

**Experiences of families of people with Autism Spectrum
Disorder in the Canterbury/West Coast area**

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Abstract

Many people would argue that New Zealand has had a poor reputation for providing support services for the families of people with an Autistic Spectrum Disorder (ASD). The limited support services available for families in this country were highlighted during the trial and the manslaughter conviction of Janine Albury-Thomson. Albury-Thomson was found guilty of the manslaughter of her autistic daughter, Casey (MOH, 1999). The sentencing judge called for an independent inquiry to be held to examine the extent of support services that were available for families affected by the disorder with a view to identifying any gaps that may exist and ascertaining whether or not government policy could be blamed (Norris, 1998). More than twelve years have now elapsed since the Albury-Thomson trial and research was needed to ascertain the experiences of families raising a child with ASD.

This research examines the experiences of families who have a child who has an ASD diagnosis. Research participants were families of people with Autism Spectrum Disorder who reside in the Canterbury/West Coast area. The research explored the support needs of families and the informal and formal supports that are available to them in this region.

This research was conducted in three parts, with each part having a distinct method of data collection allowing triangulation of research findings. Part one was a survey questionnaire distributed via a range of mediums using a snowball sampling method. The second data set was made up of two case studies that were undertaken with a semi-structured interview approach. The third set of data was elicited via a semi-structured interview process from five local service providers that provide services to those with ASD and their families. A qualitative methodology was adopted to analyse research findings. This methodological approach was selected because it gave participants the opportunity to tell their stories about the diagnostic pathway they travelled and their experiences using available services.

This research has social policy relevance as it was designed to examine the participant's experiences while using services and resources available for the families of people with ASD in the Canterbury/West Coast area. Participants told of various social, emotional, and practical impacts and of the experiences they encountered while using the various services available. While the level of awareness of ASD has increased, the diagnosis process proved to be problematic for some when using the public health system. Consistent with a 2001 study commissioned on behalf of the Autistic Association of New Zealand, participants in this study who sought a diagnosis through the public health system found it to be a protracted process. Participants attributed delays to a lack of resources or staff that had a limited knowledge of ASD and saw these factors as barriers to obtaining a diagnosis within an acceptable time frame. A more timely diagnosis was reportedly received when the private health system was used.

With regards to support offered by the agencies involved with 'day to day' contact with families it was found that overall, competent, experienced people worked for the existing agencies and they were capable of offering support where needed. However specific issues were identified by participants including a perception that case managers failed to understand their situation because they were unfamiliar with the implications of having a family member with ASD. Significantly, family members and service providers both identified a concern about a lack of suitable accommodation that can be utilised by a person with ASD. Because there is limited research into the support needs of families of a child with ASD this research provides an important insight into the

needs of a fairly marginalised, and sometimes socially isolated, group. Implications for ongoing service provision and support of families are discussed in the thesis.

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Glossary

Applied Behaviour Analysis (ABA): A style of teaching which uses a series of trials to shape desired behaviour or responses.

Asperger's syndrome (AS): A mental health disorder, classified in the Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition- Text Revision, (APA, 2000), under the section on Pervasive Developmental Disorders. Asperger's syndrome is characterised by impairment in two main domains. These are: social interactions and restricted and stereotyped patterns of behaviour, interests and/or activities.

Aspie or Aspies: A term used by persons with Asperger's syndrome to describe themselves.

Autism: A mental health disorder, classified in the Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition- Text Revision, (APA, 2000), under the section on Pervasive Developmental Disorders. Autism is characterised by impairment across three main domains. The first two are consistent with Aspergers syndrome (i.e. impaired social interactions and restricted and stereotyped patterns of behaviour, interests and/or activities). The third area of impairment includes impaired ability to communicate.

Autism Spectrum Disorder (ASD): This refers to a proposed spectrum or continuum of Pervasive Developmental Disorders (DSMIV-TR) (APA, 2000), the spectrum has been postulated to organise less severe forms Developmental Disorders (e.g. Asperger's or Pervasive Disorder- Not Otherwise Specified (PDD-NOS) to that of Autism and Autism with co morbid mental retardation. ASD has also been used to describe either autism or Asperger's syndrome. Except where authors or participants have specified Autism or Asperger's syndrome, ASD has been used preferentially within the thesis.

'New Zealand Autism Spectrum Disorder Guideline' (2008): A publication setting out procedures professionals should follow while working with someone on the Autistic Spectrum.

Carer support days: An annual allocation of days parents may use to provide informal care to allow them to have a break.

Chelation therapy: An unproven therapy intended to rid the body of heavy metals to treat autism.

Developmental disorders: This term refers to disorders characterised by severe deficits in multiple areas of development. These include reciprocal social interaction, communication and restricted and stereotyped patterns of behaviour, interests and/or activities. In the DSMIV-TR (APA, 2000) the equivalent term is Pervasive

Developmental Disorders and this section incorporates: Autism, Asperger's Syndrome, Pervasive Developmental Disorder- Not Otherwise Specified, Rett's Disorder and Childhood Disintegrative Disorder. As Autism and Asperger's syndrome are the two main diagnoses, the latter group are not covered in this document.

Developmental milestones: Markers or guideposts that enable parents and professionals to monitor a baby or child's learning, behaviour, and development.

Diagnosis: The name of an identified mental health disorder identified as present after an assessment has occurred. For example, the Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition- Text Revision, (APA, 2000) is a standardised diagnostic tool. It is used in many countries internationally (and within New Zealand) and has a set of diagnostic criteria matched to a 'diagnostic label'. When the criteria are met a mental health professional might apply or give a 'diagnosis' to the person under assessment.

D-lysergic acid diethylamide (LSD): Used as an experimental behaviour modification technique for people with autism.

Dolphin-assisted therapy: A technique intended to improve social interaction.

Dore programme: A method of improving brain function.

DSMIV-TR: the Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition- Text Revision, (APA, 2000). As mentioned above, this is a book of mental health disorders. Each mental health disorder has a code and a corresponding set of diagnostic criteria or characteristics to describe the disorder.

Echolalia: The repeating back of something that was said. A word or sentence can be repeated once or over and over again.

Electric shock treatment (ECT): A technique used to modify behaviour.

Home schooling: Formal schooling a child receives at home.

Individualised educational plan (IEP): A plan formulated by a range of professionals to assist a child identified to have special needs education.

High functioning autism (HFA): Individuals with autism who do not have a co-occurring cognitive or intellectual disability have also been described as having 'high functioning' autism

Mainstreaming: The process whereby a child identified to have 'special needs', for example a developmental disorder, intellectual impairment, physical disability etc. is placed with non-disabled peers in a regular classroom setting.

Magnetoencephalography (MEG): A non-invasive technique used to measure magnetic fields generated by small intracellular electrical currents in neurons of the brain.

Measles, Mumps and Rubella (MMR) Vaccine: proposed as an unproven cause of autism.

Neurotypical: A term used in discussions of autistic people to refer to people who are not autistic.

Needs assessment: A formal process undertaken by specific health professionals to determine what supports and assistance an individual and/or family requires to assist them to function. As the result of this assessment an individual or family may access resources and services according to the recommendations of the needs assessor.

Ongoing resourcing scheme (ORS): A funding scheme for students assessed as having very high special education support needs.

Peer support groups: These are often facilitated groups that meet regularly and provide support and education to participants. Participants may comprise of parents, siblings, or clients with a particular issue in common.

Pervasive Developmental Disorders (PDD): The section in the DSMIV-TR that covers developmental disorders such as Autism, Aspergers syndrome and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS).

Pervasive Developmental Disorder - Not otherwise specified (PDD-NOS): The diagnosis given for children who present with some of the characteristics of either Autism or Asperger's syndrome, but not sufficient symptoms are present or not severe enough for a diagnosis of either of these conditions.

Refrigerator mother: A descriptive phrase coined by Freudian Psychiatrists to describe mothers of autistic children who act coldly. The phrase described what these therapists proposed as the 'cause' of infantile autism.

Respite care: Care provided by an individual or institution to a child or young person with a diagnosed disability so that the primary care-givers, usually the parents and other family members can have a break or 'respite'. This can be day care or occur over weekends, holidays or weeks.

Self-stimulating behaviours or 'Stimming': Stereotyped or repetitive movements or behaviours or posturing of the body. A common example in individuals with Pervasive Developmental Disorders might be rocking or hand-flapping.

Sensory integration therapy: A technique designed to lessen sensory impact.

‘Special Education 2000’: A New Zealand governmental policy for the education of special needs students.

Special interest areas: A particular interest or circumscribed area of knowledge that can dominate conversation and activity in a person diagnosed with autism or Asperger’s syndrome. For example: movies, trains and Greek mythology.

Stereotyped behaviours: An abnormal or excessive repetition of an action carried out in the same way over time. Also see Self-Stimulating Behaviours.

Testosterone treatment: A treatment for autism based on the poorly supported assumption that high testosterone levels are a cause of the disorder.

Teacher aide: A person who works in school to support a teacher and special needs student.

Triad of impairments: The three areas of impairment which characterise Autism. These include: deficiencies in social interaction, communication and restricted and stereotyped patterns of behaviour, interests and/or activities.

Chapter 1

Introduction

One of the more perplexing childhood developmental disorders is Autism Spectrum Disorder (ASD). Symptoms of ASD are often first noticed by parents or caregivers and are normally detected in children between the ages of one and three years when certain developmental milestones have not been met or are delayed (National Autistic Society, 2011). While parents tend to notice a range of symptoms, many do not learn that their child has ASD for quite some time.

Autism Spectrum Disorder (ASD) is an umbrella diagnosis that encompasses autism, Asperger's syndrome and Pervasive Developmental Disorder not otherwise specified. More recently, this term has come to be used to indicate the organisation of these conditions on a continuum (or spectrum). Those diagnosed with more severe features or more symptoms given one diagnosis and those whose symptoms are at the other end of the continuum, with less symptoms or less severity of impairment, given a different diagnosis.

Because of the varied array of symptoms that may be presented, the Autistic Spectrum, in its different guises, can be a difficult concept for families and members of a child's community to understand and respond to. Autism Spectrum Disorder is now widely acknowledged as a neurodevelopmental disorder that affects the brain's ability to process information. It affects all aspects of psychological development and manifests in different ways throughout the life course (Frith, 1989). While professionals acknowledge that ASD is not a disease or a sickness, it is not contagious, nor can it be contracted via the environment (Dunlap & Bunton-Pierce, 1999) myths and stereotypes about its cause prevail. Earlier explanations, including those that attributed the onset to family-related factors, continue to impact on families caring for a child with ASD.

The degree of impairment and the range of symptoms evident differ across people with an ASD diagnosis. It is likely that no two people classified on the Autistic Spectrum would present in the same way, require the same support, type or level of intervention. Examination of the diverse formal and informal support needs of individuals with an ASD diagnosis (and their families) needs to be a focus of research.

Arguably New Zealand has not had a very good record of service provision for people with ASD. This was brought to public attention in 1998 with the manslaughter conviction of Janine Albury-Thomson for the death of her daughter Casey. Casey had autism. An outcome of the publicity and court proceedings was the Autism Spectrum Disorder Guideline that was published in 2008. The guideline was among the recommendations from the Autism Services in New Zealand inquiry which is intended to address service gaps that were identified (Ministries of Health and Education, 2008).

1.1 Aim of the thesis

The purpose of this research was to gain an insight into the experiences of families, the ways in which families function, and the formal and informal supports they access when they are caring for a dependant with a diagnosis of ASD.

1.1.1 Thesis summary

Chapter 2 will explain the diagnostic criteria of Autistic Spectrum Disorder and will examine the differences between two of the main points on the spectrum - Autism and Asperger's syndrome. The debate about the parameters of diagnosis is also explored in this chapter. In Chapter 3 an overview of the support services that are available in New Zealand is provided. As there is ¹no

¹ Autism New Zealand and Autlink do not provide the majority of day to day services a family would use

dedicated agency responsible for day to day autism service provision, it will be argued that because many existing agencies have workers skilled in providing services such an agency is not necessary and that resources would be better utilised in developing existing services rather than establishing something new.

The impacts that ASD can have on families are varied and can be as wide ranging as the impact ASD may have on the individual. Chapter 4 examines some of the impacts which may be financial brought about by the necessity for one parent to stay at home to look after the child with ASD or be more subtle when special diets are required to combat food allergies. Impacts may also extend to siblings when a family's resources have been stretched to cater for additional needs. Impacts may also be felt on a personal level and it is possible parents may feel responsible for their child's ASD. In other situations, parents may experience psychological issues such as depression or grief where the grief cycle may be followed as if the child had actually died because the child the parents knew or expected did not exist. These issues are explored in Chapter 4.

No precise cause of ASD has been identified and consequently there is no cure. The lack of scientific evidence to identify a cause has not stopped a proliferation of intervention options or 'cures' for ASD. Chapter 5 focuses on some of the fad treatments that range from being ostensibly fun activities such as in Dolphin-assisted therapy to being potentially dangerous such as Chelation therapy. It is argued that parents of newly diagnosed children could be regarded as potential targets for the purveyor of fad ASD treatments while they search for a cure for their child's ASD. Historical causes of ASD will also be examined an example being Bruno Bettelheim's 'Refrigerator mother theory', and a more recent alleged cause being the mercury in the Measles Mumps and Rubella vaccine. While not described as a fad, Applied Behaviour Analysis which arguably could have been described as one when it first appeared in the 1970s

will be included as an example of how a treatment can be established as a viable alternative following considerable verifiable empirical research that could be replicated and which verified a component that was lacking in all of the fad treatments reviewed.

A background to ASD services that are available today are outlined in Chapter 6. A history of disability services will provide a background into today's service provision. Of notable mention is the Albury-Thomson manslaughter case which formed the catalyst of service provision that is evolving today through the publication of the 'New Zealand Autism Spectrum Disorder Guideline' that is designed to inform development of future ASD support services.

In common with other members of the disability community, persons with ASD are eligible for various special education services. Chapter 7 covers services that are available and provides a background into how the services came into being. Resourcing was found to be a significant issue that affected some schools while at others, attitudes towards disability were also found to be a factor.

Chapter 8 outlines the methodology used within this study. A qualitative research paradigm was used in the survey component of this project. A qualitative approach was selected because it gave survey participants the opportunity to tell their stories.

Chapter 9 presents the research findings. Data was collected using three research approaches to enable triangulation of data. Two families participated in case studies while the survey component involved the administration of a semi-structured survey that was distributed via a range of methods. Representatives from five local service providers were also interviewed to provide, from a professional perspective, a different perspective from families about the issues and needs in this area.

In the final section of the thesis, Appendix J outlines my research journey. It will tell how my original ideas about the topic and issues for families were turned around one hundred and eighty degrees. This reflective summary demonstrates the necessity for a researcher to have an 'open mind' while collecting data - especially when the data collected was not quite what was expected.

Chapter 2

Pervasive Developmental Disorders and Autistic Spectrum Disorders Explained

The diagnosis Autism Spectrum Disorder is made according to the criteria set out in the American Psychiatric Association's 'Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition- Text Revision (DSMIV-TR)' (American Psychiatric Association, 2000). This manual covers a range of mental disorders and the manual includes the corresponding descriptive diagnostic criteria for each one. If the criteria for a diagnosis are not met, the outcome is simple – a diagnosis is not made. This manual, and the psychologists and psychiatrists who use it to diagnose children with suspected ASD, is often the focus of much attention for families.

A diagnosis of ASD comes under the umbrella of ²Pervasive Developmental Disorders. The section in the DSMIV-TR on Pervasive Developmental Disorders (PDD) relates to disorders that are most often diagnosed for the first time in infancy, childhood or adolescence. Parents and health professionals often pick up a range of significant deficits in a young child - most often across multiple areas of development. The issues, often noticed first by parents, include problems with social interaction, communication and restricted and stereotyped patterns of behaviour, interests and/or activities.

More recently there has been a tendency for mental health professionals and researchers to use the label Autistic Spectrum Disorder to refer to Autism, Asperger's syndrome, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS). The term Autistic Spectrum Disorder (ASD) has gained traction in recent years partially because of the overlap in diagnostic criteria and the growing consensus that these disorders may in fact be at different points of the same continuum. For this reason, the term ASD is used throughout this thesis.

² Pervasive Developmental Disorders include: Autism, Asperger's syndrome, Pervasive Developmental Disorder- Not Otherwise Specified, Rett's Disorder and Childhood Disintegrative Disorder.

2.1 Characteristics of Autistic Spectrum Disorder

Autism Spectrum Disorder (ASD) applies to Autism, Asperger's syndrome and PDD-NOS. The term is used to indicate the organisation of these conditions on a continuum (or spectrum). It has been proposed by a range of authors (Howlin, 2004; Attwood, 1998; Frith, 1989; Wing, 1981) that those diagnosed with more severe features or more symptoms are classified at one end of the continuum, while those diagnosed with less symptoms or less severity of impairment lie at other end. Further, the notion that these disorders can be placed on a continuum suggests that even though there can be some distinct differences between people diagnosed with Autism, Asperger's syndrome and PDD-NOS, they generally share a number of common characteristics (Attwood, 1998). The diagnostic criteria which define these disorders, and some of the issues surrounding are presented in the next section.

2.1.1 History and development: Autism

'Classic' Autism was first identified by psychiatrist Leo Kanner in 1943 (Frith, 1989). Classic autistic behaviour was described as having a deficit in linguistic and cognitive skills, most likely exhibiting a lack of eye contact with others, social isolation and a lack of communication with others beyond meeting their basic needs. Other symptoms that may be evident in a person include having fixed repetitive interests and routines. Certain motor behaviours such as rocking or arm flapping were noted to have been evident, together with an intellectual impairment. In some cases echolalia - a repetition of sounds or words that have been heard might also feature (Thompson, 2006; Mesibov, Shea & Schopler, 2005; Ciaranello & Ciaranello, 1995).

2.1.2 History and development: Asperger's syndrome

Asperger's syndrome was named after the Viennese paediatrician Hans Asperger who published a paper in 1944 which described a group of people he had been observing that displayed traits which included:

- Poor eye contact
- Lack of empathy
- Naïve, inappropriate one sided interaction
- Little ability to form friendships
- Pedantic, repetitive speech

- Poor non-verbal communication and an impaired ability to interpret other people's actions
 - Intense absorption in a special interest
 - Clumsy and ill coordinated movements and odd postures
- (Attwood 2006, p. 4)

As with 'classic' autism, the degree to which a person with Asperger's syndrome displays characteristic traits of the disorder can vary dramatically and not all traits can be noted in every person.

Formal recognition of Asperger's syndrome has been relatively recent. It was not until 1990 that Asperger's syndrome gained official recognition by the World Health Organisation. Acceptance by the American Psychiatric Association followed in 1994 (Wing, 1991). Both organisations published a diagnostic criterion that recognised Asperger's syndrome as a diagnosis in its own right. The delay in recognition was attributed to Asperger's writings being written in German during World War Two and German literature being given a low standing as a result. Wide spread recognition occurred after they were translated into English in 1981 (Howlin, 2004; Gallagher & Gallagher, 2002) Kanner's work on classic autism on the other hand was rapidly published in reputable journals and became widely read. It was a remarkable coincidence that both men described the symptoms as autism (Wing, 1981).

2.2 Continuum or discrete diagnosis

Due to the marked overlap in symptoms between Asperger's syndrome and Autism there has been debate as to whether Asperger's syndrome is a separate entity from autism or whether it is simply a less severe form. There is speculation in the literature that the American Psychiatric Association may remove the separate diagnostic criteria and classification for Asperger's syndrome and merge it into a single diagnosis of Autism in the forthcoming issue of the Diagnostic and Statistical Manual of Mental Disorders Edition Five (DSM-V) expected in 2013. One reason given for this change is that clinicians have been unable to differentiate between the diagnosis of Asperger's syndrome and 'high functioning autism' or HFA (Miller, 2010).

2.2.1 Aetiology of Autism

Recent studies have determined that autism may have a genetic origin; a study concentrating on familial autism has uncovered possible genetic changes in autistic children that were not present in their parents (Pinto et al., 2010). New research, with the aid of magnetoencephalography, suggests that a delay in the brain's ability to process sounds is implicated. The minute time delays in the processing of sounds are cumulative and the brain becomes overloaded with data (Roberts, Edgar, Zarnow & Levy, 2008). This theory explains why a conversation with someone with ASD can be punctuated by periods of extended silence while the person processes what has been said.

Another recent study had shown that a chemical fingerprint found in autistic children's urine differed from their non autistic counterparts. There is speculation that the findings may result in a simple urine test that could diagnose autism (Yap et al., 2010).

2.3 Characteristics of Autism and Asperger's syndrome

Many of the characteristics of ASD manifest in ways that impact on individual or family functioning. This can result in a particular set of support needs for the person with ASD and their family and wider support network.

2.3.1 Autism

A person with autism may display some of the following characteristics among others:

- Avoid or have poor eye contact
- Have no speech or use a limited vocabulary or repeat phrases that have been heard (echolalia)
- Flap hands or rock themselves repeatedly
- Display self injurious behaviour such as banging the head against a floor or wall
- Be aggressive or anger easily
- Be resistant to change and or become angry when there is a change to their daily routine
- Line up toys or other objects in a particular order

- Display inappropriate behaviour such as removing clothes in public or touching people inappropriately
(National Autistic Society, 2011).

A ³diagnosis of Autism requires particular diagnostic criteria, listed in the DSMIV-TR, to be fulfilled (A.P.A., 2000). In New Zealand, this diagnosis can only be given after an assessment has been undertaken by a registered psychologist or a psychiatrist. Therefore access to suitably qualified and experienced professionals is a critical step in the process.

While Autism is characterised by impairment across three main domains (impaired social interactions, restricted and stereotyped patterns of behaviour, interests and/or activities AND communication), Asperger's syndrome is characterised by impairment across two domains

³ To be given a diagnosis of Autism a person must demonstrate a total of six (or more) items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C)

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

1. Marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
2. Failure to develop peer relationships appropriate to developmental level
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. Lack of social or emotional reciprocity (for example: not actively participating in simple social play or games, preference for solitary activities etc.)

(B) Qualitative impairments in communication as manifested by at least one of the following:

1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
2. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
3. Stereotyped and repetitive use of language or idiosyncratic language
4. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(C) Restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least two of the following:

1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. Apparently inflexible adherence to specific, dysfunctional routines or rituals
3. Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
4. Persistent preoccupation with parts of objects

There must also be delays or abnormal functioning in at least one of the following areas, (social interaction, language, symbolic or imaginative play) with an onset prior to age 3 years. The issues cannot better be categorised by another Pervasive Developmental Disorder such as Rett's Disorder or Childhood Disintegrative Disorder (A.P.A., 2000).

(i.e. impaired social interactions and restricted and stereotyped patterns of behaviour, interests and/or activities).

2.3.2 Asperger's syndrome

It could be argued that the difference between autism and Asperger's syndrome is the degree of severity of the behavioural manifestations. A principal difference between the two is that a person diagnosed with Asperger's syndrome is often more verbal.

With a diagnosis of Asperger's syndrome there is no clinically significant delay in language, cognitive development or in the development of age-appropriate self help skills, adaptive behaviour (other than in social interaction) and curiosity about the environment. Again the diagnostic criteria are clearly specified in the ⁴DSMIV-TR (A.P.A., 2000) and must not be better accounted for by another specific Pervasive Developmental Disorder or Schizophrenia.

There is a range of behavioural manifestations of Asperger's syndrome and some of these are outlined in the coming section.

2.3.2.1 Special interest areas

It is relatively common for a person with Asperger's syndrome to have developed one or more areas of interest that they fixate on. Special interest areas can be found in people right across the

⁴ According to the DSMIV-TR (A.P.A., 2000), 'Asperger's syndrome' is characterised by:

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

- (A) Marked impairments in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
- (B) Failure to develop peer relationships appropriate to developmental level
- (C) A lack of spontaneous seeking to share enjoyment, interest or achievements with other people, (e.g. by a lack of showing, bringing, or pointing out objects of interest to other people)
- (D) Lack of social or emotional reciprocity

(II) Restricted repetitive & stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:

- (A) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (B) An inflexible adherence to specific, non-functional routines or rituals
- (C) Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements)
- (D) Persistent preoccupation with parts of objects

Further, the disorder must cause disturbance or clinically significant impairment in social, occupational, or other important areas of functioning.

Autistic Spectrum and the range of areas of interest can be just as diverse as the people themselves: Computers are a popular interest as are collections (Mayor, 2008; Chen et al. 2003).

One study, of 26 parents and guardians of people with Asperger's syndrome, by Winter-Messiers (2007) examined how the special interest area could be integrated into school and home life. Issues related to areas of interest in the study that were included were:

- The developmental history of the special interest
- Family history of similar interests
- The amount of time spent pursuing the interest
- The impact on other family members
- Ways which carers supported the interest
- Carer's attitudes and beliefs about the child's special interest

(Winter-Messiers, pp 141-152, 2007).

This author found that participants demonstrated extensive professional knowledge related to their special interest area that was far beyond that expected for their chronological age. Despite their 'expert knowledge', all participants were found to be reluctant to talk about their special interests due to a fear of rejection from peers. Critically, this author also found that participants used the special interest as a focus and as a means to self regulate stress, anxiety, frustration and as a means of calming themselves (Winter-Messiers, 2007).

2.3.2.2 Benefits of special interest areas

Some benefits were noted by Winter-Messiers, (2007), these ranged from emotional benefits to more physical benefits such as enhanced fine motor skills to illustrate Winter-Messiers point: improvement in hand-eye coordination brought about by an interest in fishing. This author also found that reading skills were enhanced because many participants in the study found reading about their interest was a preferred method of gaining information.

2.3.2.3 Negative aspects

In addition to the impacts noted above, some problems could occur in situations when the special interest is not completely appropriate

A boy with Asperger's syndrome with an interest in filling out Lotto forms is an example, he would enter his local news agency and spend time filling out countless numbers of forms. The

newsagent objected to the number of forms being wasted and banned the boy from his shop. Several weeks later, the news agency was broken into and all that was stolen were several thousand blank Lotto forms. It was not hard to deduce that the likely culprit was the boy (Attwood, 1998).

Instances of breaking the law were rare: a person with Asperger's was more liable to be a victim than an offender because of their naivety and vulnerability, which made them easy targets (Attwood, 1998). Little evidence existed that suggested there was any significant association between ASD and criminal offending (Howlin, 2004). The propensity people with ASD have to follow rules and their literal thought, meant that a person with ASD would more than likely follow rules rather than break them (Howlin, 2004). Managing the special interest is one way that problems could be avoided.

2.3.2.4 Communication

Communication with others is an area that can be problematic for the person with Asperger's syndrome. Misinterpretation of what was said can lead to confusion, several reasons could account for this:

2.3.2.5 Body language

Approximately seven percent of the impact of the message in interpersonal communication comes from what is spoken while the remaining 93 percent of the message is the context conveyed via body language (Bolstad & Hamblett, 2000). With these figures in mind, it can be seen that if the nonverbal cues are not picked up or interpreted correctly, the subject could be taken out of context and offence taken. Email discussion groups provide an example when a 'flame war' could erupt through someone misinterpreting the meaning of something someone had said because the visual cues that added meaning were missing.

2.3.2.6 Tone of voice

Speech patterns could also cause some misunderstanding. A person with ASD may exhibit a lack of variation in pitch, stress and rhythm together with a lack of modulation so that speech can have a monotonous or flat sound with an over emphasis on every syllable. Tone of speech can also sound 'formal' (Attwood, 1998). It is possible that to the casual listener, a person with ASD could be thought as being cold, aloof, unfriendly and unapproachable. For example, when a sympathetic response was expected, the tone of voice could convey the impression that the listener did not care when in actual fact, the opposite was the case.

No absolute cause for the speech pattern has been established and not all people with ASD display this quality. However, when this characteristic is present, it is likely that it impacts upon family, school and other social relationships (Ghaziuddin & Gerstein, 1996).

2.3.2.7 Concrete literal thought

Many people with ASD have difficulty in interpreting the exact meaning from spoken language, especially the abstract concepts and idioms, or 'reading between the lines' that are used in everyday conversation. For others with ASD, it might take some time to process the information that was received. If too much information is given at the same time, confusion and frustration might result (Clements & Zarkowska, 2001).

Lack of specificity can be a major source of problems for someone with ASD. Persons with ASD may have a high degree of verbal intelligence, but there was often a lack of understanding of the meaning of language, and the function of communication (Carrington & Graham, 1999).

An illustration being:

He can be so cheeky. And yet it's as if he doesn't know he's being cheeky. The other day I was telling him off and I said, "Are you with me? - You know expecting him to say yes Miss or whatever - and he said", "Well I'm next to you and I'm not with anyone else so I must be with you". "And it wasn't as if he was being jokey; he's like that, very serious it's hard to describe".
(Carrington & Graham, 1999 p. 37)

The teacher's remark showed how the meaning of words can be misunderstood when a literal interpretation was made, had the teacher asked "Do you understand what it is I am saying?" instead of "Are you with me" the child would have been more able to provide a more appropriate response.

2.3.2.8 Sensory issues

About 40 percent of people with ASD have some intolerance towards sounds, light, textures, smells or tastes that could lead to behavioural issues (Clements & Zarkowska, 2001; Attwood, 1998). The issue of sensory intolerance can have a significant impact on the day to day functioning of the person with ASD and their family, for example: a young child became suddenly and inexplicably upset. After an investigation, it was found that someone had switched on an electric hand dryer at the other end of the corridor to where the child was located. While the sound was almost imperceptible by others, the child perceived the sound as too intense (Attwood, 1998). Routines are a further characteristic of ASD.

2.3.2.9 Routines

For someone on the Autistic Spectrum routines are used as a means of maintaining order and predictability (Attwood, 1998). Development of structure and routine is frequently acknowledged as an essential component of parenting a child with ASD and to lessen stress within the family (Larson, 2006). Distress caused by any change in routine was seen as an additional impact on family members. Regular educational activities such as a ‘mufti day’, cultural day, or school camp can pose difficulties as can family events such as birthday parties or unexpected visitors (Attwood, 1998).

2.3.3 Pervasive Developmental Disorders

The third area to comprise the Spectrum of Autistic Disorders is the category of Pervasive Developmental Disorders -Not Otherwise Specified (PDD-NOS). This is a term used to describe individuals who do NOT meet the full criteria for either Asperger’s syndrome or Autism (DSMIV-TR (A.P.A., 2000). It is often used to describe a person who has clear features or patterns of the disorder but their symptoms are milder and do not reach the threshold for the diagnosis. It is also used to classify an individual who might have symptoms in one area (e.g. impairment in social interaction) but none in another area (restricted repetitive behaviours) and thus not meet the full diagnostic criteria. With a diagnosis of PDD-NOS there is still an expectation that there is severe impairment in social interaction associated with disrupted verbal or non-verbal communication or restricted, repetitive behaviours.

2.4 Summary

The Autistic Spectrum in its different guises can be a difficult concept to understand, because of the varied array of symptoms that may be presented. While it is accepted within the psychiatric and psychological fields that ASD is not a disease or a sickness, it is not contagious, nor can it be contracted via the environment (Dunlap & Bunton-Pierce, 1999); many myths and stereotypes prevail. Contemporary understanding is that Autism Spectrum Disorder is a neurodevelopmental disorder that affects the brain’s ability to process information. It affects all aspects of psychological development and manifests in different ways throughout the life course (Frith, 1989). The relationship between earlier explanations, including attributing the onset of ASD symptoms to family-related (and particularly mother-related) factors and impacts on families are explored in Chapter 4.

The degree of impairment and the symptoms displayed vary across people with ASD and because of this people diagnosed with this cluster of disorders present differently and require different types of support and intervention. Understanding the diverse needs of individuals (and their families) with an ASD diagnosis is a focus of this research. Next, in Chapter 3, the provision of services for people with ASD in New Zealand is considered.

Chapter 3

Genesis of Autism Services in New Zealand

The inaugural World Autism Awareness Day April 2nd, 2008 saw the New Zealand Government release a seminal document. The '*Autism Spectrum Disorder Guideline*', the publication was a world first in service provision for people with Autistic Spectrum Disorder and sets out procedures that should be followed by professionals responsible for the care of people on the Autistic Spectrum (Carter, 2008).

This guideline was a long time in the making. Some ten years earlier, a report entitled 'Autism Services in New Zealand' was published in 1998. This report followed an inquiry into the circumstances that led to the death of Casey Albury-Thomson. Casey's mother, Janine, was convicted on a charge of manslaughter (Ministries of Health & Education, 2008). Janine's trial attracted media attention where the circumstances that led to her death were outlined. As the Albury-Thomson story, legal trial, and subsequent inquiry were the catalyst of the development of autism services in New Zealand, it is helpful to consider the story of this family as a platform for this research.

3.1 The Albury-Thomson case

Testimony presented in the Court of Appeal outlined some of the circumstances surrounding the Albury-Thomson case (R v Albury-Thomson [(1998) 16 CRNZ 79]). It was asserted that Casey was almost impossible to live with, her behaviour was destructive, she would frequently rip her clothes (often exposing her body in public), bedding, or furniture covers. Her toilet habits were poor, she would urinate wherever she was and it was suggested that she would do so deliberately, whenever she was asked to do something she do not wish to do. It was also stated that Casey's sexual behaviour was inappropriate and that she would often masturbate in public or touch the genitals of males who were around her. Casey was noisy and often chanted repetitively, she would bite people around her and mealtimes had to be supervised because of her very large appetite (R v Albury-Thomson [(1998) 16 CRNZ 79]). An impression was created of a child, and then young woman, who required constant, intensive parenting and supervision.

For approximately 38 weeks a year, Casey resided at Hohepa home in Napier, and a limited amount of respite care was provided by ⁵Intellectual Handicapped Children's Society's Woburn House in Palmerston North when Casey was not at Hohepa (Morgan, 1988). It was during a break from Hohepa that Casey was expelled from Woburn House because the staff could not cope with her behaviour (Evening Standard, 9/7/98 p.2). Upon receiving the news of Casey's expulsion her mother tried unsuccessfully to have her admitted early to Hohepa. Her request was refused because they had insufficient staff available. Child Youth and Family Services (CYFS) were approached but, as Casey was over 17 years old, they declined to assist (Morgan, 1998). With no residential care options available, Casey returned to the family home.

When Janine Albury-Thomson testified at her trial, she provided the following account of the situation which ended with her killing Casey. She said that in the two weeks prior to her death, Casey's behaviour was 'completely over the top' she explained "*it was absurd and ridiculous not really describable. It was like living with a wild creature that was not chained*". Janine added that after Casey turned 17, her level of control dropped to below that which it had been when she was aged three years old. Her ability to look after herself diminished together with a reduction of her verbal skills (R v Albury-Thomson [(1998) 16 CRNZ 79]), Casey was noisy and often chanted repetitively, she would bite people around her and mealtimes had to be supervised because of her very large appetite (R v Albury-Thomson [(1998) 16 CRNZ 79]). Janine Albury-Thomson then described the events that occurred immediately before she killed Casey. She said that on that night, Casey would not stop chanting and the noise kept the family awake. It was during this time, Janine reported, that she decided to kill her daughter. Janine Albury-Thomson said that she initially tried to make Casey jump off nearby Aorangi Bridge. Casey did not comply; they returned home, and it was on the way back that the decision to strangle Casey was made (Morgan, 1998).

Janine Albury-Thomson was convicted of killing her daughter Casey in the Palmerston North High court on July 31st 1998. She was convicted on a charge of manslaughter and was sentenced to four years imprisonment (R v Albury-Thomson [1998] T 37-97). The sentence was later reduced to 18 months by the Court of Appeal (R v Albury-Thomson [(1998) 16 CRNZ 79]). When passing sentence, the judge asked for an independent inquiry into the level of support the Albury-Thomson family had received. The judge's motivation for calling for the inquiry was to assess whether or not a lack of government funding or administrative failures contributed to Casey's death (R v Albury-Thomson [(1998) 16 CRNZ 79]). The judge's request was rejected by

⁵ Now known as IDEA services

the Health Funding Authority because it said it had already made significant changes to the way support services were allocated to families of children who had severe disabilities (Green, 1998). The then Health Minister the Honourable Bill English later announced that an inquiry into autism services would be carried out (Evening Standard, 28/8/98. p.9).

3.2 The Inquiry into Autism services in New Zealand

The inquiry into autism services in New Zealand began in 1998. The inquiry was commissioned under Section 47 of the Health and Disabilities Services Act 1993 and was undertaken by Emeritus Professor of Psychiatry John S Werry. The inquiry reviewed the clinical management of Casey's care and broadly examined services that were available for people with ASD and their families generally (Ministry of Health, 1998).

The Autism Services in New Zealand inquiry reported that there were a number of areas where there were deficiencies in care in the Albury-Thomson case. These included an unacceptable delay in Casey's autism diagnosis and a finding that services that were provided were more appropriate for a person with an intellectual disability rather than autism. In addition, the inquiry found that as no agency had sole responsibility for people with autism there was a lack of coordination of care. Agencies that did work with the Albury-Thomson family did not communicate between one another (Ministry of Health, 1998).

The subsequent Autism Services report made a number of recommendations, including the need for health professionals to be better skilled in diagnosing autism, and an improved level of inter-agency communication. Responsiveness to the needs of the individual and their family was acknowledged as a critical factor, and early access to interventions was seen as a priority together with implementation of behavioural management systems and provision of adequate respite care.

The fact that autism was a lifetime disability was recognised when support for the elderly parents of middle aged children with autism living at home was recommended. The report also acknowledged that siblings of people with autism also need support (Ministry of Health, 1998). However, it was recognised that the degree of support given had to be variable because no two people with an ASD were affected in the same way (Ministry of Health, 1998).

As noted above, the lack of inter-agency cooperation was an area highlighted by the Autism Services in New Zealand report. A recommendation was made that the Ministry of Health became the lead agency on autism and that case management be co-ordinated across agencies that were involved with the disorder (Ministry of Health, 1998).

Some barriers to obtaining services were identified in the report, as was the multiplicity of support agencies that were involved in service provision. The lack of an autism lead agency was considered a barrier because it meant that service gaps between Child Youth and Family Services, Special Education Services and the Health Funding Authority (HFA) occurred (Ministry of Health, 1998). An advantage of improved communication between these three agencies would mean that the procurement of funding would be simplified because the HFA would be 'in the loop'.

3.2.1 Additional barriers

As support organisations supply services to people with ASD from their existing range of services, no specific funding was targeted to respond to the unique needs of people with ASD. An impact was that organisations had to fund services from their existing operational budgets. The inquiry noted that more funding was required across all sectors that provided services to people with ASD but acknowledged that there was little prospect of funding being provided.

As previously mentioned, based on its findings, the Inquiry recommended that a lead organisation be appointed which had the responsibility of coordinating the services that were available so that the best use could be made of existing services and the funding that was available. Additionally, the inquiry noted that clients perceived some service providers were being more focused on clarifying boundaries of service provision than they were in providing actual support services.

3.2.2 Recommendations

The Autism Services in New Zealand report took a global approach to service issues. It recommended that tertiary institutions that provided autism training reviewed their procedures; especially diagnosis. The report also recommended in-service training should be provided to workers in health, education and welfare organisations, to improve their knowledge and

practices relating to autism. The lack of uniformity of needs assessment services around New Zealand was noted and it was recommended that these services be administered equally throughout the country (Ministry of Health, 1998).

A lack of cooperation between service agencies was identified as an issue by the Inquiry. The lack of inter-agency cooperation can be traced to the early 1990s, the neo-liberalist National Government elected to office in November 1990 restructured health policy. Among the changes was the decision for the state to retreat from the provision of services in favour of contracting services to community based Non Governmental Organisations (NGOs) (Cheyne O'Brien & Belgrave, 2000).

The idea was that a split between funder and provider would enhance service provision and reduce costs (Walker, 2004). As a result, the NGOs were required to bid for contracts to perform services. The government believed that with NGOs offering services, the community would have a greater choice of service provider and that services would be delivered at a less cost to the government (Ashton, 1992).

However, an impact of the contracting environment was that the NGOs began to operate on a business model with accountability for performance and expenditure (Cribb, 2006). As the NGOs had to compete with each other to be awarded contracts, there was little contact between agencies to prevent the likelihood of sensitive commercial information being released to competitors (Stansfield, 2001). The lack of connection and collaboration created within this environment may have compounded the issues faced by the Albury-Thomsons and other families in similar situations.

To overcome the lack of cooperation between agencies Autism Services Interdepartmental Working Group (ASIWG) was established to implement some of the recommendations of the Autism Services in New Zealand report (Ministry of Health, 1999).

The Autism Services Interdepartmental Working Group comprised of representatives from Child Youth and Family Services, Ministries of Health and Education and Specialist Education Services. The objective of the group was to:

- Develop and strengthen inter-agency protocols and practices for a seamless provision of services and the provision of effective safety nets

- Address the service gaps in the support of children and adults with an ASD
- Establish a clear leadership role for the coordination of services for people with ASD and their families
- Address a lack of awareness of ASD issues across professional groups (Ministry of Health, 1999, p1)

An update on the group's activities in May 2000, announced a change of direction of their focus to professional workforce development, research service delivery and to play a role in inter-agency cooperation. While the ASIWG recognised that while there was still some way to go before services to families with someone with ASD had been achieved, it was thought that services would be better provided by existing mainstream organisations rather than the creation of a dedicated agency. The ASIWG was disbanded in December 2000 (Ministry of Health, 2000).

3.2.3 Post inquiry environment

Nine years after Casey's death, a report in the Manawatu Standard newspaper suggested that little had changed for families in New Zealand. An Autism New Zealand Manawatu branch member was quoted as saying that while the Albury-Thomson case was headline grabbing and impossible to ignore, she was watching family tragedies all the time where marriages broke up or people had accidents caused by exhaustion. The main problem, she said, was a lack of funding and parents had to haggle for inadequate support services (Rankin, 2006).

A further example was when the parents of a 14 year old boy with ASD had to make a care and protection notification to CYFS because the family was unable to cope with the boy's increasing level of violence. They had previously tried to get help but were repeatedly told that the boy's condition was not bad enough or, that waiting lists were too long (Hill, 2006).

There are similar stories, Whitworth (2005) speaking in her capacity as Chief Executive Officer of Autism New Zealand addressed a carer's workshop in 2005, she outlined her own experiences. She told the gathering that she had three sons who were on the Autistic Spectrum. Each of them was affected to a different extent. One of her sons required twenty-four hour care and while explaining this to the needs assessor, she was promptly told the service she required was only available in cases where the carer died, or suddenly became incapable of providing care. Whitworth added that this was an example of a needs assessor not understanding the

impacts of ASD. She concluded her speech by citing an example of where a mother with cancer failed to access respite care despite the fact of her telling the needs assessor that she was being held together by bits of titanium as well as being wheelchair bound. Being able to receive an appropriate diagnosis has continued to be an issue.

Lack of professional awareness of ASD symptoms has been an issue. Matthews (2007) indicated that a boy had to be examined by two specialists before finally arriving at an ASD diagnosis, it was also not uncommon for the medical profession to be unhelpful and frequently, a paediatrician would make a diagnosis but would not offer any guidance as to what to do next except to sign a form to receive a \$27 a week allowance from the government (Matthews, 2007). Aside from the 1998 Autism Services in New Zealand report, there has been little research into the impact ASD has on an individual or family. The Autistic Association of New Zealand commissioned an inquiry into the state of services for people with ASD in 2001.

3.3 Autistic Association of New Zealand research project (2001)

In an effort to overcome a lack of information about the experiences of people with autism and their families, a research project was commissioned by The Autistic Association of New Zealand. The 2001 project examined many areas of support, ranging from obtaining an appropriate diagnosis, to home support. In total, 932 families were surveyed. Ninety five per cent of families had only one member with ASD while the remaining five per cent had more than one member. In total, 979 individuals were represented by the survey. A lack of support was a New Zealand wide problem and the quality of services that were provided was shown to vary from place to place. Some of the main problems the report identified were:

3.3.1 Diagnosis

The degree of difficulty the parents encountered showed a lack of knowledge existed throughout health, welfare and educational services. Two participants to the Autism New Zealand research project detailed their experiences when dealing with the medical profession:

A prominent psychologist (in his words) asked him (my son) to touch his nose with each finger, walk a few paces and then pronounced he did not have autism (Autistic Association of New Zealand, 2001, p. IV).

While another was told:

Doctor said he is autistic which means that he will never be employed, never be in a long-term relationship but at least, he will never be a rapist (Autistic Association of New Zealand, 2001, p. IV).

Difficulty in obtaining a diagnosis is not helpful because this has to be obtained before any support can be accessed. A needs assessment is the normal method of obtaining support and this will only be carried out if a diagnosis has been made (Life Links, n.d.).

3.3.2 Needs assessment

Of the 786 people surveyed, 63 per cent had a needs assessment done while 29 per cent had not. Comments on the quality of service received varied, one participant was disgusted with the service because no support was supplied while another found themselves locked out of the adult mental health service. In many instances, the needs assessor was identified as a problem because of their lack of understanding of ASD matters (Autistic Association of New Zealand, 2001).

3.3.3 Respite care

The Ministry of Health finances a respite care facility which is separate from the carer support days that are allocated for informal care. Of the total number of people surveyed, 43 per cent had respite care while the remaining 57 per cent did not. The figures show many carers were missing out. A lack of experienced ASD carers was identified as being one reason why service uptake was so low (Autistic Association of New Zealand, 2001). Further research into the level of uptake of respite services has been undertaken.

In a March 2011 study, Autism New Zealand surveyed 2034 of their members to gauge their thoughts about the lack of respite care. Forty seven percent of participants indicated that the respite care available was not adequate. Carer support hours that were allocated were used instead with support being provided by friends of the family or by way of the holiday programmes run by some of the local Autism New Zealand branches. The results of the survey

will be used to lobby the Ministry of Health for the provision of appropriate services (Autism New Zealand, 2011).

3.3.4 Carer support

Carer support is provided in the form of carer support days that are determined by an annual needs assessment. Five-hundred and thirty-seven respondents had been allocated carer support days. The number of days allocated varied from family to family with the majority receiving a twenty eight day per year allocation (Autistic Association of New Zealand, 2001).

3.3.5 Family support

The study found that a main source of family support came from the extended family. This was the case in urban areas; the survey results showed that 63 per cent of respondents received some form of support from family members. However, it was noted that a significant number of families did not have access to other family members because of where they were situated (Autism New Zealand, 2001).

3.3.6 Satisfaction with public services

Respondents were given the opportunity to tell of their experiences they had with public sector services to have their child's needs met. Some of the parents commented:

My son has had to be removed from home because he has tried to smother his baby brother and thrown knives at me. Have had no support in trying to cope with this behaviour.

Only now after three years of fighting, our son's needs were recognised.

He was kicked out of school, he was getting bullied and teased and the school could not cope. The police caught students but still the school would not do anything.

She leaves school this year and IHC would not work together (with other agencies) to do a transition plan

Completely dissatisfied, total lack of support in my area ... public services do not exist. Compared to other countries, New Zealand absolutely appalling, seriously considered emigrating to Australia or England.
(Autistic Association of New Zealand, 2001, pp. 34-39).

2.3.7 Work and Income

Respondent's experiences with Work and Income varied. The impression that many had was that Work and Income case managers were unfamiliar with the issues involved when a family member had ASD. Some respondents were left with the impression that as their case did not fit into a black and white category, no support would be forthcoming. When approaching one of its caseworkers, one respondent was informed their child did not have autism (Autistic Association of New Zealand, 2001).

The findings of the 2001 Autism New Zealand study went on to inform the more recent 2008 inquiry into the quality of care and service provision for people with disabilities.

A parliamentary inquiry into the quality of care and service provision for people with disabilities conducted in 2008 heard that people with ASD were still unable to obtain funding for support unless they had a dual diagnosis of a mental health condition. It was also noted that there was a service gap for some people with ASD. The parliamentary inquiry also noted that improved services would be developed via the 'New Zealand Autism Spectrum Disorder Guideline' that had just been published (Social Services Committee, 2008).

2.4 'New Zealand Autism Spectrum Disorder Guideline' (2008)

Published in April 2008, the 'New Zealand Autism Spectrum Disorder Guideline' is in response to the 1998 Autism Services in New Zealand Report that found gaps in service provision existed. The guideline is designed to assist health professionals to make decisions surrounding the care and education of persons with ASD. The guideline is intended to cover the identification and diagnosis of ASD and to inform decision making that will improve outcomes for people with ASD. The guideline is evidence based, each of the recommendations have been supported by research and will be implemented on a regional or national level. The main areas the guideline focuses on are:

- Initial assessment of children, young persons and adults with ASD
- Focus on how best to provide support services
- Educational interventions
- Management of behavioural emotional or mental health issues that may be present

- Community support needs including educational or transition to adulthood
- Unique needs of Maori or Pacific peoples

(Ministries of Health and Education, 2008, pp. 34-49)

In the first two years since the guideline was published, there has been progress in the rolling out of support services for people with ASD. As of June 2010, the Ministry of Health announced a set of priorities that will see the guideline implemented that will cover assessment and diagnosis, support to strengthen families, interventions, respite care and service coordination. The Ministry of Health reported that progress to date has been made in the following areas:

Diagnosis

Targeted information has been provided to professionals in education, health and disability areas that assist with improved diagnosis protocols together with an improved timeliness of diagnosis. The information will be provided in the form of a web-based service that will cover recognition and referral of persons with a suspected case of ASD.

Information services

Five projects are currently underway that are designed to improve dissemination of information on ASD, a website *Altogether Autism* (www.altogetherAutism.org.nz) has been established to improve information and advisory services to both families and professionals.

Parent education

The Ministries of Health and Education will implement a number of educational initiatives that include programmes that are intended to improve parent's knowledge of the impacts of ASD. Parents of younger children will be targeted to assist parents with their child's communication and social skills.

Tips for Autism

A training course will be run by the Ministries of Health and Education that will provide teams of parents, carers and school teachers with skills and practical knowledge to support children between five and twelve years of age.

Interventions: ASD-specific communication and behaviour support services

The Ministry of Health has contracted Intellectual Disability Empowerment in Action (IDEA) Services to deliver ASD-specific communication and behaviour support services in the Auckland area. Following a trial in the Auckland area, the programme will be rolled out nationally. The service will be available to children and young people up to 21 years of age.

Respite Care

Respite care facilities for people with ASD or an intellectual disability have been established or are in the process of being established in a number of areas of New Zealand. A Respite service exclusively for people with ASD is being considered by the Ministry of Health.

Service Coordination

Following a review of their needs assessment procedures for working with people with ASD, the Needs Assessment Service Coordination Association Incorporated (NASCA) has made changes to existing protocols to bring them in line with the autism guideline. (Ministry of Health, 2010, pp. 1-12)

3.5 Summary

The Albury-Thomson case highlighted the level of support that was available for persons with ASD and their families. The accessibility of respite care was identified as an issue that needed to be addressed. As the court case unfolded, it was shown that a lack of experienced respite care workers existed who could deal with Casey's behaviour. It was also shown that the support that was available was not available on a year round basis because of its linkage with school terms. Casey's age (17 years) also presented a problem because of the crossover from children's to adult's services. Had she been younger, CYFS would have been available to locate respite care.

The parts of the guideline that have been or will be implemented have been based on the most important needs that were identified in the Autism Services in New Zealand report. Diagnostic delay, a lack of focus on ASD by existing agencies, a lack of appropriate respite care and cooperation between support agencies that are involved with a family were some of the issues that were identified as needing clarification. The next chapter explores some of these family-related issues in more depth.

Chapter 4

Family Matters

News of an ASD diagnosis may be a surprise for some parents, whereas for others the diagnosis may confirm the parent's suspicions that something was amiss with their child. It is natural for people to be interested in the cause of the problem or issue they are confronted with and families of children with ASD are no exception to this.

Speculation has surrounded the cause of autism since it was first identified in the 1940s (Hill & Frith, 2003). Early work on the aetiology of autism and related disorders focused on parenting and it was postulated that the behaviour and emotional detachment of a child's mother was a significant causal factor in the child developing the disorder. More recently, as noted in Chapter 2, autism has been acknowledged to be a neurological disorder and the previously popular 'mother-blaming' theories have largely been rejected. However, a sense of responsibility is frequently retained by parents of a child with ASD and this is one of the significant impacts on parents parenting a child with this diagnosis.

4.1 Impacts on parents

Raising a child with an Autistic Spectrum Disorder can evoke a range of emotional and psychological responses from parents and impact on most areas of a family's everyday functioning. Research has been undertaken that examines how families cope after a diagnosis of ASD has been received. Impacts can be contained at the parent/caregiver level or encompass the whole family, including the extended family. The impacts may be financial or involve a change in living location to accommodate the child's special needs (Kogan, et al., 2008). Ultimately, the family may implement a range of different coping strategies to mitigate these impacts (Dale, Jahoda & Knott, 2006). The purpose of this chapter is to examine some of the impacts that can occur and consider the implications of these for informal and formal supports for family members.

4.1.1 Early diagnosis and intervention

An ASD diagnosis can open pathways to support services that the family and child may require and as noted in Chapter 2 a needs assessment provides parents with a means of accessing such support. Before this can happen, of course, a diagnosis must have been made (⁶Life Links n.d.). An early diagnosis can immediately increase the support the family has access to and increase the likelihood that interventions will be put in place that may improve the child's prognosis.

Research has shown that with early intervention, between one and six years of age, there is an increased opportunity to maximise potential and skills and therefore a greater possibility that an autistic child's level of functioning could improve (Gray, 2006; McConachie & Diggle, 2006; Valente, 2004; Baird, Cass, & Slonims, 2003). These researchers raise important issues about timely access to intervention and services, but the pressure on family to seek and deliver these interventions needs to be acknowledged.

A unique set of challenges can be faced by parents when raising a child with an ASD diagnosis, such challenges can range from psychological adjustment, to coordinating, advocating for and making decisions and plans for, possible treatments (Wachtel & Carter, 2008). Organisational skills could become a critical skill set for parents endeavouring to integrate the autistic child's requirements with that of other family members without losing sight of their own needs.

Early intervention that targets the child and the parents has the potential to increase access to supports, facilitate skill development and lessen potential impacts on the entire family. These impacts, in their various forms, have been of interest to numerous researchers: They range from impacts on family members to society as a whole. A number of these will now be outlined. Psychological impacts will be the first area discussed within this chapter.

4.1.2 Psychological impacts

While a diagnosis of ASD is critical on many levels, it can still be a distressing and an isolating outcome for parents. Parents need the opportunity to accept the ASD diagnosis given to their child, take in the new information that has been provided to them, and to adjust to the contextual changes that may need to occur within the family (Wachtel & Carter, 2008).

⁶ Life Links is a company contracted by the Ministry of Health to provide needs assessment services

Once this has happened the parents are able to use the knowledge that they have acquired to explain the child's behaviour to others, thereby assisting with the child's social integration (Attwood, 2000). The process is not always that simple and the parents are often dealing with issues of stigma and the negative effects of labelling as well as their own psychological and affective reactions.

4.1.2.1 Depression

Depressive symptoms are commonly found in parents of children with developmental disorders, (Wachtel & Carter, 2008). Osborne and Reed (2008) have argued that depressive disorders are an outcome of the diagnosis and perhaps the sense of loss that the diagnosis signifies, and that the mood disorder could well be a barrier to the parents' ability to engage fully with their child.

Studies have shown that while rates of parental depression are higher than in families where there are children with no developmental disorder, there is no need for this to be the case and risks may be lowered by the provision of a suitable support network (Brobst, Clopton & Hendrick, 2009; Bromley et al. 2004).

Research has consistently shown that individuals who receive support (material, social and psychological) from significant people in their lives such as parents, partners, friends, and family, experience better physical and psychological health than those with fewer social resources available to them (Lincoln, 2000). People's perception of the social support they have available to them has been linked to individual well-being and research has indicated that it can reduce adverse psychological effects of difficult events (Pottie, Cohen, & Ingram, 2008). However, accessing and maintaining these supports, that buffer stress and enhance coping can be difficult when parenting a child with ASD due to the relative isolation caused by the very behavioural and emotional issues that the parent needs support with. Indeed, it seems likely that many people that would ordinarily form a family's support network may not be a support with parenting a child with ASD because of reduced social contact and potentially, the impacts of stigma, stereotypes, and their own lack of skills to deal with the situation.

4.1.2.2 Stress and social support

A wide body of research suggests that carer stress is by far the most common impact ASD has on a family. Parents of children with ASD have been found to be at an increased risk of experiencing psychological difficulties than their counterparts with children without a disability

(Khanna et al. 2010; Hare, Pratt, Pottie, Cohen, & Ingram, 2008; Burton, Bromley & Emerson, 2004).

In research undertaken among parents of newly diagnosed children with ASD, levels of stress were found to be higher; with a gradual reduction over time. Mothers were viewed as being at a higher risk of developing stress-related mental health problems brought about by their caregiving responsibilities and that could be exacerbated by a lack of sleep caused by either the child with ASD or the parent's stress level (Stuart & McGrew, 2009; Hoffman et al, 2008; Duarte, Bordin, Yazigi & Mooney, 2005). Evidence suggested that stress originated from many sources and could be cumulative in nature (Hoffman et al., 2008; Higgins, Bailey & Pearce, 2005).

The cumulative nature of stress was more evident when the mother was the main source of support. In certain situations, they were described as 'Swiss Army Wives' because of their responsibility for household management, parenting and bringing in a wage (Holicky, 2000). Additional sources of cumulative stress were recognised when it came from various sources such as behavioural difficulties, lack of support or financial impacts (Holicky, 2000). An important ingredient in the lessening of any impacts was the provision of supports (Stuart & McGrew, 2009). Supports may be seen by parents in a number of ways. For some, supports may be seen as a necessary means of maintaining family coherence or in others, the supports may have a fallback role (Bromley et al., 2004). Some research into the role that social support played has been undertaken.

Informal supports, such as those obtained from peer support groups, have been shown to be as important as that received from formal sources (Mandell & Salzer, 2007). Support groups provide an opportunity for emotional support, a source of information about available services, and normalising parent's experiences. Out of more than a thousand parents surveyed by Mandell and Salzer (2007) two thirds of the survey respondents had participated at one time or another in an autism specific support group.

In some instances, stress levels could be reduced if there was a perceived knowledge that help was there if it was needed. In one study of 31 women it was found that a perception that support was available if needed, reduced stress levels in a similar manner to a situation where the support was actually used (Duarte, Bordin, Yazigi, & Mooney, 2005).

The research reviewed has highlighted that parental and sibling stress can be a factor in some families and that where supports were put in place, families were in a better position to cope in a stressful environment. Where support was perceived to be available stress levels had been reduced too – even if the person did not actually use the supports.

Other than the factors highlighted in the Albury-Thomson case and subsequent report, we know little about the particular support needs of parents of a child with ASD. For instance, the support needed or sought from family members, social workers, specialist therapists, schools and education providers, and others might be quite different. If families are to be resourced practically and psychologically, then information about what is perceived as helpful to them during this process is important. Social workers have been identified as being in the best position to locate support.

Social workers are in a position to help locate the services that a family needs and would be best placed as a member of a multidisciplinary team that worked with the family to meet the family's needs (Karande, 2006; Preece & Jordan, 2006; Newsome, 2000). Help with understanding the emotional impact that could occur on the family may be necessary (Gray, 2006). Part of the understanding could be the knowledge of the role that grief played during the period of adjustment after a diagnosis has been received.

4.1.2.3 Grief and loss

Studies have shown that following the discovery that their child has serious development problems a sense of grief, sorrow, shock, or denial occurs among parents (Fleischmann, 2004). It seems likely that parents will experience a range of such emotions when a diagnosis of ASD is given to their child. These could range from a feeling of relief that the reason for the child's behaviour was finally known or there could be feelings that paralleled the actual loss of the child (Wachtel & Carter, 2008; Ozonoff, Dawson & McPartland, 2002; Aarons & Gittens, 1992).

Theories of grief and loss generally relate to human reactions to death and dying. While most of this literature focuses on individual responses, there is an unquestionable social dimension to loss and grief. Grief can be a reaction to complex losses that are symbolic (such as the child the parent's dreamed they would have), and unrecognised by friends, family and the community. But grief is not merely a psychological issue. The grieving process after the parents have been told their child had a disability could parallel those experienced if the child had actually died

because the child the parents dreamed of and planned for, cannot exist (Boushey, 2001; Huws, Jones & Ingledeu, 2001).

Doka (1989) has written on the role of society in the grief responses that have been marginalised when there is a failure or unwillingness to acknowledge a real loss has taken place. This could include parents of children with disabilities because of the misapprehension that grief only applies if someone had actually died. Doka refers to grief that is not readily acknowledged or recognised as disenfranchised grief. Disenfranchised grief is based on the notion that societies possess norms for grieving or rather 'grieving rules' that identify 'who, when, how, how long, and for whom' people should grieve.

In relation to parenting a child with ASD, the loss of the 'perfect' child is not visible, recognised, or even considered to be important by many in the wider family or society in general. Doka also argues that disenfranchised grief may develop when the grieving person is not recognised. This could be the case for parents, siblings, and extended family members of a child with ASD. Doka (1989) is meaning that as the loss is perceived rather than physical, society does not recognise the loss as being real. Society has become more aware of the impact of grief associated with less tangible or less obvious relationships and there is increasing agreement that grief associated with the loss is relevant (Corr, 2002). An example Corr uses is when a person is diagnosed with Alzheimer's disease. Because the person's personality has changed, others in the person's life regard them as being psychosocially dead meaning that the personality has died while biological life continues. This example applies to ASD because after the diagnosis, the child still lives and impacts could be even more complicated when the child is higher functioning because of the likelihood of no outward sign that anything was wrong, being evident.

We have seen that grief can result when relationships are lost, or changed in significant ways through the diagnosis of a child with ASD. Enduring this grief, it would seem, can be a long and lonely journey. Research has shown that feelings of grief are long term and the intensity of the grief increased when the parents felt they were unable to manage their child's behaviour (Benderix, Nordstrom & Sivberg, 2007). It seems likely that the emotional reaction triggered after a diagnosis has been given may continue for many years and may be more evident at particular life stages than others.

4.1.2.4 Guilt

Blame, and a related sense of guilt, which in some cases was excessive, occurred where parents held themselves responsible for the child's autism. Guilt had been identified as a common parental emotion after an ASD diagnosis had been received (Valente, 2004). Mothers may, feel guilt for something they may have done during pregnancy such as having the occasional drink or cigarette or a belief that they did not socialise sufficiently with their child while they were younger (Howlin, 1998). Several authors suggest that an understanding of the aetiology of autism can counteract such feelings of guilt and the facilitation of some type of counselling could be useful in allaying the parent's sense of responsibility (Valente, 2004; Boushey, 2001; Howlin, 1998). Early research into the aetiology of ASD (and other problems for children) focused on deficits in the maternal relationship as a causal factor so it is not surprising that there is an enduring legacy of guilt for parents and, in particular, mothers.

4.2 Impacts on the wider family

The level of understanding a sibling had of autism should be considered. 'Telling' the sibling their brother or sister had autism was no guarantee that the information was understood. It was also possible that parents overestimated the sibling's understanding of the implications involved (Mathew, Leong & White, 2002). The type of impact has been found to vary from family to family.

Several studies indicated that the presence of an Autistic child in the family had no adverse effects on siblings (Hastings, 2007; Mascha & Boucher, 2006; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Kaminsky & Dewey, 2002) while within other research a range of impacts have been noted (Orsmond & Seltzer, 2009; Macks & Reeve, 2007; Ross & Cuskelly, 2006; Williams & Wright, 2004; Fisman, Wolf, Ellison, & Freeman, 2000; Howlin, 1998). Impacts on sibling relationships were seen as significant because out of all relationships a person may have during a lifetime, sibling relationships would be among the longest lasting (Orsmond & Seltzer, 2009).

Inter-sibling jealousy brought about by the increased amount of time that parents were required to spend with the child with ASD was seen as an issue. Some siblings thought that their needs were secondary to the autistic child. A source of inter-sibling aggression was property damage or disruption to the non-autistic sibling's activities (Ross & Cuskelly, 2006; Gupta & Singhal, 2005; Williams, Wright & Young, 2004).

In situations where the autistic sibling had significant behaviour problems the inter-sibling relationship was more distant and could be jeopardised (Seltzer, Greenberg & Orsmond, 2007). An additional impact that could affect the whole family was the viability of family holidays brought about by restrictions the child's ASD placed on possible holiday destinations or accommodation (Howlin, 1998). Psychological problems are another consideration that has attracted researchers' attention.

In some situations siblings of an autistic child were seen to have a greater tendency to experience psychological problems such as depression than in a family where there was no disabled member (Hastings, 2003). While in other situations feelings of loneliness and problems with peers were among factors that could lead to a depressive episode (Gupta & Singhal, 2005). In families where there was marital stress there was an increased tendency for sibling maladjustment to occur. However, in instances when parents sought some form of formal support such as counselling impacts were lessened (Rivers & Stoneman, 2003). Not all sibling impacts were negative.

Inter-sibling relationships could be enhanced, when the special interest most people with ASD have could be used for mutual benefit, an example being a pair of brothers who had an interest in chess. The younger brother with ASD always accompanied the older brother to chess matches that the older brother was in because his analytical abilities were a useful tool. A trade off of skills could be used for mutual benefit an example was where an older sister received maths coaching from her autistic brother in exchange for her assistance to overcome the brother's dog phobia (Howlin, 1998). The 1988 movie 'Rain Man' provided a more enterprising use for special interest skills, Raymond's maths ability was used in a Las Vegas casino to count cards in a game of blackjack (Internet Movie Database, 2009). The special interest could also be used as a means of enhancing relationships.

Relationships could be further enhanced by the special interest area especially when the interest was shared (Winter-Messiers, 2007). The special interest could also be used as a means of improving relationships for non autistic family members as well as providing an incentive for the child with ASD to improve their social skills (Boyd, Conroy, Mancil, Nakao, & Alter, 2006). Siblings obtained a higher degree of social competence when they received a high level of social support from family, friends and teachers. Where a child came from a large family,

adjustment was further enhanced (Kaminsky & Dewey, 2002). There is also the possibility that support from outside the family might be necessary.

4.2.1 Peer support groups

The contribution peer support groups have made to family functioning has been recognised. Peer support group membership had a tendency to result in a decreased risk of parents experiencing psychological difficulties or loneliness. Information gathering was another function of the support groups (Kaminsky & Dewey, 2002). Stress levels were also lowered by support group membership (Pilowsky et al., 2004). Peer support groups were shown to improve the family's relationship with the outside world and brought an improved sense of control. A reduction of the amount of guilt and an increase in the level of empowerment were other aspects noted (Solomon, Pistrang & Barker, 2001).

4.3 Financial impacts

The financial impact of ASD can be felt at numerous levels; they may be in the form of an impact upon the immediate family or, felt more widely throughout the community. The diagnostic process proved to be an expensive undertaking when a lack of consensus existed between clinicians regarding how an ASD diagnosis should be reached. A lack of diagnostic capacity of some service providers was seen as a contributor to a family's expenses (Shattuck & Grosse, 2007). As we have seen in Chapter 2, diagnosis inconsistencies occur in New Zealand too. The hidden costs while caring for someone with ASD have been the subject of some studies.

A major 'hidden cost' is the amount of time that is required to care for someone with an ASD, in some families the amount of time was estimated to be in the region of 60 hours a week or the equivalent of a fulltime job (Jarbrink, Fombonne & Knapp, 2003). Using the current New Zealand minimum adult wage of \$13.50 per hour (Department of Labour, 2012) as an example, the effective cost of the unpaid care-giving to the family would be \$810 per week. Some research has been undertaken that extended the costs involved of caring for someone with ASD over the life course.

A European Union study estimated that the lifetime cost of someone with ASD and an additional learning disability to be NZ\$7,280,361 (European Commission, 2005) Assuming that

the average life expectancy of an individual in Western nations is 80 years (WHO, 2008), annual support costs would be in the region of NZ\$91,000 per year. The discussion thus far has taken a more global view. It is now timely to examine some of the costs that an individual family may face to cater for a child with ASD.

The list of needs could be varied which could include adaptations to the house to cater for behavioural issues or other expenses to overcome sensory issues. Some costs could include:

- Special equipment for the child
- Help with housework
- Adaptations to the home
- An actual change of living location
- Special food to cater for dietary needs
- Special bedding to cater for sensitivities to texture
- Replacement or repairs to the home or furniture

(Loynes, 2001 p.10)

Expanding on the food sensitivity issue mentioned above; Loynes (2001) knew of a clinic that charged between \$800 and \$1000 for allergy tests to be done. Additional impacts could occur such as the provision of soundproofing or lighting when it was required to cater for sensitivities to noise or light (Rogers & Ozonoff, 2005). Allergies could also be a consideration. An example being a boy's allergy to dust that necessitated the installation of special air filters (Glucina, 2008). In some situations, a change of residential location may be necessary that could incur additional costs.

A change of residential location could be necessary either to cater for a noise sensitivity or to a location that provided more security (such as moving off a main road) in a case where a child was prone to wander, or a house that provided more space (Glucina, 2008; Hare, Pratt, Burton, Bromley & Emerson, 2004; Loynes, 2001).

Costs of medical care additional to that which was publicly funded could impact on family budgets. In addition to the diagnostic costs outlined previously, there could be wider healthcare costs. Additional medical costs that were not funded elsewhere are common among children with ASD. In families with a limited income, difficulty accessing appropriate services could occur (Kogan et al., 2008). Some families had faced bankruptcy through the necessity to

provide out-of-pocket medical or special education interventions (Sharp & Baker, 2007). Financial issues aside, some families adopt various forms of coping strategies to minimise impacts. Numerous studies have been undertaken that examined how families coped. Some of that research will now be examined.

4.4 Coping strategies

Families may utilise more than one type of coping strategy. Some may use social service agencies while others may use informal avenues such as support groups. Local examples of support groups would be the ⁷Canterbury branch of Autism New Zealand and Autlink.

The steps a family took while adjusting to a diagnosis of ASD could be regarded as a coping strategy in its own right (Glass, 2001). Coping strategies may be used for a variety of purposes, for some families, they may be used to improve family functioning while in others, to reduce stress levels. Coping strategy development played a role in regulating parental stress levels (Gupta & Singhal, 2005). Human service workers that were skilled in providing interventions for families would be in a position to provide significant inputs. Meditation has been seen as an alternative method of reducing levels of stress (Roginsky, 2008). It should be noted that the type of strategy adopted would depend on the context of the situation at the time (Hastings, Kovshoff, Brown, Eespinosa, & Remington, 2005; Gray, 1994). Flexibility was seen as a key ingredient regardless of what strategy was chosen (Gray, 1994). Family composition has been also been the subject of research in relation to ASD.

4.4.1 Family composition

Family composition has been studied to see if this caused a variation in a family's coping ability. Family composition and the effect this had on a family's ability to adapt was viewed as a useful tool that assisted with adaptability and cohesion when compensating for the needs of a child with ASD . In families where there was a lack of cohesion, it was found that there was an impaired ability to cope with the demands of individual family members (Orsmond, Lin & Seltzer, 2007).

⁷ A description of the services these organisations provide can be found in Chapter 9

4.4.1.1 Avoidance

One could assume that when coping strategies were in place, a family would be in a more favourable position to function and that a reduction in the amount of stress would be achieved. The forgoing assumes that any problems that developed were dealt with. In some situations, families have chosen to avoid the problem rather than confront the issues. Impacts caused by avoidance have attracted some research attention. Families that utilised avoidance as an escape strategy reported more negative impacts and a decreased ability to cope with a changing environment (Hastings et al, 2005). A useful source of information could be obtained by networking either formally or informally.

4.4.1.2 Networking

The support groups attached to a number of local branches of Autism New Zealand can be seen as an example of an informal network. Networking is a valuable resource whether a network is a formal entity made up of service workers that worked with the family or an informal group of people that had similar backgrounds (Folgheraiter, 2007). Membership of parent support groups is a means of swapping different coping ideas or as a means of gaining information surrounding access to different social service support schemes (Luther, Canham & Cureton, 2005). New ideas that stemmed from membership of a parent's support group may also offer some assistance to families. Arguably, networking is a useful tool if a family is looking for other ideas to improve the manner in which the family functions.

A conclusion that can be obtained is that adaptability has been shown as a means of improving the level of family functionality. In situations where a family has been able to adapt to their changing circumstances, a higher level of functioning and a lowering of stress levels had been reported. Networking has been shown to be a useful tool for families to learn from others about other coping mechanisms. The research reviewed has shown that where families had been proactive in their approach to ASD, overall functioning had improved. How families have coped over time has also been of research interest.

4.4.2 Coping strategies over time

While much 'real time' research exists that examines how families cope in the present, there is little that has shown how families have coped over time. Gray (2006) addressed this knowledge lack. A study was undertaken that involved 26 families who resided in the Brisbane region of

Australia between 1988 and 1990. A follow-up study occurred between eight and ten years later that involved the same subjects. All the families contained a member or members with ASD whose ages ranged from four to 19 years. In the initial study, all but two lived at home while the remainder resided in residential placements. A follow-up study that occurred between eight and ten years later involved the same subjects.

In the follow-up study, coping strategies had changed together with parents' reliance on and use of formal support services. Parents' attitudes towards the support offered changed. A contributing cause of the reduction of service use was the service provider's gradual change of focus from children with autism to enrolling more children with Asperger's syndrome. The amount of reliance placed on informal support received from the extended family had also decreased. In situations where the child's public behaviour had improved, a family's social life had improved correspondingly and this had resulted in a lessening of social isolation. One coping strategy that remained constant was the parents' religious beliefs and for some, this had become their main source of coping after coming to terms with the permanency of ASD (Gray, 2006).

An eight year longitudinal study by Scorgie and Wilgosh, (2008) recorded similar findings. Rather than leaving support groups, members of the sample group remained active members. The purpose of the membership had changed from learning from the group, to teaching parents of newly diagnosed children. Similar to Gray, (1996), the amount of support received from the extended family also reduced mainly due to the death of family members. Marital relations had suffered and in some families the marriage had ended in divorce. Siblings had begun to play a larger support role and in some cases, arrangements had been made for adult siblings to become the future primary guardian.

These studies have shown that coping strategies evolved over time: using support groups as a means of gathering information after the diagnosis had been received was a strategy parents found useful. As families adapted to their new situations, the experience gained enabled families to cope with a reduced amount of support from outside. Membership of support groups either declined or the parents' role changed from that of learner to that of teacher. In some families older siblings took on care-giving roles and in some cases arrangements had been made for them to become testamentary guardians.

4.5 The ‘empty nest’

In some situations ASD symptoms abated with age, given suitable support, the possibility of a person with ASD living independently could be enhanced (Seltzer, Krauss, Orsmond & Vestal, 2001). Benefits resulting from the child with ASD living apart from the family can be two-fold, the child could learn new skills and capabilities and for the parents, relationships with other family members improved, in some cases marital relationships had also improved (Krauss, Seltzer & Jacobson, 2004). Determining the ideal form of accommodation has been of research interest.

As part of a submission to the Australian Government, Carers New South Wales reported a study into accommodation needs it undertook. It was found that outcomes for people with developmental disabilities could be enhanced if the accommodation provided was of a small scale rather than large scale as provided in an institutional setting (Carers NSW, 2005). In another accommodation study, provision of suitably qualified staff was seen as an issue together with the provision of sufficient activity programmes (Krauss, Seltzer & Jacobson, 2004). Small scale accommodation could be in the form of the group homes that are similar to those that are operated by various New Zealand NGOs.

In families where the son or daughter with ASD had left home, a period of readjustment occurred. Morrell writing in Morrell and Palmer (2006) gave an account of her experiences. She thought that planned obsolescence was part of the job of parenthood and that this had become obvious after her two⁸ neurotypical sons left for college. She was not prepared for her son with ASD to leave home. The thought had never occurred that there would ever be a ‘right time’ and that she was overwhelmed at the prospect of having him live some place else (Morrell & Palmer, 2006). Faced by the realisation that future care provision had to be made for his long term care, the journey through the confusing and fragmented world of adult ASD services began. As her son was interested in the outdoors, a residential farm programme was selected (Morrell & Palmer, 2006).

An impression gained from this review of research is that the possibility for some people with ASD to live independently in the community existed and that when this had occurred,

⁸ ‘Neurotypical is a term adopted by some people on the Autistic Spectrum to describe people who are not on the spectrum. The term is based on ASD being a neurological disorder and it is short for ‘neurologically typical’ (Morris, 2004).

improvements both for the family and the child had occurred. It would also seem that this might be contingent on appropriate accommodation being available.

4.6 Summary

This review of family impacts has shown that the type of impact a diagnosis of ASD had on a family was as varied as the degree that ASD had on the individual. Financial impacts have been found to be a significant issue that depended upon the level of intensity of the child's needs. Obtaining an appropriate diagnosis had been found to be an issue for some where additional financial costs had been incurred that were attributed to a lack of professional clinical knowledge. Siblings were affected by an ASD diagnosis in various ways. The special interest common to persons on the Autistic Spectrum was shown to be of an asset when it could be used for mutual benefit. Families have utilised various coping strategies that have been adapted to suit the individual family's needs. Where coping strategies had been successful, families had achieved an improved level of functionality. It had also been found that needs had lessened over time. A cause that was attributed either to an improvement of a child's improved behaviour or improved emotional functioning after the family had adapted to the ASD diagnosis. The role of a parents' support group also changed with time. For some parents who were still involved, their role had changed from a receiver of information to that of a giver. Given that suitable supports were put in place, persons with ASD were able to achieve independence by living away from the family. In cases where this had happened, families had reported that it was possible to achieve a degree of 'normality' and the child with ASD was able to achieve an increased level of functioning.

Chapter 5

Alternative Treatments and Fads

For about as long as ASD has been known, theories have been postulated about causes and a diverse range of interventions have been considered as possible treatment options. A Google web search using the phrase 'autism cure' will produce just under 200,000 web links that purport a cure for autism. This information is readily available to families of children diagnosed with ASD, and contributes to the idea that the symptoms of the disorder can be eliminated.

To the parents of a recently diagnosed child wanting to find a cure, many of the cures promoted could be attractive. The language used in the websites is emotive and is designed to appeal to many. The advertisers are attempting to medicalise ASD so that a cure can be claimed. The cures come with a monetary cost. A practice in the advertising is to feature testimonies from people who have claimed the 'cure' has been effective. Some will feature the results of 'research' that has been undertaken. A closer analysis of the research will reveal the evidence has been based on subjective anecdotal data that cannot be verified (Zane, Davis, & Rosswurm, 2008; Metz, Mulick, & Butter 2005)

In the era of institutional care (which will be discussed in more detail in Chapter 5), doctors would have made decisions on treatments that reflected the understanding of the time. Electric shock treatment is an example of what was seen as a means of controlling behaviour (Hilton, 2007 this chapter). In today's environment, pressure is placed on parents when they are at their most vulnerable post diagnosis to achieve as much as they can in a shorter time as they can. Research has shown that often parents try an average of seven different treatments and because so many therapies have been tried at near the same time, it is often not possible to establish which treatment, if any, had provided any benefit (Green et al., 2006). It is also possible that today's laissez-faire government policy environment where responsibility lies with the family to choose and pay for accessed services or a lack of knowledge regarding treatment options may impact on a family's decision to utilise less helpful treatment options. The treatments offered could be best described as fads.

The term fad is mentioned by a number of authors in relation to current and historical ASD treatments. A fad is a procedure or therapy that has gained recognition through its wide use rather than being based upon the result of valid scientific research and are likely to fall from use when it has been proven that the ‘treatment’ did not work (Vyse, 2005). Neurodevelopmental disorders have been the target for many controversial and unsupported treatments that were linked to commercial enterprises (Metz, Mulick & Butter, 2005); an example being Doctor Wong’s biomedical treatment book, that included a free ‘help me’ phone consultation valued at \$100 and two ‘help me’ coupons “to get advice exactly when I need it” for \$149.00 (<http://www.newautism.com/stop-autism-now-using-secrets-of-biomedical-medicine/>). The treatment offered via Doctor Wong’s website is one example of the enterprises that have capitalised on an increased awareness of ASD. In a less enlightened era, other theories and possible treatment options existed.

5.1 Early beliefs and historical treatment and fads

As briefly mentioned earlier, the precise cause of ASD has yet to be determined (Hill & Frith, 2003), and many theories prevail as to the cause. Some of the proposed causes of ASD have been based on research and others on less than scientific methods. It is currently accepted in many quarters that ASD has a biological cause rather than a psychological origin (Marohn, 2002; Seltzer, Krauss, Orsmond & Vestal, 2001).

The uncertainty and the broad theories that have been postulated about ASD have provided fertile ground for the development of alternative approaches to treatment and promotion of the idea that there is a ‘cure’ for ASD. To gain an appreciation of the treatment options that are currently available some historical treatments are reviewed in the following section. It will later be argued that one thing the historical treatments and those of today have in common is their extreme nature.

5.1.1 ‘Refrigerator mothers’

In 1943 Leo Kanner was the first to postulate an explanation for autistic behaviour, after he examined the histories of eleven children who displayed tendencies that did not fit behaviour patterns that had been previously observed. He later described the behaviour as Infantile Autism and believed the cause of autism was a cold and distant relationship between the child and its

mother (Kanner, 1943). Kanner's theory was later popularised by Bruno Bettelheim in the 1950s who also theorised autism's origin rested with 'Refrigerator Mothers' or mothers who maintained an emotional isolation from the child (Silverman & Brosco, 2007; Yazbac 2003; Marohn, 2002). At this time, ASD was interpreted in classic Freudian terms as a syndrome of ego damage that resulted from unconscious parental rejection (Silverman & Brosco, 2007). Because of the implication of the mother in the cause of ASD, it was believed that the child should be removed from the parent's care and placed in an environment that provided the necessary warmth (Bettelheim, 1972). As Laidler (2004) pointed out, the 'refrigerator mothers' theory failed to take into account the fact that in the same families, there were other siblings who received the same parental treatment, who remained unaffected. Bettelheim committed suicide at the age of 86 in 1990 (Pollak, 1997). However, the impacts of his work and perspectives continued to effect families for years to come. It was later thought that autism was childhood schizophrenia because of commonalities that existed between the two.

5.1.2 Schizophrenia

During the 1950s and 1960s schizophrenia was a popular diagnosis and it has been suggested that the number of people given this diagnosis included children that displayed autistic-like tendencies (Wolff, 2004). The fact that schizophrenia rarely appeared until after adolescence was overlooked (Paus, Keshavan, & Giedd, 2008). Mosse (1958) was an early protagonist who disagreed with the diagnostic trend. After reviewing the histories of 60 children aged below 14 years, who were diagnosed with childhood schizophrenia, Mosse (1958) found that in practically all of the cases, the diagnosis was wrong.

Childhood Schizophrenia remained a diagnosis until the publication of the Diagnostic and Statistical Manual of Mental Disorders edition three in 1980 when autism received official recognition as a diagnosis (Broadstock & Doughty, 2003). Behaviour modification then and now has been a goal to achieve an improvement of a child with ASD's functioning. The difference has been the types of treatment administered. An early method of treatment was the administration of electric shock treatment to persons with ASD.

5.1.3 Electric shock treatment

Electric shock treatment has remained a controversial treatment since it was developed approximately 70 years ago (Hilton, 2007). It fell from popularity due in the main, to reactions

from human rights lobbies when it was shown that the treatment was being misused or was being administered indiscriminately. In other cases, it was used as a form of punishment (Hilton, 2007). In recent years electric shock treatment has regained popularity for a range of purposes. In two studies a reduction of self-injurious behaviour was noted when an electric shock was delivered when the child attempted to self injure themselves (Linscheid & Reichenbach, 2002; Sherman, Swinson, & Lorimer, 1984).

5.1.4 D-lysergic acid diethylamide

Another early treatment for autism which also proved to be controversial was D-lysergic acid diethylamide more commonly known as LSD. D-lysergic acid diethylamide (LSD) like other illicit drugs had numerous uses before its use was criminalised. For example: Cocaine was a base ingredient in Coco-Cola when it was introduced in 1886, and it was seen as an alcohol free version of ‘cocaine wine’ which at the time was used as a tonic (Musto, 1991). Heroin (a derivative of opium) was first used as an ingredient in cough medicine in 1898 and later was used in other cough relieving medicines (Seddon, 2007). By contrast, LSD was seen to have potential as a therapeutic agent for people with psychiatric illnesses including autism.

Autism was regarded as a medical problem during the 1950s and 1960s and LSD was regarded as a form of treatment (Sigafos, Green, Edrisinha & Lancioni, 2007). Dyck (2008) viewed LSD’s arrival on the medical scene as timely because of a high level of enthusiasm for the possibility that psychiatric problems may be solved by biochemical means. Despite the possibilities of success, further research into the possible medical benefits of LSD as a treatment was stopped due to moral panic and hysteria that surrounded the use of LSD (Goode & Ben-Yehuda, 1994; Ungerleider & Andrysiak, 1981).

5.2 Modern treatments and ‘fads’

Autism has been described as a late twentieth century fad magnet (Metz, Mulick & Butter, 2005). When parents perceive their situation as desperate; they may be open to any treatment opportunities regardless of its effectiveness or evidence either for, or against such treatment (Brereton, 2008; Calman, 2008; Stokstad, 2008; Green, 1996). Both a lack of information and irresponsible professional encouragement contributed to the parent’s uptake of treatments (Maurice, 1999). Fad treatments were also viewed as being dangerous and a waste of money

(Zane, Davis & Rosswurm, 2008). Fad treatments have been described as ‘The great Autism rip-off’ (Calman, 2008). A number of modern day treatment fads will now be discussed.

5.2.1 Elimination diets

An inference that ASD had a biological cause has seen diets that eliminate certain ingredients becoming popular. Gluten and casein have been regarded as substances that impact on behaviour, and diets that eliminate these substances have become popular topics at parental autism conferences (Christison & Ivany, 2006). Research has been undertaken to see if eliminating either substance caused an improvement in behaviour but there is no evidence to support these claims (Mulloy, Lang, O’Reilly, Sigafos, Lancioni, & Rispoli (2009).

5.2.2 Sensory integration therapy

The sensory difficulties experienced by some people with ASD probably led to the boom in use of sensory integration therapy (Myles et al., 2004). The therapy was based on the idea that sensory integration was a neurobiological process and children with ASD experienced a dysfunction when sensory information was not processed correctly by the brain (Pollock, 2006). Again, despite its widespread use, there is little empirical evidence to support its effectiveness (Hyatt, Stephenson, & Carter, 2009).

5.2.3 Dolphin-assisted therapy

Swimming with dolphins has been seen as a means of improving interaction between a child with ASD and the outside world (Wermer, 2008). Popularity grew after it was brought to the attention of the news media (Humphries, 2003), and like the other fads described in this section, proponents exist for and against the validity of dolphin therapy as a treatment. Change in a 13 year old autistic boy’s behaviour was documented in one study based on the mother’s reporting but, like much research into appealing and sometimes expensive fads, there are significant flaws in this and other related research that has been reported (Wermer, 2008).

5.2.4 Mercury and the Measles, Mumps and Rubella (MMR) Vaccine

As we have read, symptoms of ASD normally begin to appear within the first two years of life when developmental milestones have not appeared at the correct time. As vaccines are administered during this same time period, speculation developed that vaccines and an increase in the number of children diagnosed with Autism were connected (Levy & Hyman, 2005). A commonality in most vaccines is the presence of small amount of mercury that is used as a preservative. It was the mercury content that was blamed for the increase of incidents of autism. Researcher Doctor Andrew Wakefield and others were the first to propose a connection between the Measles, Mumps and Rubella (MMR) vaccine and autism in their paper '*Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children*' that was published in the Journal 'Lancet' in 1998 (Wakefield et al., 1998).

The research was criticised for its lack of validity, a critical flaw being that the study failed to examine incidents of autism within the population that had not received the MMR vaccine (Offit, 2006; Herbert, Sharp & Gaudiano, 2002). In 2004, the majority of the paper's authors withdrew the suggestion that the MMR vaccine was connected with autism (Fitzpatrick, 2008). Publication of the paper promoted a considerable amount of discussion and further research to establish if the link existed. Five studies were undertaken with the result being that there was no connection found (Offit, 2006).

A separate study in Japan added validity to research countering Wakefield's claim. The MMR vaccine had already been withdrawn because of concerns surrounding the mumps component causing meningitis. The total number of Japanese Autism diagnoses continued to increase at a similar pace to the rest of the world (Tonge & Brereton, 2008). In the 3rd February, 2010 edition of 'The Lancet' journal the editors retracted the original article on the grounds that it had become clear that there was no causal relationship between autism and the MMR vaccine. It had also been determined that claims that the study was supported by referrals from the parents of affected children and that the necessary approvals that were obtained, for the study were false (Triggle, 2010). Wakefield has since been struck off the British medical register for bringing the medical profession into disrepute (Meikle & Boseley, 2010).

An impact from the study was that vaccination rates fell around the world and there is now the possibility that the incidence of measles, mumps and rubella within the world's population will

increase (Mooney, 2009). It is possible that the Wakefield ‘study’ encouraged the development of ‘treatments’ purported to cure autism, among them were the proponents of chelation therapy.

5.2.5 Chelation therapy

Proponents of chelation believe that ASD is caused by the build up of heavy metals in the body (Roberts, 2004). Chelation therapy is the chemical detoxification of the body of harmful elements such as lead, mercury or other heavy metals. No reliable evidence could be located that suggested that chelation therapy was helpful in treating autism and the treatment had led to the death of one child after the incorrect chelation agent had been administered (Mercer, 2009; Sinha, Silove & Williams, 2006).

5.2.6 Testosterone treatment

A more recent supposition is that ASD is linked to high levels of testosterone and the advent of premature puberty. It is also believed that testosterone levels increase the toxic effect of mercury in the body. A treatment protocol was formulated which involved the use of the chemical Lupron to lower testosterone levels which in turn increased the effect of chelation therapy in lowering mercury levels. Lupron is used as part of the treatment of prostate cancer and to chemically castrate sex offenders (Fitzpatrick, 2009; Tsouderos, 2009). Lupron has been described as a ‘miracle drug’ by its proponent Doctor Mark Geier who in conjunction with his son developed the ‘Lupron Protocol’. The Geiers then marketed the protocol and opened a number of clinics to sell the product (Tsouderos, 2009).

According to Deer (2007), the Geiers have no experience working with people with ASD. The treatment was supported by a journal article ‘*The biochemical basis and treatment of Autism: Interactions between mercury, transsulfuration, and androgens*’ published in the September 2006 edition of the journal ‘Autoimmunity Reviews’. Following complaints alleging the article’s institutional review was biased (the review panel consisted of the Geiers themselves, Mark Geier’s wife, business associates together with two parents whose children were being treated by Geier or who were pursuing MMR vaccine damages claims), the article was retracted by the journal (Deer, 2007). This intervention, like others, provided an opportunity for people to personally and professionally profit from the desire of desperate parents looking for a cure for their child with ASD.

5.2.7 Dore Programme

Another well known but under-researched intervention programme is the Dore Programme. This programme is marketed as a drug-free alternative treatment for persons with Developmental Dyslexia, Attention Deficit Hyperactivity Disorder, Dyspraxia and Asperger's syndrome. The programme is based on the assumption that 'Cerebellar Developmental Delay' is the cause of the child's problems and that the problems could be overcome by a regime of exercises focussed on the development of balance and motor skills which include among others, balancing on a wobble board and throwing and catching bean bags twice a day for ten minutes. The exercises are intended to stimulate cerebellar development that in turn would lead to an improvement in reading and social skills (Bishop, 2007; Stephenson & Wheldall, 2008).

Little empirical research is available that supports the outcomes of the Dore Programme for people with ASD. The only study which reviewed the outcomes from the Dore Programme attracted criticism that alleged the study was flawed because of a lack of control groups, poor research design, incorrect analysis and interpretation of the results that were obtained (Rack, Snowling, Hulme & Gibbs, 2007; Alexander & Slinger-Constant, 2004).

These are some of many fad treatments that have been advertised as being a cure of ASD. Many ignore the fact that ASD is a developmental disorder, as many proponents of treatments attribute ASD to biological origins. Most of the examples illustrated assume that a biological intervention is the most appropriate course of action. It could be argued that the reason a biological origin for autism has been promulgated is because of a greater opportunity to capitalise on those in the community who are vulnerable.

As ASD has more recently been accepted as being a developmental disorder, it is logical that any treatment avenues should involve developmental concerns. Behavioural aspects are the principal consideration. Much work has been undertaken to establish the most appropriate methodology to improve an autistic person's level of functionality. The only treatment that has been verified by numerous studies as being effective has been Applied Behavioural Analysis. While not recognised as a fad, it would be helpful to explore this area.

5.2.8 Applied behaviour analysis

Various forms of behaviour modification techniques have been attempted. The electric shock treatment mentioned at the beginning of this chapter was one and it could also be said that the use of LSD was a chemical means of changing behaviour. Applied Behaviour Analysis (ABA) had its origin in the 1970s and sought to maximise behavioural treatment gains by treating the children during most of the period they were awake. It was considered the ideal age to commence the treatment was below four years of age, it was believed that under that age; a child was less likely to be influenced by environmental factors that may adversely influence any gains obtained. It was found that improvement of a child's level of functioning did occur and this was confirmed by a follow up study (Lovaas, 1987). An impact from the Lovaas study was acceptance that the earlier remedial treatment was commenced; the prospect of improvement was enhanced. The number of treatment hours per week considered to provide the maximum amount of improvement was between 30 and 40 (Eikeseth, Smith, Jahr & Eldevik, 2002).

As part of the review process of a number of therapies for inclusion in the 'New Zealand Autism Spectrum Disorder Guideline', a systemic review of published research of the effectiveness of ABA as a treatment for people with ASD was undertaken in 2008 that examined literature published between 1998 and 2007. Only studies that were able to be validated through proven research methods were included. The report concluded that consistent evidence existed that proved that ABA was a successful tool for maximising outcomes for children with ASD (Ministries of Health & Education, 2008). It can be argued that ABA started as a fad in the 1970s, the success of ABA as a therapy can be attributed to the fact that appropriate research was undertaken and the reason for its effectiveness was that it targeted symptomatic issues such as behaviour associated with ASD rather than attempting a cure.

5.3 Summary

Because there is no universally accepted and understood aetiology of ASD, it is argued that no treatment for ASD actually exists. There have been many theories postulated that have proposed causes and possible treatments. Much of the research purporting successful cures has been found to be flawed where there has been inadequate use of control groups to establish the validity of the data presented or the data were analysed incorrectly.

Having reviewed the intervention options and fad treatments available to parents of a child with ASD within this chapter, the idea put forward by Metz, Mulick & Butter, (2005) that Autism is a 'late Twentieth Century fad magnet' seems accurate. It is also possible to advance the argument that when a diagnosis was first received, parents were in a heightened state of emotion and during this stage, would be vulnerable to any treatment that offered a cure for their child's ASD. Other points of increased vulnerability are likely to occur for the family of a person with ASD over time. From the literature reviewed, it would seem that interventions targeted at managing the symptoms of ASD could be more fruitful than those claiming to cure a disorder whose exact cause has yet to be identified.

Chapter 6

Autistic Spectrum Disorder as a Disability: Social Policy Issue

Families of children with ASD rely heavily on formal and informal support networks. The roles of services and community support were discussed in Chapter 3 in relation to the Albury-Thomson family case. Formal agencies provide services for people with Autism Spectrum Disorder from within their existing service framework; no one agency has responsibility for day to day service provision. This chapter will show how present disability policy in New Zealand evolved from when the first state run institutions opened in the 1920s (Bray & Gates, 2003) to the present day and how it influences the provision of services for a person with ASD.

6.1 From ‘institutionalisation’ to ‘deinstitutionalisation’

Community participation is at the heart of disability policy in New Zealand, but this has not always been the case, the change in thinking can be traced back to as recently as the 1980s, when a change in social policy focus took place that ultimately led to the closure of all state-run institutions and the opening of accommodation facilities provided by community run non-governmental organisations. An impact this change in focus had on the families of those with ASD was that alternative care arrangements had to be made. Where as previously, care was provided within the state-run institutions, suitable accommodation and trained staff was not always available in the community. The death of Casey Albury-Thomson detailed in Chapter 2 was an indication of the impacts on families that occurred when suitable support was not available. To gain a better understanding, it would be helpful to explore some of the evolution of current disability policy. New Zealand’s disability policy originally focussed on private or charitable care where individual families or charities had responsibility for care for the disabled. Institutional care was a follow-on that evolved in the 1920s until a change in focus to deinstitutionalisation that began in the 1980s (Grant, 2002).

6.1.1 Institutional care

Institutional care evolved from a perception that disabled people needed to be removed from the community because of their disruptive influence. State-run institutions were established in the 1920s. The outcome of this was that large numbers of people were congregated and segregated

from the rest of the community in establishments especially set up for the purpose, that were generally located in isolated areas (Bray & Gates, 2003). The misconceptions fuelled the stigmatisation of disability and it can be argued that with institutional names such as ⁹‘Sunnyside’ or ‘Cherry Farm’, the stigma could have been reinforced. It can also be argued that early administrators probably thought they were being destigmatising with their choice of names.

Misconceptions surrounding the establishment of the institutions fuelled the stigma towards people who occupied them. Descriptors that described disabled person as backward, an imbecile, cretin, idiot, mental sub normal or moron fuelled the stigma that surrounded the institutions and their occupants (Bray, 2003). Present day terminology has destigmatised a person with an intellectual disability somewhat after the term ‘intellectual disability’ was adopted. This description has been adopted by policy makers and service providers (Bray, 2003). The connotations of the old words became so derogatory that today they have fallen from common usage. Inappropriate labelling of a person’s disability could lead to a general lack of tolerance and understanding of people with intellectual disabilities and that could lead to a corresponding lack of appropriate treatment. The early history of autism is an example.

People with autistic symptoms were classified as being mentally retarded or as being insane (National Autistic Society, 2005). For many years, people with autism were placed in institutions and the condition was regarded as untreatable (Hall 2009; Zager, 2005). From a New Zealand perspective, an Autistic person, after being classified as being ‘subnormal’ would probably have been placed in ‘custodial care’ at the Templeton Centre near Christchurch. Templeton was originally the sole institution for this purpose until Kimberly Centre at Levin was opened on 27 July, 1945. Its establishment was in response to the Federation of New Zealand Judges call for a similar institution in the 1930s to house a growing number of subnormal or mentally defective children in the North Island. Kimberley’s first residents were children who had previously been housed at Templeton (Hunt, 2000). It is possible that institutional care would have continued had it not been for the political developments of the 1980s and 1990s.

⁹ Names of two historical psychiatric institutions, Sunnyside is now known as Hilmorton Hospital located in Christchurch and Cherry Farm, opened in 1952 to house residents from the former Seacliff mental hospital. It was closed down in 1992 (Findlay, 2009).

6.1.2 Deinstitutionalisation

Nineteen eighty four saw the election of the Fourth Labour Government, neo-liberalists within the Labour Party advocated a change in welfare provision because it was regarded as a burden the government could not afford. It was considered the Welfare State as it was, would not be required because welfare recipients would benefit from their participation in the market place and the benefits that would have filtered through would support them (Dalziel, 1992). The government was of the view that change was necessary and the Royal Commission on Social Policy was seen as the vehicle with which to achieve that goal.

The Royal Commission on Social Policy commenced its work in 1986 (Dalziel, 1992). The government hoped that the Royal Commission's findings could be used to orchestrate the change that was necessary by recommending a retrenchment of welfare provision. Instead, the Royal Commission had the opposite view when it recommended increased government involvement in welfare provision that would have enabled welfare recipients to participate more fully in society (Liebschutz, 1999). Disability issues were also examined by the inquiry. A number of areas were seen to need attention.

Three areas that related to people with disabilities were identified by the Royal Commission, areas that it considered needed more strength were:

- Dignity and self-determination for individuals, families and communities
- Maintenance of a standard of living that was sufficient to ensure that everybody could participate and have a sense of belonging.
- Responsibility of all people to be independent and self reliant to the best of their ability and contribute to society.
(Cheyne, O'Brien & Belgrave, 2000, p. 52)

The Royal Commission, the outcome of which ran to five volumes was criticised for taking too long to complete its work and for its recommendations being too diffuse and at one point the report was used as a doorstop (Barnes & Harris, 2011). No boundaries were laid down as to the extent of any welfare reform. The political and economic climate at the time meant that there was little possibility of them being implemented. It was left up to the initiative of the cabinet ministers concerned, to determine any change. The government used business leaders with known neo-liberalist views to advise it as to the course of action they should take. The advisers recommended applying commercial principles to the welfare system (Cheyne et al., 2000). The

cost of the measures proposed was an obstacle as these would have been funded via taxation. At the time, the taxation system was under pressure from an ideology that supported less personal income tax.

The restructuring of the economy from a regulated to a market-driven environment, resulted in levels of unemployment that were not seen since the Great Depression (Raeburn, 1995). The government's attitude towards the unemployed hardened as the number of unemployed increased. Their thinking was that if you were out of work it was your own fault (Raeburn, 1995). The government's attitude corresponded with the neo-liberalist belief that everyone was responsible for his or her own destiny and that if anything went wrong, it was the individual's fault and their and their family's responsibility to remedy (Raeburn, 1995).

The neo-liberalist view of the welfare state was that it inhibited the freedom to make choices and because it required taxation to run, the element of choice had been removed. In the eyes of some, taxation was regarded as theft (Cheyne, O'Brien & Belgrave, 2000). An impact of high unemployment was a reduction of the level of tax revenue collected which in turn put welfare provision under further pressure. It was felt that efficiencies should be made in service provision and a means of achieving increased efficiency was to change the method of service delivery by contracting service provision out to the private and voluntary sectors (Cheyne, O'Brien & Belgrave, 2000). The result was service providers bidding against each other for contracts and a down-sizing of the health sector workforce (Schofield, 2001; Cheyne, O'Brien & Belgrave, 2000). Specialist services for smaller groups of clients, such as those serving children with ASD and their families, were then bidding against larger and perhaps more popular services for funding. Closing the State-run institutions that housed the disabled was seen as a further area where economies could be made.

The 1960s saw the emergence of a change in the philosophy surrounding the institutionalisation of people with mental or intellectual disabilities. In the United States of America, this had its origin in the human and civil rights movement (Grant, 2002). During the 1970s, the deinstitutionalisation trend spread throughout the Western world and to New Zealand in the 1980s (MacKinnon & Coleborne, 2003). It was believed that a better quality of life would result for residents if they were moved into the community (Lemon, 2001). In New Zealand's case, it can be argued that the welfare of the institutionalised was not the prime motivation because by turning over service provision to the private sector, the government would at least in part, have achieved its goal to retreat from welfare provision. A commercially orientated environment saw

the formation of many Non Governmental Organisations (NGOs) that ultimately took over the provision of services that were originally provided by the state. Services were put up for tender; the objective of tendering was to obtain goods or services at the best possible price.

Some issues quickly became apparent with the process of tendering for social services. When applied to the disability sector, 'the best possible price', did not necessarily equate to adequate services because many NGOs were under-resourced to provide the services they were contracted to provide, as a consequence that they were obliged to provide additional funding from any additional resources they could muster (Cheyne, O'Brien & Belgrave, 2000). The pace of service development was not matched by the same pace at which deinstitutionalisation occurred. As a consequence, families were given responsibility to provide support when problems with service provision occurred (Wright, 1997). It is these shifts in responsibility that have led to families of children with ASD coping largely on their own, with support from a small number of under-resourced services. The reliance on family support was continued when a National Government took office in 1990.

Rather than moderate the neo-liberalist policies Labour had introduced, the incoming National Government took to them with a renewed vigour. Not being shackled by history, National had no qualms in reforming the Welfare State. Benefit rates were cut and a greater emphasis was placed on the contracting out and targeting of support services (McLennan, Ryan & Spoonley, 2000). The services that were provided were required to fall within output classes that were defined. The impact of this criterion meant that if a family's need did not fall within a defined output class, the service could not be provided (Cheyne, O'Brien & Belgrave, 2000). As defined by the Public Finance Act 1989, 'Outputs' were goods or services that were provided by a government department, crown entity, Office of Parliament or other person or body. They were introduced to enable greater accountability for government expenditure (MacDonald, 1999).

When a required service was not defined in an output class, the government placed a greater emphasis on support from within individual families, rather than finance services themselves (Cheyne, O'Brien & Belgrave, 2000). In essence, the government's attitude resembled that of the level of welfare provision offered in the 19th century when responsibility was placed upon the family to provide support for those in need.

The welfare reforms were so wide ranging that in some Sociological circles it was thought that the National Government had overseen the creation of the first post-welfare society in modern

times (McLennan, Ryan & Spoonley, 2001). By the late 1990s, political philosophy began to change to a less extreme approach – and one that had potential to improve the situation for families of a child with ASD.

The election of the Fifth Labour Government in 1999 signified the end of the neo-liberalist philosophy of the previous National Government and that of the Labour Government before it. In its place, a type of ‘Third Way’ method of policy-making was introduced. The Third Way philosophy sees itself being positioned between the ‘Old Left’ and the ‘New Right’. It overlooks the fact that there was no first or second way (Easton, 1998). Translated into policy-making, the ‘Third Way’ can be seen as a means whereby principles of both socialist and neo-liberalist ideologies can be combined and applied (Giddens, 1998). In terms of welfare provision, the status quo largely remained, where services were still provided via NGOs by means of government contracts. An advantage of using NGOs to provide services was there was more choice of service provider together with providing employment opportunities for human service workers. Whether having a range of providers of services for children with a specific diagnosis such as ASD was helpful is debatable. During this time the Labour Government announced numerous policy initiatives that were designed to benefit people with a disability generally. It is this later period that on which we will now concentrate.

6.2 Disability policies: The changing perception of disability

People have different ideas about what constitutes a disability. Physical or psychological disability is arguably a social construct where the concept of disability had been created to fulfil society’s efforts to address the ‘problems’ disability caused, or as a means to provide services and entitlements. Others argue that disability is functional within a society, as careers and employment result from the need to identify and then intervene to address the problem (Spicker, 1995). However it is constructed and understood, families experiences of caring for a child with ASD cannot be separated from the social construction of disability.

6.2.1 Disability as a social construct

Social constructionism can explain the way in which a set of contestable social science concepts bring a problem (such as disability) into public consciousness (Press, 2005). Arguably, in societies where no support services existed, disability may be regarded as a nonentity because the social construct of disability did not exist (Snow, 2005). For example, if a government’s

resources for disability support were non-existent, the 'problem' of disability would not exist because no policy existed that recognised that a problem existed. Whether a problem existed or not depended upon what was perceived as a problem. Poverty in Victorian England can be used as an example: Many people denied poverty existed until they were made aware of the consequences. Selected dignitaries were shown areas of London where poverty prevailed and the impact that poverty caused (Spicker, 1995). It can be argued then that in making the dignitaries aware that a problem existed, poverty was a socially constructed. Others see disability as a political entity rather than a social construct.

6.2.2 Political model of disability

The political model of disability views the social world as one where there are irreconcilable differences that arose between those who had power and those who had not (Munford & Bennie, 2001). Conflicts between those who had power and those who had not could be resolved through changes to the dominant values of society. Under a political model disability is viewed as something people experienced rather than something they had. Disability was regarded as a consequence of living with an impairment in a disabling society that organised itself in a way that it did not take into account disabled people (Munford & Bennie, 2001). Using this analogy, it is possible to argue that under a political model, it was the disabled person's responsibility to define the issues and problems and then assert their own rights to alleviate the problem. In this environment, change would be more likely to occur if individual user groups banded together to work towards change. Grey Power is an example where extra support has been provided to the elderly by the elderly lobbying the Government for changes in policy (Office for Senior Citizens, 2003). The language used to describe disability is an aspect that can influence society's attitude towards disability.

6.2.3 The language of disability

Attitudes towards disability can be influenced by the terminology used to describe it. The language of disability can impact on the treatment of people with disabilities because it conveys assumptions and beliefs about disability that set a disabled person apart from society (Ballard, 1994). As mentioned earlier, Bray (2003) outlined that words such as backward, cretin, idiot, mental sub normality and moron had been removed from common usage because of the negative connotations that were associated with these words.

A person's appearance may also influence attitudes towards them, and the disability. Stereotypical conclusions evolved from the appearance of disabled individuals that assumed the person with the disability was either sad, had reduced role expectations, or had restricted opportunities (Altman, 1981). Persons with Down syndrome can be used as an example of where attitudes have changed. In 1975, educational psychologists believed children with the condition were unable to be educated in terms of ordinary classroom or special class programmes and that the only course of action available was to place them in 'occupation' centres from ages five to nineteen years of age (Ballard, 1994).

In New Zealand today, children with Down syndrome are now fully integrated into mainstream classes during their schooling and often, they achieve significant age-appropriate academic achievements (Ballard, 1994). Ballard's point was that Down syndrome had not changed; it was the ideas about the disability and the belief that all people had the potential to succeed that had changed. An example of where success has occurred has been case of a student with Down syndrome who became the first with the condition to pass a National Certificate of Educational Achievement level one examination (Ballard, 1994). Current government policy reflects this style of thinking, and this has been influenced by input from consumer organisations that have been established to advocate for the needs of disabled people.

The purpose of many disability consumer organisations is to advocate for the needs of the disabled community. An example is the Disabled People's Assembly, which had its recommendations included in ¹⁰'To Have an 'Ordinary' Life' and the 'New Zealand Disability Strategy' (New Zealand Disabled Persons Assembly, 2004). The formation of the disability rights organisations can be traced to the 1980s and the United Nations Declaration of the Rights of Disabled Persons in 1975 to which New Zealand is a signatory (Campbell & Oliver, 1996). The declaration obligated member countries to acknowledge that disabled people had the same rights as the non disabled. In New Zealand, rights for disabled are included in the Human Rights Act 1993 that is overseen by the Human Rights Commission (HRC) which in recent times, had seen an increase in disability rights abuse complaints (HRC, 2004). The establishment of disability rights organisations and the involvement of the HRC have enabled a significant level of empowerment that has challenged the dominant social perceptions of disability (HRC, 2004). As a result of the Human Rights Act 1993, the disabled community

¹⁰ A report prepared by the National Health Committee for the Ministers of Health and Disability Issues on ways that adults with an intellectual disability could become participating members of in society. The report examined barriers that existed and ways that these barriers could be overcome.

have a tool with which to advocate for inclusion in society and to gain improved access to services that are required, or for the implementation of services that were identified as being needed. The IHC complaint to the HRC that will be mentioned in Chapter 7 is an example of where the Human Rights Act 1993 has been used to advocate for services.

6.3 The era of community membership

‘The Era of Community Membership’ (NHC, 2003) summarised the ideology of inclusiveness for disabled people. It took over from where deinstitutionalisation had left off. Now that all the psychopaedic institutions had been closed,¹¹(the Kimberley Centre in Levin was the last) (Ministry of Health, 2006), services have been in a state of development that are intended to enable former residents of those institutions and other disabled people to take a fuller part in society. Three documents that have appeared during the past nine years will now be reviewed. The ‘New Zealand Disability Strategy’ released in 2001, ‘To Have an ‘Ordinary’ Life’ released in 2003 and the ‘New Zealand Autism Spectrum Disorder Guideline’ released in 2008. These documents provide an insight into the direction disability policy in New Zealand is expected to take in the coming years. People with ASD are included within general disability policy which is supported by the ‘New Zealand Autism Spectrum Disorder Guideline’. The ‘New Zealand Disability Strategy’ was the first policy document outlining a policy direction for the provision of disability services in New Zealand.

Under the terms of the New Zealand Health and Disability Act 2000, The ‘New Zealand Disability Strategy’ (‘NZDS’) was created to develop a framework for future disability policy. The ‘NZDS’ was developed with extensive input from the disability sector. During the consultation period; the strategy attracted 700 submissions and received feedback from 68 meetings that were held around the country. The aim of the ‘NZDS’ was to guide government action that would promote a more inclusive society and provide an enduring framework which would ensure that all government departments and government agencies considered disabled people before making decisions.

¹¹ The Kimberley Centre in Levin was the last of the psychopaedic institutions to be closed which brought to an end of the deinstitutionalisation process that was started following the election of the Fourth Labour Government in 1984.

Some of the values that underpin the 'NZDS' are:

- Disabled people have a meaningful relationship with Government, communities, based on respect and equality
- A move from exclusion, tolerance and accommodation to a fully inclusive society.
- Value of the abilities of disabled people
- Human rights practiced as a fundamental cornerstone of government policy and practice (Ministry of Health, 2003, p. 3)

In addition, the strategy developed 15 objectives that would enable people with a disability to function in society to their fullest potential. Most of the objectives listed in the strategy could be related to people with an ASD. Of the 15 objectives the Government has made, four would apply more closely than the others. These are:

- Objective six which concerns fostering an aware and responsive public service.
- Objective seven which details the creation of long-term support systems that were centred on the individual that would create a quality assessment and service delivery system.
- Objective thirteen, aimed at enabling disabled children and youth to enjoy full and active lives and to ensure that the services provided to children and young people are appropriate and welcoming.
- Objective fifteen which recognises the value of families and to provide ongoing support (Ministry of Health, 2001, p. 20)

It should be noted the 'NZDS' is a policy framework document and that its purpose is to ensure the development of specific policy that is designed to address a particular issue. An example here could be the Early Bird project, a programme that was developed to provide an early intervention strategy for young people with, and families of, people with an ASD. The project is funded by the Ministry of Education and operated by Autism New Zealand (Birkin, Anderson, Moore, & Seymore, 2006). Over all, there has been acceptance of the 'NZDS' as being a broad framework that enabled the development of future disability policy and programmes. Saucier (2002) argued that if the 'NZDS' was to transform New Zealand into a fully inclusive society, the strategy's concepts required further discussion followed by concrete policy implementation and programme changes.

Areas identified where progress had to be made if the 'NZDS' ideals were to be realised:

- Promoting independence: Currently, resource constraints mean that many disability services can only maintain people at their current status, as opposed to actively promoting independence.
- Improving effectiveness of services; an evaluation framework is required that should identify weaknesses in service provision and eliminate them.
- Simplification of access to comprehensive services. People with comprehensive needs require separate eligibility assessments that would allow easier access to services. (Saucier, 2002, p.6)

In a 2004 report prepared by the Disabled Persons Assembly of New Zealand (DPANZ) in conjunction with the New Zealand Crippled Children's Society (NZCCS), similar findings were made. The report supported the 'NZDS' (which was originally suggested by the DPANZ), but a call was made for government departments, local councils and district health boards to work in partnership with disabled people and their families to formulate and enact policy that would enable disabled people to be integrated fully into society in a way the 'NZDS' intended (Disabled Persons Assembly of New Zealand, 2004). Concern had been expressed that changes that were proposed by the 'NZDS' were slow to occur.

The apparent slow pace of change has been an issue. According to the Office for Disability Issues (ODI) it was very difficult to demonstrate where changes had been made because it often took years for changes to show up in statistics and that when change did occur, it was often not possible to show a definite connection between particular activities and outcomes because they were hidden within over-all activity (Ministry of Health, 2004). The same argument can be made surrounding funding provision for services when it is impossible to measure precise outcomes when they are hidden.

A solution to the problems the ODI had experienced with collecting information surrounding improvement to disability services could be to survey the disabled community. Provided the survey was targeted at an appropriate group for example, service users, it would be possible to obtain an accurate indication of the policy's effectiveness. Of equal significance to the 'NZDS' is the National Advisory Committee on Health and Disability's (NACHD) report 'To Have an 'Ordinary' Life' and the 'New Zealand Autism Spectrum Guideline'. These publications will now be discussed.

Published in 2003, 'To Have an 'Ordinary' Life' provided a comprehensive indication of what it was like to live in New Zealand with an intellectual disability. It gave details about the type of support that was necessary for the intellectually disabled to lead 'ordinary' lives. The document set out to identify areas where improvements could be made. In the process of their investigation, the committee discovered certain areas that were cause for concern:

- **Disturbing:** Life defining services – systemic neglect of the development potential of the intellectually disabled or families, improper and inadequate health care provision. A low understanding among people in authority of the impact their decisions or actions or decisions on the lives of people with an intellectual disability.
- **Worrying:** High poverty levels, low education levels, a lack of communication support that gave little opportunity to form sustaining personal relationships and a lack of culturally appropriate services.
- **Encouraging:** Individual examples of positively supported lives and an emerging body of knowledge about what was possible and a developing self-advocacy movement who would be able to strengthen the voice of disabled people.
(National Advisory Committee on Health and Disability, 2003, p. 8)

Like the 'NZDS', 'To Have an 'Ordinary' Life' illustrated with more clarity what was needed so that people with an intellectual disability could take a full part in society. Three areas were identified:

- Refocus needs assessments, service co-ordination services and service purchasing so that they cater for a person's individual circumstances.
- Move away from the custodial ownership of service delivery such as the service provider owning the group home the individual lives in to allowing a disabled person to live in a home of their choice with appropriate support and allowing the control of personal income.
- Addressing the neglect of basic health needs. It was discovered that some adults with an intellectual disability endured prolonged suffering from treatable health conditions but were the recipients of inadequate medical management.
(National Advisory Committee on Health and Disability, 2003, p9)

Some of the problems identified by the NACHD were the result of old-style institutional thinking that regarded intellectually disabled people as being incapable of achieving in society as was stated in (Ballard, 1994).

When the 'NZDS' was released, the NACHD was still establishing the scope of the 'To Have an 'Ordinary' Life' project. It was decided that the two projects should complement each other and to do so, 'To Have an 'Ordinary' Life' was based on the 15 'NZDS' Objectives. To give more relevance to their project, it was decided to group the 15 Objectives into four categories:

- Rights for citizenship
 - Government capacity and development of support
 - Delivery of support
 - Issues faced by population groups
- (National Advisory Committee on Health and Disability, 2003, p15)

The emphasis of 'To Have an Ordinary' Life' was on participation and one of the most relevant parts of the document were the recommendations about what must be done to achieve conclusiveness.

The needs assessment area was an area where the NACHD suggested changes; the current practice involves an emphasis on a client's short term goals. The NACHD considered an emphasis on long term goals was more appropriate. Financial provision currently exists for this to be achieved, the Ministry of Health introduced a system where funding could be allocated on an individual basis that was based upon the level of a disabled person's need rather than following a predetermined funding formula that was designed to cater for all (Ministry of Health, 2003). An advantage for the disabled person would be that it would be possible to obtain services that specially catered for the person's need and would give the opportunity for a disabled person to employ staff of their own to support them. This step would empower them so that they would be able to take charge for themselves, rather than have an agency make decisions for them.

6.4 'New Zealand Autism Spectrum Guideline'

As noted in Chapter 2 the 'New Zealand Autism Spectrum Guideline' represented a world first in service provision for people with ASD. The guideline is intended to advise health professionals by covering the steps required to arrive at an ASD diagnosis, how to provide support services to people with ASD and their families, details of educational supports that may be required, and management of the behavioural and emotional difficulties encountered by people with an ASD. Support needs of people transitioning from childhood to adulthood are covered, together with the steps that should be taken if someone with ASD came into contact

with the criminal justice system. Needs of Maori and Pacific peoples were also included. One of the more significant guidelines was the requirement for professional learning and development for individuals and groups who came into contact with people with ASD. It should be noted that the guideline is being treated as a ‘living document’ because it will be constantly updated (Ministries of Health & Education, 2008).

As has been seen, the intention of the guideline was to advise existing organisations and service providers on how best to provide services to people with ASD and their families. Bearing that in mind, it can be argued that an organisation to implement the services the guideline recommended should be established in the same way as services are provided to people with intellectual or physical disabilities. A counter argument is that a duplication of services would result, because many of the organisations that are providing services from within their existing range of services already have staff that are skilled in working with people with ASD, and that a separate organisation would duplicate current services and the financial expenditure to run them.

6.5 Policy-Making ‘Top-down and Bottom-up’

All of the discussion, thus far, has related to policy currently in use, at this point, it would be helpful to gain an understanding how this policy came into being and the methods used in its creation. There are basically two types of policy processes ‘top-down’ and ‘bottom-up’ (Sabatier, 1986); these two types will now be discussed.

Top-down policy-making is policy that has been developed by someone in authority and it would be expected that it would be adopted by consumers. Another way of describing top down policy is ‘one size fits all’ or policy that was expected to work in the majority of situations (Maaka, & Fleras, 2009). A result of top down policy-making is a gap between services that were provided and actual needs (Devereux & Cook, 2000). These comments can be translated into service provision for those with ASD. People with Asperger’s syndrome have been excluded from eligibility to ¹²Ongoing Reviewable Resourcing Scheme (ORRS) funding because the funding does not cover people with behavioural or emotional disabilities (Bartleet, 2009). The adverse effects of top-down policy making was highlighted by the case of a child with Asperger’s syndrome who had missed out on almost four years of schooling because a

¹²Now replaced by the Ongoing Resourcing Scheme

funding gap prevented access to teacher aide funding because ORRS funding was not available (Collins, 2005).

The ORRS scheme was introduced by the previous National Government and targeted only those who were assessed as having 'high needs'. Despite behavioural problems that in the past that resulted in suspension, the child was assessed as not being of a high enough need. A consequence was that the school was left to provide teacher aide funding out of its own budget which was something the school was unable or unwilling to do (Collins, 2005). A bottom-up approach on the other hand, would draw attention to the areas where support was required and policy could be formulated to address the need.

Bottom-up policy-making involves a consultation process where policy is designed in response to a particular need. Bottom-up policy-making is largely based on a reaction to weaknesses found in top-down policy. A bottom-up method would ensure that policy would reflect actual needs because it would be based on an actual situation which would give the policy an improved chance of achieving what it was designed to do (Brynard, 2003).

Some of the provisions outlined in the 'New Zealand Autism Spectrum Guideline' have been the result of bottom-up policy making because of the input from various interest groups involved in the guideline's formulation (Ministries of Health & Education, 2008). Because of the specialist nature of supporting people with an ASD, it can be argued that most of the changes that occurred in ASD service provision have been the result of service weaknesses found in the community.

6.6 Summary

Attitudes towards disability and service provision have undergone change since the state-run institutions were established in the 1920s. A cause of the change in attitude was the realisation that disabled people, when given sufficient supports, were able to play a part in society to a level similar to their able-bodied counterparts. The closure of the state-run institutions in the 1980s and 1990s was a further indication of the acceptance of people with disabilities a place in society. The policies that have been laid down in the 'NZDS' and 'To Have an 'Ordinary' Life' and the guidelines contained in the 'New Zealand Autism Spectrum Guideline' have formed the basis for future growth in disability service provision.

Chapter 7

Special Education Services

In common with people with other disabilities, people with ASD have a number of special education services available to them. 'Special Education 2000' is a policy document that sets out New Zealand's special education policy (Ministry of Education, 2003). To place today's education policy in context; a look at the history of the provision of education in New Zealand would be helpful.

7.1 Disability and education in New Zealand

New Zealand introduced a compulsory state education system for children between the ages of five and 14 in 1877 (Chapman, 1992). Students with special education needs were excluded as it was expected that churches and voluntary organisations would provide education services for this group. Government education policy was in line with its general attitude towards disability. Policy makers saw disability and ill-health for that matter as a threat against the image of New Zealand being an ideal society that was characterised by 'pioneering vigour' (Moore & Tennant, 1997). Translating this into an example relevant today is the government's promotion of a 'clean green image' of the environment to attract overseas investment. A more complete discussion on social policy was discussed in Chapter 6. The deaf were the first section of the disability community to receive benefit from the introduction of compulsory state education.

The 'School for Deaf-Mutes' was established in Sumner in 1880 which was funded and run by the Department of Education. In 1890 the School for the Blind was established in Auckland funded by charitably inclined Aucklanders (Moore & Tennant, 1997). It was not until 1917 that the state provided classes to less successful learners, provision for which was made in the 1907 Education Amendment Act with the requirement to educate 'defective and epileptic children' (Greaves, 2003; Moore & Tennant, 1997).

Students with sensory or physical disabilities were educated in separate establishments which were often administered by hospitals. An example was the Templeton Centre in Christchurch which ran classes for children with intellectual disabilities (Lemon, 2001). This segregated system continued until the late 1960s and early 1970s when government policy was influenced by a worldwide trend that demanded disadvantaged groups achieved equity with their more

advantaged counterparts. As a result of this change, the special education classes that were run by the hospitals were closed and satellite classes attached to regular schools were opened (Greaves, 2003).

Today's special education policy had its beginning in 2000 with the introduction of 'Special Education 2000' (Ministry of Education, 2008). It was intended to enhance resources that were available to children with special education needs. Emphasis was placed upon the Education Act 1989 which allowed for all students regardless of disability to be given the same rights to enrol and to receive the same education as non-disabled children at a school of their choice. Provision is also made in the 'New Zealand Disability Strategy', through the strategy's aim to remove all barriers to participation in society (Ministry of Education, 2007). 'Special Education 2000' contains guidelines for the provision of special education services that are available to all students regardless of the type of disability. The Ministry of Education has seven special education principles:

1. Learners with special education needs have the same rights, freedoms and responsibilities as people of the same age who do not have special education needs.
 2. The primary focus of special education is to meet the individual learning and developmental needs of the learner.
 3. All learners with identified special education needs have access to a fair share of the available special education resources.
 4. Partnership between parents and education providers is essential in overcoming barriers to learning.
 5. All special education resources are used in the most effective and efficient way possible, taking into account parent choice and the needs of the learner.
 6. A learner's language and culture comprise a vital context for learning and development and must be taken into consideration in planning programmes.
 7. Learners with special education needs will have access to a seamless education from the time that their needs are identified through to post-school options.
- (Ministry of Education, 2008, p. 19)

The principles set out the objective of specialist education policy. According to the Ministry of Education, the aim of the policy is to achieve a world class education system that provides equal opportunities for all students.

The key objectives of ‘Special Education 2000’ are:

1. Improve educational opportunities and outcomes for children with special education needs in the early childhood and school sectors
2. Ensure there is a clear, consistent and predictable resourcing framework for special education
3. Provide equitable resourcing for those with similar needs irrespective of school setting or geographic location
4. Assist in enabling schools to take ownership in meeting the full range of student’s needs.

(Ministry of Education, 2010, p. 1)

7.1.1 Support methods

The Ministry of Education provides various types of educational support that are designed to enhance a child’s learning potential. It is at this stage that an Individual Education Programme (IEP) is developed.

7.1.1.1 Individual Education Programme

Support needs are determined by the formulation of an ¹³Individual Education Programme (IEP) (Ministry of Education, 1999). The goal of the IEP is to help teachers and specialists to deliver an effective education programme that is tailored to the student’s unique needs and to provide extra assistance for learning or the adaptation of existing teaching programmes or learning environments. An additional use is to establish what specialised equipment or materials would be needed to support students in a regular or special education setting (Ministry of Education, 1999). The IEP is also used to access the ¹⁴Ongoing Resourcing Scheme (ORS), receiving support via the Ministry of Education’s Behaviour Initiative which includes support from the ¹⁵Resource Teacher Learning and Behaviour (RTLB). The RTLB teacher is likely to be involved with children on the Autistic Spectrum. The IEP is regarded as a ‘living document’ which is valid for only a certain period of time and is usually reviewed once a term or when needs change (Ministry of Education, 1999).

¹³ The Individual Education Programme (IEP) is a method of identifying a child’s individual needs, the IEP updated on a regular basis throughout a child’s schooling.

¹⁴ Ongoing Resourcing Scheme (ORS) is a system of support given to children that have been identified as having either long or short term needs.

¹⁵ Resource Teacher Learning and Behaviour (RTLB) are visiting teachers who have responsibility for children in a number of schools.

7.2 Background to ‘Special Education 2000’

The introduction of ‘Special Education 2000’ was a significant change in service provision; in some areas, the changes were not welcomed. Various lobby groups were formed that opposed the new policy and the circumstances that surrounded its introduction.

The special needs units that existed until ‘Special Education 2000’ was introduced were closed by the then Minister of Education Wyatt Creech. It was claimed that under the new system, special needs students would be disadvantaged rather than have their educational opportunities improved. A group of parents laid proceedings in the High Court to challenge the validity the closures in 1999 (Varnham, 2002). The judge ruled that the then minister had no right to close the services if no alternative scheme was provided (Laxon, 2002). The High Court decision was appealed and the original ruling was overruled on the grounds that special needs students had the right to an education system and not a type of education that was tailored to their needs (Russo, 2011).

Following the election of the Labour Government in 1999, ‘Special Education 2000’ was reviewed. Doctor Catherine Wylie was commissioned to carry out the review. Her report published in July 2000 determined that ‘Special Education 2000’s’ goals to improve educational outcomes and opportunities were unclear. The following section deals with Wylie’s findings.

Wylie (2000) found that while some special education students had improved opportunities for education, others had actually lost opportunities. Wylie (2000) also found that confusion surrounded eligibility criteria which had led to some students missing out on funding. Wylie also determined that because schools had more autonomy in New Zealand than in other countries, they had the ability to restrict entry of special needs students, or were able to avoid their responsibility to enrol them. Wylie (2000) discovered that some schools achieved this result overtly and sometimes by covert methods. Wylie also discovered that as schools competed for academic reputation, the entry of special needs students was restricted to preserve their reputation. Additionally, a lack of knowledge and understanding of ‘Special Education 2000’ policies was identified (Wylie, 2000). The report’s findings were at variance to the conditions set out in the Education Act 1989. The Act required schools to enrol students

regardless of disability with support for students provided by the Special Education Services (Prochnow & Maw, 2003).

The Education Act 1989 allows parents to enrol their child at a school of their choice. In some cases, this does not occur and this has been attributed to a lack of resources, an example being a 15 year old boy who had missed out on schooling for four years because of an apparent funding gap (Collins, 2005). Funding teacher aide time to support students has been an issue.

Being able to provide sufficient teacher aide time has been a problem in some schools. The parents of a 12 year autistic boy had to pay the school \$2,000 per term because sufficient teacher aid resources were not available (Mandow, 2005). At another school, special needs students were sent home at lunch time or were told not to attend at all the following day (Tara, 2007).

Special units have been established with the intention of enabling students with behavioural issues to remain in the education environment. An example is the Ka Mahuri Unit located at Northcote Primary School in Christchurch. The unit's future was under threat because of funding short falls. Throughout its two year existence, the unit had encountered funding shortages due to the fact that the Special Education Grant allocated to the unit was sufficient to pay for teaching staff, but not to actually run the unit (Hann, 2008). A similar situation occurred at Riwaka School, Nelson. The school considered taking legal action against the Ministry of Education over what it considered the under-funding of special education services by the Ministry. The school claimed that it was required to pay teacher aide salaries out of its main operating budget (Reich, 2007). During his retirement speech Renwick School's principal Ian Mackey, described special education as the biggest mess schools had to face because of the way the special education system had been set up. He argued that it was destined to fail all parties because of gross under funding (Johnston, 2007). Resourcing is a problem in some schools, and in an effort to address the imbalances that have occurred lobby groups have been formed to address these issues.

The Inclusive Education Action Group is an organisation established to lobby for the provision of special education services to be provided at all schools. At the organisation's launch in August, 2007, a spokesperson for the group indicated that a spectrum of barriers existed that ranged from a less than welcoming attitude during initial parent interviews to an outright refusal to enrol a child. The spokesperson indicated a reason was that staff at the school did not have

the necessary skills to cope with the child's disability, while in others parents were asked to contribute financially to the child's teacher aide hours (Grant, 2007).

The type of disability had no bearing on the difficulties parents encountered. ¹⁶The New Zealand Society for the Intellectually Handicapped (IHC) prepared a complaint to the Human Rights Commission against practices that exclude disabled children from attending their local school. The action is being taken under Part 1A of the Human Rights Act 1993, Section 19 which provides for freedom from discrimination (IHC, 2008). Following a decision that disability support is the responsibility of individual schools, IHC is now seeking the Human Rights Review Tribunal to hear the case (Radio New Zealand News, 2012). Lawyers for the Human Rights Commission have agreed there is sufficient cause and the case will now go before the court some four years after the complaint was laid (Nichols, 2012).

Funding shortages have had a bearing on the amount of services that some schools have been able to provide. It can be argued that it was in situations where difficulties had been encountered that public awareness was raised and, that in schools where special education services were running smoothly, nothing was heard. The following is an example where special education services are working.

7.2.1 'Special Education 2000' in practice

As previously noted, New Zealand adopted a special education policy in 2000; the policy met with a mixed reception. An argument that can be made is that attitudes towards special education policy can determine the success or failure of the scheme. Some schools have taken a group approach. The Howick and Pakuranga areas in Auckland are an example where 34 schools joined forces to collect data for a survey in response to the large number of students with special needs enrolled at schools in the area to establish the extent of need (King, 2008). Part of the support may include a transitional phase to help a student to pass from one level to another.

For children with ASD transitional considerations are a relevant issue. Smith, James, Heenan, Mortimer, and Selman, (2003) gave an account of how the autistic son of one of the authors

¹⁶ IHC is the name of the umbrella organisation, service provision is now provided by two separate IHC companies, IDEA Services Limited and Timata Hou Limited (IHC n.d.).

moved to a school environment was handled. Two visits were required where he was able to meet the people who would be working with him and to explain his new environment. The transitional period could also be used for teachers to assess a child's cognitive level and to familiarise themselves with any special behaviour patterns that were evident Smith et al., (2003). Elsewhere, understanding the unique needs of students with ASD is increasing.

The 'Education Gazette' of 5 November 2007, featured an article outlining the accomplishments achieved by staff of Dyer Street School in Lower Hutt after teachers had attended a 'Tips for Autism' course. The knowledge gained changed how children with ASD were treated so that they could achieve a much better fit within the school's community. A consequence of the course was a decision to modify the environment to fit the student rather than to attempt to modify the student's behaviour to fit the school's environment. A result of the change in thinking was an improvement in student behaviour (New Zealand Educational Institute, 2007).

7.2.2 Mainstreaming

In common with students with other disabilities, the majority students with ASD receive their education in a mainstream environment. This is in line with overall special education policy set out in 'Special Education 2000'. As previously noted, teacher aides provide the support necessary to enable the student to participate in a mainstream environment with the objective being to provide improved learning opportunities for students (Mitchell, 2010). A further benefit of a student with ASD receiving schooling in a mainstream environment was an improvement in engagement and social interaction with others (Mitchell, 2010). While mainstreaming is an option for some, it does not mean that it is the best option for others.

A study by Godfrey, Moore & Fletcher-Flinn (2002) undertaken on behalf of the Ministry of Education examined the quality of learning of 11 children diagnosed with ASD. A comparison was made between progress attained between education obtained at a dedicated education centre for students with ASD, mainstream schooling and children that received education at home. It was found that the student's attainment was higher through teaching received at the centre, or at home. Students attending mainstream schooling attained less because of a lack of instruction, feedback or praise. It was noted that there was more difficulty in keeping the student on task. It was also noted that when the student had a teacher aide, better results were not guaranteed (Godfrey, Moore & Fletcher-Flinn, 2002). Jacobs (2011) was another that found

that an inclusive or mainstream education framework failed students with ASD because it failed to take into account the student's 'Autistic learning styles'. Sensory or behavioural issues associated with ASD were other factors that did not fit with a mainstream school environment. Opposition from the parents of typically developed children was encountered because of the disruption caused by the need to accommodate the needs of special education students (De Boer, Pijl, & Minnaert, 2010). Behavioural and sensory issues surrounding ASD provide a case for the special education units to be retained.

A seven year old autistic boy was banned from his mainstreamed school because of violence toward his teacher and teacher aide. The teacher received a broken wrist and his teacher aide a black eye (Turner, 2011). As mentioned previously sensory issues associated with ASD can be manifested as violent outbursts. This experience is in contrast to government policy that is based on the view that teaching children in an isolated environment (a separate unit) did not adequately meet the student's needs (Ministries of Health & Education, 2008). It should be remembered that no two people with ASD are the same and because of the difference, mainstreaming education would not be a viable option for everyone.

The 'New Zealand Autism Spectrum Disorder Guideline' is a proponent of mainstreaming, an article which appeared in the May 2008 issue of 'New Zealand Educational Institute (NZEI) Rourou' journal supported this view with the proviso that investment be provided in the professional development of teachers and teacher aides so that the maximum benefit from the guideline could be obtained. To this end, new training opportunities will be available from 2011 in the form of a new postgraduate diploma in special education which would equip teachers with the skills required (NZEI, Rourou, 2010).

In the Canterbury region, parents were asked to provide their input into what they thought of the effectiveness of special education provision in the region.

A Group Special Education Canterbury report published in 2004 provided an indication of the state of services in the region. Data were collected via meetings with stakeholders throughout the region. The report's summary indicated that 622 students were receiving other support from ¹⁷ORRS funding with 427 students receiving other types of support from the Ministry. Schools that had a disproportionate number of students with moderate special education needs were given a total of \$731,633 of enhanced funding. In addition, Special Education Canterbury

¹⁷ Ongoing reviewable resourcing scheme now merged with the on going scheme

supported programmes administered on their behalf that were run by organisations such as the ¹⁸Champion Centre and ¹⁹CCS Disability Action (Canterbury and South Canterbury) (Ministry of Education, 2004).

Stakeholders were asked to identify the areas where they thought special education service provision was working well and to identify areas where they considered improvements were necessary. Areas identified that were working well, included communication between participating agencies, improved ORRS funding and the number of educational options that were available. Teaching skills and the quality of the specialist services being offered were other areas seen that were working well. Some areas where parents thought that some improvement was necessary included information about the support that was available and access to support services together with the level of support offered to students with moderate support needs (Ministry of Education, 2004).

7.3 Summary

The provision of special education is dependent upon the resources that are available to the individual school. Some inequalities existed between schools which was evidenced by Riwaka School considering taking legal action against the Ministry of Education to secure what it considered to be adequate funding. A school's attitude towards enrolling disabled students also played a part, the 'Wylie Report' disclosed instances where covert and overt methods were employed to avoid an enrolment. Group Special Education Canterbury took a proactive approach to special education provision by reaching out to the community to obtain feedback. Staff training and development played a valuable role. The Dyer Street School in Lower Hutt found that they were able to integrate students with ASD into the school community more effectively after staff had attended a 'Tips for Autism' course.

¹⁸ An agency that provides early intervention services for children with multifaceted developmental delay.

¹⁹ Formerly known as 'The New Zealand Crippled Children Society' the name was changed to CCS Disability Action to reflect their change of role to work with disabled people of all ages in 2007 (CCS Disability Action 2007).

Chapter 8

Methodology

This research was conducted in three parts, with each part having a distinct method of data collection allowing triangulation of research findings. A qualitative methodology was adopted to obtain the research data and analyse research findings. This methodological approach was selected because it gave participants the opportunity to tell their stories surrounding the diagnostic pathway they travelled and their experiences using available services.

Part one of this study was a questionnaire distributed via a range of mediums using a snowball sampling method. The second data set was made up of two case studies that were undertaken with a semi-structured interview approach and used the same questions to those in the survey. The third set of data were elicited via a semi-structured interview process, and participants were recruited using a purposive sampling method from five local service providers that provide services to those with ASD and their families.

8.1 The research question

The current study explores the experiences and support needs of families of a child with ASD. Because the research is exploratory, a range of methods have been used to elicit various types of data which are then integrated to provide a picture of the needs and experiences of families.

Research question:

What are the experiences of families of people with Autism Spectrum Disorder in the Canterbury/West Coast area?

8.2 Research methodology

Research has its own set of terminology that guides research practice. Some of the theories that have been used to argue for or against the use of a qualitative research approach will now be discussed.

8.3 Paradigm

A paradigm is simply a theoretical framework which consists of a collection of thoughts or ideas that follow a loose collection of logically related assumptions, concepts or propositions that guide thinking and research. It does not matter whether the project follows a quantitative, qualitative or mixed methods approach because each method will follow its own set of rules (Mackenzie & Knipe, 2006). Any paradigm represents the most informed and sophisticated view that its originators had been able to devise (Guba & Lincoln, 2004). It could also be argued that a paradigm could be regarded as a living ‘entity’ because of its ability to be changed as knowledge was increased.

8.4 Qualitative research paradigm

Data collection and analysis in this study followed the qualitative research paradigm which governed how data was collected and analysed. In an ideal environment; the choice of paradigm should be dictated by the nature of the problem under study rather than by researcher’s beliefs or practices (Vogt, 2008). In the presentation that follows, the qualitative research paradigm will be discussed.

Arguably one of the more appropriate paradigms for social research is the qualitative approach because of its ability to provide a greater amount of depth to the research topic. Qualitative methods enable the context of the subject to be explored, either from a micro, or macro level (Duff, 2007). Respondents would have the opportunity to tell their stories in a more complete manner which would clearly indicate how they fitted into their environment. Qualitative research methods enable the researcher to have more flexibility to explore related issues an example being the relationship between depression and childcare (Sheppard, 2004). A qualitative approach would enable the researcher to explore related issues such as how depression was understood and methods used to overcome it. If a quantitative approach had been utilised, the questions would have been predetermined with answers given that precisely fitted the questions asked.

8.4.1 The quantitative/qualitative debate

Argument surrounds the relevancy of the use of qualitative research techniques. The argument is based on the role of objectivity versus subjectivity. Proponents of quantitative research maintain that data that had not been collected scientifically could not be seen as objective because the data collected could not be measured to prove validity.

An epistemological question that was at the source of the debate was the relationship the researcher had with the research subjects. A researcher, who was more distant and independent maintained that distance through the use of surveys and experiments, was thus able to maintain objectivity (Cresswell, 2009). Guba & Lincoln (2004) were others to debate the validity of qualitative data. They held the view that the debate related to the belief that all knowledge was the product of social construction, and because of this, it was not possible to separate social meaning from human behaviours.

Disagreements aside, Philip (1998) has argued that no research could be totally objective and error free because the methods used by the researcher, or, the choice of the research topic, would be the product of a subjective decision and, for this reason, quantification is not the wholly objective scientific methodological approach many of its followers like to portray it as being. A conclusion that could be drawn from this debate is that while scientific methods could indicate the fact that something happened, they would not be able to explain precisely how it happened in the way that it did. An example could be a study into the effect the environment had on the sensory issues that are common in people with ASD. A quantitative approach would be able to measure the impact sensory issues had on the ASD population but not the effect the sensory problems had and the measures taken to reduce the impact.

In this study, where the purpose is to uncover the experiences of families caring for children with ASD, a qualitative approach to the research is more appropriate. Rather than searching for objectivity, the research focuses on the subjective experiences of participants.

8.5 Case study research

Two case studies have been included in this project. Case study methods can be utilised to obtain an in-depth understanding and the context of the research topic. Information is collected by using a structured or un-structured interview and can be either quantitative or qualitative in nature (Cavaye, 1996). The case studies utilised in this project took the form of semi-structured interviews, the questions used mirrored those that were used in the survey questionnaire with the objective of providing a more in-depth understanding of the functioning of a family where one or more member was on the Autistic Spectrum. By using semi-structured interviews scope existed to make use of data obtained from any associated issues that became apparent during the course of the interview.

8.5.1 Limitations of case-study research

It should be acknowledged that case study research is not without its critics. Flyvbjerg, (2004) argues that several main areas for concern include: the inability to make generalisations from a single case, the results of the survey being open to bias caused by the researcher's preconceived ideas of the case, and that it was often difficult to summarise and develop general propositions and theories on the basis of specific case studies.

This discussion suggests that for the reasons outlined above, it could be concluded that case study research is not a valid research method. McKee (2006) disagrees, pointing out that if case studies were as limited and useless as some commentators believed, the case study method would not have survived across decades to become accepted by the mainstream of social research.

8.6 Survey research

Information was obtained from participants by way of a self-administered questionnaire (Bryman, 2001) that was completed voluntarily. Participants were recruited by way of advertisements that were placed in 'Mind Matters' the newsletter of the Canterbury branch of Autism New Zealand, direct approaches to support groups attached to CCS Disability Action, Canterbury and Autism New Zealand's Canterbury branch. A number of participants were solicited via the forum attached to the 'asplanet' website (<http://www.asplanet.info>).

Survey questionnaires are a useful tool in social research because of the ability to gain specific data about a particular topic and questions can be either open or closed ended (Bryman, 2001). A self-administered questionnaire was selected as an appropriate method of elucidating data because the participant would be able to answer the questions at a time that was convenient for

them. An advantage of the self-administered questionnaire is that as no interviewer is present, there would be no possibility of answers being skewed by the questions being answered in a different order to how they were presented or worded differently to the way they were written or answers being influenced by the presence of the interviewer (Bryman, 2001).

8.6.1 Limitations of survey research

There are limitations to all research methods, including surveys. In employing an online and postal administration method, along with distribution by workers in agencies, there is a risk that the response rate will be low. There is a range of limitations to using the self-administered questionnaire approach. These include:

1. While it may be convenient for the participant to complete the questionnaire in their own time, there is the likelihood of the questionnaire being forgotten due to pressure of other activities.
2. Where open ended questions have been asked, there is no opportunity for the researcher to probe an answer to gain additional information.
3. There is no guarantee the questionnaire is completed by the correct person.
4. Response rates are generally very low as compared to an interview approach or where other direct data collection methods are used.

(Bryman, 2001, pp. 130-131)

While there was potential for the disadvantages to outweigh the advantages, a self-administered questionnaire was selected to minimise the amount of disruption to the family's routine. In the case of this project, it is possible that a further disadvantage was the potential participant's perception that another survey would not improve service provision. It is also possible that potential participants felt that answering the questions could bring back unpleasant memories of the family's diagnostic journey and therefore avoided participating in the research.

8.7 Interview research

Five service providers were approached to obtain their input on services they provide and to obtain the organisation's view on service provision for people on the Autistic Spectrum. A semi-structured interview was carried out with a representative from two organisations that provided dedicated services to people with ASD together with organisations that provided services from within their generic service range. A semi-structured interview was selected because it provided an opportunity to explore the subject in more detail than if a questionnaire was used. Semi-structured interviews are regarded as the only data source for qualitative research projects; because the interview is based upon a set of previously prepared open ended questions with further depth being obtained from additional questioning that emerged as the interview progressed (DiCicco-Bloom & Crabtree, 2006). The quality of data collected can be further enhanced by eliciting further information to enrich the topic under discussion by taking a lead from the interviewee (Bryman, 2001). While a qualitative interview does have its advantages, there are limitations that could influence the validity of the data obtained.

8.7.1 Limitations of interview research

While a qualitative interview is regarded as an excellent means of obtaining data (Myers & Newman, 2007), a number of difficulties can arise that can influence the quality and depth of the outcome. These include: the artificiality of the interview setting and time constraints being placed on the interviewee or language (Myers & Newman, 2007). The misinterpretation of language could pose a problem where the incorrect information was gathered. Pre-testing the interview questions would go some way to prevent any misunderstandings from occurring. Influences that the interviewer or interviewee may not be aware of could prove to be problematic.

Information provided by the interviewees may be influenced by the interview setting or their responses may be influenced by the interviewer or the interviewee tainting the data by giving answers the interviewer wanted to hear. Interviewer bias may also influence questioning which in turn could lead to the answers being skewed one way or the other (Diefenbach, 2008). In the context of this project, an example where this could occur is where the interviewer held the opinion that services for people with ASD were substandard when the data collected suggested the opposite.

Being comfortable with pauses and judging the length of time the interviewee needed to answer the question is a skill an interviewer would find useful (Sommer & Sommer, 1997). If allowance was not made for the 'thinking time' and the interviewer rephrased the question, confusion could result which inhibit the interviewee's ability to fully answer the question. This skill would be especially useful whilst interviewing members of the ASD community who needed time to process what was said to them.

It can be concluded that when the researcher is aware of pitfalls, valuable data can be obtained from the semi-structured interview. Limitations aside, a semi-structured interview has the potential to be a very rich data source which in addition could yield an unexpected bonus through obtaining information via avenues that were not originally considered.

8.8 Method

8.8.1 Participants

PART I: The participants in Parts I and II of this research project were the parents of children with an Autism Spectrum Disorder. They could be diagnosed with either ‘classic’ autism at one end of the Autistic Spectrum or Asperger’s syndrome at the other. Because both autism and Asperger’s syndrome share many of the same characteristics, the questions were worded so that regardless of the participant’s circumstances, the questions that were asked applied equally to either situation. Participants in part III were representatives of services working directly with people with ASD and their families in the Canterbury/West Coast regions.

8.8.2 Procedure

8.8.2.1: SURVEY RESEARCH: Potential participants in this project were recruited by various means. An advertisement was placed in ‘Mind Matters’ the magazine of the Canterbury branch of Autism New Zealand. The same advertisement was placed in the online forum that is part of the Asperger’s Parallel Planet (<http://www.asplanet.info/>) website and participants were recruited by direct contact with groups such as Autism New Zealand’s Canterbury branch parent’s support group and the autism support group attached to the Canterbury branch of CCS Disability Action. Copies of the questionnaire were distributed to members. Additionally, prospective participants had the option of visiting a website (<http://sites.google.com/site/asdsurveychch/asd-services-survey>) to download a copy of the questionnaire and email it back upon completion.

8.8.2.2: CASE STUDY RESEARCH: Case study participants were obtained from among those who responded to the advertisement for participants. These were people who indicated a

willingness to be involved in the case study interviews and who provided contact details to the researcher.

8.8.2.3: INTERVIEW RESEARCH: Using a purposive approach to sampling, five service providers were approached directly and a representative of each service was invited to take part in this project.

8.9.3 Materials

The following materials were used:

- Information and consent form that was provided to each participant in the research project (Appendices A, B, and C)
- Survey questionnaire which was completed by each participant (Appendix D)
- List of questions that were used in the case study interview, these were the same questions used in the survey questionnaire (Appendix D)
- List of questions that were used in the service provider interviews (Appendix E)
- Advertisements and correspondence with providers (Appendices F, G, and H)
- Dictaphone which was used to record the case study interviews
- Lockable filing cabinet

8.10 Human Ethics Approval

An application was lodged with the University of Canterbury Human Ethics Committee, approval was subsequently received (HEC Ref: 2007/100) (Appendix I). The project catchment area was originally the Christchurch City area only. Because of the number of people who responded from outside of the city, the focus of the research was extended to include the whole

Canterbury area and the West Coast which is the same area serviced by the Canterbury branch of Autism New Zealand.

The identity of each participant was guarded. Pseudonyms were used for each survey and case study participant and the area they resided in was generalised. Service providers were given generic names. It should be noted that while it is possible to protect the identity of the survey and case study participants, the service providers could potentially be identified by the service they provided. Completed questionnaires and transcribed interviews (which were transcribed by the interviewer) and stored in a locked filing cabinet. Ethical considerations aside, an added reason for anonymity is that as Christchurch is a small community and the ASD community being even smaller, there is a likelihood of someone knowing someone.

8.11 Data analysis

A thematic approach to analysis of data is taken. Thematic analysis is a poorly defined and rarely acknowledged qualitative analytic method (Brauna & Clarke, 2006). The approach involves identifying themes or stories in the data that are common with one another that are used to build an over-all picture of the participant's circumstances. Using the question pertaining to diagnosis as an example, thematic analysis disclosed a common theme was accessing people with the experience necessary to assess and diagnose ASD. An additional theme was the 'gatekeepers' that were used to regulate access to the relevant professionals. The presence of impacts was a trend that was threaded through many of the responses. These were both negative and positive and extended from financial to those that involved the extended family where a lack of understanding precluded support from the wider family members.

Unexpected results could also be detected by using a thematic approach an example being discounting a preconceived idea that ASD dictated a family's residential location. It was

originally thought that ASD did play a part but the trend identified in the current study showed otherwise.

8.11.1 Triangulation of data

To guard against the data being skewed one way or the other, triangulation of the data was undertaken. Triangulation is the bringing together of data that has been collected from various sources and then compared. Participants that had varied points of view of the solution to the same problem could also be compared (Guion, 2002). To translate this into the context of this project, service users were likely to have a differing point of view regarding the relevancy of services that were provided to them to that of the service provider. Triangulation of the data will be able to establish a common ground where a generalised picture of the situation will be obtained that will give an indication of how effective or relevant current services offered to persons with ASD and their carers are in a system that had not been designed for their purpose.

Chapter 9

Research findings

The purpose of this research was to gain an insight into the experiences of families, the ways in which families function, and the formal and informal supports they access when they are caring for a dependant with a diagnosis of ASD.

9.1 Summary

Data were obtained via three primary sources: case studies of two families, questionnaires completed by six parents/caregivers of a person with ASD, and semi-structured interviews with representatives of five local support agencies.

9.1.1 Case study participants

Two case studies were undertaken within this research. Participants in both case studies identified themselves as Caucasian and had at least one child who had received a diagnosis of ASD within the previous five to ten years.

9.1.2 Survey participants

A total of six participants completed questionnaires. All but one family identified themselves as Caucasian with the remaining family identifying as Maori. The residential location of the families varied. Five families resided in the Christchurch area, and the remaining two resided in the greater Canterbury area. The support services these families accessed were all located in Christchurch City.

A mix of families participated in this project; one family had the mother as the sole caregiver. Diagnoses ranged across the Autistic Spectrum from Autism to Asperger's syndrome and in some cases more than one child was diagnosed with ASD. The length of time since the diagnosis was made ranged from between one and ten years prior to their involvement in the research. With the exception of one, all families resided in an urban area. The exception was one who resided in a country town. This finding conflicted with a preconceived belief that sensitivities to noise, light etcetera common to ASD dictated living location. Only one family reported their residential location was determined by ASD, this was because of school zoning rather than any symptomatic considerations.

9.1.3 Service providers

Representatives from five Christchurch community-based services that work with people with an ASD diagnosis participated in the study. All were located within the central city.

Service A

The core business of Service A is to provide information, education and support for families and professionals. This includes providing information, staff/workplace training, liaising with schools providing staff training/education and supporting IEPs, liaising with a wide range of community agencies, providing school holiday programmes and other weekly activity programmes, linking families with appropriate services and support in their area, and advocating in relation to Ministry of Education, Ministry of Social Development, Ministry of Health and Ministry of Health supports.

Estimated number of service users: Somewhere between twelve to fifteen hundred people.

As the organisation is an NGO, funding is sourced from community grants, fundraising and donations. The ²⁰OSCAR Foundation partially funds their holiday programme but for day to day funding, donations are the sole source of funding.

Service B

Service B is a specialised service for people with ASD from the age of 5 years through to adulthood. The service provides training and support to clients and their families and the agencies working with them.

Estimated number of service users: 40 to 50 people actively involved per quarter, with around 300 clients registered with the service.

The organisation holds a Ministry of Health contract that provides two thirds of their operating budget which is reviewable every two years. For the remaining third, funding is sourced from community grants.

Service C:

Service C is a needs assessment service coordination service. After a referral is made and eligibility is met, a needs assessment, which will provide a snapshot of that person's life at that point, is completed. Then, a Service Coordinator from this service tries to ensure that those needs are met by linking a client with services in the community.

Estimated number of service users: In excess of 5000 people are registered with the service. They are contracted to review every person every year and to reassess once every three years

²⁰ Out of School Care and Recreation

unless there have been any significant changes. If there have been any significant changes during the three year process or even yearly, a reassessment will take place.

Funding is sourced by way of a Ministry of Health contract.

Service D:

Service D takes referrals from people between five and 21 and the referral could be from anybody with a disability that requires support. A range of services are provided including family support workers (including support for siblings), and support for people leaving school.

Estimated number of service users: Around about 300 use the service.

A major source of funding comes from government contracts with the shortfall being made up by donations or grants.

Service E:

Service E provides a range of community support options for people with mild to moderate intellectual disabilities which does include several people who are on the Autism Spectrum. Those support options relate to community participation and include training and education, sports and recreation, vocational and work opportunities (including volunteering opportunities), support for transitioning from school, and employment support.

Estimated number of service users: There are currently 139 people in the community participation service.

The Ministry of Social Development is their principal funder for most of the training opportunities the service provides. In common with the other services, there is a funding shortfall which has to be made up from grants from various funding organisations.

A comment made that was common to most of the services was that the need to spend time to lodge funding applications and the time that was needed to account to the funding agencies meant that less time was available to spend supporting clients. The continuity of funding also presented a problem because with grants or contracts lasting for a limited time, it meant that long term planning was somewhat restricted.

9.2 Diagnosis

As it has been previously noted, ASD is a developmental disorder, clues that something is amiss maybe evident as early as one year of age. By age three, behavioural signs indicating ASD are almost always evident and parents may have picked up that things are not as they should be. Absence or delay of developmental milestones is an early indicator and one that sometimes leads parents to seek professional advice.

Parents may seek advice when developmental milestones are absent or delayed (Wetherby et al., 2004) Families may seek help from professionals at different times and with different presenting issues. In most cases, the family's General Practitioner (GP) is the first professional to be approached. The GP may refer the family to a suitable professional for a formal assessment and diagnosis.

9.2.1 Case study findings: Diagnosis

Pam and Mike

For Pam and Mike there were some early behavioural pointers that their son Thomas was different. In fact, Thomas received his autism diagnosis from a paediatrician specialising in autism some ten years ago.

Mike: When Thomas was about two [years old], I suspected that he could be [on the spectrum]. He would stand in the shower and look up at the water falling on his face and things like that.

Pam: Thomas's speech, he did not have much language at two.

Mike: [Thomas would] spin around without feeling dizzy.

Pam: He would line stuff up, one day I went into his room after he had his afternoon sleep and his cars were lined up in order of size from one side of the room to the other. Matchbox cars to the biggest truck, they were all in size order.

Pam: Four months before Thomas's diagnosis, we took him to a speech and language therapist to see what was happening with his language and in those four months, he did not make any progress whatsoever, she referred us to paediatrician. We saw [the paediatrician] privately.

Mike: [The paediatrician] specialised in Autism, Dyspraxia and also ADHD.

Pam: He gave us the diagnosis there and then the day he saw Thomas. ... He (Thomas) was playing with the tap in his rooms, he was turning it on and off, on and off. And he (the paediatrician) said I do not need to be a rocket scientist, this child is Autistic.

Mavis and Frank

In many aspects of parenting, informal networks can be a useful way of obtaining information. Mavis and Frank, who have two sons who both have Asperger's syndrome, found this to be the case. It was through informal connections or interactions that Mavis discovered that Simon may have Asperger's syndrome, further research into the subject suggested that Anton may have it too.

Mavis: The diagnosis for Simon happened purely by chance, basically through connections with other people. Simon's one to one swimming coach in the pool with him had a daughter who has Asperger's. Frank was researching for Simon and said that Anton probably had Asperger's [too]. Basically, I got a referral to go to [a local General Practitioner who specialises in Autism Spectrum Disorder]. That was the only way it happened, connections - networking.

Researching the subject was a further strategy the family employed on their journey to diagnosis.

Frank: Someone mentioned Asperger's once [in relation to Simon] so I would go to the library and I would read all about these various things and when I started reading books on Asperger's like Tony Attwood's stuff it jumped off the pages that this was the thing.

What began as wondering and informal discussions with non-professionals cumulated in seeking professional support and a diagnosis. The role of informal support and publicly available information (such as on the internet), in the journey toward (or away from) diagnosis, should not be underestimated.

9.2.2 Survey findings: Diagnosis

All survey participants reported that their son or daughter had received a diagnosis within the last 10 years. Participants reported varying experiences of the diagnostic process that seemed to depend upon on which assessment route had been followed. Those who used the public health system discussed the matter of waiting time to see a specialist. Long waiting times were reported by some participants and, when the appointment did occur, referrals elsewhere were sometimes an outcome.

Jane: After a long wait, which was further delayed because I had tried to access a different early intervention service (Champion Centre) through the GP, ²¹GSE finally agreed to do the assessment. We had our one hour diagnostic assessment by [a] GSE based psychiatrist. She felt that he was not on [the] Autistic Spectrum. But when I queried this she agreed yes he might have ASD ...

This participant felt that a lack of resources within the hospital system was a factor that slowed the assessment process for them. She said:

Jane: My son could not simply be assessed without the issue of services and then hopefully acquiring services (after diagnosis).

While others did not raise this issue, Jane believed her difficulties were caused by the lack of a continuity of care. Jane felt that a lack of resources for services was regularly brought into the conversation during the assessment process and seemed to be a barrier to progress.

²¹ Group Special Education

Some parents found the length of time needed to complete a diagnostic assessment was an issue that caused them considerable stress. While waiting for a diagnosis, parents felt like they were in a never-ending holding pattern during which time they did not have access to information or receive support. Samantha and Jane spoke of the stress that waiting created for them:

Samantha: For me and my son [seeking a diagnosis was] very stressful, no real support or help. The whole [diagnostic] process is disjointed, lacking in professionals with correct knowledge.

Jane: The diagnostic process was extremely upsetting for me due entirely to [the] long wait and stalling tactics of [the] agencies involved. Meanwhile, no advice or support was given on what to do or how to obtain useful information.

Being able to obtain a diagnosis in a timely manner would clearly be an advantage to a family. For higher functioning children on the Autistic Spectrum, diagnosis may be delayed when the subtle indicators of ASD are not recognised by health professionals.

Jane: GSE seemed ill qualified to correctly assess Asperger's type ASD. They cited the fact that my son has eye contact as a sign of no ASD.

It is known that a lack of eye contact is a common symptom of ASD, but because of the variability between individuals, not all may display the same range of symptoms that may be evident with ASD. Some people with ASD can maintain eye contact.

Where a diagnosis was obtained outside of Christchurch city, or when the diagnostic process progressed more smoothly, the waiting times to access other services and supports were reported to be less.

Jill: Diagnosis was obtained in outside of Christchurch [via a] referral to [a] paediatrician by [the] early childhood centre. [We were] lucky there were no waiting lists for Occupational Therapist, Speech Language Therapist etcetera.

Regardless of the journey to diagnosis, families were generally pleased to finally get the diagnosis to validate their own perceptions of their child, access informal support networks, and to enable them to access much needed services. The experiences of some of the participants in the current study are consistent with those reported in the Autistic Association of New Zealand's 2001 study. In the 2001 study, many participants told of difficulty in accessing personnel who were skilled in assessing and diagnosing ASD. It is possible that the difficulty participants encountered in the current study stems from the public health system being operated along market driven principles that require an increased level of efficiency for the minimum amount of financial expenditure. As ASD is a lifelong disorder, support costs can be high and by restricting access to a diagnosis, possible future state expenditure would be minimised.

It is evident from the results of this study a more timely diagnosis would be obtained if the private sector was used, this would be a viable alternative for some families who had the necessary resources. For those without the necessary resources, this avenue would be beyond their means.

9.2.3 Service providers: Diagnosis

Services who participated in this study are funded differently. But for many, a diagnosis is required in order for the agency to access funding or obtain additional supports.

Service B: Yes, you have to have a diagnosis to receive our service with all referrals coming via Life Links: the local/regional needs assessment and service co-ordination agency.

Service C: Everybody has to meet the eligibility criteria.

Service D: Over the long term, yes, however we do support families where they suspect that their child may have a diagnosis of something. Often families will not know where to go or how to get clarification, so we support people in these situations. This can be quite a common situation. If after full investigation, it was determined that the child/young person did not have a disability it would be very unlikely that they would stay on our books.

However, one organisation offers support before a diagnosis has been obtained.

Service A: To access our services you do not need to have a diagnosis.

One organisation offers a more generic service where clients may present with a variety of diagnoses, but having one is not a prerequisite to engaging with the service.

Service E: The term diagnosis is not used in our contract but there has to be evidence that a person has a disability that would be ongoing for six months or more.

9.3 Attitudes of professionals

The role of the professional in the journey of the family from diagnosis to intervention should not be minimised. Indeed, in many areas within the human services, the quality of the relationship between the worker and the client is accepted as the primary factor in producing positive outcomes for clients (Swift & Callahan, 2009; Priebe & McCabe, 2006). The potential for individual workers and the services they are employed by to make a difference to the experiences of families when a child has ASD is immense.

9.3.1 Survey findings: Attitudes of professionals

Participants in this study experienced a number of different attitudes from professionals they dealt with. While it was described in different ways, a perception that a worker doubted that the child was on the Autistic Spectrum proved problematic for some participants.

Samantha: [It] felt like [we] had to convince others [he was] on the spectrum.

Samantha felt that the onus was on her to prove that her son was on the Autistic Spectrum, this attitude could be seen as an additional stressor for the family to deal with.

A feeling of isolation that can be the result was described by Freda:

Freda: Very lonely, full of self discovery, nobody believed me so I had to believe in myself.

Some parents may feel that their parenting abilities and competencies were being evaluated in their day to day lives. One participant commented that:

Nicole: At all stages of this [diagnostic] process, I have felt judged, misunderstood, not heard and like I had to justify my feelings, description of behaviours and indeed the behaviours themselves.

Research has suggested that in some situations clinicians may be reluctant to name the condition a child may have (Tissot, 2011; Brock, Jimerson, & Hansen, 2006; Dodd, 2004).

Nicole: I was asked why I needed something to be wrong with my son, [I was told that] labels would not help him and may cause other stress.

While the motivation of professionals involved in the diagnostic process may have been to ‘spare’ the family distress, this has to be balanced against the relief that the parents would experience by knowing the reason for their child’s behaviour. It would also have the potential to minimise any stigma brought about by the child’s behaviour. The lack of a diagnosis would inevitably block support avenues: an assessment of support needs can only be obtained after a diagnosis was obtained. Labels can be useful to families for other reasons: they can convey information relating to the person, where more than one clinician is involved; misunderstandings could be avoided due to a different understanding of the terminology used.

9.4 Local mental health services

Some parents of children with suspected ASD have the resources available to pay for an assessment by a private practitioner. However, many families must use publicly available services fully, or in part, as they pursue a diagnosis for their child.

In Christchurch, the Child, Adolescent and Family Mental Health Service is a public service run by the Canterbury District Health Board. Their Child and Family Speciality Service caters for children up to and including 12 years of age and an additional service, Youth Speciality Service, for children aged between 13 and 18 years of age. Both services offer outpatient mental health services which provide comprehensive assessment and treatment services to children with moderate to severe mental health, emotional or behavioural problems. Participants who used the public health system were asked to describe their experiences and comment on the service received.

9.4.1 Case study findings: Local mental health services

Because of his age, Mavis and Frank's son Simon was referred to the Child, Adolescent and Family Mental Health Service for an assessment and possible diagnosis for ASD.

Mavis and Frank

Frank: They tried to say that Simon had ADD and ADHD and all this other stuff, they just suggested to go back to the GP and chuck him on Ritalin and go and sign up for membership with the ADHD or Aspie Society and get support from them. Nothing happened.

9.4.2 Survey findings: Local mental health services

With the exception of one participant who described a positive experience all remaining participants who accessed local mental health services described their experiences of using the public system in a less than favourable way. While research into other populations would suggest that this is not unique to this population, there are many reasons why parents may feel this way about their experiences. It is not uncommon for parents to feel marginalised and ignored by professionals and a lack of validation of parental knowledge and experience by professionals was raised by one participant within this study.

Nicole: Some professionals only see themselves as an expert (text book learnt) and do not realise the valuable resources they have in [the] parent's experience.

Brenda: Useless.

Freda: First time around, appalling. Second time: Less focus on family situation and child's behaviours and more on underlying issues [needed].

When asked how the service participants received could be improved one participant commented:

Brenda: They could close. Totally incompetent, people who actually know autism could work there. The need to shorten waiting lists and allocate specialists not registered nurses.

As ASD is a life-long disorder, transitioning from one service to another may occur over time. A difference in the responsiveness of the service and a change in the level of support given were noted by Brenda:

Brenda: Very good, we went from huge teams of specialists with monthly sometimes weekly input over 10 years to discharge at age 13 to crisis to wait, wait, wait.

A theme common in the responses was an apparent lack of understanding by professionals of the complexities surrounding Autism Spectrum Disorder.

It is important to note that all diagnoses of children referred to by participants in this study were made before the 'New Zealand Autism Spectrum Disorder Guideline' was released. The guidelines in this publication provide guidance to parents and professionals on the procedures that should be followed when assessing a child with ASD. Bearing in mind the changes that have occurred in this area, further research is necessary to obtain a clearer indication of the effectiveness of the assessment/diagnostic processes that are outlined in the guideline.

Just as the presentation and characteristics of an individual with ASD vary from individual to individual, participants encountered varying experiences along the diagnostic pathway. Similarly, the practical implications and emotional impacts of a child receiving a diagnosis varied across participants. What was common to all though, was that having the diagnosis made a difference.

9.5 Needs assessment

A common method of accessing support services is by way of a needs assessment that is undertaken by the local Needs Assessment Service Coordination (NASC) agency by way of contract to the Ministry of Health. In Canterbury, the local NASC working with people on the Autistic Spectrum is Life Links.

9.5.1 Case study findings: Needs assessment

Often there is a waiting time between when the needs assessment was requested and the assessment being carried out. Participants reported an average waiting time of three months.

Mavis and Frank

Frank: The appointment took near to six months, the waiting time was hopeless.

Pam and Mike

Pam: Two or three months, we have not had another one done, we have just had the phone call every year to update the carer support days, we get 33 days per year which covers the²² holiday programme.

Participants who had needs assessments undertaken were asked to rate the amount of focus the needs assessment had on ASD. It was found that generally, there was focus but the amount varied between families.

Mavis and Frank

Frank: No, Anton's follow up [was sent to a local provider]; their people were kind of off the track with what they were supposed to be doing. They were supposed to be coming in for Anton's benefit but they decided to supervise us and run our lives.

Mavis: I do not think it is the higher ups, I think it is the support worker because she has got her own political agenda. She is very pro-mainstream schooling.

To illustrate whether or not the parents thought their needs had been understood Mavis and Frank used Simon's schooling as an example.

Frank: For the sake of schooling, if we do finally hear from [a service provider] or something like that and they say ok, we will give Simon support in his class. I mean it is only going to get it for an hour each day. They don't go in and support social development, they seem to think they have to go in and support his education when there is nothing wrong with his ability to learn education wise. They need to be in there at certain times of the day in the playground or whatever with the kid to do the social development part. They do not even consider that.

Mavis: Unfortunately [the support worker] put on the pressure to return Simon to mainstream schooling in two years. Can you imagine putting him back into that when he does not have the social skills?

²² Run by the Canterbury branch of Autism New Zealand

Pam and Mike

Mike/Pam: Yes, there was probably more of a concern about the needs of the rest of the family which was good. When you say focussed on autism it was not clinically based, it was more “how is everyone else coping?” Making sure that we were getting a break for ourselves ...

9.5.2 Survey findings: Needs assessment

In common with the case study subjects, survey participants reported varying experiences of the needs assessments process. Some gained the impression that the needs assessor’s experience was grounded upon theoretical knowledge based upon the solutions that were offered. Others had the impression that the needs assessor empathised with their circumstances.

Brenda: Unless you live it no one knows what it is like. Too many professionals have no idea and their solutions are often unrealistic.

Jill: The [needs] assessor was thorough and was very understanding and was the first person I told everything to.

Parents of children with Asperger’s syndrome noted that service options for their children were limited.

Jane: It (the needs assessment) wasn’t too bad, but in our case, we received very little in the way of actual services so the needs assessor did not have a huge amount of impact.

Brenda: Very little available for [people with] Asperger’s, autistics have a lot more care provisions available to them. ²³Aspies’ are just expected to get on with it.

One participant noted that not all of their needs assessment had been followed up.

Nicole: Some of the supports were overlooked.

²³ Term people with Asperger’s Syndrome give to another with the condition.

It was observed that as staffing changed so too did the level of experience.

Brenda: I have an excellent needs assessor at present but staff come and go and so too does knowledge and experience.

It can be argued that a successful needs assessment would be dependent upon the needs assessor having knowledge of ASD and the client having some idea of available supports. Unfamiliarity of the appropriate eligibility criteria has been an issue for some which may lead to people missing out, as Nicole notes.

Nicole: [Information about entry] criteria and what supports are available is not openly given. Therefore, if a parent does not know what [supports] could be available or criteria for such, it makes it hard for a parent/carer to advocate [for] the supports needed.

A complicating factor is that the health service is set up primarily to cater for either intellectual or psychiatric disabilities. Because ASD is regarded as neither one nor the other, funding options to provide needed services were often limited or not available.

Where services are available, there is often a long waiting time before the service can be accessed.

Jane: I later contacted [the needs assessor] regarding behaviour management issues only to find [the] available service had [a] two year wait list.

Participants were asked for suggestions on how the needs assessment process could be improved.

Jane: I think a really good needs assessor might talk you through some of the things that might crop up as [the] child gets older. Rather than just [a] needs assessor, [the person could be] a kind of counsellor who knows ASD [which] would be [more] helpful [and] who could come up with ideas for parenting etcetera.

Perhaps not surprisingly, it was widely noted that the quality of the needs assessment depended upon the level of skill the needs assessor had in dealing with people on the Autistic Spectrum.

The amount of support that was offered varied. A reason one participant suggested was a lack of services designed for people with ASD rather than the needs assessment process per se.

Participants in this study were generally satisfied with the needs assessment processes they had been involved in. The length of time a family had to wait for the needs assessment to be carried out was a concern to some participants. On average the wait time was up to three months which was considered to be acceptable.

9.5.3 Service providers: Needs assessment

Service provider participants in this study were able to comment on the needs assessment process from a different perspective. These participants highlighted a range of factors that influence or impinge on the needs assessment process, as well as the sheer magnitude of the task they have in front of them each year:

Service C: In excess of 5000 people are registered with us. We are contracted to review every person every year and to reassess once every three years unless there have been any significant changes. If there have been any significant changes during the three year process or even yearly, we will go out and reassess.

Some agencies receive funding via referrals from Life Links. They may use this referral agency as a gatekeeper to regulate the number of people using the service as a way of managing the funding resources that they have available to them.

Service B: We use Life Links as a gatekeeper because otherwise, we would be inundated. We would not be able to continue with what funding we have - we would be just turning people away.

In a climate where funding for support services is in short supply, having someone to act as an advocate for families during the needs assessment process could be useful.

Service A: I would always suggest a referral to the NASC, sometimes I channel [families] into that as the next thing to do after a diagnosis and I would often support them through the needs assessment.

The findings from the case study and survey participants in this study suggest that it is likely that a family with a newly diagnosed member may not be familiar with the needs assessment process. A role an service could fulfil could be in providing information about the needs assessment process and to advise on what a family's entitlements are.

Service D: The criterion to access our service is that they are a person with a disability who would like support. We support all disabilities, with the exception of people who have a sole mental health issue, as there is a large infrastructure of organisations in Canterbury geared to supporting this group. We do support people with dual psychiatric/physical or otherwise diagnosis. Often families do not know of the needs assessment process, and we often support them to access this service.

A needs assessment may also be used as a means for an organisation obtaining additional support funding to support a client in their day to day activities.

Service E: We are not contractually obliged to have the needs assessment as part of our entry criteria. However, we do request as a part of our referral process a needs assessment through the local NASC or something similar. [That would be used] for someone with higher support needs.

9.5.4 Service providers: Perception of supports families need

The service providers are in a unique situation where they can develop an understanding of type of support a family may need and to be in a position to know where shortfalls may occur.

Service A: Generally they [families] need a lot more support than the health system or education system [can provide]. It's getting harder and harder to access Ministry of Education and Ministry of Health funded services. I guess what families often need the most is carer support and respite care for these young people ... Some children get ORRS funding for very high needs children. Often there will be co morbidity alongside the autism there will be something else. The majority of children with autism do not get ORRS funding, [they are] the top one percent of children with special needs. I guess what families often need the most is carer support and respite care for these young people.

The individuality of a family's situation and the uniqueness of the support needs that are required (some of which were highlighted in the comments made by parents in earlier sections) pose challenges for service provision. It is also possible that where support is lacking in one particular area, this can have a 'knock on' effect into other areas of the child's or family's life.

Service B: Everything is so individual that I cannot really clarify precisely what our service would offer a particular client because everyone's needs vary ... we generally [also] work with those who are higher functioning as many of these people are not able to access service elsewhere; mostly it is about understanding and empathy for the individual across all settings so that consistency and continuity can make a difference including what is happening for them at school or work. Otherwise, if it is not right in education, it is not right at home, and vice versa. The majority of families that we get however are . . . mostly single parent families or there are families where there are mental health issues ...

Service C: That will depend on what has been identified in the needs assessment. You can imagine that with 5000 clients, the span of needs would vary from high and complex to just a couple of hours doing home management. [The supports] would depend on each individual needs assessment and each individual client.

Arguably the most important of all of a family's needs is to be listened to and the knowledge that their needs and circumstances have been understood.

Service D: Our process is a client – centred approach, so the families identify on an individual basis what the supports are that they would like, and we develop an individual plan with them based on their wishes. Outside of the individual plan for each person, we see some common themes. Most families say they would like to be listened to, understood and respected by agencies that they utilise. Where appropriate, we are able to offer additional ideas about possible supports that the person themselves may not know of or be aware of.

It would be very useful to have some type of flexible funding to purchase supports, therapies, resources etcetera that may not be funded or available elsewhere. We spend much of our time applying for funding for various needs that are not met by government funding.

This response from the worker from Service D is consistent with the message the families gave in this study – they want to be listened to and understood.

Respite care services have been identified as a major area of support that families seek, and families certainly talked about using these services – sometimes strategically.

Service C: Across the ASD population, we have a trend that seems to be respite. Part of a process of service coordination is to identify service gaps within our region and those service gaps are then reported back to the Ministry of Health and through that data, they can then explore options if appropriate.

9.6 Accessibility

A commonality that existed across parent participants in this study was that information about ASD and information pertaining to support services that are available was not readily given to parents. Accurate information is important to parents who, as noted in earlier chapters, can become isolated, desperate, and vulnerable to ‘fads’ as they try to deal with the situation that they find themselves in.

9.6.1 Service Providers: Accessibility

Being given information on ASD after a diagnosis was made and obtaining access to a support service were also seen as important issues by the service provider participants in this study. Understanding and meeting eligibility criteria had been identified as an obstacle to accessing services and supports:

Service A: Access that is the word, access. Meeting the criteria, interpreting the criteria, GPs across the country will interpret the criteria differently for eligibility for allowances for example ... Consistency in access of services ... what one NASC does, does not necessarily mean the same so that an inter NASC transfer could end up with totally different services for one individual with the same needs... I think one of the biggest challenges is understanding ASD and the implications for families when they are trying to access services whether it be child disability allowance or carer support or integrated school or whatever. Quite often you put supports in and the child makes huge improvements so they take the supports out

and put them somewhere else and the wheels would fall off because to continue improving, they still need that one on one support...

The implications of an ASD diagnosis have been seen as a challenge for some families and obtaining relevant, readily accessible information was seen as an issue.

Service B: People should be able to get some information right from the time of looking for a diagnosis and once this is obtained and confirmed it can be all a bit vague about what happens from that point onwards. Some people in health services are good in the way it happens for families, others are not so good. Families do not know where to start. What do I need to do? Where do I go to get it? How can I do all that as well as cope with my family's needs? They need somebody they can relate to and feel comfortable with to act as a case manager for them to talk to when needed and so that they can access [information] and steer them through the system.

For some families a lack of knowledge or a lack of an information source may act as a barrier, because they have no one to approach for information.

Service D: Many families come to our service because they have had difficulties in accessing services. Families often report that it is very difficult to get support, or access to services. Part of our role is to advocate for families, to assist them to access services.

Accessibility to a service can also be about the response a person receives after acceptance into a service. For example, if a person with ASD starts utilising a service, unless the service has a reasonable understanding or empathy for this condition, it may not be a service that the person can utilise. A lack of understanding, information, and empathy can become a barrier to using a service

With needs as diverse as the Autistic Spectrum is wide, sourcing appropriate services may present a challenge for the service provider, assuming that a particular service is available, there may be no guarantee that it could be provided if the necessary funding was not available.

Service C: I guess it gets back to [the question] what services are available out there? There could be an expectation that the government should fund a wide range of services, however there could be a variety of unfunded services available that may be able to offer the supports people need. Service delivery which include a selection of unfunded and funded services takes time to develop and may not ideal because people are busy ... the funding is not always available for services families expect however this may be an opportunity to work together and start creating their own support structures . [The funding is not there] to do what families are expecting ... I think what needs to happen [is the] development of those services. There are

some good providers out there. Some providers have a focus on supporting people with ASD. These providers have a good understanding on ASD and provide good staff training to develop their skills. These (staff), can bring their learning back into the service to up skill other staff members to improve overall service delivery. This is really good because that understanding supports the family's expectation as well, which often may be what the family is wanting when they first get a diagnosis of ASD?

Power and control issues related to policy and funding may be a factor where services are available but obstacles have deliberately been put in place to limit access. This may be a physical barrier or, access to appropriate information may be deliberately limited in order to protect the service from overwork and a resulting drain on funding.

Service E: I think it is really about families being able to drive the process, I think it is about better information also there are issues of power and control that come into play as well. I think families tend to be somewhat passive recipients of a service and whether that has been driven by a school or a disability organisation. I think by and large parents engage in a process in a meaningful sort of way. There is a lot of focus on the process but I feel there needs to be some mechanisms in place that ensure greater accountability both for schools and disability agencies that may provide some of that transition support. I think there is some form of scope for mechanisms for parents to actually come together and operate that shift some of that power [of the school or support agency]. I think information is power and in the absence of that information or knowledge, parents remain largely passive [recipients]. It is only when things go wrong that things start to kick in where parents are more involved or fed more information. It is not done as a matter of course, so I have seen.

9.7 Negative and positive impacts

As discussed earlier, an initial impact that has been identified from a diagnosis of ASD is that of grief. This may occur when parents realise that the plans the parents had for their child will not come to fruition. The grief process has been described as being similar to that experienced when someone has died. In essence, this is the case because the child is seen as a different person to the one they knew. Being able to share feelings with other people would enable the parents to come to terms with the news. Various people can provide emotional support to parents and families including a support group or a counsellor. The participants in this study utilised various support avenues to share the negative and positive aspects of living with a child with ASD.

9.7.1 Case study findings: Negative and positive impacts

Arguably sharing information with family is a common course of action, following a diagnosis. However, a perceived stigma surrounding the mistaken impression that ASD is mental illness can be a barrier to disclosing this information which in turn can prevent the parents from accessing support from their extended family.

Mavis and Frank

The support received from grandparents and extended family members can differ within the same family. This was the case for Mavis and Frank:

Mavis: The sad, sad awful thing is that because there is a fear of a mental disability, what non autistic people term as an illness. My Mother for instance will tell people that Anton is asthmatic why? Because she can explain that he will come out of it but she will not tell her sister – my aunt or anyone else that he is Asperger’s because it is forever. She just will not tell her friends, anyone like that. The realisation that my mother would not tell anybody else in the family at all that Anton is Asperger’s saddened me.

Frank, on the other hand, received a slightly more favourable response from his family of origin:

Frank: I told my family about Simon and they were not too bad because I was able to explain it.

Sharing information with an audience wider than the family unit is a risk for parents but it can also have some positive results. It can help facilitate a level of understanding within the broader community the parents and children are involved in, and ultimately result in more support.

Pam and Mike

Pam: I do not think that as far as losses and disappointments [were concerned] I think that everything has been tuned into being positive really. The phone call, I did not know the lady from a bar of soap, [she] was ranting and raving at me about how Thomas cut her daughter’s tee shirt and jumped on her lunchbox. I said on the phone do you actually realise that he has got autism? ... At that point, we wrote a

letter to the kindy, we made a copy for every child's pocket for notices that go home to the parents. I think it was then a case of 'how to win friends and influence people' we had so many people ringing us, saying we really admire you for what you have done, it was so really good to have an explanation telling us how Thomas ticks ... It was a positive outcome to a nasty phone call.

9.7.2 Survey findings: Negative and positive impacts

Like the case study participants, survey participants in this study shared information about their child's diagnosis and the implications of this with a diverse range of people. The relationships within which this sharing happened included professional, family and social, and, as one participant identified, an online forum whereby the internet became a forum for information sharing.

Jane: Professionals, family, partner, friends, other parents of children with an ASD diagnosis and counsellor.

Nicole: Family, friends.

Brenda: Friends, parents of other children with an ASD diagnosis.

Freda: Professionals, family, partner, friends other parents with an ASD diagnosis.

Jill: Family, partner, friends, other people with an ASD diagnosis.

Samantha: For me and my son, we are lucky we can speak to each other ... since setting up [a] web site forum, speaking to other people on the autism spectrum there.

Participants used various avenues to share the negative and positive aspects of an ASD diagnosis. Interestingly, some parents found that a negative situation can be reframed in to a positive one when an explanation regarding the reason for their child's 'odd' behaviour is given. By explaining the reasons why the child behaved in particular way increased the level of understanding.

9.7.3 Service providers: negative and positive impacts

The service providers provided a different slant to that of the parent's perspective:

Service B: [Families getting used to the realisation that] it is not the child they expected to have, or the life that they expected to have from that. Therefore, the grief and the anger [may] last for years in lots of cases

The level of impact ASD had on a family could be varied with the degree of the impact being dependent upon the severity of the condition.

Service A: I think the challenges facing some families is just maintaining day to day care and day to day reality or normality, call it what you like.

Service C: ... it depends whereabouts [on the Autistic Spectrum]. Some children have a very mild form which affects their behaviour or severe autism where impacts are immense.

Impacts can be more subtle – and perhaps invisible to those around the family. They can be about the need to change family routines to accommodate the needs of the child with ASD or the amount of time that can be devoted to an Autistic child's siblings.

Service A: It varies so much because it depends on the individual, often that family's life and daily organisation focuses around the person with ASD, the planning, what you can fit in a day, all that sort of thing often would be totally organised in order to accommodate that person with ASD.

Stress would be a likely outcome in a family coping with a member with ASD. Importantly, some service provider participants noted that the source of the stress may not necessarily be the family:

Service A: Accessing education, accessing services, getting respite care - all of those things are challenges really.

Service D: The main themes that are reported from families re the negative impacts of disability seem to come more as a result of lack of diagnosis, which hampers

effective interventions, negative experiences with service providers, lack of appropriate supports and services, lack of awareness of extended family, friends, and wider community re disability issues. These things can result in high stress levels.

The positives are that families say it changes their priorities, they have more empathy and understanding of others, and they value their own family more.

Support issues/needs may extend to later in life. Research has shown that in many instances, the child with ASD remains in the family into adulthood.

Service B: What are they going to do when they grow up, are they going to be able to move away, am I going to be able to get the right level of support for them to do that so that I feel ok? . . . Otherwise, it comes back on families and they have got their child living with them right through adulthood and that can impinge on the things they may like to do personally, but are unable to do so as a result.

One service provider is in agreement with the family's assertions that they have access to limited choices and those choices are not always of the quality that they would wish for their child.

Service E: I think it is a case of limited options and opportunities and a low standard of quality of those options and opportunities as well. From discussions I have had with parents it is the transition of a young person from school to post school life is a flawed process and there are many challenges and unanswered questions and a lot of anxiety attached to that. I think parents are often left out of the loop and are not informed in the way in which they need to be.

It is when the parents of children with ASD age that difficulties can arise when circumstances dictate that the parents were no longer able to care for their child.

Service B: ... they have got their child living with them right through adulthood..... It may not always be appropriate because come the day when something happens for Mum and Dad, these people are left in no mans land and having to cope or move on to something else to some sort of independent living that can be much harder to do when they are older.

The limited opportunities for people with ASD and their families have been noted elsewhere.

The limitation may be caused by a lack of knowledge on behalf of the parents regarding where to go for support or the limitation may be a conscious act on behalf of the provider in an attempt

to protect the limited resources the provider had at their disposal. It may be that the resources that the parent required were not available.

Service E: Many parents do not know where to go to, whom to put questions to, what options and opportunities that actually exist. Inherent in that process is the fact that there are many gate keepers along the way and they can choose which information is passed on and what information is not. I think how a process unfolds to a large degree would depend upon the attitude and philosophy of individuals.

Outcomes may differ if the parents were better equipped with the necessary resources and knowledge about how to access the resources they needed. The resources the family had at their disposal could be used to combat the gatekeepers.

9.8 Education

‘Special Education 2000’ is a policy framework that sets out disability support services for all students. Its intention is to enhance educational opportunities for all children with disabilities regardless of the type. Schooling for children with ASD is primarily provided within a mainstream setting. Where required, supports are put in place so that the child can take part in classroom activities. An Individual Education Programme (IEP) is formulated for each child and it is from this that unique needs are established and learning supports provided. In the case of a child with Asperger’s syndrome, supports may not necessarily be confined solely to the classroom.

9.8.1 Case study findings: Education

Participants in this study utilised a number of educational opportunities. The two families in the case study part of this study spoke openly about their experiences of pursuing quality education for the sons and of the role of the teacher aide in this process.

Mavis and Frank

Frank: [Two service providers] have sent their reports to the Ministry of Education and then supposedly, we get so many hours of teacher aide support in the classroom. It is the wrong sort of support. [Anton] does not need support learning his ABCs and that is all he got time for.

Mavis and Frank were aware that the support that Anton needed was with social skills outside of the classroom rather than during class time. They thought that a more appropriate form of support would have been targeted intervention to help him develop skills in social interaction with the other students.

Pam and Mike

Thomas attends his local school and receives mainstream schooling. Teacher aide hours had not been allocated but were available, if needed. However, teacher aide time had been used in the past.

Pam: Thomas has used [teacher aide time], for the first eighteen months he had somebody everyday for a half to one hour every day.

Mike: Through his transition to school, he had his teacher aide.

Pam: Transition to school between kindy and school he had a teacher aide and a speech language therapist.

Mike: [Thomas] accesses the special needs department at the school for work with his ²⁴Neo Writer and things like that. He's not over there all the time but if there is something he needs assistance with they will sort it out for group activities or individual stuff.

Pam: The Neo Writer has been funded through the Ministry of Education while he is at the school. Thomas has another eighteen months at the school and he can use the writer until he leaves [to go to high school]. By then hopefully he will be skilled enough to use a laptop which we will probably fund because there is a gap in the ²⁵ORRS funding, he does not get ORRS funding. We have had an Individual Education Plan (IEP) done at school.

²⁴ Similar to a laptop computer, the Neo Writer has been developed as a writing tool for use in schools (<http://www.spectronics.co.nz/product/neo-2>).

²⁵ The Ministry of Education's Ongoing Reviewable Resourcing Scheme

Mike: We have just started it up again; we were getting a bit concerned [about] heading into high school and getting some things put in place.

Pam: We just thought that he was going to start slipping through gaps so we pushed for it to happen. It [the IEP] has now been implemented which is good.

Mike: One (the IEP) needed to be done for the Neo Writer so it carried on from there.

Continuity is important in the life of someone with ASD the same principles that apply to routine, apply to the persons working with them in the support sector. If a support person was working with someone on a regular basis, the same appointment time and day of the week would be of benefit. In some circumstances, change is inevitable because of changes in staff or funding allocations.

Pam: [School] has been quite hard for Thomas because he is up to teacher number four for the year so there has been a change in teachers [each term] since the beginning of this year. But, teacher four is quite onto it. He met with us one day and talked to us about the IEP and has his ‘finger on the button’. He admits that he does not know a lot about autism but he is happy for us to give him answers, he is good, he is just a young guy.

Mike and Pam thought the educational support had been focussed on autism, and because the school had a reputation for providing good support to persons with ASD, moving to an address within the school’s zone was seen as an option.

Mike: We moved into the area because of Thomas’ autism [and] because of the school’s zone. The school was known for catering for special needs. At the time, the chap who was head of the special needs department we knew of so we got ourselves positioned so that we would be in the school’s zone. That was our prime motivation for moving to this part of town.

Pam: We also moved because there was a kindy close to the school we felt we needed the kindy as well so that there would be less change.

9.8.2 Survey findings: Education

Among the survey participants, children received mainstream schooling either with or without teacher aide support. Those whose children received teacher aide support commented:

Nicole: Five hours [per week], increased one on one to aid learning difficulties and socialisation with peers.

Jill: Two hours, [it] could always be more but the school does what they can.

Some studies (Khouzam, El-Gabalawi, Pirwani & Priest, 2004; Carrington & Graham, 2001) have shown that while a child was adequately catered for in class, there was often an issue with social skills while outside of class. Consistent with previous research and participants in the case study section of this study, Jane also found that support with social skills issues was needed rather than receiving in-class support:

Jane: My son needs help with playing with other children so he can learn to interact and to meet any needs for calming himself without resorting to throwing or hitting.

Samantha: As my child is high functioning and is doing ok, there is no real support or services available. [I] did try and talk to his school, [their] response was he is ok.

As each person with ASD has different needs any support that is given should mirror those needs rather than provide a support package that is designed to fit all.

Samantha: ASD is a lifetime difference which needs to be recognised and differences supported ... as we are all individuals, each person needs to be assisted properly ...

Data showed that participants had received varying amounts of support. While in some cases in-class support was available, the need to offer support in an out-of-class setting was a consideration that was overlooked. Each special needs student is eligible for an IEP that details the type of supports required and the supports given should be based upon the need of the individual student.

Freda: Base [support] on need, equal weight [should be] given to the parent's perspective [of what that need is].

A school's ability to provide support has a bearing on the amount and type of support that is provided. Participants received varying amounts of support which was mainly in the form of in-class support by way of teacher aides.

A situation may arise where schooling in a classroom setting was not appropriate necessitating the need to home school a child. A completely different set of supports is required when a child is home schooled which can become a costly option and could cause some difficulty if a family's financial resources was limited.

9.8.3 Service providers: Education

The service providers offer a range of education services that would be either utilised for staff training and development or by someone with ASD. Both Service A and Service B offer professional training to other organisations as well as individual clients. Support is offered to families while they access support provided by the education or health systems.

Service A: Generally they [families] need a lot more support than the health system or education system [will provide] ... It's getting harder and harder to access Ministry of Education and Ministry of Health funded services.

Service D: At a national level we campaigns to raise awareness of disability to the community. We have a Disability Education and Awareness team, who go out to train organizations and schools. Where requested we provide information for parents and support them to access opportunities for more information e.g. a relevant course. We provide information to schools, which is often specific information for schools on an individual child.

Educational opportunities may also be provided to clients on the Autistic Spectrum as part of the organisation's overall service provision.

Service E: [We provide a range of options] that would include training and education, we provide some of that training and education ourselves in the form of our ²⁶ASDAN teaching and learning programme which is an ²⁷NZQA recognised

²⁶ Award Scheme Development and Accreditation Network

teaching a learning development programme developed in the United Kingdom which covers a range of foundation learning opportunities for people. We also link people with other training and opportunity providers. That could be courses at Hagley Community College or ²⁸CPIT or other private training establishments. For example, we have recently formed a relationship with an adult literacy and numeracy training provider so we have had a number of individuals go through courses there.

The type of vocational training offered is designed to enhance a client's employment prospects with a view to the client obtaining either full or part time employment.

Service E: In the last two or three years we have also a transition from schools service so we have someone currently working in a very part time capacity which is an add on to their main role. That is working with ORRS funded people in their last year at school in a way that is a brokerage type of approach so that is about working with that person, establishing their goals and aspirations post secondary school and then working with relevant agencies, organisations and so on to assist in linking people into those options. Employment support is our most recent additions to our suite of services. This year we have supported eleven people into paid work which is very pleasing, so that is continuing to evolve.

Educational support is provided at numerous levels, the first type of support received is likely to be within a classroom setting with the support mainly given in the form of teacher aide hours. The amount of time that is provided varies depending on the resources of the individual school. When a school has a reputation for providing support to students with disabilities, an option the parents have is to move to an address that is within that school's zone. Home schooling is an option where education within a classroom environment is inappropriate. This may present challenges when a family's resources are limited.

²⁷ New Zealand Qualifications Authority

²⁸ Christchurch Polytechnic Institute of Technology

9.9 Home schooling

9.9.1 Case study findings: Home schooling

Mavis and Frank

Simon is home schooled because of his inability to cope in a mainstream environment. There had been concern when he became suicidal if he was not removed from a classroom environment. The cost of home schooling placed financial pressure upon the family. Examples of the costs involved included the provision of work books and CD ROMs.

Mavis: Workbooks that you buy from Whitcoulls, if it does not get into the Simon's special interest, or it is not something that will interest him then you can forget about it. The way that they explain it (subject), if they do not go step by step, nice little baby steps onto each thing then it is incomprehensible to him. Also, CD ROMs, you have to have the interactive type like Whinny the Pooh series in maths and reading.

As the parents had indicated, there are costs involved while home schooling a child. In cases where there is financial hardship, Work and Income is often an agency that is approached for support. In recent years, Work and Income's culture of informing clients of their rights and entitlements has changed and they inform people of what their entitlements are. For persons with internet access, copies of a list of entitlements can be downloaded from their website. When approaching Work and Income for assistance to home school their child, their experience differed from announced policy:

Mavis: Oh Work and Income, I do believe that they have a policy of not informing you of what you are entitled to, to keep costs down. Why do I have this theory? Many, many appointments, many, many applications, there was only one time I ever got help for Simon's swimming classes. They fought it; they said that home schooling was a personal choice. I said it was not a choice because Simon became suicidal and tried to hurt himself with sharp knives when he was six due to an inability to cope with the mainstream school system.

9.10 Additional support avenues available to the family

Families may make use of a number of support agencies. Types of support that would be used could include assistance with house work, membership of a parent's group, such as Autism New Zealand's Canterbury branch where parents can meet others who have children on the Autistic Spectrum. Networking through this type of group would enable the exchange of information.

A community support worker or other type of support could also be involved. The type of support that may be given could range from supporting the child in leisure activities to in the case of older clients, assistance with finding a job. Arguably, one of the more useful roles that a community support worker could take would be giving the parents the opportunity of having some time-out. A number of participants made use of some type of support.

9.10.1 Case study findings: Additional support avenues

Mavis and Frank

Mavis: When I was in acute needs, the support worker was only coming in to see Simon for an hour a week.

Frank: She would take him for a walk down to the play ground, let him have a look in the toyshop and that was it.

Mavis: Unfortunately, she put on the pressure to return Simon to mainstream schooling in two years ... they only got six months worth of funding.

Frank: That is the thing too, the kid is going to be permanently on the spectrum but you only get six months of support, they must be thinking they will be able to solve all the issues in six months.

As with most of the support available, its availability is subject to available funding. As Frank observed, when a condition is lifelong support is liable to be required throughout a person's life.

9.10.2 Survey findings: Additional support avenues

Support for siblings may also be used, in some situations. The additional stresses a child with ASD brings to a family could impact on the siblings. For a younger sibling it could be the lack of a playmate or in the case of an older sibling, problems could arise from the amount of time required to cater for the autistic brother or sister.

Jill: Parent to Parent - Support for self and sibling programmes, CCS Disability Action: Support for ASD child and parents. [I] have been very grateful for any and all support.

As the Autistic Spectrum covers such a wide area and the needs are so varied, the support that is available may be lopsided. Services for persons on the lower functioning end of the Autistic Spectrum may be more plentiful, whereas for higher functioning members, shortage of services was the case. It is possible to argue that prioritisation of services is the cause because of the assumption that a higher functioning individual would be better equipped to cope on their own.

Brenda: Very little available for Asperger's, Autistics have a lot more care/provisions available to them. Aspies are just expected to get on with it

While this may indeed be the case, there would be certain areas, social skills for example, where support was needed. Gaps in service provision for higher functioning members of the ASD community were identified during the preparation process of the 'New Zealand Autism Spectrum Disorder Guideline' and these should be addressed when services suggested by the guideline are rolled out.

9. 11 Early Bird Programme: An education programme for families of children with ASD

The Early Bird programme was developed by the National Autistic Society in England and was subsequently modified and adopted for use in New Zealand. It is essentially a programme to

educate the parents of children with ASD so that they are placed in a better position to cope with their child's behaviour and to help develop their child's communications skills. The Ministries of Education and Health jointly fund the programme and it is administered by Autism New Zealand. The term 'Early Bird' relates to the programme being offered to parents soon after a diagnosis of ASD has been received (Birkin, Anderson, Moore & Seymore, 2006). A number of research participants in this study have previously taken part in the Early Bird programme.

9.11.1 Case study findings: Early Bird programme

Pam and Mike

Pam: We did that when Thomas was four, just before he started school; it was a bit 'airy fairy'.

The style of delivery was seen to be a limiting issue of the programme's effectiveness.

Pam: They [the facilitators] treated us parents as being a group of school kids.

An advantage of using a group situation to deliver the course was that it enabled the participants to exchange information with one another and to learn for other peoples' experiences.

Pam: We gleaned more information from the other parents more than the facilitator. You were kind of made to feel that you had to go. You could not say that you could not go next week because it did not suit.

A difficulty in providing a course of this type would be achieving a common ground on which to base the course when individual participants' needs and circumstances varied.

Pam: It did not make a whole lot of difference to us because we were more proactive than they wanted us to be kind of thing.

9.11.2 Survey findings: Early Bird programme

It should be noted that at the time participants in this study used the Early Bird programme, it had only just been introduced and that as time passed, the Early Bird programme would have evolved. Nevertheless, it is useful to hear the experiences of families accessing this programme in order that services continue to develop programmes in this vein.

Jane: The good part was [the] home visits by the facilitator who could address our individual needs. The part that did not work was that we were [the] only family in our intake dealing with [an] Asperger's type child and most of the course was pitched at those who did not have speech ... much information although [of] high quality, was delivered in a somewhat rote manner of reading from printed material, this made it hard to pay attention to.

By visiting the parent's home, the facilitator would be in a better position to evaluate individual circumstances and in so doing, be in a better position to cater for the unique needs of individual families. A potential drawback would be the necessity for the Early Bird programme to cater for families with children right across the Autistic Spectrum.

Increasing parents' knowledge of ASD would place them in a better position to cope with the demands ASD placed up on them. An advantage of group participation would be that parents would be able to discuss elements of the course with each other thereby obtaining an improved understanding of ASD. In addition, an opportunity to extend individual networks would provide further benefits.

9.12 Living location

Families make decisions about where they reside based on a multitude of factors including financial considerations, proximity to workplaces, lifestyle choices, support services, friends and family. When a family member has ASD, other factors may be part of the decision-making

process. For instance, sensory issues can play a major role with ASD, or the need for a secure environment away from major traffic routes may influence any decisions about where the family will live. Furthermore, school zoning may play a part where a family moves to be in the zone of a school that has a reputation for providing the type of educational support required by the family.

9.12.1 Case Study Findings: Living location

Mavis and Frank

Mavis and Frank's choice of living location was determined by the availability of housing rather than their two children having ASD.

Pam and Mike

Identifying a school that catered for the needs of a child with ASD and moving to live in that zone served by it was a conscious decision for Pam and Mike.

Mike: We moved into the area because of Thomas' autism [and] because of the school's zone. The school was known for catering for special needs. At the time, the chap who was head of the special needs department we knew of so we got ourselves positioned so that we would be in the school's zone. That was our prime motivation for moving to this part of town.

Pam: We also moved because there was a kindy close to the school we felt we needed the kindy as well so that there would be less change.

Adapting to change has been identified as a major issue for people on the Autistic Spectrum, as a period of transition is normally required for an child with ASD to adjust to a new environment and routine. Pam and Mike's decision to live in the area was also based on the practical consideration of how they could facilitate school visits from the local kindergarten, before their child started school. They were also aware of the advantage of their child already knowing some of the class members with whom they had been at kindergarten.

9.12.2 Survey findings: Living location

Survey participants resided in a mixture of town and country areas, and contrary to expectation, none of these participants identified that their choice of living location was associated with their child's ASD.

9.13 Alternative Treatments and Fads

As work on this thesis progressed it became apparent that a section that should be covered was the impact that alternative treatments and fads had on some of the ASD population. As the questionnaires had already been completed, a question regarding alternative treatments and fads was included in the case studies and the service provider interviews only.

When families are faced with a developmental condition where conventional medicine has no cure, it is not surprising that alternative methods are pursued by parents who are striving to do the best for their child.

As noted in earlier chapters, ASD has been described as 'A late 20th century fad magnet' (Metz, Mulick & Butter, 2005). A stock standard Google internet search will uncover many different treatments purporting cures that are unsupported by scientific evidence that could ultimately cost thousands of dollars. As has been noted, parents of newly diagnosed children may be in a situation where they are willing to consider any type of cure. It is this vulnerability, coupled with their sense of grief and loss, or impacts on family functioning that could lead to a search for a cure for their child. They may also be driven by desire for their child would have a chance of leading a 'normal' life. Participants were asked if they had tried or were aware of any alternative treatments or fads.

9.13.1 Case study findings: Alternative treatments and fads

Pam and Mike

At the time of the case study interview, their son Thomas was taking part in the Dore Programme. The Dore Programme is marketed as a drug free alternative treatment for persons with Developmental Dyslexia, Attention Deficit Hyperactivity Disorder, Dyspraxia and Asperger's syndrome. The programme is based on the assumption that 'Cerebellar Developmental Delay' is the cause of the child's problems and that the problems could be overcome by a regime of exercises focussed on the development of balance and motor skills which include among others, balancing on a wobble board and throwing and catching bean bags twice a day for ten minutes. The exercises are intended to stimulate cerebellar development that in turn would lead to an improvement in reading and social skills.

9.13.2 Service Providers: Alternative treatments and fads

In a system where services are administered locally and deinstitutionalisation is a feature of the care of people with a range of support needs, including ASD, family have a lot of responsibility and choice. However, the range of choice can be vast and the views about efficacy and relevancy of treatments polarising. This is something that service providers are aware of:

Service A: Yes there are lots, if something works for somebody then that is fine. But you are not going to cure autism, you are going to manage it and you are going to try and minimise the impacts of ASD There are people who support a biomedical approach. There are people who support different behavioural management programmes such as ABA therapy, the Dore programme, the Hannah programme. Yes sometimes there are positives but you have got to be very careful that if you do access a so called alternative therapy it is done with professional consultations.

It can be argued that merchants selling alternative treatments/cures for autism are taking advantage of people when they are at their most vulnerable - post diagnosis. The vulnerability of families is noted by one service provider participant:

Service A: There is a lot of stuff on the Internet that is very emotive and out of control and it can become incredibly expensive; it can overtake everybody's focus. You do have to be careful about so called alternative therapies. Some people have had results that they say are absolutely credited to whatever therapy they are using. You have to be wary ... there is a lot of hype around and you should be very careful around how scientifically evidence based the research is and quite often it is subjective, based on a very small sample base and I think that anything that talks about curing and totally controlling needs to show it can be substantiated by evidence based research.

Advertising of some treatments are often supported by research purporting the effectiveness of the treatment and frequently feature testimonials from 'satisfied' customers. Evaluation of the research has often found that the research techniques were flawed or based upon subjective opinions rather than scientific fact.

Service D: The majority of the families I work with would not have the discretionary funding to pay for any interventions, therapies etc. that are outside the government funded ones. There are numerous interventions available to address most concerns, some funded and some not. I have not heard of any 'alternative' therapies in recent times.

While arguably no longer a fad, Applied Behaviour Analysis (ABA) has been used by many people. The younger the child with ASD is when they begin ABA, greater success seems gained with this intervention method and therefore the longer they may be involved in it. Because of the intensity of the programme - up to 40 hours of therapy a week, the costs involved can be high. With any type of conventional or alternative treatments, costs are involved.

Service B: There are people out there who are spending big money on ABA, on various therapies that they hear about because they think it is going to be the answer to their prayers. They mortgage their houses in order to pay for it. If they do not do that and they have not got a home of their own, they will go without firewood and food to pay for these things because I have seen it. And, I have seen children of similar abilities who have never had those inputs but have had the traditional way of

working using visuals and social stories who have done just as well if not better. We are all individuals and it is the parent's right to choose and that is the way it should be but not to the extent of them missing out on quality of life that is going to be detrimental [to rest of the family].

Scope exists for alternative therapies to be used where there was evidence to support the effectiveness of the treatment or when other organisations had the necessary experience.

Service E: I am aware that in the whole area of autism there are a lot of fads, we are not prone to follow fads or trends that do not have any evidence basis to them, where things move out of a realm of experience, we would liaise with whomever would be the most appropriate person, people or agency ... we would not go off and do something because somebody said it was a good idea.

It will be remembered that ASD impacts on communication with others; in some situations a facilitator (not necessarily human) could be used to establish a means of communication.

Service C: There was a film about a young ²⁹boy. [His parents] were having real issues with his autism. They bought him a puppy and just by a fluke, he responded to a question [they asked] by pretending [it was the puppy who asked it], they actually communicated through the dog in the third person.

Alternative treatments for ASD abound, some may be helpful to control the symptoms and improve a child's level of functioning but not deliver a cure. It is possible to argue that because the cause of autism has yet to be established, it is not possible to cure of the disorder. The cost of any alternative intervention would be a consideration for some families. In some situations, the costs could result in hardship being experienced by family members. Service providers do have scope for trialling alternative remedies where evidence suggests that there has been some effect. Outside expertise could also be utilised in situations where a lack of experience existed.

²⁹ After Thomas (2006)

9.14 Perceptions of support provided by Autism New Zealand

Autism New Zealand's National Office is located in Wellington; they have a network of branches throughout New Zealand. Each branch provides a number of support avenues. According to their web site (<http://www.autismnz.org.nz/Branches/Canterbury.php>) support offered by the Canterbury branch includes:

- Support group meetings in Christchurch, Darfield, Rangiora and Timaru
- Holiday Programmes in Christchurch & Timaru
- Social Activities
- Regular E news keeping families up to date with happenings
- Quarterly Branch newsletters
- Local fundraising initiatives
- Workshops, training opportunities, parent education and information
- Monday Night Young Adult Support Group

The majority of participants in this project had used the services of Autism New Zealand's Canterbury branch. Parental training courses arranged by the branch and the holiday programme were two of the major services that were used. The library and the branch newsletter 'Mind Matters' were two other tools participants used.

9.14.1 Case study findings: Support provided by Autism New Zealand

In common with participants in the survey, the families in the case study were involved with Autism New Zealand in a range of ways and had multiple points of contact with the service.

Mavis and Frank

Frank: The Canterbury branch, we get their newsletter.

Mavis: We did go on that behaviour modification seminar which we paid for, and another which [we were given] tickets for.

Pam and Mike

Pam and Mike have been appreciative of the services that the branch offered. The tickets to the rugby were viewed as a special treat that enabled the family to have an unexpected break.

Mike: Holiday programme, we get their newsletter, we have used their library but not very often.

Pam: They gave us some free rugby tickets. They sent an email through saying you could get a pair of them. We knew that Thomas would not use them so Mike and David went. We got respite care with them; it was probably nice too for Thomas not to have David here for the evening. Nigel and I hired a movie and we had popcorn lollies and things.

9.14.2 Survey findings: Support provided by Autism New Zealand

Most survey participants had some involvement with Autism New Zealand's Canterbury branch and a number were very positive about the services they received.

Jane: The courses have been quite good, coffee mornings good. [I] wish they had [an] online forum ...

Depending on a family's circumstances, costs of accessing services was seen as a problem for some.

Nicole: The cost of transport and postage to access some resources available can make it even harder to access the services provided.

Those who had used the Canterbury branch's services were satisfied

Freda: [The service received was] absolutely outstanding.

Out of the services offered by the branch the following were used:

Jill: Information, advice, library books, courses and seminars, support group, school holiday programme.

With any service provided there will be people who do not feel that their needs are being met. It seems likely that when we are discussing a specialist service for a heterogeneous group of people, such as those with ASD, there will be some people who feel that their needs are not being met. Some participants in this study indicated that their support needs were not being met or there was insufficient focus placed on people with Asperger's syndrome. Support for older people on the Autistic Spectrum was another area where some participants felt increased attention should be paid.

Samantha: I did approach Autism New Zealand, the only support I have had is to ask to sell raffle tickets to raise money for them, or help stuff envelopes [which was] not very inspirational.

Brenda: They have lost touch with their client base, are not meeting the needs of Asperger's [people] and their families, are not advocating for ASD persons and families, and are not proactive in housing, employment, recreational activities, not attending to the aging ASD population, not lobbying government for Ministry of Education and Ministry of Health changes.

Participants held varied opinions. A further explanation for this could be the expectations of support that were held by parents that could not be met. Resourcing could have also been a reason, or because the Autistic Spectrum covers such a wide range of conditions, services may have to be concentrated on particular areas that were funded adequately and had higher client numbers.

9.15 Summary

Participants to the survey/case studies came from varied locations. Five resided in the Christchurch city area while the remaining two lived outside of the city. All of the families had at least one family member with an ASD diagnosis.

Among the survey participants, ASD did not play a part in the family's choice of living location. However, one of the case study subjects moved so that they could reside in the zone of a school with a known reputation for providing quality disability support to students.

Counsellors together with family and friends were mostly used as avenues to share any positive or negative aspects parents had after the diagnosis was received. Contact with other parents with children on the Autistic Spectrum was also seen as a source of support, contact was established either via parents groups such as the one operated by Autism New Zealand's Canterbury branch or via the holiday programme, also run by the branch.

For some families, obtaining a diagnosis posed an obstacle when local public health services were used. Some parents felt that a lack of professional experience and knowledge of ASD hindered the diagnosis while others were informed on more than one occasion that a lack of resources precluded a diagnostic assessment. According to the experience of one participant who was referred to the Canterbury District Health Board's Child, Adolescent Health Service, staff appeared to have little practical knowledge of ASD. Long waiting lists caused additional problems for some families. One participant felt that during the assessment for her son, she was being judged for her son's condition while another encountered a reluctance to 'label' her child. As a diagnosis was required before an assessment of needs could be undertaken, services could not be accessed until that had been done. All persons were diagnosed prior to the release of the 'New Zealand Autism Spectrum Disorder Guideline'. The guideline when implemented should assist with this process because of the procedures that have been devised to ensure a speedy diagnosis is received.

Most of the participants had a Needs Assessment undertaken and waiting times for it to be completed averaged about three months. Once in the 'system' the Needs Assessment was

reviewed on an annual basis. Some participants commented that the amount of support provided appeared to depend on the amount of knowledge the needs assessor had of ASD. An overall opinion was that the support offered was adequate. Carer support days designed for use as a means of informal support were provided to all participants and in the main, the number of days allocated was considered to be adequate. Respite care days (separate from the carer support days) were also available but was underutilised because of a lack of accommodation where there was suitably experienced staff.

Impacts varied. Acceptance from other family members or by professionals that something was wrong was seen to be an issue to some. A belief held among parents of higher functioning children was that as there was little outward sign that anything was wrong, it was difficult gain acceptance or understanding. The need to follow a structured life to accommodate an inflexibility to accommodate change placed pressure on other family members. For some, a lack of family spontaneity was an issue because of the need to plan activities in advance.

Financial impacts varied from family to family, and the extent that ASD impacted on each family was dependent on the family's financial position and the level of resources the family was able to provide, or had available. Sensory issues associated with ASD proved to be an additional expense. Finding basic items such as breakfast cereals or laundry detergent that had the right texture or did not leave a residue contributed to a family's costs. The cost of additional services or medications that were not covered by the health system provided difficulties for some.

Accessing financial support provided by Work and Income proved to be problematic when the case manager did not have knowledge of the impacts associated with ASD. One participant formed the impression that a veil of secrecy surrounded what the actual entitlements were and

that it was necessary to be familiar with what support was available before seeing the case manager.

The amount of educational support provided after the IEP was conducted depended on the amount of resources the school had at its disposal. Where support was provided it was mostly by the provision of teacher aide hours. A comment made was that in cases where a child had Asperger's syndrome, out- of-class support to help with social issues was more of an issue than actual learning support. Home schooling was used by one participant, and additional costs incurred with providing the necessary resources had proved to be an issue.

Services provided by the Canterbury Branch of Autism New Zealand had been used by many participants. Coffee mornings and their holiday programme together with access to many of the branch's resources proved to be valuable. Families also utilised educational opportunities that were offered. The Early Bird programme and attending visits by visiting experts on ASD were examples of these. The branch had seen a period of positive change as staffing and resources improved. In general, the services that were provided received a favourable response from service users.

The survey's findings epitomised the belief that no two persons with ASD are affected in the same way, and because of this, the services that families utilised varied. What could be regarded as a common denominator was that all families utilised the carer support days that were allocated.

Chapter 10

Discussion

Despite the relatively small number of participants in the current study, it was possible to gain some understanding of the experiences of parents of a dependant with ASD. Good insights were elicited into the impacts on parents and family generally, as well as their experience of using ASD support services.

10.1 Summary of the study

This study provided a snapshot of the experiences parents of a child with ASD had while using services for people with ASD. As there is no agency that provides day to day support exclusively for persons on the Autistic Spectrum, agencies provide services from within their existing offerings – and for some agencies these are generic services for clients with a wide range of issues. Following a review of the literature and reports into services in this country, it appeared that there was a general lack of support for persons with ASD across the Autistic Spectrum. It seemed plausible that if a dedicated agency serving persons with ASD exclusively was established the service limitations would be addressed. While it was found that diagnostic services required substantial improvement, this research has shown that locally the families who participated were generally well supported by agencies providing services from within their own resources. The high cost involved in accessing some educational opportunities that were offered was noted as a barrier by some participants in this study.

There is limited research into the formal support needs and experiences of families caring for a child with ASD and it is interesting to note that some of the findings of this study are consistent with the study commissioned on behalf of the Autistic Association of New Zealand in 2001. Some of the deficiencies in service delivery that were evident over a decade ago have emerged as issues for participants in this study. In both studies participants reported a belief that there is a limited pool of skilled personnel who are capable of providing a timely diagnosis had hampered their ability to access support. During the process of obtaining a diagnosis for their child, some participants received the impression that their parenting skills were being judged by the diagnostician and that they were being held responsible for their child's behaviour. As a

diagnosis is often required before support services are accessed, improvements in this area are necessary.

Varying degrees of success of the needs assessment process were reported and it was found that the more familiarity the needs assessor had of ASD, the greater likelihood of suitable supports being made available. A further consideration that could influence the success of the needs assessment was parental expectation of the type of supports that were needed and the resources that were available to provide them. It was noted by some participants that while there seems to be plentiful support for children with autism there is a lack of support for children with Asperger's syndrome.

Respite care was seen as an important issue for participants in this study. Respite care provides carers with the opportunity to have a break from the constant demands of caring for a child with ASD. It is arguably one of the most critical supports available to carers who find themselves stressed or not coping. It will be recalled that one of the service gaps highlighted in the Casey Albury-Thomson manslaughter case was the lack suitable respite care.

Participants in this study felt that the dearth of suitably qualified respite care providers, who were willing to undertake this work for relatively limited financial gain was an issue. Issues around the provision of respite care have been identified as a problem area that will be addressed in the 'New Zealand Autism Spectrum Disorder Guideline'. In contrast, carer support days, allocated as a means of obtaining informal support, were well utilised by participants in this study. The carer support allocations seemed to be much more able to be used by parents and seemed to provide crucial, if limited, support for parents who were not able to utilise respite care provisions.

Participants in this study described a range of personal and familial impacts associated with raising a child who has an ASD diagnosis. An impact that was common to most participants was the restriction of having to abide by strict routines placed on the spontaneity of family

activity and interaction with the extended family members. Some of the impacts for participants in this study arose out of other peoples misconceptions about ASD. Participants described a range of responses to the reactions of extended family or members of the community that included feeling the need to explain their child's behaviour to others, to make it clear that ASD is not a mental illness, and frustration when extended family members could not accept the fact that ASD is a life-long disability.

Additional semi-formal and informal supports were sought by some participants in the current study and these ranged from a community support worker to membership of parents' support groups. The Coffee group attached to the Canterbury branch of Autism New Zealand proved to be a popular choice. The Early Bird programme was used by two participants one was shortly after the programme was introduced and another later in the programme's development with varying experiences of success.

Families seek support from a variety of sources, including the internet. Some service providers commented on the alternative or 'fad' treatments that are widely advertised, and the high financial cost that some of them involved. One participant in this study utilised the Dore Programme and noted some success from the programme.

Routine and controlling the environment to minimise disruption are important in day-to-day life with someone with an ASD diagnosis. It had seemed possible that having a child with ASD would influence participants' decisions about residential location. However, unexpectedly, with the exception of one participant in this study who moved into the zone of a school with a proven reputation for catering for students with a disability, a family member with ASD did not determine the family's choice of residential location.

A number of participants utilised the support offered by ‘Special Education 2000’ and had IEPs in place. It was found that in some cases the support provided did not fit with the individual student when the support offered did not extend to social skills development outside of class. Continuity of teaching staff was an issue that was identified by one participant whose child had four changes of teacher in the same year.

One area that should not be overlooked is the contribution professional skills development provided by the two specialised ASD agencies to local services that are involved in the day to day support for persons with ASD. It is possible that their teaching opportunities have contributed to body of knowledge personnel working in the agencies possess – a cohort of workers that respondents were very positive about.

An issue that was common to most participants in this study was the need for them to be listened to and their needs to be understood. And, some of the parents were looking to the future when they raised the issue of services for adults with ASD.

A number of participants mentioned there was a lack of support services for adults with ASD, and this is an area that should be considered for future research and service development.

10.1.1 Participants in this study

The families who participated had at least one family member diagnosed with an ASD who resided in the Canterbury/West Coast area. With the exception of one, the choice of living location was not influenced by their child’s ASD. The only exception was when one family moved into the zone of a school with a proven reputation for catering for students with a disability. The service providers who participated in this project were able to provide their perspective on service provision in an environment when resources in some areas were limited. All service providers were located in the Christchurch city area.

10.1.3 Limitations of the study

There are a number of possible explanations for the low participation rate in the survey part of this research. Some that are suggested include:

- Bearing in mind the amount of extra time required to manage a family with a child with ASD parents did not have the time available to complete the questionnaire.
- The questionnaire recalled the frustration encountered while seeking a diagnosis or using support services.
- It transpired that during the study period there were other studies being undertaken which could have led to ‘survey overload’.
- Parents holding the opinion that as nothing had changed despite earlier research being undertaken, there was not much point in participating in another.
- The use of survey research as a method may not have been appropriate to the needs of the participant group. It may have been better to interview participants who may have welcomed the opportunity to talk to someone about their experiences.

Despite these limitations, some interesting and important information was shared and several key themes emerged in the analysis of the different survey data.

A limitation noted with the case study interviews was when some of the questions asked were not quite understood, this was overcome by modifying the question so that the context was understood but the meaning remained the same. A limitation common to both case study and service provider interviews was the potential to deviate off topic because of the varying avenues the conversation could take. To remedy the problem the original question was reiterated after a short time of discussion on the other topic.

10.1.4 Summary of key findings of this study

- The majority participants received their diagnosis via the public health system where delays were common whereas when the private health system was used, a diagnosis was obtained in a timelier manner.
- An assessment of needs had been obtained by most participants, it was found that the type of supports provided depended upon the degree of familiarity the needs assessor had of ASD.
- Respite care (as opposed to carer support which was found to be adequate) provision was seen by participants as an area that needed development because no formal support currently exists.
- Schooling was generally provided in the mainstream setting and those who had an Individualised Education Programme evaluation received the required supports.
- Services provided by the Canterbury branch of Autism New Zealand were utilised by many and were generally well received.
- A theme that occurred generally was that participants wanted to be listened to and their needs to be understood.

10.2 Key findings

Diagnosis: The majority of the survey participants had used the public health system to obtain a diagnostic assessment. A commonality in questionnaire responses was that there was a lack of understanding of ASD among professionals of the symptoms of ASD or there was a lack of available resources to make a diagnosis. An impression gained was that a system of ‘gate keeping’ was in place that restricted access to those who had the necessary experience. In contrast, those who had sought a diagnosis privately encountered little difficulty in obtaining a diagnosis for their child. Of course, private assessments are not an option for all parents, creating a tiered system of professional input and support.

As support services are accessed via a needs assessment, a diagnosis must be obtained before this can be obtained. Diagnostic delays seem to place an unnecessary burden on a family having

to ‘make do’ while the diagnosis was being obtained. Local findings corresponded with the overseas literature and the 2001 Autistic Association of New Zealand study that highlighted the need for diagnostic assessments to be provided in a timely manner.

Needs Assessment: The perception of some participants in this study was that the amount and range of supports provided to a child with ASD depended upon the degree of familiarity the needs assessor had of ASD. Parental expectations (which could account for some dissatisfaction) were identified as an issue when services that were requested either did not exist or there was a lack of available funding to provide the service requested. A number of participants had children with Asperger’s syndrome. A theme that was evident was there was little if any support available for these children. Generally the waiting time from applying for a needs assessment and it being done was in the region of two to three months which was considered to be satisfactory by many participants. However, a lack of staff continuity was seen as an issue.

Respite care/Carer support: Respite care is provided by a recognised provider and is intended to enable parents to have a break from their care-giving responsibilities. The ‘New Zealand Autism Spectrum Disorder Guideline’ identified a need for the provision of suitable services. All participants reported there was a lack of suitable respite care services available for families to use. They generally attributed this to a lack of suitably trained staff. However, carer support days, which is a separate support allocation, was used by families to provide informal care for the child with ASD as this was seen as being more accessible. It will be recalled that it was a lack of respite care that was implicated in the Janine Albury-Thomson manslaughter case. This discrepancy has been recognised in the ‘New Zealand Autism Spectrum Disorder Guideline’ when respite care provision has been rolled out this need should be addressed.

Special education: Most of the children received their education in a mainstream setting. Special education needs are determined by an IEP which is regularly reviewed. Teacher aides

were used or the facility was available if needed. Understanding needs was seen as an issue. A comment made by one participant was that it was not in-class support that was needed which is what is provided but support during break times to assist with social skill development. Parental experience contrasted with the literature reviewed, poor resourcing was seen as an issue which limited support. It is likely that the reason participants did not encounter difficulty was because the schools concerned had adequate resources. As this study only concerned a small group of people, it is not possible to indicate whether or not this is the case generally.

Alternative treatments: There is currently no cure for ASD and, perhaps because of this gap, a world wide market of interventions that purport to treat ASD exists. Many of the cures or treatments advertised are not supported by research and are invariably expensive. A question regarding alternative treatments was added after the survey component was completed when it was realised important information could be learnt. It was added to the case study and the agency interviews. It was found that alternative treatments were used by members of the local community. One case study participant used the Dore Programme with some success. Some of the agencies were aware of a number of their clients using alternative treatments and were aware of the high financial costs that were involved with some of them.

The local experience was supported by overseas research which reported that many alternative treatments were being offered. With the exception of ABA (which is the only treatment recognised by the 'New Zealand Autism Spectrum Disorder Guideline'), no other treatments reviewed were supported by reputable research.

Autism New Zealand services: Most participants utilised the services provided by Autism New Zealand's Canterbury branch. The trend reflected overseas research where support group membership was regarded as an important means of networking and sharing personal experiences. The importance of this specialist service and the identity that goes with it was clear from participants.

These points were seen as the key issues necessary to enable a family to function with a sense of normality. As a diagnosis is necessary to access most support services, obtaining one in a timely manner was seen as pivotal. Respite care or carer support was seen as a necessary component to reduce some of the pressure placed on families when a member has an ASD. Support in an education setting whether at school or at home would enable a higher quality of education to be obtained. Because of the inevitable high cost involved in procuring a ‘cure’ for ASD some awareness of the treatment fads that promise a cure and the potential pitfalls associated with them would act as a measure of protection against possible financial loss. Autism New Zealand’s role with a family is seen as valuable because of their access to resources a family may need.

Conclusion

The present study examined the experiences of parents of a member with Autism Spectrum Disorder and their experiences using informal and formal support services. It is important to note that some of the formal services are not primarily intended for persons with ASD.

An ASD diagnosis can be made from two years of age, and indicator that something could be wrong is when a child's developmental milestones are delayed or absent. The family's general practitioner is usually the first person consulted and this will normally result in a referral to a specialist service. However, access to specialist services, and the process of the child receiving an assessment for ASD was not always equal.

It has been argued that, within a context of moving to community care and increasing family responsibility for welfare and wellbeing, New Zealand has not had a very good record at service provision for people with ASD. These shortcomings were identified in an inquiry that followed the manslaughter conviction of Janine Albury-Thomson after the death of her autistic daughter Casey. The trial judge's intention, in calling for an inquiry, was to establish whether or not government policy was responsible for the Albury-Thomson family's predicament. The fact that the 'New Zealand Autism Spectrum Disorder Guideline' in 2008 was an outcome of the inquiry suggests an acknowledgement that changes were needed and that government policy of the day had played a part in the tragic outcomes for the Albury-Thomson family. The guideline sets out a procedure that should be followed during a diagnostic assessment and sets a benchmark for the type of support families with a member with ASD should receive. Because diagnosing ASD can be difficult, specific guidelines are provided that should be followed by the diagnostician.

Participants in this study used either the public or private health system. Those families that had financial resources that enabled them to access private sector assessors obtained an ASD diagnosis for their child in a much timelier manner. Families using the public system experienced delays, at times felt judged, and in some circumstances, encountered a reluctance to diagnose at all. Consistent with the 2001 Autistic Association of New Zealand study, some participants in this study formed the impression that staff did not have the necessary skills with which to carry out an assessment for ASD.

Contemporary policy focus on efficiency targets and accountability for expenditure could contribute to the difficulty families described in obtaining a diagnosis. The reluctance to make a

diagnosis could be symptomatic of a system that avoids responsibility for the ongoing costs associated with supporting a family with a child with ASD.

It must be noted, however, that participants in this study received their diagnoses prior to the release of the 'New Zealand Autistic Spectrum Disorder Guideline' in 2008. As the guideline is intended to inform professionals on support that should be provided to people on the Autistic Spectrum, scope exists for future research to establish whether or not it has contributed to an improvement in service provision. Greater understanding of the needs and experiences of families of a child with ASD is likely to improve the services that are provided to help them.

All participants reported that a needs assessment had been completed and that supports were put in place. However, perceptions about the quality of the assessment were varied, with some participants pointing to variability in the level of understanding the needs assessor had of ASD. Generally the waiting time for the needs assessment to be undertaken was three months which participants in the current study generally found to be acceptable. A lack of support for people with Asperger's syndrome was an issue for some respondents in this study. Service providers had a slightly different perspective on the needs assessment process and purpose. One service provider respondent noted that the needs assessment provided a means of gate keeping to ensure the service maintained adequate funding with which to operate while another used it to access additional funding to provide support to high needs clients. Some provider respondents saw their role as offering support during the needs assessment process, and to the newly diagnosed child and their family.

All but one respondent reported that their child with ASD attended school. Experiences with special education supports varied across participants in this study, but teacher aide support was the most commonly utilised. The amount of teacher aide support given depended upon the resources available to the individual school. A comment made by one parent was that support was needed with social skills development outside of class room - support that was not available at that point in time. Further research is needed into the supports required within the education system.

Families that participated in this study had dealt with a range of impacts over a long period of time. Impacts ranged from financial costs involved in catering for sensitivities or allergies to more personal impacts arising from a lack of understanding within the extended family or

externally about the child's behaviour. Overall, the support offered by the Canterbury branch of Autism New Zealand was found to be a valuable resource; although the cost of some of the courses that were available was seen as a barrier to some families. Further research into the lifelong needs of families is going to be critical to ensuring services remain responsive to family needs as the children with ASD and their caregivers age.

A relatively low number of participants meant that it was not possible to provide a generalised account of how the average family with a dependent with ASD interacted with support services. It was however possible to provide an account of the experiences of the individual families who participated. Regardless of the small sample size, the findings from this research have the potential to improve the lives of children with ASD and their families through generating knowledge and informing service provision. Greater understanding of which services are needed at which times in the process of seeking and receiving a diagnosis of ASD for a child in the family is required and future research in this field may address this gap.

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Appendix A: Participant Consent Form – Survey



Research project to:

Assess the accessibility to and the suitability of services provided to people with Autism Spectrum Disorder and their families in the Christchurch city area.

Survey

Participant Consent Form

I have read and understood the description of the above described project. On this basis, I agree to participate as a participant in the project.

I understand that any responses that I give will be treated as confidential.

In addition, I consent to publication of the results of the project with the understanding that my identity will not be revealed.

I understand that I may at any time withdraw from the project, including withdrawal of any information I have provided.

Participant's name (Please print)

Participant's signature

Date: _____

Appendix B: Participant Consent Form – Case

Study

Assess the accessibility to and the suitability of services provided to people with Autism Spectrum Disorder and their families in the Christchurch city area.

Case Study

Participant Consent Form

I have read and understood the description of the above described case study. On this basis, I agree to participate in the case study on the understanding that the responses I give will be treated as confidential.

In addition, I consent to publication of the results of the project with the understanding that my identity will not be revealed.

I understand that I may at any time withdraw from the case study, including withdrawal of any information I have provided.

I am aware that the interview will be audio recorded and I give my permission provided I have the opportunity to review the recording and/or the transcript should I wish to do so.

Case study participant's name (Please print) _____

Case study participant's signature _____

Date: _____

Appendix C: Participant Consent Form – Service Provider



Research project:

**Experiences of users of services provided to people with Autism or
Asperger's Syndrome and their families in the Canterbury/West Coast area.
Service provider
Consent Form**

I have read and understood the description of the above described case study. On this basis, I agree to participate in the case study on the understanding that the responses I give will be treated as confidential.

In addition, I consent to publication of the results of the project with the understanding that my identity will be kept confidential.

I understand that I may at any time withdraw from the case study, including withdrawal of any information I have provided.

I am aware that the interview will be audio recorded and I give my permission provided I have the opportunity to review the recording and/or the transcript should I wish to do so.

Participant's name (Please print)

Participant's signature

Date: _____

Appendix D: Questionnaire and Case Study

question sheet



Autism or Asperger's Syndrome Access to Services Survey

This questionnaire is part of a research project examining the experiences of parents of people with Autism or Asperger's Syndrome as a diagnosis. All responses to this questionnaire will be treated as confidential.

Participation in this research project is completely voluntary and should take no longer than 45 minutes to complete.

Your contact details are only required if you wish to be forwarded a copy of the completed report. Please supply your details on this separate piece of paper.

Please do not hesitate to contact me if at any time you require additional information or a copy of the research proposal. I can be contacted at the address above or either by phone at (03) 380-5007 or by Email pdr30@student.canterbury.ac.nz.

This project is being supervised by Ms Nikki Evans and/or Dr Annabel Taylor who are academics with the School of Social Work and Human Services. Please feel free to contact Ms Evans at 364-2987 extension 4958 should you wish to discuss any aspect of this proposed study.

In this questionnaire you will be asked questions that relate to your experiences of parenting or caring for a person with Autism or Asperger's Syndrome. You will also be asked questions about services currently available to you and your family.

A. BACKGROUND INFORMATION

1a. In what area of Canterbury/West Coast do you live? _____

1b. Did the sensory issues that are associated with Autism or Asperger's syndrome influence your choice of living location? Yes No

If **NO**, please state any other reason that influenced your decision:

2. How many adults live in the family home? 12345more

3. How many children live in the family home? 12345more

4. How many people are diagnosed with Autism or Asperger's Syndrome? 12345more

5. How old is the person with Autism or Asperger's Syndrome? _____ months/years

6. With which ethnic group/s does your family identify?

- New Zealand European/Pakeha
- New Zealand Maori
- Samoan
- Tongan
- Cook Island
- Chinese
- Korean
- Japanese
- Fijian
- Indian
- Other _____ (Please specify)

B. DIAGNOSIS

1. Thinking of the person in your care, has a formal diagnosis of autism or Asperger’s syndrome been obtained?

Yes No

2. How long has it been since the diagnosis was given? _____ months/years

3. Please make any comments regarding the pathway to diagnosis. (*Use a separate sheet if necessary*).

4. Have you experienced any disappointments and losses in this journey, if so, who do you talk to about them? (*Tick all that apply*)

- | | |
|---|---|
| <input type="checkbox"/> professionals | <input type="checkbox"/> partner |
| <input type="checkbox"/> family | <input type="checkbox"/> friends |
| <input type="checkbox"/> no one | <input type="checkbox"/> other parents of children with an Autism or Asperger’s syndrome as a diagnosis |
| <input type="checkbox"/> other (please specify) | _____ |

Please describe the disappointments or losses (*Use separate sheet if necessary*)

5 What have been the **negative** impacts of living with a person with autism or Asperger’s syndrome? i.e. on parents, grandparents, siblings, etc. (*Use separate sheet if necessary*)

DIAGNOSOIS continued

6 What have been the **positive** impacts of living with a person with either Autism or Asperger's syndrome?

i.e. on parents, grandparents, siblings, etc. (*Use separate sheet if necessary*)

7. Who do you celebrate the successes and positives with? (Tick all that apply)

_____ professionals

_____ partner

_____ family

_____ friends

_____ no one

_____ other parents of children with an Autism or Asperger's syndrome diagnosis

_____ other (please specify)

8. Has parenting a person with Autism or Asperger's syndrome had any financial impacts for your family?

Yes No

If yes in what way?

11. What has been helpful about the support the agency has given? *(Please detail)*

12. What have you **NOT** found helpful with the support given? *(Please detail)*

13. Does your family have a community support worker? Yes No *(If no, go to question 17)*

14. How long has this community support worker worked with your family? _____ months/years

15. What has been helpful with the support given by the support worker? *(Please detail)*

16. What have you **NOT** found helpful with the support given by the support worker? *(Please detail)*

17. Thinking of the support the community support worker has given, overall, was the support focused on autism or Asperger's syndrome? *(Please circle)*

1 2 3 4 5

very focused on issues
specific to autism or Asperger's syndrome

minimal focus on issues
specific to autism or Asperger's
syndrome

24. Looking now at the support you have received, overall, how focused would you say the support was? *(Please circle)*

1	2	3	4	5
very focused on issues specific to autism or Asperger's syndrome				minimal focus on issues specific to autism or Asperger's syndrome

25. Has your family accessed Youth Specialty Services? Yes No

If YES, were you satisfied with the service given? *(Please circle)*

1	2	3	4	5
very satisfied				completely unsatisfied

26. If you were unsatisfied, how could the service offered by Youth Specialties be improved? *(Please detail)*

27. Looking now at the support you have received, overall, how focused would you say the support was? *(Please circle)*

1	2	3	4	5
very focused on issues specific to autism or Asperger's syndrome				minimal focus on issues specific to autism or Asperger's syndrome

D. EDUCATION

1. If a child, is she/he:

Attending an early childhood centre Yes No

Attending school Yes No

Home schooled Yes No

If none of these options apply, please indicate in the space provided the type of education your child receives: _____

2. The Ministry of Education has a number of support services such as education support workers and teacher aides to help children with learning disabilities. Does your child have access to this assistance? *(please circle)*

Yes No

3. If YES, please state how many hours per week the support is available: _____ hours

4. Is the level of this support adequate for your child's needs? Yes No

5. If NO, how could the support given be improved? *(Please detail)* *(Use separate sheet if necessary)*

6. Looking now at the support you have received, overall, how focused would you say the support was? *(Please circle)*

1	2	3	4	5
very focused on issues specific to autism or Asperger's syndrome				minimal focus on issues specific to autism or Asperger's syndrome

7. Autism New Zealand runs the **Early Bird Programme** which is jointly funded by the Ministries of Health and Education. Has your family accessed this service?

Yes No

8. If YES, did the Early Bird Programme meet your needs? Yes No

9. If NO, how could the Early Bird Programme be improved? *(Please detail)*

E. GENERAL

1. Have you used the services provided by Autism New Zealand? Yes No

If YES, was this the

National Office?

Canterbury branch?

Please state any comments about the service provided

Thank you for the time that you have taken to respond to this survey.

Appendix E: Question list for service providers

- 1 Can you tell me about your organisation and the services you provide?
- 2 How many people would use your services?
- 3 Do the people you work with have a diagnosis, if so, what is it?
- 4 Have the people you work with had a Needs Assessment?
- 5 How is your organisation funded?
- 6 What supports do you think families need?
- 7 Can you comment on the adequacy of the services you provide?
- 8 What services would you provide if more funding was available?
- 9 Because ASD does not fit as a psychiatric or intellectual disorder, where do you think the disorder would fit the best?
- 10 If ASD was placed in a category of its own, do you think it would be easier to supply support services?
- 11 What comments can you make about government policies that impact on services used by families?
- 12 Do you think the ASD Guideline has made any impact on service provision, if so, what do you think the impact has been?
- 13 What do you think are the key impacts on families who have someone with an ASD diagnosis?
- 14 What do you think are the key issues for families accessing support services?
- 15 Are you aware of any alternative interventions that have been used by families, if so, what types?
- 16 What other services do you work closely with?
- 17 Are there any other comments you would like to make?

Appendix F: General Advert

Research Participants Wanted

Assess the accessibility to and the suitability of services provided to people with Autism or Aspergers Syndrome and their families in the Canterbury/West Coast area

Hi, my name is Paul Rawdon; I am currently a student at University of Canterbury working on a Master of Arts degree in Human Services. I am carrying out a research project into the ease of access to and the appropriateness of services that are available for people with Autism or Aspergers Syndrome. I have been the caregiver of someone with Asperger's Syndrome for the last 10 years and during this time I have gained some knowledge of the problems that can be involved when trying to access appropriate support within the community.

As part of a broader research design, I am intending to conduct a survey using a questionnaire among fifty families who have a family member who has been diagnosed with either Autism or Aspergers Syndrome. I am interested in hearing about your family's experiences of coping in a community where there are no dedicated services available.

I have set some questions in the questionnaire for people to answer that are set around social support and the effectiveness of the support services you are receiving. I am also interested in hearing of any positive experiences and/or difficulties you have experienced while obtaining an appropriate diagnosis.

I hope that talking about your experiences will be helpful and that the things that you have to say may be useful to obtain a broader indication of quality of support people with Autism or Aspergers Syndrome and their families are currently receiving.

**THIS STUDY HAS BEEN APPROVED BY
THE UNIVERSITY OF CANTERBURY HUMAN ETHICS COMMITTEE**

If you are interested in participating in this survey, please contact

Paul Rawdon

by phone at (03) 380-5007

or by email at pdr30@student.canterbury.ac.nz

for a questionnaire to be mailed to you.

or via the internet <http://sites.google.com/site/asdsurveychch/asd-services-survey>

Appendix G: Advert for ANZ e-Newsletter

Research Participants Wanted

Assess the accessibility to and the suitability of services provided to people with Autism or Aspergers Syndrome and their families in the Canterbury/West Coast area

My name is Paul Rawdon; I am currently a student at University of Canterbury working on a Master of Arts degree in Human Services. I am carrying out a research project that is designed to assess the ease of access to and the appropriateness of services that are offered to people with Autism or Asperger's syndrome and their families.

I am interested to learn of your experiences of receiving support in a community where there are no dedicated services for people with either Autism or Asperger's syndrome. I have prepared a questionnaire for you to complete which can be obtained by clicking on the download link below.

Any input that you can provide will be greatly appreciated. Please note that this survey is open to residents of Canterbury/West Coast areas only.

For additional information please contact me by phone at (03) 380-5007

By Email at paul.rawdon@pg.canterbury.ac.nz

You can download a copy of the questionnaire

(To download a copy use the link on the to right hand corner of the page).

Please return your completed questionnaire by Email to the address above or by post as soon as possible.

Mailing address:

Paul Rawdon
Student
School of Social Work and Human Services
University of Canterbury
Private Bag 4800

Christchurch 8140

Appendix H: Letter to Autism New Zealand

June 13, 2007

The Chairperson
Autism New Zealand Canterbury Branch
PO Box 42014
Addington
CHRISTCHURCH

Dear Sir/Madam

I am currently a student at the University of Canterbury working on a Master of Arts in Human Services. I have been the caregiver of someone with Asperger's Syndrome for the last 10 years and during this time I have gained some knowledge of the problems that can be involved when trying to access appropriate support within the community.

I am hoping to carry out a research project that will examine access to and the appropriateness of services that are available for people with Autism Spectrum Disorder. I am currently developing the research framework and proposal to undertake this research and am contacting you regarding this.

I have an Honours degree in Sociology and one in Human Services both of which have provided me with knowledge and skills to undertake a research project of this nature

One of the purposes of the study that I am proposing is to compare the accessibility and appropriateness of services that are available today with those that were available at the time of the release of *Autism services in New Zealand: a report by the interdepartmental 'Autism Services Project' team* report (also known as the 'Curry Report') in 1999 which was the result of the inquiry called for by the trial judge at the sentencing of Janine Albury-Thomson for the manslaughter of her autistic daughter Casey in 1998.

It is anticipated that the study will be in two parts, the first being in the form of a survey that would involve up to fifty families who will be asked to complete a questionnaire relating to the accessibility and suitability of services offered to people with an ASD and their families. The second part will consist of a case study that will involve two families who will be asked to complete a questionnaire and a follow-up interview. In addition, relevant service providers would be interviewed as a part of the case study research.

Participation in this research project would be completely voluntary and the research processes would ensure privacy of those involved.

Your assistance in publicising this project among branch members would be very much appreciated.

Please do not hesitate to contact me if at any time you require additional information or a copy of the research proposal. I can be contacted at the address above or either by phone at (03) 380-5007 or by Email pdr30@student.canterbury.ac.nz.

This project is being supervised by Ms Nikki Evans and/or Dr Annabel Taylor who are academics with the School of Social Work and Human Services. Please feel free to contact

Ms Evans on 364-2987 extension 4958 should you wish to discuss any aspect of this proposed study.

I hope that you will be able to assist me in this project by advertising the research in your newsletter and/or informing members of the research. I would appreciate it if you could consider this request.

Thank you for time in reviewing this matter.

Sincerely,

Paul Rawdon,
Student

Appendix I: Human Ethics Approval

HEC Ref: 2007/100

21 September 2007

Mr Paul Rawdon
School of Social Work and Human Services
UNIVERSITY OF CANTERBURY

Dear Paul

The Human Ethics Committee advises that your research proposal “The Accessibility to and the suitability of services provided to the families of people with Autism Spectrum Disorder in the Christchurch city area” has been considered and approved. However this approval is subject to the incorporation of the amendments you have provided in your email of 27 July 2007.

Yours sincerely

Dr Michael Grimshaw
Chair, Human Ethics Committee

Appendix J: Reflexive Methodology

Reflections on a journey

When I started this project I thought I had a pretty good grounding on Autism Spectrum Disorder was about. I had lived with someone with Asperger's syndrome for 12 years, I thought that my experience negotiating the 'trials and tribulations' of living with someone on the Autistic Spectrum would have given a good grounding for writing this thesis. How wrong I was! In fact the more I delved into the subject the more I found that I did not know.

With the broad information available, I found that it was difficult to decide what information to cover and what to leave out. As a result, I found that when I found something that was of particular interest it was easy to go off on a tangent. This was the case with Chapter 5 'Alternative treatments and fads'. The additional information I gathered could form the basis of a journal article in its own right. As there is as yet no definitive answer to the cause of ASD, there are many 'treatments' on offer and I found some of them fascinating. I found they ranged from merely expensive - all had at least some cost involved one being Doctor Wong's biomedical treatment book which included a free 'help me' phone consultation valued at \$100 along with two 'help me coupons', the total package cost \$149 to being outright dangerous, examples being chelation therapy a technique to remove heavy metals from the body and the Geier's Lupron therapy. Lupron is a chemical that among other things is used as a treatment for prostate cancer or the chemical castration of sex offenders. Out of all the alternative treatments I did review, I think the one which captivated my imagination the most was dolphin assisted therapy and swimming with dolphins – a nice thought especially if the therapy took place at a tropical holiday resort! The historical ASD treatments were also of interest, and I discovered that knowledge I acquired from the Social Control Sociology course about the early uses of drugs gave me a better understanding.

The research was a personal challenge too. When I started this work I had the hypothesis that the support services on offer to people on the Autistic Spectrum were very limited and those that did offer services had a limited knowledge. While this may have been true 15 years ago, a lot has changed. A consequence from my research was that I found that my initial impression was wrong. The impression that I now have is that things are a lot better. True, I discovered areas where improvement was still necessary for example: diagnosis and assessment procedures in the public health system. But overall, in areas where support is offered, there are many good knowledgeable people out there doing good things. Perhaps one of the most important things that I learnt was that the attitudes of everyday people and professionals impacted in some way on the amount of support received.

I originally held the belief that a dedicated agency should be established that dealt exclusively with people on the Autistic Spectrum. This was one of the questions I put to the five service providers. After one of them pointed out that to establish such a service would be a waste of resources because of the good work that is already being undertaken by existing services I could see that this was not necessary.

A consequence of the negative belief (and social justice) perspective I held prior to beginning the thesis, was that the original draft took the form of a witch-hunt. A second rendition read more like a self-help book rather than a piece of academic work. Following some *stern* comments from my supervisor, the focus evolved into the format I have today.

The journey has had its ups and downs, health issues forced delays and the impacts from the four large earthquakes and their seemingly never ending aftershocks made it difficult to

maintain focus at times. I am grateful to the university for their understanding and importantly, I felt privileged to have had people share their stories with me.

I have thought about what I would like to achieve from writing this thesis, my thoughts are that by gathering a large quantity of information from a lot of different sources, some that was unpublished such as the Autism Services in New Zealand report, I have managed to put this information into one location so that others can gain the benefit. In effect, what this thesis represents is the culmination of all the essays and projects that I have done on ASD throughout my university career.