A hermeneutic phenomenological study of the lived experience of parenting a child with autism

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Certificate of Authorship/Originality

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

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Signature of Candidate
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Abstract

It was identified that there was little published research into the lived experience of parenting a child with autism that utilised a qualitative approach. There was a paucity of material in the literature, beyond single parent accounts, for a nurse to turn to develop a beginning understanding of the experience. There was also little for a parent to compare their own experience with. This study of the lived experience of parenting a child with autism provides an exploration of the experience within the framework of a hermeneutic phenomenological approach. Initially nine parents were interviewed and the resulting transcripts analysed. This analysis was taken to four focus groups to allow the parent’s voice to remain active in the refinement of the analysis. The parents reported a strong resonance with the analysis and the discussion fell silent. The experience identified was not that of a series of activities but profound changes to the self of the parent. This is considered in the discussion in the light of the existential challenge to the parent’s being posed by the demands of parenting a child with autism. Chaos theory and its mathematical applications are considered as a potentially fruitful way to pick up the conversational relation with the question of, “what is the lived experience of parenting a child with autism”? 
Introduction

The aim of this text is to provide one side of a dialogue with the reader. By virtue of the nature of text the openness of a genuine conversation cannot be obtained but the aim is to provoke the reader to question further in the direction pointed to by the text. “Genuine questioning always involves a laying open and holding open of possibilities that suspend the presumed finality of both the text’s and the reader’s current opinions” (Linge, 1976:xxi). It is not hoped that the worldview of the author will become that of the reader, but that the reader will make their own the question which motivated the text. The question of - “what is the lived experience of parenting a child with autism”?

Two out of every five hundred parents will face the prospect of being the biological parent of a child with autism (Autism Association of NSW, 2001a; Committee on Children with Disabilities, 2001). Three DSMIV diagnoses represent the autism spectrum. The three diagnoses that form the spectrum, and which are referred to generally as autism in this study include, Autistic Disorder, Asperger’s Disorder and Pervasive Developmental Disorder not otherwise specified (Atypical Autism). There is little in the literature that goes beyond the account of single families that allows someone who is not in the position of being the parent of a child with autism to understand what the experience of parenting a child with autism is like. There is correspondingly little for a parent with a child with autism in the literature to compare their experience to. What is the lived experience of parenting a child with autism? This is the question that will be posed again and again by the text as the process of an attempt to understand this experience unfolds. The understanding reached will be, by the nature of any understanding, partial and incomplete as it is situated historically and in the facticity of the participants, the author and reader.

Hermeneutic phenomenology is used in an attempt to form a bridge that allows understanding, between the reader’s life world and that of the parents of children with autism. “It seems, rather, to be generally characteristic of the emergence of the hermeneutical problem that something distant has to be
brought close, a certain strangeness overcome, a bridge built” (Gadamer, 1967/1976:22).

The utility of an understanding of what the lived experience of parenting a child with autism is arises in two areas. From a nursing standpoint a beginning appreciation of the experience allows a point of departure from which questioning may begin, after which, closer approximations to an individual parent’s experience are made in the hope to build empathy and launch into a therapeutic interaction. From a parent’s standpoint the understanding may provide a point of reference to what other parents experience. To answer the relativistic question posed by many, in what is a less than typical parenting situation of, “is this normal”? Thus the motivation to pose the question of, “what is the lived experience of parenting a child with autism”? “The motivational background of a question first opens up the realm out of which an answer can be brought and given” (Gadamer, 1966/1976a:67).

Locating the question in the process is easy compared with the demand present in our time of locating the researcher. A process whereby the qualitative researcher is called upon, as a measure to increase the trustworthiness and integrity of the research, to consider the influence of inter subjective factors upon the collection and analysis of data. “Reflexivity where researchers engage in explicit, self aware analysis of their own role offers one tool for such evaluation” (Finlay, 2002:531).

All research irrespective of methodology involves a creative act of mind (Lyotard, 1991). Science is in effect a social activity just as much as it is a rationally regulated discipline (Johnson, M., 1999).

In reality the hypothesis of constancy the empiricist claims to find through his observations is constructed by the mind, on the basis of possibly a single observation. We cannot induce a law from a large number of cases, this is an idealising function, fabricated by the physicist which
draws its explanatory power not from the number of facts on which it is based, but from the clarity it brings to those facts (Lyotard, 1991:97).

In empirical research the fiction is then put to experimental test, but it remains that the hypothesis and choices of procedure involve an act of mind. “Because the author intended something specific, the interpretation that recovers and represents that original intention is the correct one that banishes all competing interpretations as incorrect” (Linge, 1976:xxiv). Quantitative experiments can be repeated under the same conditions and provide the same answer. The author’s intention forms a fact that is verified by the correct interpretation.

The act of mind or intentionality of the researcher in the context of quantitative research often goes unacknowledged without claims of reduced vigour or integrity of the process. “Yet this social engineer, this scientist who undertakes to look after the functioning of the machine of society, appears himself to be methodologically alienated and split off from the society to which, at the same time, he belongs” (Gadamer, 1967/1976:40).

Bruno Latour (1999) joined a group of scientists who visited the Amazon Rainforest to observe how they went about the process of science. This study provided a good example of the acts of mind involved in quantitative research. Through the study he identified several points where an act of mind took place. One example involved two scientists rubbing soil in their hands with spit in an attempt to mould it. The aim of the activity was to determine if it was sandy-clay or clayey sand. “Lacking any kind of gauge, Armand and Rene rely on a back-and-forth discussion on their judgements of taste, as my father would do when he tasted his Corton wines” (Latour, 1999:63). The question bandied back and forward of was it more clay than sand or more sand than clay? Once a decision was reached the sample was given a code. This code no longer pointed to the uncertainty of the process. The code was a sign pointing to a sample of soil with no reference to the process of determination. This particular sample, when added to many others became part of the quantitative data of the study from which facts and laws may be generated.
“Nevertheless, drawing upon positivistic methods of data collection and reasoning, scientists working in the physical sciences generally have enough confidence in their understanding of these laws to make aeroplanes and most of us have enough confidence in both the scientists and the manufacturers to fly thousands of miles in them to give papers to academic conferences” (Johnson, M., 1999:68). Despite the obvious accomplishments of quantitative science the point remains that the act of mind in the process is real and is largely unacknowledged.

Reflexivity suggests a process of self-conscious reflection. Kleinsasser states that writing to learn is another name for the process of reflexivity. “Writing to learn makes thinking visible, it can be inspected, reviewed, held up for consideration, and viewed as a set of data” (Kleinsasser, 2000:158). Those who have written of reflexivity often make it sound ubiquitously accepted and based on notions not considered by others to be problematic. Prus states that although researchers face many challenges in coming to terms with and understanding the life worlds of those they encounter, “it may be counterproductive despite some postmodernists encouragement along these lines for ethnographers (researchers) to dwell extensively on the more unique features of the researcher’s consciousness” (Prus, 1996:253). Whether self-conscious reflection is productive or counterproductive rests largely on perception of the possibility of the act of self-conscious reflection.

The question what is the thesis of this thesis requires less explanation than the question of locating the researcher, a question posed as where is the researcher in the research? The short answer to this question is that, as the question arose from the researcher so did the attempts to understand the experience of parenting a child with autism documented in the following pages.

The methodology selected to work on an understanding is described in detail in section 4. As the methodology emanates not from science but from philosophy it represents an understanding of being hence permeates the thesis and is not
restricted to describing the process of enquiry. A brief consideration of a few key concepts of the understanding of being represented at this point will help situate the researcher and answer the question that concerns to what degree is self-conscious reflection possible.

To grasp the concept that phenomenology is not a discrete entity, but a tradition that has radiated from the thinking of scholars with related ideas, is important. Each within the tradition has written with a slightly different accent, which reflects what they find salient and where they are situated historically (Lyotard, 1991). The notion of the possibility of knowledge of self has evolved through the discussions and across time.

The man considered the modern father or founder of phenomenology was Edmund Husserl (1859-1938) (Gadamer, 1963/1976). He believed at least initially that a self-knowledge was possible. The characterisation of consciousness as self-consciousness was carried forward in his work. In line with Cartesian and NeoKantian thinking an unshakable foundation of certainty was perceived to exist (Gadamer, 1962/1976a). Husserl in an attempt to elevate philosophy to a rigorous science set about a process of reduction aimed at reaching the eidos or essence of phenomena in their pre-reflective state. This reduction was aimed at removing the subjective nature of the perceiver of the phenomena. A belief in the cogito ego was subscribed to (Gadamer, 1963/1976). The assertion of Rene Descartes (Cartesius in Latin) whose works were published between 1637 and 1664 contained the notion that, “the only valid criterion of truth was reason as an immediate intuitive certainty comparable to a person’s knowledge of himself – self consciousness” (Sahakian, 1968:133).

The notion of the ability to know and understand self was propagated into modern times by Husserl, and represented an heirloom of transcendental idealism (Gadamer, 1962/1976a). Husserl perceived the self as a knowing subject or ego, which stands in relation to a world of which it is conscious (Atwood & Stolorow, 1984).
The stumbling block to the plausibility of the possibility of removing subjectivity from the process of phenomenology was the realisation that suspension of the life world was not possible (Gadamer, 1969/1976). This is the concept that whoever is involved in the process of reflection upon self is surrounded by a world that they cannot extract themselves from. In this world different things pass as axiomatic or self-evident. “History informs us that spaces and time produce highly different life worlds in which highly different things pass as unquestioningly self evident” (Gadamer, 1969/1976:188). The notion that an investigator of phenomenon could disengage from the world, or step outside the world, to provide a different vantage point from which their own isolated reflections could determine the fundamental and universal nature of experience, controlled alienation, was problematic (Atwood & Stolorow, 1984; Gadamer, 1967/1976).

Husserl’s student Martin Heidegger (1889-1976), with the leg up provided by the work of Husserl, was able to achieve the so called turn in which the emphasis of phenomenology was shifted from the question of how we know what we know to the study of being. The turn arose out of Heidegger’s critique of Husserl’s work based on concern about the felt inexplicable relapse into Neo-Kantian thinking (Gadamer, 1963/1976). In Heidegger’s work the investigators ability to be self-conscious and the desirability of this was challenged directly. The historicity and facticity of each investigator were concepts that underpinned the notion that each Being can only view the world from the point where they are at, a point which is temporal. This point represented a place defined by a historical and situational context (Gelven, 1989). Each Being is a being-in-the–world and can not step out of the world to view something. Part of the influence of being in the world is as Heidegger put it the worldliness of the world, which is never fully disclosed (Dreyfus, 1991). “Heidegger’s analytic of Dasein (being) was to render unsuspendable precisely the life world Husserl intended to reduce and to replace the transcendental ego with being whose facticity reflection could not set aside” (Linge, 1976:xivi).
As part of understanding being Heidegger does not advocate that the self should not be distinguished in some way, “but the manner of such distinction and clarification must not be that of a fictional worldless subject separate from an object world” (Gelven, 1989:71). The distinction surrounded the authenticity or otherwise of their being conceptualised within their personal manifestation of being-in-the-world. Heidegger’s exploration of truth concretised the insight that for everything revealed other things are concealed. Thus one can come to know some truths about oneself but not all of them. Revealment and hiddeness are an act of being and belong together (Gadamer, 1960/1976).

Hans Gadamer’s (1900-2002, a student of Heidegger) understanding of prejudice provides a practical example to illustrate the point. In Gadamer’s writing a prejudice is simply a prejudgement. “This is a provocative formulation, for I am using it to restore to its rightful place a positive concept of prejudice that was driven out of our linguistic usage by the French and English Enlightenment” (Gadamer, 1966/1976b:9). Prejudices as prejudgements are actually the initial point of contact with a phenomenon out of which understanding arises. It is the initial directedness of our experience, the curiosity. “This formulation certainly does not mean that we are closed within a wall of prejudices and only let through the narrow portals those things that can produce a pass saying, ‘nothing new will be said here’. Instead we welcome just that guest who promises something new to our curiosity” (Gadamer, 1966/1976b:9).

If locating oneself as the researcher as suggested by those who advocate reflexivity involves a process of reflection, identifying prejudice as a factor of potentially biasing subjectivity, in keeping with Heidegger’s idea of truth, some problems emerge. “Reflection on a given preunderstanding brings before me something that otherwise happens behind my back. Something but not everything, for what I have called the \textit{wirkungsgeschichtliches bewusstsein} is inescapably more being than consciousness, and being is never fully manifest” (Gadamer, 1967/1976:38). For everything revealed by the very nature of revealment more is concealed. Further every time one preunderstanding is reflected upon, an understanding emerges, followed by a further
preunderstanding as preunderstandings ceaselessly form ad infinitum as long as the Being is.

Finlay in the discussion of reflexivity actually invokes Gadamer to aid clarification of the concept: “In Gadamerian terms, reflexivity involves a positive evaluation of the researcher’s own experience to help him or her understand something of the fusion of horizons between subject and object” (Finlay, 2002:533). In fact Gadamer argues strongly against the process of attempts of objectification of the inquirer.

Does hermeneutics really take its bearings from a limiting concept of perfect interaction between understood motives and consciously performed action, a concept that is itself, I believe fictitious. I maintain that the hermeneutical problem is universal and basic for all inter human experience, both of history and of the present moment, precisely because meaning can be experienced even where it is not actually intended (Gadamer, 1967/1976:30).

The event of understanding is not situated in the subjective but in the transubjective.

Gadamer’s principal contribution to hermeneutics is to be found in his concerted effort to shift the focus of discussion away from techniques and methods of interpretation, all of which assume understanding to be a deliberate product of self-conscious reflection to the clarification of understanding as an event that is in its very nature episodic and transubjective (Linge, 1976:xxviii).

What takes place in understanding transcends the manipulative control of the other.

“A tone is always a heard tone, and my hearing of the tone is always intrinsically involved” (Gadamer, 1962/1976b:123). The concept of which Aristotle (384-322
B.C.) wrote in the description of hearing the tone quoted was that, the primary object of hearing was the tone, but that hearer is also conscious of the process of having heard the tone. “Every perception is perception of the perceiving and of the perceived in one, and in no way contains reflection in the modern sense” (Gadamer, 1962/1976b:123). Understanding involves interpretation as an act or event in which a person takes up what is said to them and processes it in such a fashion that it finds an answer in his or her own language. “The real event of understanding goes beyond what we can bring to the understanding of the other person’s words through methodological effort and critical self control. Indeed, it goes far beyond what we ourselves can become aware of. Through every dialogue something different comes to be” (Gadamer, 1962/1976a:58). This something transcends the subjectivity of all involved in the dialogue.

The question is then, in the absence of the ability to be self-conscious to the degree stressed in the process of reflexivity, how is demonstration of rigour and integrity possible? Kleinsasser proposed that, “Reflexivity enables the researcher to untangle personal and theoretical commitments and scrutinize ethics and epistemology” (Kleinsasser, 2000:161). The voices quoted and discussed of the guiding figures in modern times of hermeneutic phenomenology argue that this process is not in practice achievable and if it were it would be undesirable.

The very act of understanding emerges from the unique tangle, as it is the subjective me into which something is taken as part of the event of understanding. The judgement of rigour must proceed from the point of judgement of the consistency between the expressed aim of the study, the methods chosen and the reported discussion of the understanding achieved. Of course these are not the only standards by which to judge this thesis. Amongst other criteria suggested as useful in evaluating psychoanalytic case studies Atwood and Stolorow (Atwood & Stolorow, 1984:5) listed, “the aesthetic beauty of the analysis in disclosing previously hidden patterns of order in the material being investigated”. Such a criterion also applies to the interpretation achieved in a hermeneutic phenomenological study.
Phenomenology is a poetising project as it generates an incantative evocative speaking, an original telling of what an experience is like and as such a judgement of aesthetic beauty applies. “But poetising is not merely a type of poetry, a making of verses. Poetising is thinking on original experience and is thus speaking in a more primal sense” (Van Manen, 1990:13). At times the thesis may appear unconventional in this project of poetising, as the choice of grammar and style is part of a conscious effort to avoid the snare identified by Gadamer in Semantics and Hermeneutics. “He who only speaks a language in which conventionality has become total in the choice of words, in syntax, and in style forfeits the power of address and evocation that comes solely with the individualisation of a language’s vocabulary and of it’s means of communication” (Gadamer, 1972/1976:85). This individualisation represents the evocative power in the speaking of what the experience is, of parenting a child with autism. The aim of this speaking is to present a new telling of what it is, the lived experience of parenting a child with autism. A telling that is both palatable to, and consumable by, the reader.

The palate is of course a sense organ stimulated in part by the aesthetic beauty of that which is presented to it. “The beautiful is like a bridge stretching from the thing to the personal in man, over which both go forth, beyond themselves, to meet, yet both remain where they are, each within its own realm” (Maisels, 1939/1956:76). The beautiful presents like a sudden gift from without in which is delivered to someone an understanding, or experience of being, that he/she were not forced to carve out for him or her self.

The structure of the thesis builds upon a grasp of the weight of the question in the literature review (chapter 2), the process of thinking about and answering the question in the theoretical perspective, methodology and methods chapters (chapters 3,4 and 5) and the answer or understanding attained through the results and discussion chapters (chapters 6 and 7). As the question is constructed and answered in a logical fashion the information is laid out or unfolded for ease of consumption.
One in five hundred children are affected by autism (Autism Association of NSW, 2001a; Committee on Children with Disabilities, 2001). Autism imposes a great burden on the individual, their parents and family, and society (Gordon, State, Nelson, Hamburger, & Rapoport, 1993). The review of the literature demonstrates the limits of what is known of autism. Many different definitions of what autism is exist and at least in part reflect the varied ideas or theories on aetiology. There is no single autistic behaviour that once identified allows diagnosis and there is no biological marker that can be used for the purpose of diagnosis (Fombonne, 1999). The diagnosis of autism is a probabilistic statement based upon a person’s behaviour (Committee on Children with Disabilities, 2001). In autism behaviour is impaired in three main areas referred to commonly as the triad of impairment. The impairment is in communication, social skills and the manifestation of a cluster of restricted, repetitive and at times stereotypic behaviours (American Psychiatric Association, 1994; Autism Association of NSW, 2001a). Determination of which diagnosis is given within the spectrum is based heavily on clinician judgement and preference. The cause of autism, except in six to fifteen percent of cases in which there is a presumed medical cause based on a co-morbid diagnosed medical condition such as Tuberous Sclerosis, remains unknown (Buitelaar & Willemesen-Swinkels, 2000; Fombonne, 1999). There are no curative methods of treatment (Wing, 1996). Intervention is about support in the acquisition of skills that minimise the impact of the triad of impairment.

Parents are confronted with a condition in their child in which there is no known cause in the majority of cases, no cure, inconsistency in diagnosis, debate about what autism is and the appropriate definition and yet impairment that manifests in the child’s very way of being-in-the-world. The literature on parenting a child with a disability informs the reader that, parenting a child with a disability in general is more stressful and anxiety provoking than parenting a child without a disability (Brinker, Seifer, & Sameroff, 1994; Donovan, 1988; Dyson, 1991, 1993, 1997). The literature also demonstrates that parenting a child with autism is more stressful and provokes more stress than parenting.
children with other disabilities (Bouma & Schweitzer, 1990; Dumas, Wolf, Fisman, & Culligan, 1991; Fisman, Wolf, & Noh, 1989; Kasari & Sigman, 1997; Rodrigue, Morgan, & Geffken, 1990; Sharpley, Bitsika, & Efremidis, 1997; Wolf, Noh, Fisman, & Speechley, 1989). Identification of stress and anxiety tells little in the way of, the experience of parenting a child with autism. The significance of the experience is pointed to by not only measures of stress and anxiety but also quotes from parents such as the following from Maria Mombille from the film Refrigerator Mothers in which she speaks of the journey of parenting her son Shem, “this journey is carved in my soul” (Simpson, Hanley, & Quinn, 2002). What is this journey like? What is the lived experience of parenting a child with autism?

Chapter three outlines the author’s theoretical perspective. Those ideas that resonated strongly and helped to inform his understanding of how we know what we know and our being in the world. The ideas written of are not complete descriptions of philosopher’s ideas, but highlight portions of thinking that have contributed to the value placed on constructionism. These are not the only ideas that have contributed to this understanding but are ones of which the author is conscious. The theoretical perspective of the study is unpacked in this way to help the reader to judge the rigour and the goodness or consistency of the conclusions drawn from the study as the type of knowledge or understanding thought to be possible to achieve is placed in context (Kvale, 1994; Sandelowski, 1997). The theoretical perspective forms the ground out of which methodology is selected. The theoretical perspective is, “the philosophical stance informing the methodology and thus providing a context for the process and grounding it’s logic and criteria” (Crotty, 1998:3). In constructionism there is no objective truth out there waiting to be discovered. Meaning or an understanding is not discovered but constructed (Crotty, 1998). Ontological and epistemological issues in constructionism are difficult to separate as, “talk of the construction of meaning is to talk of the construction of meaningful reality” (Crotty, 1998:10).
Chapter four outlines the selected methodology of hermeneutic phenomenology. As noted already this methodology flows as a natural extension of the theoretical perspective as it is a tradition that has sprung from the philosophical perspective. Phenomenology is a critical process through which normal or everyday experiences are problematised in order to break through the clutter of accepted meaning or to reach the clearing in the woods from which the phenomena can be viewed in a new way (Crotty, 1996). In this case the phenomena is the experience of parenting a child with autism. Hermeneutics refers to the process of bringing the phenomena to light through the acquisition of meaning acquired in text (Allen & Jensen, 1990). The meaning acquired is an interpretation as the researcher is situated in the world and embedded in a historical context and can only project from this horizon (Kockelmans, 1993). The interpretation is a working out of the possibilities that are projected in understanding (Heidegger, 1927/1985). What is sought is an understanding as opposed to facts. In this case an understanding of the experience of parenting a child with autism.

The method used, and described in chapter five, needed to be consistent with the aims of the methodology and thus in line with the tradition of understanding provided for by hermeneutic phenomenology. In the use of a hermeneutic phenomenological approach there is no prescribed method of investigation or cookbook type recipe to follow (Van Manen, 1979, 1990). A method was required that opened a dialogue with parents of children with autism in which the lived experience of parenting a child with autism could be explored in a critical manner. The aim of this dialogue was to set the scene in which the buoyancy of understanding could be manifested. “We speak, therefore of having gotten into a discussion, or of being caught in a discussion, and these expressions serve to indicate the element of buoyancy in understanding that leads the conversational partners beyond their original horizons into a process of inquiry that has a life of it’s own and is often filled with developments that are unanticipated and unintended” (Linge, 1976:XXII). These discussions or interviews were fixed in writing to form text.
Hermeneutical theory is oriented to the task of interpretation of expressions of life that are fixed in writing (Gadamer, 1967/1976). Interviews continued until the dialogue lapsed into a type of silence in which the conversational partners appeared to be telling the same stories. To keep the voice of the parents alive throughout the process of analysis four focus groups were conducted.

The results of the study are presented in chapter six. The processes of analysis and interpretation have not been presented separately as, analysing and interpreting information are not separate activities that occur in a linear sequence (Kvale, 1994; Sandelowski, 1995; Van Manen, 1990). As such they are presented in narrative form in chapter six.

Chapter seven discusses the interpretation and it's relevance in terms of our current understanding of the lived experience of parenting a child with autism. Any understanding is always incomplete. “Every dialogue also has an inner infinity and no end. One breaks it off, either because it seems that enough has been said or because there is no more to say. But every such break has an intrinsic relation to the resumption of the dialogue” (Gadamer, 1966/1976a:67). Future directions for research and the resumption of the dialogue are considered.

Integrity is a factor that resides within the researcher, and thus by this very nature is difficult to bring to the fore in a process conducive to its examination by the reader, for consideration of adequacy. Integrity is about the viewpoint adopted by the researcher in which one adopts a viewpoint, “not as a distant party in the situation, but as a conscientious, thorough, curious, information-seeking representative of the scholarly community” (Prus, 1996:253). This is achieved by entering the research process with prejudices that by virtue of curiosity have lead to a question that is clear and is pursued in a thorough manner that takes into account the many ethical considerations present and leads to a new or renewed understanding, an answer to the question that motivated the study. The question that has motivated this study is “What is the Lived Experience of Parenting a Child with Autism”? 
2 Literature Review

2.1 The cost of autism

Autism, although relatively rare, has been described as a major health problem, which imposes great cost on the individual, family and community (Gordon et al., 1993). The cost of autism comes in many forms. At the most materialistic level cost can be thought of in financial terms. This is measured through resource utilisation converted to a dollar value. Until the 1980s, the community frequently incurred this cost in expenditure on institutionalisation, therapy and special schooling. Changes in laws and community attitudes has shifted the burden of care largely onto the family, under the guise of normalisation, with cost to the community measured in terms of community support and support with schooling (Bromley & Blacher, 1989; Glidden & Pursley, 1989; Llewellyn, Griffin, & Sacco, 1992). In a Cochrane reviewed study in the Netherlands Van Minnen, Hoogduin and Broekman (1997) studied the cost effectiveness of the shift of service provision to the state, from hospital to community based care for a sample of people with mental retardation and psychiatric disorders. Outreach treatment costs were reported to be 40% lower than hospital treatment costs. These costs when considering the incidence of autism remain significant. In 2000 the Department of California Schools estimate that they have spent $1.1 billion on special education services required by the state since 1980 (Groves, 2000). In Canada the current lifetime cost to the state for a person with autism is thought to be two million dollars. It is estimated that the annual 3000 new cases of autism in Canada will have an eventual cost to taxpayers of $60 billion (Autism Society Canada, 2001b). The cost to the individual relates directly to the impairment that characterises autism, the nature of which will be considered in the discussion of the triad of impairment.

The cost to families comes in many forms. These costs include direct assessment, treatment, and therapy costs that can be considered in financial terms (Hecimovic, Powell, & Christensen, 1999; Richmond, 2001). The cost on the family unit includes the burden of care and support, and potentially missed
opportunities (Browne & Bramston, 1996). The recorded murder of three children with autism on separate occasions by their parents in Canada in the five years leading up to October 2001 highlights the extreme nature of the impact of parenting a child with autism (Autism Society Canada, 2001a). The murder suicide of a 38 year old UK mother and her eleven-year-old son with autism in October 2002 by jumping off a 180 foot viaduct serves to highlight this further (Roberts, 2002). Parents are often the constant in the life of a person with autism (Domingue, Cutler, & McTarnaghan, 2000; Gombosi, 1998). An attempt to understand what the experience of parenting a child with autism is like is essential in the development of family centred interventions (Hecimovic, Powell, & Christensen, 1999).

2.2 What is autism?

As will be discussed in section 2.5 there is no known cause for autism (Elder, 1994). This poses many challenges for diagnosis as will be discussed in section 2.3. Autism is a disorder or way of being-in-the-world that is behaviourally defined (American Psychiatric Association, 1994; Priven, J, Harper, Palmer, & Arndt, 1996; Scott, Clark, & Brody, 2000). There is no single behaviour that can be considered autistic (Committee on Children with Disabilities, 2001). Autism consists of a pattern of behaviour that is characterised by excess, (i.e. behaviour of a higher frequency or intensity than that normally exhibited by age equivalent peers), behavioural deficits (behaviour exhibited less frequently or at a lower intensity than that normally exhibited by age equivalent peers), and out of context behaviour (a good example is around the age of two years it is good to begin to learn to undress but this behaviour is out of context when carried out at the supermarket) (Scott, Clark, & Brody, 2000). The behaviours form a triad of impairment in the areas of communication, social skills and restricted, repetitive and stereotype behaviours (American Psychiatric Association, 1994; Autism Association of NSW, 2001a). This is discussed further in section 2.6. This triad of impairment has formed the central element in many definitions. Priven, Harper, Palmer and Arndt (1996:525) wrote, “autism is a developmental behavioural syndrome defined by the presence of communication and social
deficits, ritualistic and repetitive behaviours and onset prior to age three years”. Davis (1996) described autism as a lifelong developmental disorder with behaviour defined by the triad of impairment. Cann (2000:20) defined autism as, “a complex developmental disability that affects social and communication skills”. Bailey, Le Couteur, Gottesman, Bolton, Simonoff, Yuzda and Rutter (1995:65) described autism as, “a severe neuropsychiatric disorder of children that results in characteristic and persistent social language abnormalities and repetitive and stereotyped behaviours”. The incongruity in labelling autism as a childhood disorder with persistent developmental features is that if a disorder is persistent in these behavioural areas, it cannot be a disorder that is confined to childhood. In line with the definitions of Priven et al and Cann, in which autism was viewed as developmental, Zilovicieus, Garreau, Samson, Remy, Barthelemy, Syrota and Lelord (1995:249) wrote of autism as, “a lifelong developmental disorder that impairs the acquisition of some of the most important skills in human life”. Devine (2000:1) used the description of autism as a, “complex developmental disability that affects normal brain development.” Herbert and Sharp (2000:1) described autism as, “a relatively rare pervasive developmental disorder marked by severe deficits in the abilities to reason, communicate and socialise”. Others have claimed like Bailey et al’s definition referred to earlier that autism is a psychiatric (Baron-Cohen, S, Cox, Baird., Swettenham, Nightingale, Morgan, Drew, & Charman, 1996), or neuropsychiatric disorder (Bailey, A. et al., 1995; Shu, Lung, & Chang, 2000). The Committee on Children with Disabilities (2001) described autism as a neurogenetic disorder.

The few definitions referred to highlight the difficulty in coming to terms with what autism is, even at a basic level. For a parent with a newly diagnosed child to seek a definition of the disorder is an important step in learning about autism. Gombosi (1998), a parent of a child with autism and a psychotherapist, wrote of the experience of a period of dislocation at the time of diagnosis. He related that there is a period of disorientation and disorganisation of associative pathways as the parent struggles to form new schemata. No near enough experience is available from personal history so outside information is relied upon. In
Definition autism is described as: a developmental disorder, a psychiatric or neuropsychiatric disorder, or a neurogenetic disorder. Each of these descriptors in part relays the underpinning theory of the authors in regards to aetiology. Some have argued that the lack of agreement on a single definition reflects the fact that there are as many presentations of autism as there are people with autism, as although pervasive, autism does not define the person (O'Neil, 1999). An alternative explanation would be that it is just confusing. A reasonable question emerges: if there is no agreement on definition how can there be clarity of diagnosis?

2.3 Diagnosis

As noted in section 2.2 the diagnosis of autism is a behavioural diagnosis (Gerlach, 1995; Tanguay, Robertson, & Derrick, 1998). There is no gold standard for diagnosis, as could potentially be provided by a biological marker, if the cause of autism was known (Fombonne, 1999). In the absence of such a marker, like all diagnosis that is based on behaviour, the diagnosis of autism remains a probabilistic statement (Szatmari, Volkmar, & Walter, 1995). Autism is diagnosed clinically as opposed to in a laboratory. As there is no single autistic behaviour, the behaviours used as the basis for diagnosis are dimensional as opposed to categorical entities (Berney, 2000). A diagnosis is a professional construct (Barker, Reynolds, & Stevenson, 1997). The diagnosis of autism is a professional construct used to make sense of the behaviour of a group of people with a similar triad of impairment that significantly impacts on their social and occupational function (American Psychiatric Association, 1994). Autism is identified by the presence of a cluster of symptoms or behaviours (Committee on Children with Disabilities, 2001).

Outside of the area of developmental psychiatry the same behaviours, can be seen as part of other constructs (Berney, 2000). The distinction between autism and prodromal schizophrenia in a young person of average or above intelligence is a professional judgement that often depends on the orientation of the assessor (Berney, 2000). Traditionally it has been estimated that autism is
associated with a degree of mental retardation in 80% of cases (Fombonne, 1999). However, over the last decade there has been a broadening of the diagnosis of autism as will be discussed in section 2.4 (Suniti & Fombonne, 2001). With this broadening of the diagnostic criteria to a spectrum approach it is now estimated that the trend with regards to the association with mental retardation has reversed and 80% of diagnosed individuals have average intelligence or above (Autism Association of NSW, 2001a). The behaviours that constitute autism have also been labelled as Attention Deficit Disorder and Borderline Personality Disorder by some clinicians who come from a different clinical orientation (Gillberg, 1998; Pelletier, 1998). There is a considerable overlap in behaviours in many disorders often first recognised in childhood and adolescence (Pelletier, 1998). This may be in part related to the proposed shared mechanism of serotonin variability in many of the disorders. Whatever the reason it is clear that much behaviour when combined can meet the criteria for many disorders. The diagnosis is the product of the sense the clinician makes of the presenting behaviour.

In New South Wales (Australia) the diagnostic and statistics manual of the American Psychiatric Association (4th edition) is used as the basis of diagnosis. If the person has the requisite number of behaviours that constitute a qualitative impairment in social interaction, a qualitative impairment in communication, and restricted repetitive and stereotyped patterns of behaviour, interests and activities, and these behaviours were observed prior to the age of three, a diagnosis can be made (American Psychiatric Association, 1994; Tanguay, Robertson, & Derrick, 1998). The term qualitative is used as the diagnosis encapsulates descriptors of behaviour that are dimensional, and not merely categorical. A difficulty with communication and social interaction is taken into account. The diagnosis does not rely on the mere presence or absence of behaviours but is concerned with pragmatics. The behaviours have to have been observed prior to the age of three. This does not mean they have to have been noted as part of a formal assessment. Parental report, and the recollection and data from other areas, e.g. preschool are taken into account.
The effective diagnosis of autism cannot occur in the environment of a one-off consult. Autism is a historical diagnosis that takes into account the description of the person’s development and behaviour across time and in as many contexts as possible (Wing, 1996). Behaviour that is characteristic of autism is often context specific (Scott, Clark, & Brody, 2000). Behaviour that is learned, or exhibited in one environment or context, is often specific to that area and does not generalise to, nor is it seen in other areas. Thus in a visit to a clinic to see a professional for assessment the clinician may see the person's full repertoire of behaviours, a very limited sample, or anything in between. Many parents have been made to feel neurotic by professionals when they have gone for an assessment and described very difficult behaviour only to have the child behave perfectly (Dudziak, 1982; Gombosi, 1998; Midence & O'Neill, 1999). Often the clinic visit is conducive to less obvious symptomatic behaviour as the interaction is one on one, and highly structured, with no onus on the individual to initiate interaction (Wing, 1996). The accuracy of formalised intelligence quotient test in people with autism, which is often part of assessment, has often been criticised as poorly representing true intellect in the determination of the presence or degree of mental retardation, as these tests are heavily reliant on communication and require a large degree of joint, or shared attention on the task (O'Neil, 1999; Scott, Clark, & Brody, 2000). As impaired communication and social skills are central to the diagnosis of autism such criticism would appear valid.

The DSM IV uses a multiaxial approach to diagnosis (American Psychiatric Association, 1994). Five levels or axis are used to separate out different levels of diagnosis. The first axis, where the diagnosis of autism is recorded, represents the diagnostic section for clinical disorders and conditions. On axis two, developmental disturbances are recorded. Axis three allows the documentation of relevant general medical conditions. This raises questions in terms of definition. If autism is a developmental disorder why is it not an axis two diagnosis? If autism is in fact neurogenetic, why is it not recorded on axis three? Does the fact it is recorded on axis one support definitions of autism as psychiatric of neuropsychiatric? Yet it comes under the umbrella term of
Pervasive Developmental Disorder. Again the common theme for parents of an element of confusion in attempting to understand the diagnostic process by referring to definitions emerges. The diagnosis of autism often takes many assessments by different clinicians over time (Hecimovic, Powell, & Christensen, 1999; Jones, 1997). In a survey in the UK of 614 parents of children with autism, Howlin and Asgharian (1999) identified that parents were generally aware of behavioural differences in their child’s development at eighteen months. It took on average until the children were five and a half to secure a diagnosis. Higher functioning children, later given a diagnosis of Asperger’s Syndrome (the relationship of this on the autistic spectrum being discussed in section 2.4) were not on average diagnosed until eleven years. This is consistent with a study done in Japan by Ohta, Nagai, Hara and Sasaki (1987) in which a questionnaire was used to explore the experience of obtaining a diagnosis for their child in a sample of parents of 141 children with autism. The age of diagnosis was younger if the child was lower functioning (i.e. having more behavioural disturbance or associated intellectual delay).

To explore correlates between behaviours and a later diagnosis of autism, Baron-Cohen et al (1996) screened sixteen thousand children to attempt to identify psychological markers that could be used in the detection of autism in infants. It was identified that the absence of pretend play (play involving object substitution or the attribution of properties not present to an object), protodeclarative pointing (pointing at an object to direct a person’s attention to it, as opposed to that in protoimperative pointing in which the aim is to obtain the object) and gaze monitoring (following someone’s gaze to see what they are looking at) correlated with a very high risk of autism. Such research has contributed to the ongoing quest to develop standardised tools to assist in the identification of the behaviours that constitute autism and for use as screening tools for children (Gerlach, 1995). Tools such as the Checklist for Autism in Toddlers (CHAT), the Child Autism Rating Scale (CARS), The Gilliam Autism Rating Scale (GARS) and other standardised tools have also found a place in diagnosis beyond initial screening, in their use of documenting behaviour across contexts, such as at home, early intervention centre and preschool. This is
important as discussed previously, as behaviour is often context specific (DiLalla & Rogers, 1994).

As an addition to the use of standardised tools, and early developmental traits, the season of birth has been studied as a potential factor with utility in diagnosis, however, no correlation was found (Landau, Cicchetti, Klin, & Volkmar, 1999).

In the DSM IV Autistic Disorder is one of five diagnoses under the umbrella term of pervasive developmental disorders (American Psychiatric Association, 1994). Three of these diagnosis form what is known as the autistic spectrum. This spectrum includes Autistic Disorder, Asperger’s Disorder and Pervasive Development Disorder not otherwise specified (Atypical Autism) (Autism Association of NSW, 2001a; Committee on Children with Disabilities, 2001). An issue in diagnosis comes from deciding not only if a person meets the criteria for an autism spectrum disorder but also which diagnosis best described their behaviour. Gilberg (1998:204) espoused a very pragmatic approach to diagnosis in which he stated, “in clinical work one of the most important points is to arrive at the diagnosis which, at the time in the demographic/cultural circumstances, will be of most help to the individual and his/her family”. Parents in many cases are left with the task of not only trying to understand what autism is but also what the diagnostic subgroups on the spectrum represent.

2.4 The autism spectrum

In the early 1940’s a Baltimore psychiatrist, Leo Kanner and a Viennese paediatrician, Hans Asperger had both identified groups of children with common impairment in the areas of communication, social skills and a markedly restricted range of interests and activities and whom often demonstrated stereotypic behaviours (Gillberg, 1998). As would be expected at this time in world history there was little collaborative effort between these two countries and neither was aware of the other’s work. Two distinct diagnostic entities were bought to life. Leo Kanner worked on the classification, or professional construct
now known as Autistic Disorder. Hans Asperger developed the concept of Asperger’s Disorder or Syndrome (Scott, Clark, & Brody, 2000). Hans Asperger later after reviewing Kanner’s construct continued to claim, that although bearing striking similarities in many areas, they were both describing separate entities (Gillberg, 1998). For the first time Asperger’s Disorder was listed as a separate diagnostic entity, as opposed to a theoretical construct, which it had previously been viewed as, in the DSM IV (Eisenmajer, Prior, Leekam, Wing, Gould, Welham, & Ong, 1996). Hence the triad of impairment central to diagnosis could now apparently be used to make separate probabilistic statements in the terms of diagnosis.

The DSM IV makes the distinction that to meet the criteria of Asperger’s Disorder intelligence must be average or above, and there has to have been no delay in obtaining words, i.e. single words must be used to communicate by the age of two and communicative phrases by the age of three. No judgement of the qualitative use of language in terms of pragmatics and prosody is made. A further distinction that was offered was that if the person met the criteria for Autistic Disorder then that was to be given as the primary diagnosis (American Psychiatric Association, 1994). As noted by Eisenmajer et al (1996), the diagnostic criteria for Autistic Disorder and Asperger’s Disorder are nearly identical and for a child with average intelligence and speech there are no clear boundaries between the disorders. Although not a diagnosis in the DSM IV, children with normal intelligence and speech are often referred to as having high functioning autism (Devine, 2000).

A further criterion to consider is Pervasive Developmental Disorder not otherwise specified. This is a diagnosis for people with the triad of impairment at sub-threshold level, or with impairment that was not identified until after the age three years, and which first appeared as a diagnostic entity in the DSM III (Mahoney, Szatmari, MacLean, Bryson, Bartolucci, Walter, Jones, & Zwaigenbaum, 1998).
As noted previously the testing of intelligence using standardised measures is often problematic due to the nature of autism. Performance is often characterised by an uneven profile with individuals who have profound delay in some areas and outstanding splinter skills, or disproportionate strengths, in other areas of development (Scott, Clark, & Brody, 2000; Wing & Shah, 2000). Hyperlexia as an example, for parents, often masks profound comprehension deficits. Parents are left wrestling with an understanding of autism, the diagnosis within the spectrum, and the inherent clinical judgement in regards to intellect and communication within the diagnosis.

Whether the three entities, Autistic Disorder, Asperger’s Disorder and Pervasive Developmental Disorder not otherwise specified are separate entities or a mere reflection of the spectrum nature of autism is a contentious issue (Eisenmajer et al., 1996; Gillberg, 1998). In fact it would appear that making such distinction might be in fact an exercise in splitting academic hairs (Gillberg, 1998; O'Neil, 1999). Eisenmajer et al (1996:1531) argued that, “the nosological validity of Asperger’s Disorder and other pervasive development disorder subtypes as discrete categories will only occur if there are differences in outcome, aetiology, or treatment, however there is little evidence to support such a notion”. Eisenmajer et al (1996) utilising structured interviews of 48 parents of children diagnosed with Autistic Disorder and 69 parents with children diagnosed with Asperger’s Disorder found that DSM IV diagnostic criteria was obviously not employed in the diagnostic decision. In the group diagnosed as having Asperger’s Disorder 43% had delayed language onset and all the subjects met the criteria for a diagnosis of Autistic Disorder. Mahoney et al (1998) also found that if strict diagnostic criteria were adhered to, all the children in their study of 147 children that had a diagnosis of Asperger’s Disorder met the criteria for Autistic Disorder. If the DSM IV criteria had been adhered to strictly the diagnosis of Autistic Disorder should have been given. Szatmari, Archer, Fisman, Streiner and Wilson (1995), in order to distinguish between a group of children with Autistic Disorder and Asperger’s Disorder had to create their own diagnostic criteria as using current DSM IV criteria they found that a large part
of their sample diagnosed as having Asperger’s Disorder also met the criteria for Autistic Disorder.

If not by operationalising the definitions in the DSM IV, what is informing the clinical judgement of how diagnostic distinctions are made between Autistic Disorder and Asperger’s Disorder? Szatmari et al (1995) identified that clinicians clustered those with more stereotypic behaviour as opposed to obsessions and rituals as Autistic Disorder. Howlin and Asgharian (1999) identified in their study that children diagnosed later were more likely to be given the diagnosis of Asperger’s Disorder. In Eisenmajer et al’s (1996) study children given the diagnosis of Asperger’s Disorder were more likely to seek social interaction but were awkward in the way they went about it as opposed to children who were seen to be ‘aloof’ and who did not attempt to initiate interaction. Tongue, Brereton, Gray and Einfield (1999) used a developmental behaviour checklist with a sample of 75 children and adolescents with high functioning autism and 52 with Asperger’s Disorder, and found that the Asperger’s group had higher levels of psychopathology, were more disruptive, anxious and antisocial. They also had more trouble with social relationships. This last finding perhaps reflected as identified by Eisenmajer et al (1999), that these children seek more contact socially. Wagner (1999) also identified that children with Asperger’s Disorder are often seen as disruptive and defiant. Attention Deficit Disorder is spoken of as a frequent misdiagnosis. She aptly pointed out that children with Asperger’s Disorder have many strengths and that this often masks their deficits. Often what is interpreted as disruptiveness is clumsy social skills combined with difficulty with interpretation of social cues. In terms of anxiety, Kim, Szatmari, Bryson, Streiner, and Wilson (2000) in a sample of 1751 community children found that those with a diagnosis of Autistic Disorder or Asperger’s Disorder had a greater rate of problems associated with depression and anxiety than the neurotypical group. However there was no significant difference in the number of anxiety or mood related problems between the Autistic Disorder and Asperger’s Disorder group. Motor clumsiness was proposed by Asperger to be diagnostically significant, however clinicians remain divided on this issue as well (Gillberg, 1998; Szatmari et al., 1995).
Without a true biological gold standard or marker, whether Autistic Disorder and Asperger’s Disorder are separate entities may never be answered (Mahoney et al., 1998; Szatmari et al., 1995). On the background of lack of certainty the argument for a pragmatic approach arises. Wing (1996:32) argued that, “each individual with Autistic Disorder is different from every other so these descriptions should be taken as a general guide and not as an exact specification for diagnosis”. Others have written of a developmental trajectory of autism in which people often move through the spectrum in terms of meeting diagnostic criteria typically first for Autistic Disorder moving to Asperger’s Disorder and then possibly, dependent on development to meet the criteria for Pervasive Developmental Disorder not otherwise specified (Eisenmajer et al., 1996; Gillberg, 1998; Szatmari et al., 1995).

All of the above discussion in terms of separating the entities on the spectrum perhaps only serves in effect to highlight the heterogeneity rather than the homogeneity of autism (Storch, 1999). It is clear that agreement only lies in the fact that, in keeping with the notion of a spectrum, autism affects people in different manners and intensity. Parents are confronted with varied definition and approaches to diagnosis, none of which can be stated with absolute certainty. All that is certain is that autism does describe a pattern of behaviour, or way of being-in-the-world, that is characterised by a triad of impairment. Gray and Attwood (1999) in “The Discovery of Aspie” wrote about the possibility of reframing what initially appears as a deficit as strength. An example of this would be the reframe of obsessive-ness as an aptitude for rigorous and repetitive tasks. However, even after many such reframes they wrote of the need to acknowledge the impact of the triad of impairment on the lives of people with autism and those with whom they relate.

2.5 Epidemiology

In order to clearly define a group of people for the purpose of development of the construct of Autistic Disorder, Kanner in 1943 focussed on a group with
severe impairment across the triad of impairment accompanied by an intellectual deficit. Over the last 30 years there has been a broadening of the perception of autism and the idea of a spectrum has become accepted (Berney, 2000; Suniti & Fombonne, 2001). This has been an evolution, or broadening of the concept, based on an increase in community awareness of autism and increased proficiency in early detection and referral by professional groups such as preschool and school staff and clinic nurses (Berney, 2000; Suniti & Fombonne, 2001). More subtle variants of the disorder are being recognised and labelled in children that in the past would have potentially been labelled defiant and odd but not referred for formal assessment. As a reflection upon the change in perception of autism the diagnostic threshold has been in a constant state of change (Berney, 2000).

Epidemiological studies have indicated a steady increase in the number of people diagnosed with autism (Fombonne, 1999; London & Etzel, 2000). This has raised much concern in the media. Change in diagnostic criteria, and the limitation in many studies of no clear delineation of which criteria were used for inclusion, has meant that comparison across time is difficult (Berney, 2000; Suniti & Fombonne, 2001).

Fombonne (1999) reviewed 23 epidemiological surveys between 1966 and 1998. Whilst acknowledging difficulties with comparison related to changing diagnostic criteria, he declared that the most robust estimates that could be made from available data were; an estimate of 18.7/10,000 for the spectrum, 5.5/10,000 for the discrete diagnostic category of Autistic Disorder, and a male to female ratio of 3.8:1. A further limitation in this review was that only studies published in English were reviewed.

For the autism spectrum this translates to the popularly quoted ratio of 1/500 people (Autism Association of NSW, 2001a; Committee on Children with Disabilities, 2001). The current lack of clarity in the validity of the separation of those diagnosed with Asperger’s Disorder and those diagnosed with Autistic Disorder, as the diagnostic decision would appear to be based on an
inconsistent clinical judgement between practitioners, means no clear estimate of the incidence of Autistic Disorder alone can truly be made. The significance in terms of the number of parents impacted on is clear. In biological terms 2/500 parents have the role of parenting a child with autism.

2.6 Cause

The estimate of the rate of identifiable, probably causal, medical disorders, of autism varies from Fombonne’s study (1999) in which the most robust estimate was thought to be 6% to Buitelaar and Willemsen-Swinkels (Buitelaar & Willemsen-Swinkels, 2000) estimate of 10 to 15% of cases. No single biomedical aetiology has been identified as the cause of autism (Edwards & Bristol, 1991). Initially psychogenic theories of autism were the order of the day. “Asperger's keen insights languished in Europe’s postwar turmoil, and Kanner’s were overrun by the Freudian juggernaut” (Nash, 2002:53). Autism was the province of psychoanalysts. Bruno Bettleheim in 1967 coined the term the refrigerator mother. Autism was thought to be the result of a cold uncaring parenting style and a deep rejection of the nipple (Autism Association of NSW, 2001a; Scott, Clark, & Brody, 2000). Such theories have now been completely invalidated, with autism considered as a neurobiological disorder (Minshew & Payton, 1988).

The neurobiological basis is supported by structural changes in the brain observed on neuroimaging and autopsy. Changes in cell structure and size in different brain structures have been observed, however none are specific to autism, or fully account for the behavioural expression of autism (Committee on Children with Disabilities, 2001; Wing, 1996). Zilbovicius et al (1995) in a perfusion study of children with autism identified significant perfusion changes in the frontal lobe in children in the 3-4 year age group, however, this normalised by the age of 6-7 years, and the authors commented that although noteworthy this would not account for the lifelong triad of impairment seen in autism. The most replicated finding is elevated serotonin levels found in over
30% of people with autism (Buitelaar & Willemsen-Swinkels, 2000). Again this is only in a minority of cases and not specific to autism.

Genetic factors are believed to play a substantial role in autism yet no specific genetic markers have been identified, or models proposed, that would account for the increased incidence in males (Creswell & Skuse, 1999; London & Etzel, 2000). Specific changes on chromosome seven were heralded with excitement (Buitelaar & Willemsen-Swinkels, 2000). However, this must be considered in the context that, autism at some point has been considered in light of potential changes to every chromosome except chromosomes 14 and 20 (Committee on Children with Disabilities, 2001). In terms of recurrence rates the argument to support a genetic link are much more convincing. The recurrence rate of autism in siblings is three to seven percent, which on it’s own does not sound high. The significance of this, however, comes from the fact that this is approximately 50 times higher than the rate in the general population (Committee on Children with Disabilities, 2001; Suniti & Fombonne, 2001). Twin studies have produced even more dramatic results. The recurrence rate in dyzygotic pairs in all studies remains at the normal sibling rate, whilst the incidence is dramatically elevated in monozygotic pairs (Bailey, et al., 1995). Further evidence in support of the spectrum nature of autism has also arisen from these studies in that siblings that were not affected by autism had a higher incidence of behaviours which resembled those seen in autism but did not meet the criteria for diagnosis (Bolton, Pickles, Murphy, and Rutter, 1998; Buitelaar & Willemsen-Swinkels, 2000). This has been referred to as the broader autism phenotype (Bailey, et al., 1995; Bolton, Macdonald, Pickles, & Rios, 1994; Bolton, Pickles, Murphy, and Rutter, 1998; Priven, 2001; Priven & Palmer, 1999). Familial aggregation of other mental disorders has been studied for possible links. Using a group of families of children with Down Syndrome (chromosomal nondysjunction or trisomy of chromosome 21) as a control, Priven and Palmer (1999) examined the family histories of families with more than one child with autism. Higher rates of depression and social phobia were identified in the family history of children with autism. These were not accounted for solely by the burden of parenting a child with autism as a first episode or significant traits were
identified prior to the birth of the children. The possibility of a shared genetic liability was discussed. The authors also raised the possibility of the contribution of what they called assortive mating. In this case socially phobic and depressed people are potentially attracted to each other. The parent with social phobia is possibly the carrier of the genetic liability of the broader autism phenotype. The mating combination potentially increases the likelihood of the full expression of the genetic liability in the offspring. Priven (2001) went on to argue that if the components of the broader autism phenotype can be isolated, an index of genes, that when present together interact to result in autism may be identified.

After attempts to grapple with the confusion inherent in the definition and diagnosis of autism little clarity is provided in response to the question of why? What caused this? Junee Waites in describing her response to her son Dane’s diagnosis encapsulates the question of why expressed so often. “My first reaction to Dane’s official diagnosis was relief. I felt grateful that my son’s problems weren’t the result of poor mothering skills, or inadequate diet or allergies or heaven knows what else. Then the shock hit me. Why, God? Why Dane? What caused this? Was it those dreadful forceps at his birth? Was it genetic, or my diet?” (Waites & Swinbourne, 2001:32). Parents are relieved of responsibility in terms of parenting style but left examining their genetic contribution to their offspring. Elder (1994) based on clinical appraisal discussed her experience of the dissolution of families on the basis of blame and debate over who contributed the autism gene. A debate, which at this time cannot conclusively be resolved. If parents plan to have more children referral to a genetic counsellor is recommended practice (Committee on Children with Disabilities, 2001).

A period of what appears normal development until some time in the second year of life at which point a child appears to regress and loose skills is not uncommon (Committee on Children with Disabilities, 2001; Davidovitch, Glick, Holtzman, Tirosh, & Safir, 2000). In a study of 39 mothers of children with autism, Davidovitch et al (2000) found that 47.5% of mothers described such regression at a mean age of 24 months. More of the mothers in this group
described feelings of guilt and all had developed personal theories of what caused autism in their child. For these mothers the quest to work through the ambiguity of aetiology was extremely important perhaps as a way of ameliorating the described feelings of personal responsibility.

Many theories of the cause of autism have been offered that are not empirically backed. These theories have come and gone as a new theory bursts onto the scene and then fizzles out, as research does not keep pace with initial optimism. These theories are quickly replaced by new and promising ideas (Wing, 1996). Many parents, particularly those whose children appeared to follow a path of normal development before a period of regression, or slowing of developmental progression, invest a lot of energy in exploration of these ideas. For parents of children who for a while seemed to be keeping pace with developmental milestones before a period of regression to an earlier stage, such as from walking back to crawling or from speech to babbling, or who just dropped off the pace of expected development, to make sense of why this has happened from the research of Davidovitch et al (2000) would seem crucial.

Two theories, which currently inform many parents’ beliefs and choices in treatment, are the theory of a relationship with an immune mediated response, and the opioid theory. As genetics and inheritance can only at this time describe vulnerability to autism, it is widely believed that for this vulnerability to be expressed there may be a complex interaction with environmental factors (Autism Association of NSW, 2001a; Committee on Children with Disabilities, 2001; Scott, Clark, & Brody, 2000; Wing, 1996). Dr Michael Golberg (1997:5) expressed the belief that, “autistic syndrome probably is a state of dysfunction induced in the brain by a dysregulated immune system”. This dysregulation when it occurs in an individual with a genetic predisposition results he believes in autism (Waldron, 2000). Burger and Warren (1998) shared this view, as one possible aetiology of autism. They proposed that the combination of a genetic predisposition in the form of an immune dysfunction when combined with an environmental pathogen results in autism. In a study using a questionnaire Boyce (1999) in a sample of 61 families identified that in families of a child with
autism 46% had a family history of autoimmune disease compared with 26% in the control sample of 46 families. These theories have lead many parents to question anything that occurred around the time of regression as the possible pathogen.

The measles mumps and rubella vaccination has been questioned extensively in the popular media as one such possible pathogen, however the current evidence favours rejection of this theory (Committee on Children with Disabilities, 2001; Recer, 2001). Vaccinations have also been questioned based on a preservative used in them called Thimerosal which has high mercury content, however no research has confirmed the association between this and autism (Devine, 2000).

The opioid theory proposes that autism may be the result of undigested gluten and casein that cross barriers in the gut and end up in circulation in the blood as exogenous opioids after which they cross the blood brain barrier. The result of early and long-term exposure of the brain to such opioids is proposed to be autism (Berney, 2000) (Whiteley, Rodgers, Savery, & Shattock, 1999). Whitely et al (1999) attempted to test this theory by the introduction of a gluten free diet over a five month period for a sample of 22 children. This was measured biologically with enzyme secretion and behaviourally through the use of behaviour scales on a regular basis. No change was observed on the biological measures. A behavioural change was reported, however it is of note that parents and teachers who completed the behavioural observations were not blind to the study.

Parents are presented with the fact that to date, despite many theories, in the majority of cases, excepting the 6-15% with a presumed medical cause, the cause of autism is just not known. Parents thus far have been presented with no consensus of definition, varied diagnostic practice, and no known cause.
2.7 Treatment

The secure or validated knowledge that has been accumulated so far in regards to the cause and correlates of autism has not lead to any curative methods of treatment (Wing, 1996). Berney (2000:24) summed up the situation expertly in, “as in 19th century exploration well mapped areas are outweighed by the unknown, from which emerge traveller’s tales of strange practices and exotic cures”. These practices based on no, or anecdotal evidence, lead to the promise of a cure, for which many parents would do or give anything (Committee on Children with Disabilities, 2001). A culture of try anything has emerged in the field of autism. A lack of discernment on the part of parents and professionals has lead to the establishment of in many cases expensive and elaborate treatments with little attention to proven effectiveness (Scott, Clark, & Brody, 2000; Smith, & Antolovich, 2000).

Amy Lennard Goehner, head arts reporter at Time magazine in the United States, described her experience in trying anything that promises to improve her son with autism’s life. “In addition to continual speech, behaviour and occupational therapy, we have dabbled in what one of our doctors called the ‘flavour of the week’ – vitamins and supplements and other ‘can’t miss’ cures” (Nash, 2002:59). The pervasive nature of autism combined with no known cause or cure has made autism, “a magnet for pseudoscience and quackery” (Herbert & Sharp, 2000:1). Much of the research is based on catch up as attempts to establish the efficacy of treatments has only occurred after the treatment are in place. A new treatment is proposed, marketed and put into practice before it is validated by research. Examples in the last decade are Facilitated Communication and the use of Secretin (Committee on Children with Disabilities, 2001; Herbert & Sharp, 2000). As soon as one treatment is invalidated it fizzles out and another bursts onto the autism scene like a fire cracker (Wing, 1996). “There is no end to the controversy regarding theories of causation and corresponding theories of treatment, theories that have been disproved for students in other disability groups routinely make the rounds as the new treatment for autism” (Scott, Clark, & Brody, 2000:412).
Intervention as opposed to treatment in autism is recommended. This intervention is aimed at support of the development of skills and behaviours to compensate for those primarily affected by the triad of impairment and associated sensory sensitivities (Autism Association of NSW, 2001a). The triad of impairment consists of impairment in the areas of communication, social skills and the presence of a restricted repertoire of activities interests and behaviours and stereotyped behaviours. These form the core symptoms regardless of the intelligence of the child (Minshew & Payton, 1988).

2.8 Impaired communication

The core symptoms in autism that form the triad of impairment are heavily inter-related. A person’s interface with the world is heavily dependent on a complex mixture of communication and social skills. The success of this interface in meeting the individual’s needs, influences the range of interests, flexibility and stereotyped behaviours (Ulliana & Kershaw, 2000). To describe the triad of impairment it is convenient to look at each of the three elements individually, however the true realisation of the impairment comes from consideration of how each element is further compounded through inter-relatedness (Bondy & Frost, 1992; Howlin, 1998).

Communication involves the use of both verbal and nonverbal communication (Schroeder, 2000). The use of English as a second language has been used as a way to describe the use of language to communicate for people with autism (Scott, Clark, & Brody, 2000). This idea is consistent with the descriptions by O’neil (1999) and Grandin (Grandin, 2000; Grandin & Scariano, 1996) both of which have had personal experience of autism, of feeling like Martians on earth or a human on a foreign planet. The impairment in the area of communication ranges from having no speech to a qualitative impairment in the use of speech (Ulliana, 2001). Kanner in his formulation of the original diagnostic construct of autism in 1943 was fascinated by the peculiarities of language in the group of children with which he worked (Mesibov & Handlan, 2000).
Many people draw comparison with the popular myth of the changeling children and the construct of autism. The myth involves wood fairies swapping children with one of their own hence the name changeling. These changelings were described as not developing any expressive use of speech, “they wont speak a word, instead she will hum and make strange croaking noises” (Grandin, 2000). This notion of swapped children alludes to an attempt to make sense of children with a different way of being, so different in fact it appeared they were a different breed i.e. wood fairies.

Communication involves both receptive and expressive domains. People with autism frequently have difficulty with auditory processing but have relatively intact visual processing (Campbell, Schopler, Cueva, & Hallin, 1996). Temple Grandin described thinking in pictures: “Words are like a foreign language to me. I translate them into full-colour movies, complete with sound, which run like a videotape in my head” (Nash, 2002:60).

The foreign nature of language and words serves to highlight the different way of being-in-the-world that autism represents. Language represents the living memory of beings coming into existence and is described by Heidegger as the house of being (Lemay & Pitts, 1994). “Heidegger maintains, that the basis of language is neither grammar nor logic, but talk. Talk as opposed to language in the formal sense, is existentially significant” (Gelven, 1989:104). Language, described as talk, is not just a tool at our disposal. “Rather, in all our knowledge of ourselves and in all knowledge of the world, we are always already encompassed by the language that is our own” (Gadamer, 1966/1976a:62). The world in which we live, and are enclosed in, is a linguistic world (Gadamer, 1966/1976a).

The neurotypical way of being-in-the-world is characterised by recognising or coding thought in linguistic symbols. The way thoughts are organised and information stored for neurotypical Beings primarily involves linguistics. The linguistic code is not necessarily words as we recognise them, but more
accurately could be described as type of mentalese. Mentalese is, “the language of thought in which our conceptual knowledge is couched” (Pinker, 1997:90).

Aristotle described how people learn to speak, and in effect think, through the acquisition of universal concepts. “In the flux of appearances, in the constant flood of changing impressions, how does anything like permanence come about? Surely it is first of all the capacity of retention, namely memory, that allows us to recognise something as the same, and that is the first great achievement of abstraction” (Gadamer, 1966/1976a:63). Out of the flux of experiences common factors are identified, coded and these are stored in memory. Over time these factors accumulate to allow the emergence of a unity of experience and more importantly a unified base of knowledge. This unified base of knowledge could be envisioned as an individual filing cabinet in the brain into which all experiences can be deposited and retrieved as required based on the individual's linguistic codes. Through the power of abstraction the individual is able to store experiences in an orderly fashion, as each experience is stored next to, and builds upon, knowledge in similar or related areas. This process begins very early but is perhaps first easily recognised at around the age of two, a time in which apparently previously angelic children turn into nasty scientists. The experiment often begins at home as the child trials behaviour and catalogues the response of family members. The experiment then moves further a field and the budding scientist tries the same behaviour in a variety of contexts such as playgroup, preschool, church, or the brother’s soccer match, all the while linguistically coding and storing behavioural responses of others to the behaviour. The child learns the concept that the same behaviour can incur a variety of responses in different contexts and begins to experiment with using modifications of the same behaviour in different contexts to achieve the same goal. An example could be the whimper that parents find adorable and respond to immediately at home may perhaps need to be a bellow in a noisy preschool to result in the fulfilment of needs. Through the development of a unified base of knowledge the child soon has a repertoire of similar or like behaviours.
The cognitive profile of people with autism includes a marked lack of abstraction ability, weak central coherence, and a rote or chunk learning style, as opposed to the more neurotypical constructionist mode of learning (Scott, Clark, & Brody, 2000). It would appear plausible in light of Aristotle’s observations that the language impairment extends beyond speech and points to the different way of thinking or cognitive profile that characterises autism. The lack of abstraction ability in autism leads to impairment in formation of categories based on similar or like features, and thus experience is accumulated as discrete non-integrated chunks. The process of experimentation referred to by the nasty scientist at the age of two, if engaged in, does not lead to a unified base of knowledge as each event, or experiment, is stored as a separate non-integrated chunk. Instead of linguistic coding in autism thought appears to be stored visually, hence Temple Grandin’s description of thinking in pictures. Weak central coherence refers to a trait in autism in which, as opposed to gestalt or big picture concepts, things can be stored on the basis of small idiosyncratic details. An example of this could be the concept of a house may be stored based on the visual cue of a red doorknob (Autism Association of NSW, 2001b). Not only is there a difference in the modality of the storage of information, with information coded visually as opposed to linguistically in autism, issues of central coherence hamper prediction of the visual basis of storage. The person with autism can only retrieve the chunk of information, when they are presented with the specific visual cue. When retrieved information comes as a whole chunk as it is stored unedited, or processed, in what would appear the chronological order as opposed to that likened to an ordered individual filing cabinet. An appropriate analogy would be the way information is stored in a computer before activation of the defragmenter function. For those with a neurotypical way of being it would appear that the process of linguistic coding and determination of where to store information is processing on the go. Trivial information is trimmed from the central meaning of concepts and importance recognised in the storage process. Those with autism have difficulty with the determination of what is important or salient and where this fits in a big picture understanding of the world (Wing, 1996). Information is stored in the chunk in which it is embedded when received.
As language is not just a tool, not just an instrument of communication, but also a basis for organising thought, impairment in language contributes to, or at least is an outward representation of, a different way of being. “It is, indeed, somewhat alarming that even logic is always based upon a purely abstract and formal consideration of relations that are meaningful only in terms of articulated sentences” (Gelven, 1989:104).

The ability to interpret nonverbal communication will be considered as central to a social skills deficit in the discussion of the social skills impairment. The difficulty with processing language is referred to as a deficit in receptive language (Autism Association of NSW, 2001b). This is reflected in a difficulty in comprehension of not only conversation, but also environmental demands (Aarons & Gittens, 1992). For a family this comprehension difficulty poses many challenges, as much interaction is verbal. A strong link between failure to comprehend demands and behavioural problems has been observed (Mirenda, 2001). The different way of being that is autism has been described by Temple Grandin as feeling like an anthropologist from mars when she has attempted social integration (Grandin, 2000). What is the experience of parenting a child with a different way of being in the world?

The problem of impaired ability to comprehend may be further compounded by difficulty with expression. People use the ability to express themselves to interact with the environment to allow their needs to be met. The use of speech in children with autism may be absent, delayed or varied in quality. For those children with autism who have speech, even in children in whom the phonology and syntax of speech has followed normal developmental patterns, problems with pragmatics (the social use of language), semantics (the ability to recognise one word can have several meanings) and prosody (the use or regulation of varied tone, rhythm and pitch) remain evident (Attwood, 1998). Heidegger in describing language as talk brought to light the phenomenon that expression and communication involve more than just the formal tools of language. “Talking is a sharing which is always more than what is represented by the explicit
verbalisation of word language” (Gelven, 1989:105). An impairment in expressive communication goes beyond a grasp of the rules of language. Many people with autism, learn by rote the rules of language, and are able to apply them in speech, but remain impaired in talk. Their communication is formal and stilted, and lacks the reciprocal element of talk (Wing, 1996). Expression through nonverbal means such eye contact, directing gaze and attention, and regulation of affect are impaired (Lord & Pickles, 1996).

Sensory impairment, or distortion, for many people with autism also can impact on both expressive and receptive communication (Scott, Clark, & Brody, 2000). Darren White’s (a person with autism) autobiography, written at the age of fourteen years, provides some insight to this.

At the age of about two I could say a fair number of words but hardly any full sentences. I was rarely able to hear sentences because my hearing distorted them. I was sometimes able to hear a word or two at the start and understand it and then the next lot of words sort of merged into one another and I could not make head or tail of it. This was a trick my hearing played on me (White & White, 1987:224).

Junee Waites observed acute sound sensitivity in her son Dane. “Every sound competes for Dane’s attention. He’s tuned into every buzz and stir. I’ll whisper something and he’ll respond from upstairs” (Waites & Swinbourne, 2001:235).

Frustration is common for the child and parents in the context of the parent child relationship related to the impairment of communication (Domingue, Cutler, & McTarnaghan, 2000). Impaired pragmatics is inextricably linked with impairment in the ability to make sense of nonverbal or extralinguistic features of communication (Koegel & Koegel, 1995). These factors combine to form the central aspects in the impairment in the area of social skills.
### 2.9 Social skills impairment

The ability to interpret another person’s nonverbal communication, and attribute a state of mind to the person based on this interpretation, is referred to as theory of mind (Gillberg, 1998; Smyrnios & Tucker, 1997). “When the layman wonders what philosophy really is, he has the idea that philosophising means defining, and taking responsibility for the need to define, the concepts in which all men think. Since as a rule we do not see this happen, we have helped ourselves by means of a doctrine of implicit definition” (Gadamer, 1962/1976b:125). One cannot see a mental state or what people think, so any judgement is at first a theory, until the person confirms it. The impairment in verbal communication in terms of expressive and receptive functions, although important, is seen by some as secondary to the impairment in social perception and interaction (Scott, Clark, & Brody, 2000).

In keeping with the spectrum nature of autism the impairment in social perception is manifested in a deficit in empathy in some and complete social avoidance or aloofness in others (Attwood, 1998; Tanguay, Robertson, & Derrick, 1998). For those who desire social interaction there is a need to help them learn the secrets of the unwritten rules of social interaction that only come naturally for those blessed with competency in theory of mind (Gray & Attwood, 1999). People with autism generally show greater interest and understanding in how things work (folk physics) than how people work (folk psychology) (Baron-Cohen & Wheelwright, 1999).

In order to maintain a conversational relationship, or talk as defined by Heidegger, contributions from at least two parties occur. To take part in this successfully the conceptual link has to be made between understanding how you feel in different circumstances and then using this information to form a hypothesis about how others may feel in the same circumstances. This is the beginning of empathy. Husserl described empathy as an intentional category. “To be subject means to have experiences; to be experienced as subject is to be experienced as having experiences. Somehow, then, the experiences of
others must form part of my intentional life, without at the same time being my experiences” (Lauer, 1967:172). To make this link a degree of competence in folk psychology is required (Baron-Cohen & Wheelwright, 1999). As this does not come naturally to those with autism attempts have been made to teach it. Some success has been achieved in the context in which these skills are taught (Minshew & Payton, 1988). However it has not been demonstrated that such teaching thus far has generalised from the context in which it was taught (Frankel, Myatt, Cantwell, & Feinberg, 1997). Thus skills, or folk psychology, taught in a social skills group may be able to be demonstrated within the context of the group but not outside the group.

For many of those without autism much of their time is spent in social interaction in the contexts of work, recreation and family. It is through this interaction that we not only explore our environment but also often learn about and define ourselves (Snyder & Stukas, 1999). The inability to fluently partake in social interaction impacts on the individual heavily but also those around them. A lack of theory of mind ability when combined with the difference in processing and storage of information further highlights the different way of being that autism represents. The job of parenting a child who has an inability to attribute states of mind to the parent in the form of empathy must surely be a challenge. Impaired communication and social skills when combined often leave the person with a restricted behavioural repertoire. The sense one makes of the environment is linked to the ability to comprehend the demands of the environment, and how one then chooses to behave (Bailey & Sheldon, 1997).

2.10 Restricted, repetitive interests, activities and behaviours. And Stereotyped behaviour

Since Kanner’s 1943 description of autism, the presence of repetitive and ritualistic patterns of behaviour has remained central to the concept of autism (Gordon et al., 1993). These behaviours may consist of stereotypic behaviours and/or obsessions. Stereotypic behaviour is defined as, “responses that appear to provide the performer with sensory input but have no obvious social
consequences” (Wolery, Kirk, & Gast, 1985:149). These behaviours often consist of spinning, twisting and flapping behaviours. Obsessions are defined as, “intense preoccupations with objects or concepts that the children continually seek out, talk to others about, or write about. Frequently children tantrum when access to their object or discussion of concepts of obsession is limited” (Charlop-Christy & Haymes, 1998:189).

Whether these behaviours are biologically driven or a function of impaired comprehension of the world is not clear. McDougle, Kresch, Goodman, Naylor, Volkmar, Cohen and Price (1995) in a case controlled study compared the nature of repetitive thoughts and behaviour in a group of adults with Autistic Disorder to a group of adults with Obsessive Compulsive Disorder. In those with Autistic Disorder the thematic content was less likely to be that of aggressive contamination, religious, sexual or somatic complaints. The themes differed from those with Obsessive Compulsive Disorder in that they were more related to a narrow focus of interest. Baron-Cohen and Wheelwright (1999) in a content analysis of core domains of cognition in a sample of children with autism discovered that unlike repetitive behaviour seen in Obsessive Compulsive Disorder, people with autism as a group did not fear that failure to engage in their repetitive behaviours or ideas would have catastrophic consequences.

So why do people with autism engage in repetitive and at times ritualistic behaviour? Is it that a comprehension deficit related to the communication impairment and deficit in social skills that sit alongside these behaviours in the triad of impairment actually cause these behaviours? Temple Grandin from personal experience talked of spinning as a way of blocking out all external stimuli when she felt overwhelmed to the point of fear of being engulfed by the world (Grandin & Scariano, 1996). She has also spoken of the need for sameness as a way to keep a confusing world predictable. The apparent obsessive need for sameness is widely referred to (Gordon et al., 1993; O'Neil, 1999; Tanguay, Robertson, & Derrick, 1998; Wing, 1996): This need for sameness is at times so pronounced that it can take on a tyrannical nature (Burnham, 2001). Junee Waites observed that for her son Dane, “the more
structure we could build into his day the calmer he appeared to be” (Waites & Swinbourne, 2001:61). In fact as Dane became older, this need for structure and predictability, became more pronounced. “Rod and I knew we must identify beginnings and endings for Dane, and never allow an empty space between activities” (Waites & Swinbourne, 2001:119). Any change to routine or unstructured time resulted in acute behavioural disturbance. The need for sameness was present in Dane from when he was a young child.

I asked him about his obsession with straight lines. ‘Why did you enjoy following the straight lines, Dane? Why did they have to be straight lines?’ He said, ‘they don’t change Mum. I can see where they go’. In other words, straight lines were predictable. At a recent art exhibition Dane was studying a startling contemporary painting. He prefers photo-realism so I was puzzled until it dawned on me that this abstract image was painted mostly in black. ‘Do you remember how you always painted in black when you were young?’ I asked him. Dane didn’t hesitate. ‘Oh yes Mum, I remember’. ‘Do you remember why you painted in black?’ ‘Oh yes! Black was finished! You don’t see through with black’. So that’s why Dane preferred black. Black didn’t change. Unlike other colours, black wasn’t translucent; nor did black-on-black produce an unexpected third colour (Waites & Swinbourne, 2001:198).

The need for sameness goes way beyond preference in its degree of intensity. The need for sameness would appear to represent a tenuous grip on a confusing and unpredictable world. Sameness is clung to in the way a person at risk of falling from a cliff clings to the rocks.

The lack of a unified base of knowledge may plausibly be the basis of the confusion surrounding the way of being that is autism. When a neurotypical Being is placed in a novel situation although anxious they often have some idea of how to proceed. The person reaches into their mental filing cabinet and finds something similar to, or like, the situation they are in. They can then trial the behaviour that was previously successful in the like circumstance. This may not
be immediately successful, but at least they had somewhere to begin and can go on to modify the behaviour until it is successful. The person with autism, even if having been in the same situation before, but in different visual circumstance (a place that looked different and hence provided different visual cues), may not be able to retrieve the chunk of information of how to behave and hence really be left without a clue. Instead of having some behaviour to trial and modify as required, they are left without any idea of how to proceed. This situation is anxiety provoking when combined with the identified theory of mind deficit. The person may not value question asking based on the assumption that what is in their head is in every body else's head and hence if they do not know what to do no one will. Alternatively the theory of mind deficit may lead to an inability to judge from the rhythm of the conversation when they can successfully ask a question. As a way to cope repetitive behaviours, or thoughts, can provide a focus to block out the threatening world. Insistence on no change will limit exposure to novel situations and is hence tightly clung to, this is done to avoid overwhelming anxiety.

Priven et al (1996) in a retrospective study of a group of 38 adolescents and adults with autism identified that a significant number of these people over time had greater improvement in the domains of communication and social skills than in the domain of ritualistic and repetitive behaviour. Whilst the relative weakness of the use of a retrospective method was acknowledged, the question was raised of whether in fact it is the restrictive and repetitive behaviour that is central to autism and perhaps contributes to the impairment in the other domains and is not the product of the other domains. Without entertaining chicken and egg type debate the message available from our current knowledge of autism is that as a disorder, or disability, it is characterised by a debilitating triad of impairment.
2.11 Impact of parenting a child with a disability

What is the impact of parenting a child with a disability generally? Initially in the literature professionals constructed a meaning of disability that included the concept that families of a child with a disability, despite the nature of the disability, were families with a disability (Glidden, 1993). A lot of research went into the formation of a description of this disability that was located in these families. An attempt was made to explicate this concept through the identification of stress as the primary focus in which parents of a disabled child were compared to parents of neurotypical or nondisabled children. It was identified that the parents of children with a disability universally experienced higher levels of stress compared to parents of neurotypical children (Brinker, Seifer, & Sameroff, 1994; Donovan, 1988; Dyson, 1991, 1993, 1997).

Questionnaires, and structured interviews that involved completion of scales, were the chosen methodology. As well as the acknowledged limitations of such methodology, which includes only allowing responses within preset parameters, further bias frequently occurred as the bulk of participants were mothers (Heaman, 1995). Initial assumptions rested on the idea that higher levels of stress must equate with higher levels of pathology (Stoneman, 1989). As it became established that the parents of children with disabilities experienced higher general levels of stress, some researchers embarked on the mission to determine whether mothers and fathers experienced different levels of stress. Even though there was variance, in some studies across some measures, no consistent overall gross difference in stress between mothers and fathers was identified (Dyson, 1997; Heaman, 1995; Krauss, 1993).

Flynt and Wood (1989) used telephone interviews to administer a questionnaire in a sample of 111 mothers of children with moderate mental retardation and identified in their sample that Negro mothers reported lower levels of stress, as did older mothers. No difference in stress related to socio-economic status was identified. However, Failla and Jones (1991) again used a questionnaire in a sample of 57 mothers of children with developmental disability and found that
older mothers perceived a lower level of family functioning. Involvement with more agencies was related to higher maternal stress (Brinker, Seifer, & Sameroff, 1994). This may be related to a trend of mothers looking for extra-familiar sources of support as opposed to fathers who tended to seek support within the family (Bailey, Blasco, & Simeonsson, 1992; Heaman, 1995; Krauss, 1993).

In attempts to further define the concept of stress, accommodations made by families were considered. Accommodations are the adjustments that family members need to make to each other’s needs to successfully live together (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996). Such accommodations occur in the construction of a daily routine that takes into account issues such as family income, paid and unpaid work demands and the family member’s social and developmental needs. In relation to children with developmental disability these accommodations have been conceptualised as hassle (Keogh, Garnier, Bernheimer, & Gallimore, 2000). Hassle referred directly to the child’s impact on daily routine in the context of the parent child relationship. In a study of 80 children with developmental delays of unknown aetiology, identified at or before three years of age, Keogh et al (2000) interviewed parents related to degree of hassle of their child. It was identified that as the child’s competence decreased the degree of hassle increased. Accommodations or degree of hassle increased in proportion to the child’s age. As children approached adolescence new competencies and problems emerged and accommodation activities increased and became more varied. This is consistent with the earlier findings by Harris and McHale (1989) that the duration of care giving activities was related to mother’s rating of difficulty in family life. In their study interviews were used, however, the results were potentially biased by the expressed focus of problematic situations or events. Not all studies found a linear correlation between, duration or time required in care, and parental perception of burden. Erickson and Upshur (1989) found that elements of both difficulty and time expenditure are important in perception of burden. They emphasised that the impact of different disabilities on perceived quality of parent child interaction needs to be considered.
Frey, Greenberg, and Fewell (1989) identified that parents reported more stress when communication skills in the child were low and that fathers found male children more stressful. Krauss (1993) discovered that fathers reported higher levels of stress related to the temperament of the child (mood and adaptability) and their ability to have an attached relationship that offered reinforcement than mothers, even within the context of similar levels of parenting stress overall. Floyd and Phillippe (1993) used video recordings to study parental interactions in 53 families with an intellectually delayed child and 51 families with neurotypical children. In the families with the intellectually delayed child there was a higher base rate of non-compliance, and less positive exchanges such as laughing, playfulness and joking in parent child interactions. These findings have particular relevance when considering the impact of parenting children with autism as noted already a disorder characterised by impaired communication and social skills combined with a marked rigidity. Autism is also a disorder more frequently diagnosed in males.

In line with the idea of inherent pathology within families of children with developmental disability Gowen, Johnson-Martin, Goldman and Applebaum (1989) in a longitudinal study compared feelings of depression and parenting competence in mothers of disabled and non-disabled children. Mean levels of depression were not significantly different, however more mothers with disabled children reached the point of depression at one time in the study. Harris and McHale (1989) also found that the depression score did not significantly differ in a sample of 30 mothers with a child with an intellectual disability and 30 mothers with neurotypical children. Glidden and Floyd (1997) used a questionnaire on resources and stress as a result of which they asserted that some of what has been traditionally labelled stress has a depressive component to it. Congruent with the notion of ongoing parental stress related to caring for a child with a developmental disability it was found that this depressive component might endure many years after diagnosis. Researchers have considered this depressive component as part of grief. Bruce, Schultz and Smyrnios (1996) used annual interviews over a three year period with 49
mothers and 49 fathers of children with intellectual disabilities to explore grief. They identified that grief is present over time and that mothers and fathers experience similar intensity of grief. Mallow and Bechtel (1999) explored chronic sorrow as an alternative to the concept of grief. Chronic sorrow does not carry the implication of a process that can be completed or resolved, as does grief. A questionnaire was utilised to explore chronic sorrow. The study had some limitations. Out of 100 questionnaires posted out only 28 were returned. This sample represented only nine couples and ten individual mothers. One further limitation was one of the inclusion criteria, which was that people had to be worried to participate. With these limitations in mind some insight into the experience of chronic sorrow was gained.

It was identified that this sorrow is triggered by different events. Mothers reported management crisis as the primary trigger where as fathers reported comparisons with social norms. Fathers were identified as radiating more toward resignation, as perhaps expected through a process of grief, where mothers reported more chronic sorrow. Young-Seideman and Kleine (1995) through a grounded theory study of parenting a child with developmental delay/mental retardation, in a sample of 29 mothers and 13 fathers, developed a theory of transformed parenting. This encompassed an entrance process and a performance process. In the entrance process parents heard the words of the diagnosis, internalised the information related to the disability and planned for change. The performance process encompassed reality construing processes, contextual processes and operating processes through the construction of reality loops. Construction of reality loops is an ongoing process of interpreting the child’s disability. Chronic sorrow was seen as a pervasive part of the performance process experienced intermittently, often triggered by milestone distress. It is of note that the entrance process relied heavily on information related to the particular disability. Making sense of the information on autism is, as already discussed, a difficult process.

Johnson (2000) also used grounded theory to interpret telephone interviews with parents of school age children with mild to moderate physical disabilities
and described the theory of parental straddling. This straddling occurred on three levels in which parents straddled alternate realities: This described as living in the past and present, attempting to view their child as normal when they were in fact disabled and parents attempting to deal with theirs and the child’s issues and feelings. This reinforces the ongoing nature of constructing reality as described by Young-Seideman and Kleine (1995). The attempt to view the child as normal is consistent with the pervasive process of chronic sorrow triggered by events that highlight the abnormal.

In much of the research pathology was operationalised as psychological stress, yet even though stress in families of children with a disability was higher, not all families were obviously dysfunctional which lead to the search for mitigating or balancing factors (Glidden, 1993): This is often conceptualised as coping (Donovan, 1988; Dyson, 1991; Flynt & Wood, 1989; Frey, Greenberg, & Fewell, 1989; Glidden & Pursley, 1989; Heaman, 1995). Parental perceptions of control and of the disability have been found to be strong balancing factors. This included a comparative frame of reference in which the child with the disability is compared to children who are more impaired (Frey, Greenberg, & Fewell, 1989). This has been referred to as comparing downward (Young-Seideman & Kleine, 1995). Families of children with developmental disabilities often found strength in religious beliefs and valued set rules and procedures for family life (Dyson, 1991). Utilisation of external support has also been identified as a positive coping factor (Dyson, 1997).

Failla and Jones (1991) identified four components of family hardiness as central features of successful coping. These factors were, a sense of control, perception of challenge and change as the opportunity for personal growth, an active orientation in adaptation to stressful events and confidence in the ability to endure. They went on to suggest that an important implication for nurses is to recognise the importance of family hardiness in the design of interventions. To help parents form realistic goals is seen as a key element. Young-Seideman and Kliene (1995) in their grounded theory study identified conversely the need for parents to guard hope. This need remained, even if others did not view the
hope as consistent with realistic goals. Attempts to determine factors, which contribute to successful management of stress through the examination of coping, is underpinned by a belief in linear causation. Families are complex nonlinear systems (Kossman & Bullrich, 1997). Complex relations within families involve overall and subsystems adaptation and child outcome rather than simple or linear relations among the characteristics of children with disabilities, characteristics of family members and adaptations of each (Brinker, Seifer, & Sameroff, 1994).

2.12 Impact of parenting a child with autism

Understanding of what autism is, and the associated clinical practice, has evolved dramatically over the last fifty years (Rutter, 1999). “Historically the autistic child’s family, particularly the parents, were studied primarily for their presumed role in the cause of the disorder” (Morgan, 1988:263). As the view of the cause of autism shifted from psychosocial to biological, the focus has shifted from the impact of the parent on the child, to the impact of the child on the parent.

Prior to 1988 there was little research on parents of children with autism (Milgram & Atzil, 1988). Since that time the pervasive stressful effect of living with a child with autism has been recognised (Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins, & Plienis, 1992). In line with the notion of stress, as in the research on the impact on parenting a disabled child in general, the bulk of the research has involved questionnaires or completion of self-report scales centred on stress, coping and depression. Significantly elevated levels of stress were identified on standardised scales (Bebko, Konstantareas, & Springer, 1987; Bristol, 1987; Clark, 2001; Freeman, Perry, & Factor, 1991; Koegel et al., 1992; Milgram & Atzil, 1988; Moes, Koegel, Schreibman, & Loos, 1992; Robbins, Dunlap, & Plienis, 1991). Researchers came to recognise universally elevated levels of stress in parents of children with autism and questioned not what is the nature of this stress, but instead what is the best way to measure it (Freeman, Perry, & Factor, 1991). Further researchers tried to
anchor the experience of parenting a child with autism by comparison to the experience of parenting children with Down Syndrome, behavioural disorder, cognitive deficit of unknown origin or chronic physical illness (Cystic Fibrosis). Neurotypical children were often used as controls. Parenting stress was universally highest for parents of children with autism (Bouma & Schweitzer, 1990; Dumas et al., 1991; Fisman, Wolf, & Noh, 1989; Kasari & Sigman, 1997; Sharpley, Bitsika, & Efremidis, 1997; Wolf et al., 1989): The risk for dysphoria was also higher (Dumas et al., 1991; Fisman, Wolf, & Noh, 1989; Wolf et al., 1989), and marital intimacy less (Fisman, Wolf, & Noh, 1989; Rodrigue, Morgan, & Geffken, 1990).

In research on parenting a child with a disability, non-disabled children were used as controls. Parenting a child with a disability was found to lead universally to higher levels of stress. Research on autism frequently used other children with a disability as controls and it was found that, in a similar way to that in which it was found that parenting a child with a disability was more stressful than parenting a non-disabled child, parenting a child with autism lead to higher stress than parenting children with different disabilities. Fathers and mothers differed in some scores, with mothers experiencing higher levels of stress than fathers in some studies (Freeman, Perry, & Factor, 1991; Moes et al., 1992; Sharpley, Bitsika, & Efremidis, 1997), yet others reported consistent measures across gender (Fisman, Wolf, & Noh, 1989; Wolf et al., 1989).

It is of interest that in the study by Sharpley et al (1997) that although it was found that females experienced more stress they also reported more confidence in child management than males. Both Wolf et al (1989) and Fisman et al (1989) identified fathers to be less prone to dysphoria. Professionals were found to estimate the stress of parenting a child with autism higher than the parents themselves (Bebko, Konstantareas, & Springer, 1987).

Very little research has been carried out using qualitative approaches (Midence & O'Neill, 1999). Reid (1999) using case studies identified the themes of imprisoned families and a vivid sense of bereavement. Families became
imprisoned as resisting the person with autism’s obsessive need for sameness and routine lead to acute behavioural disturbance and feelings of parental impotency. It became easier to become rigid to meet the needs of the person with autism only leaving the home for essential functions such as shopping. These themes appear to resonate with other personal accounts of feeling like a slave in one’s home (Hilgedick, 2001), and profound distress (Fox, 2001). Junee Waites described her experience with her son Dane. “I began to develop a fear of leaving the house with Dane. As time went by, I withdrew from everyone and everything” (Waites & Swinbourne, 2001:36).

Gray (1994) used a combined strategy of structured interviews with 33 parents of people with autism and a questionnaire of a further 172 parents and identified that withdrawal as a coping strategy was often employed. Families often found it easier to allow an atrophy of social contacts or to actively withdraw from society. Boyd (1992) after identifying increased stress levels in mothers of children with autism suggested the importance of identifying coping strategies that would lead to more successful adaptation in parents of children with autism. Gray (1994) attempted this and discovered that although some common strategies were identified, which were utilisation of service networks, reappraisal or reconstruction of life situation from a religious perspective and coping through withdrawal, families frequently varied their strategies to employ whatever worked at the time. Further the measures of parental self-report of emotional factors and personality measures, demonstrated that the outcome was the same irrespective of the strategies most commonly employed by the parent.

The call had gone out that as it was clear that the experience of parenting a child with autism was fraught with stress and came with a high degree of burden, that the nature of this stress needed to be defined and that successful balancing factors needed to be identified to allow services to provide the optimum intervention or degree of support (Koegel et al., 1992). Midence and O’Neill (1999) and Avdi, Griffin and Brough (2000) approached the problem from the perspective of looking at a smaller portion of the experience of parenting a child with autism and looked at the period of obtaining a diagnosis.
Midence and O’Neill (1999) looked at the experience of four families in the UK through a grounded theory lens. They identified six core categories as follows; concerns about behaviour and development of their child, confusion related to not being able to understand why their child behaved as it did, frustration related to incorrect diagnosis that did not give a clearer understanding, autism as a label which validates concerns as real in what amounts to an invisible condition, support acquired through having a diagnosis and the move toward acceptance.

Avdi, Griffin and Brough (2000) also in the UK used semi structured interviews with three sets of parents who were in the process of undergoing assessment of their sons for communication disorders later clarified to be autism. The expressed purpose of the study was to explore the way discourses allow and constrain the available paths of talking about children throughout the process of diagnosis. It was discovered that parents hold multiple, at times ambivalent meanings that often conflict, in their talk in this stage of the experience of parenting a child with autism. These meanings it was felt reflected dilemmas surrounding issues of disability, normality and the input of professionals. All three discourses remained post diagnosis. These findings were consistent with the notion of straddling as identified by Johnson (2000) as referred to in section 2.11.

Reconstruction of the meaning of behaviour through acquisition of the label or changing the discourse it would appear from the study of Kasari and Sigman (1997) in which filmed segments of parent child interaction were studied, has much utility in that it was felt that caregiver perceptions of the meaning of behaviour impacts on future interactions.

Dudziak (1982) interviewed five mothers of children with autism. Although the thematic analysis was primarily focussed on identification of prominent behaviours at the stages of birth, infancy and early childhood, diagnosis and initial treatment, school age and adolescence some very salient points were
identified. It was asserted that development is not always delayed but is
distorted. This was an important discovery and has great utility in the
consideration of children with autism that have average or above intelligence. In
early childhood, primarily related to the invisible nature of autism, mothers felt
blamed for their child’s behaviour. Obtaining a diagnosis was a long, frustrating
and costly process. Parents feared not being physically able to contain
aggressive behaviour as children grew into adolescence and beyond, times at
which physical restraint was seen to be potentially more difficult. Dudziak (1982)
asserted, and it was reiterated 12 years later by Elder (1994), that nurses are in
a good position to engage in research related to the impact of having a child
with autism on parents and families related to their access to families in a
variety of settings, a luxury not as common for many other professions.

Fong et al (1993), in keeping with the theme of examination of a smaller
proportion of the experience, interviewed eight parents that represented six
families in the attempt to determine what the experience of parenting an
adolescent with autism is like. The children of the parents were between the
ages of 13-15, five were males and one was female, none of the children had
an intellectual disability and two were in mainstream school classes. A potential
bias identified by the researchers was that all parents belonged to a parent
support group. Six interrelated themes were identified which were; concerns
about behaviour, concerns about social skills and communication, concerns
related to the effect on the family opportunities and effect on siblings, concerns
about education services availability and choice, relationship issues with
professionals and worry about future independence. All families related a
perception of feeling subjected to a significant amount of stress.

In the light of the limited telling of what the experience of parenting a child with
autism is and the nature of the identified stress Gray (1997) used semi-
structured interviews with 32 mothers and 21 fathers of children deemed to
have high functioning autism, to explore how parents construct a view of what is
normal family life. In line with the ambiguity of the concept of high functioning
autism, referred to in section 2.3, a limitation not acknowledged in this study
was that in terms of diagnosis, it was reported that this was made by staff at an autistic treatment centre in Queensland Australia, however the profession and the specific diagnostic criteria used were not identified. With this in mind the finding that parents readily believe that there is an objective ‘normal’ family life that most other parents experience is of great interest. Parents it was found used thematically consistent ways to measure their experience in terms of the normal. These criteria were identified as whether the family could engage in a series of standard social outings, the degree of spontaneity permitted by the child with autism on family activity and the presence of family rituals. The latter included the presence of a family routine. One mother cited the fact that the family routine never changed as evidence of normality. Further it was identified that fathers held generally more favourable assessment of family normality. Mothers were more likely to identify their parenting experience as abnormal and reported a perception of more difficulty in managing the impact of their child’s autism. For children who were aggressive concerns about the future were universal in this study.

The question of whether factors in the child are strongly correlated with parental stress was further explored by Professor Konstanttareas of the Institute of Psychiatry in Toronto and graduate students Mackay and Janes as reported by Clark (2001). It was asserted from past study that parents of children with autism face two major stressors, which include worry about the future and concern re the best way to both stimulate and manage their child. It was discovered that for parents of a child with autism that has a high degree of surgency or extroversion these concerns are greater.

2.13 Parents as part of a family

The family has been described as the basic unit of social organisation, a universal social institution (Haralambos, 1984). The family fulfils the roles of nurturance, support, socialisation and to some degree education of its members (Minuchin, 1974). Families form complex non-linear systems (Kossman & Bullrich, 1997; Smith, B., 1994; Ward, 1995). The inter-relatedness of family
members has been discussed for some time. Satir wrote in 1967 that, “when one person in a family (the patient) has pain which shows up in symptoms, all family members are feeling this pain in some way” (Satir, 1967:1). Families have come to be seen as systems that are more than the sum of the individual members, or family subsystems, which consist of coalitions between family members (Cox & Blair, 1997; Minuchin & Fishman, 1981; Tsonides, 1995). “The family as a whole seems almost like a colony animal, that entity composed of different life forms, each part doing it’s own thing, but the whole forming a multi-bodied organism which is itself a life form” (Minuchin & Fishman, 1981:12). Each family member has come to be viewed not as a nomad but as an integral part the social context of the family (Textor, 1988). In linear systems action or outcome can be predicted when given information about rules that govern the system and the starting point (Ward, 1995). Families are non-linear systems that are not predictable in this fashion as these systems are very sensitive to feedback and even slight variations can become magnified to produce great change in action and outcome (Walsh, 2000). Of course this conceptual scheme of families, it must be acknowledged, is an approximation only, as are all scientific theories, a construction that is based in the context of current understanding (Capra, 1983). Parents are part of the family system. The parent-child dyad has been conceptualised as a family subsystem (Minuchin, 1974). From the research on the impact of parenting a child with a disability in general and the impact of having a child with autism on parenting, much of which has viewed the parent-child relationship as linear, it is clear that the characteristics of impaired, communication, social skills (which incorporate the ability to reciprocate and reinforce parent potency) and behavioural disturbance (often inhibiting family flexibility) in the child all pose a challenge to the parent-child relationship. These characteristics correlate with the triad of impairment that characterises autism. Few studies provide a telling of what it is like to parent a child with autism. Domingue et al (2000) laid out the challenge for the new century as further exploration of what the experience is like of parenting a child with autism: A challenge I have taken up. This study poses the question of “What is the lived experience of parenting a child that has autism”?
3 Theoretical Perspective

The theoretical perspective of any study embodies the researcher’s understanding of what it means to be in the world and how one knows what they know. These ontological and epistemological issues are closely linked and often merge in that they exist in a shared space (Crotty, 1998). In order to allow the reader, or consumer of the research, to judge the goodness or validity of conclusions drawn it is important right from the start to unpack the theoretical perspective of the study (Kvale, 1994; Sandelowski, 1997).

Although the aim of this chapter is certainly not a complete history of the ideas of the related philosophers, an outline of theoretical perspective requires some discussion of the ideas incorporated from others in the construction of the author’s current comprehension. “Comprehension becomes a co-existence in history, which extends not only to our contemporaries, but also what was said before us, sometimes in a far distance” (Kockelmans, 1993:79).

To understand an individual’s being-in-the-world requires a discussion of some basic concepts. The concepts include; where being is located in space and time, the make up of a Being’s conscious elements, and the personal quality in a Being. These concepts form the ground out of which can arise discussion of how a Being makes sense of their world and the idea of individual construction of meaning.

The author’s conceptualisation of where being exists in space and time influences heavily the research methods selected. For those who focus on a Being’s bodily or cognitive aspects, being is seen largely as a function of space. Linear causality and response is seen as the area of investigation. A belief is subscribed to that each individual’s response is conditioned by that contingent which came directly before it, and all response thereafter rests contingent upon that particular response. Each response is seen to occur as a separate entity in space. It is almost as though through scientific endeavour we are able to separate out contingents and response shut off within themselves, and locate a
beginning and endpoint. Such cause and effect thinking has characterised much of the research on parenting a child with autism. The cause for instance seen as having a child with autism, the response increased stress levels.

Maisels in 1939 published “Thought and truth” in Hebrew in which much consideration was given as to whether being is in space or time. “The term cause implies and suggests the old separation between cause and effect, as though there were a kind of empty space between the two and as though they belonged to two different planes of existence. But, in truth, cause and effect are not in the least separated from each other” (Maisels, 1939/1956:44).

Contiguity as a concept sheds some light upon this phenomenon. “The principal of causality, upon which our cognition of nature and our very concept of nature are based, is simply this principal of contiguity” (Maisels, 1939/1956:44). This concept encompasses the notion that each point forms a midpoint in an unbroken and unceasing flux of points as opposed to a beginning and endpoint. On each side of each point contiguous processes occur ad infinitum. Does being also follow the same principle?

In 1843 Soren Kierkegaard the Danish philosopher cast many of the ideas about what constituted truth, knowledge and God up until that time into doubt, through the consideration of time (Lemay & Pitts, 1994). Although considered by Hegel in 1805 the consideration of time appeared to have little practical application (Buber, 1926-1939/1966). Kierkegaard refined the concept and embedded it in the practical world of being. As one of the forms of sickness that continue until death, Kierkegaard considered aspects of finitude and infinitude as factors of despair (Kierkegaard, 1843/1974). He identified that, “a self, every instant it exists, is in process of becoming, for the self does not actually exist, it is only that which is to become” (Kierkegaard, 1843/1974:163). The concept of futurity represented the Being’s view to, or headlong charge into, the future. Kierkegaard also identified as co-existing at any moment reflection. “The self is reflection, and imagination is reflection, it is the counterfeit presentment of the self, which is the possibility of the self” (Kierkegaard, 1843/1974:164). The
notion was conceived that at any time, a Being exists in the moment, into which is pulled through reflection the past and in the process of becoming projected into the future.

Further support for being as better represented by time than space comes from the point that a Being can only live one moment at a time as opposed to the ability to be in more than one point of space. “Man never lives time longer than a single moment. He never lives a continuous quantity of time-points, but, into the isolated time-point which he does live, memory rolls up all-past and all-future” (Maisels, 1939/1956:45). Never living for longer than a single moment may account for the experience of people feeling mentally the same across time although chronologically aging. “Time, though it subsists in the unity of its flux, subsists only in the moment, in each single moment. However, each moment of time bears within it the unity of all time. By contrast with the unity of space, which has its source outside of the single point and in the subjection of the existence of each point to what is outside itself, the unity of time is maintained by us from within each moment” (Maisels, 1939/1956:248).

The centrality of Beings in the exploration of being is perhaps the most convincing of the concepts that support the view of being as in time. Heidegger contributed to the discussion of the separation of spatiality from time in the identification of the concept of worldliness. “The homogeneous space of nature shows itself only when the entities we encounter are discovered in such a way that the worldly character of the available gets specifically deprived of its worldliness” (Dreyfus, 1991:259). Worldliness removes the potential for a pure subject orientation. Each Being is a being-in-the-world. There is no distance between the Being and the world: Each is inter related. “We are as much a part of the world as it is a part of us” (Lemay & Pitts, 1994:47). We can only know the world through our individual appreciation of it. St Thomas Aquinas (1225-1274) noted that is a particular apprehension of reality (Aquinas, 1252/1983). We can only view the world through our own perception: A perception coloured by individual reflection of the past and anticipation of the future. Time is, “not existent but is lived, and therefore has no being except within the human, as a
world juxtaposed to the world of nature which extends to infinity and subsists and exists in itself, outside of, and in antecedence to, the human” (Maisels, 1939/1956:273). It is possible to conceive a point in space as a self contained entity but to conceive a point of time with no reference to past or future is impossible.

The impact of the identification of being in time as opposed to space comes from the extension into temporality. “A point of nature, on this assumption, is no longer shut within the present as it really is, but is conditioned by the past and laden with futurity. We may put it thus: it is not spatial but temporal” (Maisels, 1939/1956:46). Temporality provided the structure for much of Heidegger’s analytic of being-in-the-world. Each Being is, “as being-already-in, being-amidst and being-ahead-of-itself, can now be seen to have what Heidegger calls an ecstatic temporal structure” (Dreyfus, 1991:244). The unity of temporal being is not dependent on continuousness as would be required if being was spatial. “It is of the essence of temporal being that its unity is not dependent on continuousness, that is to say, it is not set in the blank or void between one moment and another, but is borne and maintained in the very core of each moment, in contradistinction to spatial unity which is conditioned by what is outside of the single point, by its forced relationship with the external” (Maisels, 1939/1956:278). This temporal structure is a point of departure to examine the concepts of elements of being-in-the-world.

It has been spoken of for some time that a Being is a unitary Being and not a composite (Aquinas, 1252/1983). Aristotle (384-322 B.C.) cautioned that it is in fact a mistake to search for the elements of existing things, in which he referred to Beings (Owen, 1965). The understanding of any particular Being comes from a consideration of the Being as a whole, both subjectively and in commerce with other Beings (Buber, 1923/1970, 1926-1939/1966). The minute we begin to abstract qualities of a Being, the Being changes in character from an I to an it and the self represented by the Being’s unitary nature is lost (Buber, 1923/1970). Each Being has particular qualities, so a universal understanding
is not possible. Aristotle is quoted as saying, “universal man does not exist – particular men have particular fathers” (Owen, 1965:83).

In order to unpack the theoretical perspective of this study some consideration must be given to what constitutes a Being. Within each Being there would appear some things of which the Being is able to become fully cognizant and some personal quality that plays a part in the Being’s particular apprehension of reality. Aristotle referred to the part of a Being, of which the Being is able to become conscious, as the rational part (Anscombe, 1965). Factors of which one is conscious were considered as rational. Wishing and will are two examples of such factors. The personal quality has been referred to at different times as essence, spirit, character and personality. The consideration of essence and spirit was often encapsulated in the work of theologians and reflected in part a belief in, or more correctly faith in, God (Aquinas, 1252/1983). The consideration of character is closely associated with ethics. The personal quality of a Being in this view reflected in habitual patterns of behaviour (Anscombe, 1965). The concept of personality is simply that of the personal quality. Of the conscious and unconscious elements only the concepts of will and personality will be discussed in that they contribute directly to the assumptions that underpin the choice of methodology and method.

“Whatever exists, exists only in the present; it possesses an eternal present. But the existence of the will breaks the bound of the present; it is being not of the present” (Maisels, 1939/1956:36). Will is the realm of temporal being. “Will and being are synonymous in temporal being” (Maisels, 1939/1956:285). Will partially represents the volitional nature of being. “In fact there is in all obscurity a dialectical interplay of knowledge and will, and in interpreting a man one may err, either by emphasizing knowledge merely, or merely will” (Kierkegaard, 1843/1974:181).

Unlike a wish, will is not self limited as will wills itself, it is ever self-generating (Maisels, 1939/1956). Wishing is an element of Being that serves as a partial ingredient to will. Wishing has an element of futurity and is partially involved in a
Being’s projection toward the future. Wishes are self-limited and negate themselves in that a wish always wishes for something other than itself, rather than itself. “Its goal is handed to it from without, and though it is given in the future which is not yet, its representation already exists to the consciousness of desire, and the wish is attached to that representation as an effect is attached to a cause which precedes it” (Maisels, 1939/1956:36). Not unlike the imagination referred to by Kierkegaard a wish is a painful factor of the uncertainty of the present and the future. Wishes although future orientated are absorbed into the will. Each moment bears within the will the past and the future. This constituted by combination of conscious reflection and anticipation. Will serves a medial purpose for thought or knowledge. “Here, the principle of mediality is the self-contentment within personal being, which is entirely self-identity and self willing, and poses nothing but this identity and this will” (Maisels, 1939/1956:109). It is the conscious pulling into the moment knowledge of what has been and speculation of what is yet to come. It is through maintenance of the mediality in thought that a Being remains centralised in the world. “Out of the principle of mediality within thought, necessarily issues the creation of a world in will and time, without realisation a world which is not external but has being by and within its identity with the personal in man” (Maisels, 1939/1956:109). Time is personal time in which each moment bears the past and the future. Time cannot be realised in externality to a Being. The meaning of time is acquired from within by a Being. Will pulls time into the Being to provide a point of reference for being. A Being does exist spatially in the natural bodily condition, yet being occurs in time. Time is personal, each moment is lived in being and acquires it’s meaning through the power of the will pulling forth into the moment of being the possibility of reflection and anticipation. Each now moment is unified in that it contains all being.

Beings do not like to live personal moments in isolation and have also a will to association (Maisels, 1939/1956). Buber refers to this as a primary longing for relation (Buber, 1923/1970). The degree of the will to association varies between individuals. For some philosophers, such as Husserl, the world consists of and is defined by Beings in association in the form of communities.
(Moustakas, 1988). Each person in association comes to experience others through the pathways of empathy and co-presence. “In such a process in which I present myself to you and you present yourself to me there is an interchange of perceptions, feelings, ideas and judgements regarding the nature of truth and reality, an apprehension by analogy of one to the other. There is a continuing alteration of validity as people articulate and describe their experiences” (Moustakas, 1988:36). Through the discourse of association there is an evolution, or unfolding of the self in the process of becoming. In the process of association there is not only a generative, but also often a corrective process, as the Being is influenced by the perception and interpretation of others, or encouraged to look again with new prejudice. The other’s experience is grasped intentionally as a Being grasps a thing or experience as it is presented (Moustakas, 1988).

Along with the unique way of processing information, that would appear to be visual as opposed to linguistic, the lack of will to association in some individuals with autism has raised autism to a point of interest for many modern philosophers. However, as knowledge of the way of being that is autism increases, opposed to earlier views, we know many people with autism have a strong will to association but their attempts to achieve association are often clumsy because of impaired communication and social skills. The theory of mind deficit viewed as a central factor in the social skills problems, impacts heavily on the person who has autism, in their association. This theory of mind deficit impedes an understanding or theory of the relational I for the person with autism. Borrowing terms employed by Moustakas the person with autism may come to understand the monadic but not the intermonadic, or intersubjective (Moustakas, 1988). The person learns not to speak of themselves but merely on their own behalf (Buber, 1923/1970). The knowledge of other people opened up through empathy is lacking. Empathy is an intentional focus that opens up other people’s experiences for the Being (Lauer, 1967). The people with autism’s attempts at association are often misinterpreted or go unrecognised. The person often deals with others more as objects, or in Buber’s terms “Its” (Buber,
The person associated with, is perceived without recognition of the dimension of selfhood, and represented and related to more as an object.

Even though efforts are made to associate with others and understand their world this is achieved through the power of will pulling information about the world within to make sense of it. A being can only arrive at an individual interpretation. The sense arrived at is not just subjected to the power of will but coloured by the Being’s personal quality.

Personality refers to the Beings personal quality. All Beings are in possession of a will yet each Being is individual. As a construct personality is described with many slight variations (Fiske, 1978). Personality refers to that personal quality that results in individuality.

Ultimately, the study of individuality will have to deepen our understanding of how people abstract the gist of each other and themselves, forming schemata, expectations, or other cognitive representations that serve guiding and simplifying functions, enabling them to distil essential features from the otherwise overwhelming flood of trivial behavioural tidbits that confront the unprepared mind (Mischel, 1978:14).

Different Beings pull the same information within but are able to arrive at different interpretations. The intellect of each Being has particularity in the way that it apprehends its reality (Aquinas, 1252/1983). “The living and conscious personality bears within itself, in its own inwardness and in it’s self-identity, the entire world of individuality and will which it creates for itself” (Maisels, 1939/1956:110).

Whilst consciousness of will can be achieved the grasp of one’s personality is much more difficult, if at all possible, as personality would be active in the very attempt. Personality is creative not passive. Personality through the process of creation is in ascent as the Being is in the process of becoming. Nietzsche
(1844-1900) referred to people as the animal yet to be established in an attempt to encapsulate the continuous process of becoming (Buber, 1926-1939/1966).

This ascent is not continuous, as would be expected if considered that being is by nature spatial. The ascent varies in its trajectory. Moustakas labels the points of the trajectory as turning points or transitions. These are points of upheaval where a person’s way of being is disrupted. “Each new upheaval, each new truth alters patterns of life. Transitions are inherent in growth: Throughout life there are continual openings, chances for new beginnings, realisations of new ways of being” (Moustakas, 1977:31). Personality is pervasive in both the creation of the Being and the Being’s world.

To define personality is to define Being. Personality is pervasive. It represents the ground through which a Being has interface with the world.

The personality of which we speak is the personality of each and every man, in its singleness, in its individuality, in its manifest conscious life, in its suffering and love, in its memory of the past and its urge toward the future, in all the flux of its experiences which is poured into its self-identity. It is not some supernal personality, not an I which is above or below the living and willing I, not a superman or superior man but the man, in all the glory of his individual being during each moment of his life and in all the wonder of his personal identity during each of his experiences (Maisels, 1939/1956:112).

Personality is creative. Personality creates an ideal self and an ideal world and strives toward achievement of the ideal. Personality also transcends its individual creation to view itself as being-in-the-world, as part of the world. Personality is identity in which each moment has in it the identity of all past and all future (Maisels, 1939/1956). A Being is not the passive recipient of sensual data through perception. The personality is inherently creative in its effort to make sense of the world. Information filtered not only through a process of cognition but also through personality. Being in each moment is being in a moment that contains the influence of all that is past and future.
Personality is creative not only in itself but also of its self.

Personality is not, but becomes. Its being is not permanent like that of natural existence, which even perpetual motion and change do not rob of its property of spatial present. It is being that is generated and becomes from moment to moment. Personality is created not only from non-being which precedes man and his consciousness, but from moment to moment it is engendered out of nothing (Maisels, 1939/1956:249).

Personality bears in its entirety all identity within itself and this is recreated moment by moment. All of a Being’s personality is contained within each moment. As it is recreated personality is in process of enrichment and ascent as it heads towards cessation and death. This process is not continuous, a process of quantitative accumulation as would be expected if being occurred in space.

Each now moment, or the present, contains all of personality. “What we call present is only the bound where past and future meet each other” (Maisels, 1939/1956:248). Time in itself is not existent; it has no being excepting that within a Being. Time, and all the experiences within are lived. Each moment lived contains the whole of personality.

Personality combines with will in the will to association. “I” consciousness is part of the realm of personality. This consciousness in part is conditioned in association with other Beings. “Man’s willing of association means his willing of himself within it, his conditioning of himself by it” (Maisels, 1939/1956:290). Consciousness of others requires an element of consciousness of self or of the I. This self originates in personality. In association a Being wills the personal individuality of others as a function of the self-willing of the personality. “In the midst of daily actions and desires with their cause-and-effect contiguity, personality enters, breaking the chain of contiguity and imposing its own will on action through its self identification in past and future, and instead of contiguity comes responsibility, the responsibility of the will for guarding its individuality,
for maintaining its self” (Maisels, 1939/1956:84). Through association a Being both defines itself and creatively expands that definition through ascent.

What happens in association with an individual whose way of Being is autism, and thus by definition has a theory of mind deficit? This deficit represents an inability to attribute mental states to others, and hence a need for individuality to other Beings. It could be assumed that as part of the will to guard individuality a Being would withdraw from such association. But what is the experience for a parent who by the nature of the relationship must continue with the association? “What man wills in relation to his fellow men is the association of the individuality of each of them, not a unity of identity” (Maisels, 1939/1956:65).

Personality is a pervasive element of the Being into which the world is pulled to make sense of it. “Man in the identity of his life, in his conscious and lived reality, is man, there is no other man, and out of him issues his world, and there is no other world” (Maisels, 1939/1956:328). However, as neurotypical Beings are reliant on linguistic processing and to know the world need to name it, it is important to attempt to put into words how a Being knows what it knows (Freire, 1972).

Beings construct their own individual meanings. The theoretical assumption that has formed the basis of the present study of how Beings know is constructionism. The process of how Beings know has been discussed for some time. Although each of the thoughts discussed was regarded as complete in its time in retrospect they can be viewed as partial expression of the current understanding of constructionism. “Thought as manifestation of man, therefore, appears to us as an event in man’s history, and the progressive improvement of thought in the time-sequence appears as a progressive ascent in the stages of man’s individuality, as the evolutionary becoming of man in time sequence” (Maisels, 1939/1956:240).

Plato (428-354 BC) was one of the earliest philosophers to describe the construction of meaning in his well-known cave analogy (Bauman, 1978). In the
analogy slaves were tethered together in a cave, faced toward a wall on which danced the shadows reflected from a fire. These slaves constructed a process of meaning that came from naming the shadows. The slaves in the analogy were unable to see the items that cast the shadows so they built a whole new system of meaning. The role of naming in the construction of meaning has been widely discussed since this time. As stated by Gadamer men are condemned to meaning making. “To exist, humanly, is to name the world, to change it” (Freire, 1972:61). The slaves in this story earned respect and status by their ability to make sense of the shadows within the new system of meaning. One day a slave broke free and was able to turn to see what cast the shadows. When returned to the tethered position they tried to tell the fellow slaves of the origins of the shadows, however the other slaves had no reason to believe this slaves description, or new construction of reality over their own. What is more he/she lost the ability to see the shadows through the other slave’s construction of meaning and thus lost status in the group. Reality for the slaves was arrived at through the construction of meaning. This construction occurred within, and served them in their context.

Although well aware of the construction of meaning Plato advocated that a universal truth did exist. These truths existed he advocated, in forms that every day objects copy. These forms existed outside of time and space and were only available to humans in the disembodied state between life and death. New knowledge he claimed was a remembrance from a time in Anamnesis, the multiple cycles of life and death, when the person was disembodied and had access to original form (Lemay & Pitts, 1994).

Immanuel Kant (1724-1804) too recognised the construction of meaning in that he claimed that the human mind filters all sensory experience to make sense of it in a particularly human way. Each person filters sensory stimuli or information through the attribution of meaning. He did though believe that all humans have the same filters, or ways of construction of meaning, and thus universal human knowledge or truths could be generated.
Friedrich Nietzsche (1844-1900) extended this and articulated the belief that underpins the notion of constructionism when he stated that there is no universal truth waiting ‘out there’ to be discovered. He questioned the whole nature of truth and came to the conclusion that no such entity exists. Historically claims of truth have represented claims of power. There is he claimed, no all truth, as whatever is revealed as truth conceals a great deal and not only this it conceals the concealment (Winfree, 1999).

A shift from truth to meanings is a shift from positivism. This represents an awareness that what has in the past been called objective reality is a product of human meaning making (Packer & Addison, 1991b). Individuals construct meaning in the context in which they are situated in the world. Meaning is negotiated through interaction (Crotty, 1996, 1998). The meanings or realities that people construct are social realities (Collins, 1998). The meanings are negotiated amongst people and distributed or shared in the formation of culture (Keat, 1992).

People form meanings whilst situated within a finite context. “Fools and young men prate about everything being possible for a man. That, however, is a great error. Spiritually speaking, everything is possible, but in the world of the finite there is much which is not possible” (Kierkegaard, 1843/1974:54). Heidegger constructed the term thrown-ness to describe how people are plonked into a situated context without an element of choice or consent (Lemay & Pitts, 1994). Once situated in this context into which they are thrown they are prone to construct meaning through the cultural lens that comes with this context. The culture is thought by Heidegger to shape an individual through circumstance and the construction of meanings, however an individual engaged with the human vocation of ‘being’ can become aware of the influence of their situatedness and have an authentic existence. This comes through the adoption of an attitude of ‘care’ or ownership in which the individual becomes responsible for choices and possibilities within their context (Gelven, 1989). The individual becomes separate from ‘the one’ or ‘Das Man’ the general or undifferentiated cultural norms and realises that although still situated in their individual context
that offers a range of possibilities, although not all possibilities, they have some control over their construction of meaning.

These meanings are not static but in a constant state of flux, or are temporal, as people are beings in the constant state of becoming (Crotty, 1998). To remain static for humans is fatal (Freire, 1972). Anxiety related to approaching death prompts movement. Heidegger saw death as being followed by nothingness. Kierkegaard wrote of faith as the belief in God that is beyond proof. For Heidegger approaching nothingness generates anxiety (Lemay & Pitts, 1994). For Kierkegaard the maintenance of faith in the face of ongoing daily temptation to return to the ethics of the universal, later the Das Man referred to by Heidegger, created anxiety and movement (Kierkegaard, 1843/1974).

At any point or now moment when confronted with an experience, the meaning constructed of the experience is influenced by not only the presented sensory stimuli but also retentions from past experiences and protensions of anticipated future experiences (Steeves, 1994). The objectivist search for some fixed point of external reality that exists as an entity that is separate to those who perceive it has been abandoned when one adopts the view of constructionism (Bernstein, 1983). Frameworks or schemata developed to understand experience or phenomena are brought into being by people and do not exist in the world as independent entities (Van Manen, 1990). The search for scientific certitude in the quest to determine truths or elements of universal experience has in this study been replaced by a need to gain a new and fresh insight into what it is like to parent a child who has autism (Emden & Sandelowski, 1999).
4 Methodology

The methodology used in this study is that of hermeneutic phenomenology. Although not used as a cookbook, or off the shelf methodology, it provides the methodos or way that has informed the choice of method (Van Manen, 1990). Phenomenology is the study of phenomenon. Logy in the word phenomenology refers to a knowledge or study of something, in this case phenomenon or lived experience (Crotty, 1998; Van Manen, 1990). Heidegger in his etymological search of the word phenomenology found meaning in the two Greek symbols that make up the word. The first symbol the verb phainesthai in translation means to show itself. The second, of which phainesthai is a middle voice construction, phaino means to bring to light (Heidegger, 1927/1993). The first symbol represents the notion of shining or shedding light upon, and the second symbol the bringing to light through speech (Lemay & Pitts, 1994).

Phenomenology is a relatively new philosophy for which the finer points have remained open to debate up until this day. Anyone entering a dialogue with the concept of phenomenology is confronted with the conundrum of whose phenomenology to follow. Even if attracted to this philosophy by the power of interpretation provided through the adaptations of some of phenomenology’s later exponents, the works of Edmund Husserl (1859–1938) the man attributed with the honour of being the founder of phenomenology in its modern sense, provides a matrix into which the works of other exponents fit. These works have significant differences in terms of emphasis and interpretation, however still bear a relation to the work of Husserl (Atkinson, 1972).

Phenomenology as originally envisaged by Husserl, Heidegger’s (1889-1976) mentor, was to be the study of universal eidetic structures or essences of phenomenon (Osborne, 1994). This reflected a theoretical perspective in which a phenomenon was seen as able to be reached in a prereflective or prepredicative state: That it was possible to separate the subjective experience (the noetic) from the objective phenomena (the noematic), through the process of phenomenology (Crotty, 1996). From a constructionist perspective an obvious problem is that the only access we have to other’s experience of
phenomenon is through conscious interpretation and the only way one has to access a phenomenon is through the construction of meaning. Husserl had an awareness of this and attempted to control for this through a rigorous process of bracketing aimed at the separation of the subjective from the objective. Heidegger in opposition to his original mentor Husserl recognised that human consciousness is temporal and perspectival and that there is potentially not just one universal eidos or essential nature of a phenomenon that can be accessed but that a variety of interpretations are possible and each may be valid (Steeves, 1994). It is of note that Husserl in his later work, published in Ideas, made reference to the fact that there is not eidetic concreta: That once a single experience is plucked from the stream of conscience, the very notion that consciousness is continually fluctuating means that what you have is an image of the thing itself. This is a relative clarity as opposed to a mathematical exact phenomenology, which his more idealistic earlier work strove towards (Atkinson, 1972).

For Heidegger phenomenology although not searching for a universal essence was still more than the process of gathering the subjective. Phenomenology is a critical process in which normal everyday experiences are problematised with the aim to allow a fresh look, to get to that place, the clearing in the woods or clutter of everyday and accepted meaning, where the phenomenon can be viewed in a new way (Crotty, 1996). Phenomenology is about the development of a conversational relation with the phenomenon that is the focus of the study. The aim of the conversational relation is to break through or suspend the pre-understandings and structures of meaning that already exist and which influence the current construction of meaning about the phenomenon, to explore the phenomenon and allow the emergence of a new or renewed construction of meaning (Van Manen, 1990).

At times this happens spontaneously in our lives. After an intense experience we sometimes find we can see the world anew. We feel dislocated from our previous construction of meaning or ways of seeing the world and feel free to take a new direction or the appropriateness of our current direction is reaffirmed.
Phenomenology aims to achieve the same effect through a systematic and critical process. This is the getting back to the things themselves championed by Husserl and carried forward by Heidegger (Crotty, 1996, 1998).

Phenomena exist in the lifeworld, or simply where people live (Kerstin & Hallberg, 2001; Van Manen, 1990). Phenomena is reached through experience in people’s lives and lives are lived (Sandelowski, 1997). It is not possible to separate performance from context: To attempt this introduces a kind of privation or an absence of practice (Packer & Addison, 1991b). Hence the study of a phenomenon is the study of lived experience (Van Manen, 1990).

Phenomena do not exist as separate or discrete entities waiting to be studied. What is available to our conscious Being is a primordial flow of homogenous experiences, experiences that flow into each other in a constant motion with no clear boundaries (Schutz, 1932/1967). It is only through the process of turning towards, or attending to a particular experience that it acquires its meaning as a discrete phenomena. The process of turning toward, or focussing attention upon, has been termed intentionality.

Husserl made a great contribution to the clarity of this idea in his discussion of intentionality. This encapsulates the notion that all consciousness is consciousness of something, as outlined in the stream of cogitations, cogito and cogitatum part of the second meditation in Husserl’s “Cartesian Meditations” (Husserl, 1929/1988). The act of direction of consciousness, or turning attention toward an experience lifts it out from the primordial flow of ill-defined homogenous experience or duree as Schutz (a contemporary of Husserl's who shared ideas with Husserl although not directly working together) refers to the flow of experiences, and allows it to be examined as a phenomenon (Schutz, 1932/1967). This turning towards an experience gives the experience the artificial impression of being a phenomenon with clear boundaries as the act of turning attention to an experience is the very act of attributing meaning as this involves the process of reflection and recognition (Schutz, 1932/1967).
Recognition relies on drawing upon one’s current construction of meaning or schemata of the world to make sense of the experience. The act of turning toward an experience is the shining of light or bringing to light referred to by Heidegger in the sense he makes of the origin of the word phenomenology. Heidegger described phenomena as what can be brought to light (Annells, 1996).

Heidegger in his move from the epistemological basis of Husserl’s work in which intentional acts were individual, to the ontological basis of hermeneutics further refined the notion of intentionality. Heidegger took intentionality out of the context of a theory of meaning to a theory of being. Heidegger came to view intentionality not as a determined act but as the constitution of consciousness itself (Kockelmans, 1993). Consciousness to Heidegger was not an interior thing but a going out or project from oneself. A Being is described by Heidegger as Dasein. “Dasein is that entity which, as Being-in-the world, is an issue for itself” (Heidegger, 1927/1985:215). A Being cannot be conscious of all things at once as it is limited by human facticity and finitude. Thus consciousness is an opening oneself to this or that, not all things at once (Kockelmans, 1993). As consciousness is only manifested in the projected openness it does not have an internal reality itself. “Consciousness is able to manifest itself to itself only by the very fact that it factually discloses it’s view on things and, at the same time, impresses its own stamp upon them” (Kockelmans, 1993:71).

The aim of hermeneutics, if accepted as the letting things show themselves from themselves, renders the outcome interpretation, as a Being can only project out from a limited horizon. This horizon is where the Being is situated in, or thrown, in the world. “Dasein’s letting something be seen necessarily always has the character of being an interpretation. This is why the term phenomenology is no longer qualified by the word transcendental but rather by the expression hermeneutical” (Kockelmans, 1993:71). Interpretation is not the acquisition of knowledge or information but rather a working out of the possibilities, which are projected in understanding (Heidegger, 1927/1985). “In interpreting, we do not, so to speak, throw a signification over some naked thing
which is present-at-hand, we do not stick a value on it; but when something within-the-world is encountered as such, the thing in question already has an involvement which is disclosed in our understanding of the world, and this involvement is one which gets laid out by the interpretation” (Heidegger, 1927/1985).

This shift from an epistemological to an ontological basis also represents a move away from the pursuit of objective or foundational knowledge. Foundationalist beliefs encompass the notion that a universal essence, or truth, in which knowledge can be grounded is possible to reach when separated from the subjective: That one can step away from their context or situated being to view a phenomenon objectively. “What the anti-foundational philosophers suggest is not a search for truth conceived apart from history and culture, but, rather an examination of the relationship between human thought and human existence” (Hekman, 1986:9). The quest to determine an a-historical, or a-cultural, truth or essence misunderstands Beings as situated in a social, cultural and historical context. Hermeneutics embodies a movement from not only as noted earlier positivistic thought, but also anti-positivist thought which both acknowledge objective/subjective knowledge split (Hekman, 1986). “The enlightenment conception of knowledge fuels the objectivist/humanist debate as it is within this conception that the dichotomies of the debate co-exist. Both humanists and positivists share a fundamental epistemological assumption: the opposition of subject and object” (Hekman, 1986:168). Hermeneutics offers a horizon or place to project from which is separated from this dichotomy.

Hermeneutics is a word of Greek origin the usage of which in the Greek language refers to an explanation or translation (Crotty, 1998). It is derived from the Greek verb, hermeneueuin, to interpret (Van Manen, 1990). The word was also influenced by the noun, hermeneia, or interpretation. Both Greek words were derived from Hermes, who in Greek mythology was the wing footed messenger god responsible for the discovery of language and writing through which he changed the unknowable into a form that humans could grasp and understand (Thompson, 1990).
The recorded hermeneutic tradition began with interpretation of biblical texts and has been dated to the seventeenth century (Van Manen, 1990). When used in the context of hermeneutic phenomenology hermeneutic retains the meaning of the interpretation of meaning acquired through text. Text includes any discourse that is transcribed as well as written descriptions of behaviour (Allen & Jensen, 1990). Interpretation is the process through which a new or renewed and plausible meaning is constructed. It is the process of moving beyond mere description of a phenomenon or the cataloguing of currently accepted subjective interpretations. The text created from transcription of the discourse contains ordinary language. “Ordinary language is in some sense a huge reservoir in which the incredible variety of richness of human experience is deposited. The problem often is that these deposits have silted, crusted or fossilised in such a way that the original contact with our primordial experiences are broken” (Van Manen, 1990:61). Heidegger referred to this as a process of words becoming impoverished. The successive generations of use of words allows subtle changes in meaning and thus a break with the primordial experience that they originally named. This is problematic as it is through language, a type of extended memory, that moments of coming into being, the authentic mode of existence, are recorded. “In thinking Beings come to language. Language is the house of Being. In it’s home man dwells” (Heidegger, 1927/1993:193). As the successive layers of silt build up and words and language become impoverished, people move further from that point of being and contact with experience. Interpretation is the process of making sense of a phenomenon by breaking through the silt of current constructions.

The hermeneutic process of interpretation is circular. It involves a movement between the specific and the whole, between projection of meanings and anticipation of understanding. The aim of this process is to uncover and explicate an understanding of the phenomenon (Allen & Jensen, 1990). This has been described by Ricoeur as an unfolding of the sense potential of an experience and by Heidegger and Gadamer as letting the message, that can not be fully extricated from it’s antecedent background, have it’s say (Risser,
2000). Letting the thing be seen from its self. The metaphor of the circle in hermeneutic interpretation has been revised by many scholars but represents the dynamic movement between the part and the whole of texts to seek understanding. This understanding not as a way of knowing, but particularly for Heidegger and Gadamer, taking an ontological position, as already noted, in understanding and experiencing as a way of being (Annells, 1996; Thompson, 1990). The circle consists of two arcs. Both arcs are equally important in hermeneutics. The forward arc is one of projection. This makes understanding possible. The arc projects from a fore-understanding. Gadamer referred to this understanding as prejudice (Gadamer, 1960/1985). It is from this stance that the field is opened up for interpretation. “Every questioning is a seeking. Every seeking takes its direction beforehand from what is sought” (Heidegger, 1927/1993:45). The return arc is the movement of uncovering. The forward arc renders understanding possible and the return arc provides the space for evaluation of an interpretive account (Packer & Addison, 1991a).

Gadamer wrote of the interpretive account as the outcome of a fusion of horizons. These are the horizon of the text and that of the interpreter (Hekman, 1986). Horizon is defined as the view from where one is, their vantage point. This fusion is situated historically as the horizon of the interpreter is formed within the traditions and beliefs of the time. “The interpreter understands the action from a specific historical and cultural position and through the concepts and questions that are brought to the investigation” (Hekman, 1986:147). Gadamer formed the belief that for a text to become the object of interpretation it must pose a question to the would-be interpreter. The dialectical relationship between interpreter and text being like that of a conversation, which is reciprocal by nature. The question always bears relation to the answer expected. The medium of the dialect or conversation is language. It is through language that the fusion of horizons can take place. The fusion of horizons involves the process of translation. “Translation allows what is foreign and what is one’s own to merge in a new form by defending the point of the other even if it be opposed to one’s own view” (Gadamer, 1972/1976:94). This process is ongoing in a circular fashion. Each time a dialect is entered into with the
phenomenon there is room for a reflective evaluation of pre-understanding and a refinement of interpretation or understanding. For this study the acquired understanding becomes the interpretive account.

Interpretation, although not guided by a regimented set of procedures is certainly not an undisciplined guess, speculation, or divinatory in nature (Packer & Addison, 1991a). The fore understanding or structure (forward arc) is the reaching out to the phenomenon. This is the point of entering the circle. The researcher has the responsibility to prepare for this entry so that the subsequent research is not seen to foster mere speculation. This fore-structure is primarily of a practical as opposed to a conceptual nature. “Entering the circle in the right way is mostly getting the manner of inquiry right” (Packer & Addison, 1991a:277). This point of entering the circle cannot begin from a place of absolute certainty of unquestionable data or logic. “We begin there in full awareness that this understanding is corrigible, and that it is partial in the twin senses of being incomplete and perspectival” (Packer & Addison, 1991b:23).

In hermeneutic philosophy a stance is adopted that is engaged and concerned as opposed to detached and neutral (Packer & Addison, 1991b). It is recognised that one is already in a situation at any starting point of research and it is from here that one projects into the study. This context will affect the lens through which the study is viewed. The life world or lived experience is the ground from which all people come and it is the ground that can never be fully eliminated even if the ground is interpreted in a radically different manner than it may have been at the start of a study (Bruzina, 2000). This results, as consciousness is always constituted in a reality that is not isolated from the experiential or life world. There is no way to adopt a stance from which to view human life that is outside experience (McPhail, 1995). The appearance of phenomenon is embedded within the attributed meaning (Ogawa, 2000). Any uncovered insights will remain an intentional insight to a degree as the insight is affected by what the researcher attends to or finds salient (Davis, 1991). Having considered this again the critical nature of hermeneutics must come into play. As a method it is not a solipsistic journey for the researcher or the mere
cataloguing of the current construction of meaning. The researcher is called to be aware of as far as is possible their current construction of meaning to allow the results of the dialectical interaction with the phenomenon to surprise them. To allow the shining through referred to by Heidegger or be open to the fusion of horizons described by Gadamer. In hermeneutics this is not a formal process of bracketing as originally advocated in phenomenology by Husserl but more a process of surrendering. This surrendering is maintenance of an openness to incorporate and assimilate insight from the reverse arc of the hermeneutic circle. Wolf refers to this as surrender and catch (Wolf, 1984).

The interpretation uncovered will be a true one in Heidegger’s view if it provides an answer to the practical problem that motivated the enquiry. For Heidegger truth was an uncovering or self-showing (Heidegger, 1943/1993). Truth was seen as more than a correspondence between a theory and the ways things are, and not a universal fact, or the kind of truth disputed by Nietzsche. “What is uncovered in the course of a true interpretation is a solution to the problem, the confusion, the question, the concern, and the breakdown in understanding that motivated our inquiry in the first place” (Packer & Addison, 1991a:279). For Gadamer truth comes from effective-historical consciousness. Each interpreter brings to a text a unique horizon so as the result of the fusion of horizons there will not be the possibility of just one true interpretation. What is important is the process. Gadamer stated that this process is analogous to an I-Thou relationship. “In the I-Thou relationship I open myself to the other; I am dominated by the will to hear rather than to master and I am willing to be modified by the other” (Hekman, 1986:104).
5 Method

As already noted although there is no prescription of methods or fixed signposts, or a cookbook recipe, there is a scholarly tradition to follow in the use of methods that allows the demonstration of scholarship (Van Manen, 1990). Method in a phenomenological sense cannot be studied head-on as can be done with empirical sciences but only approached indirectly (Van Manen, 1979). Because of concerns about the value of qualitative research methods, based on the constructs derived from quantitative research of the need to be able to generalise and validity, there is a particular significance in the need to demonstrate scholarship that passes the "so what" test (Sandelowski, 1997).

Methods need to be consistent with the aims of phenomenology and investigate what the study sets out to investigate (Kvale, 1994). Methods must allow the collection of good data (Kleinsasser, 2000; LeCompte, 2000). The scientific worth of qualitative methods also derives from the ability to communicate to others the systematic approach to the study of a phenomenon (Sandelowski, 1995).

A method is required that allows the exploration of people’s accounts of their life world experiences of a phenomenon that can be converted to text to allow interpretation. A process must also be in place to check the resonance of the interpretation with a group of people who have first hand experience of the phenomenon (Van Manen, 1990).

For this study of the lived experience of parenting a child with autism, parents of children with autism participated in the study. The phenomenon or experience turned towards, or plucked out of duree, was the experience of being a parent of a child with autism. The aim was not to shed light upon the difference if any of the parenting experience of mothers or fathers. The aim was to bring to light, through exploration within a hermeneutic phenomenological framework, the experience of parenting a child with autism.
5.1 Procedures

Nine parents of children with autism were interviewed. The interviews were taped and a professional secretary with transcription experience transcribed the tapes. The transcripts were proof read whilst listening to the tapes to check accuracy. To continue the voice of the parents in the analysis focus groups were conducted. A total of nine interviews and four focus groups were conducted (see 5.2 - study participants).

Interviews are not repositories of objective facts but are mutually constructed social events out of which data is generated (Collins, 1998). Interviews are conversational in nature (Van Manen, 1990). “A conversation which is not to be confused with idle chatter, or a violent babble of competing voices, is an extended and open dialogue which presupposes a background of intersubjective agreements and a tacit sense of relevance” (Bernstein, 1983:2). To avoid the reduction of the interview to idle chatter the interviewer needs to remain well orientated to the topic of discussion (Van Manen, 1990). The phenomenological interview needs to move beyond subjective interpretation and opinion of the phenomenon to that which is experienced (Crotty, 1996).

To begin the process of engagement whilst gathering useful data to understand the context of the interviewee a short series of protocol questions were utilised to gather demographic data. These questions allowed the collection of demographic data related the interviewee and their child with autism. Such questions warmed up both parties to the conversation and had the potential to increase the interviewee’s sense of confidence to successfully participate in the conversation (Dilley, 2000). After the completion of the protocol questions the interviewee was invited to talk about the experience of the phenomenon. This invitation in an interview in a phenomenological study may be all the structure that is required (Osborne, 1994). If the conversation moved towards generalisations the request for an example of a specific instance, situation or event was used to re-orientate the conversation and mine below subjective interpretation and opinion. It was anticipated that the interviews would be
between one to two hours duration, however it was planned that they would continue until there was nothing believed relevant by the interviewee left to discuss. Interviews were conducted up until the point where no new knowledge emerged (Kvale, 1994). The average interview time was 2.1 hours. The range was one to four hours.

The act of gathering data, analysing and interpreting are not really separate activities that occur in a linear sequence. Each is related to the other and at times occurs simultaneously (Kvale, 1994; Sandelowski, 1995; Van Manen, 1990). Analysis is the process of breaking data up or down to render it able to be interpreted (Sandelowski, 1995). In effect the act of analysis begins at least from the time of the first proof reading of a transcript (Sandelowski, 1995). In this study transcripts were read through repeatedly and sifted to allow the creation of a conceptual map of predominate story lines (LeCompte, 2000). As new data was acquired through the continued process of interviews, through immersion in the data, new categories were created as demanded and some categories collapsed into broader descriptors (Burnard, 1991). Categories only earned their way into construction by virtue of their fit with and faithfulness to the data (Sandelowski, 1995). Data were grouped together that illuminated these categories and the material viewed as unusable filler found in interviews removed (Burnard, 1991). A holistic approach to the analysis of data was chosen as the text was viewed as alive, in that it played itself out in front of the researcher in a vital way. The use of a more reductionistic approach, not unlike a child who holds a pet Budgie too tight, risks strangling the data and loss of vitality even with the best intentions (Steeves, 1994; Thorne, Kirkham, & MacDonald-Emes, 1997).

Where analysis entailed breaking of the data up or down, interpretation demanded the creation of something new from the data (Sandelowski, 1995). The process of analysis allowed the data to be organised in a way that had made this possible. The circular nature of the process of interpretation meant any separation of the process of interpretation from analysis is artificial and only for the purpose to make the process by which data is transformed transparent
to the reader. The understanding uncovered was not just that of the current subjective interpretation or everyday view of the phenomenon but a new or renewed look at what makes the phenomenon what it is. This represents a revelation of a deeper comprehension of the phenomenon itself (Allen & Jensen, 1990). It must be again acknowledged at this point that a universally existential understanding cannot be achieved. Any interpretation is a construction. It is not a thing that exists in it’s own right (Crotty, 1996; Van Manen, 1990). In line with the metaphor of the hermeneutic circle the interpretation reached will be open to re-interpretation and is dialectical in nature (Annells, 1996).

Data was analysed and themes developed. The interviews were taped and transcribed. The data was analysed for the emergence of themes. The drafts of these themes were taken to four focus groups of parents of children with autism to allow further dialogue with parents of children with autism. The aim of this was to discuss the analysis and interpretation. These groups allowed a further fusion of horizons. “In this way, the hermeneutic researcher deals actively and explicitly with the dilemma of allowing one’s own theoretical or conceptual leanings to assume a privileged position” (Thompson, 1990:258). The interpretation was refined until it was felt that it represented a plausible account of the experience of parenting a child with autism. Interpretation allowed the emergence of a new or renewed understanding of this experience.

A concern has been expressed that nurses who utilise qualitative methods often work as though engaged in a cottage style industry in which they work in isolation and fail to situate their study in the wider body of research related to the phenomenon (Sandelowski, Docherty, & Emden, 1997). In order to allow the study to be situated with other research, parameters of the study group needed to be clear. In this study parents of children enrolled in a Special School for Children with Autism and in the age range of four to ten years were interviewed. This age range was selected for convenience of clarity of diagnosis by virtue of school enrolment and to avoid early adolescence, a time of numerous and complex tasks for the adolescent and often the parents who in many cases are approaching middle adulthood (Riesch & Forsyth, 1992). To be eligible for
enrolment in the Special School for Children with Autism the child must have received a diagnosis by a paediatrician or child and adolescent psychiatrist of an autism spectrum disorder. As previously noted this diagnosis will be that of Autistic Disorder, Asperger’s Disorder, or Pervasive Developmental Disorder not otherwise specified (Atypical Autism). To aide with clarity of the phenomenon under study only parents of children enrolled in the Special School for Children with Autism, in the age range of four to ten years with a diagnosis of Autistic Disorder or Asperger’s Disorder were interviewed. Parents were restricted to biological parents.

The first three of the focus groups were also formed from parents within these parameters. When the conversation had lapsed into silence with parents from this group a fourth focus group was convened. This group was made up of parents who were part of Family Support Group for parents of people with autism. The rationale of going to a new group was that the dialogue had lapsed into silence with the parents from the previous sample. To allow a new ground for the possible emergence of a new direction through the merging of horizons with a broader group the fourth focus group was convened. The parents expressed a strong resonance with the analysis and together we could find no way to expand it.

All parents who participated in an interview or attended a focus group completed a consent form (Appendix One). Parents who attended a focus group also completed a focus group data sheet (Appendix Two). For focus group one and two the parents were presented upon arrival with a package. This included the consent form, focus group data sheet and a handout representing the analysis/interpretation to that point. For focus group one this consisted of visuals that represented the major categories (Appendix Three). This was extended in focus group two to include subcategories that had been developed (Appendix Four). Prior to focus group three the analysis was developed into narrative format. This was sent home to all parents who had expressed interest in attendance at a focus group (Appendix Five). It was sent home in the communication books of their child on the Wednesday to allow reading before
the Friday group. For focus group four the parents were again presented with a package on arrival that included the consent form, the focus group data sheet and a representation of the analysis to the point in brief narrative and slide format (Appendix Six).

5.2 Study Participants

Parents were recruited for the interviews that had children that attended the Special School for Children with Autism, in the age range of four to ten years, with a diagnosis of Autistic Disorder or Asperger’s Disorder. Parents were recruited by an advertisement in the school’s newsletter and a personalised flyer sent home in the children’s communication books. Nine open-ended interviews were used to access parent’s experience of the phenomenon. Interviews were conducted in the period from the 18th February to 23rd April 2002. Six participants were female parents and three were male parents. This represented parents of seven children enrolled at the Special School for Children with Autism. All of the children were male. One family had two children with a diagnosis of Autistic Disorder. The five-year-old male was enrolled at the school and the ten-year-old female attended a Department of Education Special School Placement. Seven participants were married and living with their spouse and family. Two participants were single female parents. Only one of the children was an only child and this child lived with married parents. The age of the participant parents ranged from 31 to 47. The average age was 39.44.

Three focus groups that consisted of parents recruited who had children that attended the Special School for Children with Autism, in the age range of four to ten years, with a diagnosis of Autistic Disorder or Asperger’s Disorder, were held to allow the ongoing voice of parents through the development of the analysis. These occurred on the 5.7.02, 26.7.02 and the 9.8.02. Parents were again recruited by an advertisement in the schools newsletter and a personalised flyer sent home in the children’s communication books.
Five female parents attended the first group. These parents were the parents of five male children, four with Autistic Disorder and one with Asperger’s Disorder, with an age range of four years to six years. The parents ranged in age from 32 years to 38 years. The average age was 35.6 years. Four of the parents were married and one was a single parent. Only one of these parents had participated in the interviews.

Three female parents attended the second group. Two of these parents had attended the first group. These parents represented three male children aged four years to six years, two with Autistic Disorder and one with Asperger’s Disorder. The parents ranged in age from 32 years to 38 years. The median age was 34 years. One parent was married and two were single parents. Two of these parents had participated in the interviews.

Three parents attended the third group. One parent attended all three groups. One parent had attended group two only but had been involved in the interviews. One parent had attended no previous groups and had not participated in an interview. The parents represented three children, two with Autistic Disorder and one with Asperger’s Disorder with an age range of 4 – 5 years. The parents ranged in age from 34 years to 47 years. The median age was 38 years. Two parents were married and one was a single parent.

A fourth focus group consisted of parents recruited from the Support Group for parents of people with autism and was run on 21.8.2002. Parents were recruited from an advertisement in the group’s newsletter. Twelve female parents attended the group. The parents ranged in age from 36 – 48 years. The average age was 42 years. These parents represented twelve children with autism. One child had a diagnosis of Pervasive Developmental Disorder not otherwise specified, three children had a diagnosis of Asperger’s disorder, seven children had a diagnosis of Autistic Disorder and one child had an undifferentiated diagnosis of Autism Spectrum Disorder. The children ranged in age from 5 – 17 years, the average age was 10.1 years. The child with the undifferentiated diagnosis attended preschool, all other children attended
school. Two children currently attended the Special School for Children with Autism. A further three children had attended the Special School for Children with Autism in the past and had now moved onto other settings. Two of these children were in mainstream school and one was in a Special School Placement through the Department of Education. Two children were in an Autism Support Class in the Department of Education and the remainder were in mainstream settings. Of the children in mainstream only one was in a high school placement.

5.3 Ethical Considerations

Ethics concerns how people act. The definition of ethics provided by the Australian Nursing Council code of ethics for nurses in Australia is, “the moral practices, beliefs, and standards of an individual/s and/or a group” (Australian Nursing Council, 2002:2). Applied ethics relates to action in a particular context, in this case the context of a nurse engaged in research (Seaman, 1987). Ethics have been discussed throughout time in the philosophical struggles to understand the human way of being-in-the-world (Sahakian, 1968). In close association with the variance in the constructs of epistemology and ontology, the guiding principles of ethics have varied. These guiding principles have included rule based principles and individual virtues. Both have been attributed with primacy at different times in history. The applicability of ethical rules or virtue has been seen to vary between that of a universal nature through to that of particularism (Smith, B., 2002). Universal rules or virtues have been seen to be those which guide ethical behaviour at all times in all circumstances. Particularism involves consideration of particular circumstance. Contemporary consideration of ethics involves consideration of both the acknowledged universal human rights and the particular (Gastmans, 2002). Contemporary nursing ethics involves a consideration of principles and virtues (American Nurses Association, 2001; Australian Nursing Council, 2002; International Council of Nurses, 2000).
Nursing involves action and is hence guided by ethics. “A view of nursing in which the relationship between nurse and patient is regarded as central presupposes an intersubjective view of human beings, within which interpersonal relations are interpreted in terms of solidarity and responsibility” (Gastmans, 2002:497). The inter-subjective view of humans is driven by the long acknowledged will to association in being (Maisels, 1939/1956). Research is but one nursing action that is governed by ethics (American Nurses Association, 2001). Ethics when applied to research pose a need to consider the manner of relationship and burden of responsibility for the relationship, with the research participant.

The concept of principle based ethics has evolved in line with the human preoccupation to conceptualise good and evil. The concept of morality has evolved into the notion of beneficence and nonmaleficence, of doing good and avoiding harm. These principles are inherent in the code of ethics for Australian nurses (Percival, 1992). A tension exists in all research of the need to balance the good manifested in the acquisition of knowledge with the potential harm to the research participant that may occur in the inter-subjective field of the research (Seaman, 1987). Plato himself charged human kind with the mission of attainment of as much good as is possible (Sahakian, 1968).

The good to be acquired in the present study of the lived experience of parenting a child with autism is the understanding achieved about this experience. This understanding of this experience has not been readily available until this time to those who do not live the experience or work closely over a long period of time with those who do. To bring this good to fruition, a burden to engage in quality research and the dissemination of results rests strongly with the researcher.

The identification of harm or evil is not as clear. St Aurelius Augustine (A.D. 354-430) provided for the world a useful definition of evil or harm. “An evil will, said Augustine, has a deficient cause (not an efficient cause), for evil is merely the absence of good, a negative condition of privation or, in other words, a loss
of good, of beauty, of happiness, of virtue" (Sahakian, 1968:90). Principles guide many of the gross considerations of ethics, of how to do good, considered in the research such as the need for informed consent, the right to confidentiality and anonymity, the right to withdrawal at any time and the assurance that the choice to participate or not participate would not influence service provision, in this case by The Autism Association of NSW.

Ethics committees review research to ensure the principles are adhered to. The Australian Nursing Council in their code of ethics states, “nurses should not participate in any research or experimental treatment which has not been approved by an institutional ethics committee” (Australian Nursing Council, 2002:4). This study was submitted to, and approved by, the institutional ethics committees of The University of Technology Sydney and The Autism Association of NSW.

Ethical consideration, however, does not stop with approval of ethics committees and it is perhaps the consideration of virtue that informed ongoing considerations particular to this study.

A virtue approach to ethics differs from a principle based approach in the considered primacy of good character over a particular action. “The question of what qualities a person must have in order to be ethically good is considered as the primary factor, because the ethical quality of actions is largely determined by the ethical qualities of the agents whose actions they are” (Gastmans, 2002:99). Good qualities of character it is argued produce practical moral decisions that are grounded more in experience, beliefs and sensitivity than in rules (Spohn, 1992). Virtue ethics take into account the temporality of being. Aristotle recognised this fact more than the stoic approach of his mentor Plato (Spohn, 1992). The Being’s character was seen as in possession of an emerging quality. The development of virtues was required to continue the development in a manner that lead to the flourishing of the individual.
Whether being is seen to occur in space or time colours the debate regarding the extent to which virtue has a place in ethics. Those that view being in a spatial manner have difficulty with the subjective nature of virtue and the temporality embedded within. Such authors, invested in the ability to identify and measure discrete beginning and endpoints. Principle based ethics lend themselves more to this purpose as outcome is seen as contingent upon the application of a specific rule or principle. If personal elements are considered at all a spatial view corresponds more comfortably with the concept of static personality traits (Terzis, 1994).

Virtue ethics does not necessarily replace but can be viewed as complimentary to principle, commandment, or rule-based approaches (Spohn, 1992). In this study being was viewed to occur in time and virtue ethics are seen to compliment an explication of what motivation, that can be made conscious, informed the decision of when to and how to apply ethical principles. In this study the virtue justice, first articulated by Socrates warrants discussion. Justice as a virtue features in the Australian Nursing Council, American Nurses Association and the International Council of Nurses, codes of ethics for nurses (American Nurses Association, 2001; Australian Nursing Council, 2002; International Council of Nurses, 2000).

Justice is a virtue that encompasses balance and harmony, and it is a concept that has formed the basis of many subsequent discussions of virtue (Sahakian, 1968). Such a sense of balance is involved in the context of nursing research in the sense of balance of when the good to be gained is no longer greater than the potential harm. Virtue combined with principles help inform action when confronted with an ethical problem. An ethical problem is, “a situation that requires ethical consideration or ethical decision making, or a conflict of moral values” (Australian Nursing Council, 2002:2). In this study justice informed the decision of when to break off the relationship with the parents.

Such a decision reflects a move from the universal application of virtue and principle to the particular. “Moral particularism says to us that we ought to look
carefully at the case at hand, be sensitive to the complex and peculiar characteristics that make up the situation, and not artificially situate a given case in the light of other cases” (Smith, B., 2002:245). Kierkegaard was one of the first to consider the need to examine the particular when he introduced the concept of teleological suspension of ethics (Macquarrie, 1973). Kierkegaard discussed at length the story of Abraham and his son Isaac in his book “Fear and trembling and the sickness unto death”, in an attempt to understand how Abraham could suspend the universal ethic of not doing evil and consider slaying Isaac at God’s request (Kierkegaard, 1843/1974). Kierkegaard concluded that in consideration of particular circumstance at times factors lead to a lack of primacy of universal ideals.

The particulars of the case of this study of the lived experience of parenting a child with autism involved the ethical decision of when enough is enough. Once two focus groups relayed on two separate occasions, in a unified voice, that the understanding achieved in the analysis resonated strongly and was an accurate reflection of the lived experience of parenting a child with autism that needed no further refinement justice demanded that it was time to stop the discussion at this point. The analysis had identified the loss of self of the parent. This loss was contributed to by the time demands of care. At this point it was no longer ethically sound to continue to ask parents to give time.

The potential harm of anxiety, resultant of the process of discussion of the experience could be balanced through debriefing and counselling, both of which were offered to participants (Kidder & Judd, 1986). Time cannot be replaced, hence the imbalance at this point between the potential for good, to be achieved through potential refinement of the analysis against the harm. This was considered in the context that any analysis remains incomplete as the conversation that ceased at some point will be again picked up and extended in the direction pointed to at the time of lapse into silence. To know when no further interviews or groups will potentially provide a new or unique insight is impossible. Hence the decision of when the understanding had enough depth
rested with the balance of the feedback from the voice of the parents and the
cost of going on. The decision became ethical as opposed to methodological.
6 Results

6.1 Initial Analysis

The initial analysis was completed from the process of the nine interviews with the parents of seven male children with a diagnosis of Autistic Disorder or Asperger’s Disorder between the ages of four and ten.

From the data it became clear that the lived experience of parenting a child with autism was not about a series of activities but about profound change to the existence of the parent as a person. The change occurs not only in the experiences perceived as problematic by the parents but also in those seen to represent the positives in the experience.

The autism that is present in the parent-child relationship, pervaded the very self of the parent. This manifested as a shrinking of the parent’s self. If autism could be conceptualised as a set of impairments that limit a child’s way of being and made visible such as the shell of a turtle: The experience of parenting a child with autism was like that of metaphorically being pulled into the shell of autism. The parents experienced less spontaneity, less social contact, less things and less individual identity. Autism dominated the parent’s current and future projects and largely dictated the positives of the experience. This process of parents being pulled into the shell of autism in the context of the experience of parenting a child with autism has been laid out in the following results and picked up in the discussion.

Less spontaneity

The experience of parenting a child with autism is an experience of shrinking spontaneity. This is a reduction in the spontaneity of action and communication. Lack of spontaneity in action is characterised by a routine way of doing things. Without forewarning and planning action cannot successfully occur. Lack of spontaneity in communication is about having to express the same thing over and over: With conversations at times taking the same path with the same things said in the same sequence each time and a lack of spontaneity with how things are said. The lack of ability in abstraction and the literal interpretation of
meaning of those with autism can mean the slow death of humour and teasing as forms of communication.

Lack of spontaneity of action involves not only what is done but also the execution of action, how things are done. The parents spoke of a need to plan everything in advance. Even the female parent of a seven-year-old boy with Autistic Disorder who felt her son was not too dependent on routine spoke of a loss of spontaneity. She spoke of the need to think of everything. “He is not stuck on routine like a lot of them are. He just likes to know what he is doing, he likes to plan his day for you, but no, as long as he knows what he is doing he is happy”. For him to be happy, his planning the day for his mother was very much about the need to do things on his terms. If structure was imposed he asked until he got things back on his track. “He just stays relentlessly on the one subject”. This relentlessness is driven by a need to have things on his terms to feel secure. As the relentlessness is driven by a need it is far stronger than if driven by wish or whim. The female parent of a six year old boy with Autistic Disorder spoke of an appearance in the child of being lost without the security of routine and sameness of, “drowning in the world”. Another female parent of a five and a half-year-old boy with Autistic Disorder, spoke of the need to plan, again in a child she saw as not heavily dependent on routine. Even a trip to the shops must be planned in advance and carried out exactly as planned. “We can do whatever as long as before we go I say we are going to the shop and we will go to the ABC store and we have to do that, you can’t get up there and think I will duck into the chemist and do this and that”. Any spontaneous act met with a tantrum. A female parent of a four-year-old boy with Asperger’s Disorder clearly surmised the collective voice with, “if we say we are going to do something and the plan changes he just loses it and we have lots of tantrums. He has to be warned and things have to happen in a certain order and you can’t change it”.

For children seen by their parent as dependent on routine the challenge to spontaneity is even more obvious. A female parent of a five-year-old boy with Autistic Disorder presented an example, which bore similarity to many others. “I have to go to the school the same way each day and even if I don’t get him a
hash brown, or get his sister something, I have to go to McDonalds at xxxx and sometimes I just say Hi, they all know me because, it is so embarrassing, and basically we might not buy anything but I have to go through the drive through, then he knows if we turn left we are going to school, where as to the preschool he goes to we go a different way”. A change to this routine eventuates in acute distress in which the car is kicked, he vomits and at times develops an angry in flamed rash all over his body.

A male parent of six-year-old boy with Autistic Disorder after he discussed at length his son’s time consuming ritual of leaving the house said, “you just have to let him do it because if you don’t let him get his own way you will never hear the end of it, he just chucks a big tantrum, so people say you can’t let him rule your life, but it is easy for them, they are not living with him”.

This lack of spontaneity of action has an effect on the parent’s self: Initially as a sense of frustration. The female parent of a four-year-old boy with Asperger’s Disorder spoke of her son’s inability to tolerate change as the hardest aspect of parenting a child with autism. “He can’t handle change or unpredictable things happening, that’s the most difficult part for me, I find it so frustrating”. This frustration is more intense when other demands place constraints on time. However something more pervasive happens and the need for routine and sameness is accepted and incorporated into the self of the parent.

The perception of what spontaneity is changes. The male parent of a six-year-old boy with Autistic Disorder spoke of his current view of a spur of the moment act. “We told him three weeks before that we were going up there, it was a spur of the moment thing, we rang up the cabin and someone had just rang and said they weren’t going and we got the cabin for a week, just a spur of the moment thing and we said we are going to Seal Rocks and he had a big smile on his face”. The family goes to the same spot each time they have a holiday to accommodate the child’s liking for sameness.
The female parent of a different six-year-old boy with Autistic Disorder spoke of the feeling of entering the world of autism. “I am sort of in his way of thinking so I can help him out of a situation, yes sometimes you have to click back”. A female parent of a five-year-old boy with Autistic Disorder spoke of the feeling of autism as being contagious. “The more time I spend with him the more autistic I think I am. I think I am becoming the person living through his life. I have made myself like that so I can understand him, do you see what I mean? I have just done everything differently than I would have been with his sister, I am like a split personality now, if you can understand this, I am a different person with him, a different person with my husband and a different person with his sister”.

The same female parent talked of the perceived resistance by her husband to the loss of spontaneity. Her husband had always imagined family life as consisting of a Sunday barbeque. He was able to concede flexibility on the weekend except at the cost of the barbeque. He has to follow the same weekend routine in the same order, “first mower, then leaf catcher and then whipper snipper” etc, spending hours doing things on the child’s terms but come Sunday it is time for the family barbeque. “Yes it has never worked out so he has his barbeques on his own because xxxx always destroys them. Every family barbeque xxxx gets hurt or he just basically gets all the food off the thing and throws it in the pool and it has never worked out”. Yet every Sunday the barbeque goes ahead. The act of resistance has just become another part of the predictable routine. The child with autism watches a video and if possible his sister is put down for a sleep, “so I can go and spend some time with him, and we have some great conversations over him cooking, but he burns everything, I don’t eat meat, so it is a lovely barbeque”.

Not only is there a loss of spontaneity in all activity even communication within the activity is changed. The male parent of a four-year-old boy with Asperger’s Disorder spoke of the slow leeching of humour and teasing from the parent relationship and the translation of this to his everyday way of communicating. He spoke of learning over a period of time and negative outcomes that his son does not understand jokes. One example relayed consisted of an event with a
hairbrush and a toy helicopter. In an attempt to teach the concept that surprise can be good a toy helicopter was purchased, a really good one with all the bells and whistles to use as a surprise. The lesson was needed to counteract the bad publicity surprises receive in Thomas Tank videos, which are an obsession of the son and in which surprises are always bad. The son was asked to sit down, close his eyes and put out his hands, into which the helicopter was placed. “Once he actually got it we had to repeat it constantly, every hour he wanted to have that surprise again, so he would sit there and close his eyes for the helicopter, same toy, over and over again, he would have the same facial expressions of surprise and then play with the toy”. As a joke, after many repetitions one day, when the son sat down with outstretched hands he placed a hairbrush in them. “You know silly daddy it is a hairbrush, here is the helicopter. No we didn’t even get that far, he opened his eyes, saw the hairbrush threw a tantrum and threw the hairbrush across the room and flopped on the floor and that was it, he was into it. So I have learned no jokes period”. Upon reflection this parent stated, that although he previously loved a joke, not joking has translated to all areas of his life and is not just restricted in his relationship with his son.

The same parent spoke of teasing as being a form of communication that is not understood by his son. Any statement is accepted literally and so a lot of reassurance is needed with explanation of the intended meaning if anyone in the family teases someone in the presence of the son. “It sort of takes away the spontaneity of the moment of teasing each other when you have to break it down. It is part of my nature that I tease my wife every chance I get forgetting that xxxx is sitting in the back seat when we are driving along or whatever and then we have to stop the car get out calm everybody down and tell him that it was only a joke, Daddy was being silly and it takes all the fun out of it”. Again the change is translated to the self. “Teasing is something that is slowly going away, I still do it out of habit but nowhere near as much as it used to be. At work it has become more planned rather than spontaneous, if I tease someone I will say what can I do to him? I have to think about it rather than be spontaneous with it".
Less Social Contact

An early sign of a parent being dragged into the shell of autism is a decline in social contact. The challenge of going any places that are not part of the person with autism’s regular routine often leads to behavioural disturbance in the child. The emotional cost to the parent of managing/enduring the behavioural disturbance is greater on many occasions than the identified benefit of going out, so parents go out less. Going out less leads to reduced opportunities for social contact and old social relationships are not maintained. Another by-product of behavioural disturbance, or the unusual behaviours of children with autism, is a sensitivity of the parents to the perceived views of others and judgements that they may make of parenting competence and responsibility. Social contact is reduced to avoid the misinformed judgements of others. Married parents who do maintain social contact often need to do it singly so the child does not have to take part. Shrinking social contact represents a loss to the self of the parent as a social Being.

The female parent of a four-year-old boy with Asperger’s Disorder spoke of her circle of friends as having, “diminished a lot”. Over time and many failed social outings that were more stressful than it would have been not going, “we have learnt to not go”. The female parent of a seven-year-old boy with Autistic Disorder spoke of her social contact being minimal yet with the appearance of continuing to shrink. “I can’t see anything changing unless I get respite because as much as I try to teach what is socially acceptable, what you can and can’t do, it doesn’t always work and you can’t trust that it will because at any stage they can go and rip a glass vase off there because they might get angry or something. I can’t see it getting better really, I can see it getting more difficult”. A single female parent of a five-year-old boy with Autistic Disorder spoke of the marked difference she experienced on the weekends when she had the boys. “I was terrified when it was my weekend thinking what the hell am I going to do with them now, I was insular I would just stay at home on my own because I wasn’t game to take them anywhere, they couldn’t behave themselves to go anywhere, so we just sat here all day and I plied them with more videos and
more food until it was Sunday night. I felt insular. I just felt as though every second weekend I was abandoned and everyone else went on with their own lives”. The female parent of six-year-old boy with Autistic Disorder spoke of variance in the amount you can venture out dependent on behavioural stages. “Absolutely it goes through stages we can go out for a couple of months and socialise and then he will go through another stage and I just don’t take him anywhere. I have periods where we just hibernate, it is just easier not to do anything”.

Parents spoke of often feeling very sensitive to their perception of how others are judging them as parents based on their child’s behaviour when out of the home. Many spoke of the fact that autism is an invisible disorder. The children often look the same as any other child so they feel behaviour is judged as a product of parenting and not recognised as that accounted for by impairment.

The female parent of a five-year-old boy with Autistic Disorder encapsulated this experience in, “they are wondering what is this kid doing, he is five and a half, has a dummy in his mouth, he is doing something that you just don’t do like putting feet with shoes and socks in the creek and you’re not a very good mother. I have had a lot of people, strangers look down on me for the strange things that xxxx does at the shopping centre and wherever which makes me not take him anymore and we couldn’t tell you how many friends we have lost from not keeping up with the socialising or whatever”. The female parent of a five-year-old boy with Autistic Disorder and a ten-year-old girl with Autistic Disorder spoke of the feeling of being uncomfortable with people’s perception even if they are invited to the home. “We don’t have people over very often, only the people who know our predicament, because some of the behaviour is rather bizarre, perhaps xxxx will appear with no clothes and I go, God here we go”. The male parent of a six-year-old boy with Autistic Disorder experienced the feeling of being judged as embarrassment. “There are times when I wont take him out by myself because he will lash out for no reason it's so embarrassing”.
Along with a constriction of social contact related to the perceived judgement by others there was a corresponding lack of energy to continually explain why their children behaved in the way they did. The female parent of a five-year-old boy with Autistic Disorder spoke of feeling that autism is impossible to explain in a short conversation. “You can’t explain it to just anybody. I have found I cannot talk to people, I could not be bothered talking to people unless they know about autism”. Parents spoke of being more comfortable in social situations with other parents who have children with disabilities. The mother of a five-year-old boy and ten-year-old girl with Autistic Disorder said, “we don’t judge each other, like when their son has gone and picked up the rabbits out of their cage and nearly strangled them to death we say don’t worry about it and it will be alright, or we hammer down the rabbit cage before he comes, we don’t judge, it is not about that”.

Married parents all spoke of going out or entertaining individually. Social outings were conducted in this manner so that the parent not going out can care for the child with autism. In this way some social contact can be maintained at the cost of social opportunities as a couple and family. The male parent of a five-year-old boy and ten-year-old girl with Autistic Disorder said plainly, “quite often we just don’t go as a family. Even if people come here they have no idea of even leaving gates open and the stress that creates. I mean we had a barbeque here a couple of weeks ago and people kept saying look sit down and relax. If I sit down and relax they would be off or something like that would happen”.

**Less Things**

Parents of children with autism experienced the capability to have less things. This is related to the financial cost of the purchase of services and the child breaking things. These things range from pleasure items and trinkets to furnishings.

The female parent of a four-year-old boy with Asperger’s Disorder spoke of the choice to purchase private schooling for her son. “We could have just left it to the department (The Department of Education) to handle it but I am sure the
outcomes for xxxx would have been lower than they are”. Many parents purchased services for their children driven by the need to do everything possible. A general perception exists that services available free of cost through the Department of Education and Department of Health are not provided with enough intensity and frequency to optimise the child’s potential. A sense of doing things provided a sense of direction and hope for the future. All extra services purchased represent an additional expense to parents and hence less money that can be spent on other things.

Many parents even when able to afford nice things experienced the destruction of these things by their child when the child was frustrated or had the need to self stimulate. The female parent of a six-year-old boy with Autistic Disorder said, “everything I buy gets smashed or broken, that is my third set of tables since xxxx was born. I have windows in the house replaced every year. I wouldn’t buy a nice piece of furniture. Sometimes it gets to you, you might have a visitor and Mum and Dad will buy something or hand me money and I will say I’m not poor you know, it’s not because I don’t have it, it’s just because it’s not worth it”. The female parent of five-year-old boy with Autistic Disorder spoke of her son’s practice of visual stimulation, “he will still throw plates over the balconies to watch them smash and so it’s back to plastic”.

**Less Self**

The dominance of autism in the lives of the parents interviewed was a consistent theme. The part of self that is parent dominated all other parts. Little time or energy was left for the roles of parent as partner in a relationship or individual pursuits. The self shrank to the role of parent.

Relationships were seen to become over regulated and depleted of the necessary nourishment of spontaneity. The female parent of a four-year-old boy with Asperger’s Disorder described the relationship with her husband as, “it’s lost flexibility too”. Again this was not just flexibility of action but also how you interact. Whilst the child was awake or present there could be no joking or abstract conversation. The male parent of the child spoke of restrictions of when
you can act. “If I was to give my wife a cuddle on the lounge we would have someone between us instantly”.

In all accounts the parents spoke of the restricted availability of time. This was time for all aspects of self. The female parent of a seven-year-old boy with Autistic Disorder said that with the demands of caring for her child, “I don’t sit down long enough I am always running around”. When it comes to time, as a couple there is less, as in all areas of self except parenting. When there is time it is often only late at night after the child has been successfully settled into bed. The same parent said, “I am still going until the moment I go to bed and if I sit down I am always thinking about what my husband is going to want and I don’t always want it, I just want to sit in the chair and then I feel bad, it puts you under a lot of pressure”. Any form of intimacy is difficult as the mix of being in the same place, with enough energy and not being distracted by anxiety is rare. The female parent of a five-year-old boy with Autistic Disorder revealed the rarity of this, “we only have sex once a month now”.

Again a feeling of loss of self ease was a universal theme. The female parent of a four-year-old boy with Asperger’s Disorder described it as, “it’s sort of like you have this nervous tension there all the time. I feel like I have got less energy to handle other things. Other things bother me that I wouldn’t have worried about before”. The female parent of a seven-year-old boy with Autistic Disorder relayed that, “there is not one time that you can sit down and forget what is happening even at mum’s house, I never relax”. The female parent of a five-year-old boy with Autistic Disorder spoke of feeling constantly worried. “I don’t feel like I am relaxed. I am relaxed now but that is because xxxx is not here, even though I am thinking I hope he is ok and whatever, but I don’t relax, my husband always says just sit down, I haven’t watched television in five years”. The female parent of a five-year-old boy and ten-year-old girl with Autistic Disorder also spoke of an ongoing anxiety and worry that persists even if the children are not with you. “It is hard to relax if you did go away you are worried all the time that the person looking after them is competent”. The female parent of a six-year-old boy also spoke of this even when the child was in the care of
her parents. “Even when he is off at Mum’s it is still in the front of your mind, what is happening”? The same parent spoke of her son’s first stint of vacation care a few weeks prior to the interview. She spoke humorously of going to spy on what he was doing at the vacation care and to see if he was being cared for properly. “They were very efficient they spotted me within minutes, everyone was looking, saying who is this woman standing there”. The male parent of a six-year-old boy with Autistic Disorder highlighted the pervasive and ongoing nature of the anxiety: “Even when he is being calm, you still have that anxiety that something is going to happen”.

In terms of outlets several parents spoke of, although they felt that it was unusual, the experience of work as a sense of outlet. Work provided the opportunity to be away from the child and distracted by the necessity to focus on a task other than the child. The only identified chance to relax was for some parents the breaks at work. The male parent of a six-year-old boy with Autistic Disorder summed this up in, “well I am lucky I suppose, I can just get dressed and go to work everyday, I am quite happy at work and I get a break”. The female parent of a four-year-old boy with Asperger’s Disorder spoke of work as a diffuser of stress that has taken the role leisure pursuits occupied previously. “I throw myself into work. We used to go to the gym but we don’t have time to do that anymore”. Work also allowed one other sense of self to remain other than that of parent.

A further challenge to the sense of ease to self is that of exhaustion. The female parent of a five-year-old boy and ten-year-old girl with Autistic Disorder described this as, “I am exhausted all the time I just get more exhausted”. The exhaustion comes from the act of care and ongoing anxiety. The male parent of a five-year-old-boy and ten-year-old-girl with Autistic Disorder explained that, “I think people in general lack an understanding of how demanding it is”. There is little time to recuperate. The female parent of a five-year-old boy with Autistic Disorder spoke of feeling run down and sick since her son’s birth. This creates further anxiety as, “I think if I get any worse I can’t get myself run down because I have to be there for xxxx”. The female parent of a
six-year-old boy with Autistic Disorder spoke of feeling less rested because of not only how much she can sleep, but also because of the fact the way she sleeps has had to change. “I used to be a very deep sleeper, I didn’t hear the babies my husband always got up to the babies, so I think that adds to the exhaustion because I usually go into such a deep sleep and now I am only half sleeping when I do sleep”.

Some voices spoke of a feeling of loss of self entirely to autism. The female parent of a six-year-old boy with Autistic Disorder spoke of a loss of self. “There is not much me now. I live in the world of autism now”. The female parent of a five-year-old boy with Autistic Disorder spoke of having made the choice to give over self to parenting alone. “I think that it is my job those kids, they didn’t ask to be born, they certainly didn’t ask to be born into such a dysfunctional family so my role is to get them through this, and I figure that anything that is going to happen for me will come later and everything I need and everything fits in around the kids and if people start, like Mum and Dad start - come and do this, do that, and if I don’t think it is going to keep everything running smoothly we just don’t do it I just say no”. A different female parent of a five-year-old boy with Autistic Disorder spoke of a more involuntary consumption by the needs of her child with autism. “I am always focussed, very focussed on xxxx that nothing else around me matters anymore. I believe I have built my whole life around xxxx. I have become obsessed by him. I feel like I have stopped my life and now I live for xxxx”.

Even to have time to experience illness is a luxury that can not be afforded. The female parent of a five-year-old boy with Autistic Disorder said, “you are not worried about being sick yourself but only the implications for xxxx”. This child is in the routine of having the floor of his room cleaned when he is asleep. His routine involves eating in the room and he will only defecate in the corner of his room and nowhere else. “I have left it (cleaning the room) twice, both times I wasn’t well and I just couldn’t get out of bed, and he was very upset in the morning. I thought what is wrong with him? Everything was wrong, so it was because I had not cleaned his room properly and there was a piece of toast on
the floor and what was that doing there because he hadn’t had his toast yet and so I said to my husband never again I don’t care how sick I am or will be in the future I will always clean the room. Because it is not worth it the next day, the stress, because once he starts off bad he ends up bad and he never gets better through the whole day until he falls asleep”.

The teleological nature of the experience

Autism in the parent child relationship not only dominates that relationship but also begins to act on the self of the parent. Autism shrinks and so does the self of the parent. The over regulated nature of autism becomes the way of the parent. Spontaneity leaves the parent-child relationship and gradually the self of the parent. The parent’s world and social contact becomes smaller. In many cases the external signs of self in terms of things are destroyed and there remains less of these things. The parent’s self is transformed. All other roles of self are impacted upon. The parent’s sense of ease or personal comfort is eroded, there remains a constant sense of anxiety and exhaustion. It would appear that autism is dominant in the relationship and begins to dominate at the level of self of the parent. This occurs within the fertile ground of dis-ease characterised by anxiety and exhaustion.

Autism does not affect only the current self but impinges on the future self. The child with autism becomes central to all short term and long term projects. Every project is dominated by the need to consider the unique needs of the child with autism. The parents are periodically thrown into such autism dominated projects in times of illness and any threatened transition.

Short-term projects are dominated by the needs of the child with autism. The male parent of a four-year-old boy with Asperger's Disorder relayed that, “everything seems to be looked at with xxxx in mind regardless of what we do or what we plan to do”. The female parent of a seven-year-old boy with Autistic Disorder spoke of thinking about the future “all the time”. This in the short term includes education and intervention choices. Every developmental challenge met means the next challenge awaits. Each challenge becomes progressively
more difficult. This was described in the following by the female parent of a five-year-old boy and ten-year-old girl with Autistic Disorder, “it is like every little stage there is a whole lot more energy being put into it, it is so very busy compared with just bringing up other kids”. The number of interventions available lead to the need to consider a lot of alternatives. The female parent of a six-year-old boy with Autistic Disorder spoke of the fact that, “you are always second guessing yourself, wondering if you are doing the right thing, wondering if there is something else that you could be doing”.

Longer term projects concern the child moving to adulthood and the eventual death of the parent. The male parent of a five-year-old boy and ten-year-old girl with Autistic Disorder spoke of thinking a lot about who would look after the children after the death of the parents. “I guess when you are dead who is going to care for them and who is going to make sure their needs are met? Who is going to make sure that their hygiene needs are met? Who is going to wipe xxxx’s bottom when she is 30 and 40 and 50, and that sort of thing”? The need to have things in place is voiced a lot. The male parent of a four-year-old boy with Asperger’s Disorder reinforced the awareness of these needs irrespective of the current level of functioning of the child, “he is not that bad, being high functioning, but there is always going to be something that is going to set him off for the rest of his life. We don’t know what that is so something has to be in place to cope with that”.

Parents are thrown into these deliberations acutely in times when they are ill or feel vulnerable. Again autism impinges on the very experience of the self at these times. The female parent of a five-year-old boy with Autistic Disorder spoke of although thinking of the future a lot, such thoughts coming to the fore at times of illness and vulnerability. “During the week I was bleeding and I knew it wasn’t my periods right and I thought I can’t have cancer and die, not for myself but who was going to look after xxxx”. The female parent of a six-year-old boy with Autistic Disorder spoke of times of depression as vulnerable. “You go through stages when you are a bit depressed and that is when you do think about things like that”.

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**Positives**

The triumph of connection

Connection with the child with autism was described as a time where both parent and child were focussed on the same activity and it was clear what both parties were thinking and feeling in relation to this activity.

The parents spoke of a sense of frustration and exhaustion related to the constant effort of trying to understand the space from which the child is coming. The female parent of a seven-year-old boy with Autistic Disorder spoke of the demise of her energy on attempts to decipher even the basic feelings let alone attribution of a cause to these feelings, “I wish I knew how he felt myself”. The quest to attribute a cause for gross behavioural clues such as agitation also engender a sense of frustration and depleted energy. The female parent of a five-year-old boy with Autistic Disorder gave an example from the week prior to the interview. Her son had appeared agitated and was touching his face. “It takes up an enormous amount of time trying to work out what is going on for them. This week that was a prime example of what it is like when you know there is something wrong with him, he can’t tell you, you don’t know where it is coming from, it’s a bit of guess work and then the mere fact we had to get into a doctor. We also had to ring, as a contingency plan in case his pain escalated, we had to organise for him to be booked into Westmead Hospital to have a general anaesthetic just so someone could have a look at him to see if there was anything wrong with his mouth, it is all of those things”. Even with more verbal children a game of guesswork follows with the stakes in terms of behavioural disturbance raised with each incorrect guess. The male parent of a six-year-old boy with Autistic Disorder, a child who is verbal, described his son at times not aiding the guesswork by a lack of use of his words. “You have to keep guessing, keep guessing what he means, because a lot of times he wont use his words”. The female parent of a five-year-old boy with Autistic Disorder and ten-year-old girl with Autistic Disorder has come to the conclusion that sometimes there is no right answer to guess. “Sometimes, I think they don’t
even know themselves what it is, it is not just a matter of communicating, it is a
matter of I don’t know what is going on either. We are both guessing”.

With all of the frustration and communicative effort as the background there
emerged the sense of joy when the parent has a sense of knowing what the
child is feeling about a concrete situation. The male parent of a four-year-old
boy with Asperger’s Disorder confided, “connecting with xxxx is a rarity but
when we do connect it is marvellous, very great but it is rare”. The female
parent of a seven-year-old boy with Autistic Disorder spoke of the connection as
the joyful payout from persistence. “It takes a lot of time, sometimes it might
take an hour to find out what xxxx wants but he is so happy when I listen that he
is all smiles and it is lovely”. Parents only described times of connection when
the child either asked a question or when there were very overt signs of
happiness such as the big smile or in the case of one five-year-old boy with
Autistic Disorder, when he is “nigger niggering”, a noise that he makes and
jogging on the spot.

The child asking a question provided an insight into what they were thinking at
the time and provided the platform for an interaction even if it was one sided on
the child’s terms. The overt reaction of happiness removed all chance of
ambiguity in guesswork. The female parent of a five-year-old boy with Autistic
Disorder encapsulated this, “because I really don’t know what is in his mind and
I really don’t know how he thinks about things and you know if I think I can see
a smile on his face or he is going nigger nigger, well he does that, and I know
he is happy”. Parents spoke of setting up the situations to provide this
connection and reaction. McDonalds was a common venue for this. The female
parent of a five-year-old boy with Autistic Disorder and ten-year-old girl with
Autistic Disorder described such situations, “pathetic as it is driving to
McDonalds and getting an ice cream, they are just over the moon, just for a
simple little cone. I suppose that is where you get the pleasure”.

The pleasure was described in such terms as, winning the lottery and as a time
of pride. The rarity of the moments of connection increased the value of such
moments. Parents spoke of the children with autism’s siblings as being expected to achieve small milestones and have this connection so each and every occasion was not revered, but the rarity with the child with autism meant each occasion was noted and often remembered. These occasions provided some more energy to go on. This again however represented a change to self in the parent in the form of expectation. These moments of joy often tainted by sadness, as achievement at times highlights what the child is not doing. The female parent of a four-year-old boy with Asperger’s Disorder said, “xxxx started giggling when the duck in the video Babe tapped on the window. I went into the kitchen and had a cry. xxxx doesn’t do that. That doesn't happen. He will laugh and giggle at the most silly thing. It made me realise that we missed all of that. Seeing him laugh at the movie for the first time was good but it bought back that he is so different”.

**Patience**

Parents collectively spoke of the development of patience as a personal trait as one of the positives that arise from the relationship of parent to a child with autism. Patience is born out of frustration and remains tempered by this.

Patience was spoken of in reference to a sense of slowing down as a person. The female parent of a four-year-old boy with Asperger’s Disorder spoke of the difficulty of the process of slowing down. “That was hard for me because I am not a very patient person. I am a typical Arian you do it fast, go on to the next thing and do it fast. So for me slowing down has been hard. Slowing everything down socially, slowing everything down in the family”. Parents are put through this process by the relentless needs of the child to do things on their terms in their own time. The female parent of a five-year-old boy with Autistic Disorder explained the realisation that you can no longer hurry through things. “I see other people just go ‘stop it’, calm down! It doesn’t work on xxxx, you have to actually take the time to sit down and fix it, you can’t Band-Aid things with autistic kids”. The male parent of a six-year-old boy with Autistic Disorder spoke of the fact that to slow down and develop a sense of patience is the only alternative offered. “You get angry sometimes, but just a bit of anger builds up
and you have to give up and go and help him, because if you don’t he will keep hitting you in the face and carrying on”. The patience developed remains tempered with frustration; it is more of a surrender to the inevitable. The male parent of a four-year-old boy with Asperger’s Disorder initially stated, “I have learnt to become more patient. Everything just waits regardless of deadlines”. After further exploration of what this patience was for him when comparing it to a sense of tranquillity he revealed, “no it is also tempered with a bit of frustration so you know it is a trade off into both because even though I have slowed down, I have become more patient, there is still that frustration with not being able to get anything done at the pace you want to get it done, or if you are in a hurry or if you have deadlines. Things like that, so one tempers the other”.

The female parent of six-year-old boy with Autistic Disorder stated that the behaviour people attribute to her being laid back or patient is really attributable to a change in priorities and exhaustion. “People say you have a lot of patience, it isn’t patience it’s exhaustion, you just let it go, if he knocks over a bowl of sugar, a pot plant or something, you just think another one and don’t stress about it. It’s not patience you just lose the importance of those sort of things with a child like xxxx and go with the flow”.

So even the positives identified in being the parent of a child with autism reflect a basic change to the self of the parent. These changes represent changes not consciously selected and adopted. The change reflects the needed modifications to self to survive. Much as a rock does not choose to become smooth in response to the relentless wash of the stream or ocean wind. A change in expectations occurs and the parent identifies how to find the relatively rare moments of connection. The feeling at this time identified as the joy of parenting, but also at times mixed with a sorrow realised in the rarity of, and at times orchestrated nature, of these moments. The development of patience was spoken of by many as a positive that has arisen from their relationship with a child with autism. But this patience is mixed with frustration, exhaustion and a sense of the inevitable. The patience shaped by the behaviour that is autism.
6.2 Extended analysis after first three focus groups

The initial analysis was extended as a result of the conversation that occurred in three groups that consisted of participants recruited from parents of children studying at the Special School for Children with Autism between the ages of four and ten years with a diagnosis of Autistic Disorder or Asperger’s Disorder. The focus of the groups was the, in progress question of what is the experience of parenting a child with autism? The way I had organised this in the initial analysis was discussed. All the parents reported a resonance with the initial analysis. Although the main idea of the focus groups was to keep the parent’s voice alive through the process of analysis it was affirming to hear the comments such as that of, “this is very true” from the female parent of a six-year-old boy with Autistic Disorder. Other similarly affirming comments were, “it’s on the mark”, from a female parent of five-year-old boy with Autistic Disorder and “it’s very real” and the confirmation of it “ringing true” from the female parents of five-year-old boys with Autistic Disorder.

Participants in the first group were presented with a series of slides that represented the core themes of the initial analysis in visual format (see Appendix Three and Figure One). A brief overview of the analysis was given to the group. Participants were asked if there were things that they considered needed to be added, changed or removed. When the conversation finished each slide was used to focus discussion on the respective part of the analysis. In focus group two a series of slides were used again to present visually where the analysis was up to (see Appendix Four and Figure Two). The slides were more complex and represented the breakdown of ideas that made up each of the core areas of the analysis. The third group was presented with a brief summation of the analysis to that point in narrative form (see Appendix Five).

In none of the groups did a new direction emerge, despite continued exploration and invitations to those in the group to contribute totally new ideas or ideas not previously referred to. The analysis continued to be refined until the group fell silent at the end of the third group.
Figure One: Progressive analysis provided to focus group one

- Autism Shrinks
  - Parents experience less

- The shell
  - The analogy of the turtle: Of parents pulled into, or catching autism.

- Over Regulation
  - Less spontaneity, less social contact, less things and less self.

- Loss of Ease
  - The constant feeling of anxiety and exhaustion experienced by the parents

- Projects of Future Self
  - Impacted upon short and long term projections into the future
Focus Group One

Three important refinements emerged through the first group. One was that the consistency of the parenting experience remains but that the intensity of the parenting experience varies in correspondence with the child’s developmental and behavioural challenges at any particular time and the nature of the external pressures that exist at the time. The second was that the experience of parenting a child with autism is affected by the child’s portability and temperament. The third was that loss of self arises out of the culmination of less spontaneity, shrinking social contact and less things. Where the elements of loss of ease fitted together relative to each other was clarified.

The female parent of a five-year-old boy with Autistic Disorder spoke of the experience of parenting a child with autism as, “not always on the same level”. At times children with autism will develop a way of interaction with the world which makes them particularly difficult to integrate into home and community life. Again in regard to the fluctuating levels of intensity the mother of a six-year-old boy with Autistic Disorder to describe her response to these times raised the analogy of “hibernating”. This particular boy at one time developed an energy efficient, or shrunken means of communication, in which the one behaviour could be used to serve a number of purposes. Hitting was used to engage as well as repel. It was used to affirm pleasure and to protest. It worked in that it got people’s attention but it did make it difficult and at times painful to communicate with her son and frightening to take him anywhere. Times of difficulty are often referred to in retrospect by the parents as, “a stage”. Frustration was expressed that unlike typical development you do not work
through a stage and move on not to have it return again. Often stages are revisited and need to be re-worked through or endured until they pass.

The fact that some parents identified more strongly to the part of the analysis related to over regulation than others prompted discussion around why this was so. The group discovered the concept of portability of the child. Children who were small enough to be physically guided through things and who protested relatively quietly without behaviours such as screaming or vomiting were seen as portable. The parents of these children, although aware of over regulation in their activity and communication, felt that it was less pervasive than the parents in the group of less portable children. The two children seen to be portable were physically small and young, four and five years old. The female parent of the four-year-old boy with Autistic Disorder said, “He gets sad, he will jump up and down and say no and gets quite forceful. He will do things under duress but he is sad”. This parent spoke of still being aware of the need to prepare her son for what is going to happen and the development of extremely regulated ways of communicating. “You have to do a lot of preparing. I really have to prepare him for it you can’t just get up and say you are going”. In terms of communication, “our house is like role playing all the time, if I want to get xxxx to do something I have to act it out. His sister is Madeline, I am the nun (Madam Clovelle)”. Portability affected the intensity of over regulation as the parent could make a choice to proceed despite the protest. The experience of loss of ease through a mixture of anxiety and exhaustion, the impact on the parent’s projects, and the experience of positives was not effected by portability and was unchanged from those of the other parents. The female parent of the five-year-old boy with Autistic Disorder who was considered relatively portable said, “I often go in there at night and look at him and wonder if I am ever going to have a full future. I am not worried about what he is going to do but I think about when we get to the age when we should be a retired couple and your kids should be off having their kids and thinking about twenty years ahead”.

In terms of temperament placid children were reported generally to break less things, except in the case of self-stimulation. The theme of Less Things was still
seen by the parents to be a concept relevant to them related to the expenditure on services, both current and savings for anticipated future expenditure. The female parent of a five-year-old boy with Autistic Disorder said, “you only have limited funds and you have to allocate, you have to work out where to put your money into, less holidays and extras”. The expenses discussed varied and included therapy and petrol getting to the site of centralised service provision. The female parent of a six-year-old boy with Autistic Disorder said, “we looked into all the different therapies, to try and find what is best. We feel we have to do our best for him, if anything happened to the other two we would do our best for them too. xxxx got diagnosed at three and now he is six and in that time I have researched autism, what new things are happening. There are diets and minerals, ABA, Sunrise and probably another half a dozen that we could say we would try. I would rather try and get the best out than not try at all and him miss out”. This parent spoke of a sense of being expectant when undergoing a new or different therapy. This sense of expectancy provided a source of energy to go on and hope that things will improve. The conversation turned to the weekly expense of food. Many of the children were described as having limited and rigid diets. The female parent of a five-year-old boy with Autistic Disorder encapsulated the discussion in her comments on her child’s refusal to eat anything but brand name varieties of food. “I have to buy the good brands for xxxx, everyone else gets the cheap brands”. If this child were presented with generic brand food he would just not eat. This same parent spoke of the anticipation of future expenses for therapy, education and care if independence is not attained. She spoke of an account the family have created to put money away for xxxx’s future needs. “We are missing out on things now because we are actually thinking about things for xxxx in the future. So the kids don’t have to look after him in case we die”. The increased expenditure was compounded by the restriction on employment opportunities imposed by the demands of care of a child with autism.

The group also discussed where less self fitted in relation to less spontaneity, shrinking social contact and less things. It became clear that less self arose
from a culmination of the other three things (see Appendix Four and Figure Two).

The group discussed the elements of anxiety and exhaustion, and where in relation to loss of ease these were situated (see Appendix Four and Figure Two). It was determined that the act of care, frustration, hyper-vigilance (inclusive of monitoring others) and communication effort all contributed to a sense of anxiety and exhaustion. Anxiety and exhaustion were the everyday feeling. Anxiety and exhaustion were seen to complement each other and be indistinguishable. These were seen as the feeling that characterised loss of ease. Anxiety and exhaustion formed the baseline feeling for the parent of a child with autism.

Figure Two: Progressive analysis provided to focus group two

The handout used in focus group two represented visually the way the experience had been organised to that point.

Less spontaneity, shrinking social contact and less things were seen to culminate in less self for the parent. Until focus group one less self was seen as a separate entity existing along side the others.
Loss of ease continued to be characterised as a baseline feeling of anxiety and exhaustion contributed to by the act of care, frustration, hyper-vigilance and the communication effort.

The future self was impacted on in the short and long term. Concerns related to the future were bought to the fore at times of parental illness.

The positives of the experience were characterised by the times of connection and the development of patience.

Focus Group Two

In the second focus group the question was considered of whether the patience identified was in fact more endurance. A third positive of, a sense of achievement and competency on reflection, was identified. Frustration’s appearance as an entity separate to and contributing to anxiety and exhaustion in loss of ease was confirmed. The unique nature of respite needs was discussed.

In the process of further analysis it became unclear whether the positive identified as patience could be better represented by the term endurance. The parents identified most strongly with the term patience and justified this by
discussion of a sense of purposeful waiting. The wait was fuelled by an expectation of achieving goals and hope. The female parent of a five-year-old boy with Autistic Disorder clarified this in the following. “I don’t think it is a hope of cure as such, it is that you can see all the time changes and things that do make life easier and things like that, and things we can do now and I couldn’t have dreamt of doing before, such as outings, they were just unheard of two years ago where now we don’t think twice. That adds a lot to the quality of your life”.

The understanding of the positives of parenting was extended through the discussion out of which the identification of a third positive arose (see Figure Three). That was the positive of feeling a “Sense of Competence” when looking at the development in the child. This feeling contrasted starkly to the feeling identified prior to diagnosis of feeling a distinct lack of control and self questioned competence as a parent. The competence of the parent was seen at this time to be questioned by all including the parent. This sense of competence arose in being able to help another parent. The female parent of a five-year-old boy with Autistic Disorder said, “it is funny because sometimes with xxxx when everybody else’s kids are doing all these marvellous things and you think what am I doing wrong, and suddenly you are in the role of being able to help other mums with your parenting skills where you thought six months ago you had no skills whatsoever. I thought that was a real positive, maybe just an ego booster, you think it wasn’t actually something you were doing wrong”. The female parent of a six-year-old boy with Autistic Disorder spoke of feeling at such times, “you’re okay, you know”.

Where frustration fitted in relation to its position in loss of ease was considered by the group as, upon reflection in the process of analysis, it appeared to belong with the pervasive feelings of anxiety and exhaustion. It was felt that although at times it arose as a function of communication effort, the need to be hyper-vigilant or the act of care, frustration does warrant an independent entity. It was also believed to contribute to, rather than sit with, anxiety and exhaustion as the pervasive feeling that represents loss of ease. The female parent of a
six-year-old boy with Autistic Disorder clarified, “yes, the act of caring is tiring and it is a constant thing on your mind but it is not always the frustrating bit”.

A discussion of respite and alternative care/child minding arrangements arose in response to the realisation that over regulation was very real and other than respite, no obvious solution could be identified thus far. The parents spoke of the children’s unique communication needs and the requirement of a care provider with an established understanding of autism and willingness to get to know the individual needs of the child. This needed to be someone who is able to identify the communicative intent of the child’s behaviour. The mother of a six-year-old boy with Autistic Disorder relayed, “I think if you did have somebody with respite care if it was the same person that the child was seeing it would be more helpful too rather than having a place with different helpers and getting a different person every week. The kids have such little quirks that are so unique to themselves”. The concern of whether a carer, that was not a member of the child’s family, would make the effort to become acquainted with the quirks and be able to value the individual, was shared by all.

Hyper-vigilance was again raised. The parents spoke of feeling the need to constantly monitor not only their relationship with the child but also all others who relate to the child. This hyper-vigilance representing a felt need to act as interpreter for the other person in their relationship with the child, and as interpreter for the child, in terms of other people’s motives and the child’s feelings. This even occurred in the context of the immediate family. This felt need to be vigilant contributes to the dis-ease through anxiety and exhaustion. To leave the child with someone to allow employment to generate income presupposes the availability of someone with the requisite skills and availability. Leaving the child with someone, as identified in the interviews, does not mean leaving the sense of hyper-vigilance and associated dis-ease behind as the parent is left wondering what is happening and if everything is going as planned.
Figure three: Progressive analysis provided to focus group three

### Positives

- The triumph of connection
- Patience
- A sense of competence on reflection

A third positive was added as part of the experience of parenting a child with autism. This was a sense of competence on reflection.

**Focus Group Three**

The third group saw the understanding of less spontaneity in communication extended to include the demise of sarcasm as a way of generating humour or instigating behaviour change. The following quote by the female parent of a five-year-old boy with Autistic Disorder highlights the problematic nature of interpreting sarcasm, for an individual with literal thinking. “Yes sure, there is one instance, he was jumping on the trampoline and my Mum was watching him and he broke wind, and my Mum said, ‘beg your pardon’ and he said, ‘do you like farts Nan’? She said, ‘no I don’t’, and he said, ‘Mummy likes farts’, and she said, ‘no she doesn’t, why does Mummy like them’ and he said ‘because she says thank you very much’. This was a further example of the reduction of communication to a tool to symbolise concrete entities.

The female parent of a five-year-old- boy with Autistic Disorder provided a further example of her child’s literal thinking and the constant monitoring of communication that is required to ensure that the intended message is communicated. The parent had recognised the benefit of forewarning her son for change and had attempted to prepare him for the birth of a cousin. “We kept saying to xxxx, because they were going to call it Annabelle if it was a girl and Joseph if it was a boy, and we kept saying the baby will come soon and it’s name will be this or that, and when it was born I went running out and went Joseph is here, and he goes where is baby Annabelle? And it took ages, I had to take him out to the farm and he is still saying to my sister-in-law, where is
baby Annabelle, and she says, oh she didn’t come after all. I thought he understood that I meant one or the other, like if it was a girl or a boy”.

In discussion of the changes in communication, the lack of ability to use words to negotiate was raised. Parents reflected on the difference of the child with autism to their neurotypical children with which they observed the ability to talk the child through things and appeal to the child’s need to please others, or offer a straight out bribe. The female parent of a five-year-old boy with Autistic Disorder relayed that, “if they are whingeing you can buy such and such and that is the end of it sort of thing, but if xxxx got it in his mind in the shops that he needed to go home it would be the end of the shopping trip”.

The same parent relayed that, “I thought when xxxx couldn’t speak, because he was way over four before he started to speak, and I thought then that would be the key to the whole problem, if he could speak, I mean I knew he’d always be Autistic, but how big a problem could the rest of it be? It was only that the problems associated with the lack of speech really overshadowed what else was a problem, and once he got that under control you sort of thought oh, okay these things are very relevant”.

The notion of the fluctuating experience of parenting a child with autism was again raised. Parents spoke of set backs, or regression, at times of external pressures. The discussion arose out of the discussion of language, and the loss of spontaneity in how things are communicated. The female parent of a five-year-old boy with Autistic Disorder spoke of the fact that, “we have had set backs with sickness. He lost all his language”. This theme was extended by the female parent of another five-year-old boy with Autistic Disorder, “xxxx was hurt here last week, an accident, and he was very distressed and for the first time in two and a half years he lost his speech and just pointed, doing a lot of flapping and screeching and I had never seen it before but he was spinning and I was so disappointed, no that is not the word, I was horrified that I had lost him and he had gone back to that”. These were extreme examples of behavioural regression but served to highlight the fluctuations in the experience.
The understanding of what constitutes external pressure on the child was refined a little further. The pressure does not have to be directly on the child but can be on someone else in the family if it impinges on the sameness that the child relies on. The female parent of a five-year-old boy with Autistic Disorder spoke of having observed this in her son. “On the opposite side though, sometimes it is not always that he has been put into a position that has made it harder for all of us, it could be like if somebody is sick in the family and everyone is getting tired and cranky. I know if I don’t sleep well, I don’t cope well and if I am not coping well it rubs off on them as well, and he will get really anxious”.

The group fell silent and could determine no new direction to take the analysis. Despite numerous invitations no one could identify anything in the experience of parenting a child with autism that had not been covered.

6.3 Focus group four

Focus group four was convened with a broader group of participants to explore the possibility of a new direction in the analysis. If such a direction arose it could have been taken back to a group within the set parameters of the study to determine the resonance of the new direction with those parent’s experience. The participants for focus group four were recruited from a Support Group for parents of people with autism. The group is affiliated with the Special School for Children with Autism, but runs as a separate entity. No new direction or themes emerged. The group was commenced with the broad question of what is the lived experience of parenting a child with autism? A group of printed slides in the format of focus group two but with the addition of the third positive was handed out to visually represent the core themes of the analysis to that point accompanied by a brief narrative (see Appendix Six). Each of the slides was used to prompt further discussion in the area it represented. New ideas were vigorously sought within or totally outside, the presented themes. Again the group expressed a high degree of resonance with the interpretation presented. The female parent of a ten-year-old boy with Asperger’s Disorder, in a
mainstream class, summed the feeling up with, “it is funny you know, you tell other people about these sort of things, and they are appalled but it is so much part of our lives”. No new directions arose, however several descriptors that further elucidated the existing analysis emerged.

**Less spontaneity**

The parents in the group spoke about the loss of spontaneity in action and communication. Many vivid examples were discussed that illustrated these concepts. The female parent of a seventeen-year-old male with Autistic Disorder, who attends a Department of Education Special School, provided an example from the week prior to the group. “Monday afternoon he threw a tantrum. The other kids came home and took a can of drink out of the fridge, and because they took a can of drink out of the fridge he lost it, because he didn’t want to have it until dinnertime, and his routine has to be their routine. We live in a prison. He lost it. He totally lost it”. The mother of an eleven-year-old girl with Autistic Disorder, who attends a mainstream class, spoke of the excessive need for routine as, “very binding”. Both of the people with autism had been former students of the Special School for Children with Autism.

In discussion of over regulated ways of communicating, as well as the decline in teasing and humour the parents spoke of the frustrating and tiring nature of repetitive conversations. Not just what is said, but also the tone of conversation, was identified as succumbing to over regulation. The female parent of a five-year-old boy with Autistic Disorder who attends the Special School for Children with Autism, expressed that, “I find it very exhausting. He says the same thing over and over, not the same thing, he has little scripts and it will be about the white lines on the road, or he is going to get a motor bike when he grows up, and Mum likes purple motor bikes or whatever and it goes on and on, and it just wears you down. The same thing, over and over again”. The female parent of a ten-year-old boy with Asperger’s Disorder, who is in a mainstream class, provided a similar example in the group discussion. “We had some seeds to plant in spring. I remember he must have asked the same bank of ten questions over and over. The closer it got to spring the worse it got. It was just hopeless.
When the first of spring came we didn't even plant the bloody things. The day had come, and it left his mind after that”. The female parent of a five-year-old boy with a diagnosis of Autistic Spectrum Disorder, not yet in school, pointed out that, “you get in trouble if you give a different answer”. All the parents agreed that you have to stick to the script.

It is not just what is said, but also how things are said, that becomes over regulated. Many of the parents in the group spoke of the fact that, raised or angry voices particularly upset children with autism, even if the communication is not directed at them. The female parent of a seventeen-year-old male with Autistic Disorder, a former student of the Special School for Children with Autism, said, “we have the same thing, we can’t raise our voice to the other two (his teenage siblings) because xxxx becomes anxious and starts to chin and bang his head, and he thinks it is him, even if its directed at the other two”. The female parent of a five-year-old boy with Autistic Disorder, who attends the Special School for Children with Autism, spoke of the need to separate her children when the boy’s sister is in trouble. “If xxxx’s sister is getting in trouble about something we have to divide off, my husband deals with the discipline issue with his sister while I stay with xxxx and take the sting out of it for him, because he looks so worried and stressed that this is going on”.

**Less social contact**

The parents in the group discussed a decline in social contact. A process was discussed where Christmas cards replaced personal visits and phone calls, and gradually even the cards lost meaning and stopped. The parents spoke about anxiety related to how others judge their competence as parents when the children with autism behave in a way that differs from their age equivalent neurotypical peers. The female parent of an eleven-year-old girl with Autistic Disorder, who attends a Department of Education Autism Class, said in relation to the comments of others, “I find you just get to stand on your feet and then someone else comes along and knocks you straight off again”. Common comments discussed, with which the parents have been confronted included the message from others that the child needs physical intervention such as a smack
or belting, and needs to be bent to the parents will. Such comments often pre-em‐
empted by, ‘if he or she was mine I’d’. The same parent described a recent
incident that illustrated this point. “We are just starting to go horse riding. We
just got another second hand car but she wont go in it yet. The other day she
was upset and the neighbour leaned over the fence saying, if she was mine I
would make her do this or that. I wouldn’t take her if she wouldn’t go in the car”.
The female parent of an eleven-year-old girl with Autistic Disorder, a former
student of the Special School for Children with Autism, now in a mainstream
class, described such comments by others as a form of insult. “It is like an
underhanded insult isn’t it”.

Less things
The resonance of less things, varied within the group. All parents related
strongly to the expenditure on services and therapy. Others also felt that the
capability to have less things, due to the child’s destructiveness had strong
resonance. The female parent of an eleven-year-old boy with Pervasive
Development Disorder not otherwise specified, who attends a mainstream
class, spoke about her son’s destructiveness. “I was going to take the door off
xxxx room. He started off with a hole about the size of a five-cent piece and now
there are big holes in the back of his door, and I told him I will take the door off.
I suppose if we took the door off he would attack something else”. The female
parent of a ten-year-old boy with Asperger’s Disorder, who is in a mainstream
class, said in regard to breaking things, “they always seem to do things which
are expensive”. She told the story of her son recently breaking a stick off in the
door lock of the car and the subsequent need to replace the lock at great
expense.

Less self
Again the dominance of autism in the lives of the parents as a culmination of
less spontaneity, less social contact and less things was a consistent theme.
The pervasiveness of the effect of autism in the form of catching autism again
came up in conversation. This was expressed by the female parent of a
seventeen-year-old male with Autistic Disorder, a former student of the Special School for Children with Autism, who said, “I think I caught it years ago and it has stuck”. The same parent said her neurotypical children often point this out. “Like, Mum I am not Autistic, stop talking Autistic to me”.

**Loss of ease**

The restriction on the experience of other areas of self other than that of parent, by time demands and exhaustion were discussed. The female parent of a ten-year-old boy with Autistic Disorder, who attends a Department of Education Autism Class, spoke of being constantly busy with parenting until the children go to bed at night and then, “you are too exhausted to talk”. The parents emphasised that parenting is a seven-day-a-week job. “There is no end of the week”. Short-term projects were dominated by autism. The female parent of a five-year-old boy with Autistic Disorder, who attends the Special School for Children with Autism said, “you have to go through all these different steps to accomplish something”. Anxiety occurred in relation to making sure everything will run smoothly. Several parents contributed to the comment of, “he will not go to bed unless he has ice-cream and it has to be Neapolitan, and if you don’t have it, you have to go to Coles and get it from the one particular shop”. Thoughts of the future and the dependence of the children were intertwined.

**The positives**

Again the parents felt a strong resonance with the notion of the triumphant times of connection and the development of patience. The patience spoken of as developed, remains tempered by frustration. The female parent of a twelve-year-old boy with Autistic Disorder, a former student of the Special School for Children with Autism, now in a mainstream class, said, “I think where the patience comes from is that you know if you don’t do something that this child wants, you know what the consequences are going to be, so you just do it, you know it will be worse if you don’t”. This sparked the telling of many humorous stories in the group. Stories such as that which arose from the question raised recently by a ten-year-old boy with Asperger’s Disorder, who attends a mainstream class, as told by his female parent of, “Mum you have to think of
another job for me other than an inventor. I said why? He said because what if I
don’t invent anything?” In line with the discussion of employment the female
parent of a five-year-old boy with Autistic Disorder, who attends the Special
School for Children with Autism, shared the following story. “We read
newspapers and talk about it and look at the picture and there was a picture of
fire-fighters and I said to xxxx, what are the fire-fighters doing? He said, putting
water on the fire. I said, why? He said, to make it nice and clean”. The same
parent told another story in which her mother who suffers from Dementia was
involved. “There was one time when I was at my Mother-in-law’s place and she
was on about somebody stealing her remote control. She was convinced that
these things were happening, so I was explaining to her that the cleaning lady
wouldn’t steal her remote control and I was so intent on the conversation with
her that I didn’t notice that xxxx was pulling all her dining room chairs out and
lining them up in a line, and hers was the sixth one, it was the last one. So when
she stood up to reach for something he stole the chair from under her”. The
story of lining things up lead to a story of a seventeen-year-old male with
Autistic Disorder, a former student of The Special School for Children with
Autism, now a Department of Education Special School student, and his
obsession with flags. “I took him up to Queensland on a flight to Movie World
and Bugs Bunny tried to pinch his flag and he copped Bugs Bunny in the nuts.
Bugs Bunny was walking like this (demonstrated uneven gate) and had to be
helped away. We all knew then Bugs was a boy”. The discussion of humorous
stories, lead the female parent of an eleven-year-old girl with Autistic Disorder,
a former student of The Special School for Children with Autism, now in a
mainstream class, to reflect that, “you don’t have a choice, you have to be
patient, because of the situation you are in. In retrospect things can be funny,
but at the time you are embarrassed, but later you can laugh. I can see humour
in things”. The group agreed that nature of the humour was retrospective, as at
the time a whole lot of different emotions occur. Not unlike the sense of
competence upon reflection which was identified in an earlier group, the
collection of humorous anecdotes and a sense of life not being mundane in a
typical sense upon reflection was discussed, but no true consensus was arrived
at as to whether it represented one of the positives of the experience of
parenting a child with autism. It perhaps more plausibly represented a by-product of the experience. The humour, it was felt could only be appreciated by those who understand autism and was limited in the forums in which it could be shared and appreciated without compromising the dignity of the person with autism.

Focus group four provided discussion of many experiences that made the depth of the analysis greater.

6.4 Summation

The lived experience of parenting a child with autism is not about a series of activities but profound changes to the self of the parent. Autism is a different way of being-in-the-world. This way of being poses many challenges for the individual as they attempt to assimilate to the way of being that characterises the neurotypical population. The stress of having a different way of being-in-the-world leads to a very restricted and repetitive set of behaviours that shrinks in response to challenges. It shrinks in terms of spontaneity and the very repertoire of behaviours.

In the experience of parenting a person with this different way of being-in-the-world, the pervasive nature of autism is further demonstrated, as it flows into the self of the parent. The experience of parenting a child with autism is characterised by loss for the parent. There is a loss of self and loss of ease. The loss is not only felt in the present experience of parenting, it is also projected into the future, in both short and long term projects. Even the positives identified in the experience represent a change to self. The positives identified were the triumph of connection, development of patience and a sense of competence on reflection. The elements of the experience of parenting a child with autism remain ever present, but vary in intensity across time in response to the child’s behaviour.

The restricted and repetitive way of being-in-the-world that characterises autism is one of over regulation. This over regulation is shared in the social situation of
parenting and pervades the parent’s way of being. The parents experienced this as a feeling of autism being contagious. Parents spoke of feeling as though they themselves had caught autism. The elements that contribute to this experience of loss of self to autism are; a loss of spontaneity in both action and communication, shrinking or loss of social contact, and less things.

Spontaneity in action is lost as it becomes markedly easier to conform to the person with autism’s need for sameness and routine. Initially families resist this but as the amount of effort this requires outweighs the foreseeable possible gains, parents soon learn to lose spontaneity. The parent’s way becomes one of routine and predictability. For the parent the very sense of spontaneity changes. The portability, or the ease with which a child can be moved through activities in opposition to their expressed wishes effects the impact of loss of spontaneity on the parent.

It is not only action that becomes over regulated but also communication. Initially this is restricted to interaction with the child but eventually pervades the parent’s way of communicating in general. All abstract forms of communication are lost. This includes humour that is not very visual and strictly cause and effect, such as slap dash step on a ladder to have it come back and hit you in the head humour. Abstract humour results in confusion and unpleasant behavioural sequelae that trains the parent to not engage in it. Teasing loses it’s potency when it has to be translated for the person by a process of breakdown and explanation. As the person is sensitive to interaction that occurs around them, teasing other family members also ceases and teasing eventually leaves the parent's repertoire as a spontaneous behaviour. Likewise sarcasm is not understood and vanishes through the same process. Not only what is said but also how things are said becomes over regulated. Raised voices or an angry tone, are again misinterpreted by the person with autism, and result in confusion and distress. The parents lose the spontaneity of yelling at any of the kids in the family or each other. The communicative response repertoire of the parent shrinks and hence their personal interface with the world is altered.
Social contact also shrinks. This is closely linked to the reduction in spontaneity in origin and process. For the person with autism social situations pose the threat of confusion and stress that arises from unpredictability. Difficult behaviour often results as the person with autism becomes overwhelmed. To avoid the difficult behaviour parents learn to venture into social situations less. It becomes easier to remain at home where the person with autism feels relatively safe and comfortable and hence behaves in a less challenging fashion. When parents do venture out they report feeling sensitive to the perceived judgement of others upon their competence as parents. A sense of being blamed for the unusual behaviour in what often looks like a very normal child is experienced. Parents lose the energy to continue to attempt to explain the complex behaviour that is autism and it is again easier to avoid social contact. As a result of going out less and avoiding social contact old contacts atrophy and parents report feeling socially isolated. If social contact does occur it is often with other families with a child with autism as a bond is formed on the basis of a mutual understanding of the children’s behaviour.

Loss of things, both actual and potential also contributes to a loss of self. Loss of actual things occurs as the result of breakage and destruction by the child. This can arise in the situation of frustration, for self-stimulation such as that which occurs from watching glass shatter, from pulling things apart or simply doing things to see what happens. Parents spoke of a capability to have less things around the house. Less things represent a loss to self in the form of the restricted ability to express self through the acquisition and collection of material things. This loss also represents an ongoing financial stress that impedes spending in other areas. The impediment of spending, results in a loss of potential things. The cost of therapy and services also restricts funds available to spend on other, or luxury, things. The challenging nature of autism means not only that there is less money to spend but also that opportunity to go out to earn money is reduced related to the availability of childcare. The availability of childcare is impacted upon by the anxiety discussed as hyper-vigilance.
The experience of parenting a child with autism is characterised by a loss of ease for the parent. The parent’s baseline, or everyday feeling, is one of a mixture of anxiety and exhaustion. This feeling is contributed to by the demands of the act of care, hyper-vigilance, communication effort and frustration.

The act of caring for a child with autism is demanding and continuous. Parents spoke of feeling constantly exhausted related to the demands of care. The demands of care impede even the quality of sleep of the parent. Parents discussed the felt need to be aware of what the child was doing at all times which meant only lightly sleeping so as to be able to detect movement. Anxiety was generated by the parental attempts to anticipate the child’s needs to avoid distress and the resultant behaviour. The parent experienced a feeling of hyper-vigilance. The parents have taken on the roles of interpreter for others in their relations with the child and interpreter of the world for the child. Autism generates confusion in the child and in others in their social interaction with the child. Parents felt the need to be aware of how the child was responding to the world and acting to make the world appear a predictable and safe place. Parents monitored all interactions with the child when they were present, inclusive of interaction with other family members. Parents attempted to buffer the impact of family members on each other. Even when the child was not present the parent experienced a sense of hyper-vigilance and wonder related to where the child was and what they were doing. The challenge of communicating with the child with autism contributed greatly to the feeling of anxiety and exhaustion. This included the over regulated way of communicating but also the sense of guesswork of what the child needed. Wrong guesses, even in verbal children, were punished by an escalation in distress and the related behaviour. Frustration was generated at times by all of the other three precipitants of anxiety and exhaustion but was viewed as an individual entity. Frustration was not described as ever present like anxiety and exhaustion. Frustration at times was like a bell tolling a further slip into the way of being of autism.
The parent not only experienced the pervasive effects of autism in the present, but in all future projects. Short-term projects were heavily influenced by concern for how the person with autism would cope. Day to day activities were dictated by the need for sameness, routine and predictability. The question of how the child with autism would cope with any proposed activity was prominent in the parent’s thoughts. This was reinforced by past experience of distress in the child that resulted from lack of preparation or less than optimal conditions. Long-term projects were impacted upon by the question of, what degree of independence the child would attain and the degree of support that will be available. Parents were thrown acutely into such concerns at times of personal illness. The question of who would look after the child, if the parent were no longer able to, was very common.

There were positives identified in the experience of parenting a child with autism. Even these positives represented a change to the self of the parents. The positives that were identified were the triumphant moments of connection, where the parent was reasonably sure they knew what the child was thinking and feeling, the development of patience and a sense of competence upon reflection. Set on the background of the frustration of the communication effort with a child with autism, and the pervasive feeling of not being able to mutually connect around an activity or thought, related to the child’s need to do things on their terms to navigate a confusing social world, there emerged the joy experienced at times of a felt connection. Such connection occurred when the parent knew what the child was thinking and feeling. Sometimes this was when the child asked a question even though the conversation remained on the child’s terms. Often the parent had consciously orchestrated the moment through the use of high preference activities, such as the trip to a MacDonald’s store. The positive identified at such times represented a change to the expectations of the parent.

The development of patience, which was seen to be a positive of the experience of parenting a child with autism, was not the voluntary acquisition of a valued trait. Patience was taught in the parenting relationship and remained
tempered by frustration. Parents over time learnt that to attempt to rush through things or modify the child’s behaviour took more energy than the foreseeable benefit so learned to meet the child’s needs. It was described as a process of giving over to the needs of the child. Patience was distinguished from endurance by the purposeful nature of waiting for a change in the child’s behaviour in the future that will allow more flexibility. The lack of negotiability with a child with autism was discussed in this context. The parent does not choose to become patient but is worn into it. This is much the same as the rock in a mountain stream, or the cliff exposed to ocean spray and winds, does not choose to become smooth, but the inevitable happens.

The parents also spoke of a sense of competence that arose from reflection on the experience of parenting a child with autism to the point where they are currently situated. Parents spoke of only being able to appreciate behavioural change in the child by looking back to where they started, often prior to the time of diagnosis. The sense of competence was also identified in the context of assisting another parent. This contrasted starkly to a feeling of blame, and being blamed, for the child’s autism. These feelings were particularly prominent in the period prior to formal recognition of the problem, and the ensuing labelling of the problem, in the process of diagnosis. The sense of competence on a day-to-day basis was challenged by the child with autism’s need to be in control.

The experience of parenting a child with autism is that of the experience of profound changes to the self of the parent. The pervasive nature of autism becomes obvious when consideration is given to the experience of parenting a child with autism. Autism creeps into the selfhood of the parent not unlike a cloud of smog insinuating into a city on an otherwise cloudless day. The experience is characterised by a loss of aspects of self and the parent’s sense of ease. The pervasive nature of autism is not only in the present but autism dominates future projects. Even the positives identified by the parents represent a change to the self of the parent in the form of expectations, attributes and a sense of competence. What is the lived experience of parenting a child with autism? The experience for the parent is a change to their way of being-in-the-
world. This is an enforced change that happens in a pervasive and progressive manner. As it is a change in the way of being it is present and future that is changed. The parent does not develop autism as such but is impacted upon by the triad of impairment. The parent’s social and communicative interface with the world is altered. The parent is subjected to a restricted and repetitive way of being-in-the-world. This change in the way of being experienced by the parent is associated with an ongoing feeling of anxiety and exhaustion.
Discussion

The current study used a hermeneutic phenomenological approach to explore the lived experience of parenting a child with autism. It was identified from the review of the literature in section two that there is a marked deficit in research that used qualitative approaches in an attempt to gain an understanding of the experience of parenting a child with autism (Midence & O'Neill, 1999). The only phenomenological study of the experience of parents of people with a diagnosis of autism was that by Fong et al (1993). They studied the experience of parenting an adolescent with autism.

In the current study an understanding of the lived experience of parenting a child with autism has been arrived at that highlights the profound changes that occur to the self or Being of the parent. A permeation of autism into the self of the parent occurs in the social context of parenting a child with this different way of being-in-the-world, the way of being that is autism. The nature of the experience is one of loss for the parent. The self, or way of being of the child, dominates the present and colours all anticipation of the future. As this process occurs parents subjectively experience a feeling of dis-ease characterised by anxiety and exhaustion. The experience varies in intensity over time although still within the structure described. Some positives emerged in the study. These were the development of a sense of patience, the triumph of connection and a sense of competence-upon-reflection. These changes also reflected a change to the parents in the form of expectation. At the point of completion of the initial interviews the metaphor of autism as a shell, like that of a turtle’s, into which the parents were pulled was employed. The experience was described as that of a shrinking of the parents self. Perhaps a more unifying metaphor would be that of autism as a vortex into which the parents are sucked through the vehicle of the parent child relationship. This occurs in a progressive manner as the parent moves down the cone toward the centre of the vortex. The rate of decent toward the centre increases as the parents are depleted of the energy required to resist.
Opinion varies as to whether a phenomenological study requires a discussion in the traditional sense. The value of a formal discussion is that the findings can be situated within the body of understandings of the experience of parenting a child with autism. The risk is to succumb to the opposing goals of an explanation. “The ideal of explanation must, then, combine two mutually opposing goals: to keep that which is to be explained intact as it appears and at the same time to reduce it as much as possible to that with which we are already familiar, of which we have knowledge, or more generally, that which is considered basic reality” (Needleman, 1975:36). The challenge is to maintain the integrity of the interpretation amongst attempts to combine it with what is already known and thus considered, at least partially, verified as reality. The richness of phenomenology is that it is able to make patterns, or structures of experience, accessible that existed previously as a foreign language, especially to those with no experience of the phenomenon (May, 1967). In the translation, or sense making exercise of discussion, some of the richness may be lost, just like in any translation between languages.

Rollo May, an American psychologist, wrote of a recurrent fear that plagued him that consisted of what would transpire between St Peter and himself at the Pearly Gates, at the time that the decision of ascent or descent would be formalised. May was deeply concerned that he would be accused of nimis simplicando. St Peter would bellow in accusation;

You have spent your life making molehills out of mountains – that’s what you’re guilty of. When man was tragic, you made him trivial. When he was picaresque, you called him picayune. When he suffered passively, you described him as simpering; and when he drummed up enough courage to act, you called it stimulus and response. Man had passion; and when you were pompous and lecturing your class you called it the satisfaction of basic needs, and when you were relaxed and looking at your secretary you called it release of tension. You made man over into the image of your childhood Erector Set or Sunday School maxims – both equally horrendous. In short we sent you to earth for seventy-two
years to a Dantean Circus, and you spent your days and nights at sideshows! Nimis simplicando (May, 1967:4).

Similarly any attempt to pull apart and discuss the experience of parenting a child with autism too poses the risk of St Peter's wrath and accusation of nimis simplicando. The experience for the parents is certainly characterised better as a mountain than a molehill.

As identified in the literature review much of the research into the experience of parenting a child with autism has arisen out of the spatial view of being in which linear cause and effect thinking dominates. The parents became the objects of the research with the aim of measurement of the effect of the stimulus, the child with autism, on them. It was determined that parenting a child with autism is stressful, and in fact, more stressful than parenting neurotypical children or children with other disabilities. The underlying conception of the Being in this process, the objectification of the Being and determination of the response to the experience provided little in the way of telling what the experience is like (May, 1967). Twachtman highlights the inadequacy of such descriptions in the following.

A heart attack is recognised by one or more of the following symptoms: shortness of breath, pain across the chest or back, heaviness or weakness in the limbs, and pain radiating down the arm. It would be unfathomable, if not disastrous, to treat these symptoms as separate and distinct from one another. Approached from such a perspective, the physician might well recommend an inhaler for the breathing difficulty and a sling for the arm pain. The absurdity of this type of myopic, out-of-context treatment is immediately obvious when dealing with a medical problem. Unfortunately, out-of-context intervention is often standard operating procedure for dealing with children with autism (Twachtman, 1995:134).

The interpretation acquired through the current study supports the assertion of the stressful nature of the experience of parenting a child with autism. The
parents spoke of an ongoing feeling of anxiety and loss of ease. However, if I
dare conjecture at this juncture, this is only one element of the experience, not
the distinguishing feature but an element just as radiating pain down the arm is
just an element of the phenomenon of a heart attack. Fong et al (1993) in the
qualitative exploration of the experience of parenting an adolescent with autism
also identified the presence of stress as a reportable factor.

Professor Konstanttareas of the Institute of Psychiatry with students Mackay
and Janes reported that the degree of surgency or extroversion in the child
affects the parenting experience (Clark, 2001). Gray (1997) identified that for
children who were aggressive, parental concerns re the future were greater. In
the current study the finding of the impact of portability on the degree of
spontaneity possibly bears some similarity to the suggestion that factors in the
child may have some impact upon the intensity of the experience of parenting a
child with autism.

In the current study parents experienced less spontaneity, less social contact,
and less things. Fong et al (1993) in the study of the parents of the adolescents
with autism relayed feeling that having a child with autism placed restrictions
upon their personal life. This is in line with the theme of imprisoned families
identified through case studies by Reid (1999). The process of imprisonment
was strikingly similar to the shrinking social contact identified in the current
study. In the case studies families reported that it was easier to meet the child’s
rigid need for sameness and only leave the home for essential functions. In the
current study succumbing to the need for sameness extended to a loss of
spontaneity in communication and action as well as the shrinking social contact.

Gray (1994) who utilised structured interviews to explore how people cope with
autism identified withdrawal as a coping strategy in which social contact was
allowed to atrophy in avoidance of the stress that results from social contact.
Gray (1997) reported that one parent in a study exploring the construction of
normal family life cited the families never changing routine as evidence of family
normality. In fact this parent may have been alluding to the *loss of spontaneity* identified in the current study.

In terms of the ability to have *less things* Fong et al (1993) also identified that parents of children with autism are adversely affected financially by the experience related to costs incurred by their child. In the current study the opportunity to have *less things* was related to the financial demands of parenting a child with autism and also in some cases, the destruction of things by the child.

In Fong et al’s study (1993) parents expressed uncertainty in regard to the future. In the current study autism dominated both short and long term projections into the future by the parents. Concerns intensified at times of parental illness.

The experience of parenting a child with autism identified in this study is unfolded in the findings. It bears similarity in the areas discussed above with the small number of other studies identified into the experience of parenting a child, or adolescent, with autism. These are the elements that reflect the shrinking nature of autism. Still the question that begs discussion at this point is what is the significance of the experience of parenting a child with autism? An answer to this question provides the “so what” of the understanding.

The consideration of the significance of the experience is approached through the lens afforded by existential analysis. This provided one plausible structure within which to articulate the meaning acquired in the present study. Chaos theory is introduced at the end of the discussion as a new lens through which further research may be fruitful to further consider the experience of parenting a child with autism. This as discussed is a lens not too far separated from the ones used to view the question in the current study.

The understanding of being as furnished by Heidegger provides a point of departure for the discussion. Heidegger was strictly a philosopher and as such
he was primarily concerned with the question of being as opposed to the nature of Beings (Mills, 1997): He was no humanist who pursued the goal to improve humanity (Crotty, 1998). His ontological explorations provide the ground in which to interpret the experience but are missing the further link into the direct clinical practice of nursing, the issue appreciated by clinicians of where the issue hurts, or the shoe pinches (May, 1967). In Europe Ludwig Binswanger (1881-1966) and Medard Boss (1903-1990) have attempted to bridge the gap and take Heidegger’s ideas and apply them in the human field of psychoanalysis in Daseinsanalysis. These works are further complemented by those of Rollo May (1909-1994), an American psychologist who although dropping the title of Daseinsanalysis has taken a phenomenological approach to his clinical practice. May however retains a Husserlian influence in his thinking as he speaks of the possibility of self-consciousness and an ability to bracket one’s preconceptions in practice. He attributes the influence to his relationship with Professor Cairns who translated Husserl’s Cartesian Meditations into English (May, 1967). Apart from this influence he makes direct use of the ontological view of being proposed by Heidegger and extended into practice by Binswanger and Boss.

The shrinking nature of the parent’s self in the form of less spontaneity, less social contact and less things reflects something of the nature of autism itself. The mechanism, or way that, the parent’s very existence is affected by autism must be addressed. The works of Binswanger, Boss, and May in which structures of dispersion of self into the world of others, or shrinking of self, have been addressed provide some insight into the process, the how, of the question: how are parents sucked into the vortex of autism?

Heidegger’s exploration of being, provided an ontological point of departure to discuss an experience of being. The experience of being is not a function of a summative enumeration of factors of mind and body when combined with a concept of soul or any other composite. A Being, or Dasein, as referred to by Heidegger is a being-in-the world and this Being is more than the sum of these parts (Binswanger, 1947/1975). The process of attempting to explore parts of a
Being as a mode of being is transcended in the same way as nursing is trying to achieve with the concept of holism. What is obtained is a philosophical understanding of the Being’s wholeness (Binswanger, 1947/1975). The Being’s humanity is not fractured, fragmented and potentially destroyed in the process of studying it (May, 1969b).

Binswanger, Boss, and May each subscribed to some common underlying assumptions that arose from their understanding of the work of Kierkegaard and Heidegger. By way of an introduction, to understand their worldview, it is necessary to briefly discuss the assumptions that are inherent in Daseinsanalysis. These are the same assumptions that underpin this research project and were covered in the theoretical perspective and methodology sections in greater detail. As discussed in the methodology section Heidegger viewed Dasein as an entity whose existence, as a being-in-the-world, is an issue for itself (Heidegger, 1927/1985). “Dasein is, in its being, concerned essentially with being itself, in other words, that its whereto and wherefore is always directed toward itself” (Binswanger, 1947/1975:215). The whereto and wherefore hints also to the futurity of being. Being always projects into the future, a projection of its power-to-be, it is always ahead of itself (Binswanger, 1947/1975). Inherent with being-in-the-world, is being-with-others in the shared space of the world (Boss, 1979). This is the worldliness of Dasein, a being-in-the-world in the shared space of others. A Being extends into the world and pulls the world within to make sense of it. “To know and comprehend the outside world the person who is not a passive receptacle must literally grasp it, and he can do this only by extending to that world in whose immediate vicinity he already is” (Boss, 1979:225). Being is a realm of openness its relation with the world. Heidegger used the term care to describe Dasein’s responsibility for preserving its own possibilities within its open relationship with the world (Lemay & Pitts, 1994).

Dasein has the responsibility to determine it’s unfolding of potentials and not allow this to be determined by the others with who the Being is in relation. Heidegger noted the powerful and at times seductive nature of the demands of
relationships on the Dasein from others, which he called Das Man. Yet, “being is to be defined as the individual’s unique pattern of potentialities. These potentialities will be partly shared with other individuals but will in every case form a unique pattern for this particular person” (May, 1969a:19). The Being’s potentials are not limitless, as discussed in the theoretical perspective section, but are limited by the situated-ness or in Heidegger’s terms where the person is thrown in the world. What is of import for each Being is the existential potentiality within the context in which they are situated. Heidegger revealed that each Being is temporal in nature (Dreyfus, 1991). The only certainty is constant movement toward the point in time of death. Anxiety is experienced as a result of the knowledge that death approaches and the challenge of maintenance of self. The life circumstance that holds within it all potentiality varies throughout life. Each moment, as discussed in the theoretical perspective, that a Being experiences on its journey toward death is not shut within the present alone but coloured or conditioned by the past and laden with futurity. “All that we know of its throwness (as already being-in-the-world) the being-in-advance of itself of the Dasein, its futurity, is through and through implicated with its past. Out of both these temporal ecstasies the authentic present temporalises itself” (Binswanger, 1947/1975:214). The self of the being is constantly refined through actualisation, or failure to actualise, potentials on the way to death. The self is inevitably in debt and experiences guilt periodically as, in the actualisation of some possibilities other possibilities are left unfulfilled, as each Being is finite in the terms of time and duration (Sahakian, 1974). What happens when a Being is thrown into relatedness with another Being, which has the different way of being that is autism, in the role of parent? What happens to the parent’s self?

An examination of the affect of a phenomenon upon the existential potentialities of those involved provides the foundation for a meaningful discussion of the phenomenon. A discussion of a phenomenon is able to proceed in a way that does not fracture it by reduction to one element and therefore sacrifice the inherent humanity. It also hopefully does not lead to oversimplification and
render the author vulnerable to St Peter's accusation of nimis simplicando in the future.

In nursing and psychiatry, discussions often proceed on the basis of similarities of symptoms and syndromes commonly dictated by terms provided by the Diagnostic and Statistics Manual or the International Classification of Diseases. Examination of existential potentiality and the impact of phenomenon upon them, what Binswanger and Boss termed Daseinsanalysis, provide a different viewpoint. “Instead of a disease unit consisting of a small and perhaps also clinically and symptomatically rather varied class (such as anxiety), we have here a unity of definite existential structures and processes” (Binswanger, 1957/1975:251). The phenomenon can be discussed as a whole in its relation to those involved, in this case the phenomenon of the lived experience of parenting a child with autism and how this experience impacts upon the parent’s existential potentialities.

This discussion at this point needs to be set within further parameters. The discussion flows from the view of being as outlined in the theoretical perspective. There is no claim that it is a view taken in from some perch upon an Archimedean point from which the phenomena is surveyed and its relation to those involved can be viewed with absolute certainty (May, 1967). The structures identified are one plausible structure and do not provide substance to reify as an accurate description of absolute reality. The ideas of Binswanger, Boss, and May are situated in the context of psychotherapy and use language that may offend some parents. Terms such as neurosis and anxiety have specific meaning and it is the meaning that lends itself so well to this discussion and not the term. The term neurosis has entered the common vernacular and become impoverished over time, the specificity of the original meaning lost, and value added to the term in the form of negative connotation. This discussion is not an attempt to psychotherapise the experience of parenting a child with autism, or add more jargon, but a route to a meaningful discussion of what that experience is. Psychotherapy has had a particularly troubled association with autism since the early observations of Bruno Bertleheim that autism as a
phenomenon resulted from a cold and uncaring parenting style. This discussion is not a reversal of blame, again within the language of psychotherapy. The child is not blamed for the impact upon the parent’s potentiality, the impact results from the relationship between those with a different way of being-in-the-world. It is not a linear cause and effect explanation that is achieved but an understanding of the phenomena, that like any insight may hint toward options for nursing intervention and potentially fruitful areas of further investigation.

In the interpretation loss of self is referred to. This is manifested through loss of spontaneity (in action and communication), shrinking social contact and the opportunity to have less things.

In a Being’s open relations with the world there is a degree of interpermeation. “Beyond, beneath, in the midst of all supposedly separate subjects and objects, there is a process of interpermeation and communion, through and through (what are ordinarily called) self and world, wherein self and world flow into each other, continuously, simultaneously, wherein one’s very being permeates the world as the being of the world permeates one’s self, wherein self is world and world as world is self” (Adams, 1999:4). This interpermeation occurs as the Being grasps and pulls the world within, or ventures out into it, to make sense of it. The world is interpreted as related to the self. In the relationship of parenting, the parent in their openness is exposed to powerful demands by the child to engage fully in a relationship (Boss, 1979). As in any relationship there is a degree of interpermeation. By virtue of the engaged and long term nature of the parent-child relationship the degree of interpermeation is great. The autism of the child is able to pervade the parent through this process, hence the comments by parents of the feeling of catching autism and loss of self. This encroachment occurs through the mechanisms of; a loss of spontaneity, isolation from others, and the opportunity to have less (defining domestic) things.

Loss of spontaneity in action and communication results in an over-regulation of being. One of the significant features of a being-in-the-world is that of openness
and responsiveness which requires flexibility (Boss, 1979). Fixedness decreases ability for responsiveness and the closing off of potential. Fixedness in action and thought in Daseinsanalysis is termed neurosis. As communication becomes over regulated thought follows, as neurotypical Beings think in language (as discussed in the literature review). “Language is every man’s spiritual root. For it is language that envisions and thinks for all of us before any one individual brings it to the service of his own creative and intellectual powers” (Binswanger, 1943/1975:222).

*Shrinking social contact* has significance particularly when combined with a *loss of spontaneity* as it is through interaction and discourse with others that challenge of, and correction of, the over-regulation can occur (Binswanger, 1956/1975). It is also within the relatedness of being-in-the-world, the shared world with others, that a neurotypical Being fulfils it’s potentiality (Boss, 1979). A restriction of social contact is a restriction of a Being’s, “inherent being-together with others in a shared world” (Boss, 1979:283).

The opportunity to have *less things* in a domestic sense has significance that, when combined with over-regulation and decreased or *shrinking social contact*, can pose further challenge to the self of the parent. An exploration of the place of things in daily life by Jacques De Visscher revealed that the things that surround Beings in their daily life become virtual extensions of their corporeal life (De Visscher, 1998). Household things, it was found, have a place in the mediation between the owner and the facticity of their domestic life.

In this study, the lived experience of parenting a child with autism was to experience *less spontaneity*, *less social contact* and *less things* in their life. These effects were experienced in the present and projected into the future as consideration of autism dominated all future projects. Autism encroached into the Being of the parent, experienced by the parents as *less self*. The experience of *less self*, and thus less opportunity to unfold potentials of the self, has been discussed at length by Binswanger and Boss in their consideration of various structures of, or ways of being-in-the-world. Comparison of the experiences of
the parents in this study with those structures serves as a frame of reference from which to discuss the experience of parenting a child with autism.

In 1949 Binswanger wrote of the case of Lola Voss. Lola Voss had a diagnosis of Schizophrenia and as part of that experience had the symptoms of what then was described as autism. As Binswanger was in Switzerland and writing in German he was not using the concept of autism developed by Leo Kanner in Baltimore (see literature review). Binswanger in consideration of Lola’s condition wrote, “when we talk about autism, we must first of all think of existential analysis and of losses of world and self or at least a reduction of the potentialities of world and self” (Binswanger, 1949/1975:337). He goes on in 1957 to describe a process in which the Being is worn away by the existential problems of the person and the corresponding tension. This process is accompanied by extreme anxiety and latter apathy. The extreme point of complete loss of self and alienation of the Dasein is described as, “the completely unfree mode of insanity, a mode in which the Dasein of it’s own free will renounces neither life nor social life. What, rather, is renounced is life as independent selfhood” (Binswanger, 1957/1975:259). A radical capitulation of self occurs into insanity. This occurs in a process from active to passive suffering. Martyrdom is seen as active suffering whereas psychosis or insanity is passive. “We may say that, as a martyr, the Dasein was still to a degree capable of self rule, or that, to put it another way, the Dasein still proceeded within an experiential consistency so that, as it were, what was involved was a leap, rather than a sundering from the world. But in the passage from martyrdom to insanity, from self-sacrifice to being sacrificed at the hands of others, the Dasein progressively loses regency over itself” (Binswanger, 1957/1975:260). As a martyr the individual puts aside areas of existential freedom at the cost of anxiety. If the self continues to be encroached upon and self is progressively lost, psychosis or insanity in the form of complete loss of self may follow.

Boss also wrote of Schizophrenia as a Being’s forfeiture of existential autonomy, a Being engulfed by others (Boss, 1979). What this results in is a
total disturbance to the Being’s personality or selfhood. The rigid way of being and withdrawal from social contact is described as Schizoid behaviour or autism. “This characteristic behaviour of the Schizophrenic in psychiatry called Schizoid behaviour or autism amounts to a radical destruction of human being” (Boss, 1979:226). In a case study Boss wrote of one person whose self was totally engulfed. “His time would not pass because it was not his time, rather he lived in the time of others. His past and present were equally not his own, and the unfolding of his future, as in the other temporal dimensions, was determined by other people” (Boss, 1979:227).

It must be stated that the aim of this discussion is not to diagnose parents, or predict oncoming catastrophe but to extend the appreciation of the experience of parenting a child with autism through consideration of the similarity in process between the existential upset discussed by Binswanger and Boss and the lived experience of parenting a child with autism. It would appear the concept of autism has been for a long time associated with loss of self, particularly through rigidity and social withdrawal. The concept of loss may have been what set the pattern of blame of parents in motion as it was wrongly assumed people with autism had a neurotypical way of being-in-the-world and somehow lost it, as opposed to having a completely different way of being.

For parents with a neurotypical way of being, autism, through the process of interpermeation, may be represented by such concepts of loss of, or encroachment upon, self. This loss to the parent is not the fault of the child, but the result of the dominant demand of autism in the social parent-child relationship. This fits with contemporary thinking expressed by Carol Gray in her video, Writing Social Stories, in which she stated that, by definition a disorder of social impairment is shared with all who relate with the person who is thus impaired (Gray, C, 2000).

In this study the loss was found to affect the parents not only in the present but was also projected into the future, just as it was in Boss’s case study of the person whose self was totally engulfed and who lived the time of others. It may
be that the total loss of selfhood in the process of movement between Martyr to insanity is delayed by the lack of frailty in the parents pre-existent self as such frailty was seen by Boss as a necessary element in Schizophrenia. This frailty perhaps corresponds to contemporary theories of genetic susceptibility to Schizophrenia and underlying bio-physical factors. The relative nature of Boss’s view of Schizophrenia is highlighted in his view that any diagnosis of Schizophrenia must be qualified by the question of, “Schizophrenia under the excessive demands of which pattern of human relationship?” (Boss, 1979:236).

Both Binswanger and Boss in their discussions of the process of loss of self wrote of the significance of anxiety. In the present study of the lived experience of parenting a child with autism a loss of ease, or dis-ease, was identified. The feeling was characterised by an ongoing feeling of anxiety and exhaustion. This was felt to occur as a result of the culmination of the demands of the act of care, frustration in daily life, a need to be hyper vigilant of the child and their interactions with others (even within the family), and the ongoing effort of communication with the child. These factors on face value carry with them plausibility without seeking any further existential explanation of the dis-ease, yet the description of anxiety in the existential writings fits so closely with the parent’s experiences of loss that consideration of these deepens the understanding attained.

In the consideration of anxiety’s place in existence Heidegger was influenced by the thought of Kierkegaard. Kierkegaard wrote of anxiety as the dizziness of freedom (May, 1967). Anxiety was viewed as an integral part of existence hence the title of Kierkegaard’s book, “Fear and trembling and the sickness unto death” (Kierkegaard, 1843/1974). Anxiety is inherently involved in the struggle to maintain self and actualise potentials.

Heidegger’s notion of care encompasses the belief that each Being has the responsibility to preserve its own potentiality in the world. Dasein is a Being whose existence bears meaning for itself. The Being remains centred within its own existence. By necessity the Being is open and responsive to the world and
participates in other Beings. Yet within this participation, “every existing person has the character of self-affirmation, the need to preserve its centeredness” (May, 1969b:75). All participation with other Beings poses a risk of loss of centeredness. In the present study the early analogy of parents pulled into the shell of autism and the later analogy of parents being sucked into the vortex, are descriptions of such a process of loss-of-centeredness.

In the case of Lola Voss and her experience of autism as a part of Schizophrenia, acute anxiety was described by Binswanger, to which he attributed an existential cause. “The existence was dominated, even consumed by anxiety. But this anxiety as I have emphasised repeatedly is basically not feeling of affect, but an expression of existential anxiety, that is, of the draining of existence and its progressive loss of world. Of course, loss of world is accompanied by loss of self” (Binswanger, 1949/1975:337). The case of Schizophrenia is a radical manifestation of the loss of self in which the personality is totally disrupted and the Being is engulfed by other Beings, or the things of the world. Boss cautions, however that, “there is no special kind of relationship that the Schizophrenic maintains with others that is not to be found, under certain circumstances, among healthy people” (Boss, 1979:236). This opens the space in which to consider the process as applied in circumstance other than that of the development of Schizophrenia. Such circumstance is that in which centeredness in the self is disrupted or lost and not corrected through social discourse. This loss of centeredness corresponds to the loss of self that culminated from loss of spontaneity in action and communication, shrinking social contact and the opportunity to have outward representation of the corporeal self in less things, elucidated in this study as part of the phenomena of parenting a child with autism. In line with the teleological aspects of being these losses were projected into the future.

As anxiety is a normal part of being, efforts have been made to distinguish between normal or healthy anxiety, and unhealthy or pathological anxiety. Of course without some degree of anxiety there would be no pressure to get out of bed on many days and decisions or choice of any kind may not occur.
Historically anxiety has been attributed with a role in the fight and flight mechanism that allowed our ancestors to outrun the Sabre Tooth Tiger or fight the Woolly Mammoth and live to reproduce. Heidegger described anxiety as part of being, inherent in the quest to break away from Das Man, which offers the seductive hope of distraction and settled-ness, and in the knowledge that death is universally certain (Dreyfus, 1991). The knowledge that death is certain, and fulfilling individual potentials constitutes the freedom referred to by Kierkegaard of which anxiety is the dizziness. This is the freedom as an open and responsive Being to fulfil the potentials offered within the Being’s thrown situation or context.

In medicine and nursing, phenomena are often converted into the language of symptoms, seen as determinants of health or illness. These symptoms are considered in reference to the function or malfunction of people. Symptoms are seen to possess a teleological reference to future well-being (Needleman, 1975). One such phenomenon that is discussed as a symptom is anxiety. Alternatively, as part of the holistic perspective of an analytic of existence, anxiety is looked at in terms of its relation to freedom of the Being in fulfilling its existential potentialities (Boss, 1979). In psychoanalytic terms as a way of distinguishing between healthy and unhealthy anxiety, unhealthy anxiety has been termed neurosis. The proposed mechanism of neurosis and the associated anxiety provides further insight into the origin of, or at least a contributing element to, the parent’s anxiety.

In the present study a loss of spontaneity in action and communication was identified. Loss of spontaneity leads to rigidity. Rigidity results in a loss of openness and responsiveness to other Beings and experiences.

What we find in psychotherapy is that the behaviour of the neurotic personality can be predicted fairly rigidly, because his behaviour is the product of compulsive patterns and drives. But although the healthy person is predictable in the sense that his behaviour is integrated and he can be depended upon to act according to his own character, he always
at the same time shows a new element in his behaviour. His actions are fresh, spontaneous, interesting, and in this sense just the opposite of the neurotic and his predictability (May, 1969a:31).

In the study of the experience of parenting a child with autism the drive toward a loss of spontaneity was described as provided externally by the child’s autism. Parents initially resisted compliance but the behavioural sequelae in the child reinforced an over-regulated or rigid way of being. The child relied on routine and predictability to negotiate the demands of the neurotypical world and became acutely distressed if the routine was interrupted. This distress was manifested in behaviour that was difficult to manage and distressing to the parents. The need to avoid this behaviour outweighed the benefit from the disrupted spontaneous act or communication and eventually an over regulated way of being interpermeates into the self of the parent.

Kierkegaard referred to neurosis as shut-upness, a situation in which the person is shut up from himself and others (May, 1967). Being shut-up from others has significance in terms of the shrinking social contact experienced by the parents in the study and the reduction of opportunity for correction through discourse with others. The shut-up person lacks this communication or openness that characterises health and is in despair. “This personality is characterised by various forms of rigidity, unfreedom, vacuousness and tediousness” (May, 1967:69).

Binswanger’s discussion of extravagance follows on from Kierkegaard’s concept of shut-upness (Binswanger, 1956/1975). In extravagance there is a development of rigidity. “Extravagance means more than merely being stalled in that what is involved is not only the impossibility of experiential progress forward, but rather the strict attachment or bondage to a particular level or rung of human experience” (Binswanger, 1956/1975:347). All experience is fixed in an inflexible manner within this bondage. As in shut-upness the Being stands in isolation from discourse or traffic with others. “Thus, withdrawn into intercourse or traffic with itself alone, such a process can only wear itself out until it
becomes a mere staring at a Medusalike, psychotically rigidified problem, ideal or nothingness of anxiety” (Binswanger, 1956/1975:348). Extravagance was posed as the opposite to choice of oneself in an authentic mode of being.

Anxiety in the neurotic sense arises from a fear of loss of self, or dissolution of the personality. A perception of the possibility of the Being being thrown back upon itself and in its isolation ceasing to be (Boss, 1979). This can be an internal process or one that occurs in relation to other Beings as in the loss of self of the parents in the analogy of the turtle in this study, of being pulled into the shell of autism, or more descriptively sucked into the vortex, or from the parent’s perspective of catching autism. “It may well be in our day of conformity and the outer directed man, that the most common neurotic pattern takes the opposite form, namely the dispersing of one’s self in participation and identification with others until one’s own being is emptied” (May, 1969b:76). Such a process is described by the dispersion of the self of the parent in their relation with their child with autism.

Anxiety in this sense arises from the struggle of the self to preserve it’s being, it’s selfhood arisen from the freedom to pursue it’s own existential potentials along it’s path to certain death. As pressure builds from the outside to capitulate, in this case the demands of autism, an inner battle rages. This battle is, “namely the conflict within the person as he confronts the choice of whether and how far he will stand against his own being, his own potentialities” (May, 1969b:81).

When there is no sense of choice a sense of impotence may develop. This sense of impotence further contributes to anxiety (May, 1967). When there is a sense of choice anxiety can be generated through a conflict of values. “It is the essence of man’s nature to interpret his values in the context of his relation to other people and their expectations” (May, 1967:76). Parents are subjected to a strong expectation in Western culture that they are responsible for caring for their own children. In Australia the limited options for residential placement for children with disabilities further reinforces the expectation that parents care for
their children at home. A choice to preserve self in the form of escaping the demands of the child through placement (if available), or even respite care, may generate anxiety as it comes into conflict with these values.

Unhealthy anxiety over a prolonged period leads to feelings of depersonalisation and apathy (May, 1967). This apathy may partially be associated with the ongoing feeling of exhaustion that is mixed with anxiety. Certainly this discussion of the potential association of the exhaustion, that together with anxiety underlies the dis-ease unfolded in this exploration of the experience of parenting a child with autism, is not intended to detract from the business of parenting a child with autism, and the very plausible cause of the exhaustion in a purely physical sense. Yet the perspective of apathy, or being too tired to resist further encroachment upon self that has arisen from experience of unhealthy anxiety over a period of time, also appears plausible.

As discussed conflict of values results in the experience of anxiety as the Being attempts to resolve the conflict or hold two opposing values. The positives that were experienced by the parents in this study may be understood in light of a Being’s natural mechanism of managing conflict proposed by May. “The transforming of values, and meeting the related anxiety, is one side of creativity. Man is the valuator who, in the very act of valuing, is engaged in moulding his world, making himself adequate to his environment and his environment adequate to himself” (May, 1967:81). The positives identified in the study represented a change to the parent’s expectations, or a moulding of their world in an attempt to make the environment adequate to them. The positives were the triumph of the rare moments of connection, development of patience and a sense of competence upon reflection.

A commonly held value is that a parent should experience some positives in the relationship with their child, or from an open exposure of self in a relationship. A failure to identify positives may generate further anxiety as the parent’s being is in conflict with their values. As an attempt to mediate values through a creative change of expectations the conflict is appeased as some positives are
experienced, even if these were radically different to those expected or experienced with other children in the family.

The positive of *the development of patience* and the involuntary nature of this with the accompanying analogy in the interpretation of a rock in a mountain stream not choosing to be worn smooth, resonates with Binswanger’s description of existence being worn away as though by friction and the existential retreat that follows (Binswanger, 1957/1975). The parent’s creatively reframe such challenge to their existential potential as a positive in the attempt to accommodate it through an attempt to mould, making the environment adequate to them through a change in the act of valuing.

Discussing, and unfolding the meaning potential of, the interpretation of the lived experience of parenting a child with autism acquired through the present study, with a view to the meaningfulness of the experience to a being-in-the-world has highlighted the impact of the experience upon the parents. The understanding reached by its holistic nature has transcended attempts to look at small features of the experience in isolation, both objective or subjective and arrived at an understanding of the unitary structure of the way of being-in-the-world (Binswanger, 1947/1975). The structure consists of acute risk to the self of the parent who is engaged in an open relationship with the child. Autism interpermeates into the self of the parent, or the parent is sucked into the way of being that is autism, through over regulation of their way of being. The parents subjectively experienced unhealthy anxiety and exhaustion as they attempted to maintain their centre and creatively mould themselves to be adequate to the demands of the relationship and mould their perception of the situation to more closely approximate their values. These existential processes occur entwined within the ardent and non-relenting practical or every day demands of caring for a child with autism. As relayed by Charles Hart, the parent of a person with autism, “it’s easier for us to change our customs than it is for them to change for our convenience” (Hart, 1995:68).
The way of being-in-the-world of the parent of a child with autism described is just one understanding. “The western scientific community has seemed particularly prone to believing that a systematic description of phenomena is reality, itself, rather than an epistemologically contrived version of reality” (Johnson, F., 1985:113). The understanding was dialogued with the ideas of Binswanger, Boss, and May to further elucidate the inherent structure of the experience of parenting a child with autism. The word elucidate has arisen from the root lux which derives from light (Sahakian, 1974). The aim of hermeneutic phenomenology, as discussed in the methodology section, is just that, to bring to light a phenomenon. The writings of Binswanger, Boss, and May have not gone without criticism. The underpinning assumptions of their work, and for that matter hermeneutic phenomenology on which their world-view is based, that a Being is: a Being aware of it’s existence and hence an issue for itself, in the process of becoming and having the responsibility for guarding it’s being and striving to fulfil potential, has troubled some writers. The criticism is often based on an oversimplified view of these assumptions (Maddi, 1996). The most common criticism is based on the view that a Being is seen as free to choose from an unlimited possibility of choices in the process of fulfilling it’s potential or becoming. “In a profound sense life is what you make of it” (Hjelle & Ziegler, 1976:253). Others such as Maze (1983) wrote of the unlimited freedom of choice, or infinite possibilities, in terms of frustration related to the impossibility of securing knowledge of determinism. Neither view has considered the concept of thrownness with the inherent acknowledged limitation on the availability of choices through the situated-ness of the Being, which are assumptions that underpin hermeneutic phenomenology. “An oversimplified existentialism would have it that you can choose yourself to be any way you wish. You simply leap out of your situation and your past” (Maddi, 1996:164). Further the aim of hermeneutic phenomenology is to seek an understanding of the structure of an experience not a determinative mechanism.

How can this understanding contribute to the nursing care of the parents of children with autism? This study provides an understanding that was in the past not existent, for parents to compare their individual experience to, in an attempt
to answer the relativistic question of whether their individual experience is similar to the experience of other parents with children with autism. For the nurse it provides access to what the experience is like, a general conception from which exploration of individual parent’s experiences can occur.

In terms of specific intervention none are provided in the context of this study as the aim was to acquire an understanding of the experience. No axiomatic need for a specific intervention emerged beyond the need for nurses where possible to work with parents with the goal of the parent arriving at an understanding of their personal being-in-the-world. As there is no cure for autism, how do parents choose themselves (strive to fulfil their own potential) in the face of the unrelenting real world problems, even with this understanding of the challenges to their existential potentials?

On some occasions it may be helpful for parents to value themselves and make time for small pleasures in place of taking the position of martyr for the child. The example of the participant’s experience who had not watched television in five years and felt totally engulfed by autism may be one example of a concrete situation in which the possibility of reorientation of the parent’s perspective within the context of a therapeutic relationship toward choice of self in some way would lead to the parents increased quality of life. Such reorientation would foresee-ably be possible by the acquisition of insight through therapy with a nurse. Many times however, it would appear that as the child with autism can learn planned spontaneity at best, at times for the parent to remove the impairment to the ability to be responsive and open and allow fulfilment of individual potentials, would require the child to be removed. I am not suggesting a reversal to institutionalisation, but the use of respite care.

Respite care would be one way to allow time for the parent to experience spontaneity and a re-emergence of self: To allow the parent to move away from the centre of the vortex toward the outer rim. This acknowledges the thrown nature for the parent of living in proximity to the vortex but acknowledges the
potential prevention of complete absorption of the parent’s self in the relatively existentially dangerous vortex core.

The parents in focus group two discussed respite care. The match between the care available, that is currently provided through both government and non-government agencies, in terms of availability, service type and the characteristics of providers and perceived need appeared poor. Fong et al (1993) in Canada also reported restricted availability of services. The parents in the current study described a hyper vigilance even when the child was in the care of someone else, which included family. Fong et al (1993:109) reported that parents perceived in their study, “even when the adolescent was at school, the parent’s responsibility for supervision did not end”. From the discussion of respite care with the parents in the current study, and Fong et al’s findings it would appear that in order for the parents to be able to focus on their own potentials, or achieve a sense of openness and spontaneity, they need confidence in whoever is caring for their child. This is confidence that the carer is competent and can contain any situation in a humane and caring fashion without the need to contact the parent. To be able to communicate with the child a degree of consistency of carers is deemed desirable. The care also needs to be available in a flexible manner without the requirement to book weeks or months in advance, or be restricted to set times, such as 1-3pm every second Saturday. The amount of time needs to be sufficient so that it is not spent catching up on work and domestic duties, or in time devoted to catch-up with the siblings of the child with autism.

Nurses who work with families in which there is a child with autism have a role in educating families about respite options, advocating on behalf of families to obtain services and lobbying for better service provision. The nurse will often need to enter into therapy with the parents to explore the impact on their existential potentials before they value respite care. This may just mean simply to open a dialogue with someone who has been removed from the generative and corrective powers of simple discourse with fellow Beings. The dialogue itself may have therapeutic outcome in the form of recognition of the need for
action in the form of self-choice. It may require the nurse to lead a dialogue in a structured manner with the aim to aid the parent’s return from extravagance. Often values related to childcare need to be discussed openly and acknowledged before they can be considered in light of the parents structure of being.

The nature of nurse lead psychotherapy with parents of children with autism may be given some direction from the ideas of Binswanger, Boss or May. From Binswanger’s perspective a nurse working in a psychotherapeutic relationship with the parent of a child with autism would, “attempt to bring the patient to a point where he can see the manner in which the totality of human existence or being-in-the-world is structured and to see at which of its junctures he has overreached himself” (Binswanger, 1956/1975:348). Binswanger compares a Being who has succumbed to extravagance to a mountain climber who has climbed too far out onto a precipice and thus requires the assistance of another to return. Perhaps in terms of the parent of a child with autism it may be a parent who has been sucked too close to the core of the vortex. The nurse would take the role of this other. “The goal of psychotherapy is to bring the patient safely back down to earth from his extravagance. Only from this point is any new departure and ascent possible” (Binswanger, 1956/1975:349). Of course unlike the helper on the cliff the nurse would not take the role of rescuer and enforce upon the patient a pre-existent understanding such as that acquired in this study but would work with the individual in acquiring their unique and personal understanding of the structure of their own experience. This study would not provide the map just a rough idea of some of the terrain of the experience that may be encountered.

Boss would have the nurse identify anything in the parent’s being-in-the-world that impairs the manifestation of their existential potentials (Boss, 1979). Of course such impairment of the parent’s freedom to carry out their possibilities for relating to all they encounter in many cases will not be restricted to their way of being-in-the-world as the parent of a child with autism, each parent as a temporal Being will bring different elements to the encounter. For Boss the aim
of all therapy is lusis, a word derived from the Greek meaning of liberation (Boss, 1979). This lusis is arrived at through assisting the patient to realise potentialities that until the time of therapy remained not actualised as they were hidden, disturbed, or distorted in the parent’s experience of being-in-the-world. Therapy is aimed at identifying anything that impinges on the Dasein’s experience of being-in-the-world. As being-in-the-world inherently involves being-with-others the parent’s social behaviour is explored through consideration of all relationships. The understanding acquired in this study tags some things that may arise in the therapeutic relationship with the parent.

For May the therapeutic goal for the nurse would be to assist the parent’s, “seeing that he is the one who is threatened, that he is being, who stands in this world which threatens, that he is the subject who has a world. And this gives him the possibility of insight, of inward sight, of seeing the world and his problems in relation to himself. And thus it gives him the possibility of doing something about his problems” (May, 1969b:99). The goal is not to eradicate anxiety but to work towards orientating the parent to constructively confronting unhealthy anxiety (May, 1967). The characteristics of the existence of being provide a structural base for the psychotherapy. Again this study is but one understanding however it does provide nurses with a view of the ground that may be seen before engaging in individual therapy or a therapeutic relationship with a parent.

The understanding acquired in the present study of the lived experience of parenting a child with autism was potentially limited in part by the small representation by male parents in the study. As described in the study participants section, only three out of the nine interviews were conducted with male parents. No participants in any of the four focus groups were male. No major differences based on gender emerged from the interviews. However the voice of male parents did not stay alive through the analysis, as did the voice of female parents. The aim of the current study was to gain an understanding of the experience of parenting a child with autism. Nothing emerged in the study from the limited male parent voice, or descriptions from the female parent’s
perception, of a gender difference in the experience. As discussed in the literature review research into parenting a disabled child in general has been potentially biased by the imbalanced representation of male and female parents who have participated in the studies (Heaman, 1995). McConkey (1994) aptly listed male parents in the class of hard to reach parents. It does provide the ground for a further study in which gender difference in the experience and perhaps perceived roles in parenting a child with autism are explored.

Further implication for research is that of the choice of method for future research. The identification of a method that may be of use in furthering the understanding of the lived experience of parenting a child with autism whilst remaining true to the exploration of being-in-the-world, in a shared world.

The use of chaos theory and the complex mathematical process associated with the study of non-linear dynamics has potential as method that may contribute to further understanding of the experience of parenting a child with autism. Some may say that such a choice may be reductionistic in that the motivation to use it slips a little into the Baconian doctrine of pursuit of knowledge as power and the associated quest to understand, if not control, being as nature (May, 1967). Further, some may claim that it may even be an attempt at making the Procrustean bed onto which facts can be acquired in an empirical investigation and stretched to meet the preconceived pattern (May, 1967). Yet the conceptual scheme of families and the relationships there-in discussed in the literature review as that of non-linear systems and the understanding of over-regulation as part of the experience of parenting a child with autism acquired through the current study, lend themselves to an exploration of the experience through the lens and methodology provided within the context of chaos theory.

Chaos theory provides a way to look at the health, or otherwise, of non-linear systems. Chaos theory is a mathematical theory that posits small changes in systems initially can lead to chaotic and unpredictable changes in later systems (Barker, 1996). Not all systems are well behaved and thus follow a linear cause
and effect path as once assumed (Goldberger, 1996). Such systems are described as complex and nonlinear. Complex systems cannot be understood by individual analysis of the components of the system (Goldberger, 1996).

Chaos in western thought, a tradition that has been historically consumed by the need to find order and predictability in nature, was a metaphor for disaster in systems (Capra, 1983). In psychiatry for instance chaotic thought was associated with madness. This however, never held congruence with the rigid patterns seen in neurosis and the accompanying relative predictability of behaviour. Chaos theory contributed to the realisation that, for many systems over regulation or linearity was unhealthy (Andrade, 1995). In fact regular behaviour was periodic in mathematical models and represented decomplexification or ill health (Haigh, 2002). Healthy systems on the contrary maintain complexity and are chaotic. Such systems are dynamic and adapt. Loss of complexity, or chaos, is characteristic of disease and loss of adaptation (Goldberger, 1996; Andrade, 1995). “If you’re wrapped up in some periodic, monotonous dynamic, you’re in no shape to contend with the environment” (Smith, B., 1994).

Healthy systems maintain complexity and are chaotic. Such systems are dynamic and adapt. Loss of complexity, or loss of chaos, is characteristic of disease and loss of adaptation. Examples of phenomena within Beings that illustrate the point are: an over-regulated heartbeat represents an arrhythmia, an extremely over regulated brainwave represents a seizure, over regulated breathing is equated with Asthma or Cheyne-Stokes respiration, and over regulated firing of muscle fibre bundles is found in parkinsonian tremor (Andrade, 1995). Over regulated patterns in relationships may also reflect this loss of adaptability and represent ill health of the relationship (Smith, B., 1994).

Newman (1999) potentially has provided a different view of the use of chaos theory than the quest to gain power over and control nature, when the use is applied to a consideration of the individual rhythm and timing with the people with which the nurse relates in practice. “The development of this knowledge is
progressing by letting go of the view of science that divides life into manipulable parts and embracing a view based on undivided wholeness, flowing movement, evolving pattern, uncertainty and unpredictability” (Newman, 1999:230). Through the use of chaos theory, the rhythm in the parenting relationship with a child with autism can be studied to see if any clues arise that help make further sense of the over regulation discussed in the current study. Of course in a therapeutic relationship with the parent of a child with autism, the nurse would need to pick up on each parent’s individual beat, however the type of music in which the beat may arise, or the backbeat, may be demonstrated. Identification of the rhythm or backbeat of the relationship between parents and their children with autism may possibly contribute further in the way of clues as to the constitution of beat production.

The theoretical perspective that underlies the application of chaos theory shares much in common with that of hermeneutic phenomenology used in the present study. It has been said of chaos theory that although it is a theory that has arisen from mathematics it shares company more with the humanist than empiricist (Reed & Harvey, 1996). In fact chaos theory has made obvious the act of mind involved in science as it became clear that what science was sure of previously is now disproved. “Physicists have come to see that all their theories of natural phenomenon, including the laws they describe, are creations of the human mind, properties of our conceptual map of reality, rather than reality itself” (Capra, 1983:317). As discussed in the introduction the map conceived by science has often been very accurate, hence our trust in plane travel, but the fact remains they are just maps or approximations. Chaos theory embodies a move in the aim of science to the gaining of wisdom through understanding along with manipulation of nature, as opposed to the aim of control alone (Barker, 1996).

Both chaos theory and hermeneutic phenomenology share the conceptual underpinning assumption that a holistic approach to inquiry is needed that takes into account the facticity of the phenomena, temporality, and openness.
It is acknowledged, in chaos theory that a holistic perspective of study is required (Goldberger, 1996). A Being is seen to be more than the enumeration, or sum of, it’s parts (Griffiths & Byrne, 1998). Chaos theory is concerned with systems and acknowledges that to understand a system it is not enough to break it apart and examine each fragment. The system may be large or small. Beings can be considered systems at the individual level or in their relationships with others.

Facticity is acknowledged in the interconnectedness of being as part of a system (Walsh, 2000). The complex and individual nature of a Being’s interconnected relationships, or interconnecting factors are acknowledged (Pediani, 1996). It is acknowledged that a study of humans necessarily involves consideration of where they are situated, or in Heidegger’s terms thrown, in regards to the complex interaction of social factors (Griffiths & Byrne, 1998).

Beings are seen as temporal, or in the language of chaos theory, dynamic and in a constant state of flux (Barker, 1996; Capra, 1983; Copnell, 1998; Coppa, 1993; Haigh, 2002). This makes sense with consideration of the rhythm of being (Newman, 1999), or the fluidity of being and the analogy of flowing water (Barker, 1996; Capra, 1983). Being is not viewed as a point fixed in space but moving through time.

The notion of openness is also shared in both theoretical perspectives. The Being is open to environmental stimuli (Coppa, 1993). However the interaction is not unidirectional, the Being is more thoroughly described as constantly interacting with the environment in which an open exchange between the individual and the environment takes place (Copnell, 1998).

Many consider these assumptions are also shared between chaos theory and nursing theory (Copnell, 1998; Coppa, 1993; Pediani, 1996; Walsh, 2000). Chaos theory has not been used pragmatically as a research tool in nursing in an extensive way as yet (Haigh, 2002). However it’s potential use and use as a metaphor to understand nursing relationships appears a convincing possibility.
The use of chaos theory as a tool to research issues in mental health has also been advocated (Ethlers, 1995). It has been used to explore mood in Bipolar Disorder and thought processes in Schizophrenia (Ethlers, 1995; Paulus, Geyer, & Braff, 1996): The notion of loss of complexity representing pathology in mental illness is partially supported (Paulus, Geyer, & Braff, 1996).

The idea that over-regulation represents loss of complexity and health, at least metaphorically, provides some insight into the difficulty faced by a Being whose way of being is autism: This way of being-in-the-world characterised by a need for sameness and predictability in action and communication. As discussed in the literature review adaptability to change is impaired by their restricted and repetitive way of being-in-the-world. This need for sameness also translates to thought through obsession. No studies have been identified that apply chaos theory as a metaphor, or use the mathematical applications as a tool in research, in any area related to autism.

The understanding reached through the present study is that there is an interpermeation of the way of being that is autism into the self, or personality, of the parent through the parent-child relationship. The understanding reached provides an understanding of the structure of the relationship. This is in no way the definitive universal understanding, as discussed in the introduction and theoretical perspective: to achieve such an understanding was not the aim of the study and indeed was not thought possible. Different and equally plausible understandings may be reached of the same phenomena. Yet a structure has been uncovered that is consistent with elements of that which was found in the small number of other studies that have explored pieces of the experience of parenting a child with autism. It is also consistent with the reports of, or description of, the experience of individual parents as discussed in the literature review. A structure has been identified that warrants further exploration.

Mathematics becomes a relevant tool in scientific exploration once structure is conceptualised (Duncan, 1995). It could be argued that as well as a
considerable amount of shared ground in the theoretical perspective both
hermeneutic phenomenology and chaos theory methods and applications are
potentially further linked in that qualitative measures can be used to clarify the
nature or structure of a system before analysis by a quantitative or model
building method such as offered by chaos theory applications (Griffiths & Byrne,
1998; Haigh, 2002).

The production of numbers, or a visual model of some kind, of the parent-child
relationship within the experience of parenting a child with autism and a
comparison with the neurotypical experience, has special relevance in the
current climate of reliance upon evidence based practice. Evidence based
practice for many remains accompanied by a constricted view of what
constitutes evidence: This view is often influenced heavily by positivistic notions
(Barker, 1996; Griffiths & Byrne, 1998). Resource allocation is often tied to the
requirement of the production of evidence within the narrow view of what form
the evidence must take. Numbers or a model may provide more effective
ammunition, or evidence, to secure resources such as those required for the
provision of adequate respite for the parents of children with autism.

The application of chaos theory possibly would also allow a visually represent-
able model of the process of interpermeation in the parent child relationship.
This may help in the answer to the often-asked question, is this normal? This
would contribute in a valuable way to the work toward the acquisition of insight
into the need and ways to change the dynamics in their parent-child
relationship. The place for, and use of, such interventions as respite care may
become clearer to some when a model such as that which could be potentially
generated through the application of the tools of chaos theory is presented to
them in a visual format.

The practicalities involved in design of research that facilitates movement from
metaphor to research are complex (Goldberger, 1996). The lag in the use of the
mathematical tools of chaos theory as a research tool may be attributed in part
to the complexity of mathematics involved (Reed & Harvey, 1996).
The commitment of The Committee on Government Reform in the United States of America was announced in April 2002, to address the inequity of the distribution of research funding from which autism currently suffers. This potentially signals a fruitful time to apply for research grants for study of autism related areas internationally (Umovitz, 2002). The Committee identified that in America, at the rate of 1:500 referred to in this study, potentially 574,000 people have autism as a way of being-in-the-world. This compared with 313,000 persons estimated to have Acquired Immune Deficiency Syndrome (AIDS) yet less than three percent of the research funding that went into AIDS related research was spent on research funding in autism. In terms of the experience of parenting a child with autism, at least in general terms biologically, 1,148,000 people are affected in America. Such numbers, even when the ratio is applied to Australia’s smaller population, combined with the significance of the experience of parenting a child with autism understood from this study, must provide a convincing argument for the need for further research into the lived experience of parenting a child with autism. The provision of more funds for autism related research would help with the pragmatics of the process.
UNIVERSITY OF TECHNOLOGY, SYDNEY
CONSENT FORM - STUDENT RESEARCH

I __________________________, (participant's name) agree to participate in the research project, the lived experience of parenting a child with autism being conducted by Andrew Cashin, School of Nursing, Midwifery and Health (ph 9514 5727) of the University of Technology, Sydney, for the purpose of his Doctor of Philosophy degree.

I understand that the purpose of this study is to explore the lived experience of parenting a child with autism.

I understand that my participation in this research will involve participation in an interview of approximately two hours duration and/or a focus group of one and a half to two hours duration. These will be audio taped and later transcribed.

I am aware that I can contact Andrew Cashin, or his supervisor Dr Cheryl Waters, The school of Nursing, Midwifery and Health (ph 02 9514 5741), if I have any concerns about the research. I also understand that I am free to withdraw my participation from this research project at any time I wish and without giving a reason. Not participating in, or withdrawal from, the study will in no way effect availability of service provided through the Autism Association of NSW.

I agree that Andrew Cashin has answered all my questions fully and clearly.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way.

________________________________________  ____/____/____
Signed by

________________________________________  ____/____/____
Witnessed by

NOTE:
This study has been approved by the University of Technology Sydney Human Research Ethics Committee, and the Autism Association of NSW Ethics Committee. If you have any complaints or reservations about any aspect of your participation in this research which you cannot resolve with the researcher, you may contact the University Ethics Committee through the Research Ethics Officer, Ms Susanna Davis (ph: 02 - 9514 1279, Susanna.Davis@uts.edu.au). You may also contact the Autism Association Ethics Committee through the director of services. Any complaint you make will be treated in confidence and investigated fully and you will be informed of the outcome.
Appendix Two
Thank you for taking part in today’s focus group to explore the lived experience of parenting a child with autism. Please complete the data sheet below and the consent form on the next page prior to the start of the group. The data sheet is designed to assist with the collection of demographic data.

Note: no parent or child will be identified by name in any publication or discussion of results from this study.

**Focus Group Data Sheet**

Date of group:

Participants Name:

Date of birth:

M / F (please circle corresponding letter)

Marital status:

Number of children living at home:

Name of child with autism (if more than one child with autism include details of each child):

Child/children with autism’s date of birth:

Diagnosis – Autistic Disorder Asperger’s Disorder PDDnos (please circle corresponding diagnosis)

School attended:
Appendix Three
Autism Shrinks
The shell
Over Regulation
Loss of Ease
Projects of Future Self
Positives
Appendix Four
Focus Group 2

Ongoing Analysis
Over Regulation

Over Regulation
(Less self)

- Less Spontaneity
  # In action and communication
- Shrinking social contact
- Less things
  # Expenses and breakage
Loss of ease

Anxiety/Exhaustion

- The act of care
- Frustration
- Hypervigilance
  - # Includes monitoring others
- Communication effort
Future Self

- Short term projects
- Long term projects
- Being thrown in acutely if ill
Positives

The triumph of connection

Patience
Appendix Five
From the data it became clear that the lived experience of parenting a child with autism was not about a series of activities but about profound change to the existence of the parent as a person. The change occurs not only in the experiences perceived as problematic by the parents but also in those seen to represent the positives in the experience.

**Autism shrinks**

The triad of impairment represents a challenge to the person with autism. The basic tenants of communication and the skills needed to socialise themselves are impaired. In order to navigate any situation in society the person forms rigid and overly regulated ways of behaving. This allows navigation through a world that is very social and heavily dependent on communication. These ways of behaving represent an extreme lack of flexibility and hence adaptability to change. The stress presented by the need to adapt to change, or behave spontaneously, leads to a retreat to even more regulated ways of being in the world. The more confronted the individual the more the retreat to the need for sameness and routine as an attempt to grasp a control afforded by predictability. The more the person retreats to sameness the more circumstance dictates the need to become more flexible and so a vicious cycle of shrinkage followed by stress, which is accommodated by further shrinkage of the person’s horizons, occurs. Hence the notion that autism shrinks. The intervention strategies put forward in the guise of early intervention are about coaxing the
person to expand their horizons within a supportive framework in which an increase in stress is not automatic and in this way shrinkage is managed and horizons slowly expanded. In this tentative phase educators and parents are very aware that stress will lead to regression. It is not unlike when a child tentatively coaxes a turtle from its shell. The turtle comes a bit forward then regresses a little until it is sure it is safe and then the turtle comes out a little further. Any stress is like a loud noise or hit on the nose with a rolled up newspaper, the turtle will quickly recoil and be reluctant for some time to again venture out of the shell. The turtle will only come out as far as is needed to achieve its goal. An example of which may be to secure a food reward offered by the child. From this study it would appear that the child with autism metaphorically pulls their parents into their shell with them.

The goal of the study is to study the lived experience of parenting a child with autism. The collective voice of parents involved in the interviews and focus groups spoke of a sense of shrinking self which was recognised in the experience of less in; spontaneity, social contact, things and hence individual identity. Autism emerged as a pervasive contagion, which not only effects the parent child relationship but the selfhood of the parent. The child with autism dominated the projects of self. The voice sang out to ensure that the positives were acknowledged in the relationship with their child. The positives were the rich times of feeling a connectedness, which resulted from the conjoint focus of attention on the same object at the same time and a mutual sense of happiness. Patience was also spoken of as a personal quality bought to the fore by parenting a child with autism. Both positives involve a change in expectation and traits forged by circumstance. The intensity of the experience fluctuates in response to the child’s current behaviour and portability.

Less spontaneity
The experience of parenting a child with autism is an experience of shrinking spontaneity. This is a reduction in the spontaneity of action and communication. Lack of spontaneity in action is characterised by a routine way of doing things. Without forewarning and planning action cannot successfully occur. Lack of spontaneity in communication is about having to express the same thing over and over, with conversations at times taking the same path with the same things said in the same sequence each time and a lack of spontaneity with how things are said. The lack of ability in abstraction and the literal interpretation of meaning of those with autism can mean the slow death of humour and teasing as forms of communication.

The lack of spontaneity of action has an effect on the parent’s self. Initially a sense of frustration. “He can’t handle change or unpredictable things happening, that’s the most difficult part for me, I find it so frustrating”. This frustration is more intense when other demands place constraints on time. However something more pervasive happens and the need for routine and sameness is accepted and incorporated into the self of the parent.

The perception of what spontaneity is changes. “We told him three weeks before that we were going up there, it was a spur of the moment thing, we rang up the cabin and someone had just rang and said they weren’t going and we got the cabin for a week, just a spur of the moment thing”.

Not only is there a loss of spontaneity in activity even communication within the activity is changed. “We find even when xxxx isn’t around we talk the way we do when he is around. It just happens”. Any statement is accepted literally and so a lot of reassurance is needed with explanation of the intended meaning if anyone in the family teases someone in the presence of the child with autism.
“It sort of takes away the spontaneity of the moment of teasing each other when you have to break it down”.

Less Social Contact

An early sign of a parent being dragged into the shell of autism is a decline in social contact. The challenge of going any places that are not part of the person with autism’s regular routine often leads to behavioural disturbance in the child. The emotional cost to the parent of managing/enduring the behavioural disturbance is greater on many occasions than the identified benefit of going out, so parents go out less. Another by-product of behavioural disturbance or the unusual behaviours of children with autism is a sensitivity of the parents to the perceived views of others and judgements they may make of parenting competence and responsibility. Social contact is reduced to avoid the misinformed judgements of others. When out parents spoke of often feeling very sensitive to their perception of how others may be judging them as parents based on their child’s behaviour. Many spoke of the fact that autism is an invisible disorder. The children often look the same as any other child so the parents feel behaviour is judged as a product of parenting and not recognised as that accounted for by impairment. Along with a constriction of social contact related to the perceived judgement by others there was a corresponding lack of energy to continually explain why their children behaved in the way they did. Married parents who do maintain social contact often need to do it singly so the child does not have to take part. Going out less leads to reduced opportunities for social contact and old social relationships are not maintained. Shrinking social contact represents a loss to the self of the parent as a social being.

Less Things

Parents of children with autism experienced the ability to have less things. This is related to the financial cost of the purchase of services and for some parents the child breaking things. These things range from pleasure items and trinkets to furnishings.
Less Self

The dominance of autism in the lives of the parents interviewed was a consistent theme. This arose from the culmination of less spontaneity, less social contact and less things. The part of self that is parent dominated all other parts. Little time or energy was left for the roles of parent as partner in a relationship or individual pursuits. The self shrank to the role of parent.

Some voices spoke of a feeling of loss of self entirely to autism. “There is not much me now. I live in the world of autism now.” “I am always focussed, very focussed on xxxx that nothing else around me matters anymore. I believe I have built my whole life around xxxx. I have become obsessed by him. I feel like I have stopped my life and now I live for xxxx”.

Even to have time to experience illness as an individual for the parent is a luxury that can not be afforded. “you are not worried about being sick yourself but only the implications for xxxx”.

Autism in the parent child relationship not only dominates that relationship but also begins to act on the self of the parent. Autism shrinks and so does the self of the parent. Spontaneity leaves the parent child relationship and gradually the self of the parent. The parent’s world and social contact becomes smaller. In many cases the external signs of self in terms of things are destroyed and there remains less of these things related to expenses. The parent’s self is transformed. All other roles of self are impacted upon. The parent’s sense of ease or personal comfort is eroded, there remains a constant sense of anxiety and exhaustion which arises from the act of care, frustration, hypervigilance (including monitoring others in their relationship with the child) and communication effort. It would appear that autism is dominant in the relationship and begins to dominate at the level of self of the parent. This occurs within the fertile ground of dis-ease characterised by anxiety and exhaustion.
Autism does not affect only the current self but impinges on the future self. The child with autism becomes central to all short term and long term projects. Every project is dominated by the need to consider the unique needs of the child with autism. The parents are periodically thrown into such autism dominated projects in times of illness and any threatened transition.

Short-term projects are dominated by the needs of the child with autism. "Everything seems to be looked at with xxxx in mind regardless of what we do or what we plan to do". Thinking about the future “all the time”. This in the short term includes education choices. Every developmental challenge met means the next challenge awaits. Each challenge becomes progressively more difficult. “It is like every little stage there is a whole lot more energy being put into it, it is so very busy compared with just bringing up other kids”. The number of interventions available lead to the need to consider a lot of alternatives. “You are always second guessing yourself, wondering if you are doing the right thing, wondering if there is something else that you could be doing”.

Longer term projects concern the child moving to adulthood and the eventual death of the parent. “I guess when you are dead who is going to care for them and who is going to make sure their needs are met, who is going to make sure that their hygiene needs are met, who is going to wipe xxxx’s bottom when they are 30 and 40 and 50, and that sort of thing”. The need to have things in place is voiced a lot. “He is not that bad, being high functioning, but there is always going to be something that is going to set him off for the rest of his life. We don’t know what that is so something has to be in place to cope with that”.

Parents are thrown into these deliberations acutely in times when they are ill or feel vulnerable. Again autism impinges on the very experience of the self at
these times. “You go through stages when you are a bit depressed and that is when you do think about things like that”.

Positives

The triumph of connection

Connection with the child with autism was described as a time where both parent and child were focussed on the same activity and it was clear what both parties were thinking and feeling in relation to this activity.

The parents spoke of a sense of frustration and exhaustion related to the constant effort of trying to understand the space from which the child is coming from. “I wish I knew how he felt myself”. The quest to attribute a cause for gross behavioural clues such as agitation also engender a sense of frustration and depleted energy. “It takes up an enormous amount of time trying to work out what is going on for them. This week, that was a prime example of what it is like when you know there is something wrong with him, he can’t tell you, you don’t know where it is coming from, it’s a bit of guess work and then the mere fact we had to get into a doctor we also had to ring, as a contingency plan in case his pain escalated, we had to organise for him to be booked into Westmead Hospital to have a general anaesthetic just so someone could have a look at him to see if there was anything wrong with his mouth, it is all of those things”. Even with more verbal children a game of guesswork follows with the stakes in terms of behavioural disturbance raised with each incorrect guess. “You have to keep guessing, keep guessing what he means, because a lot of times he wont use his words”. Some have come to the conclusion that sometimes there is no right answer to guess. “Sometimes, I think they don’t even know themselves what it is, it is not just a matter of communicating, it is a matter of I don’t know what is going on either. We are both guessing”.

With all of the frustration and communicative effort as the background there emerged the sense of joy when the parent has a sense of knowing what the
child is feeling about a concrete situation. “Connecting with xxxx is a rarity but when we do connect it is marvellous, very great but it is rare”. The connection is described as the joyful payout from persistence. “It takes a lot of time, sometimes it might take an hour to find out what xxxx wants but he is so happy when I listen that he is all smiles and it is lovely”. Parents only described times of connection when the child either asked a question or when there were very overt signs of happiness such as the big smile, or in the case of one boy when he is “nigger niggering” a noise he makes and jogging on the spot.

The child asking a question provided an insight into what they were thinking at the time and provided the platform for an interaction even if it was one sided on the child’s terms. The overt reaction of happiness removed all chance of ambiguity in guesswork. “Because I really don’t know what is in his mind and I really don’t know how he thinks about things and you know if I think I can see a smile on his face or he is going ‘nigger nigger’, well he does that, and I know he is happy”. Parents spoke of setting up the situations to provide this connection and reaction. McDonalds was a common venue for this, “pathetic as it is driving to McDonalds and getting an ice cream, they are just over the moon, just for a simple little cone. I suppose that is where you get the pleasure”.

The pleasure was described in such terms as, winning the lottery and as a time of pride. The rarity of the moments of connection increased the value of such moments. Parents spoke of the children with autism’s siblings as being expected to achieve small milestones and have this connection so each and every occasion was not revered, but the rarity with the child with autism meant each occasion was noted and often remembered. These occasions provided some more energy to go on. This again however represented a change to self in the parent in the form of expectation. These moments of joy often tainted by sadness. As achievement at times highlights what the child is not doing. “xxxx started giggling when the duck in the video Babe tapped on the window. I went into the kitchen and had a cry. xxxx doesn’t do that. That doesn’t happen. He will laugh and giggle at the most silly thing. It made me realise that we missed
all of that. Seeing him laugh at the movie for the first time was good but it brought back that he is so different”.

**Patience**

Parents collectively spoke of the development of patience as a personal trait as one of the positives that arises from the relationship of parent to a child with autism. Patience is born out of frustration and remains tempered by this.

Patience was spoken of in reference to a sense of slowing down as a person. “That was hard for me because I am not a very patient person. I am a typical Arian you do it fast, go on to the next thing and do it fast. So for me slowing down has been hard. Slowing everything down socially, slowing everything down in the family”. Parents are put through this process by the relentless needs of the child to do things on their terms in their own time and the subsequent realisation that you can no longer hurry through things. “I see other people just go stop it calm down, it doesn’t work on xxxx, you have to actually take the time to sit down and fix it, you can’t Band-Aid things with autistic kids”. The fact was that to slow down and develop a sense of patience is the only alternative offered. “You get angry sometimes, but just a bit of anger builds up and you have to give up and go and help him, because if you don’t he will keep hitting you in the face and carrying on”. The patience developed remains tempered with frustration it is more of a surrender to the inevitable. “I have learnt to become more patient everything just waits regardless of deadlines”. This is not a sense of tranquillity or a sense of purposeful waiting, “no it is also tempered with a bit of frustration so you know it is a trade off into both because even though I have slowed down, I have become more patient, there is still that frustration with not being able to get anything done at the pace you want to get it done, or if you are in a hurry or if you have deadlines. Things like that, so one tempers the other”.

On occasion the behaviour people attribute to being laid back or patient is really attributable to a change in priorities and exhaustion. “People say you have a lot
of patience, it isn’t patience it’s exhaustion, you just let it go, if he knocks over a bowl of sugar, a pot plant or something, you just think another one and don’t stress about it. It’s not patience you just lose the importance of those sort of things with a child like xxxx and go with the flow”.

In the focus groups we considered the idea of whether this was patience or endurance. It was considered more patience as it is fuelled or maintained by a hope for the future, “I don’t think it is hope of a cure as such, it is that you can see all the time changes and things that do make life easier and things like that, and things we can do now and I couldn’t have dreamt of doing before such as outings, they were just unheard of two years ago”. When such changes are observed on reflection a sense of parental competency emerges.

So even the positives identified in being the parent of a child with autism reflect a basic change to the self of the parent. These changes represent changes not consciously selected and adopted. The change reflects the needed modifications to self to survive. Much as a rock does not choose to become smooth in response to the relentless wash of the stream or ocean wind. A change in expectations occurs and the parent identifies how to find the relatively rare moments of connection. The feeling at this time identified as the joy of parenting, but also at times mixed with a sorrow realised in the rarity of, and at times orchestrated nature, of these moments. The development of patience was spoken of by many as a positive that has arisen from their relationship with a child with autism. But this patience is mixed with frustration, exhaustion and a sense of the inevitable. The patience shaped by the behaviour that is autism.
Appendix Six
From the data it became clear that the lived experience of parenting a child with autism was not about a series of activities but about profound change to the existence of the parent as a person. The change occurs not only in the experiences perceived as problematic by the parents but also in those seen to represent the positives in the experience.

**Autism shrinks**

The triad of impairment represents a challenge to the person with autism. The basic tenants of communication and the skills needed to socialise themselves are impaired. In order to navigate any situation in society the person forms rigid and overly regulated ways of behaving. This allows navigation through a world that is very social and heavily dependent on communication. These ways of behaving represent an extreme lack of flexibility and hence adaptability to change. The stress presented by the need to adapt to change, or behave spontaneously, leads to a retreat to even more regulated ways of being in the world. The more confronted the individual the more the retreat to the need for sameness and routine as an attempt to grasp a control afforded by predictability. The more the person retreats to sameness the more circumstance dictates the need to become more flexible and so a vicious cycle of shrinkage followed by stress, which is accommodated by further shrinkage of the person’s horizons, occurs. Hence the notion that autism shrinks. The intervention
strategies put forward in the guise of early intervention are about coaxing the person to expand their horizons within a supportive framework in which an increase in stress is not automatic and in this way shrinkage is managed and horizons slowly expanded. In this tentative phase educators and parents are very aware that stress will lead to regression. It is not unlike when a child tentatively coaxes a turtle from its shell. The turtle comes a bit forward then regresses a little until it is sure it is safe and then the turtle comes out a little further. Any stress is like a loud noise or hit on the nose with a rolled up newspaper, the turtle will quickly recoil and be reluctant for some time to again venture out of the shell. The turtle will only come out as far as is needed to achieve its goal. An example of which may be to secure a food reward offered by the child. From this study it would appear that the child with autism metaphorically pulls their parents into their shell with them.

The goal of the study is to study the lived experience of parenting a child with autism. The collective voice of parents involved in the interviews and focus groups spoke of a sense of shrinking self which was recognised in the experience of less in; spontaneity, social contact, things and hence individual identity. Autism emerged as a pervasive contagion, which not only affects the parent child relationship but the selfhood of the parent. The child with autism dominated the projects of self. The voice sang out to ensure that the positives were acknowledged in the relationship with their child. The positives were the rich times of feeling a connectedness, which resulted from the conjoint focus of attention on the same object at the same time and a mutual sense of happiness. Patience was also spoken of as a personal quality brought to the fore by parenting a child with autism. Parents also spoke of a sense of competence upon reflection. These positives involve a change in expectation and traits forged by circumstance. The intensity of the experience fluctuates in response to the child’s current behaviour and portability.
Focus Group 4

Ongoing Analysis
Less self

Less Spontaneity
# In action and communication

Shrinking social contact

Less things
# Expenses and breakage
Loss of ease

Anxiety/Exhaustion

- The act of care
- Frustration
- Hypervigilance
  # Includes monitoring others
- Communication effort
Future Self

Future Self

Short term projects
Long term projects
Being thrown in acutely if ill
Positives

The triumph of connection  Patience  sense of competence upon reflection


communication and socialisation (pp. 53-69). New York: Delmar Publishers.


