"JUST DOING THE BEST THAT WE CAN"

The Experience of New Zealand Parents Conducting A Home Based, Early, Intensive, Intervention Programme for their Child with Autism

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*This thesis is dedicated to the loving memory
of my mum, Margaret, who taught me
that I could do anything if I
believed in myself,
and to my little miracle Sesilia
who rekindled that belief.*

Abstract

The ever increasing number of children being diagnosed with Autistic Spectrum Disorders, has led to a prolific body of research highlighting the effectiveness of and examining variables associated with, early and intensive intervention programmes for children with autism in both home based and school settings. Utilising grounded theory methodology, the primary objective of this research was to explore the complex experiences of New Zealand parents who employed a home based early intervention programme for their child with autism.

The sample group consisted of seven primary caregivers of children with autism currently enrolled in a home programme in the greater Auckland area. Participants completed The Life Stressors and Social Resources Inventory and Becks Depression Inventory II and in depth interviews were conducted.

The findings indicate that parents choosing to implement such a programme are forced to take action and develop various strategies to ensure that available resources are fully utilised. The belief that they were doing the best they could for their child with the information and resources available to them at this time ensured continuity of the programme and aided acceptance of their child's condition. Adjusting their goals and expectations to fit plays an integral part in helping these parents to maintain balance in their own and their families lives.

The implications of these findings for future research and for professionals working with this population are discussed.

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Introduction

Background

Autism is a pervasive developmental disorder characterised by deficits in three main areas of functioning: social interactions, communication, and behaviour, which is often restricted, repetitive and stereotyped. (DSM-IV-TR; American Psychiatric Association, 2000). Research released by Dr Ivar Lovaas in 1987 demonstrated that early and intensive intervention programmes for children with autism utilising applied behaviour analysis methodology could reduce the above-mentioned deficits and vastly improve the capabilities of almost all children with the disorder (Lovaas, 1987).

The ever increasing number of children being diagnosed with an Autistic Spectrum Disorder has led to an upsurge in the number of families choosing to use early and intensive intervention programmes for their child with autism. This has led to a prolific body of international research highlighting the effectiveness of and examining variables associated with early and intensive intervention programmes for children with autism in both home based and school settings. The number of families choosing to implement these programmes in New Zealand is increasing. However, literature examining the programmes and their impact of them on families in a New Zealand context is scarce.

Rationale – Personal Contribution

Having worked with children with autism and asperger's syndrome for six years as a behavioural therapist in home based intervention programmes, I had been given the unique opportunity to observe both the positive and negative aspects of parenting a child with autism. I was familiar with international literature documenting the adverse effect that parenting a child with autism often had on parental well being and tragic events portrayed in the New Zealand media in 1998 brought the nation's attention to the plight of parents of autistic children. This was the catalyst for the design and implementation of this study. It was evident that the support available to parents who faced the

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sometimes daunting task of raising a child with autism was minimal and that services that could be of assistance were often insufficient to meet parents multiple needs (Autistic Association of New Zealand, 2000).

Working alongside families, I observed that the stressors that these parents faced on a daily basis, not only within the home but also from external sources, were numerous. However, despite these extreme circumstances the parents I worked with appeared to cope to a reasonable degree despite the additional challenges that accompany orchestrating a home programme.

Purpose of the Study

The purpose of this study was to examine and document the experience of parents who had chosen to conduct an early and intensive intervention programme in their home in addition to the usual challenges of raising a child with autism. This study was designed to explore firstly how they did this and secondly the impact of it.

Significance of the Study

Through in-depth interviews with the primary caregiver, this study developed a clearer understanding of these parents' experiences and although it doesn't provide the reader with a generic formula on how to run a home programme and maintain a sense of normality, it does provide a unique and important window into the journey of these families as they strive to help their child live with and overcome some of the hurdles imposed by living with autism.

Chapter Two

Autism Overview

In 1943, Leo Kanner published a paper titled "Autistic Disturbances of Affective Contact" in which he described a group of eleven children who displayed social aloofness, an indifference to others and stereotyped and repetitive play. Kanner subsequently identified this group of behaviours in children as 'early infantile autism' - the first diagnostically recognised description of Autism. His criteria included ten categories: 1) the inability to develop relationships with people, 2) delay in speech acquisition, 3) noncommunicative use of speech after it develops, 4) delayed echolalia, 5) pronominal reversal, 6) repetitive and stereotyped play, 7) obsessive insistence on the maintenance of sameness, 8) lack of imagination, 9) good rote memory and 10) normal physical appearance.

Over six decades have passed since Kanner's initial description of the disorder, and it is now readily accepted that 'Kanner's autism' is not a discrete disease entity with one etiology, but is rather one of several syndromes on a spectrum of autism and autistic like conditions (Gillberg, 1992). Wing (1971) who described autism as a spectrum of disorders in which varying degrees of impairment are represented, reduced Kanner's criteria to three broad interacting zones of deficit. This triad of impairments includes, qualitative impairments in social interaction; qualitative impairments in communication; and restricted repetitive and stereotyped patterns of behaviour, interests and activities. This now forms the basis of the diagnostic criteria for autism in one of the major classification systems in use, the revised DSM-IV. The Diagnostic and Statistical Manual, Fourth Edition (DSM-IV-TR; American Psychiatric Association, 2000, p.75) describes Autistic Disorder as the presence of qualitative impairments in several different areas of development – 1) social interaction, 2) communication and 3) restricted, repetitive and stereotyped patterns of behaviour, interests and activities. A degree of deficit in each of these areas must be present to warrant a diagnosis of Autistic Disorder and

onset must occur in infancy with symptoms manifesting prior to three years of age.

Pervasive Developmental Disorders

Other disorders generally classified in the autistic spectrum include Childhood Disintegrative Disorder, Pervasive Developmental Disorder- Not Otherwise Specified and Asperger's Syndrome. Childhood Disintegrative Disorder is characterised by the deterioration of intellectual, social and language functioning over a period of several months in children of approximately three to four years of age who previously had normal functioning. After the deterioration, these children closely resemble children with autistic disorder. Pervasive Developmental Disorder, Not Otherwise Specified (PDD,NOS) is a diagnosis used when there are symptoms similar to those seen in autism, but where the criteria are not met for a specific pervasive developmental disorder. The DSM-IV-TR defines PDD,NOS as severe pervasive impairment in communication skills or the presence of stereotyped behaviour, interests and activities with associated impairment in social interactions. Compared with children with autism these children have better language skills, more self-awareness and generally have better outcomes (Sadock & Sadock, 2003).

Asperger's syndrome is the focus of considerable interest and disagreement as researchers try to determine a framework that will accurately and consistently differentiate between those with high-functioning autism and those with Asperger's syndrome. At this time Asperger's syndrome is viewed by some as a dimension of autism and the term is used to describe individuals with similar but milder deficits than autism (Leekam, Libby & Wing, 2000). Others use it to describe a similar yet separate disorder with recognisable differences in behavioural, cognitive and adaptive functioning (Szatmari, 2004). The current framework in the DSM-IV requires that the individual exhibit qualitative social impairment and restricted interests and patterns of behaviour and differentiates between autistic disorder and Asperger's syndrome through exclusionary characteristics. The diagnosis of Asperger's syndrome is made in the absence of clinically significant delays in language, cognitive development or age

appropriate self help skills. Evidently the most obvious distinction between Asperger's syndrome and autism is the absence or presence of language delay and dysfunction although some delay in language has been seen in over one third of clinical samples (Sadock & Sadock, 2003). They also differ in that individuals with Asperger's syndrome are more likely than those with autistic disorder to seek social interaction. However, attempts to develop relationships are often hindered by impairments in reciprocity and behavioural oddities. The prognosis for individuals with Asperger's is variable and is dependent to an extent upon the level of social skills the individual acquires and is further improved for those with normal IQ. (Sadock & Sadock, 2003).

Autism

The prognosis for children with autism is also variable and it is generally considered to be a life long disorder due to the degree of deficit exhibited by these individuals. An illustrative description of these deficits follows.

Children with autism often avoid eye contact, seem to dislike being touched or held and usually are unable to understand their own and others emotions or discern meaning from an expression, gesture or one's body posture. Their play lacks variation and spontaneity and is often repetitive. For example, they don't play appropriately with objects, and they are often observed lining toys up or repeating a certain sequence with a specific toy over and over again. Children with autism prefer to engage in solitary activities and generally will not seek attention or comfort from peers or parents. As such they usually fail to develop peer relationships to an appropriate developmental level.

Spoken language is either absent or delayed. In those who develop speech, it is often characterised by pronomial reversal – replacing 'I' with 'You' and/or echolalia – the repetition of words or sentences spoken by others. Echolalic speech is usually noncommunicative and frequently contextually inappropriate. For example, they may repeat a television advert they heard the day before in response to being asked their name. Children with autism also tend to interpret speech quite literally and as older children fail to comprehend the subtleties of sarcasm. This often results in confusion or they may respond to a statement

such as "just hop over here for a minute" by literally hopping over to the person.

The behaviour, interests and the activities that children with autism engage in are often termed bizarre and are often what draws attention to these usually otherwise normal looking children. Children with autism frequently have an intense preoccupation with specific inanimate objects such as vacuum cleaners, subjects, such as dinosaurs or television antennas, or parts of objects such as corners. They often adhere to specific non-functional routines or rituals such as placing photos in a certain order, only ever turning left, or waiting until the entire family has eaten breakfast before putting their shoes on. In addition, stereotyped and repetitive motor mannerisms are also exhibited by a number of autistic children. This may include, hand flapping, spinning, eye rubbing and teeth grinding. These behaviours are often exhibited when the child is either anxious or excited. Impulsivity may be seen as well as self-injurious behaviours, aggressiveness and odd responses to sensory stimuli such as over sensitivity to sound or touch. Abnormalities in eating, sleeping and mood have also been observed. In addition, approximately 75 percent of children with autistic disorder have mental retardation (Sadock & Sadock, 2003) and epilepsy is very common with up to 32 percent of individuals with autism suffering grand mal seizures at some time (Gillberg, 1992; Sadock & Sadock 2003). Understandably, these deficits and oddities make these children a challenging group to parent and teach.

Prevalence Rates

It used to be thought that autism was exceedingly rare. However, this is no longer the case. The broadening conceptualisation of autistic spectrum disorder and the lack of clear delineation of where the spectrum of autistic disorders begins and ends has resulted in a large range of prevalence rates being reported. Current prevalence rates suggest that autistic disorder occurs at a rate of about 5 cases per 10,000 children (Sadock & Sadock, 2003). Child specific rates for New Zealand are not available, nor are autistic disorder specific rates. However, current New Zealand statistics report a rate of at least 1 in 1000

people in New Zealand having an autistic spectrum disorder (AANZ Inc. 2004) with the diagnosis of boys outnumbering girls 2:1 for autism and 6:1 for Asperger's syndrome (Ministry of Education NZ, 2000). Evidently, autism is more prevalent in boys than girls, with current international statistics suggesting a ratio of around 3.5 or 4.0 to 1 (Fombonne, 2003a). The likelihood that siblings of those with autism will also have an autistic spectrum disorder is between 2 % & 4% which is greatly increased from the .16% in the general population. Autism is not specific to any particular race or ethnicity and although previously believed to be a disorder of the upper-middle class, epidemiological studies have failed to find an association between autism and social class (Fombonne,2003a).

Theoretical Explanations

Since the early 1940s autism has been studied extensively. Although the diagnostic criteria for autism have changed very little over the decades, the theories regarding the etiology of the disorder have evolved and changed significantly.

Psychodynamic. Early theories developed from a psychodynamic perspective, and as is true for most psychodynamic theories of deviant behaviour, the parents, and most frequently the mother were seen as the problem.

In his early work, Kanner (1949), described the parents of the children he was observing as emotionally cold, undemonstrative, introverted, and obsessed with the details of their own lives. Time Magazine quoted Kanner as saying that children with autism were the offspring of "parents, cold and rational, who just happened to defrost long enough to produce a child" (Steffenburg & Gillberg, 1989 in Gillberg, 1992). Further to these observations, Kanner asserted the notion that autism was withdrawal from a cold mechanistic environment in which the individuals chose to seek solace in solitude (Kanner,1949).

In Bruno Bettelheim's 1967 book 'The Empty Fortress' Bettelheim purported that autism represented a defective emotional relationship between the child and his or her parents, especially the mother. Based on this belief, Bettelheim's psychogenic treatment approach called for autistic children to be separated from their parents. Psychotherapy was used as the primary form of treatment in order to reduce the inner conflict that these children were thought to be exhibiting.

Theories of parental causation have largely been dismissed, as there is no satisfactory evidence to suggest that any variables associated with family functioning lead to the development of autism. In addition, psychodynamic based interventions did not result in any improvement in the children's functioning (Lovaas, 1987).

Genetics. Research examining the personality traits of the relatives of autistic individuals continues, however, as studies explore the genetic heritability of autism. Wolff, Sukhdev and Moyes (1988) interviewed the parents of autistic children. Eight of the 21 mothers and eight of the 14 fathers were judged to have 'schizoid' personality traits compared with 0 out of the 39 in the control group. In 1990, these researchers further examined the specific personality characteristics noted in their 1988 study and reported that the mildly unusual personality features of these parents may best be referred to as, social gaucheness with a tendency toward the single-minded pursuit of special, often intellectual interests (Narayan, Moyes & Wolff, 1990, p.528) a description which is somewhat similar to Kanner's initial observations.

Murphy, Bolton, Pickles, Fombonne, Piven and Rutter (2000) conducted similar research in which they sought to determine whether or not the relatives of individuals with autism would have an increased expression of personality traits that might be conceptualised as a milder expression of some aspects of autism. They assessed the personality traits of parents and adult siblings of 99 individuals with autism and 36 with Down's syndrome. They found that the traits of anxious, impulsive, aloof, shy, over-sensitive, irritable and eccentric

were significantly increased among the autism relatives. Analysis of results revealed three broad groups of traits, two of which appeared to reflect impairments in social functioning and a third group of anxiety related traits. Their findings led them to conclude that particular autistic like personality traits may exist to a lesser degree in the family members of some autistic individuals and that some of these traits may be a manifestation of the liability to autism.

The focus of research looking at the genetic heritability of autism has shifted in recent years from trying to identify certain phenotypes to more systematic attempts to identify susceptibility alleles. Volkmar, Lord, Bailey, Schultz and Klin's, (2004) recent review of research reported that data received to date from epidemiological, twin and family studies indicate that, in the vast majority of cases, autism stems not from a single gene but from ten, to possibly twenty genes that occur in various combinations and result in a susceptibility to autism.

Biological. Debate surrounds what environmental and/or organic factors set off autism in people who are genetically predisposed but research has identified various potential triggers. Frith's (1989) comprehensive work highlighted the potential influence of several factors including the elevation of blood serotonin, dopamine system impairments, viral infections, immune dysfunction and prenatal and perinatal complications. High serotonin levels are found in about a third of children with autism. It is thought that this may be associated with low IQ. However, to date this remains unclear (Gillberg & Coleman, 2000). Abnormalities of dopamine metabolism have been recorded in cerebrospinal fluid studies of autism resulting in higher levels of homovanillic acid (Gillberg, 1992). This is thought to be associated with increased withdrawal and stereotypes in some autistic children. Viral infections have also been implicated due to reports that a viral infection preceded the onset of autistic symptoms in some children. The impact of a virus on the central nervous system at specific times may result in autistic like symptoms. For example, much debate surrounds the Measles Mumps Rubella

vaccination as some families assert that exposure to the measles virus caused autism in their child. However, it should be noted that to date "not a single link in the complex chain of causality hypothesised by anti-MMR campaigners has been substantiated." (Fitzpatrick, 2004, p.7). Prenatal and perinatal factors have also been studied as possible links to autism as autistic children show more evidence of prenatal (Volkmar et al 2004) and perinatal complications (Sadock & Sadock, 2003) than comparison groups of children. These may include low birth weight, toxemia and bleeding, breech presentation, low Apgar score, haemolytic disease, respiratory distress, meconium in the amniotic fluid, prematurity, infantile spasms, rubella and toxoplasmosis in pregnancy, delayed cry or apnea, and illness and poor vigor in general (Frith, 1989).

Research trying to determine which specific brain mechanisms underlie the cognitive, behavioural and social-emotional deficits that define autism remains a difficult task due to the complexity of the neuroanatomical and neurochemical systems and processes involved. However, current research has highlighted and continues to investigate several brain mechanisms that are thought to be involved. Because components of the limbic system mediate memory, social and affective functions, there has been significant interest in its circuitry and anatomy in causal models of autism. Saitoh, Karns and Courchesne's (2001) study of 59 individuals with autism ranging in age from 29 months through to 42 years, confirmed that there is anatomical abnormality within the hippocampal region of individuals with autism with the area dentata being significantly smaller in individuals with autism. The amygdala has also been found to be anatomically different (Pierce, Muller, Ambrose, Allen & Courchesne, 2001).

Courchesne, Carper and Akshoomoff (2003) looked at the head circumferences which correlates with brain size, of 48 two to five year olds with autism, in order to determine whether brain growth was accelerated. They found that it was, and that the rapid growth period coincided with the time period in which autistic symptoms usually become evident. The children's heads were not

significantly enlarged at birth, leading to the proposal that there are specific events in the first few months of life which result in brain enlargement and that accelerated rate of growth may serve as an early warning signal for the risk of autism. These results have important implications when coupled with Akshoomoff, Lord, Lincoln, Courchesne, Carper, Townsend and Courchesne's (2004) recent finding that when measured using MRI techniques, variability in cerebellar and cerebral size can, in 92.3% of cases identify individuals with autism and in 85% of cases correctly classify the child's level of functioning.

Volkmar et al's 2004 review of literature summarised biological findings to date by stating that "there is now consistent evidence for abnormalities in overall brain size with developmental differences that may point to specific growth processes that have gone awry" (p.145). Research is now trying to determine what causes this accelerated growth and considering the implications of the rapid growth, what if anything can be done to intervene.

Summary

Even though the exact etiology of autism is not yet known, current research findings continue to support the neurobiological model that an individual has a genetically determined predisposition which is subsequently overlaid with one or more as yet unknown organic and/or environmental variables which consequently result in some form of organic brain dysfunction. This dysfunction expresses itself as the symptoms of autism.

Chapter Three

Parents of Developmentally Disabled Children

Parenting a Developmentally Disabled Child

Over the years research has shifted focus from looking at the effect that parents have on the child with disabilities to the effect of the child on the parents. It has been determined that the experience of parenting a child with disabilities is by no means uniform and each family's reactions and ability to cope and adapt are impacted upon by a wide variety of variables. Research reporting the positive aspects of parenting a child with disabilities is somewhat limited (Ferguson, 2001). In stark contrast however, research regarding the adverse impact on parental well-being from parenting a child with disabilities is extensive. This section will provide a general overview of literature relating to parenting a child with disabilities.

Research by Erickson & Upshur (1989) examined care-taking roles in a group of 202 families with children aged two or younger. They compared perceptions of more difficult care-taking tasks between three groups of mothers who had children with either Down's syndrome, motor impairment, or developmental delay and a control group in which the children had no disability. Their results indicated that the difficulty and amount of time devoted to care-taking tasks varied in relation to the nature of the child's disability. For example, mothers of children with Down's syndrome and developmental delays reported more care-taking difficulty whereas mothers of children with motor impairments reported more total care-taking time. They concluded "the different patterns of care-taking burden point to the unique impact of infants with different disabilities on their caregivers."(Erickson & Upshur, 1989, p255). This is important when considering Beckman's (1983) study of parents of 31 handicapped infants who found that the greater the number of caregiving demands the more parent and family problems were experienced.

Bristol, Gallagher & Schopler (1988) examined differences in depression, marital adjustment, disruption to family life and parenting quality between the parents of children with developmental disabilities and the parents of normally developing children. They found that the parents of children with developmental disabilities had more problems with regards to marital adjustment and experienced more disruption in their family life. In addition, they found differences in the care-taking roles performed by the fathers, with the fathers of children with developmental disabilities assuming less responsibility for family and general household tasks and offering less support to their wives. The importance of these findings becomes evident when examining the subsequent data analysis which revealed that, among the mothers of children with developmental disabilities, maternal adaptation and depression were strongly correlated with level of support from the child's father. This interaction effect indicates that marital disharmony may be one of the potential problems for these parents. Bristol et al. (1988) concluded that support from the father increases marital satisfaction and that expressive support from one's spouse is the best predictor of quality parenting for both mothers and fathers. They stated that ability to work together and meet the challenges that children with disabilities present on a daily basis predicts the parent's well being and subsequently the quality of care that they are able to provide for their child.

A review of early literature by Gallagher, Beckman & Cross (1983) examined the sources of stress associated with parenting a child with disabilities. They reported that parental stress appeared to increase in relation to the child's age and was also affected by the time required and intensity of the child's daily care-giving demands. Other factors highlighted in their review were financial difficulties resulting from the need for additional care, equipment and specialised programmes, marital problems due to increased stress and tension in the marital dyad, and increased social isolation resulting from the child's difficult personality characteristics and/or degree of physical incapacitation. Their review noted that although some stressors were common to parenting a

child with disabilities there were significant differences in the level of stress experienced by parents based on the diagnostic category of the child.

Child Characteristics. Konstantantareas and Homatidis' (1991) paper examining the effects of developmental disorders on parents, identified child characteristics that are related to parental stress. Their findings indicated that both increased age and gender were related to stress, with boys being consistently rated as more problematic. In addition to this, symptoms causing the most stress in caregivers appeared to be impairment in verbal communication, unevenness in cognitive functioning and impairments in human relations.

Marital Problems. There is a common preconception that having a child with disabilities is a burden and consequently has an adverse effect on the marital relationship. However, this assumption is beginning to be challenged (Ferguson, 2001). Risdal and Singer (2004) conducted a meta-analysis of 13 studies that examined either prevalence of divorce in families of children with and without disabilities or prevalence of marital discord in families of children with and without disabilities with the intent of clarifying the impact on marriage of parenting a child with disabilities. Their findings confirm that there is a wide range of family responses to having a child with a disability ranging from positive adaptation in which families are strengthened, to a negative impact on marital adjustment arising from the additional challenges and stresses that having a child with a disability puts on the marriage. Overall however, their findings revealed that the existence of a disability in the family is positively correlated with an increased level of marital strain with an average increase of 5.97% of marriages ending in divorce among families of children with disabilities. They note that "although these increases are much smaller than previously assumed, they do indicate the existence of marital difficulties and the need for better forms of family support for some families of children with disabilities." (2004, p.101)

Grief. The existence of marital difficulties may be due in some part to the difference in ways that mothers and fathers experience grief. Bruce & Scultz (2002) highlighted differences in the grieving process between mothers and fathers post-diagnosis. They found that most mothers take on the role of primary caregiver and remain at home to care for the child. They are confronted on a daily basis with their new reality and subsequently actively work through their grief accordingly. Fathers, however, often continue to work, and as such, are provided with a constant distraction. They are often unaware of the implications of their child's diagnosis and as such the grieving process is often delayed or sporadic.

Bruce & Schultz' work also refers to the unique form of grieving and feeling of loss experienced by parents of children with disabilities as non-finite loss. Their longitudinal research with 49 couples that were parents of children with intellectual disabilities aged between 3 and 21 years old investigated this concept. Their study found that amongst parents of children with disabilities, grieving is an ongoing feature and results from the disruption of a significant attachment. Over time, there are often triggers in the environment such as birthdays or particular milestones passed or missed which accentuate or reactivate the parents' fears and highlight the discrepancies between their child and others. As the source of grief is always present, grieving becomes an ongoing task with parents left in a state of limbo as they instinctively continue to seek what has been lost. This is often termed non-finite grief or loss.

Summary. Through reviewing the research related to parenting a child with disabilities, it has been reiterated that the experience is extremely demanding, with families encountering numerous challenges and stressors that typical families never do. The difficulty and time associated with care-giving is greater than that in typical families and parents may be locked in a perpetual cycle of grief. When this is combined with certain child characteristics, additional financial strain and the social isolation that many families experience, it may result in decreased parenting quality, parental stress, parental depression and marital discord. Research has also shown that the

extent to which parental well-being is impacted is, in many cases related to the child's diagnosis and the subsequent nature of their disorder. Parents of autistic children share in the above-mentioned struggles and are often presented with more challenges.

Parenting an Autistic Child

The invisible nature of autism, the lack of relatedness exhibited by the child and the lack of social acceptance and awareness of autistic behaviours are all unique variables that make parenting an autistic child a demanding task. Understandably, parenting these children imposes both physical and emotional strains on parents that by far exceed the levels experienced by parents of typical children. This section will examine the stressors experienced by some parents of children with autism and will consider the impact that having a child with autism has on both the parents and their families.

Stressors. Literature relating specifically to parenting a child with autism has suggested that due to the unique challenges and experiences associated with raising an autistic child, the level of stress and stressors faced by the parents may be inherently different than those faced by other parents of children with developmental disabilities. Subsequently, predictors of, variables associated with, and gender differences in the stress associated with parenting a child with autism have been well documented. This literature frequently uses both the term stressors and stress. For the purpose of clarification, these two distinct variables are defined below.

Stressors are specific life events or occurrences of sufficient duration and intensity to create a change in the individual's ongoing life pattern (Byrne & Cunningham,1985). Examples can range from the birth of a disabled child to a change in one's accommodation. Stress, on the other hand, refers to the individual's response to the stressor, consisting of patterns of physiological and psychological reactions that are both immediate and delayed (Rabkin & Streuning, 1976).

Holroyd and McArthur (1976) conducted a study in which they compared the amount of stress reported by parents of children with autism, children with Down's Syndrome and children who were outpatients in a psychiatric clinic. There were 22 children in both the autism and Down's syndrome group and 32 children from the clinic group. They found that mothers of autistic children reported the most overall stress, greater child dependence, and greater limits on their time, indicating that mothers of autistic children may experience a higher degree of stress than parents with children with certain other disabilities.

In order to determine whether there was a characteristic profile of stress associated with parenting an autistic child, Koegel, Schreibman, Loos, Dirlich-Wilheim, Dunlap, Robbins and Plienis (1992) examined the stress profiles of 50 mothers who had a child with autism and compared them with a normative sample. Their sample group was diverse in that it varied in both geographical and cultural environments and the children were of different ages and levels of functioning. The results they obtained were consistent with previous literature reporting elevated stress scores across domains relating to the child's prolonged dependency, limitations on family opportunities, and the child's cognitive impairment. The consistency in the mothers' stress profiles across the varying populations suggests that there may be a characteristic profile of stress associated with parenting an autistic child that is relatively constant across many variables.

Additional child characteristics were identified as stressors in Gray's (1994) qualitative study examining stressors and strategies among a sample of Australian parents with autistic children. In addition to supporting the above findings his research highlighted the child's inability to adjust to changes in his or her environment, inappropriate eating and toileting and inappropriate sexual expression as significant stressors for parents.

External Stressors. Research discussed thus far has focussed on child and family characteristics as stressors. However, recent research has explored potential external stressors which will now be discussed. Midence & O'neill

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(1999) investigated the experience of parents in the diagnosis of autism. The findings identified obtaining a diagnosis for their child as an additional stressor for these parents. Difficulty obtaining a diagnosis and misdiagnosis for some families caused parents to question their parenting skills and abilities and resulted in confusion, despair, blame and isolation from family and friends thus exacerbating parental stress. Kohler (1999) examined the services received by young children with autism and their families and found that 44% had difficulty or delays in the diagnostic process with some parents reporting up to four visits to different psychiatrists before getting an accurate diagnosis. In addition, he found that once receiving a diagnosis many families experience difficulties or delays in accessing services. Bristol (1984) found that the differences in the receipt of formal services were correlated with differing levels of stress in families of children with autism. Gill & Harris (1991) and Weiss (2002) found that it was not necessarily the amount of support received, but the perceived availability of support that affected mothers. They found that the perception of support appeared to moderate the extent to which mothers were affected by stress related and depressive symptoms. Thus, if families are having difficulty accessing services their perception of support availability is likely to be low, hence increasing stress related and depressive symptoms.

Once families have obtained professional services for their child with autism, other identified stressors arise with regards to service provision, intervention characteristics and professionals' expectations. Kohler (1999) found that families with children with autism had to access a number of different services in order to meet their child's diverse needs. The sheer number of services resulted in further demands on parent time as they had to interact, liase with and transport their children to multiple service providers. The lack of inter agency collaboration became an additional stressor in some cases as parents were being given contradictory or competing advice with regards to therapeutic interventions. Gallagher et al (1983) & Bruce & Schultz (2002) noted that subsequent to receiving contradictory advice some parents encounter blame and criticism when they are too overwhelmed to implement the programmes

required by the different professionals, so, although intended to be supportive, parent-professional interactions can be an additional source of stress.

Summary. Research has identified that the time demands, prolonged dependence, limitations of family opportunities, level of cognitive impairment and inappropriate behaviours are all stressors that impact on the experience of parenting a child with autism. External stressors such as difficulties obtaining a diagnosis, multiple service providers and intervention characteristics have also been identified. In addition, parents of children with autism have been found to have a characteristic stress profile that is relatively constant. Research has shown that the level of stress that they experience related to parenting is higher than that experienced by other parents of children both with and without disabilities.

Impact of Stressors

Holroyd and McArthur (1975) examined the impact of children with Down's syndrome and children with autism on their families. In addition to stress, mothers of children with autism also experienced increased moodiness and were more prone to illness. Mothers reported feelings of grief and ambivalence over the amount of time they devoted to the child at the expense of their own personal time and that of the family.

DeMyer (1979) conducted an extensive study spanning nearly twelve years in which she sought to obtain a better understanding of autism. Part of her research involved observing and testing fifty five autistic children and interviewing their parents. With regards to parental well-being she found that mothers of children with autism expressed feelings of guilt, anger and often doubt with regards to their parenting ability. She also found that the incidence of depression was higher amongst these parents than her controls, with about one third of her sample presenting with reactive depression.

Depression. Depression, which theoretically represents an unresolved and persistent reaction to loss, related to, but different from normal grieving,

continues to be a factor for some parents of children with autism. More recent research by Olsson & Hwang (2001) assessed parental depression in families of children with autism using the Beck Depression Inventory. They found that fifty percent of mothers with children with autism had elevated depression scores, with the average score across the 216 participants depicting mild depression. In addition, they found that fathers of autistic children had the highest depression scores when compared to fathers of children with intellectual disabilities and fathers in the control group.

Gender Differences in the Parenting Experience. Using the Questionnaire on Resources and Stress, the Coping Health Inventory and the Beck Depression Inventory Moes, Koegel, Schriebman and Loos (1992) sought to determine whether mothers and fathers experienced the stress of raising an autistic child differently. Their sample consisted of eighteen mothers and twelve fathers. In comparing the results they found that mothers' stress scores were significantly higher than fathers across the three inventories. The mean Beck Depression Score for mothers was nearly twice as high as that of fathers. This result suggests that the impact of caring for a child with autism on the psychological well-being of parents is significantly greater for mothers than fathers. The small sample size in this study means that generalisation of these specific results is somewhat limited.

Findings that mothers suffer the adverse effects of parenting a child with autism to a greater degree than fathers may be due to the fact that in most instances mothers spend more time with, and assume greater responsibility for the day to day care of the child with autism. As a result, opportunities for employment outside the home and subsequent respite from the disorder are limited and personal growth is constricted. In addition, mothers have no additional source of self-identity and self-esteem. Adding to their stress is the fact that as part of their role as caregiver, mothers must interact with the public on a regular basis. Subsequently, they are faced with the challenge of trying to integrate a child with extreme behavioural problems and a normal appearance into a society that lacks awareness of and as such is un-accepting of autistic

behaviour. People often attribute child misbehaviour to poor parenting. One can imagine that trying to meet society's expectations of a 'good mother' could cause the mother of an autistic child, as noted by DeMyer (1979) to doubt their parenting competence. Furthermore, it is not easy to nurture a distant and unresponsive child which children with autism often are (Gray, 1994). Subsequently, feelings that they are an ineffective parent may be further exasperated in mothers by the lack of reciprocation in the parent - child relationship. The cumulative effect of these stressors may well account for the differences in mother and father's experiences in parenting a child with autism. The impact on mother's psychological well-being could potentially result in a pervasive lack of confidence and low self-esteem as found by Fisman & Wolf (1991) in their sample of mothers of autistic children.

Gray & Holden (1992) assessed parental depression, anxiety and anger in a sample of 172 Australian parents with children who had autism. Once again they found that mothers experience more distress than fathers, with mothers reporting significantly higher levels of depression and anxiety than fathers. As in DeMyers' (1979) study anger was also found to be a commonly experienced emotion. Higher anger scores were found to be related to the gender and age of the child, with parents of boys and younger children reporting higher anger scores than those with girls and older children. The number of children was also found to be significantly related to anger. This is thought to be due to the additional demands on family resources and the added challenge of balancing time demands between children with significantly different needs. Parents may also require more co-operation from typically developing siblings when they have a child with autism and subsequently have expectations of sibling behaviour that is beyond their developmental capabilities. This may result in increased frustration for both the siblings and the parent.

Sibling Relationships. Findings from research investigating the effect of a brother or sister with autism on typically developing siblings are inconsistent. Some research (Fisman and Wolf, 1991; Rodrigue, Geffken & Morgan, 1993) has found negative outcomes for siblings of children with

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disabilities with increased anxiety, negative self-esteem, behavioural problems and somatic complaints being reported, while other research has reported positive findings such as less conflict and greater warmth in the sibling relationship. (Fisman, Wolf, Ellison, Gillis, Freeman & Szatmari, 1996). Fisman, Wolf, Ellison & Freeman's longitudinal study, published in 2000, looked more specifically at the adjustment of siblings of children with pervasive developmental disorder. Results showed that these children were at risk for adjustment difficulties with teachers identifying high levels of internalising difficulties, and parents reporting high levels of externalising difficulties, consistently over the three year period. Interestingly, their results indicated that the adjustment of the unaffected sibling was more closely related to siblings' perception of being treated differently by their parents than to the siblings' relationship with each other.

In more recent research River and Stoneman (2003) found that most typically developing siblings viewed their relationship with the child with autism in a positive way, especially in instances when the child with autism was chronologically younger. Their research showed that a predictor of the quality of the sibling relationship when a child has autism was marital stress. When marital stress was higher, typically developing siblings reported less satisfaction with the sibling relationship. However, due to the interaction effect it is difficult to draw conclusions from this research, as it may be the negative sibling interactions creating family stress which in turn is resulting in marital discord.

Impact on Marital Relationship. Research examining the marital relationship in couples with autistic children is once again variable, ranging from no significant difference when compared with a normal population to increased marital problems and divorce rates. Koegel, R., Schreibman, L., O'Neill, R., & Burke, J. (1983) assessed marital adjustment of parents of autistic children and found that these parents' scores were similar to those of a normative group of happily married couples. Byrne & Cunningham (1985) stated that the marital relationship in families with children with disabilities

corresponded to the quality of the marital relationship prior to the birth or diagnosis of the child, rather than any direct influence of the child.

Fisman & Wolf (1991) investigated both mothers' and fathers perceptions' of marital adjustment in parents of children with autism. Marital intimacy was the primary construct and was compared with perceived parenting stress and depression. They found that amongst fathers, as with mothers, that both parenting stress and depression impacted on marital intimacy and that lower marital intimacy was more significantly related to depression than parenting stress. Previously discussed research has already highlighted the relationship between parenting a child with autism and increased levels of depression and stress, so, although controversy persists with regards to the direction of influence – does the effect of parenting related stressors impact negatively on the marital relationship or is it a troubled marital relationship that impacts negatively on the child's behaviour subsequently exacerbating the effect of parenting stressors. It is evident that marital discord to one extent or another may result for many of these parents.

Summary. This section has looked at research regarding the impact of stressors that arise from parenting a child with autism on parental well-being and family functioning. It is evident that the experience is multi-faceted and impacts on all members of the family positively or negatively to some degree. It has become clear that there is a strong interaction effect between the stressors that arise from having a child with autism in the family on the marital relationship, the parent child dyad, sibling relationships and well-being, and parental well-being. This makes it difficult to draw conclusions with regards to causation about any of the variables discussed. However, it is evident that if not given the appropriate information and support, the cumulative effect of stressors in these families could easily result in a perpetual cycle of negative interactions.

Adjustment and Adaptation

Not all parents of children with autism present with high levels of stress or depression however. Despite the daunting challenges, many families adjust remarkably well. To explain this phenomenon Lazarus & Folkman (1984) suggest that the stress an individual experiences is not a simple function of the number of demands placed on that individual but that if that individuals personal coping resources are adequate to meet the demands being placed on them, then the person may successfully adapt. An individuals coping resources were conceptualised into the five following categories by Lazarus and Folkman; social networks, problem solving skills, general and specific beliefs, utilitarian resources and a final category encompassing health, energy and moral. Being able to access and utilise these resources in response to a stressor helps to determine the outcome. Some of the coping response areas conceptualised by Lazarus and Folkman have been investigated in research specific to parenting a child with autism and will be discussed in more detail later in this chapter.

A second model that identifies outcomes as the result of an interaction between the primary stressor and family resources that has been influential in developmental disabilities literature is the Double ABC-X Model of adjustment and adaptation (McCubbin & Patterson, 1983). This model, built on Hills, (1958) ABCX family crisis model was developed to investigate the observed differences among families in their adaptation to stressful situations and is useful in explaining the differences in familial responses to having a child with autism.

The Double ABCX examines how much and what type of stressors (A); mediated by what personal, family and community resources (B) and by what family coping responses, processes and perceptions (C) shape the course and ease of family adjustment and adaptation over time (X) (p. 7, 1983). There are two central features of this model. Firstly, it takes into account the stability of the family prior to the introduction of the primary stressor, noting that this will in turn influence the family's vulnerability to the impact of the subsequent

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stressor, event or transition. Secondly it acknowledges the family's perception of the stressor as being of up most importance, noting that efforts to redefine a situation as a challenge and as an opportunity for growth plays a useful role in facilitating family coping. In this model adaptation is considered to be a continuum of outcomes that reflect a families efforts to achieve a balanced 'fit' post-crisis adjustment. McCubbin and Patterson state that "successful adaptation in a less than perfect world calls for a general orientation by the family which reflects a sense of acceptance and understanding that this is the best they can do under the circumstances." (1983, p.19)

Earlier in this chapter stressors or part A of the Double ABCX model were examined and the impact that they had on some families discussed. The remaining part of this chapter will focus on examining intervening variables, parts B and C of the Double ABCX model that have been identified in literature to date.

Intervening Variables

Social support has been repeatedly identified as an influential resource in literature relating to coping and adaptation in families of children with autism. This support may be derived from one's spouse, family, friends or various service providers and in general terms is best defined as any information leading the person to believe that he or she is loved, esteemed, and valued and is part of a network of mutual communication and obligation (Cobb, 1976).

With more specific regard to parents of children with disabilities Dunst, Trivette, & Cross (1986) defined social support as a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing and emotional and psychological support. It may also refer to formal services one receives from professional-based organisations and/or services from other organisations that the family deems to be important such as social clubs and churches. Social support has been shown to have a buffering effect such that high-stress families with high social support cope better than do similarly stressed families with

low social support (Friedrich, Wilturner & Cohen, 1985; Gallagher et al., 1983).

In addition to support, certain parent characteristics such as personality attributes and coping style have also been identified as contributing factors . As Paykel stated "it is not merely the event, but also the soil into which it falls." (Paykel, 1979, p.259). Research which has focused on factors that may prevent or alleviate the stress often experienced by parents of children with autism will now be discussed.

Coping style, support & parental characteristics. Frey, Greenberg and Fewell's 1989 study examined various factors that they thought might mediate the impact of a child's disability in a sample of 48 mothers and 48 fathers of young children with disabilities. Using a multidimensional approach they examined the effect of social network, coping styles and parent belief systems in terms of comparative self-appraisal to other parents in similar circumstances, on three aspects of parent functioning – parenting stress, family adjustment and psychological distress. Results indicated that parents whose perceived personal control was strong and who rated their ability to cope highly had better outcomes across all three examined domains. Mothers who also rated the coping efficacy of their spouse highly had better outcomes across the three domains, once again highlighting the importance of spousal support in this population. The effect of social support and perceived criticism differed between fathers and mothers, with mothers placing more importance on social support, especially the amount of assistance contributed, than fathers. This was thought to be due to the fact that mothers do the preponderance of childrearing and as such they may value assistance more than fathers. The level of social support affected the family adjustment of mothers, but was not related to parenting stress or psychological distress, and the impact of perceived criticism was negligible. In contrast, the fathers' results indicated that they were strongly affected by family criticism with it impacting negatively on both their parenting stress and psychological distress. With regards to coping styles, results indicated that a problem-focused coping style resulted in less

psychological distress for both mothers and fathers, less parenting stress for mothers, and better family adjustment for fathers. An avoidant coping style resulted in greater psychological distress for both mothers and fathers and poorer family adjustment for fathers. Although no conclusions regarding causality could be drawn from this study Frey et al's findings highlight which variables may influence the psychological well-being of parents of children with disabilities. They determined that depending on their nature and availability, coping resources can lead to either resilience or vulnerability in the face of what could potentially be a family crisis.

Dunn, Burbine, Bowers & Tantleff-Dunn, (2001) examined moderators of stress in a sample of 58 parents of children with autism. They found, as in previous research that stressors were not a direct predictor of negative outcomes, but that their influence was moderated by social support and coping style. Interestingly they found that although social support buffered the effects of stress, methods of coping were a better indicator of outcome. Parents who engaged in positive reappraisal and confrontive coping fared better than parents who engaged in escape-avoidance. Escape-avoidance was found to correspond to increased depression, isolation and spousal problems whereas positive reappraisal and confrontive coping corresponded to an increased likelihood to seek support and a better spousal relationship.

Weiss (2002) examined how social support and the personality attribute referred to as hardiness impacted on the level of stress experienced by mothers of children with autism. Hardiness was defined as a constellation of characteristics including commitment, challenge and control; "commitment, refers to a general sense of purpose and a tendency to be an active and involved individual. Challenge refers to the perception of events as opportunities. Control refers to the degree of influence one perceives over events in ones life." (Weiss, 2002, p.118). Her findings showed that more hardy individuals were less prone to depression, anxiety and feelings of depersonalisation and were more likely to perceive support as being available to them. Perceived social support from one's spouse was predictive of fewer somatic complaints

and greater feelings of accomplishment in parenting, and coping abilities appeared to be boosted by perceptions of control, self-efficacy and a general sense of purpose. Thus, the personality attribute hardiness is an important buffer against stress and it appears that it is not only the actual receipt of functional support that ameliorates stress but the perceived availability.

Sharpley & Bitskia'S (1997) research found that amount of actual support was important but parents who perceived that the family members giving assistance had a clear understanding of their child's difficulties and needs were less anxious, depressed and also had higher levels of confidence in their own ability to handle their child's major difficulties.

In 2002 Boyd reviewed literature examining the relationship between stress and lack of social support in mothers of children with autism. He found that informal support, which was defined by Bristol & Schopler (1983) as a network that may include the immediate and extended family, friends, neighbours and other parents of children with disabilities, seemed to be a more effective stress buffer, particularly spousal support, for mothers of children with autism. In contrast, formal support - assistance that is social, psychological, physical or financial and is provided either for free or in exchange for a fee through an organised group or agency was not as effective at buffering stress (Bristol & Schopler, 1983).

Professional support. Professionals play an important role in the lives of families with children with autism. In order for professional interactions with families to be perceived as supportive they need to be solution focused rather than deficit focused. Interventions need to build on the strengths and assets that already exist within a family and utilise the skills and knowledge that parents already possess. Parents need to be treated as partners in a professional relationship and be acknowledged as capable members of a team working towards a common goal (Annan, *in press*). Careful consideration should be given towards the parents' emotional status and their subsequent ability to process information. Bruce & Schultz (2002) suggest that sometimes

professionals underestimate the emotional impact of the information they deliver to parents and often overestimate what the parent actually understands.

The outcomes stemming from professional intervention in families with children with autism is becoming a popular research topic. This review focuses on findings related specifically to interventions that are home based. Bristol, Gallagher & Holt (1993) found that the depressive symptoms in mothers who participated in a psycho educational treatment programme decreased over time, in contrast to mothers without treatment who showed no change over time. Hastings and Johnson (2001) found that family involvement and beliefs regarding the efficacy of the intervention impacted on parents' stress levels in home based intervention programmes. They also determined that having a programme in the home did not increase a family's risk for stress. Everett (2001) found that programmes that involved a collaborative relationship between parents and professionals and considered the family's needs and strengths in addition to the child's also buffered the deleterious effects of parenting a child with autism.

As such, training programmes which help parents to make sense of the manifestations of autism and provides strategies that promote behavioural management and aid child development support parents in that they enhance feelings of control, confidence and efficacy thereby counteracting the negative emotions often associated with the care giving demands of children with autism. These factors form the basis of the programmes under study which are discussed in the following chapter.

Summary. Coping style, personality attributes, perceptions and beliefs have all been shown to play an integral part in forming resilient parents and families. Spousal support and informal support such as that from relatives has been shown to be of great benefit, especially when those offering the support had a clear understanding of the child's difficulties and needs.

Chapter Four

Home Programme Origins

Background

Behaviour modification research has greatly influenced the treatment programmes offered for children with Autism by providing scientifically validated treatment models that have been shown to be consistently effective in teaching specific behaviours. (Green, 1996; Harris, Handleman, Kirstoff & Fuentes, 1991; Lovaas, 1987; Weiss, 1999) One of the most influential studies in the use of behavioural modification with children with autism was that of Ivar Lovaas and his colleagues. Initial work carried out by Lovass and colleagues (1973) highlighted the effectiveness of behavioural interventions in helping to alleviate some of the core deficits of children with autism. His research indicated that children's positive and negative behavioural symptoms could be successfully modified using principals of operant conditioning (Skinner, 1953). This involves the presentation of a stimulus such as a question or a command, to evoke a specific response. Following the correct response the child receives something tangible thus increasing the likelihood that the child will respond in the same way to the stimulus the next time it is presented. If the child's response is not that which is desired, a form of punishment such as a frown or a loud 'no' is used and will decrease the likelihood that the child will respond in that way again.

However there were limitations to Lovaas' original work in that many of the children's skills were situation specific and non-adaptive, that is, they were unable to generalise what they had learnt in the controlled laboratory setting to their home or other environments and they were unable to adapt responses to similar, yet different stimuli. For example a spoon is still a spoon even if it is a different colour (Lovaas, Koegel, Simmons, & Long, 1973).

This finding lead to a shift in the treatment setting and the introduction of programmes that were designed to be applied in other settings such as the home, classroom or community.(Schopler, Mesibov, & Hearsey, 1995)

Lovaas developed and researched a home based programme that aimed to ameliorate deficits and increase the social, language, academic, daily living and functional play skills of the child through a high rate of one on one interactions in consistent, predictable, structured environments. He reported outstanding positive results. At follow-up after two or three years of treatment when the children were between 6 and 7 years of age, findings showed that experimental group subjects did significantly better than control group subjects. Of the 19 children in the study group, nine children achieved "best outcome" defined as normal intellectual functioning (IQ>85) and regular educational placement without special assistance and there was an average increase in IQ scores across the group of 20 points to a mean of 83 (Lovaas, 1987). The features of the programme that are thought to be accountable for the success were: 1. the intensive nature of the programme, 2. early intervention, 3. the use of empirically derived therapeutic techniques, 4. instruction in the home environment 5. the inclusion of parents and 6. the inclusion of teaching interactions with similar aged children. (Lovass et al., 1989)

In response to the subsequent demand, clinics were established and service providers evolved, offering Lovaas style programmes to families in their homes. Each family would be assigned a team of well-trained therapists to work with the child in their home, school and community for an average of 40 hours per week. Supervisors would visit weekly to change and up-date the treatment plan. In addition, parents were extensively trained in the programme procedures in order that treatment could take place for almost all the child's waking hours assisting in the generalisation and maintenance of skills learnt (Lovaas,1987) Programmes similar to this that do not adhere to the strict guidelines of the Lovaas treatment model are numerous and are usually referred to as ABA programmes due to the fact that they utilise the principals of applied behaviour analysis.

The New Zealand Context

By the early-1990's families in New Zealand had learnt of Lovaas' early, intensive, home-based behavioural intervention model. Scientific publications and parental testimonies reporting outcomes of normal functioning (Maurice, 1993) prompted some parents of children with autism to seek a similar form of treatment for their child. Unlike America, the United Kingdom and Australia there were no centres in New Zealand offering trained, supervised therapists. Subsequently parents who chose to use this model of teaching had to educate themselves, create a programme for their child derived from various sources of literature and then set about sourcing and training their own therapists from universities and the general population.

At the time this study was conducted there were several options available to parents who wanted their child to participate in an early intervention programme utilising applied behaviour analysis methodology. In the Auckland area, parents were able to access these types of programmes through three different private service providers in addition to the parent constructed and directed home programme. Two of these service providers offered home based programmes and the third was offered in a specialist centre setting. The two service providers offering home based programmes were similar in that they both provided families with trained therapists who would work with the child in the home and school setting and both provided experienced supervisors who developed individualised treatment plans and ongoing parent and therapist training.

Possibly due to the prohibitive expense of the programmes offered by private service providers (AANZ, 2000) many parents continue to develop their own programmes for their child. The body of literature providing intervention programmes and ideas for children with autism has grown considerably in recent years, and as such most parents do not follow one particular programme or scripted curriculum but instead incorporate ideas from several sources. As such, each programme is unique in terms of content due to the fact that aims

and objectives are determined by the parent in order to meet what they see as being their child's specific needs. (Godfrey, Moore & Fletcher-Flinn, 2002)

These types of programmes have been described in other research as "parent-directed programmes" (Smith, Buch & Gamby, 2000) or when a professional consultant is employed, "parent-managed programmes" (Bibby, Eikeseth, Martin, Mudford & Reeves, 2002). Possibly due to extensive academic debate surrounding A.B.A type programmes (Gresham & McMillan, 1997; Lovaas, Smith & McEachin, 1989; Schopler, Short & Mesibov, 1989) many families have encountered barriers in establishing these programmes including discouragement by other professionals and services. (AANZ Inc. 2000)

Relevant NZ data regarding parent managed or directed programme is lacking. However, recent UK studies have found that programmes that are created or managed by parents have less favourable outcomes than those previously reported for professionally run programs (e.g.,Lovaas, 1987).

Bibby et al. (2002) followed 66 children who were participating in parent-managed intensive intervention programmes over 32 months, in order to ascertain whether parent-managed intensive behavioural intervention reproduced Lovaas's clinic based results (Lovaas, 1987).

Results failed to find significant gains on standardised tests for IQ, adaptive functioning or language after a period of twelve months. Bibby et al. (2002) concluded that that the model of parent-managed applied behaviour analysis provision that has developed over the last decade, in most instances is not sufficient to bring about substantial benefits for the child with autism.

Smith et al. (2000) conducted a study which assessed child, therapist and parent variables in parent-run, home-based, behaviour analytic treatment programmes for six preschoolers. Findings revealed that parent run ABA programmes may be less effective than professionally run programs in that although initial skill acquisition was rapid, it did not lead to long term developmental gains. They suggest that this may have been partly due to their

finding that treatment quality amongst parent-employed therapists was lesser than that provided by clinic trained therapists.

Similar findings were reported in a recent evaluation of some programmes for children with autistic spectrum disorders in Auckland, (Godfrey, Moore & Fletcher-Flinn, 2002) which evaluated the effectiveness of three different forms of intervention. 1. That offered by mainstream settings in which the child received either early intervention or inclusive service support from a government funded agency, 2. Home-based programmes and 3. A programme offered by a specialist centre utilising precision teaching methods.

Eleven children took part in the evaluation and findings showed that children who were in programmes utilising behavioural methodology received significantly higher rates of instruction, praise and feedback and subsequently spent greater amounts of time on task and emitted no stereotypical behaviours. However, they found that there were no discernable differences between the children when they were observed in a mainstream setting stating that:

"the academic benefits associated with home programmes did not appear to translate into more adaptive social behaviour." (Godfrey et al. 2002 p.xv) The evaluation found that although there were some good programmes available at a high cost to families there was no, one, coherent programme that offered an optimal service and outcomes for children with ASD in accordance with that suggested by international literature.

These findings, however, do not necessarily negate the efficacy of such programmes but rather highlight the importance of providing parents with ongoing support to assist them to maintain new skills and cope with new challenges that arise as their child continues to develop. The benefits of such programmes to parents and their children are not always determinable by measurable outcomes or comparable to those dictated by international studies. (Whitaker, 2002).

Accessing Services

The time and financial demands placed on parents running home based programmes for their child with autism is referred to repeatedly in relevant New Zealand literature (AANZ 2001; Godfrey et al 2002). Some government assistance is available to aid parents with these demands.

In April 2001 The New Zealand Disability Strategy was launched with the aim of removing the barriers preventing disabled people from participating fully in society (Minister of Disability Issues, 2001). As such, disability support services are provided to some individuals with autism to promote inclusion and participation. The fund holder for Disability Support Services is the Health Funding Authority, although other government organisations such as the Ministry of Education also have some responsibility to provide services for these children under the Special Education 2000 initiative. In order for families of children to be able to access this funding they must first undergo a needs assessment to determine whether or not they are eligible for personal care related support and other services. The assessment process aims to identify and prioritise needs. Families are then offered what are considered to be the most appropriate services and support options for their assessed needs (Ministry of Health, 1999) Service provision often encompasses respite care, daily personal care and equipment eg: fencing a property to prevent the child from running away.

However, many parents perceive the assessment and service co-ordination processes as difficult and confusing as they attempt to access multiple services in order to meet their individual child's needs (Ministry of Youth Affairs, 2000). Tucker (2004, p.149) found that many parents perceived the needs assessment process to be based on measuring failure rather than strengths to the extent that some families would leave the house looking like a mess to send the message that they weren't coping in order to secure services. The Autistic Association National Survey (2001) reported that many parents were dissatisfied with the needs assessment process and the support available for them and their child. As an example 52% of families who were allocated carer support hours were unable to find suitable caregivers to utilise them. It was

also noted that the provision of appropriate programmes for children was dependent on a family's ability to pay privately and their knowledge of autistic spectrum disorders rather than need. While policies and services for each child may promote inclusion and participation, the actual delivery of a fully inclusive world for these children will be achieved only if each individual agency or service is able to access the funds and expertise required to meet an individual child's needs. (Sullivan, 1998).

Summary

This section has provided a snap-shot of the origins and development of the programmes that will be referred to in this study. It has also highlighted financial and time demands that are placed on parents as a result of providing such a programme for their child and the ongoing problems associated with trying to secure appropriate support and services.

Chapter Five

Method

Qualitative Naturalistic Inquiry

The main aim of this research was to explore and better understand the experiences of parents attempting to conduct an early intervention programme in their home, in addition to the usual challenges of raising a child with autism. The exploratory, yet personal nature of this research lends itself primarily to qualitative methodology within a naturalistic paradigm.

Data obtained through qualitative methods is described as providing depth and intricate detail that is unable to be captured by quantitative methods and is deemed to be most appropriate when the researcher wants to understand what people's experiences mean to them in their own terms and context (Patton, 1990, p.32). The goal is to give an honest account of the participant's experiences with little or no interpretation on the part of the researcher, presenting findings in the spontaneous and meaningful way that they were actually expressed (Strauss & Corbin, 1990, p.21).

The benefit of naturalistic inquiry is that it provides the researcher with rich and realistic information about the participants' everyday circumstances. "Naturalistic ontology suggests that realities are wholes that can not be understood in isolation from their contexts, nor can they be fragmented for separate study of the parts" (Lincoln & Guba, 1985, p.39). This research took place in the family home allowing the researcher to observe and experience the parents' reality for a period of time. The qualitative research approach was able to provide a holistic look at these families that would not have been attainable through other methods of inquiry such as quantitative methods alone.

Research Design

In order to best explore the experiences of parents conducting early and intensive home based early intervention programmes for their child with autism, data was gathered via semi structured interviews and the completion of two measures.

In recent years, qualitative research has grown, resulting in a complex family of interrelated methods and approaches. The benefits of mixing quantitative and qualitative methods are noted (Holliday, 2002, p.21). As such, the present researcher chose to incorporate quantitative measures, not to partially validate the qualitative analysis as suggested by Denzin (1970) but rather as an approach for further grounding and extending on the knowledge obtained with qualitative methods. This provides a means of increasing scope, depth and consistency in methodological proceedings (Flick, 2002, p.227). Methods of data collection are described in more detail below.

Semi structured interviews. Rossi & Freeman (1993) identified three types of interviews – the informal (conversational) interview, the semi structured interview where questions are prepared but room is allowed for elaboration, or the structured interview where questions are strictly adhered to.

For the purpose of this research a semi structured interview was chosen. This allowed for questions to be prepared but also left room for participants to talk at length about their own experiences should they so choose. The interviews were developed through consultation with previous research in the field and in conjunction with university staff members familiar with qualitative research. The interview was presented to and scrutinized by peers working within the field of autism to ensure that the questions were not leading or biased in any way.

A structured list of questions was used to explore the experiences and challenges of running a home programme. A tape recorder recorded the interview.

The use of a cassette recorder in interview situations is thought to make the documentation of data independent of perspectives, thus achieving a naturalistic recording of events (Flick, 2002, p.166). After informing the participants about the purpose of the recording, they tended to forget about the recorder and the conversation took place naturally, including when they were discussing distressing or highly personal matters.

Initially it was intended to take notes during the interviews. Patton (1990) advised that even when interviews are tape recorded, notes can assist in later analysis, including finding pertinent quotations on the tape. It has also been suggested that note taking can provide a form of feedback to participants that what they are saying is important and being taken seriously. However, note taking in interviews is not always endorsed. Whyte (1982) considers that it may distract the interviewer from focusing fully on the informant, and may make the interview disjointed.

After discussions with both the project supervisor as well as peers who had undertaken qualitative research, the option of note taking was abandoned as it was thought it might be off-putting to the participants as well as resulting in missed pertinent information. It was instead decided that notes regarding body language, the tone of the interview, specific events that occurred during the interview and other nonverbal elements would be made in an interview diary following the interview but not while with the participant. This enabled the interviewer to focus fully on the participant's story. When issues arose requiring further information, elaboration was sought and the participants were able to freely incorporate information of importance to them into the interview.

Issues of reliability and validity also required consideration. Lincoln and Guba (1985) have identified several strategies for increasing the credibility of qualitative research, trustworthiness, credibility, dependability and transferability which can be enhanced through the use of the following activities.

Prolonged Engagement. Here the researcher spends considerable time prior to collecting data in becoming familiar with the phenomena under study, and enough time in the field to be able to notice irregularities in the data. (Lincoln & Guba, 1985, p.302). The researcher has spent six years working with children with autism and their parents thus providing an insight and background into their experiences. An extensive literature review was also conducted in order to familiarize the researcher with existing studies and literature on this and related topics.

Peer debriefing. This aids the credibility of the research as it assists in identifying and managing distortions that may come about due to potential researcher bias and interpretation. Weekly consultations with my supervisor as noted in the information sheet to participants, were beneficial in that she exposed me to questions about the study from an unbiased perspective that encouraged me to clarify interpretations and identify blind spots. Her input exposed me to different perspectives that I may have otherwise overlooked.

Triangulation. The use of different sources or methods in the collection of data. (Denzin & Lincoln 2000). I made use of data obtained through interviews, observations and inventories, feedback from supervisor and interview diary notes.. The use of different sources of information works to extend and enrich the data.

With regards to issues of reliability Kirk and Miller (1986) suggest that in interview studies reliability is enhanced by careful transcription of interviews, through coding of information and justification of data extracts chosen. In order to satisfy these requirements transcription was done verbatim and data extracts were systematically sorted and coded. All quotes selected for use in the present study were carefully chosen to ensure they were reported in the context in which they were intended.

Structured Measuring Instruments

Becks Depression Inventory-II. Depression was measured by the participants' scores on Beck's Depression Inventory II (BDI-II) (Beck, Steer & Brown, 1996). The BDI II was selected for this study because it is the most widely used and thoroughly researched self report measure of depression severity and instructs the client to respond in terms of how he or she has "been feeling during the past two weeks including today" (manual p.8) which is consistent with the DSM-IV time period for the assessment of major depression. The BDI II contains 21 multiple-choice items each of which assess a different symptom or attitude. Scores range between 0 and 63. The guidelines suggested for interpreting the placement of individual scores into a range of depression severity are: 0-13 absence of, or minimal depression; 14-19 mild to moderate depression; 20-28, moderate to severe depression; 29-63 severe depression. Sufficient internal consistency reliability coefficients have been reported and evidence of construct and factorial validity have been published (Dozois et al., 1998).

Life Stressors & Social Resources Inventory – Adult Form. A measure entitled Life Stressors and Social Resources Inventory – Adult Form (LISRES-A) was developed by Moos, R. & Moos, B. (1994) to measure life stressors and social resources and their relationship to each other and to aspects of individual health and well being. The profiles this measure generates can identify specific life domains that might be problematic and as such aids in identifying areas in which intervention may be helpful. The LISRES-A is made up of 16 scales covering the 8 domains that have been identified as the most significant sources of life stressors and social resources; physical health, home & neighbourhood, financial, work, spouse or partner, children, extended family, friends and negative & positive life events.

Internal consistency reliabilities range from .77 - .93 for the stressor scales and from .50 - .92 for the social resources scale. Research findings (Moos et al. 1989) support the construct validity of both the stressor and resource indices and substantiate the value of measuring both ongoing and new life stressors.

Ethical Issues

Before embarking on any research it was necessary to obtain ethical approval from the Massey University Regional Human Ethics Committee. To gain approval the committee required detailed information on the research procedure, subjects, consent procedures, information given to participants, utilisation and storing of data, preserving anonymity, risks and benefits to participants and a brief background and summary of the proposed research. This information was presented to the committee for consideration and the protocol was approved and consent granted.

To ensure the protection of the participants, each participant was provided with written information in the form of an Information Sheet outlining the purpose of the study. They were also invited to ask questions to clarify any issues that they were unsure of. All subjects were made aware that the interviews were to be audiotaped and the interview did not proceed until it was ascertained that participants were comfortable with this.

Informed consent was obtained from participants via a signed consent form. The consent form included a statement regarding the participant's right to refuse to answer questions and their right to withdraw from the study at any time. To assure anonymity, all identifying information about the participant and their family was changed. Participants were assured that although brief quotations from interviews would be used, nowhere would these be attributable to an individual person.

Participants and Procedure

The sample of parents participating in this study were all residents of Auckland, married and currently living with their spouse. Ages ranged from 31-48 and all had a child with a diagnosis of an Autistic Spectrum Disorder. All were conducting early and intensive interventions programmes for their child with Autism and all had begun this when the child was between two and four years of age.

Participants were recruited through an e-mail advertisement that was circulated by the local Autism Association or Home Therapy Support Group meetings. In both instances the researcher presented her proposed study and invited interested parties to contact her. An information sheet (Appendix A) outlining the purpose of the study, the time commitments, risks and assuring anonymity and confidentiality was then sent out to those who had shown interest. Included with the information sheet was a consent form (Appendix B) which parents signed after reading the information sheet and mailed back to the researcher indicating their willingness to participate in the study.

The researcher then made contact with the parents and established a time and place to conduct the interview. The meeting consisted of a block of un-interrupted time in order to conduct the in-depth interview (Appendix C). All interviews were carried out in either the dining room or the lounge of the participant's home. In most instances there were children in the house but their therapist or another caregiver was tending to them. Confidentiality and anonymity was again assured in addition to ensuring the interviewee had no further questions before commencing the study. Participants then filled out a sheet outlining demographic information (Appendix D) in addition to completing a scale (Appendix E) after instructions were given by the researcher. An additional inventory (Appendix F) was also explained to participants, this was then left with them to be completed within the next week at a time suitable to them. The researcher arranged to collect this when returning with the interview transcript.

All interviews were conducted face-to-face and audiotaped. All subjects had consented, in writing, to the interview being taped and all were given the option of turning off the machine at any stage or refusing to answer any question. The option of stopping the tape recorder was never utilised by the participants. However, the researcher chose to turn it off at one stage when a participant became upset to the extent that she could not speak. Participants had been provided with information prior to the interview with regards to

whom they should contact should they wish to discuss further any issues aroused by their interview. All participants were reminded of this option following the completion of the interview.

No notes were taken during the interview. However, entries regarding the tone of the interview, significant events that occurred during the interviews and non-verbal elements were made in an interview diary following the interview. These were not made in the presence of the participants.

Data Analysis and Reporting

Interviews were transcribed verbatim, as soon as possible after the completion of the interview. Minimising the time delay between interview and transcription allowed the researcher to effectively record perceptions and note events such as a child coming into the room, while the interview was still fresh in the interviewer's mind.

Transcription of the interviews by the interviewer served two purposes. Firstly, the cost of having interviews transcribed was extremely prohibitive. Secondly, listening to each tape and typing its contents helped to develop a greater familiarity with the data. Once the data was transcribed, a copy of the transcript was returned to the participant. They were invited to read and check the transcript and make changes to anything that they felt did not project the true meaning of what they were trying to convey. In several instances participants made additional comments to clarify points rather than make any significant changes. These additions were noted on the transcripts used for analysis. Once all interviews were transcribed and feedback from participants received the transcripts were read and re-read a number of times. This allowed for further familiarisation with the contents of the interviews.

Grounded Theory

The data was analysed using a grounded theory approach. This is a qualitative method which according to Henwood and Pidgeon (1995), is a useful method for handling and making sense of initially ill-structured qualitative data. It is

an open-ended and flexible approach that allows the researcher to follow clues and ideas as they develop. The process involves simultaneous hypothesis generation, data collection and data analysis and as such the theory emerges from the data and not as a result of testing prior hypotheses (Bowers 1988).

Strauss and Corbin (1990) describe grounded theory as a qualitative method that examines the interaction of events by using a systematic set of procedures to develop an inductively grounded theory about a phenomenon. Following their recommendations the data was examined line by line to conceptualise the ideas and concepts reported by the participants. Recurring concepts that became apparent through this process were then grouped together allowing for the creation of themes, which were given provisional names using terms that were evident in the data. In the next stage of analysis connections between themes were analysed. Themes that related to each other became categories. Theoretical sampling procedures were used to confirm, and refine each of the categories linking them to other categories with the same conditions, context or consequences. Patterns or repeated relationships of categories were analysed and integrated until core categories were created. The core category is defined by Glaser & Strauss (1999) as the category which, through its prevalent relationship with other low-level categories, accounts for most of the variation in the social phenomenon being examined.

Illustrative quotes were then chosen from each category for use in the body of the report based on their being the most representative of parent's experiences. Where applicable pseudonyms were used to protect the identity of participants. The coding applied to these quotes, fore example (J61) allowed for easy reference to raw data if confirmation of context or justification of data extracts chosen was required at a later date. The letter denotes which category the quote stemmed from, the first number depicts which participants made the comment and the second number indicates which of that participants quotes in that category it was.

Structured Measuring Instrument Analysis

The grounded theory approach lends itself well to the utilisation of quantitative measures, Glaser and Strauss (1967) stated that "each form of data is useful for both verification and generation of theory and in many instances, both forms of data are necessary" (p.17). In this instance, structured measuring instruments provided a means of increasing scope, depth and consistency in methodological proceedings, and were utilised for further grounding and extending on the knowledge obtained through qualitative methods (Flick, 2002, p.227). Results from each of the measures were scored in accordance with the applicable manual and the results for each participant were then displayed in bar graph format for easy reference during the emergent theory process.

Chapter Six

Quantitative Results

This chapter presents the demographic information of participants and results from the structured measuring instruments used in this study. Participant's demographic information and relevant information regarding their autistic child is presented first. Depression severity scores are displayed in figure 1 and sources of life stressors and social resources for each of the participants are displayed in figures 2 through to 8. A summary of the data displayed in figures 2 – 8 is displayed in table 2 and 3. This information is intended to provide a context for the qualitative analysis that follows.

Demographic Information

The primary caregivers who partook in this study were all mothers of children with an Autistic Spectrum Disorder diagnosis. All were married and residing with their husbands. The age of the participants ranged from 31 through to 48 with a mean age of 41.43 years. Of the seven participants, four described themselves as stay at home mums, three had some form of part time employment outside the home and one was in full time employment. All of the participants reported having received some form of secondary qualification with three participants having also received a tertiary education. Six of the participant's annual family income was $60,000+ with the remaining participants income being between $50,000 to $59,999 thousand.

The children that the primary caregivers spoke of were all males ranging in age from 3 years through to 8 years. Each of these children had received a diagnosis of Autistic Spectrum Disorder between the ages of 2:3 years through to 3:6 years of age. At the time of the study the shortest period that a parent had had a diagnosis for their child was 9 months. The longest period was 5 years 9months. The time between diagnosis and the commencement of a home programme for these children ranged from one month through to 23 months. Of these seven children, three had siblings with autistic traits.

Depression Data

Depression was measured by the participants' scores on Beck's Depression Inventory II (BDI-II) (Beck, Steer & Brown, 1996). The BDI II was selected for this study because although subject to response bias, it is the most widely used and thoroughly researched self-report measure of depression severity.

The BDI-II has also been successively used in research with specific regard to parenting children with developmental disabilities. In addition, participants depression severity was considered to be an important component of this research as previous research has indicated that depressed people are likely to report significantly more stressful events than people who are not depressed, are less likely to use problem solving coping responses and have fewer and less supportive social resources (Billings, Cronkite & Moos, 1983).

The BDI-II, which instructs the participants to respond in terms of how he or she has been feeling during the past two weeks including today, has excellent test-retest reliability, high internal consistency, and moderate to high convergent validity (Arnau, Meagher, Norris & Bramson, 2001) Evidence of good construct and factorial validity has also been published (Dozois et al, 1998).
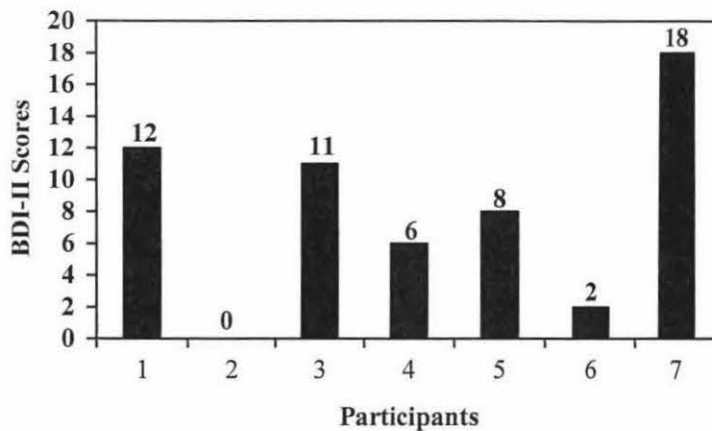

Figure 1: BDI-II Scores Across Participants

In the present study the participants' BDI-II scores ranged from 0-18. Using the suggested guidelines for interpreting the placement of individual scores into a range of depression severity, seven of the participants had scores that fell into the range of absence of or minimal depression and the remaining participant fell into the mild range.

Life Stressors and Social Resources Data

The aim of this study was to examine the experience of New Zealand parents who had chosen to implement a home based early intensive programme for their child with autism in addition to the usual challenges of having an autistic child. In order to do this it was considered pertinent to evaluate the life stressors and social resources impacting on these parents' experience.

The choice to evaluate these variables was based on prior research that had indicated that both life stressors and social resources and the interaction between them are associated with health and well-being and can, in turn influence the appraisal of life events and the choice and effectiveness of coping strategies. With specific regard to this study research has indicated that life stressors and social resources can play a significant role in ones ability to recover from stressful events and transitions such as a child receiving a diagnosis of Autism. Access to social resources may influence adaptation by facilitating the use of more active coping strategies, whereas individuals in more stressful contexts may be more likely to experience new additional stressful events which may in turn contribute to an increase in ongoing stressors and a decline in social resources. (Moos & Moos, 1994).

As such, the use of the Life Stressors and Social Resources Inventory – Adult Form (Moos, R & Moos, B., 1994) in this study allowed the researcher to determine what resources participants perceived they had access to, what variables were currently presenting as stressors and allowed the researcher to compare and contrast these variables across the participants determining any commonalities whilst also tapping into information about areas that may have been difficult to access through an interview alone.

This measure has been used with both depressed patients and healthy adults to examine the association between specific life stressors, social resources and functioning outcomes (Moos & Moos, 1994). It is made up of 16 scales covering the 8 domains that are the most important sources of life stressors and social resources, physical health, home and neighbourhood, finances, work, spouse or partner, children, extended family and friends. These domains are examined in more detail below.

The physical health domain examines the number of medical conditions the participant has had for over twelve months; the home and neighbourhood domain assesses problems with the physical condition of home and neighbourhood; the financial domain assesses the total family income and any problems such as an inability to pay bills; the work domain assesses any problems with pressure, unpleasant physical conditions, and difficult co-workers or supervisors as stressors and then examines support, challenge and independence provided by the work environment; the spouse or partner domain assesses interpersonal problems with spouse or partner and level of support and empathy evident in that relationship; the children domain assesses behavioural and emotional problems as seen in children living at home and determines the support available through the relationship the participant has with the children; the extended family domain looks at interpersonal stressors related to mothers, fathers and other relatives and assesses the level of support and empathy available to the participant from theses people; the friends domain assesses the same variable as the family domain but with reference to friends.

The scores obtained from each domain of the LISRES-A are placed in one of seven categories depicting varying proximity of scores above and below what is considered average. The equivalency of these scores to percentages is described in the table that follows.

Table 1: Interpretation of LISRES-A T-Scores as Depicted in Figures 2-8

T-score range	Description	Abbreviation	Equivalent % range
Less than 34	Considerably Below Average	CBA	Less than 6%
35-40	Well Below Average	WBA	7-16%
41-45	Somewhat Below Average	SBA	17-33%
46-54	Average	A	34-66%
55-59	Somewhat Above Average	SAA	67-83%
60-65	Well Above Average	WAA	84-93%
Greater than 66	Considerable Above Average	CAA	Greater than 94%

Figures 2 through to 8 provide a visual representation of the perceived level of stressors and resources present in the participants of this study's lives. Interpretation of the t-score values depicted in figures 2-8 maybe located in Table 1 on page 51.
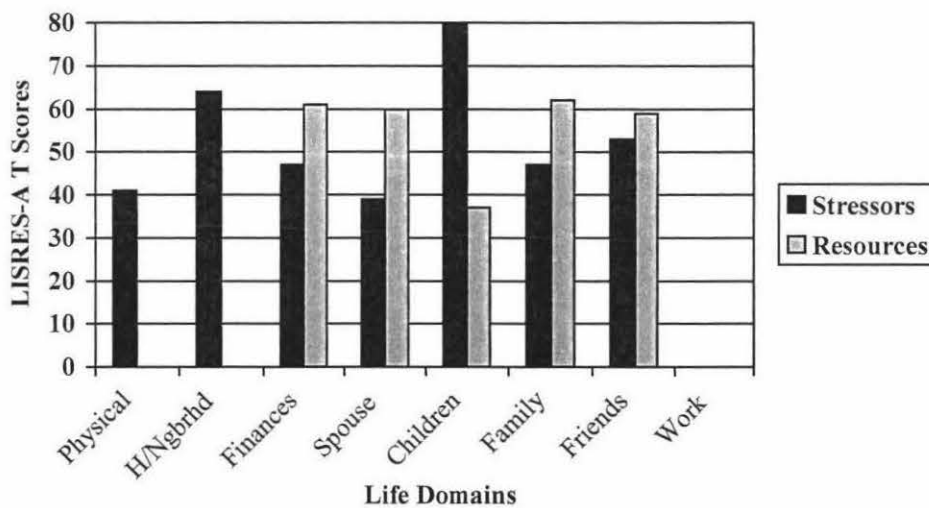
Figure 2: Identified Stressors & Resources Across Life Domains, Participant 1
Participant one's scores depict that finances, family and friends are average stressors for her whereas spouse, physical health and home and neighbourhood fall to varying degrees below average. The perception of stress relating to her children is considerably above average. In terms of resources finances, spouse and family are well above average. Friends are somewhat above average and her children are well below average.

51
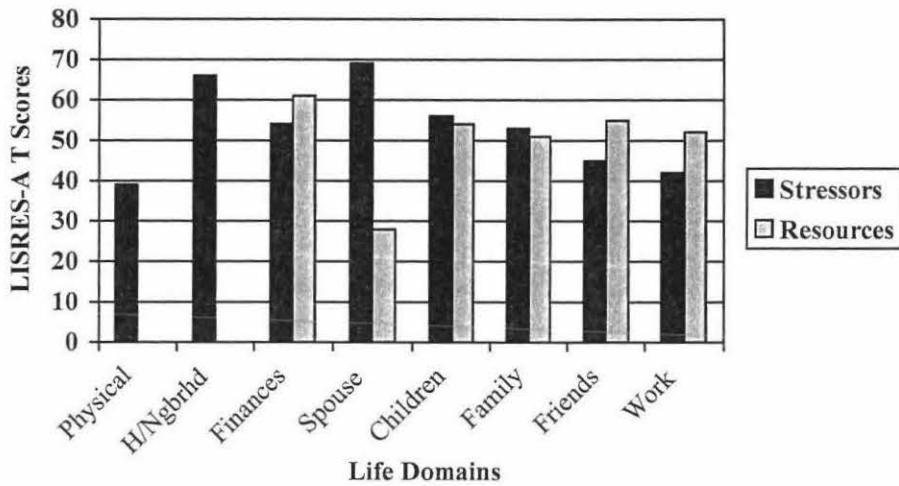
Figure 3: Identified Stressors & Resources Across Life Domains, Participant 2

Participant two's scores show that physical health is a well below average stressor in her life. Friends and work are somewhat below average stressors, finances and family are average stressors, children are somewhat above average stressors and home and neighbourhood and her spouse are considerably above average stressors. With regards to resources she considers her spouse to be considerably below average. Children, family and work are average, friends are somewhat above average and finances are well above average.
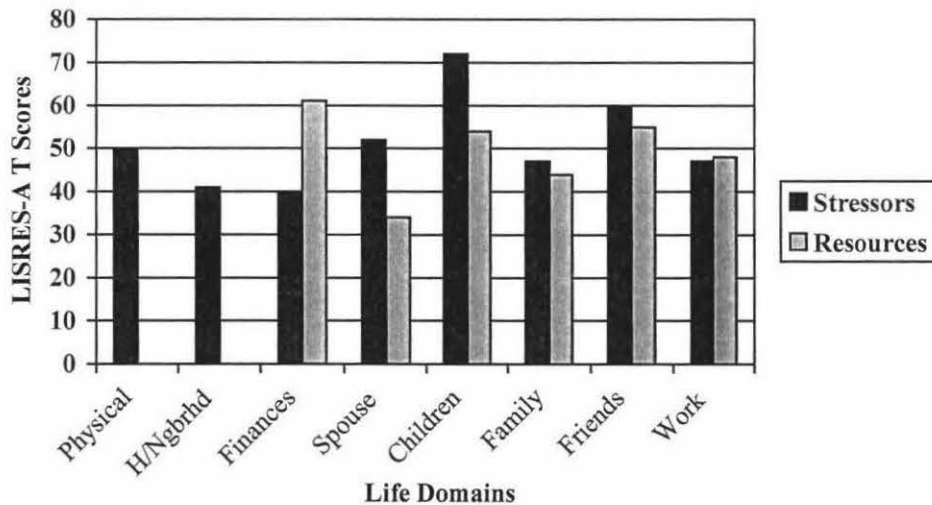
Figure 4: Identified Stressors & Resources Across Life Domains, Participant 3

Participant three's score depicts that finances are a well below average stressor and home and neighbourhood are a somewhat below average stressor in her life. Physical health, spouse, family and work are average stressors and friends are well above average stressors. The domain of children is a considerably above average stressor. With regards to resources, spouse is perceived as a considerably below average resource and family somewhat below average. Children and work fall into the average category, friends are somewhat above average and once again finance are well above average.
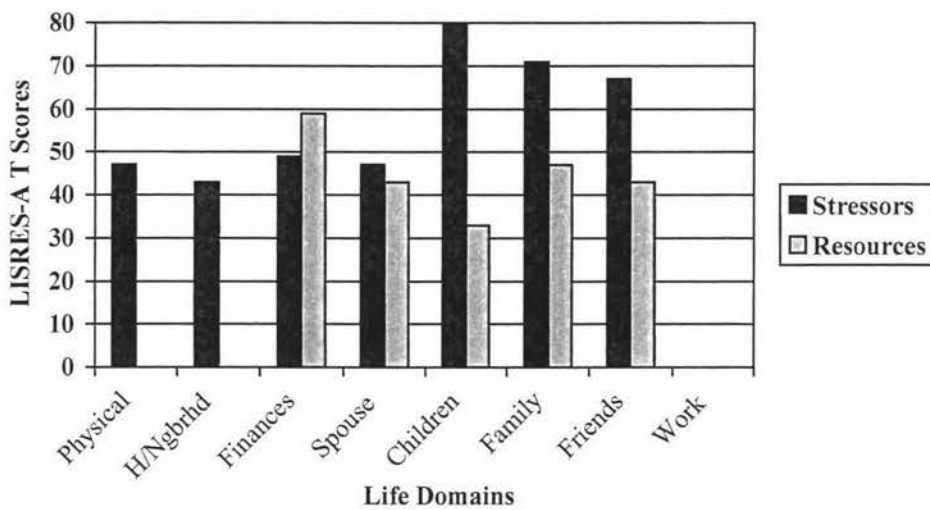
Figure 5: Identified Stressors & Resources Across Life Domains, Participant 4

[1]Participant four's scores depict that home and neighbourhood is a somewhat below average stressor. Finances and spouse are average stressors and children family and friends are considerable above average stressors. With regards to resources, children are perceived to be considerably below average, spouse and friends are somewhat below average, family are average and finances are somewhat above average.

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[1] Interpretation of the t-score values depicted in figures 2-8 maybe located in Table 1. on pp. 51
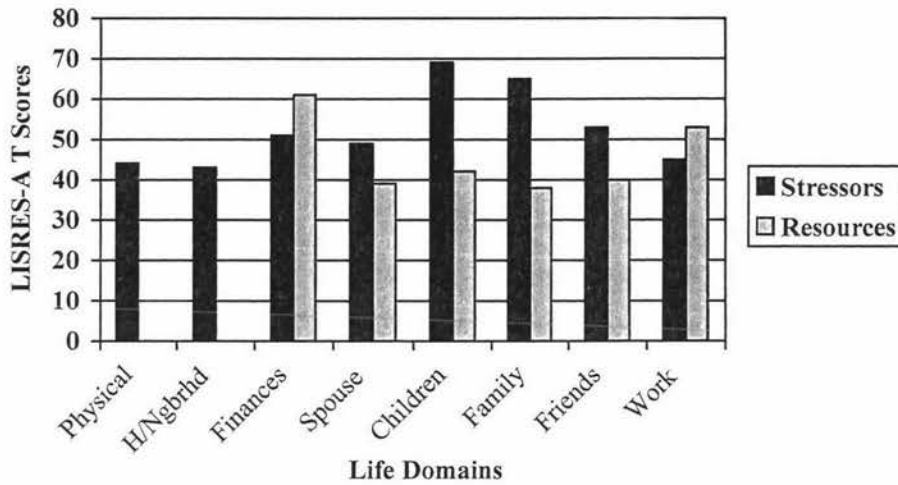
Figure 6: Identified Stressors & Resources Across Life Domains, Participant 5

Participant five's scores depict that she perceives physical health, home and neighbourhood and work to be somewhat below average stressors in her life. Finances, spouse and friends are average stressors, family is well above average and children are considerably above average stressors. In terms of resources spouse, family and friends are well below average, children are somewhat below average and work is average. Finances are well above average.
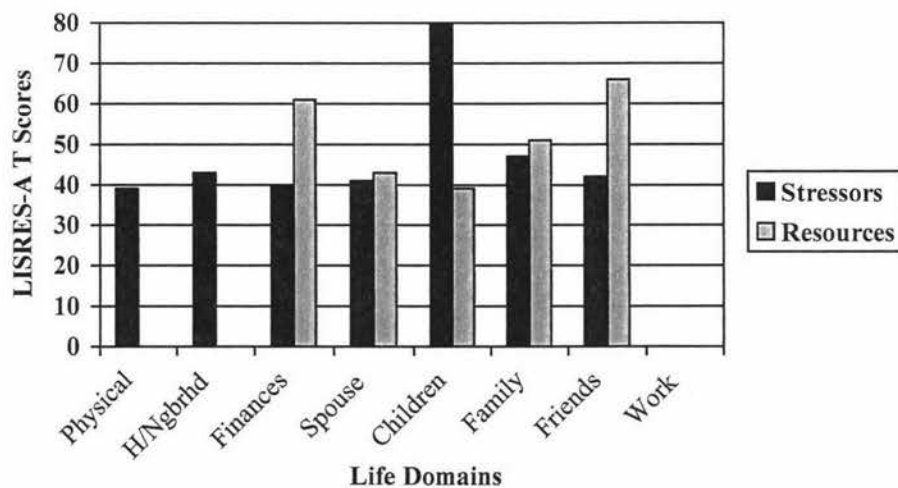
Figure 7: Identified Stressors & Resources Across Life Domains, Participant 6

Participant six considers physical health and finances to be a well below average stressor. Home and neighbourhood, spouse and friends all fall into the category of somewhat below average and family are considered average stressors. Children are a considerable above average source of stress. With regards to resources children are well below average, spouse is somewhat below average and family is average. Finances and friends are perceived as well above average resources.
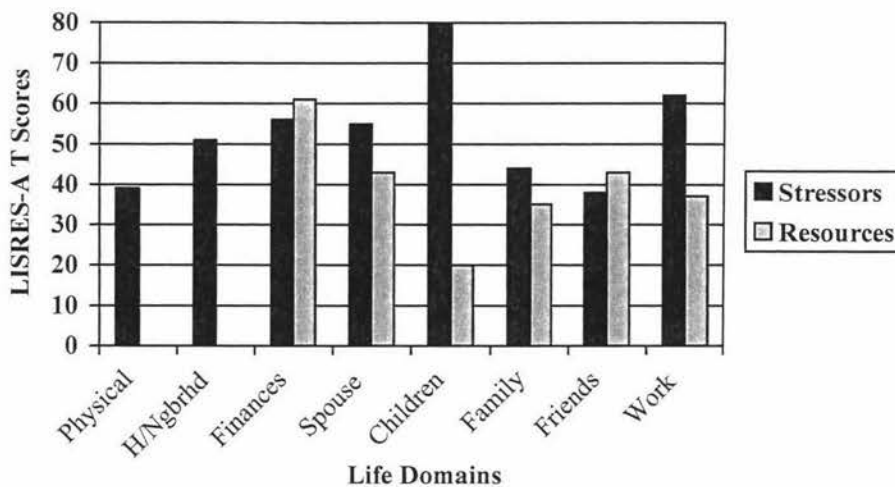
Figure 8: Identified Stressors & Resources Across Life Domains, Participant 7
Participant seven's scores show that she perceives physical health and friends to be a well below average stressor, family are somewhat below average and home and neighbourhood are average. Finances and spouse fall into the category of somewhat above average stressors, with the domain of children being perceived as considerably above average and work well above average. With regards to resources children are a considerably below average resource, family and work are well below average and spouse and friends are somewhat below average. Finances are a considerable above average resource for this participant.

Figures 2 through to 8 depict participant scores on The Life Stressors and Social Resources Inventory – Adult Form (Moos, R. & Moos, B. 1994) which aids in identifying specific life domains of the client that might be problematic and benefit from intervention. In addition it identifies areas of strength that

assist in ensuring that any interventions are built on the supportive aspects of the clients life. Evidently, there was a great deal of variability across the participants' responses and for this reason the results have been summarised in tables 2 and 3. However, one notable constant was that all participants identified the domain of children as a somewhat above or considerably above average stressor in their life.

Table 2: Summary Table of LISRES-A Stressor Standard Scores Across Participants

Participant	Finances	Work	Spouse	Children	Family	Friends	Physical	Hm & Ngbrhd
1	A	N/A	WBA	CAA	A	A	WBA	WBA
2	A	SBA	CAA	SAA	A	SBA	WBA	CAA
3	WBA	A	A	CAA	A	WAA	A	SBA
4	A	N/A	A	CAA	CAA	CAA	A	SBA
5	A	SBA	A	CAA	WAA	A	SBA	SBA
6	WBA	N/A	SBA	CAA	A	SBA	WBA	SBA
7	SAA	WAA	SAA	CAA	SBA	WBA	WBA	A

Table 3: Summary Table of LISRES-A Resource Standard Scores Across Participants

Participant	Finances	Work	Spouse	Children	Family	Friends
1	WAA	N/A	WAA	WBA	WAA	SAA
2	WAA	A	CBA	A	A	SAA
3	WAA	A	CBA	A	SBA	SAA
4	SAA	N/A	SBA	CBA	A	SBA
5	WAA	A	WBA	SBA	WBA	WBA
6	CAA	N/A	SBA	WBA	A	CAA
7	CAA	WBA	SBA	CBA	WBA	SBA

Chapter Seven

Qualitative Results

The Diagnostic Process

Pre-Diagnosis

Anecdotal accounts and systematic surveys such as that carried out by the Autistic Association of New Zealand in 2001 indicate that the diagnostic process is a major source of frustration and disillusionment for some parents. Many parents find that professionals such as General Practitioners and Paediatricians do not possess an in-depth knowledge of autism, resulting in misdiagnosis or diagnosis a considerable time after the parent expressed their initial concerns.

For the parents in this study it was either the delay of language development or a sudden change in their child's behaviour that prompted them to seek medical advice. In most cases, the first avenue of inquiry was to rule out hearing difficulties with tests and grommets. When tests came back clear or inconclusive and the introduction of grommets did not result in improved language development, most parents continued to visit their GP or Paediatrician trying to find an answer to their significant concerns.

Several of the mothers reported that they felt health professionals didn't take their concerns seriously being told to 'just wait and see' or being told they were over-reacting. Many of the mothers were concerned by the lack of support they received and disappointed that they didn't receive any further referrals, having to initiate any further investigations themselves. This mother describes her experience with her then three year old son:

> I'd been going to our GP constantly with ear infections, then I went to a
> private ENT and had grommets put in. We thought, he's not talking
> because he's got so many ear problems, so that was a bit of a
> complicating factor. But of course the grommets had gone in and there
> was still no speech. I got a little more assertive. I had to keep going
> back repeatedly because I was concerned and the medical profession,
> well the people we dealt with, didn't think it was a problem – he would

talk when he was ready. I kept going back to our family paediatrician, then I went and asked for a second opinion and I found a different paediatrician who said 'well he might be autistic'. One saying yes he is and one saying no he's not and I thought right, I want a definitive answer on this, still no speech, so then I asked the second paediatrician to send us to Starship where it all got sorted out last August. I did all the initiating. It, took a year after the grommets went in to get a firm diagnosis. (B11)

Receiving the Diagnosis

In New Zealand, diagnosis is not the responsibility of a single professional group, so for many of the families it was a hit and miss process finding someone who was able to give them a definitive diagnosis. One of the parents even went to the extent of taking their child overseas to see a specialist. However, once finding someone qualified to diagnose, many parents were disappointed by the absence of multi-disciplinary diagnostic assessment or any formal testing to determine their child's specific deficits. These mothers recall their experience:

We had been in there ten minutes and he said your son is autistic, no cure. Sorry, he'll always be autistic, here's your WINZ form, here's the number for SES and the Autistic Association, I don't think there's any need for me to see you again. Goodbye. (B23)

The diagnosis was absolutely pathetic. There was no speech work, no analysis of his behaviours on any sort of scale, I found it absolutely appalling. (D51)

I think that the diagnostic procedure is quite terrible really. I mean there is no nice way of telling someone that their child has autism. Every child should have a 'proper' assessment on diagnosis. I don't think that they should be diagnosing the way that they do. It's like the child walks into the room, you gives some anecdotal evidence and the doctor says oh yes, its autism (B61)

Reactions to Diagnosis

On receiving the diagnosis parents described feelings of disappointment and devastation but also expressed relief to know what was wrong and to finally have a label to work with. It removed the uncertainty of the situation. These illustrative quotes reflect parents' reactions to the diagnosis.

I was actually relieved to get the diagnosis. I came out of the hospital thinking thank God someone has finally recognised this and understands and we can get some help. Of course that comes with huge disappointment because while there isn't a diagnosis there is always that chance that they are going to start talking at a later time. So, yes you have to come to terms with the fact that this is what he's got and its not going to go away. You can't take a course of pills or have surgery and that in itself is hugely disappointing. The disappointment and the grief comes and goes ..... but I think overridingly, I am an intensely practical person and I would rather know what it is and face up to it and get on with it than keep fudging it. I was just so relieved as well as being disappointed. (C11)

It was freaky but I was expecting it. You sort of have a time line of grieving and guilt. I think I had already done most of the grieving and I all wanted now was a label so I knew where to go next and how to deal with it. (C21)

I spent the six months afterwards thinking and waiting. I needed to cope with the diagnosis before I could go back and figure out what to do. (C25)

Most parents were dissatisfied with the diagnostic procedure and felt that it should be improved. Several of the parents stated that they understood that their practitioner's reluctance to give a diagnosis may have been to avoid false-positive diagnosis in younger children, but felt that once a diagnosis had been decided upon that they should be provided with clear, concise information regarding autistic spectrum disorders in general, and more specifically with regard to how it affected and may continue to affect their child. The general view was that this could be achieved if the child was given a 'proper' assessment at the time of diagnosis providing them with valuable information regarding their child's strengths and deficits.

Chapter Eight

Becoming an Expert Parent

Agencies and Services

At the time of diagnosis most parents are advised to contact several public service providers in order to initiate the assessment process required for them to receive both financial and practical assistance. However not all receive this information.

> "It took until I had a breakdown for somebody else, one of the kids teachers, to say to me, well why aren't you getting I.H.C hours and home support? Nobody had told me that I was eligible for it or any support."(D65)

Even though they had been given some names and phone numbers many of the parents were confused with regards to who they should be contacting and why and what they should be receiving.

> "Its absolutely crazy how it is decided (the amount of assistance received) and even for people to understand what is available and what they're entitled to. People have no clue and there is no avenue for finding out. It is all very disjointed – top secret."(D55)

All parents in this study making contact with public service providers for the first time had the expectation that these services would have the resources and expertise to make a significant difference for their child. Most were disappointed when they had to wait between two and six months for their child to be seen, and all of the parents in this study found the quality and frequency of the public services input both inconsistent and inadequate.

> "I think you're always going to want more than what is available but the services definitely weren't that great. They never really spent anytime with the children so essentially they had no idea about how they were developing anyway. I always think it is bizarre that you can go to a meeting about a child you don't even know." (D63)

"I realised after several months that we weren't going to get anywhere solely by using those resources. There was just simply not enough funding, enough time, enough expertise to make a difference. It finally dawned on me that if we wanted to make a difference we would have to pay privately and find our own people and this is what we have done." (D12)

"I think S.E.S. should sit down at the beginning and say 'all we can do is drip feed you a bit of time and a bit of information and you have to get everything else sorted out yourself'. They should say this right at the beginning, and just make very clear the limitations between what they are providing and what more can be achieved." (D31)

The variance in the number of hours a child received support for and the level of funding received was also of concern to parents. Several parents stated that it appeared that the level of service and funding provided was based more on the parents' ability to secure funding and knowledge of what was available, rather than the actual needs of the child. This parent had secured the most funding for her child, receiving 58 days of respite care each year in contrast to an average of 26 days received by the other 6 parents interviewed. She described how she had secured and maintained this level of support:

"You have to be a really horrible person to get this stuff. It's like you're known as a horrible person in this field but in other areas of your life everyone is 'oh, she's lovely'. I know other kids like Andrew who get hardly any hours, so unless you actually go in and demand it you don't get anything." (D54)

None of the parents interviewed were in a position to state that their experience in obtaining services was without any stress or difficulty. However, some parents had much more challenging experiences than others. Two of the parents in this study found the process of securing public funding so complicated that after several attempts they gave up. Those that persevered reported difficulties in maintaining the hours at annual review based on their child's improvement, frustration at having to find the people to work the hours themselves and reported that having to justify why you needed services to be humiliating and demeaning.

Parents also reported that more collaboration was required between the various public services in planning, funding provision, implementing and ensuring continuity of intervention services.

The Clock is Ticking

A number of parents also expressed the need for more information regarding possible avenues of support and in hindsight felt that the limitations of public service providers should be emphasised, and more direction given with regards to possible treatment programmes at the time of diagnosis instead of wasting valuable time. This mother talks of her frustration at not being informed about potential interventions at the time of diagnosis.

> "There was one thing that really did absolutely frustrate me and that is that I didn't even know there was a choice of interventions. I remember the paediatrician saying when she found out that I was trying to choose a programme, "well, there is no evidence to suggest that these types of programmes are any more effective than other types of programmes." I was like 'programmes'? plural?. What programmes are you talking about, I didn't even know there was a choice of them, why didn't I know there was a choice!
>
> I wish, I really wish that the paediatrician had said to us at the start, well none of these things have been 'proven' to be particularly effective, but here are four things you should look at and here are some ways of looking and I think we would have. That hopelessness and that sort of emptiness about what's going on, that could have been addressed much earlier on. You just waste so much valuable time."
> (D31)

Taking Control: Programme Origins

After diagnosis the journey of becoming an 'expert' parent for their child began. Parents became focused on sourcing information and obtaining services for their child. The need for action at the same time as the parent needs to grieve the diagnosis is quite common and understandably not easy to manage. As this mother explained:

> "I tried reading a couple of books – one that was recommended was 'Let Me Hear Your Voice' by Katherine Maurice. I could only get through half the first chapter because it was so real, it was so what I was feeling. I needed to cope with the diagnosis before I could go back and figure out what to do. I really had no support, nobody who knew anything about autism was there."(C24)

An additional challenge for parents at this time is the enormous amount of information that is published about autism and various purported treatments. Many parents were overwhelmed by the vast quantity of information and found the task of retrieving relevant information and identifying treatment models with the potential to benefit their child was arduous.

> "You just waste so much precious time – I wished there was some independent person that I could go to that would say 'Right, these are the options, this is what's available, your child is here on the spectrum, therefore these things here might be more useful than those.' But you have to find that out for yourself." (D11)

Once they had obtained information about strategies and skill development most parents found that they lacked the confidence to implement it. Although the benefits of it were acutely obvious, parents found it difficult to adapt and apply to their child's specific needs. Parents also stated that they didn't want to start anything they couldn't undo, and as such required the assistance of someone with experience. The parents in this study all chose to implement an intervention programme based upon the science of applied behaviour analysis. Many of the parents found out about the effectiveness of this form of therapy through sheer luck, or many hours of research due to it being against most organisations policies' to endorse any particular form of intervention.

Once deciding on a form of treatment programme parents then had the difficult task of finding people with the expertise required to effectively intervene. As people with qualifications or experience in applied behaviour analysis in New Zealand were few and far between, many parents had one person with experience overseeing the programme and then had to rely on well meaning people with little expertise to implement the programmes.

Based on her experiences overseas, one mother felt that the programmes in New Zealand were inferior to those in other countries as a result of this but the benefits of the programmes were still evident in the children. She stated:

> "I've never met a happy autistic child who hasn't had intervention" (J51)

An Emotional Whirlwind

Once they had received a diagnosis for their child, many of the parents described a similar emotional cycle. Initial feelings were those of devastation, loss, guilt and anger as they struggled with the implications of the diagnosis. In turn this grew into a form of relief that they now had an explanation for their child's behaviour, their concerns had been validated and the sense of doubt regarding their parenting abilities started to ebb. Having a label to work with allowed them to start sourcing support and information specific to their child. Parents then attempted to develop an understanding of autism while struggling with the reality of having to care for a child that was never going to be 'normal'. For many parents, relief soon turned to panic, despair and helplessness as they sought and waited for assistance and found that which was forthcoming to be limited all the while knowing that the clock was ticking. Following this realisation all the parents attempted to take control of the situation and access the resources required to run a home programme for their child while at the same time dealing with the ceaseless uncertainties and feelings of anxiety associated with autism.

Chapter Nine

Running a Home Programme

Time

All the parents spoke of both positive and negative aspects of having a home programme. One recurring theme was the amount of time involved. Most parents described co-ordinating a home programme as a full time job. Having the programme meant that an enormous number of hours each week were allocated to sourcing and creating resources, co-ordinating therapists, keeping themselves informed and assisting their child to generalise and maintain the skills they were developing. These mothers explain:

> "It takes so much time to organise his life. It is unbelievable. Communicating with all the people who are involved in his life and just keeping up with all the research and keeping up with everything, it takes a lot of time which I just wouldn't normally have had to put in to raising a child."(H54)

> "Coordinating what we do for our kids is pretty much a full time job, I would spend an enormous number of hours each week being involved in the 'ongoing ness' of it."(H61)

Of notable concern to parents was that the time they were putting into the autistic child maybe putting their other children at a disadvantage. As a result many parents made a conscious effort to counteract the time imbalance by spending time with their other children when their autistic child was engaged in therapy.

> "The programme has given me time specifically with Ella and that's improved things for both her and me dramatically." (I31)

Therapists -Practical Help and Emotional Support

Although the general running of an early intervention programme was very time consuming, the practical help that was available to parents as result of having a programme in the home worked as a form of respite in most cases, in

that when the child was working with the therapist the parents felt they were able to have a break from having to care for and monitor their child. Many of the parents felt that their therapists were the only ones they could leave their child with as they were hesitant to leave their child with family and friends who were not informed about or sometimes unwilling to learn about Autism.

> "I think it's very hard for a mother to get a break from them. Its hard to find people that you can leave your children with because they're not great on changes in routine and that sort of thing. It's very hard to find people that would be prepared to take them, let alone people you are prepared to leave them with."(M62)

Many of the parents made reference to the fact that friends and family 'just don't seem to get' autism. As such they continue to interact with the child in a 'normal' way and then complain about the child ignoring them. Consequently parents felt like they always had to apologise or make excuses for and explain their child. Parents therefore greatly appreciated the therapist's presence in that there were other people around on a daily basis who had a clear understanding of autism and their child's subsequent needs. Many saw their therapists as someone that they didn't have to explain things to and could let their guard down around. In some instances it helped the parents to cope knowing that there was someone else who was working towards the same goals as them, and supporting and subsequently validating their decision to run a home programme. Most parents felt that their therapists were their biggest source of practical support.

> "The fact that you are not doing it all by yourself and that other people are interested in his well being and the outcome was of a huge benefit"(K61)

> "Because we have been able to access therapy that actually helps, people who can understand and help. It's been a huge relief, it has lifted a big burden." (M11)

Better Able to Understand & Manage Child's Behaviour

Parents found that one of the additional benefits of having a home programme was that they and other members of the family also had the opportunity to learn skills and strategies that helped them to understand their child's behaviours. Having therapists present often encouraged parents to be consistent and gave them confidence in implementing the strategies they had learnt. Most parents referred to the fact that although coordinating the programme required additional work on their part, in the long run it had made their lives somewhat easier. As a result of being taught about the programme they were able to generate alternative explanations for their child's behaviour and were also able to identify potentially problematic situations and intervene in an appropriate manner resulting in less frustration for both themselves and their child.

> "we've been able to use the philosophy of the programme to teach him common everyday things that we take for granted but are often difficult for autistic children. It's really opened up a doorway I guess, we now know when to intervene to stop negative behaviours and when to let things go. He is much happier, he isn't so frustrated, he isn't so locked away in his own little world."(K12)

> "It's just been invaluable. Family life – it's such a struggle not knowing what to do. You can read all the books in the world but until you've had someone stand there and individualize your child's needs for you, you don't know what to do. They're individuals, there isn't one formula for all these autistic children.(K21)

In some instances, understanding their child's behaviours also worked to change the parent's perspective of their child, it helped them to see their child's potential and gave them hope.

> "Its increased my expectations of him and every time I have done that he has responded. Its has reinforced my confidence in his potential and the likelihood that he will achieve his potential" (K33)

Small Steps to Success

All the parents spoke of a difficult time in which they were struggling to accept the implications of the diagnosis and what it might mean for their child's future and the limitations it might put on them as a family. Seeing their child stuck in their own little world made many parents question their competence as parents and engulfed them with a sense of failure. The feeling that there was no light at the end of the tunnel, or that they were stuck in a hole that they had to claw their way out of, that this was it, made many parents feel incredibly isolated.

The introduction of a home programme helped many of the parents work through this stage as they were witness to and felt somewhat responsible for, their child's small successes. Confidence and feelings of accomplishment in parenting are related to more positive outcomes for parents of children with autism and as such being involved in a programme that provided strategies to assist with behavioural management and the fact that they were actively promoting their child's development had a positive effect on most parents.

> "the fact that he is progressing and doing well makes me feel a whole lot better. It's just a really difficult thing when ..... first of all your child isn't like everybody else, isn't developing in the same way, when things start moving along in a positive way it just alleviates so much of that depression, that doom and gloom."(K41)

> "well because the programme has helped Grant, it has helped me. I mean, when he was at his worst, I was at my most depressed and it was very difficult dealing with his behaviours then. Because he's now listening and comprehending more and trying to speak more and communicating better, because he is happier, obviously I am a whole lot happier."(M41)

All the parents in this study would recommend a home programme to another parent of a child with autism.

Chapter Ten

Parenting and Autistic Child is Different from Parenting a Normally Developing Child

It's a Chronic Disorder

> "Everyday when you've got to look at it and it's everyday, everyday, everyday..."(M42)

As a result of having an autistic child, all the parents in this study felt that their experiences were uniquely and inherently different from those of friends and family and would continue to be so for many years to come.

This mother conceptualised what she saw as the differences between her own experience and what parents of typically developing children experience:

> "The constancy of it, you can't take a holiday from it. You can't take a day off and say I don't want to do Autism today. Trying to juggle all your children's needs. The behavioural issues, you can understand a two year old having a tantrum but when your kid's a lot bigger and can actually physically hurt you, I think that's difficult to deal with. The fact that it's two steps forward and one step back. They're progressing then they're not and that there is always so much further to go. The fact that it feels like such a huge job. Even if you have good support, at the end of the day, you're the one making the decisions. It's resting on your shoulders and if you make the wrong decision ...... I think that is a huge burden for mothers"(M62)

Adjusting to the presence of a developmentally disabled child takes time and grieving the loss of the perfect child is ongoing. With autism there is no known cure so even though parents make every concerted effort to help their children meet their full potential through offering intervention, there is an awareness that life is never going to be what they expected it to be and consequently goals and expectations need to be adjusted to fit their new reality. Parents gradually came to realise and accept that autism permeates and would continue to do so, every facet of their family's life.

"The worries and the stress ….. it has its acute phases but it is chronic. It is in everything you think about, everything you are planning, every aspect of your future all revolves around that child's needs" (N31)

Grieving the loss of the perfect child is ongoing for these parents and there are often triggers such as birthdays or specific milestones that accentuate or reactivate the discrepancies and fears. This grief however is also frequently triggered by what others may consider to be insignificant events. This mother speaks of one such episode:

"the grieving period that parents of these children have will never go away. I think you grieve for the things that will never be but you are forever reminded. I can remember it hitting me one day when I took him to Chipmunks (a local playground). Every other kid is 'mum, I want this and I want that' and I was just standing there screaming at him to 'get socks, get socks, get socks' when he is at the top of the slide. It's things like that." (N71)

The Role of the Parents

The needs of an autistic child in many cases create changes in expected parental roles and responsibilities. Parents no longer defined themselves simply as Mum or Dad but saw themselves as advocates, teachers, activities co-ordinator, employers and buddies for their child. The predominant goal for the parents in this study in their role of parents of an autistic child was to ensure that they did everything they could to help their child meet their full potential. Many felt very alone in this role.

"If you don't do it, there's nobody else who will." (M51)

For most parents helping their child meet their full potential meant doing everything in their power to ensure their child received the resources and support that the parent perceived they needed. All were frustrated by the fact that they had to fight for resources to which they felt their children were rightfully entitled.

"Having to justify why you need a service. I myself find that humiliating and demeaning but at the end of the day we do what we need to do."(F51)

"We were told that if we continued to do the programme they would take away his educational support worker at kindy. That was awful because we were struggling to pay for the therapy and there was no way we were going to be able to pay for that as well. They didn't do it in the end because my husband threatened them with legal action, but it was very stressful, the fact that we were actively dissuaded from doing it."(D64)

Each parent recognised the huge commitment that they had in the role of parent to this child, over what would normally have been expected of them, had they been a parent of a neuro-typical child. This mother explains:

"Parenting a child with special needs is a lifetime of advocacy on behalf of your child and you never stop advocating and fighting for them, pitching battles with professionals, authorities, other children, other parents. You are constantly encountering ignorance, sometimes fear, and you're constantly looking out for your child to make it as easy as possible, so you kind of anticipate a lot of things and find ways of making things as easy as possible, it is a lifetime of advocacy. You can never afford to take the easy route, it is hard work."(J11)

Isolation/Alienation

Everyday life, previously taken for granted, becomes disrupted for parents of children with autism who are presented with the daily challenge of trying to go about their lives and complete mundane tasks such as the grocery shopping with a child who is normal in appearance but with extreme behaviour problems in a society that lacks awareness of, and as such is un-accepting of the socially inappropriate and sometimes aggressive behaviour that is typical of autistic children.

"I couldn't take Brendan into a shop, he would scream and scream and scream." (K21)

The easy way of coping with this challenge would have been for parents to remain home in an environment that was safe and predictable for their child

where they could respond to their child's behaviour in an appropriate way without being judged by members of the public. Evidently most parents felt that this was not in their, or their child's, best interest.

> "you have to make the choice that you are either going to fit in or you end up isolated which happens to a lot of people unfortunately." (H52)

For many parents part of adjusting to life with an autistic child was making a conscious decision to develop strategies that they could incorporate into their daily lives to minimise the effects of autism so that they could carry on as normally as possible. One such strategy implemented by a mother was going to the supermarket at a quiet time and letting her child wear 3D glasses and a woolly hat to minimise the stimulation overload that usually ensued from the combination of fluorescent lights and crowds of people.

Another isolating factor of autism is the lack of understanding and/or knowledge of friends and family. A supportive environment reduces parental anxiety and aids adaptation to having a autistic child so one can understand the temptation for some parents to minimise the effects of autism by surrounding themselves only with people who are knowledgeable about autism and who interact with their child in such a way that it would not highlight their child's deficits or trigger autistic behaviours. As this mother explains:

> "its very distancing, even people who are genuinely interested, they bend down to say hello and he doesn't make eye contact or he doesn't smile and it's like they've tried, but then what are they meant to do. I've had to come up with strategies to stop myself wanting to cut people out of my life if they're not responding in a way that I want them to. I find it's very instinctive on my part that, o.k, you're not going to be nice to him – I don't want you in my life."(N31)

It is important to note that the isolation of families with children with autism is two fold. There is the physical isolation that ensues from having a child who doesn't know how to and doesn't care to interact with other people and there are the feelings of isolation the feeling that nobody else can possibly

understand what you are going through. This mother describes her perception of both forms.

> "You are living in a world that you are actually not a part of. I mean, they're denied the world because of their disability but you're denied it too. You suddenly don't have access to the things that other 'normal' people do. You lose friends, you lose contact, some people think it's catching or like cancer. I just think you feel incredibly isolated and that your life is so incredibly different from anybody else's" (N62)

It's an Invisible Condition

The fact that most autistic children's outward appearance is physically normal also produces some unique challenges for parents. Many parents felt that their child's normal appearance contributed to delays in a definitive diagnosis as well as impeding the support process.

> "It is frightening. If they see Down Syndrome on a piece of paper of course they get funding but because our kids look normal people think that they don't need help."(G71)

Parents also found that due to their child's normal appearance people tended to dismiss their concerns and insist on normalising their child's abnormal behaviour.

> "It's really unhelpful when people pretend that there is nothing wrong. You don't share that your child has a neurological disorder with people lightly but because he looks normal they'll say stuff like 'oh my child does that' or 'he'll be fine'. You don't want sympathy but when people try and dismiss it, it is actually very counter productive to what you are dealing with. (N61)

Having a child who looked normal also meant that parents felt that their parenting skills were being judged when their child was engaging in autistic type behaviour in public. Subsequently, they found that they frequently had to explain or justify their child's behaviour and their response to that behaviour to complete strangers. Consequently, many parents saw themselves as having a social responsibility to raise public awareness about autism. Some parents felt

it would have been easier if their child had some obvious form of impediment that would go some way to justifying their child's behaviour in the public eye.

> "If a kids in a wheelchair or has Down's syndrome people look at them and think 'poor little handicapped child – having a bad day?', but with Andrew its like they look at me and think 'bad parent'".(J52)

It's a Different Kind of Love

One of the unique variables of parenting a child with autism that parents spoke of is the lack of reciprocation. The intensity of this deficit was acutely apparent to parents who also had a neuro-typical child.

> "We have a child who doesn't have autism and she seeks you out, she wants to share things with you not just use you to do something because it's her current stim. (Stimulative activity). She wants to talk with you, not at you, your approval is actually important to her."(J61)

Although many of the children enjoyed cuddles and were sometimes affectionate most did not actively seek social interaction with their parents or respond to their parents emotions. This evidently impacts on the parenting experience. This mother shares her insights.

> "I think parenting any child is difficult let alone a child who doesn't respond to you in a normal way. When you've got a child who's not, ……., they do emotionally connect with you but it's not a normal form of contact. I think the biggest thing about autism is that autism has to be the best definition of unconditional love I have ever seen because you don't get back. It's easy to love someone who loves you back, but with autistic kids they can't do that so it has to be unconditional. You have to put a lot of your own needs aside. (J53)

Many parents were philosophical and could see the positive side of the experience speaking of it as a gift and an opportunity to learn.

> "I don't think unless you have had a special needs child you really know, it's a different sort of love you have for that child. What is so unfair for a start is that it unlocks a very special sort of love that you don't have for your other kids. Everything in comparison seems so easy for them. I think when you're working with a child with autism any successes are more fantastic than someone standing up and being awarded a gold medal at the Olympics. Things like that are pretty special." (N54)

Chapter Eleven

Support

Parent Support Groups

Parent support groups go some way to addressing the feelings of isolation that often accompany parenting a child with autism.

> "I don't think anyone understands unless they are dealing with it themselves which is why I think it is important that you do know some other parents. You need to know you're not the only one doing it."(L61)

Most of the parents interviewed were involved with a parent support group. Some of them were considered to be informal and were described as more of a "coffee morning" run by the mothers themselves while another was considered to be quite formal and focussed and was chaired by a psychologist from an outside agency. The focus of all the support groups however was on sharing – sharing of information, resources, ideas, understanding and emotions.

> "It is just parents who get together once a month and talk about their difficulties, experiences and stuff. As a parent you need to be out there searching all the time. If you come across a problem you have to go searching for the answer, asking questions. You only find stuff out by networking. You ring up other mothers and ask personal questions of perfect strangers and hope that they are sympathetic and that they will pass on some helpful hints."(J71)

It was evident that parents valued their time at support groups due to the concerted effort that was required on their part for many of them to attend. Some had to travel for well over an hour to attend a group adding to the already severe constraints on their time. Some had to organise additional childcare as children were not allowed to attend the more formal group.

> "It's a hassle to get there but I do it because I think it is so important, when I get there, there is really good information, really good people and of course there are other mothers with exactly the same problems,

so you can let your guard down a little bit because you know everyone else in the room, all those who are there also have this problem in their life."(L11)

Parent support groups helped parents to recognise that there are other parents with experiences that are similar to their own. This in turn validated their experiences and provided them with a safe and supportive forum in which they could ask questions and pose problems that they may not have felt comfortable presenting to a professional or another parent whose child did not have autism. For many parents it was a forum in which the ceaseless uncertainties and feelings of anxiety associated with parenting a child with autism could be addressed, comparisons made and valid responses and information given by others who had been there.

In addition to attending the support groups many of the mothers made themselves available to families who had recently received a diagnosis and some extended their involvement by lobbying for services and funding at a regional and national level.

Spousal Support

When discussing support, most of the mothers in this study identified friends and other family members such as their mother or sister as their greatest source of emotional support over and above their husbands. However, all the mothers interviewed considered their husbands to be supportive but in more of what is best described as a behind the scenes role rather than providing overt emotional support. This may have been due to the difference in how the parents perceived the situation.

> "Men are different to women …. That's an obvious statement isn't it!(Laughter). But he kind of just gets on with and does what has to be done. He doesn't have the emotions that I have. He kind of looks at it more in a business sense, well I've got to work a bit harder to make more money to pay for all the things that have got to be done."(L43)

In some instances the reliance on others for emotional support appeared to arise from the fact that the husband was still coming to terms with the diagnosis in

his own mind and as such his wife didn't perceive him as capable of providing emotional support at that point in time whereas in others it arose from the fact that they felt their husband didn't quite understand the implications of the diagnosis enough to be able to offer the emotional support they needed.

> "My husband's getting better. I think it is very hard for men to get their heads around it, harder in some ways than it is for women. Because they're not the one physically at home doing the caring putting up with the problems all day it's very difficult. They need to spend time with the family to see what is actually going on. Once they've done that there's usually ….. they're much more prepared to accept and understand. (L15)

Family

The level of familial support available to the families in this study differed depending on family circumstances. Absence of support from family both emotionally and physically was a recurring theme whether it be due to family being deceased, not living in close enough vicinity to provide practical support to the family or due to disregard and denial from family members who could not understand or did not want to try and understand the implications of having a child with autism. Some of the parents felt this disregard might be due to autistic like traits that were apparent in family members that may have prevented them from empathising or realising the magnitude of the child's difficulties. The generation gap was also a problematic factor in some instances. One mother encountered old fashioned beliefs instilled in her in-laws which resulted in the demise of a possible avenue of support.

> "His parents still blame me for Matt being autistic. The refrigerator mother. Unfortunately they are not welcome here any longer as she made it such a personal issue."(L22)

Other parents received both emotional and practical support from some family members.

> "I definitely would have gone mad without my mother, I must say she was very supportive" (L34)

This mother found that her sister acted as a liaison between herself and the rest of the family clarifying concerns and correcting misunderstandings, which in turn led to other family members being accessible to provide practical support.

> "My sister is great, she comes and baby-sits and stuff. She knows what's going on and she will keep the rest of the family informed. A lot of the time, family won't be straight up with you because they know that you have got a lot to deal with but she's really good. She informs them and mashes any silly ideas they have. My mother has just started coming round, she has started to have Matt over a weekend." (L21)

Friends

Due to the nature of their child's disorder most parents did not feel comfortable relying on friends for practical support such as child minding. Instead friends seemed to offer social and emotional support.

> "You can tell friends everything, all about it. I think family are too close sometimes, they are fragile as well. But friends are brilliant."(L22)

Time with friends offered parents respite from their child and afforded them the opportunity to re-charge their batteries. Caring for an autistic child can become an unrelenting task in which the rest of the world is easily forgotten. Time with friends presented parents with the chance for a change of perspective.

> "Getting out with my friends really is good. I try to make sure that friendships are evenly weighted so they're not hearing about my problems more than I am hearing about their problems. Everyone has got their problems and they are of primary importance to them. You need to do that thing of looking at someone else's life."(L34)

Chapter Twelve

Surviving Autism

Having a child with autism was not a circumstance that any of the mothers interviewed expected to find themselves in and obviously was not something that they had prepared for. The challenging behaviours of children with autism are often stressful and difficult to manage without the additional stressors of having to put in considerable time and effort to get an accurate and timely diagnosis; encountering difficulties in securing funding and assistance for your child; struggling with the lack of appropriate services; taking on the challenge of sourcing information about possible treatment programmes for your child; and having to orchestrate a team of therapists and professionals to implement a programme. However, each of these exceptional women did this and were somehow able to maintain a sense of balance in their lives despite the obvious challenges.

These mothers spoke of factors that they felt were helpful and had positively contributed to their ability to cope.

Acknowledging and Addressing Emotional Anguish

Many of the parents thought that acknowledging the emotional anguish that accompanies the diagnosis of autism rather than pretending everything was o.k was a key factor in coping with this overwhelming situation.

> "Its really important that you allow yourself to grieve and I think that is really hard for people around you, particularly your partner because he sees you crying all the time, but I think that is very important because you can't move on until you have actually allowed yourself to feel that emotion."(M61)

> "If you pretend to ignore the pain, I mean the mental pain and anguish and grief, it will wait for you. You can go on for years and be busy busy busy and it will wait for you, it will get you in some way or another, it will make you deal with it so in that way, I think the sooner

that you listen to it and the sooner you listen to your body, physically, mentally or both the sooner that you can grow from the experience and move onto the next stage of your life."(M64)

Addressing the emotional anguish for some parents involved talking with close friends over a few glasses of wine whereas several other parents sought additional medicinal or psychological support. These parents describe how it helped.

"I was very sad. I cried a lot, just when I saw other kids talking and that. I was definitely clinically depressed. So I went to the GP and started taking Aropax. I'm off it now, but it definitely helped with the transition from 'he has this, no he doesn't, this isn't fair' onto, give me all the information and I will do with it what I can."(M43)

"When I became depressed which was about five months after the diagnosis, drugs were a great help. As my psychiatrist said, they allow you to sit on the edge of the whirlpool rather than being in it all the time."(M64)

This mother found that psychological support helped her to reinterpret and reframe her experience.

"There have been times when I've gone to see a psychologist, just to make sure I'm not going mad. You need it, it puts everything back into perspective"(M21)

Knowing Your Own Limits

All the mothers in this study were able to recognise their limits and capabilities.

"I can only do the best that I can for him within my personal capabilities without compromising my own health and well being. If I'm not ok, im not going to be able to look after him."(J21)

This in itself helped them to cope but also prompted them to utilise other resources in such a way that the number of times that they were in situations where they felt that they were being pushed beyond their limits were kept to a

minimum. This utilisation of resources could broadly be described as being organised and ranged from careful management of staff hours to ensure that overlaps were kept to a minimum to imaginative use of strategies and resources. This mother was well aware of her limitations and describes how she perceived her subsequent role.

"I need to think of myself as the conductor of the orchestra. You can't play all the instruments and it is bad for you if you to try and do that"(H62).

Coming to Terms with and Adjusting to Autism

"Understanding that he is different and coming to terms with that, the fact that he learns differently, just coming to terms with the fact that he is going to be so far behind. It's really hard, its one of the hardest things that you have to come to terms with as a parent."(J42)

Accepting their child's condition was of paramount importance to many of the parents and greatly influenced the parents' ability to cope. For many of the parents coming to terms with autism was a process of negotiation whereby they adjusted their goals, dreams and expectations for their child to fit their new reality. In turn, they gave their child tools and implemented strategies that aimed to minimise the effects of autism so that their own and their families' lives could continue on as normally as possible.

Focus on the Positives

Valuing and having a positive perception of their child also aided parental coping. All the parents in this study when asked were easily able to identify positive traits in their child such as "a wicked sense of humour".

"You need to be careful that you don't get so locked up in the fact that your child is autistic, you need to realise that they are still a child and sometimes you just need to take time out and have fun with them. Appreciate all the wonderful things about them instead of always focusing on the deficits. (J61)

They were also able to identify ways in which they and their family had benefited from the presence of an Autistic child.

"You do need to be philosophical about it. I know that the grieving never finishes but now that I have sort of gone through that, I just have to think that there is a reason for it. I think every crisis and every tragedy in a person's life gives them the opportunity to learn. Apart from all the awful things it opens your life up to a lot of other wonderful things, people, situations. Things that you would never have experienced if you didn't have a child with autism."(N62)

Chapter Thirteen

Discussion

As a result of having a child with autism the parents in this study embarked on a journey of discovery, frustration and adaptation that was uniquely and inherently different from that which they had expected. The roles that they undertook on this journey were many and varied and were essential to them being able to access information and resources from the medical community, educational sector and support agencies, which would help them to achieve their goal of enabling their child with autism to reach its full potential. All the parents in this study felt that they needed to become an expert parent for their child and as a result were confident that they were doing the best that they could for their child with the information and resources that they had available to them at the time.

Integration of Quantitative Results with Relevant Literature

The aim of this study was to examine the experience of New Zealand parents who had chosen to implement a home based early intensive programme for their child with autism in addition to the usual challenges of having an autistic child. The study was designed to explore firstly how they did this and secondly the impact of it. From a theoretical perspective it was considered pertinent to determine whether the parents who had implemented a home based programme were able to do so as a result of additional fiscal resources that others may not have access to, or whether their life was free from additional stressors and demands such that one could differentiate them from a normative population. As such the Life Stressors and Social Resources Inventory and Beck's Depression Inventory II was administered.

The administration of the Life Stressors and Social Resources Inventory revealed that all participants were in the highest income bracket. Previous research (AANZ 2001; Hastings & Johnson, 2001; Godfrey et al. 2002) has

suggested that financial strain is one of the highest sources of stress for families who partake in home programmes. Financial strain was an above average source of stress for only one parent in this study suggesting that access to financial resources may be one of the components that allow parents to partake in and continue home based intervention programmes making it a very select group in the autistic community. Other results obtained via the Life Stressors and Social Resources Inventory were unremarkable bar two. The high level of stress reported in the domain of children and the overall perception that spouses fell below average as a resource.

For all parents as suggested by current literature, children were a considerably above average source of stress which suggests that although parents are doing all they can to help their child reach their full potential it does not fully counteract the negative effect that comes with having a child with a diagnosis of autism. As a resource, all but one parent's perception of their spouse fell below average. Current literature suggests that the implications of this are potentially adverse with regards to maternal well-being as spousal support in this population is repeatedly identified as being an effective buffer against stress (Frey et al 1989; Boyd, 2002) and results in fewer maternal somatic complaints as well as greater feelings of accomplishment in parenting (Weiss, 2002). These findings were not supported, however, in the current study.

The results obtained through the Beck's Depression Inventory II were not what was expected based on previous literature (Gray & Holden, 1992; Moes et al. 1992; Olsson & Hwang 2001). Of the participants in this study, one parent presented with depressive symptoms. This unexpected result can possibly be accounted for through the application of Lazarus & Folkmans theory (1984) which suggests that the stress an individual experiences results from an imbalance between the demands placed on that person and the resources available to them. If an individuals personal coping resources are adequate to meet the demands being placed on them then that person may not experience events as stressors but may instead successfully adapt. It appears in this study that most parents had successfully utilised various coping resources including

utilising a social network, holding specific beliefs about the situation, and using specific problem solving skills and coping strategies that enabled them to adapt successfully to the situation. That is not to say, that they did not experience depressive symptoms at some time during the process.

Consistent with current grief literature (Bruce & Schultz, 2002) the Becks Depression Inventory II provided evidence that suggests that the time frame between the diagnosis and the assessments has an effect on depressive symptoms. Those who had had the diagnosis for a longer time had lower BDI II scores. The qualitative findings suggests that this may be due to the fact that these parents had had more time to access variables that previous research has shown ameliorates some of the deleterious effects of autism. These include, accessing social and professional support (Dunn et al., 2001; Weiss, 2002), having had more time to see, obtain and understand information with regards to how autism affected their child (Bristol et al., 1993) as well as have developing more confidence in their own ability to handle their child's major difficulties (Sharpley & Bitskia, 1997).

Integration of Qualitative Findings with Relevant Literature

Just doing the best that we can is the resultant grounded theory account of seven parents journey to provide their autistic child with what they perceived to be the best option available to them to help their child reach their full potential – a home based, early, intensive intervention programme. The process of doing this was made up of several stages including obtaining a diagnosis, becoming an expert parent, and the implications of running a home programme. Acknowledging and adjusting to autism and accepting it as a constant in their lives was an ever-present component throughout all stages of the process. Although each parent was working towards a similar goal each of their experiences was unique.

The initial stage of obtaining a diagnosis for their child was difficult for each of the parents in this study. Consistent with Mindence & O'neil's 1999 finding, all the parents in this study found the process stressful and confusing causing them to question their parenting skills and abilities. Once they received a

diagnosis, as in Kohler's 1999 study many of the parents experienced difficulties or delays in accessing services for their child and once having obtained services struggled to make sense of what was available. They were also frustrated by the lack of interagency collaboration and the competing advice offered by different agencies. The realisation that public agencies were not going to be able to provide what their child needed pushed parents into the second stage of the process, becoming an expert parent.

Parents' narratives showed that the process of obtaining and deciphering the information necessary to become an expert parent was again an arduous one. Success at this stage relied heavily on the parents' perseverance and the common belief that more could be done for their child. The personality attribute that enabled parents to persevere could best be defined as hardiness.

Weiss's study of mothers of autistic children in 2002 defined this attribute as a constellation of characteristics including commitment, challenge and control. Commitment referred to a general sense of purpose and a tendency to be an active and involved individual. All the parents in this study displayed this characteristic in their pursuit of knowledge about autism. Challenge referred to an individual's perception of events as opportunities, the parents in this study could all have sat back and thought "my child has autism and that is that". However, instead they saw it as a challenge and made enquiries and pursued information and implemented programmes that could potentially aid their child. Control refers to the degree of influence one perceives one has over events in one's life. These parents displayed a common belief that they had an element of control over events in their lives and accordingly made a conscious effort to help their child with autism either recover from it or live with it to the best of their ability. Weiss' study asserted that individuals who possessed the personality attribute of hardiness were less prone to depression and anxiety and were more likely to perceive support as being available to them. The parents narratives with respect to periods of depression and perception of support tend to support this assertion.

Parent perception of availability of support played a critical role in the implications of 'running a home programme stage'. The task of finding people with the expertise required to effectively run a home programme is a difficult one in New Zealand and a hurdle which could have caused many parents to give up. However, the parents in this study perceived that there was support available and persevered until they secured it. All parents perceived their therapists as their greatest avenue of support both emotionally and practically.

The collaborative relationship that developed between parents and therapists has been found to buffer the deleterious effects of parenting a child with autism (Everett, 2001). Parent narratives provided a clear illustration of this effect. When therapists weren't involved the parents often perceived the presence of their child as a perceptual cycle of negative interactions, that is the parent observes their child's behaviour but is too tired and depressed to intervene so the behaviour continues and often escalates. Once a therapist is involved who has a clear understanding of autism and the child's subsequent needs, they are able to intervene and the child's behaviours begins to improve. Parents see the improvement and their own mood improves to the extent that they also are motivated to respond to their child's behaviour. Therapists then assist parents to learn skills and strategies that in turn enable parents to understand and predict their child's behaviour, this allowing them to intervene in an appropriate and effective manner resulting in less frustration for both themselves and the child.

Narratives tended to support Hastings and Johnsons 2001 finding that beliefs regarding the efficacy of the intervention impacts on parents' stress levels and depressive symptoms. In addition, this confrontive method of coping rather than reverting to escape/avoidance tends to correspond with a decrease in the deleterious effects of parenting a child with autism such as depression and isolation and has been shown to result in better spousal relationships and an increased likelihood to seek additional social support (Dunn et al., 2001).

The parents' narratives alluded to the fact that the increased likelihood to seek additional support had a social desirability component. When they didn't possess the skills to understand and manage their child's behaviour they felt inadequate and lacked confidence in their ability to parent and didn't want to reinforce those feelings of inadequacy or failure by having to be reliant on others and ask family and friends for assistance. As their confidence in their parenting abilities increased as a result of being able to predict and manage most of their child's behaviours, parents were less anxious about appearing inadequate to others and more comfortable asking for subsequent support. In addition to this, the parents' narratives revealed the attitude that once they had developed skills they were better prepared to inform family and friends about autism and better able to teach others the skills necessary to form a relationship with their child.

Teaching others about autism and their child worked in many cases to change the parents' perception of their own role and their expectations of their child. This was an important component of acknowledging and adjusting to autism. Acknowledgment and adjusting to autism was an ever present component throughout the stages of this grounded theory account and acceptance of it as a constant in their lives was a process of negotiation whereby parents adjusted their dreams, goals and expectations for their child to fit with their new reality whilst at the same time providing their child with the necessary tools and consciously implementing strategies that aimed to minimise the effects of autism enabling their own and their families' lives to continue on as normally as possible. Applying McCubbin and Patterson's, 1983 Double ABC-X Model of adjustment and adaptation to the situation provides a succinct summary of the process.

By providing a home programme parents perceived that they were doing something worthwhile and proactive. This enabled them to redefine the situation in a more positive light and this assisted them to adapt accordingly.

Successful adaptation to a stressor through utilisation of personal, family and community resources combined with positive family coping responses and effective, realistic processing of the situation resulted in a more positive perception of the situation and families adapted accordingly. As stated by McCubbin and Patterson "successful adaptation in a less than perfect world calls for a general orientation by the family which reflects a sense of acceptance and understanding that this is the best they can do under the circumstances." (1983, p.19)

Recommendations for Professionals Working with this Population

The comments of the seven parents involved in this study indicate that the diagnostic process is a major source of frustration and disillusionment amongst this population. The fact that parents had to initiate or maintain investigations when they felt that something was amiss highlights the need for better awareness of developmental problems in young children amongst health professionals. Best outcomes for children with autism are reported to occur when intervention is early and intensive. Not recognising symptoms at an early age denies these children the benefit of this.

The confusion that was reported with regards to accessing services and funding should also be addressed. Professionals need to be aware that a parent's ability to process information in times of grief and stress may be hindered and as such steps should be taken to ensure that parents receive information in a way that they can process and utilise it.

This study also identified a number of positive aspects that arose as a result of having a home programme benefiting both the parents and their child. Having additional information regarding autism and being given information specific to their child helped many of the parents to better understand their child's behaviour. This resulted in less frustration and confusion and in many cases improved the parents' perception of their child. Having therapists present afforded parents respite periods. It also provided parents with a supportive

environment in which they gained confidence in and added consistency in the use of behavioural strategies in everyday interactions with their child. Once again this decreased the frequency of frustrating interactions. Finally, parents' strong belief that they were doing the best for their child with the information and resources available to them at this time appeared to result in improved optimism in parents. The implications of the above mentioned aspects of this study should be taken into consideration by those who are involved with developing and implementing home programmes or other related parent training and information programmes and should be considered by those supporting families conducting home based intensive intervention programmes.

Limitations of the Research

Although the main findings of this study are supported by other research both qualitative and quantitative, generalisation from this study is of course limited. The results only represent a snapshot in time and the sample of participating parents was small and limited to one geographical area with the study focussing exclusively on parent reports with no confirmation or validation from other sources.

Future research in this area may be better served by the use of a comparison group to determine if there is an inherent difference in the coping strategies, the frequency and types of stressors and the utilisation of resources of parents of children with autism who are conducting a home programme compared to those who are not.

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Appendices

Appendix A

Information for Participants

Project Title: The experience of New Zealand parents conducting home based, early, intensive intervention programmes for their child with autism.

Researcher: Katherine Nathan

My name is Katherine Nathan. I am a postgraduate student at Massey University. I am conducting research for a Masters degree in the department of Psychology under the supervision of Cheryl Woolley, a senior lecturer in psychology and a senior child and family psychologist. You are invited to take part in this research which aims to explore the experiences of New Zealand parents who have chosen to conduct a intensive, home based, early intervention programme for their child with autism.

This study is composed of two parts, your participation will involve, firstly, the completion of two self-administered scales which will take approximately an hour, and secondly your involvement in an interview. The interview can take from one to two hours and will be audiotaped. You may decline to answer some of the questions if you wish.

There are no risks of harmful effects resulting from participation in this study. However, there is a possibility that some participants may experience some discomfort following the interview. Should participants wish to further discuss any issues aroused by the interview they will be advised to contact:
- Their Autism Support Group
- Autistic Association (09) 276-1396
- Parent Aid (09) 837 3744
- Presbyterian Support (09) 262 840
- or if necessary the research supervisor (Cheryl Woolley).

Confidentiality is assured in this study. The only person who will know what is said will be the researcher and the research supervisor. (Cheryl Woolley, Massey University.) All information generated from this study will be confidential. No individual will be identifiable in the final report and all consent forms, tapes and typed interviews will be kept in a locked cabinet, accessible only to the researcher.

Participants will be given a summary of the results and will be notified when the completed thesis is published. To assure anonymity the presentation of findings in this evaluation will be ordered by themes, not individual comments. The presentation will ensure that participants remain anonymous. Brief quotations from interviews will be included in the report but nowhere will these comments be attributable to an individual person.

Participation in this study is entirely voluntary. You can withdraw from the interview at any time and you can withdraw the information you have provided at any time for four weeks after the interview.

If you would like to participate in this study, or require any further information please contact:

The Researcher: Katherine Nathan
                     School of Psychology
                     Massey University
                     Albany
                     (09) 443 9799 ext:9091

Project Supervisor: Cheryl Woolley
                     School of Psychology
                     Massey University
                      Palmerston North
                     (09) 443 9700 ext 2076

Katherine Nathan

Appendix B

Consent Form

Project Title: The experience of New Zealand parents conducting home based, early, intensive, intervention programmes for their child with autism.

Researcher: Katherine Nathan

I have read and understood the Information Sheet for participants in this study. My questions about the study have been answered to my satisfaction and I understand that I may ask further questions at any time. I also understand that my participation is voluntary and that I am free to withdraw from the interview at any time without needing to provide a reason. I may also refuse to answer any particular questions in the interview. Following the interviews I have the right to withdraw my input at any time during the next four weeks.

I agree to be interviewed and provide information to the researcher on the understanding that it is confidential, and that I will not be identifiable in the final report, as outlined in the information sheet.

I agree to my interview being audiotaped for the purpose of transcription and analysis only. I understand that I have the right to ask for the audiotape to be turned off at any time during the interview.

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

I

(full name)

                hereby agree to take part in the study.

Signed:

Dated:

This project has been reviewed and approved by the Massey University Regional Human Ethics Committee, Albany Campus, Protocol MUAHEC 02/001. If you have any concerns about the conduct of this research, please contact Associate-Professor Kerry Chamberlain, Chair, Massey University Regional Human Ethics Committee, Albany, telephone 09 443 9799, email K.Chamberlain@massey.ac.nz

Appendix C

Demographic Information

Primary Caregiver

Name _____

Age _____

Relationship to Child _____

Marital Status _____

Occupation _____

Ethnicity _____

Education Level _____

Child

Name _____

D.O.B _____

Diagnosis _____

Age at Diagnosis _____

Age when commenced home programme _____

Siblings

Name	D.O.B	ASD Traits

Appendix D

Semi-structured Interview

Diagnosis

What was it about your child that led you to seek a diagnosis?

How did you initially respond to these concerns?

Can you tell me what steps you had to take in order to get an ASD diagnosis for your child?

How did you react to the diagnosis?

How did your spouse/partner react to the diagnosis?

Who did you tell about the diagnosis and when?

Can you describe how you were feeling at this time?

Were there anything's that you did during this time that you found helped?

Were there anything's at this time that you found were unhelpful?

Services & Interventions

What information regarding services and interventions did you receive at the time of diagnosis?

What assistance did you receive from public services?

What public services is your child receiving at present?

What services are you receiving from private organisations or professionals?

Describe your impressions about the various services your child is receiving?

What did/do you find helpful?

Are there services that you know of that you chose not to participate in?

Programme Origins

How did you find out about early intervention programmes?

What motivated you as a parent to investigate the possibility of a home programme?

Did you try and other methods of treatment prior to the programme?

How long had you had the diagnosis for when the programme started?

Can you tell me how setting up the programme came about?

How many hours was your child doing a home programme for when you first started?

Have those hours increased or decreased?

Can you give me an idea/outline of your child's week at this time?

Financial Support

Do you receive any outside funding assistance?

Does this money assist in the running of your home programme?

What percentage of funding do you provide?

Do you receive any other forms of support or funding such as resources, volunteer therapists etc?

Do you feel that the impact on your financial situation as a result of running a home programme has had any influence on your stress levels? If so in what way?

Programme Involvement

Can you explain your involvement in the programme for me?

Are their aspects of the programme that you have found particularly helpful? Unhelpful?

Has having a home programme affected other areas of your life? If so, in what way.

Can you describe what sort of impact the programme has had on your family as a whole?

Programme Experiences

What kind of changes have you noticed in your child since the programme began?

Did you notice any instant changes? (If not what encouraged them to persevere)

Do you feel more able to teach your child specific things as a result of the programme?

Do you feel the programme has had any effect on your ability to, or level of confidence in being able to cope with your child? If so how?

Would you recommend a home programme to another parent of an autistic child?

Has the programme changed your perspective with regards to your child's future?

Support/Coping

As the parent of a child who has been diagnosed with ASD how do you see your role as a parent?

What aspects of parenting a child with ASD do you see as being unique or different?

Are their some things that you find difficult to manage/cope with? If so, what?

Are there times when caring for your child feels like it is stretching you beyond your personal limits?

Who do you consider to be your biggest source of practical support?

Who do you consider to be your biggest source of emotional support?

How would you describe the level of support provided by your spouse?

What is the best thing that you do that helps you cope on a daily basis?

What do you consider to be your child's greatest strengths and attributes?

Is there anything further that you would like to add?

LISRES-A

by Rudolf H. Moos, PhD

This inventory contains questions about your background and health, your work, and your relationships with friends and relatives. Please mark all your answers on the separate LISRES-A Answer Form. **Do not write in this booklet**.

On the first page of the Answer Form, please fill in your name, today's date, your sex, and your age. Then fill in your marital status (never married, married, separated, divorced, widowed, etc.), your education (number of years completed), your ethnic group (African-American, Asian, Hispanic/Latino, Native American, White, Other) and your current employment situation (full-time, part-time, both, not employed).

If a question does not apply to you, please write **N/A** ("Not Applicable") in the margin next to that question on the answer form. If you do not wish to answer a question, please circle the number of that question to show that you have purposely skipped it. All your answers are strictly confidential.

Some items require a **Yes** or **No** answer and look like this: **Y   N.**

For these items, circle the appropriate response:
    Circle **Y** if your response is **Yes.**
    Circle **N** if your response is **No.**

Some items require a different kind of response and look like this: **DY   MY   MN   DN.**

For these items:
    Circle **DY** if your response is **Definitely Yes.**
    Circle **MY** if your response is **Mainly Yes.**
    Circle **MN** if your response is **Mainly No.**
    Circle **DN** if your response is **Definitely No.**

Some items ask about how often things happen and look like this: **N   S   ST   FO   O.**

For these items:
    Circle **N** if your response is **Never.**
    Circle **S** if your response is **Seldom.**
    Circle **ST** if your response is **Sometimes.**
    Circle **FO** if your response is **Fairly Often.**
    Circle **O** if your response is **Often.**

A. PHYSICAL HEALTH

Items 1 - 26 in this section have two parts (a and b). For each of these items, *answer part b only if you answer "Yes" to part a.*

Have you had any of these medical conditions *in the past 12 months?*
(Circle **"Y"** only if diagnosed by a physician.)

  1a. Anemia (low blood).....................................**If Yes:** b. Did it start in the last year?
  2a. Asthma or allergies....................................**If Yes:** b. Did it start in the last year?
  3a. Arthritis or rheumatism.............................**If Yes:** b. Did it start in the last year?
  4a. Serious back trouble ....**If Yes:** b. Did it start in the last year?
  5a. Chronic bronchitis....................................**If Yes:** b. Did it start in the last year?
  6a. Cancer...**If Yes:** b. Did it start in the last year?
  7a. Diabetes ....**If Yes:** b. Did it start in the last year?
  8a. Heart trouble..**If Yes:** b. Did it start in the last year?
  9a. High blood pressure ....**If Yes:** b. Did it start in the last year?
10a. Kidney trouble..**If Yes:** b. Did it start in the last year?
11a. Stroke..**If Yes:** b. Did it start in the last year?
12a. Stomach or duodenal ulcer.........................**If Yes:** b. Did it start in the last year?
13a. Other ....**If Yes:** b. Did it start in the last year?

Have you had any of these ailments *in the past 12 months?*

14a. Frequent cramps in the legs ....**If Yes:** b. Did it start in the last year?
15a. Pain in the heart or tightness
     or heaviness in the chest ....**If Yes:** b. Did it start in the last year?
16a. Trouble breathing or shortness of breath.............**If Yes:** b. Did it start in the last year?
17a. Swollen ankles ....**If Yes:** b. Did it start in the last year?
18a. Pains in the back or spine...........................**If Yes:** b. Did it start in the last year?
19a. Repeated pains in the stomach ....**If Yes:** b. Did it start in the last year?
20a. Frequent headaches....................................**If Yes:** b. Did it start in the last year?
21a. Constant coughing or frequent
     heavy chest colds.....................................**If Yes:** b. Did it start in the last year?
22a. Stiffness, swelling, or aching
     in any joint or muscle ....**If Yes:** b. Did it start in the last year?
23a. Getting very tired in a short time................**If Yes:** b. Did it start in the last year?
24a. Trouble climbing stairs or getting outdoors..........**If Yes:** b. Did it start in the last year?
25a. An injury that has caused you problems..............**If Yes:** b. Did it start in the last year?
26a. Other ailments ....**If Yes:** b. Did it start in the last year?
  27. Were you hospitalized in the last year?

B. HOME/NEIGHBORHOOD

In the last year:

  28. Did you lose your home through fire, flood, disaster, or a major catastrophe?
  29. Did you move to a worse home?

Have any of these things happened to you or to your spouse or partner *in the last year?*

30. Car burglarized?
31. Home burglarized?
32. Personally assaulted?
33. Trouble with the law (other than minor traffic violations)?
34. Automobile accident?

(DY = Definitely Yes / MY = Mainly Yes / MN = Mainly No / DN = Definitely No)

The following questions have to do with your home:

35. Is it well kept up (e.g., painting, repairs)?
36. Is the amount of living space comfortable?
37. Is there enough heat in the winter?
38. Is it cool enough in the summer?
39. Is the inside lighting adequate?
40. Is it quiet enough?

The following questions have to do with your neighborhood (the two or three blocks around your home):

41. Are the houses in the neighborhood well maintained?
42. Are the streets clean and free of litter?
43. Is it safe to walk alone in the neighborhood at night?
44. In general, are the people who live near you (within one block of your home) good neighbors?

In the last year:

45. Did you build your home or do a major remodeling of it?
46. Did you move to a better home?

C. FINANCES

Have any of these things happened to you *in the last year:*

47. Did you take on a large mortgage, loan, or financial obligation?
48. Has your financial situation gotten worse?
49. Have you gone on welfare?
50. Were you involved in a civil lawsuit (noncriminal)?

(DY = Definitely Yes / MY = Mainly Yes / MN = Mainly No / DN = Definitely No)

Do you have enough money to afford:

51. Good medical and dental care when you (your family) need it?
52. Leisure activities and entertainment?
53. Furniture or household equipment that needs to be replaced?
54. The kind of car you need?
55. A large, unexpected bill (over $500) for auto repair, etc.?
56. Adequate food and clothing?
57. Has your financial situation improved *in the last year?*
58. Have you gone off welfare *in the last year?*
59. What is your total annual family income (your earnings plus those of others who live with you)?
    Circle the number on the answer form that corresponds to your income range.

    1 = less than $20,000   4 = $30,000 - $34,999   7 = $50,000 - $59,999
    2 = $20,000 - $24,999   5 = $35,000 - $39,999   8 = $60,000 or more
    3 = $25,000 - $29,999   6 = $40,000 - $49,999

3

D. WORK

In the last year:

60. Did you change to a worse job?
61. Were you laid off?
62. Were you fired?
63. Did you stop working or quit for reasons other than retirement?
64. Were you demoted at work?
65. Did you find out that you were not going to get an expected promotion at work?
66. Did you suffer a business loss or failure?
67. Did you take on a greatly increased workload?
68. Did you start regular work for the first time?
69. Did you return to work after not working for a long time (after at least 3 months)?
70. Did you change to a better job?
71. Were you promoted?
72. Did you have a significant success at work (other than a promotion)?
73. Did you start a business or profession?
74. Did you expand a business or professional practice?

If currently not employed, and you have not held a job in the last month, go to SECTION E (SPOUSE/PARTNER).

(N = Never / S = Seldom / ST = Sometimes / FO = Fairly Often / O = Often)

How often does each of these things happen in your current job?

75. Does your supervisor criticize you over minor things?
76. Do you have conflicts with your coworkers?
77. Do you have conflicts with your supervisor?
78. Is there constant pressure to keep working?
79. Does there seem to be a rush or urgency about everything?
80. Are there unpleasant physical conditions on your job, such as too much noise or dust?
81. Do you talk with your fellow employees about your work problems?
82. Are your coworkers friendly toward you?
83. Do you get adequate recognition for your contributions at work?
84. Are responsibilities at work clearly defined?
85. Is your work really challenging?
86. Can you use your own initiative to do things?

E. SPOUSE/PARTNER

87. Have you been separated in the last year?
88. Have you been divorced in the last year?
89. Have you been widowed in the last year?

If you were in a relationship in the last year:

90a. Did your relationship change for the worse in the last year?
  b. **If Yes:** Did you separate for more than 2 weeks?
91. Was your engagement broken in the last year?
92. In the last year, did you stop seeing someone you had been seeing exclusively?

93a. Does your spouse or partner have any medical conditions or ailments, such as cancer, heart trouble, arthritis, high blood pressure, severe shortness of breath, constant coughing, or frequent colds?
   b. **If Yes:** Did it begin in the last year?

94a. Does your spouse or partner have any problems with emotions or behavior, such as depression, excessive drinking, severe memory problems, or trouble with the law?
   b. **If Yes:** Did it begin in the last year?

95. Was your spouse or partner hospitalized in the last year?

96. Have you been married in the last year?

97. Did you become engaged in the last year?

98. Did you start seeing someone exclusively in the last year?

If you were in a relationship in the last year:

99a. Did your relationship change for the better in the last year?
   b. **If Yes:** Did you get together after a separation of more than 2 weeks?

If you do not currently have a spouse or partner, go to Section F (CHILDREN).

(N = Never / S = Seldom / ST = Sometimes / FO = Fairly Often / O = Often)

How often does each of these things happen with your spouse or partner?

100. Does he or she disagree with you about important things?

101. Is he or she critical or disapproving of you?

102. Does he or she get on your nerves?

103. Does he or she get angry or lose his or her temper with you?

104. Does he or she expect too much of you?

105. Can you count on him or her to help you when you need it?

106. Does he or she cheer you up when you are sad or worried?

107. Do you confide in him or her?

108. Do you share mutual interests or activities with him or her?

109. Does he or she really understand how you feel about things?

110. Does he or she respect your opinion?

F. CHILDREN

Have you or your spouse or partner experienced any of these events *in the last year?*

111. Became pregnant and were sad about it?

112. Had an abortion?

113. Had a miscarriage?

114. Had a stillbirth?

115. Had a premature infant?

116. Found out that you cannot have children?

117. Experienced the death of one of your children?

118. Became pregnant and were happy about it?

If you do not have any living children or stepchildren, go to Section G (EXTENDED FAMILY).

119a. Do any of your children have any medical conditions or ailments, such as cancer, heart trouble, arthritis high blood pressure, severe shortness of breath, constant coughing, or frequent colds?
   b. **If Yes:** Did it begin in the last year?

120a. Do any of your children have any problems with emotions or behavior, such as depression, excessive drinking, severe memory problems, or trouble with the law?
   b. **If Yes:** Did it begin in the last year?

121. Were any of your children hospitalized *in the last year?*

122. How many children or stepchildren do you have *living with you now?*

The following questions are about the children living with you now. If you do not have any children or stepchildren living with you now, go to item #128.

(N = Never / S = Seldom / ST = Sometimes / FO = Fairly Often / O = Often)

How often do any of the children living with you now:

123. Misbehave or disobey you?

124. Have bursts of anger or moodiness?

125. Act stubborn or have temper tantrums?

126. Make demands on you?

127. Get upset over small things?

The following questions are about your current relationships with your children.

How often do *any* of your children:

128. Disagree with you about important things?

129. Get on your nerves?

130. Get angry or lose their temper with you?

131. Expect too much of you?

132. Are any of them critical or disapproving of you?

133. Can you count on them to help you when you need it?

134. Do they cheer you up when you are sad or worried?

135. Do you confide in one or more of them?

136. Do you share mutual interests or activities with them?

137. Do they try to understand how you feel about things?

138. Do they respect your opinion?

G. EXTENDED FAMILY

The following questions ask about your mother or stepmother. If you have both a mother and stepmother, refer to the person with whom you have the *most contact.*

139a. Is your mother (or stepmother) living?

   b. **If No:** Did she die *in the last year?*

If your mother/stepmother is not living, go to item #154.

140a. Does your mother/stepmother have any medical conditions or ailments, such as cancer, heart trouble, arthritis, high blood pressure, severe shortness of breath, constant coughing, or frequent colds?

   b. **If Yes:** Did it begin *in the last year?*

141a. Does your mother/stepmother have any problems with emotions or behavior, such as trouble with the law, depression, excessive drinking, or severe memory problems?

   b. **If Yes:** Did it begin *in the last year?*

142. Was she hospitalized for any reason *in the last year?*

(N = Never / S = Seldom / ST = Sometimes / FO = Fairly Often / O = Often)

When you spend time with your mother/stepmother, how often:

143. Does she disagree with you about important things?

144. Is she critical or disapproving of you?

145. Does she get on your nerves?
146. Does she get angry or lose her temper with you?
147. Does she expect too much of you?
148. Can you count on her to help you when you need it?
149. Does she cheer you up when you are sad or worried?
150. Do you confide in her?
151. Do you share mutual interests or activities with her?
152. Does she really understand how you feel about things?
153. Does she respect your opinion?

The following questions ask about your father or stepfather. If you have both a father and stepfather, refer to the person with whom you have the *most contact*.

154a. Is your father (or stepfather) living?
    b. **If No:** Did he die *in the last year?*

If your father/stepfather is not living, go to item #169.

155a. Does your father/stepfather have any medical conditions or ailments, such as cancer, heart trouble, arthritis, high blood pressure, severe shortness of breath, constant coughing, or frequent colds?
    b. **If Yes:** Did it begin *in the last year?*
156a. Does your father/stepfather have any problems with emotions or behavior, such as trouble with the law, depression, excessive drinking, or severe memory problems?
    b. **If Yes:** Did it begin *in the last year?*
157. Was he hospitalized for any reason *in the last year?*

(N = Never / S = Seldom / ST = Sometimes / FO = Fairly Often / O = Often)

When you spend time with your father/stepfather, how often:

158. Does he disagree with you about important things?
159. Is he critical or disapproving of you?
160. Does he get on your nerves?
161. Does he get angry or lose his temper with you?
162. Does he expect too much of you?
163. Can you count on him to help you when you need it?
164. Does he cheer you up when you are sad or worried?
165. Do you confide in him?
166. Do you share mutual interests or activities with him?
167. Does he really understand how you feel about things?
168. Does he respect your opinion?

The following questions are about your relatives other than your spouse, children, or parents.

Have any of the following events occurred *in the last year?*

169. A relative died?
170. A relative moved to a distant place?
171. A serious conflict with a relative?

(N = Never / S = Seldom / ST = Sometimes / FO = Fairly Often / O = Often)

When you spend time with your relatives how often:

172. Do any of your relatives disagree with you about important things?
173. Are any of your relatives critical or disapproving of you?

174. Do any of your relatives get on your nerves?

175. Do any of your relatives get angry or lose their temper with you?

176. Do any of your relatives expect too much of you?

177. Can you count on any of your relatives to help you when you need it?

178. Do any of your relatives cheer you up when you are sad or worried?

179. Do you confide in any of your relatives?

180. Do you share mutual interests or activities with any of your relatives?

181. Do any of your relatives really understand how you feel about things?

182. Do any of your relatives respect your opinion?

H. FRIENDS AND SOCIAL ACTIVITIES

Do not include parents, relatives, or spouse or partner as friends when answering these questions.

Have any of the following events occurred *in the last year?*

183. A friend died?

184. A friend moved to a distant place?

185. A serious conflict with a friend?

(N = Never / S = Seldom / ST = Sometimes / FO = Fairly Often / O = Often)

How often:

186. Do any of your friends disagree with you about important things?

187. Are any of your friends critical or disapproving of you?

188. Do any of your friends get on your nerves?

189. Do any of your friends get angry or lose their temper with you?

190. Do any of your friends expect too much of you?

191. How many clubs and organizations (e.g., church groups, union, PTA, bowling team) do you belong to? (0, 1, 2, 3, or more than 3)

192. How many close friends do you have, people you feel at ease with and can talk to about personal matters? (0, 1, 2, 3, or more than 3)

(N = Never / S = Seldom (less than twice a year) **/ ST = Sometimes** (several times a year) **/ FO = Fairly Often** (once or twice a month) **/ O = Often** (every week))

193. How often do you attend religious services?

194. How often are you in touch with the friend or friends to whom you feel closest?

(N = Never / S = Seldom / ST = Sometimes / FO = Fairly Often / O = Often)

How often:

195. Can you count on your friends to help you when you need it?

196. Do your friends cheer you up when you are sad or worried?

197. Do you confide in any of your friends?

198. Do you share mutual interests or activities with your friends?

199. Do your friends really understand how you feel about things?

200. Do your friends respect your opinion?