both a problem-focused and emotion-focused strategy as parents seek advice, assistance and information, as well as moral support and understanding (Carver et al., 1989; Mackintosh et al., 2005). The diagnosis presented a turning point for many parents and prompted a concerted effort to find relevant information and resources. Searching for information after the diagnosis can help manage the overwhelming emotional impact of receiving a diagnosis (Lutz et al. 2012; Whitaker, 2002) and regain some sense of control over a new and challenging situation (Marshall, 2004).

When parents encountered gaps in services they moved into activism and advocacy roles which can result in a sense of empowerment. Parents expressed a strong desire to help others, and through their fight to secure services they wished to prevent other families from experiencing the same frustration and feelings of isolation that they had experienced. This sentiment is similar to Ryan and Cole's (2009) qualitative study of mothers of children with ASD. They felt their struggles finding a diagnosis, securing support for their child's needs at school and searching for family counselling could be informative for other parents and teachers. They too had developed skills through their personal research, conferring with specialists and navigating through the health and education systems for services and support.

There are some outstanding examples of parents building resilience in this study through empowerment, with turning points highlighting this evolution. Tessa was committed to helping other parents navigate the bureaucratic hurdles to school support and Tanya had started a parent support group to help other parents with "the knowledge and skills that they need to cope". Abbie said, "There's no one else in the

world that's going to advocate for your child like you are, but it's about building relationships that are supportive" and Camille said, "If you are not happy, don't put up with it; fight for what you think is the right thing".

Planning ahead and solving problems. Planning ahead and solving problems shows an adaptable and fluid response to challenges that can result in a positive influence on child behaviour (Baker et al., 2011). Parental coping responses paralleled the findings from Woodgate et al.'s (2008) qualitative study of 16 families raising children with autism in Canada who utilised purposeful planning to head off potential problems and actively help their children reach their full potential. In this study, the intense and pervasive demands directly associated with AS resulted in a determined effort to problem solve and plan. To adapt to stressful environments, it is imperative for parents to strategise to keep stressful events from repeating (Taylor, 1983).

Stepping back was noted as another effective strategy and can be viewed as a problem-focused coping strategy, or restraint coping (Carver et al., 1989). Parents who utilised this response made the conscious decision to step back to manage the stressor. Experience had shown that further engaging with their child at critical moments inflamed the situation and taking a step back protected parents' precious energy levels.

Strengthening intrapersonal assets. Bandura (1997) explains that a resilient efficacy emerges through perseverance, and experience overcoming obstacles. This was apparent in many of the parents' narratives, such as the statements from Leah and Brett: "We do handle things pretty well on our own" or Natalie and Leo: "With our family we've done it ourselves, we're just a little unit of three". Abbie reflected, "I have to manage it, because if I don't, you know, what have you got". Limited resources and support for the ongoing challenges in their lives had resulted in resolute determination, but parents had also accumulated a life time of hands on experiential knowledge.

Patience, a sense of humour and a positive outlook were tested *and* used well. Positive emotions such as humour and optimism help individuals to cope effectively with stress by regulating negative responses and opening up thinking for possible solutions (Tugade & Fredrickson, 2004). Walsh (2006) states:

A positive outlook has been found to be vitally important for resilience. Key elements involve hope and optimism; focus on strengths and potential; initiative and perseverance; courage and en-*courage*-ment; and active mastery and acceptance. All are essential in forging the strength needed to withstand and rebound from adversity. (p. 64)

The parents in Altiere and von Kluge's (2009b) study spoke of 'enhanced' patience and Brett in this study captured it aptly: "You've just got to have a lot of patience and you've got to persist at it…" He said that he tried "not to sweat the small stuff" and that he was confident that being patient with his son was "going to pay off in the end". Durand (2014) ascertains that parents' optimistic approach to themselves and their child influences their success in helping their child behave better. There were several parallels to the findings from King et al.'s (2009) study of 16 families of children with ASD or Down syndrome as parents demonstrated optimistic perspectives by focusing on their child's potential and strengths, accepting difference, and striving to change the environment. Parents continued willingness to ask for help reflected their great need as well as their perseverance.

Combined with turning points, these coping processes illustrate parents' positive adaptation to the stressors associated with raising their child or children with AS. Furthermore, they reveal the development of resilience in their families as they build up a base of knowledge, strategies, resources, and self-efficacy. These processes show parents making meaning as they focus on their child's strengths and potential; seek out resources and help; take a proactive stance to head off problems and use their resourcefulness to solve the ones they do encounter; and build up personal stores of patience, perseverance, optimism, confidence, and sense of humour.

Turning Points and the Resilience Process

A significant contribution of the findings point to how turning points reveal the process of parents building resilience during their life course. These turning points primarily revolved around receiving a diagnosis after several years of uncertainty; coming to terms with an autism spectrum diagnosis, such as reconciling societal views of disability with their personal feelings for their child, or finding unification

together as a family; securing much needed school support; or witnessing their young adult take their first steps to towards independence.

Parents' retrospective accounts of their turning points included descriptions of drawn out battles that involved substantial time and energy investments for them and their families. A predominant feature in parents' narratives is when *help* was finally found or given, relieving the built up stress. Examples of timely help include the behavioural specialist in Sandy and Ian's narrative; the proficient home tutor Camille found; and the community programme that provided the needed structure and discipline for Kathryn and John's son. The diagnosis opened a door to essential information and support for many parents. Erin expressed that the diagnosis was her turning point because "there's something he needs help with, and now I can help him, I can go and talk to people about it". For Brett's turning point, a diagnostic label was "very helpful" in giving him a framework to better understand his son.

Furthermore, these turning points revealed the tension between parents' perspectives raising a child with AS and societal notions of disability and parenting standards. Susan's turning point included the realisation that her son was "the same beautiful kid that he's always been" even though the medical diagnosis communicated a 'disorder' and the education system listed him as a 'special need'. She did not think of her son in terms of deficits or dysfunction (Connor, 2013; Phillips, 1990). The dissonance this created for Susan and other parents in the study illuminates the additional stress of what outsiders consider 'normal'. Parents do not feel that their children are 'less than'; rather, their children hold distinct and unique gifts with great potential. Societal standards for parenting were evident in parents' turning points as well. Gayle shared that when she received the diagnosis she could stop "battling" as she finally understood why her son was not responding to traditional parenting measures. She could approach the challenges from a different angle and "feel okay about it". Leah said she felt like a huge weight had lifted when her son was diagnosed and she realised she was not a 'bad parent'.

Abbot (2001) ascertains that "a major turning point has potential to open a system the way a key has the potential to open a lock…action is necessary to complete the turning" (p. 259). There were examples in the parents' turning points that revealed this determination, for example when Sandy stated "we're not going to sit here and take it anymore". A pivotal moment occurred for these parents when a new, particular direction was judged necessary, and taken with a "new belief, new

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courage" (Bruner, 1994, p. 50). Leah shared, "I'm not too afraid of actually turning around and saying I need help". After prolonged delays and years of distress, parents propelled themselves into action soon after receiving the diagnosis (Fleischmann, 2004). Turning points demonstrate parents' decisiveness and conscious action that resulted in a changed direction.

Turning points can cause disequilibrium with the potential for improved functioning afterwards (Patterson, 2002). The new direction alters the destination for parents' lives (Wheaton & Gotlib, 1997). Most of the turning points shared in this study generated a positive change in parents' daily lives and created a healthier trajectory in their life course. There were several examples of positive outcomes and descriptions of a more hopeful future, with parents embarking on more sustainable directions. After Abbie reflected on her turning point, she said her family can now rebuild and improve their relationships. Yvonne's self-awareness and perspective on remaining flexible and open to change helped her to mentally prepare for future difficulties related to her son's behaviour. She took a proactive stance that prepared her for future challenges (Walsh, 2013). These successful outcomes can then have a positive influence on parents' perceptions of future stressors (Bandura, 1997).

Narrative inquiry allowed for the parent, as a narrator, to imbue meaning to the significant moments during their life course (Clausen, 1995; Nünning, 2012). The turning points in this study expand our understanding of the coping and resilience building process. They are important markers along a parents' life trajectory. Turning points show opportunities opening up, improvements in family functioning, and positive changes in self-concepts, expectations and perspectives (Rutter, 1996). Weiss (2002) found that "coping appears to be boosted by perceptions of control and self-efficacy and by a general sense of purpose" (p. 125) and Bandura explains that building personal efficacy "involves acquiring the cognitive, behavioural, and self-regulatory tools for creating and executing effective courses of action to manage ever-changing life circumstances" (p. 80). There is potential for turning points to contribute to self-confidence and ability as parents successfully weather disequilibrium (Bandura, 1997). Bandura (1997) calls these "enactive mastery experiences" that provide authentic evidence of efficacy development. Parents can draw on turning point experiences to traverse subsequent challenges with increased competency. The turning points identified by parents in this study demonstrate improvements in relationships and support networks, perspectives on challenging

circumstances that are constructive and the successful implementation of strategies. These turning points identified in parent narratives add a new dimension to our understanding of the process of building resilience through personal and family gains.

Complexity within Coping

The positive adaptations parents made in response to the challenges in their daily lives revealed the multifaceted and ongoing nature of coping (Patterson, 2002). Complex dimensions were found within parents' coping responses and resilience building processes. For example, multiple stressors could occur simultaneously, prompting a complex coping response. Coping responses were interconnected, for example, a positive outlook influenced parents' perspectives and meaning making regarding AS; or the difficulties finding appropriate support led to advocacy and perseverance. Parents also shared that strategies that worked for one situation did not work for others. A rise and fall in a family's ability to meet challenges over time was found depending on the changing conditions within the family's environment and the resources available (Rutter, 1987). Changes in the family structure and dynamics, such as divorce, remarriage and the amalgamation of children from other relationships, relocation, job changes, family illness, and so on created peaks and troughs in parents' attempts to build resilience. Furthermore, contradictory facets were noted within parents' perspectives and coping responses.

Family resilience theory recognises these varying circumstances, settings and strengths within coping processes (Walsh, 2006). There are diverse responses and corresponding effectiveness from one set of challenges to another, with recursive processes occurring over time (Walsh, 1996). For example, the coping skills needed for the aftermath of a significant disruption, such as the diagnosis, can differ from those utilised for long term stressors (Walsh, 1996). McCubbin and Patterson's (1983) Double ABCX model can be applied to parents' diverse coping processes as they attempted to manage the multiple events in their daily lives, for example, the unpredictability of their child's behaviour and their child's sensory sensitivities (Aa), their own personal resources, such as self-efficacy and problem solving skills (Bb), altered perceptions as their perspective changes and they attribute meaning to the event (Cc), and a reconceptualisation as events become normalised for their family

(X). Parents are tasked with multiple roles when raising a child with ASD, contributing to the complexity of their lives. Sousa (2011) writes:

> These mothers are expected to be nurturers as well as the external translators, advocates, and soldiers with expert, specialised knowledge in varied medical and nonmedical fields, including law, education, behaviour analysis, pharmacology, sensory integration, motor therapies, and bureaucratic minutia. These are divergent skills sets that require sizable commitments of time, money, and education. (p. 239)

Furthermore, as the family unit grows, so too does its potential for complexity. In this study, family members struggled to find their 'fit' between each other (for example, sibling adjustment to altered family routines and perceptions of unfair discipline; different adjustment times between partners to the diagnosis; or the new dynamics of blended families) and within 'family-to-community' levels, especially regarding lack of awareness of behaviours associated with ASD and the resulting stigma.

There were examples in parents' narratives of contradictory responses that revealed manifold dimensions, such as embracing the quirkiness of their child while also avoiding public outings and potential behavioural upsets, or stress being both distressing condition and a conduit for growth (Folkman et al., 1986; Hutcheon & Lashewicz, 2015; Myers et al., 2009). Ambiguity was present as parents worked to regain mastery and control after significant events, such as after turning points, and when they wrestled with medical interpretations of their child's makeup, outside judgement and their own concepts of their child's behaviour. This contributes to the O'Brien's (2007) work on ambiguous loss theory and how parents can demonstrate conflicting or contradictory emotions as they cope with the circumstances around their child with ASD, such as struggling with anxiety and uncertainty about their child's future while simultaneously demonstrating hopefulness.

Rutter (1987) emphasised the complex processes that occur over time as coping and adaptation develop. Parents in this study were in the *process* of developing resilience; they are a population under duress due to the challenges associated with AS and the lack of appropriate and sufficient resources in their environments. Diverse strategies were necessary to meet the variety of demands they encountered and when stress levels were significantly high, parents' abilities to manage were compromised. The findings from this study are testament to the critical need for adequate support to protect family well-being and nurture resilience. These

narratives give a glimpse into the complexity of raising a child with AS and the adaptations parents must make over time.

Building Resilience within Social Systems

These findings illustrate how the family functions within a radius of social interaction and influences. The child lives within a nest of siblings and parents; parents develop relationships with school personnel, extended family, work colleagues, and neighbours; media information and societal values on ASD are influential; and government policies on resource allocation have an impact on the family. Bronfenbrenner's (1979) ecological systems theory can illuminate the complexity of the challenges families face; the wide ranging influences on their ability to cope; the interaction between person and context; and the families' capacity for development. A socioecological perspective has particular significance on how disability is viewed and what responsibilities are expected for micro (family, school); meso (how interrelationships are supported); exosystem (medical and school districts); and macrosystem (cultural beliefs about normalcy and disability or resource allocation decisions). A chronosystem outlook also considers the long range stressors for parents as their child grows, enters adolescence and matures, and the personal changes parents make across time (Bronfenbrenner, 1979).

The findings from this study show parents developing effective coping strategies over time as they interact in different contexts with a wide variety of people (Boss, 2002). As parents communicated between home, school, and health environments to increase their child's competency, their own grew as well. Interaction in different settings with knowledgeable mentors, such as behavioural support staff, teachers, and other parents of children with AS, contributed to parents' coping skills, growth and development as valuable information and skills were attained (Bronfenbrenner, 1979). Strong links between systems had the potential to strengthen the social ties that were jeopardised when parenting a child with AS and improved parents' capacity to build resilience (Plumb, 2011). These connections could directly affect parents' ability to build competency in their parenting roles, either in a positive or negative manner. For example, in Sandy's turning point, her knowledge of effective strategies and resolve were strengthened through her relationship with the behavioural specialist. The specialist helped to convince the

school leadership of her son's needs while supporting the teacher in making the necessary accommodations. This solidarity facilitated Sandy's personal growth towards resilience.

Bronfenbrenner hypotheses that positive development occurs during interaction in culturally diverse settings (1979) and when proximal processes occur regularly over extended periods of time (2005). One example of proximal processes occurs when parents learn the necessary skills to navigate health systems as they search for a diagnosis and meet with specialists. These skills can then be applied to education environments when resources and support are needed. Parents pick up the necessary skills as they navigate different contexts, for example, the knowledge that Tessa gained through several rounds of funding applications for specialist support could then be applied in her search for affordable family counselling.

The findings from this study show parents building resilience through their experiences with ongoing challenges and coping responses, through their dedication to their families, and through their turning points. Are they resilient now? An excerpt from my reflective journal written directly after the first interviews reveals my initial resistance to applying this concept to their experiences:

> …the parents are so stressed and battle weary. After visiting with them and hearing their stories it seems that exploring their resilience might be inappropriate. When someone is being pulled taut, it seems disrespectful to say, "Look at that! You haven't snapped yet, well done!" Their experiences show the *necessity* of resilience though, due to the lack of resources, 'bad' parent perception, their child's sensory sensitivities that curtail social interaction, the child's quick temper and meltdowns, the dissonance between their personality and their child's, and so on and so on. I think studying their experiences and understanding the big picture is most important – they need to be heard and *understood.* The social structures families must interact with – schools, health services, the community, are creating extra stress for them too. Outsiders need to know about their situations for their family's sake. (18-5-2013)

> …I have been thinking about the analogy of being stretched taut. Maybe resilience is not that parents' haven't snapped, but that they can stretch farther than they ever thought possible, and have the capacity to rebound. (20-5-2013)

After conducting the second interview and analysing their narratives, there is evidence of every parent in this study building resilience. As Walsh (1996) explains,

"resilience is forged *through* adversity, not *despite* it' (p. 7, emphasis in original). Parents are strongly committed to their child and family's well-being. They have gained expertise and managed a myriad of challenges and demands with limited resources. They pinpointed significant challenges outside of their family, signalling ecological risks to healthy family functioning that must be addressed. Parents are overcoming difficulties throughout the child's growing years, and with sustained effort they are gaining the skills, experience and fortitude to rebound from setbacks. Examples include Neva who struggled through two generations of unanswered questions and frustration and was determined to protect her daughter from the perception that she was a 'bad' parent and find the necessary support for her grandson. Tessa's narratives are another example that shows her determined resolve to secure school support throughout her son's primary and middle school years. Now her useful expertise and willingness to help can guide other parents. The stories that parents told reveal the *progression* of building resilience. As they face multiple challenges over the course of their child growing up, they gain efficacy and proficiency. Parents successfully negotiated difficult circumstances and integrated what they learnt into a new self, experiencing transformation. Analysis showed a conscious and resolute effort from parents to gain control over stressful circumstances and attain resolution from stressors that had built up over time. Next, it will be more productive and realistic to ask as Ungar (2011) suggests, are the environments that parents interact with responsive to their needs?

Implications

Parents faced multiple challenges in this New Zealand study raising their children on the autism spectrum. The challenges outside of their family complicated their efforts to cope with the problems directly associated with AS. It is imperative that we examine the risks to parents' well-being within the context of their lives, prioritise the aspects that are malleable with long term effects, and set in motion other protective processes (Luthar et al., 2006). The focus for building resilience needs to shift from individuals to environments that can be responsive to parents' needs (Ungar, 2011). Pearlin and Schooler (1978) speak about the deeply rooted problems within society that force vulnerable populations to manage without adequate support: "Coping failures, therefore, do not necessarily reflect the

shortcomings of individuals; in a real sense they may represent the failure of social systems in which the individuals are enmeshed" (p. 18). Family resilience can be better understood when symptoms of distress are linked with stressful contexts (Walsh, 2003c). Families are resilient because they have been driven to adapt due to the additional challenges associated with AS, a general lack of understanding from others and inadequate support and resources from the health and education sector.

Parents need to be adequately supported to nurture their children as they grow to achieve the best outcomes. It is vital that parents' coping abilities are not damaged through persistent, cumulative, and/or secondary stressors or through poorly resourced, fragmented or unsuitable service systems. Positive mediating influences can counter the impact of stressful conditions (Walsh, 2013), especially when they are salient within a particular life context (Luthar et al., 2006). In addition, proactive planning can help prepare parents for the future without the stress and complications of crisis management (Levine, 2009).

The challenges raising a child with AS is best viewed within the context of all the other demands and events that occur in a family – how they intersect and are compounded by other stressful events, for example, a family member's hospitalisation, pay reduction or job loss, moving house, new partnership and so on. A socioecological perspective has important implications for the professionals that interact with or support parents raising children on the autism spectrum. Socially structured barriers can inhibit parents and families (Seligman & Darling, 2007). The characteristics of the family's community must be taken into consideration, for example the availability of public programmes, government policies on resource allocation and societal norms (Patterson, 2002). Cumulative stress has the potential to weaken positive coping responses and additional stressors can be the tipping point that leads to family breakdown (Walsh, 2006). To increase positive outcomes and foster resilience for families raising a child on the autism spectrum, the findings from this study point towards identifying and intervening early, raising parents' capabilities and self-efficacy when managing their child's problem behaviours, fortifying social support, ensuring respectful parent and professional relationships, and channelling school resources to where they are most needed. Lastly, turning points can inform timely involvement for service professionals at critical opportunities.

Early identification and intervention. Parents' experiences indicate that early identification and intervention could prevent the frustration that builds up regarding their child's difficult behaviours and uneven development. Parents felt that a 'wait and see attitude' did not take their concerns seriously and added unnecessary delays to finding relevant information and support. The New Zealand Autism Spectrum Disorder Guideline (Ministries of Health and Education, 2008) requires that health and education practitioners monitor developmental milestones in a proactive fashion and elicit concerns from parents about their child's development and behaviour. To recognise the early signs of the autism, training is instrumental for general practitioners, paediatricians, psychologists, home visiting nurses, social workers, and teacher in day cares, preschools and primary schools. It is critical that red flags are monitored and referrals made to specialists when appropriate. Professionals must listen to parents' legitimate concerns to build an in depth profile in the early stages and assess the child's response to intervention (Whitaker, 2002). A plan of action developed early with a multi-disciplinary approach will reduce the impact of challenging behaviours and improve outcomes for families (Ministries of Health and Education, 2008). Moreover, since identifying high functioning autism is difficult and many of the characteristics are not evident until a child attends school, information about effective strategies to address challenging behaviour is greatly needed in the interim. Access to behavioural modification support can markedly reduce stress levels for parents at this time. When Erin tried to find answers about her son's odd behaviours, she said a panel of specialists "didn't give you any strategies to go with, they just told you we can't diagnose". Early intervention can support families to build a resilient foundation to manage subsequent ecological stresses (Kalil, 2003).

Increasing parent capabilities and self-efficacy. The challenges directly associated with AS in this study included numerous behaviours with difficult presentations. Parents' narratives included challenges with self-regulation such as the child becoming upset quickly or demonstrating angry and violent behaviour; high rates of anxiety, fear and depression; high sensory sensitivities, such as aversion to certain foods, clothing and noise; inflexible and unreasonable behaviour, and obsessions and compulsive behaviour. These challenging behaviours are out of the realm of typical parenting experiences, skills and abilities, and parents had trialled

several strategies in their attempts to manage them productively. Being judged about their parenting prowess combined with challenging interactions with health and education professionals eroded parents' confidence over time. Previous studies have found parents raising children with ASD feeling stressed, anxious and feeling overwhelmed as they tried to manage their child's behavioural problems (Lutz et al., 2012; Whitaker, 2002). Lecavalier et al. found in their 2006 study that behavioural problems were found to be related to caregiver stress more than any other characteristic associated with their child's autism spectrum disorder. Hence, it is crucial to assess parental stress levels and the child's behavioural problems that can inhibit overall family functioning (Rao & Beidel, 2009).

Support professionals are in the position to decrease anxiety, stress and depression, increase parent confidence and foster resilience through behaviourally based family intervention programmes that teach parents how to effectively manage ASD symptoms (Bitsika et al., 2013). Family support that raises self-efficacy can mediate a mother's anxiety and depression in connection with her child's behavioural challenges (Hastings & Brown, 2002). Furthermore, changes in perceived efficacy can produce long lasting and positive results (Bandura, 1997; Durand, 2014; Levine, 2009; Sofronoff & Farbotko, 2002).

From the parent's perspective, practical and specific applications of information, strategies and skills were seen as critical to manage their child's troublesome behaviours at home and outside of the home. Parents expressed in their interviews that professionals would explain *why* their child had troublesome behaviours, but it was equally as important for them to know concrete methods for *managing* those behaviours. Knowing why helped with patience, tolerance and forgiveness, but knowing *how* built the necessary skills to manage the behaviour effectively. Yvonne said "because you know the diagnosis is nothing really, as a parent what you want is the strategies to help deal with it". Parents in this study openly shared their desires to learn specific strategies to manage their child's difficult behaviours and were grateful when they able to benefit from behavioural support, such as the examples Anne and Sandy shared. When parents were not able to find appropriate behavioural strategies for their child, they expressed frustration, such as the stories told by Brett and Leah. Behavioural management training can give parents workable strategies that both decrease their child's problem behaviours and

increase their self-efficacy in managing those behaviours (Sofronoff & Farbotko, 2002).

The early stages after the diagnosis could be supported with a two-person system that pairs mentors with parents, contributing to self-efficacy and building resilience (Bronfenbrenner, 1979; Walsh, 2006). This mentor could act as a "guide, counsellor, service coordinator, facilitator" that could minimise stress for parents (Stace, 2011). To build a sense of competence, there needs to be sensitivity to the parent's stage of development along with their comfort level and social status in different settings (DuPont, 2009). Support for parents as they gain experience and confidence can have a continued positive impact for family well-being. Furthermore, professionals in a supportive role can help families develop their social networks and link into larger systems, such as parent support groups, schools and health services groups (Kalil, 2003). A multiple level support structure that includes service professionals and other parents of children diagnosed with ASD could provide both emotional and tangible forms of guidance (Shacar, 2006).

Community programmes running parenting courses need to be aware of children on the higher end of the autism spectrum so they can offer relevant, pragmatic advice and raise parent self-efficacy effectively, as well as being culturally appropriate (Bevan-Brown, 2004; Seligman & Darling, 2007). Moreover, parent education programmes that strive to be more inclusive of fathers has positive implications for both fathers and mothers (Kroodsma, 2008). Professionals can help parents incorporate positive appraisals of their self-efficacy to contribute to continued success.

When parents' self-efficacy is raised through the provision of specific behavioural intervention for their child, then parents can manage the difficulties that troublesome behaviour causes for them and their family more successfully. In addition, "the stronger the perceived self-efficacy, the more active the efforts" (Bandura, 1978, p. 141). Bekhet et al. (2012) assert that intervention can strengthen protective factors for resilience by increasing positive cognitive appraisal, resulting in heightened self-efficacy, sense of coherence, and positive family functioning.

Social support needs. Social support can provide the much needed emotional connection, practical assistance, feedback and resources for this population at risk. Lack of social support inside and outside of the family contributes

to stress levels for mothers and fathers (Hastings, 2003) and increases likelihood that stressors would correspond to isolation (Dunn et al., 2001). The stressful challenges in these parents' lives can be mediated by strengthening the interrelationships between their family, friends, and community (Walsh, 2003c). Ekas et al. (2010) argue "social supports could be conceptualized as providers of knowledge as well as providers of instrumental and emotional support. Social supports empower mothers by giving them hope and leading them to positively appraise the future" (p. 1282).

Parents trust and respect the profound level of understanding other parents have gained raising children with challenges (de Wolfe, 2013; Whitaker, 2002). Parents are "uniquely qualified" to offer support to each other, which benefits both the giver and the receiver and has a transforming effect on the process of coping and adaptation (Kerr & McIntosh, 2000, p. 309). Parent support networks can promote a sense of belonging, a safe haven to share difficulties and improve emotional well-being through acceptance and recognition (Altiere and von Kluge, 2009b; Boyd, 2002; Gill, 2013).

A simple tool to improve family life congruence and counter the social isolation parents experienced in this study could be to encourage parent-to-parent relationships (McConnell et. al, 2014). As Tessa said "you don't know until you live it, *thinking* you know is different to knowing". Other parents' experiences are valued and seen as both sources of information and support (Mackintosh et al., 2005). Emotional needs are also met, as when Sandy said "just hearing other peoples' stories and realising you're not alone". Parent support groups can offer ample opportunities to facilitate the exchange of practical strategies and strengthen social bonds between parents keeping them informed and less isolated (Ministries of Health and Education, 2008). Social validation along with skill development can improve personal efficacy (Bandura, 1997). A network of self-sustaining practices is built (Carpenter, 2000) through beneficial advice and emotional support (Carver et al., 1989).

It is important to note though that mothers in this study said they chose not to participate in parent support group meetings due to family time constraints, the practical aspects of child care, personal energy levels, long travel distances and preferred ways of interacting. For example, Brett and Leah found online forums and blogs from other parents useful, relevant and easy to access. Other parents also mentioned the helpfulness of one-on-one support on the telephone or informal get-togethers. However the support is structured, successful attendance and learning is

dependent on an awareness and sensitivity to family needs and constraints (Kroodsma, 2008).

Parent groups have the potential to meet the needs of its members in a powerful and satisfying fashion. Shared experiences strengthen the bonds within the group and supplement those ties lost as a result of parenting a child with AS. Participating parents can pool their knowledge, share strategies, shore each other up, and advocate for better services. There are opportunities to "co-construct a group narrative" that can serve as a collective identity (de Wolfe, 2013, p. 186). There is potential for the members of the group to gain resilience collectively. Furthermore, a solid network can be achieved on the national level when collaboration between vested groups is encouraged (Luthar & Cicchetti, 2000).

Respectful parent and professional relationships. The data analysis revealed that a large number of specialists interacted with parents before, during and after the diagnosis. This interaction had the potential to create additional stress in parents' lives. However, when relationships evolved from a foundation of trust and respect then positive outcomes were possible. Carpenter (2000) writes that when professionals acknowledge the depth of knowledge families hold about the child and position the family at the heart of service delivery, then a more responsive and respectful partnership develops. Bronfenbrenner noted the importance of encouraging mutual trust and reciprocity, working towards common goals and respecting the balance of power for who those who act on behalf of the developing person and their well-being. The relationship between parents and professionals should be based on negotiated equality and parents' viewpoints regarding their child recognised and valued (Goodley & Tregaskis, 2006; Stace, 2011) as "the values, knowledge, preferences and cultural perspectives of the family should be respected and evident in services and resources" (Ministries of Health and Education, 2008, p. 63).

In this study, parents shared how challenging it was to be honest with professionals about their difficulties managing their child's behaviour at home. Sometimes parents were not forthcoming about their challenges, especially if they had already experienced stigma about their parenting or there had been disrespectful responses from professionals in the past. Several of the mothers in the study shared their reluctance to be direct with support workers or teachers about their difficulties

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managing their child's difficult behaviours, for example, the interaction mentioned previously between Leah and child family services. As a consequence, professionals do not discover the reality of parents' day to day lives and the relevant circumstances that can sorely test patience levels. It is important that supporting professionals create a safe environment for parents to discuss the challenging aspects and strategies that have been trialled and acknowledge that parents are already stretched beyond their coping limits with the demands associated with an autism spectrum disorder (DuPont, 2009).

Professionals are obligated to understand "relevant issues *from the family's perspective* instead of from the service providers' perspective on what families need, or worse yet, on what services are available" (Blacher & Hatton, 2007, p. 545, emphasis in original). King et al. (2009) counsel service providers to learn the perspectives and priorities of parents and use this knowledge to engage in a sensitive and responsive manner. Since people are shaped by social structures, the perspectives of parents "may not be shared by the professionals who provide services to them" (Seligman & Darling, 2007). Professional support that matches family perspectives can help parents form a stronger sense of coherence and promote resilience (Bayat & Schuntermann, 2013, p. 419).

Relationships that have "mutual trust, a positive orientation, goal consensus between settings, and an evolving balance of power" can support parents' development (Bronfenbrenner, 1979, p. 212). The recognition that parents are experienced and knowledgeable about their child creates reciprocal and respectful relationships that are "bidirectional" in their nature. Bronfenbrenner (1979) believes that when the child's parents and teachers form a strong relationship, becoming primary dyads, then parents can serve as a "catalytic power", enhancing the child's development (p. 211).

A strengths-based approach can promote supportive and trusting relationships between parents and practitioners (Tedeschi & Kilmer, 2005). In conjunction with increasing parents' understanding of their child's development and their confidence in their ability to parent, intervention, support and counselling should concentrate on the needs of the *entire* family, especially at critical periods (Bevan-Brown, 2004, 2015; Higgins et al., 2005; Wolf et al., 1989). For example, programmes that include siblings can open up communication between family members, strengthen bonds and promote productive coping strategies (Tsao, Davenport, & Schmiege, 2012).

Parents hold a wealth of knowledge about what does or does not work with their children. They are highly motivated to see their child succeed and their family function well. Professionals that interact with parents with respect for their experience and perspectives, an awareness of the high demands associated with raising children with AS and the ability to utilise strengths will build trusting relationships.

Targeted school support and funding. Hans Asperger advocated for educational approaches that built on the child's strengths and a deeper understanding of the condition (Frith, 2004). Targeted help could reduce long range problems, such as anxiety, depression, vulnerability to bullying and school dropout (Attwood, 2008; Brewin et al., 2008; Winter, 2011). Parents related experiences of their children with AS being severely stressed at school due to sensory overload, poor social understanding, the effects of being bullied, and inability to organise their work, with flow on effects to their families at home; hence attention is critical in these particular areas. Teachers need to assess the child's sensory, social and organisational needs to tailor their learning effectively (Church et al., 2000).

Based on the findings from this study, targeted school support is specifically needed to help children with AS in the following areas: coping with anxiety and sensory sensitivities, for example, decreasing exposure to noise and crowds; teaching social skills; preventing opportunities for the child to be bullied; improving executive functioning, such as starting and completing tasks, remembering and following multi-step instructions, planning, organising, self-monitoring; modifications for coordination difficulties, especially handwriting tasks; and preparing for transitions and changes in routines. School transitions were identified as a major challenge for families due to their child's resistance to change and the longer time needed to settle their child into the new environment. Unfamiliar environments and new routines had the potential to elevate anxiety levels both at school and at home. Support for transitions, such as beginning, changing or leaving school is highly recommended (Bevan-Brown, 2004; Ministries of Health and Education, 2008). In addition, support for transitions can be extended to parents. Bronfenbrenner (1979) stated that impending transitions can be improved when "information, advice, and experience" is shared initially and on a continuing basis with members of both settings (p. 217). Development is enhanced if everyone trusts each other, agrees on goals, stays positive and shares power. Teachers can tap into parents' insight and abundant

knowledge about their child and brainstorm potential strategies when new settings are introduced.

Within the health and education systems in New Zealand, it is very difficult for children on the higher end of the autism spectrum to access funds for their learning needs. Education officials must rethink the application process and implementation for learning support. A deficit model seriously disadvantages parents of children with AS. There is an impression that children on the higher end of the autism spectrum do not need educational support due to their average and above average intelligence and their ability to excel in their area of special interest. This leaves children without the essential help they need to function well overall (Ludlow et al., 2012) A diagnosis can *inform* practice rather than used as a gatekeeper for support and resources. In this study, there were examples of parents' unsuccessful efforts to access funds and extra support, and those parents who are not savvy regarding the processes for resource allocation are considerably disadvantaged. Parents of the older children in the study deeply felt the lost potential of their children and stated that it should be a given that all children be supported for their learning needs.

Support at critical times. Expertise and support at critical junctures, such as at turning points, can have a positive influence on parents' abilities to build resilience (Masten, 2001). In this study, turning points revealed the positive effects that professionals can have at critical times, for example, the understanding and open-minded teachers Leah found at her son's new school after experiencing stigma at the previous school; the knowledgeable and committed home tutor Camille found for her daughter after several unsuccessful school placements; and the responsive hospital counsellors for Natalie and Leo's son when he was struggling with the effects of bullying and depression. Professionals demonstrating a willingness to help featured strongly in parents' turning points. In Sandy's narrative, she said the behavioural specialist was "the best thing that happened to us". This specialist not only brought the needed expertise to improve learning outcomes and decrease anxiety for her son at school, he bridged the gap between home and school when this relationship had met an impasse. In other parents' narratives, there were examples of parents seeking open-minded and willing school staff when they changed schools for their child. This implies a need for a heightened awareness and sensitivity for parents'

stress levels and the positive impact a cooperative ally can have when those stress levels reach a crisis point.

Support for families can strengthen positive adaptation to stress and protect families' resilience. Formal and informal systems need to be identified and incorporated into intervention (Tedeschi & Kilmer, 2005). The findings from this study show the importance of understanding and capitalising on family strengths, and matching supports to their needs and circumstances. Moreover, their stories show how resilience is fostered through positive interactions between families and their communities. To enable families to build capacity, resources must be available and accessible, culturally relevant and meaningful (Ungar, 2011). If the socioecological conditions are unfavourable in which families work and live, then they will struggle (McConnell et. al, 2014).

The transformative nature of turning points can have positive flow on effects and may be an underlying mechanism for the development of resilience. New insights and beliefs, improved self-efficacy and renewed hope can strengthen parents for future challenges. Family support must help parents restabilise after turning points and also prepare for fluctuations over time within different domains. Professionals could encourage parents to reflect on their personal turning points and through the act of retelling, perspectives and strengths identified. Professionals can help parents "form their own narratives about their experiences" to encourage meaning making, a stronger sense of coherence, and promote resilience that matches family perspectives (Bayat & Schuntermann, 2013, p. 419).

Families demonstrating resilience still need support to meet their family needs and combat the stressors encountered outside of the family unit. There is a caution that parents seen as 'doing well' will not qualify for services if service delivery is predicated on a level of dysfunction or only delivered when there is a critical need. Community support needs to be seen from the perspective of *protecting* healthy family functioning from current and future demands. Maintaining and protecting well-being must be seen as a collaborative ongoing responsibility.

In summary, intervention and support should "target salient vulnerability and protective processes that operate across multiple levels of influence" (Luthar & Cicchetti, 2000, p. 867). Professionals need to assess needs within the context of their daily lives and capitalise on parents' expertise while building dynamic, collaborative relationships (Carpenter, 2000; Levine, 2009; Woodgate et al., 2008). A

concerted effort to strengthen parents' abilities to communicate and share strategies with other parents will help stem the isolation felt in this group. Raising self-efficacy, early identification and intervention and targeted school support will moderate the significant stressors parents must cope with raising a child or children with AS. Furthermore, a relational resilience approach acknowledges that parents are part of a family system and support can result in positive gains for relationships within families (Walsh, 2003c). As family support benefits all family members it also creates potential for the positive effects to radiate outward in a multitude of settings, for example, the parents' workplace, the child's adjustment at school, and the family's involvement in the community.

Limitations

Although urban, suburban and rural families were represented in this study, participants came from one central geographical region in New Zealand. The results reflect the particular cultural values, beliefs, behaviours and patterns from these social environments. The participants were able to afford the time to meet for two interviews with the majority choosing to meet in their own homes, and do not represent those families whose circumstances would not allow them to do so. By the nature of the study, narratives were co-constructed between me and the participants, and the findings were interpreted based on my life experiences and cultural background.

The sample size, though ample for a narrative study, was small in comparison to larger qualitative studies. Efforts were made to accommodate all parents that wanted to participate and hence were not randomly selected from the volunteer group. Parents volunteered for this study and hence may represent a specific population capable and willing to participate in research. Adverts asking for volunteers were placed with organisations that support parents raising children on the autism spectrum or with disabilities, and the vast majority that responded belonged to Cloud 9, an organisation that provides information on Asperger syndrome and support to parents, professionals and the community. The participants represented here would be those who seek out information and support, and are willing to be members of a parent support community, and therefore do not represent those who have not joined. The participants also had access to a computer and were

computer literate, and hence do not represent those who choose not to have a computer, cannot afford one, live in isolated areas, or are not knowledgeable about its use. Though fathers were part of the participating group, three times more mothers participated in this study. Despite these limitations, this research makes a contribution to an understanding of the experiences of those who participated in the study with important implications for improved practice.

Future Research

The challenges that parents described raising a child with AS and the additional stressors within the social contexts they lived, such as community, health and education environments, were prominent in these parents' narratives. Further research on the particular factors that can moderate these stressors could contribute to families' abilities to cope and function well. For example, a further exploration is warranted of the moderating role positive perceptions has on stress and its dynamic properties, such as whether it is present early in the adaptation process or if families rely on this strategy as needed to restore balance (Hastings & Taunt, 2002).

The examination of parents' lives over an extended period of time would give additional insight into how they build resilience (Walsh, 1996) with the potential to capture additional turning points if and when they occur. An examination of particularly stressful points in time is needed, for example, before, during and after the diagnosis; school, adolescence, and adulthood transitions; and when the family structure changes, such as divorce or remarriage.

An increased understanding of the experience of stress in parents' lives and coping responses during these times of heightened challenges could lead to more appropriate interventions (Cridland et al., 2014). Additional research into turning points, specifically how adaptation results in a more positive direction and the complex effects of an altered trajectory on families' ability to cope with subsequent stressors is warranted. A more in-depth investigation of parental experiences and coping responses could reveal developmental processes, stages, critical junctures and the transactional nature between people and their environments.

There is a need to conceptualise family resilience to include the influences and complex processes of interaction beyond the family unit (Kalil, 2003). Longitudinal studies of the processes involving positive adaptation and growth as the child

matures and demands change for families would further contribute to family resilience theory and increase understanding of families' needs (Cridland et al., 2014; Lutz et al., 2012; Ministries of Health and Education, 2008). Exploring the environments and support systems that best nurture and promote resilience and respond in a culturally sensitive manner would be beneficial (Bevan-Brown, 2004; Ministries of Health and Education, 2008).

Lastly, research that captures the experiences and perspectives of all the family members including fathers, siblings, and the child with ASD would provide a well-rounded view of positive adaptation.

Conclusion

The narratives collected and analysed in this study from parents raising a child with AS in New Zealand contributes to our understanding of family experiences and the substantial accommodations they make in their daily lives. Overall, the intensity of parenting a child with AS, combined with limited understanding from outsiders and inadequate health, education and social support resulted in considerable stress for parents. The narrative inquiry approach used in this study provided a clearer and holistic picture of the stressors parents were experiencing within their social environments and how stress was productively managed. The discovery of turning points added increased insight into the processes of coping and resilience building. These turning points expose the weight and impact of years of stress and the resolved efforts to overcome this stress in a constructive manner. This insight offers the potential to develop more empirically and comprehensive theories about social influences and development processes in resilience building, and the importance of support at critical junctures. This research adds rich examples of parents addressing complicated problems with skill, resourcefulness and stamina. They have developed expertise that other parents, researchers and professionals can draw from.

Parents of children with AS are at risk of the ill-effects of stress in their lives and the resulting damage that can flow through the family and into the community. Walsh (2003c) counsels that "just as individuals need supportive relationships to thrive, family resilience must be supported by social and institutional policies and practices that foster their ability to thrive" (p. 11). A collaborative effort is needed to

protect healthy family functioning and encourage resilience as there are wide ranging benefits for doing so and conversely, long lasting consequences for not. Silberman (2015, 12:50) stated, "To be sure, autistic people have a hard time living in a world not built for them. [Seventy] years later, we're still catching up to [Hans] Asperger, who believed that the 'cure' for the most disabling aspects of autism is to be found in understanding teachers, accommodating employers, supportive communities, and parents who have faith in their child's potential".

It is hoped that the findings from this research contributes to a more sensitive response to family needs and their stability when raising a child on the autism spectrum. Bronfenbrenner (1979) claims that the "most stable and enduring base" for expanding nature of interconnections through a person's life is their *family* (p. 232) and Seligman and Darling (2007) assert that "the family is the primary and most powerful system to which a person ever belongs" (p. 18). Increased understanding and targeted support has the potential to bolster a family's ability to manage the present and future challenges associated with AS. In addition, an increased sensitivity to the *context* that families live in is imperative to facilitate supportive environments that encourage positive processes (Ungar, 2011).

This study gives parents' "a more evocative force so that these storytellers could hear each other, and so that they could be heard collectively" (Frank, 2012, p. 36). With regard to what stories communicate to us, Cotton and Griffiths (2007) explain:

> The point is not to tell some universal truth about the world, but rather to tell particular truths in order to allow us all, tellers and hearers, to reassess what we understand of the world and so of our own possible actions within it. (p. 550)

Narrative research deepens our understanding of people's experiences and reveals the social and cultural impact on their lives (Polkinghorne, 2007). The voices of parents of children with Asperger syndrome add a valuable contribution to our understanding of what 'disability' means. Their narratives capture the realities of raising a child where society questions their abilities as capable parents and ignores the needs of the parent and the child. Their experiences are valuable in research as barriers, stigma, and limited support are exposed (Connor et al., 2008; Linton, 1998). Narrative inquiry presents a method to better understand a population that deals with

exceptional stressors on a daily basis; the barriers and constraints parents face while managing difficult situations; and the positive adaptations they have implemented in the process of building resilience.

Many of the participating mothers and fathers expressed a desire to improve other parents' lives through their personal experiences of trial and error and to raise awareness in the general public about AS. They hope their struggles will be shared with those in the educational arena so teachers are better informed and can accommodate different needs in the classroom; so medical professionals can recognise the condition earlier; and so government officials will properly fund parent programmes and allocate the needed resources to schools. They told stories of raising difficult children in difficult circumstances. They described children that were inherently worthy of love and deserving of support regardless of the need for an 'official' diagnosis or the 'severity' of the condition. They confessed their weariness and desire for help. They need support that capitalises on their child's and their own strengths, and assistance maintaining their families' well-being. They demand respect as people that are well versed in their child's habits and needs. Therefore their stories are ones of redemption, quest, confession, and a plea for action. Their stories are not fixed stories, but ones that will continue to develop as others interact and strive to understand their experiences and perspectives.

Clandinin (2006) wrote:

> …human beings both live and tell stories about their living. These lived and told stories and talk about those stories are ways we create meaning in our lives as well as ways we enlist each other's help in building our lives and communities. (p. 44)

An increased understanding of the challenges raising a child with AS and the ways parents build resilience contributes to those efforts.

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Appendix A

Initial interview questions:

Tell me about your child and your family.

Describe how you learned about Asperger syndrome.

Tell me about how you came to a diagnosis for your child.

Tell me about some challenging times or situations parenting your child with Asperger syndrome and what your responses were.

Describe the type of support you have had as a parent of a child with Asperger syndrome and give an example of a time when you either needed help, or received support that was helpful.

What are the positive and/or negative aspects of having a child with Asperger syndrome?

Are there any other examples or particular times that stand out for you as a parent?

Follow-up interview questions:

Overall, what do you see are the main challenges to parenting a child with AS?

What are your personal strengths for managing those challenges? What strategies do you use and what family resources are helpful? Can you give examples?

On reflection, has there been a turning point(s) raising your child and why?

What would you like to see happen in the next year (or in the short term) for your son or daughter?

What would you want to see happen in the long term?

What would have been or would be most helpful to you as a parent, your child, your family?

Dear Parents and Caregivers

My name is Jo-Lynne Jack and I am currently working on my doctoral studies. I have been a teacher from preschool through to secondary school, and have worked in the area of special education for fifteen years. For my thesis I am researching parents' experiences of raising a child or children with Asperger syndrome, the perceptions and meaning of Asperger syndrome in their lives, and the productive coping strategies being used that contribute towards resilience. To this effect, I would like to invite you to share your stories over 2 interviews. You may share your stories individually, with your partner or with a support person. The interviews will last approximately 1–2 hours each, with the second interview scheduled at your convenience 3-4 months after the initial interview. The interviews can take place in your home or at a convenient location, such as a room at a local parent support organisation.

The ages of your child or children should be between 5–21 years of age, be living at home, and have a medical diagnosis of Asperger syndrome. The interviews will be informal and you will have the opportunity to talk about the areas that are important to you. I intend to collect narratives of experiences from approximately a dozen families across New Zealand.

I am hoping the research will help other parents adjust to the challenges of raising a child with Asperger syndrome, as well as inform parent organisations when they are planning their support programmes and services. Your experiences will provide valuable insights into what works well for parents coping with difficulties and the process of how families build resiliency.

My supervisors are Dr Judith Loveridge (04 463 6028; judith.loveridge@vuw.ac.nz) and Dr Vijaya Dharan (04 463 6402; vijaya.dharan@vuw.ac.nz) and this research has been assessed and approved by the Victoria University Faculty of Education Ethics Committee. Due to the small size of the community involved in the study, there is a possibility your participation may not remain anonymous. However, I will treat the experiences you share confidentially though the use of pseudonyms and the removal of identifying details. The interviews will be audio recorded and stored in a secure location; the transcribed interviews will be stored in password protected files; and the transcriber will sign a confidentiality agreement. All records will be destroyed 5 years after the completion of the research. You have the right to withdraw from the research study at any time during the interview process without the need to explain why and can request a copy of the transcripts. In addition to the thesis, there is potential for the information gathered to be used in journal articles and conference presentations.

Please feel free to contact me or my supervisors with any questions. If you have any concerns about ethical issues please contact Dr Allison Kirkman, Chair of the Victoria University of Wellington Human Ethics Committee (04 463 5676; allison.kirkman@vuw.ac.nz). I look forward to meeting you.

Kind regards
Jo-Lynne Jack
jo-lynne.jack@vuw.ac.nz

Appendix C

Looking for parents of children with Asperger syndrome to interview.

Children need to be ages 5–21, living at home, and have a medical diagnosis of Asperger syndrome.

Parents can be interviewed individually or with their partner.

There will be two interviews lasting 1–2 hours
at your home or a convenient location.
These will be scheduled at your convenience about 3 months apart
with Jo-Lynne Jack, a PhD student.

Your participation will help other parents adjust to the challenges of raising a child with Asperger syndrome.

I am happy to discuss the research further or meet with you before you decide to participate.

Please contact:
Jo-Lynne Jack
jo-lynne.jack@vuw.ac.nz

This research has been assessed and approved by
Victoria University Faculty of Education Ethics Committee

Appendix D

Parent experiences of Asperger syndrome

Parent Consent Form (Research)

	Please tick if agree
I have had the research objectives about parent experiences of Asperger syndrome explained to me.	
I understand there will be 2 interviews, approximately 1–2 hours each and about 3–4 months apart scheduled at my convenience.	
I understand that I have the right to withdraw up until the end of the second interview and that I do not have to explain why.	
I understand that my name and identifying details will not be used.	
I understand that the interviews will be audio recorded and then transcribed, and the transcriber will sign a confidentiality agreement.	
I understand that I may request a copy of the transcripts.	
I understand that the audio tapes and transcribed records will be stored safely and destroyed after 5 years.	
I understand my responses may be used in papers or presentations that are about parent experiences of children with special needs.	
I consent to being interviewed.	

Name: _____

Signed: _____

Date: _____

I would like to receive a short summary of the research findings.   Yes / No

Address to send the summary:

_____

_____

Appendix E

Confidentiality Agreement
Transcription Services

I, _____, transcriptionist, agree to maintain full confidentiality in regards to any and all audiotapes and documentation received from Jo-Lynne Jack related to her doctoral study on *Parent perceptions and experiences of Asperger syndrome and positive adaptations*. Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audio-taped interviews, or in any associated documents;

2. To not make copies of any audiotapes or computerized files of the transcribed interview texts, unless specifically requested to do so by Jo-Lynne Jack;

3. To store all study-related audiotapes and materials in a safe, secure location as long as they are in my possession;

4. To return all audiotapes and study-related documents to Jo-Lynne Jack in a complete and timely manner.

5. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I will have access.

Transcriber's name (printed) _____

Transcriber's signature_____

Date _____

Appendix F

Example of Thematic Code Definitions and Development

This appendix contains 1) a sample of code definitions and 2) an example of thematic code development.

1) Sample of initial code definitions

After the initial interview, parents' narratives primarily contained stories of the difficult and stressful *characteristics of Asperger syndrome*, with several codes created under this category. Specific stories that related to parenting, school issues and diagnosis were listed as separate categories at this time.

Parent experiences: An occurrence that is perceived, understood and remembered about raising their child with Asperger syndrome; a situation that left an impression or invoked a strong feeling.

Asperger syndrome (AS): Characteristics related to or compounded by the child having Asperger syndrome.

> **Angry and upset**: Child with AS being quick to anger or showing anger or crossness.
>
> **Anxiety**: Showing excessive anxiety, fear and worry.
>
> **AS in girls**: Characteristics and issues specifically related to girls with AS.
>
> **Communication**: Difficulties communicating feelings, personal needs, and information about a past event; difficulties understanding nonverbal cues or inferring meaning; difficulties initiating and maintaining conversations.
>
> **Comorbidity diagnoses**: Comorbidity diagnoses received.
>
> **Coordination**: Challenges to fine and gross motor coordination.
>
> **Depression**: Depression and suicide attempts.
>
> **Early indicators**: Developmental milestones missed or reached early; signs of unusual behaviour before age 5.
>
> **Inflexibility and unreasonableness**: Being inflexible in thinking and unyielding in behaviour, parents commenting on the unreasonableness of their

behaviour, child having strong opinions, the world is 'black and white', child having a strong sense of justice.

Literal understanding: Following the strict meaning of the words, phrases or conversation; difficulty with figurative or metaphorical meanings.

Obsessions and compulsions: Dominating behaviour that resists intervention or modification.

Puberty: Issues related to body changes and transition to teen years compounded by AS characteristics.

Sensory sensitivities: Hyper and hypo sensitivity to sound, taste, touch, smell, sight, and sensory seeking behaviours.

Social skills: Issues related to developing appropriate social skills, interactions and relationships with others.

Special interests: An area of intense focus and subsequent expertise.

Unpredictable behaviour: Behaviour that is difficult to anticipate; unexpected, erratic and with variable actions.

Violence: Meltdowns, explosive behaviour, and aggressiveness that involves self, others and property.

Parenting: Issues related to raising their child with AS, such as discipline, teaching, bonding, juggling work, and shared interests**.**

Bonding: Issues that impede or facilitate the bonding between parent and child.

Discipline: Examples of parents trying to discipline or teach what is expected in the family.

Shared interests: Sharing interests together or not finding shared ground.

Parents as teachers: Parents teaching their children, family, outsiders and teachers specific skills to manage challenges associated with AS; parents helping with child's school work because their child did not understand what to do, how to do it, or felt confident asking teacher for clarification; parents as experts as they accumulate strategies and confidence in what does and does not work.

School: Issues related to the child with AS attending and adjusting to school.

Transition: Issues related to times of transition, for example, early childhood to primary, primary to intermediate, and intermediate to secondary.

Diagnosis: Stories revolving around the diagnostic process.

Identity: Parents' perception of AS and as a parent of a child with differences.

Label: Issues related to an AS diagnosis, either positive or negative.

2) Example of thematic code development for *belonging*

After the initial interview analysis, *belonging* was not identified as a code regarding parents' experiences and the challenges within those experiences. The challenging characteristics directly associated with AS were the predominant codes generated early on, such as *angry and upset* and *inflexibility and unreasonableness*. However, issues related to the child's limited *social skills* were noted, such as difficulties communicating feelings or understanding other people's emotions.

After the follow-up interview analysis, additional examples of social skill challenges were identified, such as the child having few or no friends, and the child's unpredictable behaviour and heightened sensory sensitivities jeopardising and curtailing parents' social interactions and relationships. After subsequent readings and analysis, the code *belonging* was created and defined as "a sense of belonging desired for parent and/or child". Following are two examples logged under this code from Camille:

> I guess other parents, again primary school years [parents] were very protective of their own children and didn't necessarily appreciate having a child that was different in the class, particularly if it was a child that lashed out and, and hit. And so I know there are mothers' groups where, you know, where they'd get together for coffee for example and I was probably, I was never invited. I was kind of on the periphery, they'd all talk to me in very friendly [way] but I think they were concerned as to what that might lead to in terms of interaction with their children and whether they could cope and things like that, so very subtle but still there.

> …being marginalised, but we find, particularly probably my daughter drawn more to the fringes of society because they don't fit so easily in to the norm and some of those fringes are perhaps not necessarily what you want for them but if they find acceptance and tolerance there how can you blame them for wanting to go there?

Further analysis expanded the *belonging* code to a category titled 'Sense of belonging endangered' and the following codes created underneath: *Lack of*

acceptance for parent and child – marginalised, ostracised and isolated by others, child has few or no friends, and *bullying for child at school,* and *negative emotions.*

1) Sense of belonging endangered
    a) Lack of acceptance for parent and child
        a. Marginalised, ostracised and isolated by others
        b. Child has few or no friends
        c. Bullying of child at school
    b) Negative emotions experienced by child and parent due to not fitting in – disappointment, frustration, grief, fear, worry, humiliation, and embarrassment

After an additional reading, another code was created under the 'Sense of belonging endangered' category titled *Worried about child's future – employability, independence and relationships* as it related to social belonging in the workplace and community. A separate category was created for *Negative emotions* as these emotions pertained to numerous other categories.

1) Sense of belonging endangered
    a) Child has few or no friends
    b) Bullying of child at school
    c) Worried about child's future – employability, independence and relationships

Collapsed 'Sense of belonging endangered' into 'Lack of acceptance' category as the issues related to belonging in parents' narratives pointed to a lack of acceptance, and a more conceptual thematic category titled **Challenges to understanding and acceptance** was created. Placed additional categories under this larger thematic category that included 'Lack of awareness, knowledge or familiarity about AS' and 'Lack of tolerance and empathy':

1) Challenges to understanding and acceptance
    a) Lack of awareness, knowledge or familiarity about AS
        a. Public embarrassment and withdrawal
    b) Lack of acceptance
        a. Bullying at school
        b. Child has few or no friends
        c. Parents worried about child's future regarding employability, independence and relationships
    c) Lack of tolerance and empathy

      a.   Judgment

      b.   Decisions regarding disclosure – potential for stigma and privacy issues.

After specifically analysing parent narratives for coping responses, positive belonging coping examples were identified and placed in the category 'Support'. Several codes for 'Support' were subsequently created that included *community support* and *parent group support*. An example follows:

> And knowing that you could now go and type something into Google or look for a book in the library or ring and ask for a support group, you know just made it not quite so alone, now it was actually something that more than one person had to deal with. (Leah)

Created 'Connectedness' category and placed new code of *Seeking support from family, friends and other parents of children with ASD* underneath.

1) Connectedness
   a) Seeking support from family, friends and other parents of children with ASD.

Collapsed 'Connectedness' into 'Developing resources' category as this title captured both the motivation and result of connecting with others and seeking support. Moved *Researching information and securing help* and *Advocacy* under this larger conceptual category.

1) Developing resources
   a) Researching information and securing help
   b) Seeking support from family, friends, and other parents of children with ASD
   c) Advocacy

Appendix G

Example of Parent Narrative Thematic Analysis

This appendix contains an example of thematic analysis featuring Sandy and Ian's narratives from the initial and follow-up interviews.

Sandy and Ian are parents of three teenagers. Their second child, Phillip, is 14 years old and was diagnosed with Asperger syndrome when he was eight. Sandy shared some early experiences parenting Phillip:

> He would get very frustrated with everything, nothing was right for him, even before he could talk he would scream and point. I could just see because I guess I've worked with children quite a bit…and I'd already had a child, and I know you should never compare one child to the other but when things like this happen you do, why is he like that? It would be a scream, a point, a shake of the head and the banging of the head started really young, banging his head against walls and floors, whatever was available. At that time, 6–12 months, really young so [thought he would] grow out of these sort of things, he's just angry. And then as he got older, especially the toddler years they were awful. He was the cutest child and I thought, you know, if he wasn't so cute I might have strangled him a few times. He was, he was just angry, irritable, didn't speak that well, but his older brother seemed to know what he wanted. Just watching him with things like puzzles, he was very good at puzzles, but his hand coordination obviously wasn't up to what he thought he was capable of doing. He'd get very angry, he'd know where a piece of puzzle would fit and he knew it went in there, great big chubby hands and a small puzzle piece, you could see him and then he would scream and the puzzle would go flying, and all hell would break loose. If something was moved in his room, he'd have all his teddies lined up in his bed or cot, and he would know if it was in a different place, or if they weren't all there. He had about 30 of them.

This excerpt described the *challenges associated with Asperger syndrome,* such as *self-regulation problems* – Phillip *becomes upset quickly and demonstrates angry and violent behaviour* – and *obsessive behaviour* regarding his teddy bears that needed to be lined up in a certain order. Sandy noted that Phillip behaved differently from his sibling and the other children

Sandy had worked with, possibly indicating that Phillip's behaviour and *development did not fit a 'norm'*.

Both parents elaborated separately on Phillip's obsessive behaviour when he was two and a half years old. Here is Sandy's version:

> I remember one particular night, you know how some nights just blend into others and some stick out. There was one night I was saying goodnight to him, he must have been about two and a half, this was still [overseas] and we moved here when he was two and a half, so he was like 'dog'. I said 'No, you've got your dog', so showed him, he said, 'No dog'. I said, 'They're all here'. And he got angrier and then flung himself out of bed, ran into another part of the house and came back with another dog. He knew it was missing. I was like, 'OK, that's where it goes'. He wouldn't go to bed until everything was in its place. Then we had my sister in law come to visit, he would have been not quite two, and I'd asked him to go and get something and my sister in law said, 'Look I'll get it', picked it up and gave it to him and he went ballistic. Snatched it off her, threw it on the floor and he picked it up and ran back to the other room where it was, came back stood there for a second, then went back and got it and came back with the same toy that she had initially given him. We've got a very strong willed child now, at that stage I was leaning towards there's definitely something, but I don't quite know what…

After moving to New Zealand when Phillip was around three years old, Sandy related what happened next:

> …I remembered talking to someone or hearing something on TV, not sure what it was, but I remember Googling Asperger's and thinking he's got something. There wasn't a lot of information on it because a lot of the things said they have to have this, this and this. And I'm thinking, well, he's got that, the social side of it was very hard, and even at kindy and things he always hung out with the teachers. And then with family it was always with the adult, he just got on better with them, there were no arguments when he was close by so it was easier to have him there. It was quite hard pinpointing what it was, I really thought he had Asperger's, but after I Googled I thought I'm not sure if he has, does he have to have all of these or just some of them? Then I didn't realise how great the spectrum was. Over the years we've learnt so much more about it. He was about three that I first went to the doctor and said can he be, can you send me to someone, I don't know what to do or who to ring…they put him on a Watch Wait and Wonder programme, which basically didn't do anything for me because we watched, waited and I wondered what the hell was going on. I wasn't really quite sure what that

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programme was about, what we were supposed to achieve. And we would go down as a family, and the psychologist would just watch the kids play together. We would bring all three children, not every time, the first few times we brought the whole family and she just watched how he interacted, which was a bit stressful being in a little room together with the five of us, and thinking we have to act normal.

All four of the main themes are identified in this early parenting experience: *the challenges associated with Asperger syndrome, challenges to understanding, challenges interacting with health services and education services,* and *challenges to family dynamics*. Sandy found Phillip's odd behaviour *out of the ordinary and difficult* when her son quickly angered and became irritable. There was an example of *rigid, obsessive behaviour* regarding the teddy bear and who was allowed to replace it in the predetermined line of stuffed animals. These behaviours showed some of *challenges with Asperger syndrome*. Sandy related going to the doctor with her concerns regarding AS, and the referral for the family to attend an observation programme. Sandy experienced additional stress when her parenting skills and relationship to her son were closely examined and she expressed frustration in her ability to find appropriate support and answers. Health and education professionals showed a *lack awareness, knowledge or familiarity with ASD* and with children on the higher end of the autism spectrum*,* missing Phillip's early indicators. From the mother's perspective, the doctor and the referral to Watch, Wait and Wonder did not *acknowledge her concerns adequately* and the *education and health system did not deliver appropriate and timely support*. Sandy was not able to advance to another specialist until she completed this programme which further *delayed finding a diagnosis*. Other parents in the study referred to this stressful and exasperating time before their children were diagnosed as the 'Lost Years'. The programme added additional stress to her family as all family members were required to participate and to "act normal", creating *challenges to family dynamics* and *conflict with siblings*.

The early year experiences continued to be challenging for Sandy. The difficult aspects of AS and its influence on the other family members created *challenges to family dynamics* and *conflict*:

Sandy: …he would be able to pick up pieces of furniture and throw them across the room, which was when I often had to barricade myself in another room with the kids just until everyone calmed down, and make sure he was safe. That was really difficult, those [years] probably from

age of two and a half to five, six when he was so physical, he didn't know where to exert that energy and it wasn't okay to pick up furniture and throw it at people, or to belt the hell out of your brother and bite him, all those other things…Ian used to come home angry every day, and I just thought there was something going on with Ian, and I realised he would come in the door and Phillip's standing there grizzling, and Ian is so patient, calmest man I've ever met and he's flying off the handle within 30 seconds of being home from work. This isn't what I wanted my family to be like, so something's not quite right here. And everyone is like walking on egg shells around Phillip, tread carefully. I thought this isn't right, why should we be wandering around stepping on egg shells around Phillip, because we don't want an explosion or someone crying? I looked at my family from a distance and I thought no, we need some sort of intervention. Ian is getting angry and he comes home upset, then I'm upset because he's upset, both going off at Phillip, and then [my other two children get] less of our time. And when we were doing things when he was calm it was beautiful. It was the most wonderful family picture. Everyone was doing their own thing.

J: What would be the balance between calm times and ones when you were always on edge? Is it more of one than the other?

Sandy: It was definitely more on edge, especially those toddler years. That's why we went to get help, I can't live like this.

J: Did you go back to a paediatrician?

Sandy: We did this for about six months at the place in the Watch Wait Wonder programme, then one day she said 'I think we've done all we can, we'll discharge him'. At this stage he was still in kindy so four [years old], so I spoke to his kindy teachers, I confided in them because I was finding it so difficult. And the head teacher there, he does just mostly stick around with the adults, he would hide under tables quite frequently, and occasionally he was okay with the children, he didn't ever get into fights at kindy, it was only at home that he was aggressive. He never threw any furniture at kindy, never beat anyone or anything like that, so when I approached the head teacher who was very supportive, she was lovely, but she said 'Look, he's just a lovely little boy, he's a wonderful child'. But he doesn't actually communicate very well with the other children, he doesn't socialise with them, even in a group you could see he was on the outside looking in…

Sandy's discharge from the Watch, Wait and Wonder programme echoed several other parents' experiences. When the programme's expertise was exhausted or a

definite answer was not found then the family was dismissed and left without the needed support. This shifting of responsibility for the problem back to the family left them with fewer avenues to pursue regarding their problems and concerns, underlining the *challenges interacting with health and education services.*

Sandy had had reservations about her son since he was six months old, which became more acute when he started preschool. She received a medical diagnosis for her son when he was eight years old, with the official diagnostic process covering nine months, indicating a *long medical diagnostic process.* Sandy used the following analogy to describe this journey:

> …there were a lot of difficulties when he was younger…after you get through each hurdle you think this is a clear run now, but no, we used to think there was a path, now we realise it's just a whole bunch of hurdles.

Sandy's reference to "hurdles" was repeated later in her narrative:

> …he was doing OK at kindy and I think because he had such loving support from the teachers that were there. And then when he started school he didn't really like it. It's quite a big jump from kindy to school for a typical child. He didn't like the routines and the hiding under a table became more. He was always one to take off his clothes, that was always a big thing. It sort of stopped by 5–6 but he did it a lot when he was little. And when it first happened I just thought, oh just let him do it, he's not hurting anyone…so we had a lot of issues with the swimming pool, in public stripping off clothes, as I say, that was another hurdle we got over and that was behind us.

Sandy also said, "I think that schooling thing is the biggest hurdle to get over". Sandy's allusion to overcoming obstacles during a race captured her perspective of the challenges she faced regarding her sons' behaviour or her interaction with school staff. Her experience over time changed her view from one or two hurdles to several. This *belief system* revealed *meaning making* that contributed to Sandy's ability to manage ongoing challenges and trials in her daily life. She mentally prepared herself for the next obstacle. This excerpt also featured *longer time needed for school transitions* and a *heightened sensory sensitivity* to clothing. This sensory sensitivity to clothes meant he took them off whenever he could when he was young, bringing about public embarrassment and humiliation for Sandy when outsiders found this behaviour unacceptable.

*…*I managed to get through an awful pool incident we had, but most of the time when the stripping started I would say, it was like supermarkets, shopping malls and things like that, I would usually say 'Who's going to get fairly cold?' I wouldn't say 'Don't take your clothes off'. I tried to be a mother that didn't say 'don't' a lot, especially when you're in public and people are watching you. You know, 'You're going to get cold', little things [like that] and he would always strip down, but as long as he left his underwear on then I'm just going to leave him, then yeah, we would normally try and get to the car as soon as possible. The taking off of clothes didn't bother me if we were at home, you can run around naked if you like because there's going to come a day when he's not going to want to do it anyway, so that was okay at home.

Sandy was put in a vulnerable position when her son's unusual behaviour met with outsiders' *lack of awareness, knowledge or familiarity about AS*. Later in her narrative she spoke of being mortified after an elderly gentleman filed a formal complaint at the pool and consequently she had to fill out official paperwork in front of a pool employee in response to that complaint. When her son took off his swimming togs at later outings, she told him to put them back on and then "checked in" with everyone within earshot, saying loudly, "EVERYONE ALL RIGHT?" Sandy described herself as a "mama bear" that would come out roaring if need be.

I think everyone thinks he's older than he is; he's very tall for his age so when he was 3–4 and stripping off clothes, people thought he was a 6–7-year-old, and thinking 'Why is he doing that?' I'm like, 'Because he's 3 and that's what 3-year-olds do'. I became really defensive. I got a harder shell on me than I first did years ago.

Repeated exposure to *social stigma* and *judgemental* responses to her son's difficult behaviour meant Sandy developed a "harder shell". These experiences led her to head off possible criticism before it happened. Sandy demonstrated *perseverance* by continuing to take her family swimming and participate in community activities.

A recurring refrain throughout Sandy and Ian's interviews was the belief they were not being *heard* or respected for their own *expertise*, especially when they suspected their child was on the spectrum. Sandy related this encounter confiding her suspicions to her son's teacher:

I said to her a couple of months later, 'Phillip is still having trouble settling in, I think he's on the spectrum'. 'No he's not'. I hadn't even finished my sentence and she said, 'No he's not'. I said, 'Well, he's in the middle of

being diagnosed at the moment'. It was a long process, it took forever, so talking to this teacher, she said, 'No he's fine'. I didn't say it out loud, but you've only been teaching him for a couple of months, I've been his mother for eight years.

Sandy described this teacher's reaction as a "slam the door in your face, she didn't even want to know about it, just 'No, he hasn't got it' and that's it, I said, 'Well, actually we're seeing psychologists as we speak'". *A resistance to listening or acknowledging parents' concerns* created barriers for parents to be open and led them to think they were "neurotic" or overly worried. Sandy said she wanted to tell this teacher: "No one's the same, so whether he was going to be diagnosed Asperger's or not it shouldn't have mattered, it should have been look, what can I do for your child that you think would be helpful?" This *lack of respect or acknowledgement* contributed to Sandy's stress and created a *tenuous partnership.*

Sandy described her interaction with the next year's teacher:

Then the years after have been difficult because the next teacher he had, lovely teacher, but really old school. She's been teaching for 20 years, [and would say] 'No he's lovely, no problem at all, beautiful child'. I said, 'You should come and visit me at home'. He was coming in and banging his head, all the head banging started again against the walls, the whole hate me, hurting his arms, biting himself. It was an awful time settling back in, because we keep moving and during his first 5–6 years we moved house about 5 times…

Other professionals did not take Sandy's concerns seriously regarding her son's needs, pointing to the issue of *who knows best* and professionals' *lack of awareness* about how AS presents in children:

Yeah and talking to other people, a lot of people were like 'No, he hasn't got it'. 'Well, *you're* not the expert!' But I wouldn't say that. I'd think Phillip's quite different from a lot of other children, he knows when to put it on and when to not, they said 'No, Asperger's people can't do that', but after speaking to a lot of people, a lot of people say their child does that too, a little angel at school and a devil at home, or the other way around. I would rather him be an angel at school, after saying that all these years he was a little angel, sometimes I'd like him to be a bit of a devil at school because then the teachers would say actually there is something. But at the same time that's really hard on friendships. Because speaking to other parents too, they have the problem where their child was just diabolical at school, so then had no chance of making any friends.

Everyone talked about that child all the time, didn't want to be friends with that child, and I thought gosh, that would be worse…

Comparison helped Sandy cope with the *duality between her son's behaviour at school and at home*.

Sandy said that *finding a diagnosis* helped her *make sense of the origins of AS*:

I think the biggest thing too is don't beat yourself up all the time. We did that for a long time. What did I do that was wrong? Was it when I was pregnant because I was depressed…so I thought, was it me, did I do this? It wasn't until he had the diagnosis, then I thought, well, there's nothing I did or didn't do. I think a lot of parents think what did I do wrong? Was there something when I was pregnant I should have done, shouldn't have done? You just don't know until you have that diagnosis. And the diagnosis is wonderful because so many people say I'm not telling anyone, don't want a label, I don't want him diagnosed, I'm not labelling him. But it's been probably one of the best things that we've had is giving him a label. Because people understand him, they've got more patience. I don't go out with a placard [that says] 'My child has Asperger's'. And now that he's old enough to understand that's what he has, we talk about it quite openly now.

Sandy and Ian's narratives showed the struggles managing the difficulties associated with AS, and what the diagnosis *meant* for them and their son. Ian described some of the ways the family would cope:

…well he would always seem to be grouchy, you're like a little old man at two. You think he'd grow out of it, but he never grew out of it, until you realised he's grumpy because probably he sees the world differently and how do you adapt to that? Took us awhile to adapt because *we* would always change, we would change the way *we* reacted. If he was going to have a fit because he couldn't have that book, we'd tell the other two kids, 'Don't take the book' because he wants the book. So we would adapt our way to suit him and we were going crazy.

Ian showed *acceptance* of his son's point of view: "He sees the world differently". Ian also tried to circumvent potential temper tantrums through collaboration with the other children, *planning ahead and problem solving*.

Sandy shared the potential for *conflict with siblings* when she said, "Yeah, I think there might be times when they feel like murdering him, but you know that's

normal too to feel like that". Sandy spoke of how difficult it was to respond to Phillip's *violent behaviour*:

> Phillip was quite violent, which was really hard because Ian and I aren't violent. He's never seen it. He's never seen either of us hit each other. There were times I wanted to hit Phillip, but I restrained myself, or I would leave the house for everyone's safety.

As their son grew older, his violent episodes gradually subsided and were replaced with *anxiety*. This progression paralleled other parents' stories. Sandy explained how they discussed the diagnosis with Phillip:

> We discuss it openly in front of the children at home, and whenever there's anything, anyone new in our lives I always tell the adult. When I say it they go, 'Oh, *that's* what it is'. So a lot of people have picked up on it, but are being too nice to say anything. Now with Phillip, it's more managing his anxiety, that gets quite high at times, I just have to remind myself every now and again that life can be really difficult for him, he sees things in a different way and that's what, I guess when you tell a parent to explain to their child what they have, I guess it all depends on their age at the time, we told him he just has something, we never used the word Asperger's until a few years later, he just sees the world in a different way than other people do. He would often say to me after we'd explain to him, he would say, 'Is that because I see the world in a different way?' I'd say, 'Yeah, it is'.

Sandy gave Phillip a *positive reinterpretation* of his anxiety when she explained to him that he just saw the world "in a different way". She is also spending *extra time to educate* others and her son. Sandy revealed *meaning making, problem solving*, and *patience* here*:

> Sometimes it's a wonder, sometimes it's a blessing…you notice things that other people don't notice. It's all good, good stuff, but when you get angry and anxious we have to now work out how to manage that, and we have over the years. Because each child is so different, and obviously each parent is so different, we all have to come together first, and it's like feeling each other out, certain things really annoy Ian and I'm like 'What's your problem?' And then the same things happen and I might fly off the handle, and Ian's like, 'What's your problem?' It's all just growing together too, I look at [our other son] and I think 'Gosh, you've had it hard sometimes'. I don't know how many times I've told [my other son] off because of something Phillip's done, because I get angry and I don't

want to upset Phillip, so [his brother] gets the brunt of it, yet he's turning out okay. He's going to be 14 in a couple of weeks, and people have said if he was going to be horrible you'd already notice it.

Sandy articulated how "each child is so different" prompting different approaches and a working commitment within the family to *understand and accept* each other. Sandy demonstrated *positive reinterpretation* when she said, "there's so much to learn, every day I learn something different, and discover something different about Phillip" and "it's all good, good stuff". She viewed difficult situations as opportunities to learn and build expertise about how best to parent her son.

Ian shared his own journey parenting his son:

[I am more] tolerant. The main thing is it's really education, because we have an understanding of the syndrome, of his makeup. You have a better understanding of what he's thinking and then you just ask things differently, and there's nothing wrong with that. I can't say, change the way we react to him, no, I still yell at him sometimes, and you're still a 12-year-old boy, you should know better, but certain things you understand, oh he does that because that's just his makeup, and it's a lot easier now that we understand.

As Ian *researched information about AS* and as he gained a better understanding of his son he was able to cope better.

Turning Points

A *turning point* for Sandy revolved around a *school breakthrough* when she finally received much needed support for her son. A behavioural specialist from an outside service implemented accommodations at school that were successful for Phillip and his teacher. The specialist relieved the pressure Sandy was under trying to get school staff to acknowledge and work with her son's needs. She said "he was able to influence things at school that over the course of four or five years we couldn't do, it's getting someone in with an official title". Sandy elaborated:

Everything changed, and it wasn't until [a specialist service] went to the school and observed him in class, and he spoke to the teacher about all of the things she could be doing, and she took them all on board, everything he had mentioned to do and I had another friend at the school at the same time, whose child was also on the spectrum but hadn't been

officially diagnosed, they were having a lot of difficulties at school. I said, 'This labelling thing is great, as soon as he was officially labelled they couldn't do enough for us'.

J: Why do you think that's so?

Sandy: I don't like to think of teachers being arrogant or ignorant of Asperger's because it is a relatively new thing, and they don't know enough about it. They don't go to training, there's nothing in their training that covers that, and there's so many children with it now. I think it's probably always been there, but when we were kids we were considered naughty children, not on the spectrum. I think it's always been there, just now there's a diagnosis, and teachers really don't like parents telling them what their child is or isn't.

Sandy speculated on how Asperger syndrome has been characterised in the past and how it is interpreted in the present, *making sense of it.* She also noted the difficulty of professionals not acknowledging *parents' expertise and knowledge* about their son, but instead more readily accepted a medical diagnosis and advice from educational specialists. This illuminates the reluctance and resistance parents encounter at school. Ian said the teacher "realised that there was a point to all this, it wasn't just mumbo jumbo, it was actually true, or it helped". This *turning point* revealed school staff finally understanding and making the necessary accommodations. For these parents, an intervention from an outside party was able to prompt the teacher and principal to take the AS diagnosis seriously. Ian said, "They had to get back and tow that, get back on the line and it really was a turning point". A more positive tone emerged in the narratives when the relationship with the school improved and everyone was *moving in a forward direction*.

Due to a long waiting list for its services and limited funding, the local specialist intervention service was not able to support Sandy and Ian's son at school long term. After meeting their goals over a course of a few months, they withdrew their support. Sandy described this point in her experience:

I sat here and cried when we had [the specialist] tell us that right, he's signing off now, he's done all he can and I understood that. [They] have a waiting list of about two years and he was the best thing that happened to us, as I said since he was diagnosed. I just burst into tears and said 'You can't leave us now!' All I could see was doom and gloom. Phillip has got to go into intermediate, he's going to get picked on, bullied and it's funny

because I always end up in tears talking about Phillip, I just think he's come such a long way.

The need for continued support at this critical time is highlighted and the pressures felt by parents noted. The outside support helped raise Sandy and Ian's *capabilities and self-efficacy* in dealing with Phillip's needs at school and at home. This coincided with a second *turning point* when Sandy discovered a personal realisation about AS, along with a workable strategy at home:

> I think the turning point was when Phillip turned around nine…and I realised Asperger's was actually something they never get over. We had spent years treading on eggshells around Phillip, including our other two children, and I realised that our best medicine was humour…Phillip's got a great sense of humour and he could and still can be brought out of a funk as long as we use the humour correctly…when we really noticed we could use the humour to our advantage, and that's when I was able to turn it around and start joking with him instead of mollycoddling him, and then getting the teachers on board somewhat. And just realising that we have, we have two other children, you know sometimes it just opens your eyes and think you know these two children could be suffering just as much if not more, and we're not going to sit here and take it anymore.

This example revealed the impact a child with AS can have on the entire family. Sandy's resolve gave her strength to cope with the challenging aspects of AS and the effects on her family. Sandy used *humour and strengthening her intrapersonal assets* to diffuse the tension that built up, and this in turn created a more positive environment to live in. She said her son was "very funny, he's got a great sense of humour. I think over the years that will hold him in good stead" and Ian said it was his son's saving grace:

> …there is an inside joke, don't get me wrong, now, he's still alive because he has a great sense of humour and he does, quick wit, he's very funny, but when he gets down on himself it's sort of like there's that grumpy old man again, oh, that's just your wiring, how do we change that, not too sure.

Sandy also reflected on forgiveness as a productive coping strategy: "I forgive easily which is a great strength to have". She valued this as a means to get through difficult situations and approach the following challenges with a clean slate, her way of *accepting* each other's' foibles, and then *problem solving* and *preparing* for the next

day. She said forgiving means "it's done and dusted and it's… water under the bridge now". She described how forgiveness can work both ways:

> We always have at the end of the day, I always lie on his bed with him and say goodnight, and we have a little chat about anything that's gone wrong or right during the day, and I explain to him why I went off my trolley at him earlier in the day, said 'I'm sorry if I upset you, but I did it because of this or that', then I'll ask him how he feels about it, and that's usually when I get an apology. That's the whole thing, isn't it?

Sandy continued:

> And just saying sorry is really hard sometimes for people, what I did was wrong, especially if I have yelled at him, which I often do. I try not to, but it happens, and I'll explain to him why I did it. Then when he realises the reason why, sometimes I honestly think he has no clue that he was the reason I yelled. Then when he's calm at the end of the day, it's a nice time to do it, he can go to bed, like I don't bring things up and say you shouldn't have done this or that. I want him to go to bed happy, and it's a nice time of the evening to do it, all relaxed.

Acceptance is a component of forgiveness in these examples. Sandy acknowledges the challenging nature of Phillip's world perception and the pressure it puts on her as a parent. She takes *extra time* to debrief and decompress with Phillip at the end of the day. Sandy has created a positive climate to help Phillip learn about social nuances and his effect on others, and to distress together.

Developing resources and *support* from other parents is mentioned often and strongly in Sandy's narrative. Here was one example:

> The greatest thing I've ever used has been meeting other parents with children similar, or even not necessarily on the spectrum…or have been diagnosed, it's just meeting other parents and seeing what they're going through, and offering insights. Everything is helpful, it doesn't matter if you've tried something before, as the child gets older you think, oh try that again, see if it works this time, and just hearing other people's stories and realising you're not alone. Sometimes I come back and think gosh, we're actually all right.

Comparison came through again along with *developing resources* as a new community of people is found. Sandy finds a *sense of belonging and acceptance* here. In addition, she learns helpful strategies from people who have lived through similar situations: "The very first thing I found the most valuable for us, was talking to

other parents who have been diagnosed whether recently or a long time ago, it was the most valuable thing I've done".

Sandy gave an example of when she used *problem solving* and *stepping back* as an effective coping strategy:

> Okay, I'll use art as an example. He quite likes his art, and the beauty with art, is it doesn't have to be perfect, but he wants it to look how he has imagined it in his mind. And quite often we've been doing things together and I love my art and crafts, but I'm no artist, but I really enjoy it, and I have to show him that I'm making mistakes too. That it's okay to make mistakes, sometimes making a mistake ended up being really good in the end, especially with art when you're painting a mould or anything like that, great things can come from mistakes. I think he's finally getting it, years ago he would have been drawing this beautiful picture, done a wonderful job and made a little wee mistake over here, and the whole thing gets screwed up and thrown away. Then all hell breaks loose, and I would just have to step away. Once he's in that mode, it's straight downhill. And there's no point trying to bring him back, or trying to get the paper out and iron it out again because there's a mistake on it, and that tiny little mistake even if you could rub it out, it's ruined his whole picture. Now that he's got a little older, he's seeming to understand, to talk about things. 'Hey Phillip, you've made a mistake, that's fine'. And try and get him before he gets into upset mode. 'Let's come back in half an hour and we'll discuss it. What can we do with this mistake? What do you think we could do? Can it be rubbed out? No? Okay. If it can be rubbed out, great, if it can't, you can build on it, build around it or put something on it, especially with art because it's so easy to change'.

Ian said that *stepping back* worked for him too:

> …then he'd get mad, sometimes you just have to walk back, take a step back, but why would he want to do the hardest kind of task, because that's what he thought he had to do, or he wanted to do it that way. And I haven't found a way today to change that once it's clicked in, I don't, I haven't found a way to change it…

Sandy and Ian showed an acute awareness of when to actively problem solve with their son and when to pull back. Sandy's *positive outlook and patience* influenced her ability to *persevere* as well, *additional intrapersonal assets*:

> I think one of my strengths, I think I'm quite, quite patient, I'm not, I could still work on it, but I think I have a really good amount of patience and I think in situations that Phillip seems to bring to us is a great thing.

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Their growing understanding of how the aspects of AS affected their son was instrumental in helping Sandy and Ian manage. Their coping responses displayed a willingness to try different approaches and they showed a steady determination to carry on. They have experienced a wide range of difficulties within their family as well as outside as they searched for a diagnosis, secured support and dealt with public misconceptions. Their *turning points* demonstrate the influence that an outside mentor (behavioural specialist) and a positive adaptation (sense of humour) can have to change their trajectory to a more positive direction. These trials contributed to building resilience for this couple and demonstrated the wider influences, both negative and positive on their ability to cope.