A Portfolio of Academic, Therapeutic Practice and Research Work

Including an Investigation of Factors Influencing Depression and Anxiety in Parents of Children with an Autistic Spectrum Disorder, and Implications for Therapy

By

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**Statement of Anonymity:**

The confidentiality of clients and participants has been protected throughout this Portfolio. Wherever client or participant material is referred to, names have been replaced with pseudonyms and any identifying information has been changed or omitted to preserve the anonymity of those concerned.
Introduction to the Portfolio

This portfolio provides an overview of my journey through doctoral training as a Counselling Psychologist, and endeavours to give a coherent account of my personal and professional development. It consists of three dossiers reflecting my Academic, Therapeutic Practice and Research work, and whilst it is essentially an academic piece, it also a very personal one reflecting my own developmental, cultural, social and situational background, and my associated feelings, thoughts, attitudes and beliefs.

Reasons for training as a Counselling Psychologist

Both my background and my experiences have contributed to the range of topics I have chosen to explore throughout my training, and they are also relevant to my decision to become a Counselling Psychologist. Having worked with the partnership between horse and rider for most of my adult life, and as the mother of three children, I had long held a keen interest in relationships, development, thoughts and behaviour. At a key stage in my life (when I became divorced), I decided to extend my education. In light of my interests and experiences, and a desire to become ‘a counsellor’, Psychology seemed to be the natural choice.

Throughout my first degree, I developed a ‘passion’ for psychology, and became increasingly drawn to the idea that training to be a therapist would be ‘right’ for me, and would sit comfortably with my other roles. Towards the end of my studies I undertook a module in psychotherapeutic psychology, where I discovered that the humanistic values and a belief in human potential (which are congruent with my own ideology), are rudimentary principles of Counselling Psychology (Strawbridge & Woolfe, 2003). With this in mind, and with a continuing desire to learn and achieve academically, as well as an interest in research and aspirations to help others on an informed but equal basis, undertaking doctoral training to become a Counselling Psychologist seemed to be part of a natural and logical process.
The Academic Dossier contains three essays, selected to highlight the range of topics I have explored throughout the course and to reflect the diversity of epistemological stances inherent in counselling psychology. The first essay is drawn from thinking about 'Lifespan Development' and focuses upon the period of 'adolescence'. It looks at the extent to which classical theories of adolescence are supported by research evidence relating to adolescent well-being and functioning, and considers and identifies Focal theory (Coleman, 1990) as a theory of adolescence which might be of particular use to counselling psychology practice. This piece represents in many ways the beginning of my 'becoming' a Counselling Psychologist, and it outlines a theory of hope and coping, which reflects my own positivist approach. The second essay examines a theoretical framework that I find especially useful in helping to understand the development of disturbances in a person's sense of self, namely Kohut's (1977) 'self-psychology'. Undertaking this piece of work, which describes and considers Kohut's concepts of the 'mirroring' and 'idealizing' transferences and their relationship to clinical practice, provided me with an invaluable 'stepping-stone' towards my understanding of clients and the nature and importance of the therapeutic relationship, and also helped me as I struggled to reconcile ideas from psychoanalytic theory with the humanistic approach.

The final essay, drawn from the beginning of my third academic year, describes the emergence of Cognitive Behavioural Therapy and outlines its theory and philosophy, with emphasis on the importance of the therapeutic relationship and illustrations from my own practice. At this stage I was still grappling with a new approach and its associated techniques, however, this piece of work foreshadowed a major transition in my development as a Counselling Psychologist, where I seemed to find a 'missing dimension' which greatly enhanced my understanding and therapeutic skills.
Therapeutic Practice Dossier

The Therapeutic Practice Dossier provides a brief description of each of my three clinical placements, their client populations and my professional activities. It also contains a Final Clinical Paper, which seeks to provide a personal 'snapshot' of my ongoing development as a Counselling Psychologist and to give some insight into how I engage with theory, research and practice. It describes my developing awareness of different aspects of the therapeutic relationship and my movement towards integration, as well as some of my struggles along the way. Also, it discusses my own personal therapy, which provided me with understanding of my own processes, and support throughout some of the more demanding phases of the course.

Research Dossier

The Research Dossier contains three reports, one from each academic year of the training course. There is a consistent theme concerned with the exploration of what it means to be the parent of a child on the autistic spectrum, and how this relates to Counselling Psychology. The first report, the Literature Review titled ‘Autism: A review of the history and research, and implications for Counselling Psychology’, was inspired in part by curiosity arising from the fact that I have a child of my own with Asperger’s Syndrome, or high-functioning autism. This is not the only reason, however, that ‘autism’ became my chosen area for investigation. I find the topic in general to be intriguing due to its range and complexity and connections to all other areas of psychology, and because it seems to be so inexorably linked to theories and factors relevant to Counselling Psychology.

This first report explores the history and research literature relating to autism, and highlights that there has been very little work done to investigate the perspectives of parents of children on the autistic spectrum, and that historically parents appear to have been blamed for their child’s condition. The implications for Counselling Psychology
practice, in particular for therapists who may come to work with clients who have this
disorder, or who have children with the disorder, are considered.

In my second year, on the basis of the findings, I conducted a qualitative study (Research
Project: 1) titled ‘A shift in focus: Exploring the voices of parents of children on the
autistic spectrum’, in order to get ‘the other side of the story’. This work allowed me to
integrate my counselling skills with research in the interviewing of ten individuals, and to
attempt to inhabit their phenomenological worlds, albeit through the lens of my own
interpretative framework, in order to explore their personal experiences and points of
view associated with being the parent of a child on the autistic spectrum. In keeping with
the psychodynamic approach that I was working with clinically at that time, and due to
the nature of relational problems associated with autistic spectrum disorders, the findings
are placed within an Object Relations framework. The participants’ unique experiences
of parenting a child with an autistic spectrum disorder are considered, and the therapeutic
implications of the analyses discussed.

In interviewing these parents, who as a group have been described in the past as
‘refrigerator parents’ due to their ‘lack of warmth’, I was particularly struck by their
sincerity and concern for their children, and the lengths to which they seemed prepared to
stretch in order to try to achieve the very best that they could for their child. What I also
detected however, were possible symptoms of depression and this seemed to be born out
in the findings where loss, isolation, tiredness and guilt were consistent themes. On the
strength of this, I felt motivated to conduct a quantitative study (Research Project: 2) in
my third year, titled ‘An investigation of factors influencing depression and anxiety in
parents of children with autistic spectrum disorder and implications for therapy’. In
keeping with the clinical approach I was using at that time, this piece of work takes a
largely cognitive stance and looks at the experiences, attitudes, and levels of depression,
anxiety and locus of control in parents of children on the autistic spectrum, and compares
these to those of parents of children with Down’s syndrome and a control group.
There were significant differences between all three groups, with parents of children with an autistic spectrum disorder obtaining the highest levels of depression and anxiety. The findings are placed within the framework of Hobfoll’s (1989) Conservation of Resources theory which is again, an holistic theory concerned with coping, and the potential implications for therapy are discussed. Each of the two empirical pieces of work also contains a statement of ‘personal reflection and the use of self’, which address my motivations for exploring the topic under investigation, and these pieces of work were particularly useful in helping me to develop and integrate my self-reflective skills.

Self-reflection

Self-reflection is a vital component of both ‘becoming’ and ‘being’ a Counselling Psychologist. Throughout my training, with the help of my supervisors and colleagues and use of personal therapy, I have been able to heighten my awareness of my own processes and how these impact upon and interact with those of ‘the other’, as well as how they influence my own reactions. I view self-reflection as an important and ongoing aspect of personal development and growth, as well as a crucial component of my long-term professional development as a Counselling Psychologist, and hope that this is reflected in my work.

Conclusion

In conclusion, this portfolio contains an account of the academic, therapeutic practice and research ventures I have engaged with throughout my doctoral training. I have attempted to place each piece in context, and hope that together they provide insight into my movement towards ‘becoming’ a Counselling Psychologist.
References


Academic Dossier
Introduction to the Academic Dossier

This dossier contains a selection of essays submitted throughout the PsychD course. The first essay is drawn from the area of ‘Lifespan Development’ and is concerned with the period of adolescence. It looks at the extent to which classical theories are supported by the research evidence relating to adolescent well-being, and identifies a modern framework useful to Counselling Psychology. The second essay explores the work of psychoanalyst Heinz Kohut and his ideas on the development of the self, in particular his concepts of the ‘mirroring’ and ‘idealizing’ transferences. The third essay outlines the theory and philosophy relating to Cognitive Behavioural Therapy, and its background, with emphasis on the therapeutic relationship, and contains illustrations from my own practice.
Theories of adolescence: Research and strategies for coping

Introduction

The traditional, or classical theories of adolescence all imply an extreme and difficult transitional period in the life of every person. They describe an extended period of storm and stress, crisis of identity and generational gap, through which all must pass at their peril. This essay seeks to outline the main classical theories of adolescence, including those of Freud (1905) and Erikson (1968), and to examine the findings of the relevant research, in order to assess the measurable strength of the classical picture. The somewhat different picture of the adolescent period which will emerge, can be seen to fit with Coleman’s Focal theory (1974, 1978, 1979, 1980), and this will be outlined. Focal Theory takes a very different stance from the classical theories and is an explanation of adolescent coping, rather than one of adolescent struggle and turmoil. It has, therefore, strong implications for Counselling Psychologists in their practice as it emphasises the positive strategies used by adolescents to manage this important stage of their development. This in turn provides a framework for considering how and why things might go wrong for some young people, and indeed, how they might consequently be assisted.

Classical Theories

Adolescence has traditionally been conceptualised as a time of ‘storm and stress’ (Hall, 1904). Whilst the term ‘teenager’ only entered our vocabulary after the 1950s, this transitional period between immaturity and maturity has been recognised in one form or another since ancient times. Probably the earliest theory of adolescence was G. Stanley Hall’s recapitulation theory (1904), which mirrors the volatile history of the human race. Whilst this theory is now only of historical interest, it has contributed significantly to
classical picture and become part of popular culture, both of which portray adolescence as a 'problem age'.

The most influential theories of adolescence, which form the basis of the classical picture, are those of Freud and Erikson. Both of these theories address personality and development, but in somewhat different ways. Freudian theory, or instinct theory, emphasises the notion of infantile sexuality and describes a number of psychosexual stages, through which the individual must pass. Relevant to the adolescent period is the genital stage which Freud considers to be the storm that occurs after the relatively calm latency stage. According to Freud, during the latency period (5/6 years – puberty) the balance between the id, the ego and the superego (the tripartite structure of the personality), is greater than at any other time in the child’s life. However, with the onset of puberty, the relative harmony within the child’s personality is dramatically disrupted as the id begins to make powerful new demands in the form of sexual desires.

Anna Freud (1937) believes that her father over-emphasised the development of sexuality in childhood and neglected its adolescent manifestation. She considers the ego defence mechanisms used prior to puberty, become no longer adequate to deal with the sudden upsurge of instincts and on the strength of this identifies two new adolescent defence mechanisms, namely asceticism and intellectualisation, whereby adolescents deprive themselves of pleasurable experiences and discuss and read at length about anxiety-provoking subjects.

Other psychoanalytic theories of adolescence focus on regression and re-workings of earlier childhood conflicts as described by Freud. For example, Battle & Offer (1971) consider much of the stereotypical and negative adolescent behaviour which adults, and particularly parents, find so difficult, to be triggered by reactivated ambivalence and frustration previously seen around the age of two. They term this behaviour, whereby adolescents do exactly the opposite of what their parents want, negative dependence. Blos (1967) considers the struggle to separate from parents to be a second individuation process and in light of these explanations, it can be seen how psychoanalytic theories
help to paint the classical picture of adolescence as a period of intense conflict within the self and with others.

In contrast to Freud, Erikson’s theory of development, although also characterised by stages, extends throughout the lifespan and is primarily psychosocial, as opposed to psychosexual. Whilst both men agree that there is a biological basis to development, Erikson (1966) believes in addition that the individual must be psychologically and socially ready to move from one stage to the next. Corresponding to adolescence is the stage, or task of identity versus role confusion, the positive outcome being to emerge as ‘being oneself’. Whilst many would consider Erikson’s theory to be more optimistic and less deterministic than Freud’s, allowing for variability within and between the stages, the importance of achieving a sense of identity at the optimum time, that is during adolescence, is stressed.

Erikson’s theory also emphasises the social aspects of development, claiming that Western society has invented adolescence as a moratorium, or authorised delay of adulthood. During this time young people are expected to extend their education and decide who and what they wish to be, but whilst this has certain advantages, Erikson points out that this may also cause great confusion. For example, whilst biologically prepared for adulthood, adolescents are legally and socially restricted. Furthermore, Erikson predicts later psychological difficulties if choices are made too early, termed premature foreclosure of the moratorium. Marcia (1966), inspired by Erikson, identifies four stages or statuses of adolescent identity formation, each representing a struggle to finally achieve commitment, and again both imply an inevitably arduous and difficult period for most young people, although Erikson does refer to this as a normative crisis.

Other theories contributing to the classical picture, such as those of Meade (1928, 1949) and Benedict (1934, 1954) were formulated partly in reaction to Freud’s instinct theories. They too see adolescence as a period of conflict and stress, but consider it cannot usefully be understood in isolation from cultural norms and institutions to which young people belong. For example, Meade believes adolescent problems to be mainly due to social
factors, in particular the wide range of choices open to the individual in a rapidly changing world. Whilst again, the difficulties of adolescence are emphasised by these theorists, their focus is more social, encompassing such issues as discontinuity of social roles and lack of rites of passage within the Western culture.

Certainly, it would seem that each of the classical accounts of adolescence discussed describe a period of great struggle, conflict, disharmony and upheaval, affecting well-being and functioning. However, it is important to note that none of these theories is supported by empirical evidence, although each has made some important contribution. Perhaps the most influential and intuitively acceptable account is that of Erikson whose emphasis on the need to establish a sense of identity during the adolescent phase seems particularly plausible, and also testable.

Research

Identity, or the self-concept, generally refers to three major components: self-image, self-esteem and the ideal-self and investigation of these aspects has produced some interesting results. When investigating the self-image, answers to the question 'Who am I?' typically produce two categories of answers. Those referring to social roles, such as son or daughter, and those relating to body-image. Undoubtedly, the onset of puberty brings with it enormous bodily changes and Erikson considers these changes to disturb the previous trust placed in our bodies achieved at an earlier stage of development. Reasonably, the self-concept is likely to undergo a dramatic and extensive change at this time due to changes in body-image, and some studies have shown this to be the case.

Crawford and Unger (1995) record a drop in self-esteem at puberty in girls (who tend to gain weight at this time) related to dissatisfaction with appearance. Yet, an earlier study (Jones & Bayley, 1950) found a rise in self-esteem at puberty in boys, this difference between the sexes perhaps reflecting social values. Simmons and Rosenberg (1975) found lowered self-esteem to be more common during early adolescence than late
childhood or later adolescence, but in this study, this was more evident in boys than girls. The evidence for an identity crisis, therefore, seems to be somewhat inconsistent. Indeed, Offer, Rostov and Howard (1981) conclude that no increase in disturbance of self-image occurs during adolescence at all.

The variation in the findings may well be due to research problems including consistency and validity, as the notion of identity is a complex concept with different meanings to different people although, individual identity researchers have attempted to address this by operationalizing it within the terms set by their own theoretical framework. However, measures of self-concept and self-esteem in adolescents may also be confounded by a number of artefacts, such as the use of defence mechanisms if feelings are truly very strong, negative or unstable at this time. For example, the defence of reaction-formation (Freud, 1936), whereby conscious thoughts and feelings are the very opposite of unconscious thoughts and feelings, could destabilise any findings.

Other research has looked at the ‘storm and stress’ component of the classical picture. Rutter, Graham, Chadwick and Yule (1976) conducted a large study on the Isle of Wight and found hardly any difference in the number of 10-year olds (10.9%), 14-year olds (12.5%) and adults (11.9%) judged as having psychiatric disorders. They conclude that a substantial proportion of 14-year olds with problems had them since childhood, and only 20% of teenagers agreed with the statement ‘I often feel miserable or depressed’. Offer (1969) also found the large majority of adolescents adjust well to the transition of adolescence, are in touch with their feelings and develop meaningful relationships with significant others. Whilst these studies have their obvious merits, criticism might be that large scale surveys often fail to take into account that individual adolescents may not feel willing or able to reveal their innermost feelings, or that they prefer to use socially desirable responses. Also, that the picture may change as the social and historical context (including the expectations laid upon adolescents) alters.

Whilst not ignoring the limitations of research, there does seem little empirical support for the classical picture of adolescence as a time of identity crisis, storm and stress, and
there seems to be little support for the notion of a generation gap. Whilst there certainly does appear to be some change in self-esteem during adolescent years, there seems to no real evidence to suggest higher levels of distress or loss or function than at other times. From the clinical point of view, there is certainly a dramatic change in the nature of psychiatric disorder in adolescents, but the rate of prevalence does not substantially increase (Rutter & Rutter, 1993). Childhood disorders such as bed-wetting, fears and phobias tend to decrease, whilst substance abuse, eating disorders, schizophrenia, parasuicide and depression tend to increase. This is a vital consideration for Counselling Psychologists as twin studies suggest that emotional distress can often trigger genetically based disorders.

So, in the light of the evidence, how can we reconcile the empirical data indicating large stability and well-being in adolescence, with the classical picture? Coleman & Hendry (1990) see the truth as lying somewhere between the two versions. The consider that most of the data is based on clinical data giving a distorted picture and drawing conclusions from a-typical patients. Furthermore, they believe that because certain adolescent behaviour such as drug-taking and vandalism is very threatening to adults it is given disproportionate and sensationalised attention by the media. Coleman & Hendry propose that whilst classical theories all contribute to our knowledge and understanding, and still retain some relevance, what additionally is required is a theory of adolescent normality.

Focal theory (1974, 1978, 1979, 1980), based on a study of 800 boys and girls at ages 11, 13, 15 and 17, provides just this. Participants were given a set of identical tests dealing with image, being alone, heterosexual relationships, parental relationships, friendships and large group situations. Findings indicate that attitudes towards all these issues change as a function of age, but more importantly, concerns about different issues peak at different ages for both sexes. That is, at different ages particular sorts of relationship patterns come into focus and are most prominent, but no pattern is specific at one age only. Patterns overlap and there are also individual differences, so that just because an issue is not a predominant feature of a particular age does not mean that it will not be
critical for some individuals. This indicates that in order to adjust to so much potentially stressful change, and to do so with relative stability, the adolescent copes by dealing with one issue at a time. In other words, they spread the process of adaptation over a span of years, attempting to resolve first one issue and then the next. Different problems and relationship issues come into focus and are tackled at different stages, so that the stresses resulting from the need to adapt to new modes of behaviour are rarely concentrated all at one time. From this it can be concluded that those who, for whatever reason, have more than one issue to cope with at a time, are more likely to develop problems (Coleman & Hendry, 1990).

Implications for therapy

There has been an overwhelming amount of empirical support for focal theory (Kloep, 1999; Goossens & Marcoen, 1999) across social and cultural situations (Kroger, 1985) and it has generally been regarded as an important contribution to the theoretical framework for understanding adolescence (Siddique & D’Arcy, 1984; Meadows, 1986). Focal theory also has important implications for Counselling Psychology. By providing an understanding of how most adolescents cope successfully with the numerous pressures placed upon them, it enables us not only to see how things might go wrong, but also how we might help. Knowing that an overload of personal issues, or issues tackled prematurely, is likely to lead to difficulties allows us to think in terms of therapeutic strategies. For example, whilst approaches that employ the humanistic core conditions and directly address issues of self-esteem are likely to be very helpful, those which also focus on cognitions and identifying, prioritising and targeting specific problems, in conjunction with planning and evaluating behaviour, may potentially be more useful. Group work may also be beneficial in providing insight and support and ‘normalising’ adolescents’ difficulties, and also offering strategies for relieving stress and coping. Family therapy could be a further useful option, addressing dynamics, communication issues and frustrations within the family system, and thus helping to reduce the number of issues that the adolescent may have to tackle once.
Conclusion

In conclusion, it can be seen that there is little empirical support for the classical picture of adolescence, as described by those such as Freud, Erikson, Benedict and Meade, as a period of conflict storm and stress. Some evidence does indicate a drop in self-esteem in early adolescence, but this is a far cry from the classical picture which tends to be reinforced by the media. To some extent adolescence can be conceptualised as a social construct and the pressures and values of Western society are certainly likely to cause difficulties beyond those of biological change. A large issue contributing to the picture is the enormous change in the nature and severity, although not prevalence, of clinical problems in adolescence.

Focal theory makes an important and practical contribution to the study of adolescence. It provides a new and more hopeful perspective and a framework enabling us to see how the vast majority cope by focussing on one major issue at a time. This has important implications for Counselling Psychologists in practice as it allows us to see where and how problems might arise, and to devise appropriate therapeutic interventions, such as cognitive behavioural or family therapy, to improve functioning and well-being. Altogether, this more positive picture of adolescence which has emerged, may prove to be infinitely more use to us in relieving distress, preventing serious disorder and bringing about personal change, than the classical picture of inevitable conflict and turmoil. Furthermore, it may also be an indication that the adolescent period represents more of a problem for adults, than it does for adolescents themselves.
References


Introduction

This essay outlines Kohut’s ideas regarding personality development, places them in context with classical psychoanalytic theory, and describes how they help our understanding of the development of disturbances in a person’s sense of self. This essay also evaluates the usefulness of the therapeutic concepts proposed by Kohut, namely the mirroring and idealizing transferences, with illustrations from my own clinical practice.

Self Psychology

Heinz Kohut (1913-1981) was an eminent psychoanalyst who deeply admired Freud and his work. Owing to difficulties experienced within his own practice, Kohut gradually became critical of some aspects of Freud’s theories and began to reinterpret these and develop ideas of his own. His very original ideas were considered highly controversial and received much criticism from the psychoanalytic community, and many from orthodox orientations rejected them entirely. Despite this, his ideas have also received considerable acclaim and been heralded as providing a significant advancement in psychoanalysis.

Kohut’s ideas focus primarily around understanding and explaining the development of the self and its impact on the person’s mental health within the context of human interactions. ‘Self Psychology’, as these ideas have come to be known, arose directly from Kohut’s difficulties with Freudian theory, in particular the libido theory. According to Freud, individuals are driven by sexual and aggressive instincts to gratify their urges on various targets, usually other people. However, Kohut’s theory proposes that individuals do not seek relationships with other people primarily to gratify these instinctual needs, but that these needs are secondary to a basic need for human
relatedness. Whilst Freud also considered pathological behaviour to arise from frustration and repression of these sexual and aggressive instincts, Kohut in contrast believed that it is threats and damage to the self, which produce aberrant sexual and aggressive behaviour.

Whilst Kohut’s views regarding the development of personality were rather different from Freud’s, he remained at pains to explain that fundamentally his theory of the self represented an extension to, or an enrichment of classical theory, rather than a replacement. Both men shared the view that the infant has no sense of self, being unaware of any differentiation from its environment. Freud considered the infant cannot tell it is separate from the person who holds and feeds it, and all its psychic energy, or frustration and desire, is directed at this undifferentiated self. He termed this initial human position the stage of primary narcissism, deriving the concept from the Greek mythological story of Narcissus, the handsome youth who spent his time gazing lovingly at his own reflection in a pool. Freud considered the infant gradually overtime begins to realise the existence of others, firstly the primary caregiver and then those in the outside world. Slowly more and more of its psychic energy becoming directed outwards away from the self until a state of object-relatedness is achieved. According to Freud, the more complete the shift of energy away from the self, the more healthy the person, and by adulthood little energy should be concerned with self-issues.

Kohut’s view however, was somewhat different. He proposed that whilst Freud’s view of increasing differentiation towards a mature capacity of object-relatedness remained valid, a second important strand of development occurs in parallel. That is, the development of the self, a process which Kohut believes to extend throughout the lifespan of the healthy individual. Whilst Kohut agreed the infant does indeed start off in a state of primary narcissism, or blissful self-love, it is from this point his ideas begin to diverge. Before proceeding though, it is important to establish a meaning of object-relatedness.
Object-relations theory places object-relations central to psychoanalytic theory and treatment, however, there are a number of different meanings of object-relations which vary between models. For Freud, an object refers to a target of the instincts, that is sexual or aggressive drives, and thus an object can be another person, a part or parts of a person, or a thing. Importantly, for Kohut objects are defined as other people, either internal or external to the person, and may be real or imagined. Whilst external objects are real people, internal objects are mental representations of people or things that exist within the self. For this reason, Kohut termed them self-objects because the individual experiences them as an integral part of the self. Self-objects generally denote psychologically important people who support the cohesion of the self, by helping regulate the tensions and stresses that arise which the individual is incapable of handling for his or her self. Thus in infancy these self-objects are most likely to be parents or primary caregivers who respond to the baby’s needs for warmth, food and comfort; in childhood also friends, relatives and teachers, and in adulthood partners and political or religious leaders.

It can be seen, therefore, that for Kohut the need for self-objects lasts throughout the lifespan to aid us with the problems and difficulties that confront us, and also that somehow these self-objects must be gradually transformed and integrated into our personalities so that we can act in psychologically healthy ways.

From the primary narcissistic position, within Kohut’s thinking, the infant slowly begins to develop a sense of self through the interactions and ministrations of those taking care of it. Through the positive interactive processes of care, support and love the child comes to develop a core or nuclear self. Whilst Freud’s psychosexual theory of development describes oral and anal fixations arising from sexual frustrations at this early stage, Kohut attributes these fixations to the child’s defensive efforts to cope with damage to the nuclear self that has been caused by un-empathic care giving.

Kohut places strong emphasis on the nature and quality of early care-giving, as well as social interaction, for the development of a healthy, or non-pathological self. He considers that should an infant not receive sufficiently responsive care-giving, it is likely
to establish a grandiose self involving the unconscious belief that he or she is perfect, in order to try to restore the original state of perfection. Individuals with grandiose styles of thinking and behaviour belong to one of the subgroups of disorders relating to disturbances to the self. This particular category, that of the narcissistic personality and behaviour disorders, has been a major focus of Kohut’s work leading to an extremely useful framework for therapeutic intervention as well as for conceptualisation. His work also sheds light on other pathological and important disorders of the self, namely psychosis and the borderline states, but the important questions which arise are what exactly is it that Kohut considered to be so essential during development for a strong and healthy sense of self, and how might things go wrong?

The mirroring transference

In Kohut’s view, three strong needs must be fulfilled in order for the self to develop fully. That is the need to be ‘mirrored’, the need to idealize and the need to be like others, and each of these concepts has important implications within the therapeutic transferences. The need to be mirrored is the way in which parents fulfil what Kohut termed the grandiose-exhibitionist need, that is the need to be made to feel special, wonderful and welcome. This is done through very subtle cues of gesture, expression and tone of voice, in other words, the way in which parents take delight in their child, and in particular the way in which the mother empathises with her baby’s needs and reflects, echoes and confirms his or her sense of greatness (Kohut & Wolf, 1978). However, clearly no parent or caretaker can immediately respond with optimum warmth and positive attention at all times, owing to such factors as tiredness, preoccupation or distraction, and for Kohut this creates an important situation for the infant. As long as this failure to mirror does not happen too often or too traumatically, the infant learns to draw on the memory, or internalisation, of the positive experiences with the parents and learns to survive without the mirror, at least for a brief time.
What infants gain from this experience is the belief and understanding that for short periods they are able to mirror themselves, achieved through a process Kohut termed ‘transmuting internalization’. This he considers to be an extremely important stage of development and one necessary to curb the infant’s unrealistic grandiose and exhibitionist needs. In other words, in healthy development of the self, parents or caretakers provide empathy and warmth in conjunction with optimal frustrations to facilitate transmuting internalizations, leading to the ability to mirror or respond positively towards the self. Also, through these gradual frustrations, in conjunction with love and support, parents help set realistic limits on the infant’s actual abilities and talents. This process of transmuting internalization allows the infant to ‘decathect’, or discharge, some of the primitive narcissistic libido from the grandiose self and invest it in a new emerging psychic structure, that of the more independent nuclear self. In summary, according to Kohut one of the keys to healthy maturation, or the transition from primary narcissism to the nuclear self, is phase appropriate and gradually limited self-object support.

Children who have been well-mirrored know they are likeable and attractive, in spite of any messages they may receive to the contrary from the outside world. They no longer ask or care whether they are the most wonderful one of all, as their self-esteem has already been firmly established in infancy. Children who have not been well-mirrored, owing to their parents or care-givers own psychological difficulties, are likely to have had their grandiose-exhibitionist needs traumatically frustrated. This may lead to repression owing to the pain of acknowledging their needs and the belief that they will never be gratified, which in turn prevents these needs from being integrated into the personality, leaving them split or walled off from the ego. For example, a boy insufficiently empathized with and mirrored by his mother may seek to ward off feelings of inadequacy by fixating on his grandiose-exhibitionist self and acting as if everyone is his slave and under his control, becoming bossy, throwing tantrums, and even hitting his parents. A girl with similar unfulfilled needs, may fantasise in a grandiose way that she is precious and insist that she has the most fashionable clothes and jewellery, later becoming almost totally absorbed with her self and her appearance, and affecting her relationships with others. Both these people are likely to continue to experience feelings of worthlessness
and insecurity with occasional bouts of unrealistic grandiosity and boasting when their unfulfilled needs for mirroring briefly break through into consciousness, thus demonstrating their stunted sense of self.

The idealizing transference

According to Kohut, mirroring is not the only strong innate need which must be fulfilled in order to establish a strong nuclear self. There is also a need for an ‘idealized parent imago’, that is a need to identify with and idealize a strong, calm, admired and knowledgeable self-object. This is in order to restore the balanced state of primary narcissism, disturbed by the shortcomings of parenting or when the external world becomes too confusing or threatening for the immature ego to cope with. Kohut considered girls tend primarily to idealize mothers and boys their fathers (Kohut, 1977). However, the most important point is that the infant has a seemingly omnipotent self-object which, again through optimal frustration and transmuting internalization, they can consolidate into a cohesive self-structure or nuclear self, in order to gain the confidence to cope with the difficulties of the external world. The outcome of successful internalization of an idealized parent imago is largely the ability to soothe and comfort oneself when painful events occur producing anxiety, guilt or shame; to gain realistic ideals and to develop the mature aspects of personality such as humour, empathy, creativity and wisdom. Those who have not had the opportunity to develop this part of the self, perhaps having had parents who constantly denigrated each other, are likely to exhibit little vitality or joy for life.

The third need Kohut deemed important for the developing self is the need to be like others, or the alter ego need. That is, for the child to know they share important characteristics with one or both parents in order to develop a sense of belonging and prevent a sense of being different. Whilst little has been written about this need in the development of the healthy self, because Kohut originally considered it to be part of the mirroring process, it is helpful to bear in mind when considering certain transferences.
Kohut's ideas concerning the development of the self are extremely helpful for understanding how disturbances of the self may occur, and also provide useful classification depending on the nature and severity of the problem. Interestingly, for Kohut parental pathology, such as depression or paranoia, plays a major role in the aetiology of disturbances to the self and he does not discount a biological basis. He considers psychosis to be the result of extremely serious and protracted damage to the self, and when few defence mechanisms are available. In schizophrenia for example, he considers the nuclear self to be disorganised and chaotic due to biological and constitutional factors, in conjunction with a lack of joyful and empathic responses to the child's existence and assertiveness, and the lack of opportunity to merge with an idealized self-object (Kohut & Wolf, 1978). Therefore, Kohut believed that in such major disorders the parents might have failed to meet both the need to be mirrored and the need to idealize.

The second subgroup of disorders consists of the borderline states where again the nuclear self is in a state of functional chaos, but the sufferer is able to prevent total collapse into psychosis through the use of complex defence mechanisms. For example, among the borderline states are the schizoid personality disorder whereby individuals achieve emotional distance from others through emotional coldness and flatness, and the paranoid personality disorder whereby this is achieved through hostility and suspicion.

The third subgroup consists of the narcissistic personality and behaviour disorders, all associated with fundamental issues of self-esteem relating to early parental responsiveness and idealization. Kohut described four types of narcissistic personality disorder, the understimulated self; the fragmenting self; the overstimulated self and the overburdened self, each relating to difficulties such as grandiose styles of thinking, hypersensitivity to criticism and over reactions to failure, which interfere with effective interpersonal functioning. Kohut also listed several narcissistic behaviour disorders including mirror-hungry, ideal-hungry, alter-ego-hungry, merger-hungry and contact-
shunning personalities. Whilst the first three disorders are relatively mild, the last two are considered much more serious types of psychopathology (Wolf, 1988).

Clinical practice

Kohut's ideas about the way in which the self and disturbances of the self develop, arose from a fundamental but important question he applied to each of his clients. 'What is it that this person has not received from their parents?' He then asked 'What can a therapist do about it?' From this second question, and based on the findings from the first, Kohut devised the therapeutic concepts of the mirroring and idealizing transferences. Whilst in classical psychoanalysis transference revolves around unfulfilled sexual and aggressive conflicts, in self psychology the disturbances relived are usually not sexual in nature, but caused by damage to the self in early childhood. On this basis, it is extremely useful in the therapeutic encounter, if therapists ask themselves Kohut's same original questions.

In the mirroring transference, clients relive early experiences in which the mother or father failed to mirror them, and seek to be validated by the therapist's approval. In the idealizing transference clients relive early experiences in which their father or mother failed to fulfil their needs for a comforting protective figure and see the therapist as an admired and powerful figure who will help them and protect them. In the alter-ego transference clients seek the comfort and acceptance from the therapist that their own parents failed to provide. In my own practice I have encountered clients whose personalities and behaviour seem to demonstrate each of these transferences. For example, a female client, who was anxious and depressed, had experienced her single mother as very irritable and withdrawn. She constantly appeared to be seeking my approval and reassurance, as well as my opinion, particularly about what I thought of her, and this suggested that her experiences had resulted in a weakened 'nuclear self'. It seemed as if she lacked the ability or confidence to rely on her own judgement and to 'self-soothe', and thus required from me the warmth and attention of being mirrored,
which I tried to provide through empathy and careful use of my expressions and tone of voice.

These three types of transference are particularly helpful when therapists are able to respond appropriately, remaining non-critical, non-defensive and tolerant, having worked through their own unresolved narcissistic disturbances and counter-transference needs. If the transferences are successful, the therapist will be drawn into these narcissistically pathological situations where they will gain better empathic understanding of their clients and will be able to offer explanatory interpretations about the origin of the pathologies (Kohut, 1971). These transferences allow clients to build self-structures not built when a child, through the process of transmuting internalizations, resulting in a more cohesive and autonomous self.

**Conclusion**

In conclusion, Kohut’s very original ideas regarding parent-infant interactions and what he terms the transmuting internalization of self-objects, provide an extremely useful framework to help us understand the development of disturbances within a person’s sense of self. The therapeutic concepts of the mirroring and idealizing transferences feel intuitively ‘right’, fitting well with Franz Alexander’s notion of psychoanalysis as a corrective emotional experience (Kahn, 1977). Kohut’s work also emphasizes the importance of empathy, favoured by many other theoretical orientations, not as an equivalent to sympathy or compassion but as a tool to collect accurate objective data about the inner subjective state of the person. In doing so, Kohut highlights the point that the classical therapist’s lack of empathy may in practice fuel a client’s narcissistic difficulties. Altogether, Kohut’s ideas are comprehensive, highly heuristic and have useful applied value. They represent an enormous shift in classical psychoanalytic thinking and have stimulated extensive debate and research whilst making important contributions to understanding the development of psychopathology relating to the self and issues of transference within the therapeutic process.
References


Cognitive Behavioural Therapy: Theory, philosophy and the therapeutic relationship

Introduction

This essay outlines the theory and philosophy relating to Cognitive Behavioural Therapy (CBT), and describes the background from which it emerged. It highlights the importance of the therapeutic relationship, discusses how difficulties within the relationship might arise and be conceptualized, and provides illustrations from my own clinical practice.

CBT is a comparatively recent development in psychological treatment, but has been found to be particularly helpful across a wide range of disorders. It works to address the dysfunctional thoughts and feelings associated with many clinical problems, in order to change the manifesting maladaptive behaviours. CBT is sometimes considered to bridge the gap between purely behavioural methods and the dynamic psychotherapies, and, unlike many other ‘talking’ therapies, is underpinned scientifically and thus amenable to evaluation and clinical trial. It is the most widely and confidently accepted form of therapy today, dominating both practice and research around the world (Orlinsky et al., 1994).

Background

Early behaviour therapy utilized experimentally established principles of learning for the purpose of changing unadaptive behaviour (Wolpe, 1958). Namely classical conditioning (Pavlov, 1927) and operant conditioning (Thorndike, 1898), and on the basis that ‘faulty learning’ lies at the heart of many disorders, and can be ‘unlearnt’, these two orthodox conditioning principles gave rise to a number of therapeutic behavioural techniques. For example, systematic desensitization (SD) (Wolpe, 1961) - based on the notion that it is impossible for two opposite emotions, such as anxiety and relaxation, to
co-exist at the same time, and flooding, whereby prolonged exposure to the stimulus leads eventually to extinction. Both these methods have proved useful in the treatment of phobias and obsessions, although Marks (1973) proposed that it is not the inhibiting effect of relaxation on anxiety that works in SD, but the exposure itself, which allows a person to disprove any predictions that something awful will happen. In keeping with this, Williams and Hargreaves (1995) suggest that the grading of exposure in SD helps build up the person’s confidence to cope with the exposure, and this method is often used within the CBT framework today. Behaviour modification, based on the reward principle, is still commonly used with those with learning difficulties and children with autism (Lovaas et al., 1967), as are Token Economies within psychiatric hospitals and therapeutic communities (Davidson & Neale, 1994). However, these methods have been subject to ethical scrutiny, and praise and attention by the therapist have emerged as more useful methods of reinforcement and highlighting the central nature of the therapeutic relationship.

By the 1970s, behaviour therapy was the treatment of choice for many disorders and links began to be made to physiology with the aid of biofeedback techniques. Later, those such as Rachman and Hodgson (1974) proposed that psychological problems could be conceptualized in terms of loosely linked behavioural, cognitive/affective and physiological response systems which accounted well for the wide range of symptom patterns reported by patients. At the same time, work began to look at those for whom behavioural treatment had failed (Foa & Emmelkamp, 1983), particularly those experiencing symptoms of depression, and ideas concerning cognitive variables began to evolve. In particular, Bandura’s (1965) work on observational and social learning (modeling) drew attention to the informational and motivational aspects of reinforcement, as well as cognitive factors and the processes between stimulus and response, such as memory and attention. This lead to the proposal of a model of self-control (Bandura, 1974) generating explicit cognitive constructs including attributions and self-instruction, and a model of self-efficacy (Bandura, 1977) mediated by subjects’ perceptions of their ability.
Accordingly, those such as Mahoney (1974) and Meichenbaum (1977), pointed out that because behaviour is largely controlled by the ways in which we think, the most logical and effective way of trying to change maladaptive behaviour is to change the maladaptive thinking that lies behind it. Meichenbaum (1975) was then perhaps the first to propose a cognitive approach to therapy, which generated interest amongst behavioural researchers, and started to link the two concepts together. Drawing on Bandura’s work, and known as self-instructional training, it suggested behavioural change brought about by altering the instructions patients give themselves, away from upsetting, maladaptive thoughts, to more adaptive self-talk.

However, despite the 'cognitive revolution' in psychological theory and research, the now very influential cognitive therapy of Beck (1970, 1976) took much longer to become generally accepted. Similar in many ways to Rational-Emotive Therapy (Ellis, 1962) which cites irrational thoughts as the main cause of emotional distress, it also drew upon Kelly’s (1955) Personal Construct Therapy which aimed to change a client’s way of construing the world in order to make better sense of it, and make more accurate predictions, through collaborative questioning and testing with the therapist. Initially, Beck’s cognitive therapy was applied mainly to depression, as the negative thinking characteristic of the disorder seemed to be more than just a symptom, playing a central role in its maintenance. Beck (1967) proposed that depression originates from attitudes and assumptions laid down in childhood, resulting in a vulnerability to cognitive distortions and automatic negative thoughts, creating a vicious circle of negative thought about the self, the world and the future, known as the cognitive triad of depression. Thus he considered that if the ‘faulty thinking’ (or maintaining mechanism) could be identified collaboratively with the therapist, it could be replaced by collecting evidence against it.

Whilst purely cognitive approaches have been widely employed, it was the successful treatment of panic disorder (Clark, 1986) that truly welded the cognitive and behavioural approaches together. CBT has since been found to have wide applications, being helpful in conditions difficult to treat in other ways. For example, eating disorders; obsessive
disorders; sexual and marital problems; anxiety; somatic difficulties and some aspects of chronic mental illness.

**Philosophy**

Underpinning CBT, are also a number of rationales drawn from early philosophies. For example, Epictetus (200 AD) wrote 'people are disturbed not by things, but the views which they take of them' (Loeb, 1989), and Buddhism espouses the maxim that 'freedom from suffering occurs through disengaging from our thoughts and observing them with neutrality'. Based upon this range of theory and principles, CBT today is grounded in the following assumptions. Firstly, that we need to learn to distinguish between what we can and cannot control. Secondly, that we need to understand that our response to a situation depends upon our attitudes and not upon the situation. Thirdly, that attitudes are learnt and, therefore, can be unlearnt, or changed, and fourthly, that it is not an event or situation that causes distress, but our beliefs about it.

**Theory**

CBT is phenomenological in as much as it looks at the view of the self and it's relationship to the world. Much of the treatment focuses on the opportunity for new adaptive learning and is based in the 'here and now' with an assumption that the main goal is to help clients bring about changes in their lives outside the clinical setting. Problem solving is an integral part of treatment and all aspects of therapy are made explicit to the patient with whom the therapist works in a collaborative manner. Together they strive to identify problems and plan strategies within a structured, goal-orientated and time-limited framework. CBT uses a combination of cognitive and behavioural procedures to help the patient identify and change the targeted maintaining mechanisms. Commonly used treatment procedures include the presentation and personalization of the relevant cognitive theory of maintenance; the use of behavioural 'experiments' to help
clients try new ways of behaving and to help them test their expectations of the consequences of behavioural change, and the systematic identification and evaluation of dysfunctional thoughts and assumptions.

In order to understand the origin of a client's problems, the therapist assesses thoughts, moods, behaviours, biology and environment, which are all interlinked and, therefore, partly influencing each other. However, the emphasis is on identifying and evaluating the thoughts maintaining dysfunctional mood, and on behavioural change. Each emotional state, regardless of origin, is accompanied by characteristic patterns of thinking. For example, anger is often accompanied by thoughts of unfairness and violation, and anxiety by thoughts of danger and vulnerability. By helping clients to identify, evaluate and change dysfunctional patterns of thinking, therapeutic changes in mood and behaviour can occur, which may in turn help clients change their environments and lead to biological shifts.

Three levels of cognition are addressed in the cognitive component of CBT: automatic thoughts, underlying assumptions and schemas, or core beliefs. Automatic thoughts are considered to be the stream of unplanned and unreasoned thoughts, as well as images, words and memories that flow in a constant stream through the mind throughout the day, and are quite specific and difficult to turn off. Underlying assumptions, whilst not consciously articulated, are the rigid and conditional rules or beliefs that guide expectations and behaviour. They tend to be over-generalized and relate to achievement, acceptance and control, and whilst active in situations relating to individual specific vulnerability, are often culturally reinforced. Schemas represent a person's core beliefs about the world, the self and others, developing early on in life in relation to the environment and relationships with carers, thus acting as filters for the processing of all other stimuli (Beck et al. 1979). Early maladaptive schemas tend to be activated by events resulting in high levels of affect and are highly resistant to change. These three levels of thinking are intrinsically linked, with schemas giving rise to underlying

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1 Schema Therapy, evolved from CBT, distinguishes between Schemas and Core Beliefs, considering the former to be more deeply ingrained than the latter and established at an earlier preverbal stage (Young, 1990, 1999).
assumptions and determining the nature of automatic thoughts. For example, a schema of "everyone always leaves me" perhaps based on an early relational loss might lead to an underlying assumption such as "if I’m not perfect, no one will love me" giving rise to automatic thoughts such as "I’m failing, I’ll be all alone".

Understanding the interplay between levels of thought and moods, behaviour, physical functions and environment is central to CBT and forms the basis for case conceptualization (Beck, 1995), or understanding upon which work is based. Importantly, case conceptualization is developed in a collaborative manner with the client, highlighting the need for a warm, empathic, genuine and trusting therapeutic relationship. Criticism of CBT in the past has been that it is too mechanistic, fails to take account of the therapeutic relationship and pays too little attention to interpersonal and environmental variables (Safran & Segal, 1990). However, those such as Beck et al. (1979) and Goldfried (1982) emphasize the intrinsic importance of a positive therapeutic alliance to facilitate change within the CBT model. Because CBT is a self-help model encouraging independence in problem solving, it is also important that the therapist is open, straightforward, curious and transparent, and that interventions are demonstrably linked to the case conceptualization. Conceptualization is derived directly from information provided by the client in sessions and can therefore be used to make predictions about the outcomes expected for interventions and experiments, and provide ideas for how goals might be achieved.

CBT employs a number of specific techniques to examine and shift errors of thinking. In particular, guided discovery is an important method based on Socratic questioning2, which allows the therapist to ask a series of questions in such a manner as to elicit information outside the client’s current awareness, thus helping to discover alternative meanings. In other words, rather than simply pointing out information that contradicts a depressed client’s negative beliefs, the therapist aims to elicit from the client an alternative perspective which they find credible. For example, “How have you reached

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2 Socratic questioning aims to provide illumination by answering a question with a question until the respondent comes to their conclusion through heightened awareness.
this conclusion?” “How could you look at the situation differently?” or “Is there any evidence to suggest that this interpretation isn’t 100% true all of the time?” Importantly, the therapist must listen carefully and empathically not only to what the client says, but also to what they do not say, in order to identify faulty thinking.

Other cognitive techniques used to examine and modify thinking include the introduction of a daily thought record to heighten awareness of links between thought and behaviour; use of a decision matrix to weigh up the costs and benefits of ways of thinking; rating scales to assess and heighten awareness of perceived levels of emotion; methods of distraction to interrupt maladaptive thought processes; downward arrow exercises to expand ideas and meaning, and imagery to unfold experience in order to identify and challenge beliefs.

Behavioural techniques include activity-monitoring schedules to provide information about what might be maintaining current symptoms, and also guide future activities and rate the pleasure they produce. Relaxation training, such as paced breathing for anxiety management; behavioural rehearsal to help explain, clarify and practice more effective communication and coping skills, and behavioural experiments to challenge dysfunctional assumptions and core beliefs and test the validity of automatic negative thoughts.

*The Therapeutic Relationship*

Whilst the CBT model, along with its techniques, can be highly effective, it still remains largely dependent on the therapeutic relationship and the skill and characteristics of the practitioner. Beck et al. (1979) stress that “the aspiring cognitive therapist must be, first, a good psychotherapist” (p. 25) and emphasizes the need for therapists to be sensitive to and skillful in dealing with transference reactions. I found this important aspect of CBT particularly significant in my own clinical practice within a specialist eating disorders service. In this setting, many clients presented with co-morbid difficulties such as
depression, alcohol and substance misuse, self-harming behaviour and personality disorder. Many reported chaotic early histories, and often seemed hard to engage and resistant to change. Therefore constant monitoring of transference and countertransference feelings was vital in order to develop awareness of the nature of their early schemas, and form a therapeutic bond.

Whilst much of the treatment in this setting was based upon Fairburn’s (Fairburn et al., 1993) cognitive behavioural model of maintenance for bulimia nervosa\(^3\) (whereby cognitions relating to low self-esteem and over-evaluation of shape and weight and associated behaviours are addressed), I found Fairburn’s transdiagnostic model for theory and treatment of eating disorders (Fairburn et al., 2003) especially helpful. This proposes that in certain patients, one or more of four additional maintaining processes interact with the core eating disorder maintaining mechanisms, producing obstacles to change, namely, clinical perfectionism, core low self-esteem, mood intolerance and interpersonal difficulties. This model seemed to fit particularly well with my own experiences of clients, highlighting the difficulties in keeping these often complex clients engaged, but also providing understanding and direction for change.

In light of this, I was particularly mindful of how an individual’s schema established during early childhood can interfere with the therapeutic relationship. I paid special attention to the way in which they arrived for therapy (were they sent by someone else, did they have a history of cancellation or numerous previous therapists?); the way in which they presented in sessions (with hopelessness, restlessness or reluctance to talk, or with a tendency to ‘all or nothing’ thinking) and the associated transference and countertransference feelings (such as uselessness, rejection or a desire to ‘over-feed’).

According to Bowlby (1969, 1980), early schemas relate to the ability to survive; the reliability of caretakers; abandonment and direct physical danger to the self. As an infant’s helplessness can only be overcome by secure attachment to a love object, any

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\(^3\) An interlinked cycle of low self-esteem; over-valuation of eating, shape and weight and their control; strict dieting and other weight control behaviours; binge eating; compensatory vomiting or laxative misuse (Fairburn, 1993).
disturbances during this early phase would be expected to affect future information processing, making them vulnerable to threats of abandonment or survival. Thus, a person establishes an object concept, or schema, with an associated system of attachment behaviours, which serves as a prototype for interpersonal relationships, which becomes manifest in the therapeutic relationship. In my own practice, early attachment difficulties were seen not only in these clients’ personal lives, but also in the high number of DNA’s and cancellations, demonstrating their ambivalence towards me as the therapist, as well as the therapy and change.

Whilst I questioned and explored clients’ maladaptive schemas when they become manifest in the therapeutic relationship, it is important to remember that some ambivalence can also be accounted for within the framework of Prochaska and DiClemente’s (1986) model of stages of psychological change. For example, it can be conceptualized as their having been in the “contemplation” stage, and this reflects uncertainty that was addressed throughout the therapy. However, in order to elicit understanding of a client’s underlying schema I sometimes would say “You said you are not sure about coming here and feel embarrassed about having these problems and reluctant to talk about them. I wonder what thoughts you are having about this. Could you complete the following sentence? I feel uncomfortable talking about this because I think ……” This would produce responses such as “no one will love me if they find out” and “you’ll think I’m completely useless” reflecting core schema of being rejected or unlovable. Having identified these, the work was then to address the underlying assumptions and automatic thoughts, using a range of CBT techniques, particularly collaboration, and being mindful to stay in the role of scientific observer (Beck et al, 1979).

‘Homework’ compliance is an important part of treatment in the CBT model, and when asked to complete Food/Mood diaries, some clients had a tendency to either make them ‘perfect’, by being beautiful written, although devoid of cognitions and feelings other than ‘hungry, and guilty’, or they failed to comply, making excuses or changing the subject. I would address the ‘perfect’ writing with praise, being mindful of the client’s
low self-esteem, but also use guided discovery or downward arrow exercises to elicit understanding that 'content', or 'what's inside' is also important. In relation to non-compliance, I also used a 'cost and benefit' technique, to increase the client's awareness and motivation after exploration of the underlying levels of cognition (which often included fear of failure and thus rejection). Whilst CBT models for eating disorders stress the need for therapists to be firm and authoritative with regard to homework and psychoeducation, collaboration and the ability to instill hope are also key factors.

Beck et al. (1990), however, highlight the fact that a collaborative therapeutic relationship is often taken for granted, and note that problems such as 'non-compliance', 'resistance' and 'negative transference' are commonplace in clients with interpersonal problems (Beck et al. 1990). This observation seems particularly salient to the type of difficulties encountered in the eating disorders setting, but these 'difficulties' can be seen as rich sources of information, and thus, 'vehicles for change' (Safran, 1998). On this basis, Safran (1990a) proposed the integration of cognitive therapy into interpersonal therapy and suggested the concept of self-perpetuating 'interpersonal schema' (Safran, 1990a; Safran & Siegal, 1990). These are presented as a generalized representation of self-other relationships, and this fits well with previously described ideas relating to attachment theory (Bowlby, 1969; 1980). Significantly, these interpersonal schemas are seen as interactional, and not just evaluations of the self and environment, and it is suggested that they invite an 'action tendency' or 'hook' which pulls others into responding to them in schema confirming ways. This has been described as a 'cognitive-interpersonal cycle' (Safran, 1990a; 1998) or 'schema maintenance (Young et al. 2003) whereby, for example, somebody who views their self as unlovable is more likely to experience others as rejecting (Safran & Siegal, 1990). Thus, Safran (1990b) sees the therapeutic relationship as the ideal arena for clients to address interpersonal schemas and to test out hypotheses, expectations and beliefs, allowing them to experience new ways of relating to others. Young et al. (2003) describe this as 'limited re-parenting' whereby the therapeutic relationship "provides a 'corrective emotional experience' specifically designed to counteract the patient's Early Maladaptive Schemas" (Young et al., 2003, p182).
Young et al. (2003) also highlight the fact that the idea of triggering of Early Maladaptive Schemas in the therapeutic relationship is similar to Freud’s concept of transference, whereby the client “is responding to the therapist as though the therapist were a significant figure form their past” (p.179). In this way it can be seen how the cognitive-interpersonal, or schema approaches acknowledge the importance and usefulness of these mechanisms. This allows the therapist to consider that which may be triggering their countertransference, and can be more cautious of responding in counter-therapeutic, or schema-confirming ways (Scaturo, 2002). Whilst this model goes someway to reconciling the psychodynamic and cognitive models, it does not, however, take into account the importance of therapist’s own schemas. This aspect of the relationship is addressed in part by work by Rudd and Joiner (1997) who proposed a Therapeutic Belief System framework for identifying the client’s and the therapist’s belief system about the client. They consider that the client’s beliefs about the therapist can lead to viewing them on a continuum from victimizer to collaborator to saviour. The client will also view them self on a continuum from victim to collaborator to caretaker. Thus, therapists can then see clients as victims or aggressors, responding accordingly as an aggressor, saviour or victim, which is a useful consideration particularly when working with clients who have received inadequate or abusive parenting.

Conclusion

In conclusion, it can be seen, that whilst CBT has evolved over time as an empirically based, popular, reliable and effective method of treatment, like other approaches, much of its effectiveness relies upon the nature and understanding of the therapeutic relationship, and its use as a vehicle for change. This aspect is particularly salient when working with clients with interpersonal difficulties and maladaptive interpersonal schema, and recent models allow for the integration of useful concepts from other approaches. In all forms of therapy, the overall quality of the therapeutic bond is a strong predictor of outcome (Orlinsky, Grawe & Parks, 1994), and this is particularly important point to remember when attempting to master the wide range of techniques specific to the CBT model.
References


Therapeutic Practice Dossier
Introduction to the Therapeutic Practice Dossier

This dossier relates to my therapeutic practice. It contains brief descriptions of the three clinical placements that I undertook during training, the client populations and my professional activities. In addition, it also includes a Final Clinical Paper, which aims to provide an overview of my development as a Counselling Psychologist, and give insight into how I engage with theory, research and practice. It describes my developing awareness of different aspects of the therapeutic relationship and my movement towards integration, and also discusses my own use of personal therapy.
Clinical Placements

Year 1: NHS Primary Care Service

My first year placement was in an NHS Primary Care setting, based in a small health centre on the outskirts of London. The service received referrals from General Practitioners within the health center and from a small practice nearby, and also from the district nurses and health visitors. The service consisted of one part-time chartered Counselling Psychologist linked to the Psychology department in the Trust, who was psychodynamically orientated, and provided me with weekly supervision.

The service offered brief interventions (usually 6 - 12 sessions) and the client group spanned a wide range of ages, social classes and ethnic backgrounds. Presenting problems were diverse, ranging from panic disorder, alcoholism, bereavement and depression, to post-traumatic stress disorder, personality disorder and the early onset of psychosis. As a result, the service had an important role in terms of assessment and decision-making concerning the referral of clients to appropriate services, as well as therapeutic intervention.

My responsibilities involved conducting assessments, making referrals and providing individual psychological therapy. I also wrote assessment and discharge reports for each of the clients I saw, and liaised with other professionals. The placement did not offer any opportunities to attend meetings.
Year 2: NHS Psychotherapy Service

My second year placement was within an NHS Adult Psychotherapy Department situated in an economically strong semi-rural area near London. The service received referrals from General Practitioners, Psychologists, Community Psychiatric Nurses, Social Workers, and Consultant Psychiatrists working in other settings. The service was staffed in all by twelve people, a Consultant Psychiatrist and Psychotherapist, a Psychotherapist, two art therapists, one group therapist, six trainees and a medical secretary, and had a waiting list of up to six months. The service provided individual or group interventions, including group psychotherapy and art therapy, and offered long-term, psychodynamic orientated therapy.

The client group was pre-dominantly white British and spanned all social classes. Clients presented with a range of relatively enduring presenting difficulties including depression and anxiety, interpersonal and sexual difficulties and issues arising from life events such as loss and bereavement.

My responsibility was to conduct long-term psychodynamic therapy with individual clients who had been assessed by the Consultant Psychotherapist. I had the opportunity to observe a number of assessments conducted by the Consultant Psychotherapist, from whom I also received my weekly supervision. The placement did not offer the opportunity to attend meetings.
Year 3: NHS Specialist Eating Disorders Service

My third year placement was in an NHS Eating Disorders Specialty Team, based in an affluent semi-rural town in the South East of England. The service accepted referrals from Trust-wide Community Mental Health Teams only, and treated those with moderate to severe disorders. The team consisted of a Consultant Psychiatrist, a locum staff grade Psychiatrist, two psychodynamic psychotherapists, a Clinical Psychologist, a specialist Eating Disorders Dietician, a trainee Counselling Psychologist, and a medical secretary.

New referrals were discussed fully by the entire team at bi-weekly Allocations meetings and prioritized and allocated according to need. The client group was predominantly young white female, from a range of social classes, presenting with anorexia and bulimia nervosa, and binge eating disorder. Most clients had co-morbid problems such as depression and relational difficulties, and some also had self-harming behaviours, addictions, obsessions or compulsions, and issues associated with their personality.

After several opportunities for observation, my role was to conduct both individual assessments, and joint assessments with the psychiatrists, and to contribute to the decision-making regarding appropriate therapeutic input. Also, to provide individual Cognitive Behavioural Therapy for between 10 and 40 sessions, where deemed appropriate. In addition, I planned and conducted a Cognitive Behavioural Therapy group for mixed eating disorders, with the specialist Eating Disorders Dietician as co-therapist. I attended and contributed to all bi-weekly Allocations and Team meetings, and attended monthly Psychology Department meetings and monthly Adult Mental Health Team meetings organized by the Trust, when possible. I liaised with other members of the Eating Disorders Team on an on-going basis, and occasionally with other professionals where appropriate.

I attended Care Plan Assessment meetings for some of my clients, and wrote assessment and discharge reports for them all. I used a number of psychometric tests, both before and after treatment with each client, in order to evaluate treatment. I attended weekly
supervision with the Consultant Clinical Psychologist, and conducted a statistical analysis to evaluate my group work, and co-authored a paper on the subject for submission.
“So when I sit down with someone, I take my troubles and feelings and I put them over here, on one side, close, because I might need them. I might want to go in there and see something. And I take all the things that I have learned – client-centered therapy, reflection, focusing, Gestalt, psycho-analytic concepts and everything else (I wish I had even more) – and I put them over here, on my other side, close. And then I am just here, with my eyes, and there is this other being.” Gene Gendlin (1989).

Introduction

This paper describes and reflects upon my evolution as a Counselling Psychologist, being mindful that I am still very much engaged in the process, and yet to consolidate my professional identity. I aim to discuss the ways in which my training and experiences have contributed to my development to date, and look at how I have learnt to integrate learning from theory and research, as well as the use of my self, into my clinical practice. I shall begin by describing how I arrived at the course and my understanding of what it means to be a Counselling Psychologist, and then give an account of my training and exposure to the core models taught on the course, namely, the Humanistic; Psychodynamic and Cognitive Behavioural models. I shall illustrate each of these with clinical examples and highlight my learning from clients and supervisors, as well as my own personal therapy.

The Challenge

I came to the course as a mature student and mother with a newly acquired degree in Psychology, but no experience whatsoever of working in mental health or related
services. Having often assumed a helping role within various contexts, and spent most of my life working independently with children and horses, I had however, developed a strong sense of relationship and awareness of ‘being with’ the other. I was also aware that I had developed an empathic and intuitive way of listening and thinking about others and interpreting different behaviours, difficulties, strengths and needs. For me, therefore, the biggest challenge of the course has been to learn how to reflect upon the processes involved in this and to articulate, or make explicit, my reactions and understanding. Also, to explain the ways in which I arrive at the interpretations and conclusions that I do, and then evaluate these. I feel that over time, these skills have gradually emerged through the use of theory, research, supervision, feedback, reflection upon ethical, social and contextual issues, and personal therapy. Also, the help and challenges of my family, clients and peers have been very helpful, although at times painful, and I now recognize this complex process to be the essence of my ‘becoming’ a Counselling Psychologist. Like Bion (1975), I see this as a lifelong task, and understand that my learning will constantly be mediated and updated by experience.

Personal Therapy

I consider that my ‘becoming’ a Counselling Psychologist started long before I arrived on the course, and part of this process involved the personal experience of having had therapy. At one or two difficult times in my life, when I have felt I needed greater understanding, I have sought therapy and had some very different experiences. The first ‘therapist’ I encountered simply left me alone with a relaxation tape and, needless to say, I did not return. From this experience, and after finding a new practitioner, I was able to discover what it is that I feel makes a ‘good enough’ therapist (and one that I have aimed to model myself upon). This transpired to be one who is ‘present’, genuine, warm and empathic and able to frame their challenges within a supportive and collaborative context, thus facilitating heightened self-awareness, learning and personal change. Much like a ‘good enough’ parent, or teacher.
From seeking therapy at the right time, I also learnt how very useful and powerful, as well as at times difficult, it can be. However, when I engaged in therapy on the basis of a requirement of the course, I experienced things in a rather different way. It seemed that at that stage, when there was so much going on and I was trying to make sense of and assimilate a tidal wave of new information, 'the time was not right' for me. Whilst I was able to reflect upon why this might be, it gave me valuable insight into how futile it might be to try to work with someone who feels they have been 'sent' to therapy. It also allowed me to experience psychoanalytic therapy, and conclude that this particular approach is not 'right for me', either as a client, or a therapist, and some of the reasons why this might be. Later, with more awareness of the demands of the course and my own clinical practice, and having identified aspects of my self and my experiences that I wanted to explore, I entered therapy again, this time with a therapist using an integrative approach, which I found particularly useful. I learnt a great deal more about my self, my conflicts, feelings and ways of thinking and relating, which was useful in many areas of my life. I found it particularly helpful in learning to tease apart what is mine and what might be my clients', in order to reduce the chances of my acting to serve my own needs rather than theirs, whilst feeling supported in the venture.

Upon reflection, this experiential understanding of what it is like to 'be a client', or 'having been on the receiving end' has been helpful in several ways. Not only has it provided me with a good model, it has also allowed me to examine my own feelings and fears arising from work with clients in practice, which in light of the notion that the therapist can only take a client as far as he/she has gone themselves (Rowan & Jacobs, 2002), has been very important.

*Understanding the Nature of Counselling Psychology*

Looking back I think my formal interest in psychology began when by chance I read 'The Divided Self' by R. D. Laing, which described the 'meaning' of mental illness, and described the development of a person's schizophrenia within the family context. I found
this both intriguing and stimulating, and began to read more and more. When I was later taught on my first day as a psychology undergraduate that the best predictor of treatment outcome is the quality of the relationship (Spinelli, 1994), I felt my path was set. I then began placing one foot slowly and tentatively in front of the other on what seems to have been a very long, and at times, exhausting journey. I started by undertaking mainly clinical courses during my first degree and learnt to appreciate that theory must inform practice, however, I remained unhappy with the traditional medical model whereby practitioners are seen as 'doing' something to the 'patient' to 'cure' some kind of 'illness' (Woolfe, 1996), perhaps because I dislike having things 'done' to me.

As my understanding and awareness developed, I discovered that my viewpoint was consistent with the philosophy of Counselling Psychology, which places the uniqueness and diversity of each individual at the center of practice and stresses the primacy of the therapeutic relationship. This relationship is characterized by the humanistic, or person-centered conditions of empathy, congruence and unconditional positive regard (Rogers, 1951), whereby the helper is viewed as working in collaboration with the client to facilitate growth and development of the individual's potential, quality of life and well-being (Maslow, 1968). I found that this doctrine felt intuitively 'right' for me and was thus very appealing. Whilst this perspective is clearly not unique to Counselling Psychology, it is the additional promotion of self-reflection and self-awareness on the part of the therapist, as well as the links between theory, research and practice, or the 'scientist-practitioner' model, which seemed to set Counselling Psychology apart (Woolfe, 1996). Indeed, in light of my own experiences of therapy and my awareness of the importance and increasing need for greater understanding and accountability in therapeutic work (O'Brien & Houston, 2000), it seems to me that these factors constitute essential components of 'best practice'. This is not to say, however, that I have not at times struggled at length with each one of these aspects, particularly when seeking to integrate them into my own evidence-based work. Through trying to constantly update and modify my learning and understanding, and through making mistakes, I have learnt how to be more flexible in my thinking and more open to alternative ideas, and also, to recognize and let go of old ideas, or ideas that no longer 'work' for me.
Integration

Clarkson (1998) considers that the integration of theories, concepts or techniques is 'more a verb or a process, than a product or end result' and that 'any good, competent and growing counselling psychologist is always integrating themselves whether between or within 'schools', their professional and life experiences or between themselves and the learning they forge in the relationship with their clients' (p.260). Strieker and Gold (1993) also see integration as a process, an open-ended and constantly evolving set of methods and constructs influenced by new ideas and information with, at its core, the needs and goals of each individual client within their own specific context. This viewpoint fits well with my own, whereby I consider that therapy should be client-led, with work evolving from 'being with' the person and a sense of 'not knowing' (Casement, 1991), rather than a fixed idea about 'doing to'. At the same time, it seems equally important to have, and be mindful of, up-to-date knowledge of the evidence-based usefulness of different theoretical approaches and techniques, particularly in relation to specific types of difficulty. Furthermore, to have the ability and flexibility, as well as the judgment, to be able to draw upon, or integrate these when and where appropriate. The development of such techniques and skills seems to me to be an ever-evolving process, necessary to try to meet the needs of each complex and individual client, in an ethical, informed and accountable fashion, and is something I shall constantly strive to achieve.

In my own practice, I place the development of a good therapeutic relationship at the center of my work, and take a holistic view of each client. I look at them as an individual, and try to conceptualize the unique pattern of their emotions, beliefs and cognitions associated with their inner world, within the context of their social, cultural and economic environment. This has been particularly important and helpful in my work with clients with eating disorders owing to the, often complex, nature of their difficulties. From working with these particular clients, and by being open to my mistakes - which they have been quick to let me know about, I have learnt an enormous amount, and with the help of supervision and my colleagues, I have developed the ability to 'stand back'
(by not ‘trying so hard’) and to integrate aspects from different models into the work. I always aim to learn from my clients and attempt to understand their subjective experiences and constructions of reality within a useful theoretical framework focusing primarily on wellness, development and growth. In keeping with the ethos of Counselling Psychology, I feel more comfortable engaging with them as a collaborator (Strawbridge & Woolfe, 2003), rather than the ‘expert’. However, this has not always been easy, particularly when I have been with clients who have a tendency, or ‘need’, to idealize. Over time, I have learnt to manage this by placing myself ‘alongside’ the client, in order to see things and acknowledge them from their point of view, and then ‘moving back’ to help gain and offer alternative perspectives, and thus providing ‘optimal frustration’. I find that the use of this ‘movement’, which is an ongoing process, helps me to engage clients and to overcome the sense of ‘being stuck’ that can arise when positions, roles or communication within the relationship become static.

The Therapeutic Relationship

As previously emphasized, Counselling Psychology places the relationship at the heart of the therapeutic enterprise, and I agree with Rogers (1951; 1961) who suggests that the therapeutic relationship can provide the conditions for personal growth across therapeutic models. According to Norcross and Goldfried (1992), it is the properties of the client, the therapist and their particular relationship, which determines more than any other factor, the effectiveness of psychological therapy, and I believe this is true. Kahn (1991) goes so far as to propose ‘the relationship is the therapy’ (p. 1) and whilst I agree that the relationship is central in determining the outcome of therapy, as supported by the research (Spinnelli, 1994), and that ordinary human relationships can have therapeutic value, I do not consider that the client/therapist relationship alone is necessarily sufficient. I see it more as the core, or main constituent of a theoretically and ethically informed therapeutic encounter, which as a common factor may account for the failure to find significant differences in outcome of psychotherapy between different theoretical approaches (Lambert & Bergin, 1994; Stiles, Shapiro & Elliot, 1986; Smith & Glass,
Over time, however, and by working within different models, I have come to see that the relationship with clients can have many different facets.

Clarkson (1995), in seeking to describe the ‘betweenness’ of people describes five different types of relational modality and writes: ‘relationship or the interconnectedness between two people has been significant in all healing since the time of Hippocrates and Galen’ (p.29). One modality that I have become increasingly interested in is the transpersonal relationship, which refers to the spiritual dimension of the therapeutic relationship (Gendlin, 1967), which may be because of my intuitive nature. This, I have discovered, is noted within the Jungian tradition (Jung, 1969) and the humanistic/existential perspectives (Rowan, 1983) where there is ‘acknowledgment of the influence of the qualities which presently transcend the limits of our understanding’ (Clarkson, 1995, p.41). Clarkson writes ‘the essence of the communication is in the shared silence of being-together, in a dimension impossible to articulate’ (p.43) and this phenomenon is one I have often encountered in both my own practice and my work with autistic children associated with my research. It appears to me to be a very pure and heightened sense of ‘truly being with’ or ‘alongside’ a person, and ‘doing’ or ‘having done’ something together. It is a sense of ‘us’ within a shared moment, producing a form of mutual spiritual connectedness that transcends language, and one that I feel is very healing. I have a sense that this may relate to what Trevarthen (1977) terms intersubjective communication, or intersubjectivity, which he highlights as a vital occurrence within the mother-infant dyad, and at times I wonder if my experience as a mother, particularly as a mother of a child on the autistic spectrum, has contributed to this awareness of non-verbal attunement with ‘the other’. It certainly feels to me to be something very natural and very special. My thoughts about this aspect of the therapeutic relationship give me a sense of having come full circle, and an appreciation of what it was that attracted me to the course and this type of training, in the first instance.

The process of developing explicit awareness of different aspects of the therapeutic relationship, untangling them and placing them within theoretical frameworks has been at times both a struggle and a triumph for me, and constituted perhaps the most invaluable
part of my learning and 'becoming' a Counselling Psychologist. It has enabled me to reflect in an informed way and with far greater personal awareness upon 'how' and 'why' I am 'being-with' a client in the manner that I am, and in what way this might or might not be helpful to them.

**The Scientist-Practitioner**

Whilst the therapeutic relationship is clearly central to the therapeutic process, it is obvious that much about its nature, as well as that of the intervention process, still remains unknown, or unconfirmed. This is perhaps partly due to the difficulties associated with the traditional 'scientific' methods of investigation, whose mechanistic views do not lend themselves well to exploration of the therapeutic encounter. Counselling Psychology has sought to address this difficulty by demonstrating the usefulness of using qualitative research methods in addition to quantitative ones. In this way, and by using open-ended interviews, or compiling case studies in addition to simply administering questionnaires, it has become possible to get far closer to aspects of the therapeutic process than before. Furthermore, by combining qualitative with quantitative techniques, it is possible to demonstrate and employ a truly pluralistic approach. In my own work, I have found this combined technique to be extremely interesting and productive, with the 'science' evolving from participants, rather than being done to, which again fits with my own philosophical stance, whereby the individual remains the 'expert' on them self.

**Integrating and Learning from Research**

Whilst I agree with Wilson & Barkham (1995), that 'psychotherapy practitioners are continuously employing, monitoring, evaluating and testing hypotheses at the moment-to-moment level with individual clients' (p.50), I feel that it is also important to conduct research on a more formal, or observable basis too. Importantly, I also agree with the
perspectives of Palmer (2000), who considers that 'conducting research is part of constructing one’s own professional identity and having one’s own voice' (p.339), and McLeod (1997) who argues that involvement in professional writing and research is a key aspect of a counsellor or therapist's development. Certainly, I feel that my own research ideas have evolved alongside my personal development and training as Counselling Psychologist, and added to my sense of 'who I am'.

The direction of my research was set in motion before I started the course, by my reaction to hearing the term 'refrigerator parent' (Kanner, 1943) used to describe the parents of children with autism. Whilst it made me very curious, it also made me rather angry, as it seemed to me to be potentially short sighted and unjust. Aware that this term still lingers, particularly amongst professionals, and wondering why this might be, I conducted a literature review in my first year, which highlighted the fact that there have been almost no studies to establish the parents' perspective. On this basis, in my second year I undertook a qualitative study, and using my counselling skills, conducted a series of taped open-ended interviews with parents of children on the autistic spectrum which I then subjected to interpretative phenomenological analysis (Smith, 1996, Smith, Flowers & Osborn, 1997, Smith et al., 1999), an analytic method commonly used to 'explore in detail the participant's view' (Smith et al., 1999, p.218). It is a method particularly suited to the ethos of Counselling Psychology as it is significantly influenced by social-interactionism, trying to see how individuals make sense of their experiences, rather than attempting to produce an objective statement about them, whilst recognizing the dynamic interaction between their phenomenological account and the researcher's interpretation.

Whilst using this method resulted in the study feeling very much my own, and perhaps the most exciting and rewarding investigation I have ever carried out, interestingly, writing it up transpired to be incredibly hard. In the first instant, I felt overwhelmed by the amount of words I had to contend with, particularly as participants stories seemed to pour out as if they were 'uncorked', which in itself seemed to show a strong need to have their 'bottled-up' perspective heard. Secondly, in order to make the work truly phenomenological, I had started with no conceptual framework in mind, which made
things even 'harder for me to digest'. Knowing that I have tendency to become very 'blocked' in my thinking when 'too much is going on inside my head' and I feel as if I am being pressured, and using my learning from previous experiences, I 'stepped away' from the work for a short while, putting it aside in order to allow my thoughts the opportunity to start flowing freely and spontaneously again. I was then able to see quite easily what I wanted to do and in keeping with the psychodynamic approach I was using at the time, decided to interpret the findings within an Object Relations theory framework. I was struck by the similarity of the themes that arose from the data, and so on the basis of Marshall (1998) who describes illnesses such as depression as 'learned patterns of socially deviant behaviour or idiosyncratic thought that (result) from stress, powerlessness and isolation' (p.67), (themes which arose again and again), in my third year I decided to investigate these aspects further, using quantitative methods. Again, much to do with this study fitted naturally well with the cognitive-behavioural model which I working within at that time, and thus, I can see how my learning from theory and practice has informed my research, and hope that my findings from research might go some way to informing my practice.

*Learning from Practice*

I have, perhaps, done the majority of my 'real' learning within my placements, which I feel highlights the void between intellectual learning and experiential learning, much like why 'telling' someone 'how' to 'get better' is never sufficient. I also think that I have often learnt more from what I have found difficult and what has 'gone badly' (and my reaction to it and the ways I find to cope), than from what has been easier and 'gone well'.

For example, in my first year, I undertook a placement within an older adult specialty team, where I was to use a humanistic approach. This is based on the notion that individuals have an inherent need for, and drive towards, growth and self-fulfillment, or self-actualization, and given the opportunity and appropriate conditions, the healthy,
although hidden self (organismic self) will emerge (O’Brien & Houston, 2000). Whilst the placement was interesting and entirely of my own choice, I began to find things increasingly difficult, particularly as most of my clients were in-patients and very ill and several of them died. Although aware on an intellectual level that I needed to be able to ‘step in and out’ of the client’s world, I started to feel generally (and oddly) helpless, confused, angry, fearful, isolated and unwell, and unfortunately, due to my total lack of experience and perhaps not wishing to appear ‘unsuccessful’ or ‘unable to cope’, I tried to deal with these unusual feelings by myself. In addition, I found that I could not discuss them even with my psychoanalytic therapist, perhaps because he too was in his 80s and it did not seem ‘safe’ and consequently, aspects of my learning and coursework began to suffer. As a result, I took some time away from the course, but still certain of wanting to become a Counselling Psychologist, started therapy with a new (younger) therapist. Here, by looking at my experiences and examining my feelings and making links, I learned to tease things apart and came to understand the ‘true’ meaning and extraordinary power of ‘transference, counter-transference and projective identification’, and how to identify it. I also learnt more about myself and how through my self-sufficient tendencies, I had let this situation arise.

Although overall, the whole experience was difficult and unpleasant, I think it taught me some of the most useful and essential of things I needed to know. Now I find I am unable to be with any client without thinking about all aspects of the relationship, and also checking carefully how I feel myself, and identifying what is and what is not mine, both in and out of the room. The experience also taught me the importance of therapeutic work being client-led, rather than prescriptive, and also how to use personal therapy and supervision effectively. This involved learning to be more open and reflective, even with the most difficult thoughts and feelings, and prepared to examine these and aspects of my self, at any time.
Year 1

I returned to re-start the course, feeling far more 'like myself' and whilst eager to use my new understanding and self-awareness, I was also anxious and aware that my confidence had been badly shaken, and I realized I had to 'look after myself' by being more open when I encountered difficulties. I undertook a new psychodynamic placement in an NHS primary care setting, which offered brief interventions (6 – 12 sessions) where, under the guidance of a chartered Counselling Psychologist I was able to begin working with a range of clients and presenting difficulties. These included men and women, both young and old experiencing symptoms of anxiety, panic, agoraphobia, depression, post-traumatic stress, bereavement and low self-esteem. Later, as my skills developed and through good use of supervision, I learnt to identify clients with personality disorder, addiction and the onset of psychosis within the assessment process, and how to effectively refer these clients on to specialist services. At times this was rather scary, and sometimes I felt out of my depth, but by being open about these feelings in supervision, I learnt how to use them effectively. Using person-centered skills, and again through the use of supervision, I started to develop psychodynamic understanding in situ and then began learning how to make interpretations based on links between how the client presented, the difficulties they brought to therapy, my responses and reactions, and the theory. Although I knew about the theory behind this, I found actually thinking and 'being' in this way extremely difficult at first, but gradually found myself warming to its possibilities.

I was also, however, encouraged to use psycho-education and cognitive-behavioural techniques for panic disorder, which I found worked well, and this added to my confidence. On this placement, my supervision was well structured, informative, supportive and consistent, and yet also challenging and flexible. This provided me with an excellent model for the future, and with fair and positive feedback, my confidence began to re-emerge, which again felt like good experiential learning.
As I began to expand my recognition and understanding of the transference/counter-transference relationship (Clarkson, 1995) and the corresponding ways in which clients relate to themselves and others, I became able to integrate the theory. I started thinking about my clients in terms of attachment theory (Bowlby, 1979) and developmental stage (Erikson, 1980), as well as ego strength (Freud, 1936) and mechanisms (Klein, 1946) and levels of defence. Furthermore, I discovered object relations theory to be a particularly helpful and salient way to think about clients’ difficulties (and over time this has become a very useful conceptual tool). However, I also found trying to integrate so much theory into practice at this stage still very difficult, and upon reflection I was perhaps ‘trying to do too much at once’.

Kohut’s (1971) self-psychology, however, proved invaluable in bringing together for me the humanistic and psychodynamic approaches, as it emphasizes both the therapeutic relationship and transference as central, with empathy used as the main therapeutic tool. Mrs. S., a very large, thirty-two year old married woman with a young son, was referred to me due to chronic anxiety, panic and sleep problems, as well as ‘pain and tension in her jaw’. It transpired that she attributed her difficulties to problems with noisy neighbours, rather than her troubled relationship with her husband and early experiences of violence and poor parenting. She seemed to have an immature personality and used ‘splitting’, ‘projection’ and ‘denial’ as defences against her underlying feelings of vulnerability, anger, fear and helplessness.

In the sessions, I often felt confused and helpless, as well as wary and anxious, which with the help of supervision and my previous experiences, I was able to identify as projective-identification and this enabled me to gain a sense of what it was like to be ‘in her shoes’, which helped me to empathize (Winnicott, 1949). Mrs. S. also tended to ‘idealize’ me, which I understood in terms of the ‘idealizing transference’ (Kohut, 1971), which at times made me feel very irritable and ‘stuck’. Her account of her early experiences suggested that her needs for comfort and protection remained unfulfilled, and indeed, her marital difficulties had been triggered by her husband’s ‘failure to protect her’ from the neighbours, and it seemed that she saw me as a powerful and admired figure.
who could help and protect her. Whilst I understood this, I had not yet gained sufficient skills, or perhaps confidence, to ‘work’ with this transference, and often felt unusually naïve, clumsy and inadequate, which was very uncomfortable. I coped with this by seeing that whilst these feelings were partly my own associated with being a trainee, they also represented something of her. However, I was able to provide warmth and encouragement in response to her need for validation and approval in the ‘mirroring transference’ (Kohut, 1971), which for this client seemed considerably better than nothing.

Year 2

In my second year, I undertook a psychodynamic placement in an NHS adult psychotherapy department where, under the supervision of a consultant psychiatrist/psychotherapist, I was able to offer five (quite difficult and emotionally demanding) clients, with a range of difficulties, weekly therapy throughout the year. I found this placement very informative and supportive, and felt that by being able to offer longer-term therapy, I was given the space and time to develop my reflective and practice skills. Here I gained good experiential learning about object relations theory (as I was very much ‘the bad object’ to Mrs. Jones, my client diagnosed with borderline personality disorder, particularly towards the end of the placement when it seemed I would ‘abandon’ (Masterson, 1976) her), as well as the reparative and transpersonal relationships (Clarkson, 1995). I also learnt to start working with dreams, fantasies and unconscious wishes, as well as the ‘idealizing’ transference. At first this all seemed very daunting, and I relied heavily on theory and supervision, but over time as my skills developed it began to feel far more natural and I gained confidence.

Mrs. A., a divorced woman with a teenage daughter, had been suffering from breast cancer and depression associated with the loss of her breast and the sudden death of her ‘perfect’ father. This client’s illness had caused her considerable financial hardship and sense of failure, and she found it almost impossible to ask others for help. Whilst her
depression was perhaps associated with her intense feelings of loss (Freud, 1927), she also tended to use ‘splitting’ (Klein, 1946) as a defence, projecting all the ‘bad’ into some people (or objects), and all the ‘good’ into others (including myself). Her idealization of me resulted in unusual feelings of inadequacy, which again, I recognized as projective identification, and I wondered how long it could last. I sensed the presence of a harsh super-ego and found myself desperately wanting her to ‘ease up on herself’ (or perhaps me) and ‘have some fun’. Whilst the stress of her situation may have brought about a ‘retreat to the ‘paranoid-schizoid position’ (Klein, 1957), on the basis of her experiences at the hands of an abusive mother, it seemed that this was perhaps a habitual way of operating. By working with both the ‘mirroring’ and ‘idealizing’ transferences (Kohut, 1971), using warmth, reflection and interpretation, and also bringing into her awareness her need to be ‘perfect’ or be ‘punished’, it seemed as if the split between her ‘all good’ father and ‘all bad’ mother was reduced and she was able to see both ‘good and bad’ in each. This appeared to result in a greater ability to ask for help, a less punitive relationship with her own daughter, and an improvement in her mood and behaviour. Thus, with the help of supervision and by using empathic interpretation, containment (Bion, 1962) and mirroring, I tried to provide a developmentally reparative relationship (Clarkson, 1995). Supervision and personal therapy was particularly important for me whilst seeing this client, as at times her difficulties tapped into some of my own fears resulting in feelings of sadness and an intense desire to help.

Whilst occasionally I was aware of the transpersonal relationship with Mrs. A., this way of ‘being with’ became a feature of my work with Mr. P., a very large, highly intelligent 56-year old man with a disabling stammer, and chronic anxiety and depression. As a child he had witnessed his violent alcoholic father (who later committed suicide) trying to murder his mother. He too tended to ‘idealize’ me and interestingly, whilst unable to speak to anyone else at all, spoke freely to me, believing I had some ‘special training and understanding’. I struggled with this for a while, but through supervision came to recognize that this particular client needed to attribute these qualities to me in order to feel ‘safe’ enough to communicate, which was vital for him, and I came to feel more at ease. However, during one session he stammered so badly he could not talk at all. It
transpired that he had brought to show me his only photograph of his father, an enormous, frightening looking man. He sat by my feet (much like a child) as we looked at the picture and talked about it together, and this was one of the most powerful therapeutic encounters I had experienced so far. From then on we would often sit in peaceful 'companiable silence' and I came to realize that this client had perhaps also struggled with Asperger's Syndrome throughout his life, and to just be able to 'be with' someone without fear, was therapeutic for him in its self. Supervision played a particularly important part with this client, as my first feeling when seeing him had been one of unusual fear.

At some point during this placement, I started to see a pattern. I realized that many of my clients seemed to idealize me, and I started to see that this might be associated with my hesitancy, through cautiousness, to make challenges. On this basis, I found I was able to be more proactive and take more risks, and this was an important and useful part of my development which resulted in feelings of greater competence.

*Year 3*

During my second year my confidence in my skills grew considerably. However, when I started my third year placement and had to change to the cognitive-behavioural (CBT) model, I felt unpleasantly 'de-skilled'. Whilst this was not entirely unexpected, I was surprised at how much I actually struggled to begin with, particularly as I have always used CBT techniques on myself. Specifically, I found it very difficult not to automatically conceptualize, respond to and talk about clients in terms of psychodynamic theory, and I began to feel 'silenced', under pressure and very 'stuck', which I recognize now as resistance. However, whilst I knew that given space and time this would change, a very simple but positive remark from one of the course team "come on, you should be good at this" suddenly 'freed me up'. This helped me to realize that this was a very powerful example of the usefulness of CBT, and I began to feel positive and re-invigorated and able to embrace the model.
Now, whilst I continue to find it useful to reflect upon clients' issues in terms of psychodynamic theory, I also find that I can 'think' and talk about their difficulties, as well as work effectively with them, within the CBT model. This fits well with my holistic philosophy, and gives me a sense of unity and competence, perhaps arising from the ability to now work both 'top down' and 'bottom up', resulting in far greater confidence in my skills.

In the eating disorders setting, emphasis is placed on the need to spend as much time as necessary engaging the client and developing the relationship (Beck et al., 1979), before proceeding to the first stage of the model, and my work with Ms. M. demonstrated this. Ms. M. seemed like 'very hard work' and I came to realize that this was how we were both experiencing CBT, and with the help of my colleagues I was able to recognize that my response was to try to 'over-feed her'. However, her underlying schemas of being 'useless' made it almost impossible to use the model and after learning from supervision that the approach has limited value with those with no academic attainment, I reverted to a more dynamic approach. I was disappointed and felt uneasy when this client eventually dropped out of therapy some time later, on the verge of revealing "something awful" she "did" as a child, and I had an unusual sense of 'failure'. I coped with through discussing it in supervision, rationalizing it and being philosophical.

The CBT model for eating disorders, could be considered integrative as well as holistic, and is unique in that it suggests that eating disorders should be seen on a continuum, rather than as discrete categories, and I found this particularly useful as a learning tool. On the basis of the model, my supervisor suggested that I conduct (with the dietician as co-therapist) a previously untried group for mixed eating disorders, with a view to writing a paper. At first my heart sank as this seemed very daunting, but after a considerable amount of hard work with both my supervisor and the dietician, the group eventually 'came together'. And I loved it. It was exhilarating and demanding and sometimes I was left feeling exhausted, as if I had just conducted an orchestra through a particularly fast and moving piece. The fact that the group was so successful, with all 8 members still present at the end of 13 sessions, felt like the most incredible achievement, and when I
evaluated the outcome and found statistically significant changes in mood, behaviour and beliefs I felt intensely gratified and rewarded. However, I am also acutely aware that the success of the group was mainly dependant on the *joint* skills of the dietician and myself, and our own good relationship and attunement, was perhaps the key.

I found this last placement particularly demanding, as I had to learn a range of new skills in addition to CBT, for example, administering, scoring and interpreting psychometric tests, and working jointly with other professionals. However, working as part of a team suited me well, and I was able to consolidate a great deal of my learning through the support and help of my colleagues.

**Conclusion**

In conclusion, this paper has tried to provide a glimpse of my journey towards ‘becoming’ a Counselling Psychologist. As I look back over my training and experiences, it is extraordinary to note what a varied and often difficult path it has been. As I have moved along, I have learnt not only about my clients, the practice, theory, and research, but also about myself, my strengths (empathy, warmth and perseverance) and my limitations (I can’t fix or know everything, and occasionally I make mistakes), and how to identify and be mindful of these. What I have particularly enjoyed is the sense of triumph and achievement that has come with discovering how to meet each of the many challenges I have encountered along the way. Now, as my doctoral training draws to a close, I realize that this is not the end of the route, but the beginning of another.
References


Research Dossier
Introduction to the Research Dossier

This dossier comprises of three reports, one is a literature review and two are empirical studies. There is a consistent theme relating to ‘autistic spectrum disorders’ running throughout the work, and this arises from my own experiences of having a child with this disorder. The literature review examines the history and research associated with autism, and suggests that children with an autistic spectrum disorder and their families are a group at risk of developing psychological problems. It also identifies ‘the parents’ perspective’, as a gap in the work. The second report, which is a qualitative study, was undertaken with the aim of bridging this gap, and investigates the experiences and associated thoughts and feelings of parents with a child on the autistic spectrum. The themes arising from the data suggest that parents experience a number of difficulties associated with their child’s disorder, and these issues are placed within an Object Relations theory framework and the implications for therapy discussed.

The third piece of work is a quantitative study investigating levels of depression and anxiety in parents of children on the autistic spectrum and examines their experiences, attitudes and locus of control. Comparisons are made with parents of children with Down’s Syndrome and a control group, in order to establish factors which are unique to this particular group. The results are considered within a framework of resource loss, and implications for Counselling Psychology are considered.

Each piece is written and presented in the format of an article suitable for submission to an appropriate journal, and notes for contributors are included.
Autism: Review of the History and Research and Implications for Counselling

Psychology

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Autism: A Review of the History and Research, and Implications for Counselling Psychology
Abstract

This report reviews the history and research literature associated with autism since its first description by Leo Kanner in 1943. It outlines both autistic disorder and Asperger's Syndrome, which are often viewed together as a continuum (called the autistic spectrum), and looks at similarities and differences between the two. It describes the main areas of difficulty, namely socialization, communication and imagination, which are known as 'Wing's Triad', and looks at a range of associated biological and genetic factors. Cognitive theories associated with autism, such as Theory of Mind are outlined and discussed. Issues relating to visual attention and intersubjectivity, and their associations with Attachment theory are highlighted, as is the possibility of a biological link. The report suggests that the difficulties associated with autism may cause psychological problems for both the individual and their family, and are therefore, issues for Counselling Psychologists. Direction for future research is suggested.
Keywords: Autism, Asperger, Parents, Attachment, Counselling Psychology
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Introduction

To review the literature on autism is a truly monumental task as books and articles relating to this mysterious disorder currently run into tens of thousands. The sheer volume of research gives some indication of the complexity of the problem, as well as the number of different approaches involved in the active search for understanding. This particular review, therefore, seeks merely to outline the direction of work relating to the subject, from its original description to the present day, and to highlight issues that might be relevant to Counselling Psychologists. It also aims to identify appropriate new directions for research. Having a child of my own with high functioning autism, or Asperger’s Syndrome, inspired me to undertake this piece of work, and therefore, may have shaped my selection and interpretation of articles, particularly those associated with aetiology and parenting, in which I was especially interested.

The Origins of Research

It would seem that the curious cluster of symptoms we now call autism (see Appendix A) has always existed. Folktales of odd, reclusive and naive individuals abound across all cultures, and stories of wild children unable to speak and respond to others have appeared throughout history. One of the most memorable, the tale of Victor the “wild boy of Aveyron” who was the talk of Paris society in 1800, is told in Truffuat’s (1970) film ‘Wild Child’. The word ‘autism’, derived from the Greek word ‘autos’ meaning ‘self’, was first used by Bleuler in 1908 to describe the withdrawal seen in adults with schizophrenia. However, autism as a specific syndrome was first identified in 1943 by Leo Kanner in a journal called The Nervous Child. This now classic paper entitled ‘Autistic Disturbances of Affective Contact’ still today provides one of the best introductions to the subject. It begins intriguingly,

“Since 1938 there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that
each case merits - and, I hope, will eventually receive - a detailed consideration of its fascinating peculiarities”. (Kanner, 1943, p.217).

The paper goes on to clearly describe eight boys and three girls who appeared to suffer from a baffling and previously undocumented disorder which Kanner names ‘autism’, because the strangest quality of these particular children seemed to be their total lack of interest in other people.

Defining the Disorder

Kanner captured virtually every symptom of autism recognized today, such as parroting others’ words, endlessly spinning, hours spent on ‘projects’ such as opening and shutting a door or arranging objects in a special or mysterious order, and indeed, fury when objects are moved or altered. However, as Dolnick (1998) points out, of greatest importance was the fact Kanner was not distracted by some of the apparently crucial differences between the children (p.171). Most notably, some had language and quite outstanding vocabularies whilst others had none, and some seemed to be retarded whilst others had the most extraordinary memories and cognitive gifts such as musical or mathematical abilities. What Kanner recognized as significant was the children’s apparent failure to use language as a means of communication and he felt that the unifying factor was the children’s sense of aloneness and “the children’s inability to relate themselves in the ordinary way to people and situations from the beginning of life” (Kanner, 1943, p.242).

This first paper on autism highlighted the following set of features deemed characteristic to autism: extreme autistic aloneness; anxiously obsessive desire for the preservation of sameness; excellent rote memory; delayed echolalia; over-sensitivity to stimuli; limitation in the variety of spontaneous activity; good cognitive potentialities and highly intelligent families. However, Kanner later isolated just two of these many features of
autism as the key elements - extreme isolation and obsessive insistence on the preservation of sameness (Kanner & Eisenberg, 1956).

Asperger's Syndrome

Remarkably, around almost exactly the same time but on the other side of the world, Hans Asperger (1944) published a dissertation concerning 'autistic psychopathy' in childhood. According to Francesca Happé,

"It has taken nearly 50 years for Asperger's original paper, 'Die 'Autistischen Psychopathen' im Kindesalter', to appear in translation in English (Frith 1991b). ..... Hans Asperger deserves credit for some very striking insights into autism: some insights which Kanner (1943) lacked and which it has taken us many years of research to rediscover". (Happé, 1994, p.11).

Whilst both Kanner and Asperger agreed on many features of the disorder which both men so strikingly named autism (thus reflecting their common belief that the child's social problems were the most important and characteristic feature of the disorder), there were three main areas where they disagreed. The first was that of language abilities, and whilst Kanner wrote: "As far as communicative functions of speech are concerned, there is no fundamental difference between the eight speaking and the three mute" (Kanner, 1943, p.243), Asperger contrastingly reported that all four of his cases spoke fluently with freedom and originality. With regard to motor abilities, Kanner noted clumsiness in only one of his cases and remarked on the dexterity of four, concluding all were very skilful in terms of finer muscle co-ordination. This contrasts sharply to Asperger's findings indicating all four of his patients were clumsy with difficulties not only in sports, but also in fine motor skills such as writing.

This feature forms part of a wider difference between Kanner's and Asperger's beliefs as Kanner considered the autistic child's impairments to be primarily social, having better
relations with objects, whilst Asperger believed his patients showed disturbances in both areas: "the essential abnormality in autism is a disturbance of the lively relationship with the whole environment" (Asperger, 1944, translated in Frith 1991b, cited in Happé, 1994, p.12). The third area of disagreement concerned the children's learning abilities. Kanner considered his patients learnt best by rote fashion, whereas Asperger thought his patients performed best "when the child can produce spontaneously" suggesting they were "abstract thinkers" (Asperger, 1944, translated in Frith 1991b, cited in Happé, 1994, p.12).

These differences between the two men's work have engendered considerable controversy and debate over the years, giving rise to the question: 'Were these two men really describing the same condition?' Some argument still remains as to whether there is an autistic spectrum whereby less impaired, or 'high functioning' autistic children fit the observations described by Asperger. Indeed, the term Asperger's Syndrome (see Appendix B) was first used by Lorna Wing (1981) in order to gain recognition for very able autistic children who do not fit the Kanner stereotype. Most authors consider that the variation of autism manifested across individuals does support the notion of an autistic spectrum, because whilst some children with autism do avoid social contact like Kanner's cases, others are merely passive or even actively social, though in a peculiar way (Wing & Gould, 1979; Wing 1988). However, it should be remembered that Asperger himself felt that the pattern of impairments he described occurred in both those of high and low intelligence, and this is an important point for Counselling Psychologists to remember when working with such clients.

**Wing's Triad**

In order to investigate whether autism is a true syndrome, rather than a cluster of symptoms that co-occur by chance, Wing and Gould (1979) conducted a large, and important study in south London of 35,000 children known to the social, health or educational services. They were able to conclude that handicaps in social understanding,
communication and imagination tend to co-occur in the same individual and do not simply arise together by chance in those diagnosed with autism. This triad of impairments, that is, problems with socialisation, communication and imagination (sometimes known as ‘Wing’s Triad’), are now considered to be the main, or core, characteristics of autism and form the basis of diagnosis today (Rutter & Schpoler, 1987). The other behavioural characteristics, as described by Kanner and Asperger are, therefore, considered to be typical of autism, but not universal.

At this point it is important to note that as autism presents with such a large degree of variation, it subsequently causes many difficulties for researchers and practitioners. This is because there still exists very little ‘purity’ of diagnosis and therefore, there is often little homogeneity between subjects. Indeed, up until the 1960s, the term ‘childhood schizophrenia’ was used interchangeably with autism and the two were believed to have strong links (Rutter, 1978). Whilst autism has since been shown not to be connected in any straightforward way with schizophrenia, and those deemed autistic are not especially likely to become schizophrenic, important authors such as Frith and Frith (1991) do consider there are certain similarities, mediated by the age of onset. However, this gives a clear indication that research has not been straightforward owing to diagnostic and sampling difficulties, as well as owing to the enigmatic complexities of the disorder.

In his seminal paper identifying autism, Kanner also quite naturally sought to provide an explanation for the symptoms he saw and as a result, made several observations which would prove to have serious long-term consequences. He wrote “All of our patients have come of highly intelligent parents .... in the whole group there are very few really warm-hearted fathers and mothers” and “ .... the question arises whether or to what extent this fact has contributed to the condition of these children” (Kanner, 1943, p.250). As Dolnick (1998) so critically points out, whilst these remarks at the end of a lengthy paper sounded almost casual, they were to become “the pivot of the entire autism debate” (p.176).
‘Refrigerator’ Parents

Despite having also observed in his original paper (1943) “the children of our group have all shown their extreme aloneness from the very beginnings of life” (Kanner, 1943, p.250), by 1948 Kanner appeared to have arrived at the almost certain conclusion that the behaviour of parents was to blame for the children’s difficulties. He wrote “Maternal lack of genuine warmth is often conspicuous” and “Many of the fathers hardly know their autistic children” (Kanner, 1948, p.387). Also,

"Most of the patients were exposed from the beginning to parental coldness, obsessiveness, and a mechanical type of attention to material needs only. They were the objects of observation and experiment conducted with an eye on... performance rather than with genuine warmth and enjoyment. They were kept neatly in refrigerators which did not defrost. Their withdrawal seems to be an act of turning away from such a situation to seek comfort in solitude". (Kanner, 1948, p.398).

This dramatic picture, painted by the now highly influential Kanner, of ‘refrigerator’ parents whose coldness and rejection were responsible for their children’s autistic symptoms, was to last a very long time and have devastating effects on many families. A sample of parents’ accounts can be found in Dolnick’s book ‘Madness on the Couch’ (1998) and as the author points out “The explanation would soon make its way - suitably modified by others - out of the medical journals and into the popular culture” (p.178). Critically, he also writes: “Against the wave of books and magazine articles preaching the new gospel, what chance did a mere mother have?” (p.178). It would seem, therefore, that as a direct result of Kanner’s observations and subsequent explanations, instead of being helped and supported, and their accounts positively attended to and respected as valuable sources of information for research, these unfortunate parents largely found themselves labeled, blamed and subsequently silenced.
The anti-parent message continued to be expounded widely. Another leading authority on autism, Bruno Bettelheim, published several influential articles including ‘Joey: A Mechanical Boy’ (1959) which also pointed an accusatory finger at a lack of parental love. By the time he published his famous book *The Empty Fortress* in 1967, Bettelheim had likened autistic children to prisoners in concentration camps whose only chance of survival was to vanish into the background, avoid eye contact and disappear into a private world of fantasy. He also wrote “I state my belief that the precipitating factor in infantile autism is the parent’s wish that his child should not exist” (Bettelheim (1967, p.239). Clearly, this was truly damning stuff for parents.

Anecdotal reports that some children had seemed ‘normal’ until around ten months but had then begun to deteriorate, also fuelled the poor parenting explanation. A somewhat different, but equally fault-finding account was proposed by Green and Schecter (1957) who considered autism to be caused by over-involvement by parents and excessive anticipation of the child’s needs. This, they believed, led to disturbance of the normal frustration-gratification cycle, resulting in a failure to develop normal symbolism and thus language. A third approach to explaining parental failure considered inconsistency to be the key, whereby parents were warm one minute and then rejecting the next. However, no matter what the explanation, parenting style continued to be deemed to blame.

*Supporting Ideas*

The notion that parenting style was responsible for autism soon came to be scientifically underpinned by the work of John Bowlby, the British Psychoanalyst who headed a project by the World Health Organisation to investigate the mental health of child victims of the second World War. In 1951 he published his seminal work *Maternal Care and Mental Health* which outlined the importance of maternal bonds and continuous care, factors still recognized today as vital to child development and long term mental health. Crucially, he wrote “mother love in infancy and childhood is as important for mental
health as are vitamins and proteins for physical health” (Bowlby, 1951, p.12). Bowlby’s work also stressed the instinctive nature of attachment and the importance of timing in attachment formation, factors both influenced by the discovery of ‘imprinting’ during a ‘critical period’, by the pioneering ethologist Konrad Lorenz (1935). However, whilst Bowlby never explicitly linked his ideas to autism, many others did, thereby lending weight to the expanding ‘refrigerator’ parent account.

Bowlby’s work also seemed to support the Freudian psychoanalytic concept of human development which describes the existence of uniquely formative periods for personality development and proposes that the first relationship acts as a model for all later relationships (Freud, 1933). As a result, psychoanalysis has often had a large part to play in the treatment of autism. Other influential work, such as that by Erikson (1950), proposed that through interaction with its mother the infant learns a sense of basic ‘trust’ or ‘mistrust’ of the world in general, or other people in particular. This also seemed to fit well with the common explanation for autism, as did memorable work by Harlow and Zimmerman (1959). Having conducted a series of experiments with monkeys, they were able to demonstrate that infant monkeys became attached to and preferred the ‘contact-comfort’ of a surrogate wire monkey ‘mother’, covered in soft terry-towelling, with a puppet face, rather than a plain wire monkey which provided milk. Their findings were considered to extend directly to human infants and contrasted completely with the ‘cupboard love’ theory of attachment dominant prior to Bowlby’s work which had taken the view that babies become attached to whoever feeds them. Therefore, Harlow’s results seemed to provide not only excellent support for the new idea that an infant’s primary need is for love, not food, but also for the enduring notion that autism could be caused by a lack of parental love.

It can be seen, therefore, that for many years whilst parents of autistic children were being held responsible for their children’s difficulties on the basis of observations, assumptions and interpretations by leading figures such as Kanner and Bettelheim, others such as Bowlby, Lorenz, Erikson and Harlow came to inadvertently propose ground-breaking theories which on the surface seemed to provide scientific evidence in support.
As late as 1971, Harlow, writing in the *Journal of Autism and Childhood Schizophrenia* still claimed families characterised by coldness, ambivalence, double binding messages and lack of physical comfort were likely to cause the development of infantile autism and Tinbergen, in 1973, whilst accepting his Nobel prize, gave a speech drawn from his earlier work (Tinberg, 1972), along much the same lines. The important question, therefore, is when, how and why did things begin to change?

**The Beginnings of Change**

When attempting to account for the belief that parents were at fault, according to Donellan (1985), it is important to remember that at that time there was almost no notion that psychology and neurology were linked, and that all the children with autistic symptoms were being examined by psychiatrists who were looking for psychological rather than physiological explanations. The fact that the children all looked so normal—indeed, many were very beautiful—served to further compound the belief that these children had been born ‘normal’, as did the finding that so many had islets of ability or splinter, or savant, skills.

In 1964, after much research and on the basis of having an autistic son of his own, Bernard Rimland produced a small volume entitled *‘Infantile Autism’* which questioned the origins of autism. Rimland pointed out several rather obvious facts which linked autism to factors other than parenting style. He highlighted the important points that not all parents fitted the Kanner stereotype of being cold, rejecting and aloof and even those who did, invariably had other perfectly normal non-autistic children. He also referred back to Kanner’s original observation that most autistic children behaved unusually from birth, and drew attention to the striking fact that three or four times more autistic children are boys (who are valued in our society), than girls, in keeping with findings from other disorders. Whilst Kanner agreed to write an encouraging preface for Rimmland’s book, indicating his increasing ambivalence regarding causes, it received sharp criticism from the influential Bettelheim who argued that any biological abnormalities were likely to be
effects rather than causes of autism. However, the book also received some degree of interest and began to stimulate research, although it took several more years before the focus on explanations for autism really began to alter.

Over time, clinical reports started to indicate that brain abnormalities and retardation were common in autistic children, and as many as one in three went on to develop epilepsy (Rutter et al., 1967), supporting the notion of strong underlying genetic and biological causes. Importantly, in 1969, Schopler and Loftin were able to show that the only emotional problems found to be common amongst the parents of autistic children were disorganized thinking which appeared to be correlated with guilt-inducing psychodynamic interventions. In the same year, Kanner himself finally retracted his accusations about parents acquitting them in a speech to the National Autism Society at the Sheraton Hotel in Washington, D. C., yet it was still not until the mid-1970s that the picture really began to change.

In 1976, Clarke & Clarke showed that children with a history of horrifying mistreatment and almost total neglect failed to show any evidence of autism, and Curtiss (1977) described the well-known case of Genie, a young girl found tied to a chair in almost complete isolation for 13 years who, in contrast to the autistic children removed from their homes by those such as Bettelheim, quickly made bonds with her carers after rescue. Importantly, in what seemed to be a long overdue study, DeMyer (1979) was able to demonstrate through the application of standard personality questionnaires, that parents of autistic children were indistinguishable from parents of normal or brain-damaged children, and that they had significantly fewer problems than parents who had normal children but were out-patients at a psychiatric clinic. Consequently, DeMyer made the suggestion that parents may have appeared aloof and wary owing to the certain knowledge they would be blamed for their children's difficulties and were, therefore, perhaps 'frozen' with fear.
Early Research

A search of the early literature reveals that the vast majority of research focused on individual case studies of the children and their parents, exploring their background, cataloguing their behaviour and interpreting their interactions with therapists. However, some truly extraordinary, unethical and needless to say fruitless, experiments were also performed. For example in 1959, Freedman and Ginsberg removed between 54% and 63% of the blood of several autistic subjects, replacing it with blood from ‘normal’ people. They reported no improvement in the adults, but a slight improvement lasting several days in the child! Experiments with drugs were extremely popular and children were given a wide range of stimulants and sedatives, often leading to severe withdrawal symptoms (Lehman et al., 1959). Experiments were also conducted using hallucinogenic drugs such as LSD, allegedly in the vain hope that it would promote the use of language (Freedman et al., 1963).

Additionally, a number of experiments were conducted looking at visual attention and others using punishment and reward. A series of figure preference and visual figure-ground experiments were conducted in 1954, whereby children were rewarded with money for correct answers (Jackson, 1954) and punished by electric shock for wrong answers (Smith & Hockberg, 1954). It was found that children favoured non-shocked figures and reward increased performance in those who expressed feelings about winning or losing money. It seems particularly interesting that the children’s perceptual abilities were being investigated at such an early stage in research, especially in light of current work, and the finding that autistic children responded to reward has played an important part in behavioural modification-type therapies and remains part of treatment programmes today.
Work during the 1960s continued to make links between autism and variations in perception. Evans (1968) reviewed and discussed the literature concerning relationships between various visual skills and disordered human behaviour including infantile autism, and Hingten and Churchill (1969) proposed that the behavioural paucity associated with infantile autism is related to fundamental disturbances of perceptual processes. Williams and Wilkins (1969) considered autism to be a defensive stance against incoming stimuli experienced as overwhelming or noxious. Whilst the notion of a defensive stance lacks clarity, recent work, such as that by Talay-Ongan and Wood (2000), has suggested that hypersensitivity, as well as hyposensitivity, across auditory, tactile, gustatory and vestibular domains in autistic children, may have an inhibitory effect on developmental processes for social interactivity, attachment and communication.

Michael Rutter (1966), who has made many extremely useful contributions to the study of autism over the years, stressed the idea that autism was not part of schizophrenia, nor was it emotional, and suggested as early as 1968 that its many manifestations are explicable in terms of cognitive and perceptual defects. A particularly interesting finding in keeping with this idea was found by Frith and Hermelin (1969) who reported autistic children are particularly skilled at making jigsaw puzzles by shape, rather than picture. Other work during that decade looked at a variety of aspects, although with limited success. For example, Judd et al. (1968) investigated chromosomes but were forced to conclude it was not possible to demonstrate hereditary factors with the cytogenetic methodology available at that time.

Hutt et al. (1966) were able to demonstrate EEG abnormalities which suggested a chronically high state of arousal and Rimland (1965) proposed the reticular formation (responsible for levels of arousal) to be a possible site for lesions, perhaps due to hyperoxia with a genetic susceptibility. From a more practical point of view Scanlon et al. (1964) suggested the usefulness of speech therapy and Leighton (1969) drew attention to the difficulties faced by parents, such as lack of sympathy and compassion in the
community. However, once again much work continued to focus on recording details of the children’s behaviour and providing psychoanalytic interpretations. For example, Bender (1961) suggested autistic thinking is a normal part of development which persists or becomes exaggerated as defence against anxiety and disorganisation in many types of problem.

The 1970s

Throughout most of the 1970s autism attracted a fairly limited research interest. Tustin (1972) linked the development of autism to a mouth-experienced type of depression caused by becoming aware of the separateness of the nipple at too early an age, whilst Williams and Harper (1974) considered sensory deprivation at a critical period, to be the problem. Maier (1971), on the other hand, in an almost unbelievably horrific-sounding experiment involving the isolation of a 5-year old boy in an almost empty room for 74 days, claimed a significant improvement in the child’s relationships with others as a result!

Rutter (1972) pointed out that the term ‘childhood schizophrenia’, which was still being used by many, had outlived its usefulness and Rimland noted that 1 in 10 autistic children had savant skills (1978). Lockyer and Rutter (1970) noted striking discrepancies between non-verbal skills such as jigsaw-type tasks which often far exceeded verbal ability, and Rutter and Bartak (1971) proposed that social and behavioural abnormalities in autism are secondary consequences to cognitive and language impairment. Importantly, Rutter was also able to demonstrate that monozygotic twins have a far higher concordance for autism than dizygotic twins (Folstein & Rutter, 1977), indicating a strong genetic component.

The link with perception, however, continued to prove of interest to researchers. Bryson (1971) used matching-to-sample tasks to test the ability of six autistic children to make visual, vocal and fine motor responses to visual and auditory stimuli. The conclusion was
that the basic difficulty in autism was not an avoidance of auditory and visual stimuli *per se*, but rather a deficit in the ability to make cross-modal associations.

One of the most interesting observations, was made by Lovaas (1971) who considered that the underlying problem in autism is an over-focus of attention. This is an important consideration for Counselling Psychologist who should be aware that individuals with autistic spectrum disorders often appear to have difficulty focusing their attention appropriately, and sometimes seem to get their attention 'stuck'. This has potential implications for the type of therapeutic approach, the nature of the therapeutic relationship and the subsequent interpretation of transference and countertransference feelings and responses. Based on his observations, Lovaas went on to develop a form of treatment known as the Lovaas Method or Applied Behavioural Analysis, which involves reward and intense parental input, and is one of the most widely used approaches used to aid the development of children with autism today.

In keeping with Lovaas's observations, towards the end of the decade, Curcio (1978) demonstrated that autistic children do not seem to share and direct attention through protodeclarative pointing in order to share their interest, or by following an adult's point or gaze. This again has implications for the therapeutic relationship as it suggests that difficulties may arise with engagement, and also with the understanding and reciprocation of subtle visual and attentional cues.

Overall, the impression one gets from reading the literature on these early studies is that researchers seemed almost at a loss as to where to begin in their quest for understanding the complexities of the disorder. Psychoanalytic theories refused to go away, drug testing was rife but proved to be of little use and investigative technology was extremely limited. It seems almost as if all that could be done was to watch, wait and wonder, although among a few, there appears to have been an instinctive feeling that perceptual abnormalities might hold the key to the problem.
The 1980s – Cognitive Theories

In the 1980s, owing to the emergence of cognitive psychology and better diagnostic techniques, research into autism exploded. It appeared that the problem needed to be explained on three levels, and whilst the behaviour had by now been well-documented, the biological and cognitive aspects needed to be addressed. The task faced by the cognitive theorists, therefore, was to explain the specific pattern of deficits and preserved abilities across the three areas of socialization, communication and imagination described by Wing and Gould (1989).

Theory of Mind

In 1985, Baron-Cohen, Leslie and Frith, who have since become some of the most eminent and prolific researchers into autism, proposed that autistic children lack a Theory of Mind. ‘Theory of Mind’ is a term first used by Premack and Woodruff (1978), arising from their work with chimpanzees and meaning the ability to attribute independent mental states to self as well as others, in order to explain and predict behaviour. It is a theory which appears to instinctively fit well with the highly influential work by Piaget (1923/55) on children’s developing representations and movement away from egocentricism. Theory of Mind was not considered to be a conscious theory but an innately given cognitive mechanism allowing for a special sort of representation, that is the representation of mental states. It is usually considered that ordinary children, from around the age of four, understand explicitly that people have beliefs and desires about the world, and that it is these mental states, rather than the physical state of the world, which determine a person’s behaviour. (However, it is now generally recognized that children may understand this implicitly much earlier.)

The ability to represent the thoughts of self and others is often referred to as ‘mind-reading’ or ‘mentalizing’ (Frith et al., 1991) and it is interesting to speculate what effect a lack of this fundamental ability (or ‘mindblindness’ - Baron-Cohen, 1991) might have. It
certainly seems possible that the world could be experienced in a very frightening, confusing and unpredictable way. Therefore, it seems important that Counselling Psychologists should be aware of this potential aspect of the autistic person’s difficulties, particularly when trying to conceptualize their problems, or ‘look into their world’.

The philosopher Dennet (1978) considered only understanding and predicting a character’s behaviour based on false belief could show Theory of Mind conclusively, because otherwise the real state of affairs (or the subject’s own convictions) could be appealed to without the need to postulate mental states at all. On this basis, Baron-Cohen et. al. (1985) devised a classic task to test false belief. The ‘Sally-Ann’ task is considered to be highly reliable and involves showing a child two dolls. One, called Sally, places her marble into her basket and leaves the room and whilst she is away the other doll, named Ann, moves the marble to her own box. When Sally returns, the child is asked the test question “Where will Sally look for the marble?” The child’s subsequent response indicates whether or not they have appreciated Sally’s false belief. According to this study, most of those with autism, and children under four, indicate that Sally will look in the box to where they saw the marble being moved, rather than in the basket where Sally left it. Baron-Cohen et al. found that 80% of autistic subjects and 80% of controls under four years were unable to answer the false belief question correctly. However, 86% of the children with Down’s syndrome in the study were able to answer correctly, indicating that acquisition of Theory of Mind is not simply related to IQ or reasoning power, but a specific mental ability which appears to develop in ordinary children in a recognizable way, by around the age of four.

These findings, implying that autistic children lack a specific cognitive mechanism stimulated enormous research into Theory of Mind, which still continues today. Perner et al. (1987) also devised a false belief task involving a Smartie tube containing pencils, which produced the same findings as the Sally-Ann task, as did a host of other false belief tasks, but there remains today considerable debate as to the processes involved in performing such tasks. However, the notion of mind-blindness does not answer all the questions about autism and fails to account for the fact that around 20% of autistic

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children consistently pass false belief tasks (Baron-Cohen et al., 1985). Indeed, in my own undergraduate project (Hamlyn-Wright, 2000) it was found that 70% of the autistic children could pass the standard Sally-Ann task compared to only 60% of the 4–5 year old controls, which gave rise to the speculation that autistic children may possess the ability to learn such tasks. Although, this is not to suggest that the skill then generalizes to other tasks or situations. Consequently, the conclusion might be that whilst a failure to mentalize is certainly a typical deficit in autism, it is not the core or primary impairment, and as Sheinkopf and Mundy (1995) point out, the cognitive mechanisms suggested for minding reading, do not recognize the possible social-emotional functions of this particular ability.

The 1990s - Other Cognitive Ideas

Russell et al. (1991) proposed a somewhat different reason for failure on false belief tasks. Having designed the Windows Task whereby the child has to point at an empty box, in order to be rewarded with the chocolate in the other box, they found that pre-school children had particular difficulties due to the urge to point to cognitively salient objects, rather than an inability to mentalize. Carlson et al. (1998) later linked this finding to the inability to suppress the perceptual stimulus. An experiment by Clements and Perner (1994) however, seems to have particular significance to Theory of Mind, as well as current work. It was suggested that attention may play a key role in understanding false belief and by monitoring where children looked in anticipation of a protagonist reappearing, they were able to conclude that whilst children gain explicit understanding of false belief by around 4 years of age, implicit understanding can be detected much younger in ordinary children.

Considerable work has focused on children’s representations, particularly in relation to the differences between mental and non-mental representations, non-mental representations in this instance meaning mental representations other than those relating to mental states. Leslie and Thaiss (1992) and Happé (1994) have each suggested autistic
children's difficulties rest with mental, rather than non-mental representations and Leslie and Thaiss (1992) found that autistic children had no difficulty understanding non-mental representations. Their competence in this area has also been demonstrated with 'false' maps (Leslie & Thaiss, 1992), 'false' drawings (Charman & Baron-Cohen, 1992) and 'false' photographs (Leekham & Perner, 1991). Interestingly, Zaitchik (1990) was able to demonstrate that 3-year old control children have considerable difficulty with the 'false photograph' task, and work by Swettenham et al. (1996) supports the idea that conceiving the mind as a camera aids autistic children in predicting behaviour, a concept often used to help autistic children today.

**Weak Central Coherence**

A further interesting and still relevant theory, proposed by Frith (1989), relates to the notion of Weak Central Coherence. She suggests autism is characterised by a specific imbalance in integration of information at different levels. A characteristic of normal information processing appears to be the tendency to draw together diverse information to construct higher-level meaning in context - thus the term 'central coherence'. The notion of Weak Central Coherence implies that autistic subjects are peculiarly free from normal contextual restraints and this can be seen reflected in their over-literal use of language, as demonstrated in the homograph reading test (Happe, 1997); the fact they are less likely to succumb to 2D visual illusions Happe (1996); and their remarkable performance on such tasks as the Embedded Figures Test (Witkin et al., 1971).

In 2001, Briskman et al. postulated Weak Central Coherence as an additional cognitive abnormality in autism, a lack of which might account for the individuals who are consistently able to pass false belief tasks. In support of a biological account of autism, as well as the theory of Weak Central Coherence, was the finding that fathers of boys with autism showed an information processing bias favouring part/detail processing of wholes/meaning (Happe, 2001). This finding has not only important implications for understanding autism, but from a therapeutic point of view, also allows us to see where strengths might lie.
The Weak Central Coherence theory also appears to tie in with the influential, but very general, theory of ‘executive function deficits’, an umbrella term covering a host of higher cognitive capacities and thought to encompass Theory of Mind. However, through studies of a brain-damaged patient with executive function deficits and frontal lobe damage, Bach et al. (2000) seemed able to demonstrate that the ability to understand mental states and affective responses remains separate from executive functioning, lending support to a modular theory of Theory of Mind.

From this review, it can be seen that cognitive theories and concepts, such as Theory of Mind, the ability to suppress the perceptual stimulus, the nature of representations and Central Coherence each provide useful information to help Counselling Psychologists understand the nature of autistic spectrum disorders and their associated difficulties, and to think about how clients with this disorder might present. Through comparisons with ordinary and developmentally disordered children, it would seem we have also learnt a considerable amount about the normal course of child development. However, it is important to remember that cognitive theories only provide a link between biology and behaviour and that they fail to account for factors such as social co-operation and collective ambitions.

Contrasting ideas

Of particular importance when attempting to examine the vast and very dominant literature on Theory of Mind, is the need to consider the contrasting ideas of Hobson. Hobson (1991) argued against the notion that children develop or even need a Theory of Mind, proposing that what they acquire is knowledge of persons with minds, and that they do so through experience of interpersonal relations. The capacity for understanding others, he suggests, is constituted by innately determined perceptual-affective sensibilities toward the bodily appearances and behaviour of others, and he considers theories such as Theory of Mind to be non-developmental, non-social and overly cognitive (Hobson, 1990). Hobson also points out that the capacity for pretence, usually lacking in autistic children, develops on the basis of prior abilities to perceive the nature
of other people’s relatedness to the world, and interestingly, draws upon evidence from studies of congenitally blind children to support his ideas. In a (1998) paper, Hobson suggests that the significantly poorer Theory of Mind found in congenitally blind children, is directly attributable to their lack of vision.

Visual attention and social bonds

In 1996, Wainwright and Bryson again highlighted abnormalities in autistic children’s ability to disengage and shift attention, and Townsend et al. (1996) noted significant cerebella damage, proposing that this may affect the speed at which attentional resources can be activated. Townsend et al. (2001) also recently identified abnormalities in spatial attention networks in autism corresponding with cerebella damage, again supporting the notion of over-focused attention. Furthermore, in keeping with reports of enhanced and unique item detection in autism, O’Riordan et al. (2001) found that children with autism perform better than controls on difficult visual search tasks.

A number of other studies associated with visual processing appear to support Hobson’s ideas. Phillips et al. (1993) were able to demonstrate the importance of eye contact in learning Theory of Mind, and noted that handicapped and control children, but not autistic, made eye contact after an ambiguous action by an adult. Baron-Cohen, (1995) found that autistic children have particular difficulty with face processing, and Phillips et al. (1995) noted a failure to realize that eyes convey information about a person’s mental state. Using the Eyes Task, it was also found that autistic children are severely impaired in the ability to infer mental states from photographs of eyes (despite finding photographs helpful in other ways), and significantly impaired in ascribing complex mental states to facial expressions (Baron-Cohen et al., 1997).

It would seem, therefore, that recent work on visual attention and processing fit particularly well with Hobson’s reasoning, and with other previously mentioned ideas. Importantly, overall there seems to be the suggestion that visual attention and/or
processing ability, which are unusual in those with autism, have important implications for learning about others. On this basis, it seems reasonable to propose that these factors would also play a large part in the processes involved in developing early bonds and attachment, and this in turn has implications for the nature of the therapeutic relationship.

**Etiology and Biological Factors**

Other angles of research have also produced interesting findings, especially those relating to epidemiology and biological factors. Work by Howlin and Asgharian (2000) found the mean age for diagnosis of Asperger's Syndrome to be 11.13 years, and 5.49 years for autism, highlighting the need for earlier diagnosis, thereby leading to more effective intervention. Lord and Rutter (1994) found a prevalence of 0.02% - 0.05%, and Gillberg (1984) reported 62% of people with autism are also left-handed, which is particularly interesting and in keeping with genetic and biological ideas. Gillberg (1990) also found autism all around the world and in all social classes.

Baron-Cohen and Hammer (1997) drew attention to cognitive sex differences, and their results indicated that the female brain proved better at Theory of Mind tasks at complex levels, whilst the male brain appeared to be superior in spatial tasks, such as the Embedded Figures test. On the basis of the finding that parents of children with Asperger's syndrome show a stronger than normal male brain, Baron-Cohen (1999) made the suggestion that autism is the manifestation of an extreme male brain, which again suggests biological, or hemispherical influences. What is particularly appealing about this idea is its attempt to de-pathologize autism, and from this perspective it is even possible to hypothesize that autistic traits, such as a fascination with objects and numbers, may be adaptive in the modern computerized world.

However, Steffenburg (1991) reported that 90% of autistic people show brain damage or dysfunction, perhaps linked to the high rates of epilepsy previously mentioned, and Rutter and Schopler (1987) reported that as many as 75% have an IQ below 70. The
association between epilepsy and intellectual impairment fits well with the suggestion by Rapin and Katzman (1997) that sub-clinical epilepsy may play a role in the developmental regression of the one third of toddlers who lose their language skills and become autistic.

Evidence for a genetic base for autism has been found in studies such as Smalley et al. (1988) who reported autism to be 50 times more frequent in the siblings of autistic people than in the population at large, and August et al. (1981) who demonstrated that non-autistic siblings show a much increased incidence in other cognitive impairments such as language disorders and social impairments. However, whilst twin studies indicate a far higher concordance for monozygotic than dizygotic twins, concordance is not perfect, indicating other factors must also have a definite part to play. As Rodier and Hyman (2000) point out, genetic and environmental influences are not mutually exclusive causes of birth defects and a combination of both is usually essential to the etiology of congenital abnormalities.

Environmental Influences

Many environmental influences have been suggested, which may conjoin with a genetic susceptibility to cause autism. One of the most enduring has been that of prenatal viral infection and this has been supported by epidemiological studies such as Fatemi et al. (2000). Prior (1991) considered that the high incidence of autism in 'rubella children' to be suggestive and indeed, there has been much recent concern about children appearing to develop autism after the Measles, Mumps and Rubella (MMR) vaccination (Kawashima et al., 2001), although DeStefano and Chen (2001) report no epidemiological evidence for a causal association. Goodman (1991) argued that the birth complications often associated with developmental disorders may be a result rather than a cause of autism and suggested that complications in early pregnancy, such as congenital rubella, may be responsible for birth difficulties.
Neuropsychological Findings

Ciaranello and Ciaranello (1995) also link pre-natal viral infection to autism and cite a growing body of evidence for associated neuronal maturation defects particularly in the cerebellum and limbic structures. According to Abell et al. (1999), the cerebellum and amygdala have both been implicated in social cognition in animal, imaging and histopathological studies. Happé et al. (2000) also cite evidence from brain-injured patients to support the notion of a neurological substrate for social insight, that is the ability to represent thoughts and feelings. Baron-Cohen et al. (2000) focused on the role of the amygdala, suggesting that it had a social function, and found that the amygdala in autistic participants lacked activation when subjects were asked to make inferences about thoughts and feelings from the expressions of another person's eyes. Other work, such as Insel (1997) also suggests a neural basis for social bond formation, and proposes that neuropeptides are implicated in the central mediation of attachment. On the strength of these findings, it would seem that there are an enormous number of complex factors associated with autism, and it is not always easy to delineate between causes and consequences. However, the notion of a biological basis for attachment is extremely interesting.

Attachment

On the strength of the realization that Theory of Mind develops in a social context, research into the issue of attachment in autism appears to have come full circle. Whilst parents are no longer considered to blame for their children’s difficulties, their relationship with their autistic child still represents a vital source of information, and it is important to remember that attachment is a bi-directional process. This consideration has important implications for Counselling Psychologists, as it seems likely that parents also suffer as a result of difficulties in the attachment process. Work over the last ten years has indicated that autistic children do display attachment behaviours, although sometimes in slightly unusual ways (Ozonoff & Malin-Cole, 1991; Buitelaar, 1995: Dissanayake &
Crossley 1997). Fonagy (1996) suggested that secure attachment facilitates Theory of Mind and this would appear to emphasize the notion that the fundamental ability to socially interact has important developmental consequences. Significantly, whilst Capps et al. (1994) found the children in their study demonstrated attachment behaviour, they also noted that they were less responsive than controls to bids for joint attention.

Attention and Intersubjectivity

Several researchers, such as Baron-Cohen (1991) and Fonagy and Target (1997) have each, over time, suggested that joint attention is crucial to the development of Theory of Mind. On this basis, it would seem that two strands of research have begun to interlink, and whilst one has attended to the visual and attentional abilities of autistic children, the other has focused on the intersubjectivity of human relationships.

The notion of ‘intersubjectivity’, or ‘intersubjective communication’, whether explicit or implicit, is an extremely important new area in developmental psychology. It has emerged as a common denominator in approaches to interpersonal engagements in early infancy and children’s understanding of others’ thought and emotion. As noted earlier, Hobson (1991) proposed that an infant’s Theory of Mind develops through its relatedness to others, and work by Trevarthen (1999) has highlighted the need for intimate relationships and companionship in the growth of the brain and personality during infancy. According to Trevarthen, human beings are not merely social, but also inherently cultural. He draws upon evidence from cultural and human evolution, embryology, brain genetics and infant behaviour to suggest that babies are born with innate motives in their complex brains. These innate motives then lead them to learn through communication about intentions, interests and feelings of trusted companions, in order to interpret a common reality (1997/9). Trevarthen also considers that from birth, infants are capable and interested in engaging ‘protoconversationally’ with the dynamic thoughts and enthusiasms of caregivers (1999), and suggests that the infant’s mutual self-
other-consciousness plays the lead role in developing co-operative intelligence for cultural learning and language (2001).

In light of these concepts, it is interesting to consider the autistic child’s striking and well-documented fascination with objects. Williams et al. (1999) make the important point that whilst objects are usually considered to afford actions (Gibson, 1979), these actions are learnt within a social context. Therefore, difficulties with social interaction seem likely to result in the unusual use of objects.

Conclusion

Having reviewed a considerable amount of literature associated with autism, and integrated the different strands of research, it seems that a picture useful to Counselling Psychology has emerged. By making links between a range of different aspects from the biological to the relational, it seems possible to conclude that whilst infants may be born with an innate drive and potential for human relatedness, the ability to interact with the world and with others to maximum efficiency (thus achieving social and cultural awareness) is likely to be mediated by attentional mechanisms, and vice versa. Arguably, abnormalities in the attentional/social mechanism may be the primary deficit in autism, leading to the manifestation of a range of ‘downstream’ disadvantages, such as the inability to mentalize or even to comprehend the myriad of complex signals displayed in the human face. Should such an explanation ever prove to be correct, it would seem easy to imagine how deficits in socialization, communication and imagination, as well as attachment, might occur.

Having looked at the literature from the conception of the term ‘autism’ until the present day, the statistical facts (relating to issues such as male gender, left-hand bias and epilepsy) do seem to enhance the idea of a biological, or neurobiological basis for the strengths and deficits associated with the disorder. This in turn, appears to go some way to undermining the notion of ‘refrigerator’ parents and exonerating them from blame,
however, this is not to say that attachment difficulties do not arise as a result of autism. Indeed, it must be very hard for parents to feel ‘ignored’ or ‘unnecessary’ by their child, and even worse for a child who is unable to ‘connect with and follow’ with its mother.

Furthermore, two areas of research appear to be striking by their absence. One area relates to therapy, and the other to the thoughts, views, feelings and experiences of the parents. Whilst this may seem somewhat strange, it is perhaps explainable in light of the traditional notion that ‘parents are to blame’. It would also appear that each of these two areas currently falls within the educational psychologists’ domain. However, in light of the fact that relational and bonding difficulties may arise as a result of attentional problems in the mother-infant dyad, and with consideration of the fact that these problems may have the potential for long-term consequences in terms of the psychological and emotional well-being of each, it seems reasonable to suggest that these are issues that Counselling Psychologists should be able to address.

**Future Directions**

Firstly, it seems essential that Counselling Psychologists should be aware of the ways in which autistic spectrum disorders manifest and the difficulties that they create, particularly the more subtle variations seen in Asperger’s Syndrome. This is in order to make accurate and informed assessments of clients, who may not have any formal diagnosis but who are presenting with emotional, psychological or interpersonal difficulties associated with the disorder, and to plan effective treatment. Secondly, it seems crucial to find out what the difficulties really are for the families of children on the autistic spectrum, particularly the mothers as they are such a vital part of the equation, and also because they represent such a rich source of information.

A pilot study by Midence and O’Neill (1999) found mothers of autistic children have a tendency to blame themselves and often GPs were dismissive of parents’ early concerns. On this basis, it is suggested that mothers in particular may also be psychologically at
risk, and it is proposed that future work should be directed at listening to the voices of parents in relation to their experiences and worries about their children, in order to identify how Counselling Psychologists might be of help. Not only in offering support, but also in helping to improve the vital parent-child relationship, clearly so crucial to child development.
Appendix A


To meet diagnostic criteria for autistic disorder, a child must evidence a total of at least six items from the three categories shown in the table, with at least two from category 1 and one from each of categories 2 and 3.

1. **Qualitative impairment in social interaction**

   *Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture and gestures to regulate social interaction*

   Failure to develop peer relationships appropriate to peer level

   Lack of spontaneous seeking to share enjoyment, interests or achievements with other people

   Lack of social or emotional reciprocity

2. **Qualitative impairments in communication**

   *Delay in, or total lack of, the development of spoken language in individuals with adequate speech*

   In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

   Stereotyped and repetitive use of language or idiosyncratic language

   Lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level

3. **Restricted repetitive and stereotyped patterns of behavior, interests and activities**

   *Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus*

   Apparently compulsive adherence to specific, nonfunctional routines or rituals

   Stereotypes and repetitive motor mannerisms (e.g. hand - or finger – flapping or twisting, or complex whole body movements)

   Persistent preoccupation with parts of objects
Appendix B

DSM-IV (American Psychiatric Association, 1994) Diagnostic Criteria for Asperger’s Disorder

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

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

B. Restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:

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

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g. single words used by age 2 years, communicative phrases used by 3 years).

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

F. Criteria are not met for another specific Pervasive Developmental Disorder of Schizophrenia.
MATERIAL REDACTED AT REQUEST OF UNIVERSITY
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A Shift in Focus: Exploring the Voices of Parents of Children on the Autistic Spectrum

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A Shift in Focus: Exploring the Voices of Parents of Children on the Autistic Spectrum
Abstract

On the basis that a review of the literature associated with autism identified an under-investigated area of research (Hamlyn-Wright, 2001), this study seeks to explore the individual experiences and associated thoughts and feelings of ten people, in relation to their role as the parent of a child with an Autistic Spectrum Disorder. Participants each gave an open-ended taped interview prompted by a semi-structured interview schedule. Results were analysed using Interpretative Phenomenological Analysis (IPA) in order to gain 'an insider's perspective' (Conrad, 1987) of the topic under investigation, whilst recognizing the dynamic nature of the research process. Interpretations and analysis were informed by Object Relations theory and yielded four key themes: 'Processes Associated with Diagnosis'; 'Interactions with 'The System''; 'Family Relationships' and 'View of Self by Others'. The participants' experiences seem to suggest that whilst having and caring for an autistic child can be stressful and tiring, it is the difficulties associated with diagnosis, 'the system' and 'others' they seem to find most stressful. Implications for Counselling Psychology are considered.
Keywords: Asperger's Syndrome; Autistic Spectrum Disorder; Autism; Experiences; Parents.
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Introduction

A review of the vast body of literature associated with autism (Hamlyn-Wright, 2001) highlighted an almost complete lack of research into the emotional world of the parents with children on the Autistic Spectrum\(^4\). This seemed curious in light of the very central role that historically they have been deemed to play in relation to their children's difficulties. On this basis, the current investigation was undertaken with the aim of listening to the voices of this particular group and hearing about their experiences, thoughts, feelings and concerns, in order to try to gain an 'insider view' (Smith, 1996, Smith, Flowers & Osborn, 1997, Smith et al., 1999).

When Leo Kanner first identified autism as a specific syndrome, he seemed to suggest parents could in some way be responsible for the children's difficulties. "All of our patients have come of highly intelligent parents ... in the whole group there are very few really warm-hearted fathers and mothers ... the question arises whether to what extent this fact has contributed to the condition of these children" (Kanner, 1943, p.250).

Within a few years, Kanner (1948) had begun to paint a dramatic picture of what were to be termed "refrigerator parents" whose coldness and rejection were responsible for their children's autistic symptoms. Not long after, Bruno Bettelheim, another influential author, published 'Joey: A Mechanical Boy' (1959) which also pointed an accusatory finger at a lack of parental love as the cause of the children's perplexing behaviour. This damning image of the parents of autistic children fast made its way out of the medical journals and into popular literature, and influential work by Erikson (1950), Bowlby (1951) and Harlow and Zimmerman (1959) seemed to scientifically underpin the notion that parenting style was responsible for autism.

In 1964, however, Bernard Rimland drew attention to the fact that autism can be linked to other factors. Many of these 'damaging' parents had other perfectly normal children, and

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\(4\) The Autistic Spectrum includes autism, or autistic disorder (DSM-IV, 1994 (Appendix A), ICD-10, 1993), as well as high-functioning autism or Asperger's Syndrome (DSM-IV, 1994 (Appendix B), ICD-10, 1993). For the purpose of this report, and in accordance with current National Autistic Society convention, all those 'on the spectrum' may be considered, and at times referred to, as autistic, or as having an Autistic Spectrum Disorder.
it was noted that many autistic children went on to develop epilepsy. By the late 1970s, research started to shift away from the notion of explicit blame, and began to look at other causal factors such as genetics through twin studies (Folstein & Rutter, 1977), and anomalies of attention Curcio (1978). In the 1980s, cognitive psychology was found to be a salient dimension for the understanding and conceptualization of autism and work by Baron-Cohen, Leslie and Frith (1985) proposed that children with autism lack a Theory of Mind. However, apart from a pilot study by Midence and O’Neill (1999) suggesting mothers of autistic children display a tendency to blame themselves, the research is notably lacking in the exploration of parents’ thoughts, feelings and experiences (Hamlyn-Wright, 2001).

Only recently have studies begun to look at the families of children with autism in a different way. Whilst in past, they may have been seen as merely ‘objects’ or ‘investigative tools’, they now seem to be considered in a more empathic way, as real individuals affected cognitively and emotionally by the nature of their situation. In other words, as well as focusing on the possible causes and phenomenology of autism, researchers seem to have become more aware of and interested in the types of issues which might be relevant to Counselling Psychologists. For example, the stresses and strains that having a child with an autistic spectrum disorder places upon parents and families, and also the emotional processes associated with accepting their child’s disorder, and their methods of coping. Recent studies have looked at: moderators of parental stress (Dunn et al., 2001); perceptions and satisfaction upon receiving a diagnosis (Nissenbaum et al., 2002, Brogan & Knussen, 2003); strain on the family system (Sivberg, 2002); the relationship between stress and lack of social support (Boyd, 2002); psychological adjustment of siblings (Verte et al., 2003); sibling relationships and marital stress (Rivers & Stoneman, 2003) and stress and parental well-being (Hastings, 2003). However, each of these investigations is somewhat specific in nature and can arguably, therefore, be seen to constitute a reflection of what is of particular interest, relevance and importance to the individual researchers, rather than what might be of genuine significance to the families themselves.
A very recent review of autism research (Charman & Clare, 2004) concluded that the distribution of research on autism published in the last five years (n = 1,222) as indexed by the Institute for Scientific Investigation® (ISI) author count, was: 52% Symptoms; 20% Intervention; 18% Causes; 4% Diagnosis; 4% Family and Services and 2% Epidemiology. This, in conjunction with the fact that autism is more common than previously recognized (Wing & Potter, 2002), highlights the need for investigations exploring the phenomenological accounts of parents with an autistic child.

Parents’ perspectives may also have important social, political and cultural implications. Duncan Gardham in the Daily Mail (February 26th, 2004) reports that parents concerned about a possible link between the MMR (Measles, Mumps and Rubella) vaccine and autism (Uhlmann, 2002) “have been accused of abusing children” (headline: p. 35). The chairman of a national action group is quoted as having responded “Mothers have been blamed for autism since the 19th century and it is breathtaking that this is still happening today”.

On the basis of the research, the current study aimed to increase the shift in the focus of investigation by exploring the phenomenology of being a parent of a child with an Autistic Spectrum Disorder. By listening empathically to the previously unheard voice of this growing population of adults (who perhaps in many ways are the real experts on children with autism), it was hoped to gain valuable understanding and insight to add to our body of knowledge, and perhaps inspire fresh and relevant initiatives in research, therapeutic intervention and support. In light of the relational difficulties associated with autism, both historically and symptomatically, and thus the implications for Counselling Psychology, Object Relations theory was considered to be a salient lens through which to interpret the findings. Object Relations theory is essentially an interpersonal approach concerning the mother-infant dyad. It emphasizes that the primary human motivation is to have relationships with others, and that a person’s character or personality is significantly shaped by their early interactions with primary caregivers during critical stages of development. It describes a complex process towards individuation, whereby
the infant uses the primitive defences of splitting and projection, in order to manage intense and conflicting feelings (the paranoid-schizoid position).

Method

Analytic Strategy

In order to gain an in-depth account of participants' experiences and associated thoughts and feelings, a series of individual taped semi-structured interviews were conducted and subjected to interpretative phenomenological analysis (IPA). This is an analytic method developed by Jonathan Smith (Smith, 1996, Smith, Flowers & Osborn, 1997, Smith et al., 1999) that is commonly used to “explore in detail the participant’s view” (Smith et al., 1999, p.218) and capture the meaning to the participant of the topic under investigation. The approach is phenomenological in so far as it is concerned with the individual's personal account of matters, trying to see how they make sense of their experiences, rather than attempting to produce an objective statement about them. At the same time, IPA recognizes the dynamic interaction between a participant’s phenomenological account and the researcher’s interpretative framework, acknowledging that whilst “trying to get close to the participant’s personal world” (Smith et al., 1999, p.218), this objective will never ultimately be fulfilled as the experience is inevitably interpreted through the researcher’s own conceptions.

It is a method significantly influenced by social-interactionism, whereby meanings are drawn from the process of social engagement and interpretation, and can be described as a double hermeneutic process, as participants seek to make sense of their own world, whilst the researcher tries in parallel, to make sense of the world of the participant (Smith & Osborn, 2003). On this basis, the use of Object Relations theory to inform interpretations seems particularly salient, as it is an interpersonal approach that allows for a self-other perspective.
On the basis of using an idiographic approach to the analytic process, the basic principle of which is interpretation through sustained engagement with the data, participants were restricted to 10 individuals (Smith, 1966).

Participants

Ten participants were recruited through newsletters sent to 600 members of the National Autistic Society (Appendix C). This represented 100% of those responding to the request for volunteers. Each was aged 18 years or over, and the parent of at least one autistic child (see Table 1. for demographics). All participants were professionals from London and the South East, and all, apart from one, were married. Two participants were Asian, and eight were white British.

Broach et al. (2003), also using participants recruited through the National Autistic Society, found a lone parent rate of 17% for families with a child with autism in England and Wales, but noted that respondents were over-represented by those from London and the South East. A study by Wing (1980) found that those fathers in South West London joining the National Society for Autistic Children were of significantly higher social class than those fathers of autistic children from the same area who did not. In light of this, it seems possible that participants in the current study may perhaps be only regionally and/or socially representative.

Ethical Issues

Before participants were recruited, ethical approval was obtained from the University of Surrey’s Ethics Committee (Appendix D). Participants were given both verbal and written information about what the research would involve (Appendix E) and issues of confidentiality were explained. Written consent to participate in a recorded interview was then obtained (Appendix F). All participants were made aware both before and after
the interview that they could pause or stop the interview at any time and withdraw from the research at any time. After the interview an opportunity was given for them to reflect upon their experiences and ask questions. All participants reported that they found the experience positive, cathartic and/or therapeutic. Some participants were offered relevant contact information where deemed necessary. All names and certain other identifying data have been altered to protect confidentiality.

*The Interview*

Each interview was conducted on a one-to-one basis within the participant’s home. Interviews were taped and semi-structured, using schedules developed specifically for this study (Appendix G), and piloted with the participation of two parents with autistic children. The schedules were based on the literature and aimed at promoting open discussion about individuals’ experiences of having and caring for an autistic child, and listening and prompting skills were drawn from Counselling Psychology training. Interviews were open-ended, lasting on average around one and a half hours.

*Analytic Procedure*

The interviews were transcribed in full and each line numbered. Firstly, each interview was assessed thoroughly, read repeatedly and key issues, terms, phrases and processes identified and noted in the left-hand margin, along with the researcher’s thoughts and observations arising in response to the text. Commonalities between accounts were then sought and clustered into themes that attempted to capture something of the quality of what was represented in text, and these were recorded in the right-hand margin. In order to introduce structure into the analysis, the themes were then considered in relation to one another and clustered into recurrent super-ordinate themes, with shared meanings and reference, that seemed to capture most closely the individuals’ major concerns. These super-ordinate themes were checked across transcripts, moving back and forth between
the data, to ensure that each had truly evolved from, and was grounded, in the data. To ensure a balanced analysis, and possibly reduce overly idiosyncratic interpretations, the themes were then re-assessed by the researcher’s project supervisor. Finally, a summary table of themes was drawn up.

Evaluation

The following evaluative criteria for qualitative research, proposed by authors such as Stiles (1993); Elliott et al. (1999) and Yardley (2000), were used as the framework for facilitating evaluation of the study:

1. The sample is sufficiently described to enable readers to judge how widely results might apply (see Table 1).

2. There are ‘credibility checks’ such as having a second person and/or the original informants check results against the data.

3. A detailed outline of the analytic procedure renders it transparent to the reader.

4. The interpretation should be internally coherent and persuasive.

5. The researcher’s perspective has been made available to the reader (Appendix H).
Results

The issues that were raised and the themes that emerged from the data seemed striking in cohesiveness across participants\(^5\). Four super-ordinate themes were identified, each with a number of sub-themes.

*Major Themes and Sub-Themes:*

1. Processes Associated with Diagnosis
   - Emerging awareness
   - Emotional reactions
   - Guilt and blame

2. Interactions with 'The System'
   - Relating to others
   - Rejection
   - Asking for help
   - Conflict

3. Family Relationships
   - Spouse
   - Siblings
   - Self

4. View of Self by Others
   - Troublemaker
   - Outsider
   - Bad mother

\(^5\) Brackets ( ) denote an explanatory word, or words, inserted by researcher. Double speech marks " " denote an exact quotation by the participant. Single speech marks ‘’ denote a colloquialism or quotation within a quotation. 3 stops … denote the omission of extraneous words within a quotation.
1. Processes Associated with Diagnosis

Obtaining and/or accepting a diagnosis seemed to be an extraordinarily lengthy, complicated and traumatic process for almost all participants. It appeared to involve a range of powerful emotions and defensive mechanisms, and was spoken about at length and in depth. Three sub-themes emerged from the data. ‘Emerging awareness’; ‘Emotional reactions’ and ‘Guilt and blame’.

Emerging awareness

There was considerable range in age at diagnosis, seemingly mediated by a number of factors, such as the nature of the child and the severity of their difficulties; parental experience; time taken by ‘professionals’, and ‘readiness to hear’. Almost all participants showed a tendency to avoid or minimize ‘the problem’, or attribute it to some resolvable or external factor.

One parent (Carol), a health professional, knew “instinctively from birth” that something was “not quite right” with her child and sought immediately to gain help and understanding which she attributed to her knowledge and confidence drawn from her training. Despite this, obtaining a diagnosis was still difficult and took more than three years, which she considered to be due in part to the specific nature of autism. Two participants with older children also noticed differences almost from the start, but both felt their children were simply ‘late developers’. Other participants claimed not to have suspected a ‘problem’ with their child until it was pointed out by to them by someone outside the family.

For example, two had their attention drawn to difficulties by child-minders when their children were around 18 months old, but were reluctant to locate the problem within their child.

“We just thought we’d got problems with the childcare” (Paul).
Around the same age, another parent became aware of her daughter’s language difficulties, but again located the problem outside her child, blaming herself instead.

“I just thought what am I doing wrong?” (Amelia)

Two took their children to specialists for hearing tests when they were two years old, thinking the problem would be comparatively minor, and at around three and a half, one child’s nursery school was the first to point out problems.

“They said she wouldn’t play with other children ... also her speech wasn’t as good as it should be” (Claire).

Other parents had similar experiences when their children were slightly older, but some seemed to recognize that they may have been utilizing defensive processes.

“I think I had been in denial” (Elizabeth).

One parent did not become aware of an autistic spectrum disorder in relation to her older son until much later, despite having a younger child with autism, and only then when consulting a psychiatrist when he experienced emotional difficulties in his teens.

Noticing, or having their attention drawn to something ‘being different’ about their child, appeared to be the beginning of, for most parents, a long and difficult process, in both emotional and practical terms.

Despite suspicions from birth, Karen remembered thinking “well, he’s just a late developer”. However, she started sharing her concerns with professionals when he was 15 months and not walking. The process of diagnosis took around five years and Karen found herself engaging with one professional after another, being told either “something is not quite right” or “whatever it is, it doesn’t seem too bad”. First she spoke to her health visitor who suggested she “wait and see”, then to his playschool who asked her to take him away, then to the new nursery school that informed her he had ‘special needs’.

She spoke to a different health visitor who referred her to a doctor at the child clinic and “as far as she was concerned, he was okay”. The new nursery school contacted an educational psychologist who said “well something’s not quite right ... let him start school and, er, see what happens”. The head teacher of the infant school, however, demanded “within two weeks” that he have a statement of special needs. Karen then took her son to a pediatrician who recommended a speech therapist who in turn said he had
semantic pragmatic disorder. She then returned to the pediatrician who “explained that that was part of the autistic spectrum”.

Karen’s story was very typical, with diagnosis often taking several years. Some mothers initially raised concerns with Health Visitors who tended to have given reassurances rather than made referrals, which they seemed happy to accept. However, most parents sooner or later found themselves being referred, and re-referred, between a bewildering number of professionals before obtaining a diagnosis, which may have made making helpful, trusting relationships with them difficult. These professionals included speech therapists, audiologists, occupational therapists, GPs, pediatricians, dieticians, child psychologists, educational psychologists, teachers and head teachers and even social services.

“a stream of professional people … eighteen people who were involved at that particular time” (Linda).

Elizabeth’s son did not receive a diagnosis until he was ten, despite her having taken him to three different educational psychologists and Amelia “struggled on” until her daughter was fourteen and in a special school. Only Rachel and Becky had different stories.

“We just thought it must be a problem with his hearing, so we went along to see the audiologist, and within five minutes of him looking at Lee, and not getting enough eye contact, he said ‘your child is on the autistic spectrum’” (Becky). Interestingly, no matter what their difficulties, or when diagnosed, all parents remembered at least some degree of difficulty in their child’s acquisition of language. Even Elizabeth, who described her son as “very bright … in the top 4% of the country”, recalled a problem with his language skills and having to do “little exercises”.

It seems that ‘becoming aware’ of an autistic spectrum disorder was a difficult process for almost all participants, and they tended to employ a number of psychological defences, such as denial, projection and minimalization, in order to protect themselves from the ‘loss of the perfect child’ (Freud, 1936). However, once they started to become consciously aware of difficulties and began actively seeking answers for their child, it appears the diagnostic procedure was for most, both confusing and unsatisfactory, with
little evidence of their having experienced cohesive guidance or support from professionals. This could have been due to a number or reasons, or combinations of reasons, including diagnostic difficulties associated with the specific nature of autism; lack of awareness in professionals, or parents’ ‘unwillingness or un-readiness to hear’. However, these early experiences of the disorder are likely to have had a lasting impact on participants’ internalizations relating to the acquisition of help in relation to their child.

*Emotional Reactions*

Emotional reactions to obtaining an autistic spectrum diagnosis or ‘label’ were generally very strong and mixed, and accounts were at times harrowing. In most cases they seemed linked to the length of time between the onset of worries and acquiring the diagnosis, and also the amount of effort put in to obtaining, or avoiding it. Almost all parents were visibly moved when recalling the moment they were given the diagnosis, and several parents recalled feelings of relief. Whilst this may have been due in part to a lengthy struggle for understanding being over, it also seems likely to be linked to a release from feelings of guilt.

“A relief. Knowing I had not done something wrong ... it wasn’t us” (Amelia).

For some, relief was mixed with feelings of shock, but for others it was simply shock. Karen, recalled this at an earlier point when first told her child had ‘special needs’, suggesting feelings of shock may be linked to lack of awareness or denial, as well as perhaps, preconceived notions of what disability, or autism, might mean. One participant, interestingly the only male in the study, also remembered associated feelings of anger, implying that there could be important gender differences in experienced emotion, as well as expressed emotion, in relation to having a child with an autistic spectrum disorder.

“Furious ... the shock, the numbness and the disbelief” (Paul).
Several participants recalled trying to use denial as a defence after the initial shock and before a gradual process of acceptance. Only one admitted consciously, actively and consistently trying to avoid a diagnosis or "label" of autistic spectrum disorder, which may have been partly due to cultural reasons. She too described a range of complex feelings and gradual process of acceptance.

"I'm very old fashioned, Asian mum ... in denial ... in the end we realized we needed a diagnosis because couldn't get any help ... the transition from being normal to labeled, was just awful" (Fiona).

Only one participant, also an Asian mother, whose daughter has epilepsy and was already in a 'special' school by the time of diagnosis at age eight, seemed dismissive.

"I'd had such a hard time, it didn't make much difference. It didn't change Emma's life, it didn't change Emma, it didn't change circumstances at all" (Claire). The attitudes of these two mothers could suggest that in other cultures having a diagnosis, or label, may be associated with stigma.

All participants, apart from Claire, seemed to eventually experience a diagnosis as 'useful' in so far as it allowed them to become active in seeking the best ways to help and understand their child, including gaining access to support and funding.

"We could start to understand ... get an idea of what it's like for him" (Becky).

However, for others, it seemed to produce a split, or dilemma.

"It was very difficult to access the system ... it is horrendous without any diagnosis. The tragedy is, once you have a diagnosis, then you are faced with something, so you are caught in a horrible trap" (Paul).

Guilt and Blame

Many parents talked with feeling about an ensuing sense of guilt, loss and bereavement after diagnosis (feelings which are concordant with those noted by other researchers in relation to the diagnosis of serious disorder in a child, for example, Osborne and Coyle, 2002)

"Guilty about 'how did we create this child? Should we have done it?' ... There is this huge sense of loss, the loss of the dream, loss of a child. A sort of bereavement" (Paul).
Interestingly, despite feelings of guilt, none of the participants could recall having ‘done’ anything to cause their children’s difficulties, yet nor did they seem to seek to blame anyone but themselves.

“A lot of times we sort of blamed ourselves” (Amelia).

All appeared to have considered at some time, a range of possible explanations including birth difficulties, vaccination, genetics, allergies, the environment and so forth, as well as interactions between these factors, but seemed to remain largely unconvinced. Most appeared more concerned with caring for their child ‘in the here and now’.

“That’s not something that bothers me particularly … I just concentrate my energies on sort of helping him now” (Karen).

No participant referred spontaneously to the MMR vaccine, but when asked directly, all felt it could be a contributory factor in other cases.

“…not entirely blameless” (Rachel).

Carol pointed out her son was never inoculated, and both Karen and Amelia stated categorically that their children had not been affected by their MMR injections.

“Because I kept a daily diary” (Amelia).

However, almost all participants seemed to consider genetics played an important role. One parent with two sons on the autistic spectrum felt strongly.

“I often accuse my husband (an engineer) of being ‘classic Asperger’” (Linda).

She also mentioned several other members of her own family whom she considered had similar traits, and another parent, with two daughters on the spectrum felt much the same.

“I can see traits in myself, and I can see traits in my husband. Certainly, my father is very odd in many ways and quite anti-social” (Rachel).

From an Object Relations perspective, it may be that feelings of guilt and/or anger relating to having an autistic child are at times split off and projected on to others, or introjected by others within the family system, in order to protect the self or ‘good enough mother’ (Winnicott, 1962) and/or to protect the child. Importantly, not one set of parents had had another baby after realizing their child had difficulties, perhaps to avoid further stress on the family system or further feelings of guilt/anger. Three had been to see geneticists and seemed to be agonizing over the decision.

“One of the worst things for me is not knowing whether I should have another child. I’m worried about having another autistic child” (Carol).
Another parent was also worried about genetics and the effect of a second, possibly autistic baby, on her non-autistic child. However, most parents emphasized their deep love and respect for their autistic children and the pleasures that they gain from having them, suggesting the formation of strong attachment bonds (Bowlby, 1951) in spite of, or perhaps because of, their difficulties.

"We wouldn’t change anything about him because his personality is wonderful, it’s unique, it’s lovely" (Fiona).

"Still love that child, still proud of that child, you still wouldn’t swap that child for anyone in the world" (Becky).

The findings suggest an enormously difficult and complex, emotional and psychological process for parents in relation to arriving at and coming to terms with a diagnosis for their children and the assorted array of associated emotions, responsibilities, dilemmas and concerns that come with it. However, almost all participants highlighted a lack of information or support offered to them at this extraordinarily challenging time and only one, a mental health worker, had sought therapeutic help.

"You get your diagnosis, and it’s ‘BINGO, off you go’" (Elizabeth).

Overall, the range of feelings reported by the participants in relation to diagnosis all fit well with almost all models of bereavement. For example, like Bowlby (1951), Parkes (1996) proposes four dimensions of the grief process:

- Phase 1: shock, numbness and the pain of grieving.
- Phase 2: manifestation of fear, guilt, anger and resentment.
- Phase 3: disengagement, apathy and aimlessness.
- Phase 4: a gradual hope and a move in new directions.

However, the loss for participants appeared to be not just the loss of ‘the perfect child’, but also the loss of self-esteem (see Theme 4), the loss of future and the loss of hope for eventual independence.

"If I start worrying about the future, then I do get quite miserable, also depressed. ... We’re looking ahead at many years of dependency, she’ll be there forever" (Rachel).
On this basis, and within the framework of Parkes’ (1996) model, it seems as if many of the participants, particularly those with younger children, were still in the process of grief, perhaps because of the pervasive nature of autism and its specific associated problems and demands.

2. Interactions with ‘The System’

Difficult interactions with ‘the system’ including schools, teachers and the education authority seemed almost universal to all participants to a greater or lesser extent. Fighting to obtain help and funding for their children, and have them included and placed in the most appropriate educational environment, seemed the biggest concern (after diagnosis) for all the parents interviewed, and each talked at great length about the difficulties, humiliations and injustices they felt they had encountered. Several sub-themes emerged: ‘Relating to others’; ‘Rejection’; ‘Asking for help’ and ‘Conflict’.

Relating to others

For many participants, starting playschool or school, was when their children really began mixing with, and being judged by others, and was perhaps also when many first truly started to make comparisons and become aware of their children’s difficulties in relating. For many parents of ‘neurotypical’ children this can be a difficult and emotional period of transition, but for the parents in this study, it often appeared to be traumatic.

“It was his first social engagement, I suppose, and that’s where it all came out” (Fiona).

It seemed that once children started in education, participants had to begin facing the problems drawn to their attention, or confirmed by teachers, and they then found themselves entering into an emotional and relational ‘battle zone’.
Rejection

One of the most distressing things for parents, and perhaps the main trigger for conflict, was that many children were soon asked to leave or were excluded from activities or social events, such as lunch, parties and plays due to ‘poor behaviour’, resulting in intense feelings of rejection.

Claire

At the first school “she didn’t have any friends and she was disruptive and we were called in ... and told to take her out of school ... it was very hard at the time to cope with”. At the new school “We got letters from the head teacher, it all seemed to be happening again ... which was a total nightmare ...we wrote to the governors, made a big fuss ... but eventually they got rid of us which was just awful”.

One mother was distraught when after making enormous personal sacrifices in order to educate her son privately, his new school excluded him after only two weeks.

“Devastated, absolutely devastated” (Elizabeth).

Two families were particularly distressed at having been told to keep their children home during Ofsted inspections, and began to feel under attack.

“bullied ... discriminated against” (Fiona).

Two others retaliated by taking legal action against Local Authorities for the exclusion of their children. Experiences of rejection appeared to be the main trigger for feelings of threat and also intense anger in many of the parents.

“Furious, bloody furious!” (Elizabeth)
Asking for Help

One of the most endless causes of worry and frustration for all parents with school age children was obtaining a statement of special needs. This is a legal document outlining a child’s difficulties and needs, and is essential in order for a mainstream school to obtain funding for one-to-one help or supervision, or to gain entrance to a ‘special school’.

"Without a statement you are in 'no man's land'" (Elizabeth).

The greater a child’s needs, the more the Local Education Authority (LEA), is required to provide, and without it, most children on the autistic spectrum are excluded. All parents, despite some having the highest possible levels of education, found it unreasonably difficult and time-consuming, trying to obtain a statement.

Carol

“I knew, and had heard of, lots of people’s struggles with the local education authority”, so she was “absolutely appalled” when the LEA just “threw it (her application) out straight away. At that point I’d got really depressed and I had sort of hit rock bottom because … it was such a struggle to get him diagnosed, and I thought that … once I had achieved that, it would be more sort of home sailing really, it would be easier. But suddenly, there I was confronted with yet another battle on my hands”. “I had to get the special needs code of practice book out and read it from cover to cover and learn exactly what they were supposed to be doing, and I would say on average every four weeks or so, I would have to 'phone my case officer to tell her what she should be doing”.

Her account was not untypical.

“The statementing process I think, is very, very difficult. No one really tells you how to do things, and you know, I’m educated, my husband is educated, and we found it difficult … I found it hard enough to fill it all in and I’m used to writing documents and filling things in … even then we had to ask for it to be re-assessed because we got the lowest level” (Rachel).

Often parents came to feel that the LEA on whom they were dependent for help for their children, was conspiring to make obtaining this most crucial document as difficult for them as possible.

“And also the deadline. You’ve got a week, 15 days to do it. Over half-term. I mean that’s a STUPID thing…” (Fiona).
Whilst in terms of Object Relations Theory, this might suggest a retreat to the paranoid-schizoid position (Klein, 1946), possibly due to levels of stress, the fact that four sets of participants’ statement forms, when finally completed, were then reported ‘lost in the post’, cannot be entirely ignored. It would seem that that their strong feelings of anger, resentment and mistrust may have arisen from feelings that their needs, as well as those of their children, were not being adequately met (Bowlby, 1951).

Conflict

Conflict, perhaps based on unmet needs seemed to have led to a sense of having to ‘fight’, or ‘do battle’ which were themes that arose again and again in each and every interview in relation to issues regarding education, bureaucracy, funding and support, and this seemed to engender a good deal of resentment.

“Looking after Evan is tiring, but it’s not that, it’s the battle with the school and the system ... we really did go to war really with the LEA ... we just had such a fight on our hands”. (Carol).

A sense of having to fight may also relate in part to parents’ feelings of having no means of control over the frustrations, limitations and constraints of the education/funding ‘system’ upon which they are so dependent for their child’s well-being.

“We had a massive battle with the County ... I think for the first time in relation to our children, we felt out of control”(Rachel).

Alternatively, it may be that these feelings are related to the shortage of resources for children with special needs, again leading to ‘envy and attack’ (Klein, 1946)6.

“resources are limited and people ... have to fight” (Elizabeth).

There were also more personal and individual reasons for having to ‘fight’.

“I battle with unfairness” (Elizabeth).

However, all parents emphasized the need for more help, support and research and some highlighted the need to be ‘heard’, perhaps indicating that participants feel rejected, enraged and let down in a number of ways by ‘the system’, or those upon whom they are forced to rely, again leaving them with little trust and expectation of help.

“Nobody’s actually respecting us, or listening to us” (Fiona).

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6 Bearing in mind the social type of parents participating in the study, this could also be linked to the finding by Vivian and Brown (1995), that those with higher socioeconomic and educational status tend to have higher expectations and consequently experience relative deprivation more acutely.
3. Family Relationships

Whilst participants seemed open and familiar with talking about obtaining a diagnosis, and animated when recounting their lengthy battles with ‘the system’, they seemed more reticent to reflect upon the effects of having a child on the autistic spectrum on their family relationships. Whilst this may have been defensiveness, or anxiety about the context, it also seems to suggest an awareness of difference between internal and external relationships. Three sub-themes emerged from the data: ‘Spouse’; ‘Siblings’ and ‘Self’.

Spouse

There seemed to be a strong general belief that having a child with an autistic spectrum disorder placed a strain upon parents’ relationships.

“I know of so many homes where marriages have broken up because of the autism ... there is a need for something to prevent that happening” (Karen).

However, among the participants in the study, some felt their difficulties had actually strengthened their relationship.

“I know they say 8 out of 10 marriages dissolve ... but ours has got stronger because we’ve needed each other” (Amelia).

Despite reporting feeling closer though, some still expressed problems due to tiredness.

“Emotionally, we feel quite drained, so perhaps more trivial things blow up into arguments, just because we’re so knackered, basically” (Becky).

Lack of support was also a major theme.

“We’re united because we had such a fight on our hands ... but we never have time for each other, we’ve not had a night out since Jo was born, and Jo’s four now” (Carol).

One participant was visibly distressed when describing her relationship with her husband.

“It’s brought us closer together, me and my husband ... but we’re absolutely shattered ... we can’t be intimate or anything because we are too tired ... it’s been months ... we’re sad and we’re hurt ... underneath we’re in agony” (Fiona).

Not having enough time for each other was a common complaint.

“My husband and I pass like ships in the night, it’s almost like the children are batons” (Rachel).

However, others with older children alluded to deeper more complex problems.
“I don’t know many people who are still together, actually, with autistic kids”. “Our relationship, I think has suffered. I think it has really suffered … we’ve discussed separation … one of us moving out. We never quite come to the conclusion about which one it should be … to actually split up would just exacerbate the situation” (Linda).

“We went through a bad stage one time when he used to lose his temper all the time … he’s never here (now)” (Claire).

Difficulties within parental relationships, brought about by the specific stresses and strains of having and caring for a child with an autistic spectrum disorder, seem strikingly evident. Tiredness, and arguments arising from this, as well as lack of opportunity for time alone together seemed to be key factors.

**Siblings**

Less than half the families in the study also had a non-autistic child. All seemed to feel that these children had suffered in a range of ways, particularly in terms of the amount of attention they received and in their ability to service friendships.

“In many ways she’s an only child … I think she suffers a lot … I think she gets the thin end of the wedge” (Becky).

Difficulties in having friends home, was a prominent issue.

“It’s been hard on my daughter because she’s been more reluctant to have friends round than she would have been” (Karen).

“He’s obviously suffered … he couldn’t go anywhere, he didn’t have friends” (Amelia).

Some parents felt that their non-autistic children had been affected in positive ways also.

“It’s made her quite maternal at an early age” (Becky).

“She wants to work with special needs children” (Karen).

However, there were additional concerns about the future for these siblings and the responsibilities they might tend to take on.

“When we are older … we don’t want the responsibility of caring for Lee to fall completely on his sister’s shoulders” (Becky).
Comparatively little was said about non-autistic siblings, which may have been a reflection of the small number in the study (four non-autistic), or the specific focus of the study.

*Self*

When asked about the effect of having a child with an autistic spectrum disorder on themselves, it was as if a floodgate opened and participants expressed a range of strong negative thoughts and emotions, and several seemed visibly distressed. Emotions seemed linked to feelings of being cut off, different and punished.

"I got really upset the other day … I got really emotional and just started crying and I was thinking 'oh god!' … I feel left out and picked on … we’re seen as the problem family … isolated" (Fiona).

"At times I feel I can’t cope … angry and resentful with the world … I think why us?" (Paul).

"We just couldn’t go on any longer, because she was suicidal … it made me feel very low and unworthy of anything … this desperation that no one really cares … nobody outside your four walls" (Amelia).

"Why me … what have I done wrong? … Sometimes I resent Camilla … I feel guilty about it, obviously. I feel guilty about everything … I do get quite miserable, also depressed … I don’t like the feeling of being different … sometimes I get quite paranoid" (Rachel)

"I want somebody to help me … I’m wobbling a bit as you can see’. ‘I’m often reluctant to acknowledge my anger at what I’ve had to give up” (Elizabeth).

These feelings seemed to arise from the relational problems associated with the difficulties in having a child on the autistic spectrum such as exclusion, lack of social opportunities and sense of ‘having to fight’, as well as marital difficulties, leading to feelings of poor self-worth and loss.

All parents drew attention to their tiredness.

"You get tired … never off duty … it’s exhausting” (Rachel).

However, some also noticed positive changes in themselves.

"I have learnt a huge amount about myself, become definitely a different person … much more patient and much more accepting … more tolerant” (Rachel).

One reflected upon the process.
"I’ve changed ... Many of my difficulties have been because I didn’t have anyone to walk with me ... through this transition ... into this new mum. ... I’ve been quite defensive ... I felt that it was our fault ... but also that I’ve got to protect my son, myself, and our family (Fiona).

Whilst all of the participants appeared to be coping effectively, reflecting upon the effects of having a child with an autistic spectrum disorder on themselves and their families, seemed to reveal a range of painful negative cognitions and emotions, as well as dissatisfactions and stresses within their relationships. However, most seemed to balance these with positive emotions and cognitions, and all described a range of psychological coping strategies, mechanisms and processes including caring for themselves, attending support groups, religion, helping others, work, and thinking positively, suggesting largely ‘good enough’ (Winnicott, 1962) ‘internal objects’ of their own (Klein, 1946). In other words, through having had optimum care-giving themselves, whereby they received sufficient mirroring (Kohut, 1977), holding (Winnicott, 1962) and containment of their feelings (Bion, 1962), the parents in this study each seemed to have developed a cohesive sense of self allowing them to find positive ways to soothe themselves and cope.

4. View of Self by Others

It seemed almost all participants felt others viewed them in an extremely unfair, negative light because of their autistic child, and most recounted some particularly hurtful and memorable encounter that had led them to change their behaviour or expectations of others. However, not all were able, or perhaps willing, to engage in the concept.

“I don’t know, they don’t discuss it with me” (Claire).

Three recurrent sub-themes emerged from the data: ‘Troublemaker’; ‘Outsider’ and ‘Bad mother’.

**Troublemaker**

Many felt they were viewed as a troublemaker as a result of their ‘having to fight the system’ to try to gain adequate provision for their child.
“(Fighting) it’s not in my nature ... with hindsight we should have done earlier, it IS a battle” (Amelia).

Whilst participants may at times have felt compelled to adopt a ‘false self’, or to act in ways they would not naturally chose, from an Object Relations perspective, interpretation of complex projections might re-account for the origins of ‘the trouble’ (Freud, 1936).

**Outsider**

All participants emphasized feelings of isolation and exclusion, and several including Linda, Elizabeth and Amelia felt it was the worst thing about being the parent of an autistic child.

“People avoid asking us round ... we are very isolated as a family” (Claire).

“I feel left out. Even his grandparents have distanced themselves, it’s not just the authorities” (Fiona).

“People haven’t wanted to know us ... I feel alienated” (Amelia).

“You are always the outsider” (Paul).

Supportive or confiding relationships are generally considered crucial to emotional well-being (Fairbairn, 1955), particularly at times of stress (Brown & Harris, 1978; Coyne & Downey, 1991) and people commonly and affectively cope with adversity by seeking comfort, support and advice from friends and family. Therefore, the levels of isolation reported by participants seem likely to be detrimental to psychological health.

**Bad mother**

The idea that they were seen as ‘a bad mother’ was also a particularly strong perception, and one that appeared to make mothers feel both very hurt and angry. This seemed to arise from a lack of awareness about autism in others.

“A bad mother because you’ve created a problem for society” (Fiona).

“My brother said ‘I can bring up my dogs better’ ... I was so upset” (Amelia).

“They see me as a bad mother who can’t control her child” (Becky).

Strikingly, the notion of ‘refrigerator parents’ also seemed to remain alive.
"I went (in a professional capacity) to a talk, a well known ... psychologist ... the strong implication of her talk was 'refrigerator mother', STRONG implication. And I was so angry ... I walked out" (Linda).

Whilst participants largely considered that others viewed them negatively on the strength of their autistic children’s behaviour, and their own tenacious tackling of 'the system', this may have been a projection of their own fears, in order to protect their 'ideal' self (Kohut, 1977).

Overview

This study aimed to highlight the issues and concerns central to parents of children on the autistic spectrum. Participants transpired to be educated and middle class, making it interesting to speculate whether this reflects the type of person more likely to have a child on the autistic spectrum, more likely to join the NAS, or more likely to volunteer to participate in research. Strikingly, however, participants seem socially similar to those first described by Kanner (1943) which may suggest that this type of parent is more likely to seek help, understanding or 'a label'. The avoidance of, and seeming disinterest in obtaining ‘a label’ by the two Asian participants may indicate cultural differences.

In light of the relational difficulties central to autism, as well as the difficulties with ‘others’ reported by participants, Object Relations Theory, which seeks to describe the development of human-relatedness and the self-other relationship, was considered to be a salient lens through which to view and interpret the findings. Four main themes, with a number of sub-themes, arose directly from the data.

'Processes Associated with Diagnosis', the first major theme, indicated difficult, protracted processes mediated by participants’ 'readiness to hear' and professionals’ ability, or willingness, to recognize the problem. A number of psychological defences, such as denial, minimalisation and projection seemed to be utilized by participants, and perhaps also professionals, in order to protect against 'the loss of the perfect child' (Freud, 1936), suggesting secure attachment bonds between parent and child had already
been formed (Bowlby, 1951). Emotional reactions to diagnosis were especially strong and almost all participants became visibly moved when recalling these feelings, which included relief, shock, anger, guilt and denial, in keeping with reports by parents in other similar work (Osborne & Coyle, 2002). Relief seemed to come from having harboured feelings of guilt associated with a sense of responsibility and desire to be a ‘good enough’ mother (Winnicott, 1962), whilst shock appeared to relate to denial, used perhaps to protect both the self and the child. Anger was only expressed by the male participant, giving rise to speculation as to the whereabouts of the angry feelings of other participants. These often seemed to have been split off and projected into outsiders (Klein, 1946), or professionals, or other members of the family, but at times turned in on the self (Freud, 1917). Whilst most also referred to an acute sense of loss and bereavement in keeping with a number of models including Parkes (1996), which again suggests strong attachment, several, particularly those with younger children, seemed to remain engaged within the grieving process. It also appeared, however, that feelings of loss were not entirely due to the ‘loss of the perfect child’, but also to the loss of hope, expectation and perhaps self-esteem (Kohut, 1977).

Almost all participants seemed to be have accepted a diagnosis, or were working towards accepting a diagnosis, on the basis that it facilitated understanding, direction and access to services, although this could be seen as defensive reaction-formation. However, the study highlights the difficulties associated with obtaining a diagnosis, and on the basis that there are links with mental health issues (Tantam, 1991), it seems Counselling Psychologists could be helped by being aware that clients with an undiagnosed autistic spectrum disorder (such as Asperger’s Syndrome) may present with relational difficulties and symptoms of anxiety and depression, as well as obsessional and self-injurious behaviours.

‘Interactions with ‘The System” , the second major theme, encompassed a range of difficult emotional and practical experiences, leading to feelings of being out of control and disempowered. Starting school seemed to highlight children’s problems and cause participants distress, particularly when they were excluded from academic and social
activities, or even asked to leave entirely. Complex processes appear to have come into play on the strength of this major 'rejection' or 'attack' (Klein, 1946) resulting in feelings of being 'in a battleground' and having 'to fight'. Certainly, it would seem that there are very real difficulties in obtaining the appropriate education, support and funding for children with an autistic spectrum disorder. However, the pressure of trying to deal with these factors and the associated bureaucracy, whilst coping with the physical and emotional demands of caring for an autistic child, seems at times to have caused overwhelming distress, and at such times, participants appear to have 'retreated to the paranoid-schizoid position' (Klein, 1946).

The third major theme, 'Family Relationships', produced rather less material which may be an indication of a conscious, or un-conscious, reluctance or inability to think about the consequences of having an autistic child. Whilst some participants felt it had strengthened their relationship with their spouse, almost all reported marital difficulties arising from tiredness and lack of time alone together. Certainly, this seems a worthwhile area for further exploration, particularly by Counselling Psychologists, in order to gain deeper understanding of the problems and psychological and relational mechanisms at work in this particular group. The effect on siblings was little mentioned, perhaps reflecting the demands of having an autistic child within the family system. However, having friends home seemed to be a major and important difficulty, and whilst developing an early awareness of the needs of others was constructed positively, this again may be another useful area for investigation.

The opportunity to reflect upon and talk about the effect of having an autistic child on themselves seemed a positive experience for participants. However, most expressed a range of painful, negative cognitions and emotions such as self-blame, loss, guilt and worthlessness, and drew attention to physical symptoms such as tiredness, which in clinical terms could be an indication of depression (Beck, 1996). In light of this, it may be that for this particular group, the projection of angry feelings onto others, rather than 'turning them in on the self', serves as an especially useful unconscious mechanism to defend against overwhelming feelings of depression (Freud, 1917).
Most participants also recounted a range of conscious psychological strategies for coping. These included caring for themselves, attending support groups and having religious beliefs, which all tend to be useful processes. However, many also indicated that they tend to sublimate feelings through helping others and avoiding feelings through work, which may prove less effective in the longer term. Thinking positively, a particularly good and well-known strategy for mental health (Beck, 1976) seemed to be regularly employed, although this could be viewed as a defensive reaction-formation process, or simply denial (Freud, 1936).

When asked about their 'View of Self by Others', virtually all participants reported strong negative impressions, that is as a troublemaker, bad mother and outsider which they associated with overwhelming feelings of being both physically and emotionally isolated, and many felt that this was the worst part of being the parent of an autistic child. In light of the emphasis that Object Relations Theory places on the fundamental need to relate to others, and relationship being the essence of what it means to be human, it seems reasonable to suggest that this is indeed one of the most difficult aspects of being the parent of child with an autistic spectrum disorder. However, to what extent isolation is a product of the need to split off and project feelings of anger, shame and envy into others in order to protect the self and/or the child (based on the assumption of secure attachment\(^7\)), or a genuine rejection by society, remains to be clarified. This, in conjunction with participants' feelings of 'needing to be heard', suggests considerable room for further investigation, and a number of implications for Counselling Psychology.

Whilst this study has focused on the interpersonal and intrapersonal aspects of being the parent of a child on the autistic spectrum, it should be remembered that theses processes take place within a wider social and cultural context. On this basis, the study highlights the perceived need for greater social awareness and acceptance of autistic spectrum disorders, and also better diagnosis, provision and support.

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\(^7\) This assumption is based on the participants' reported efforts to help and protect their child, as well as transferential feelings during interviews and research indicating autistic children do demonstrate attachment behaviour, albeit in slightly unusual ways (Buitelaar, 1995; Dissanayake & Crossley, 1997).
Appendix A


To meet diagnostic criteria for autistic disorder, a child must evidence a total of at least six items from the three categories shown in the table, with at least two from category 1 and one from each of categories 2 and 3.

1. Qualitative impairment in social interaction

Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture and gestures to regulate social interaction

Failure to develop peer relationships appropriate to peer level

Lack of spontaneous seeking to share enjoyment, interests or achievements with other people

Lack of social or emotional reciprocity

2. Qualitative impairments in communication

Delay in, or total lack of, the development of spoken language in individuals with adequate speech

In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

Stereotyped and repetitive use of language or idiosyncratic language

Lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level

3. Restricted repetitive and stereotyped patterns of behavior, interests and activities

Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

Apparently compulsive adherence to specific, nonfunctional routines or rituals

Stereotypes and repetitive motor mannerisms (e.g. hand - or finger – flapping or twisting, or complex whole body movements)

Persistent preoccupation with parts of objects
Appendix B

DSM-IV (American Psychiatric Association, 1994) Diagnostic Criteria for Asperger's Disorder

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

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

B. Restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:

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

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g. single words used by age 2 years, communicative phrases used by 3 years).

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

F. Criteria are not met for another specific Pervasive Developmental Disorder of Schizophrenia.
Appendix C

Research on parents' experiences: Appeal for participants

Sarah Hamlyn-Wright is a mature post-graduate student of Counselling Psychology, whose son has an Autistic Spectrum disorder. She is currently conducting doctoral research at the University of Surrey looking at the experiences of the parents of Autistic children. Historically, this particular group of parents has had little positive attention paid to the thoughts, feelings and beliefs that they hold, relating to their children and their difficulties.

On this basis, and coming from the perspective that 'parents are the experts on their child', Sarah feels it is time for their observations and opinions to be heard, in order to look at the impact of things on both the individual as well as the family. She would very much like to hear from any parents, therefore, who would be willing to be interviewed as part of this research. For further details please telephone Sarah Hamlyn-Wright on:

MATERIAL REDACTED AT REQUEST OF UNIVERSITY
25 March 2004

Ms S Hamlyn-Wright
Department of Psychology
School of Human Sciences

Dear Ms Hamlyn-Wright

'A shift in focus' – exploring the voices of parents of autistic children. A qualitative investigation (EC/2004/21/Psych)

I am writing to inform you that the Ethics Committee has considered the above protocol (and the subsequent information supplied) and has approved it on the understanding that the Ethical Guidelines for Teaching and Research are observed and the following condition is met:-

- That you submit the amended documents, as mentioned in points 3 and 5 of your letter dated 5 March 2004, for the Committee's records.

For your information, and future reference, the Guidelines can be downloaded from the Committee's website at http://www.surrey.ac.uk/Surrey/ACE/.

This letter of approval relates only to the study specified in your research protocol (EC/2004/21/Psych). The Committee should be notified of any changes to the proposal, any adverse reactions, and if the study is terminated earlier than expected, with reasons.

I should be grateful if you would confirm in writing your acceptance of the condition above, enclosing the amended documents.

Date of approval by the Ethics Committee: 25 March 2004
Date of expiry of approval by the Ethics Committee: 24 March 2009

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee

cc: Professor T Desombre, Chairman, EC
Dr R Draghi-Lorenz, Supervisor, Psychology
Appendix E

INFORMATION SHEET FOR PARTICIPANTS

‘A Shift in Focus’ – Exploring the Voices of Parents of Autistic Children.
A Qualitative Investigation

Historically, the parents of autistic children have had little positive attention paid to their thoughts, feelings and beliefs relating to their children and their difficulties. This study aims to explore these issues through the use of taped interviews, in order to gain a better perspective on the experience of being the parent of an autistic child.

Each volunteer will be required to talk for approximately one hour, about their thoughts, feelings, beliefs and experiences relating to their autistic child, and the impact of things on themselves and their family. The interview will be tape-recorded, but can be stopped at any time.

Volunteers have the right to withdraw from the study at any time, without giving reason.

Confidentiality of all identifiable information and data will be maintained at all times.

Sarah Hamlyn-Wright
Psychology Department, University of Surrey
January, 2004

Tel: [REDACTED] MATERIAL REDACTED AT REQUEST OF UNIVERSITY

This study is supervised by Dr. R. Draghi-Lorenz at the University of Surrey ([r.draghi-lorenz@surrey.ac.uk](mailto:r.draghi-lorenz@surrey.ac.uk)) who can be contacted by e-mail.
Appendix F

CONSENT FORM

‘A Shift in Focus’ – Exploring the Voices of Parents of Autistic Children.
A Qualitative Investigation

I the undersigned voluntarily agree to take part in the study on the experiences of the parents of autistic children. I have read and understood the Information Sheet provided. I have been given a full explanation by the investigator of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been advised about any discomfort that may result and have agreed to inform the investigator immediately if I suffer any deterioration in my well-being. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

I understand that all personal data relating to volunteers is held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved. I understand that I am free to withdraw from the study at any time without needing to justify my decision and without prejudice. I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of Volunteer................................................................................................................
Signed..................................................................................................Date.........................

Name of Investigator.............................................................................................................
Signed..................................................................................................Date.........................

Name of Witness ...................................................................................................................
Signed Date

Name of Volunteer................................................................................................................
Signed Date

Name of Investigator.............................................................................................................
Signed Date

Name of Witness ...................................................................................................................
Signed Date
Appendix G

INTERVIEW SCHEDULE

‘A Shift in Focus’ – Exploring the Voices of Parents of Autistic Children.
A Qualitative Investigation

1. Starting from the beginning, when did you first think something might be different/wrong?
2. What did you notice?
3. What did you do/How did you feel?
4. When did you get a diagnosis/Can you tell me about that?
5. Did this have an impact on your relationship?
6. What did you attribute the autism to?
7. What help did you get/How did you feel?
8. Then what happened/How did you feel?
9. What impact do you think this has had on you/the family?
10. What is the most difficult thing about being the parent of an autistic child
11. How do you think others see you/relate to you as the parent of an autistic child?
12. Is there anything else you would like to tell me/talk about?
13. How are you feeling now?
14. Are you Okay?
15. What was it like talking about things?
16. Do you have any questions?

Sarah Hamlyn-Wright
Psychology Department, University of Surrey
January, 2004
Appendix H

Personal Statement

The focus and interpretation of this investigation is undoubtedly influenced and coloured by my own experiences as the parent of a child with Asperger’s Syndrome, and it is particularly important to recognize this in light of my having used Interpretative Phenomenological Analysis (IPA). For example, I am sure that I had hoped on some level to challenge the myth of the ‘refrigerator parent’ as I had felt angry and indignant since first having heard of it, and this may have caused me to view parents in a particularly favourable light. By using Object Relations Theory, which looks at things ‘in relation to the other’, I sought to introduce a degree of balance and reflection in hope of reducing some of this inescapable bias. In general, I was simply curious.

I was excited by the opportunity IPA gave me to meet other parents with children on the spectrum and explore their experiences, in order to try and find out what were the relevant issues for them. I felt this was important in light of the gaping hole in the research, as well as the current trend in the media towards once again discrediting parents. I was also curious about what, if any, the implications for Counselling Psychologists might be.

I had no idea what to expect when I started out on the project, although I suspected I would hear from those keen to criticize the MMR vaccine. However, this did not prove to be the case. All of those volunteering appeared to be people passionate about helping their children and keen to raise awareness of the difficulties that parents and families face. I found almost all of the participants warm and aware, although one or two seemed slightly less so. Whilst this could have been due to a number of reasons such as social factors, tiredness or depression, I felt one person in particular showed signs of ‘being on the spectrum’ herself, as did one of the husbands I met, which was intriguing but not ethical to pursue.
Almost all participants spoke at length and in depth, and I was overwhelmed by the literally hundreds of thousands of words I had to transcribe. To what extent this reflected my keenness to hear, or participants need to talk, I am not sure. What struck me, however, was how very similar their stories were to each other’s, and in some ways to my own. Major differences related to the fact that my son did not ‘get a label’, or formal diagnosis until his mid-twenties, but then as several people commented in relation to older members of their own family, “they didn’t have it then”. Many of the feelings participants mentioned were familiar and whilst I was prepared on a cognitive level to revisit old emotions, occasionally this was difficult. Generally, however, I felt this enabled me to empathize in a way that helped participants truly ‘open up’.

 Personally, I had been always been happy to accept my son as he is and assumed his language problems and restricted interests were related to his profound dyslexia (and left-handedness!). Certainly, I had sometimes wondered what, if anything, I might have done to cause his difficulties but quickly realized that they could not be altered and focused on trying to help instead. I had grown up with the belief that any child is a gift and that if they have difficulties or disabilities, they simply require even more love and acceptance. Therefore, whilst on occasion I experienced feelings of frustration and disappointment, mainly on his behalf, I don’t remember ever experiencing any huge sense of shock or loss like the parents in the study. However, I can appreciate that on some level this research could be driven by defensiveness or feelings of maternal guilt.

 I did not enter into any battles with the education system, as my son was offered a statement, something I had never heard of, and when things became too difficult for him at a school, I simply moved him, albeit somewhat crossly wondering how they could be so blind to his strengths and abilities! Most of his education including his one-to-one help was privately funded, and it never occurred to me to find him a label. Whether this was due to ignorance or denial, I am not sure, but with hindsight, I know it would have helped me to understand his perspective better and make things easier for him. Whilst I know others often defined me by his behaviour, which was at times upsetting, I was lucky enough to have two other neurotypical children who largely redressed the balance.
One of the most difficult things for me has been the fact my son initially appears so ‘normal’, and this has meant that people have rarely made allowances for him. He has often been bullied, which was something I was surprised to find did not come up in the current investigation, but in this respect I have certainly experienced the ferocious protectiveness of motherhood that I sensed in parents when they were talking about ‘fighting the system’. Unlike them, however, I have never felt isolated or the need to join a support group.

Something that surprised me was how closely my own manner of thinking seemed to match that of some participants, and this observation floated around on the edge of my consciousness for a while. It was only when I realized I was being rather ‘autistic’ myself in writing up the research and finding it ridiculously frustrating and difficult to move away from some of ‘the facts’ during the anonymisation process, that I remembered participants mentioning the “obsessive gene”. Whilst this was perhaps partly done in jest, I was suddenly able to recognize this tendency towards unshakeable focus within myself, and I found this particularly intriguing and thought provoking, especially in relation to things I had learnt about myself on the course, and ideas I have about autism and attention.

Overall, I found carrying out the project extremely informative and rewarding and hope it goes some way towards helping us as Counselling Psychologists expand the ways in which we think about our clients, their families and their difficulties, as I know it has certainly helped me.
I1: So, if you’d like to just start at the beginning

P1: Right

I2: You’ve got two boys

P2: I’ve got two boys um, Stan, who’s nearly nineteen, in a couple of weeks time, and Will who’s sixteen this summer. Will has er, has been diagnosed, was diagnosed at four and a half with high functioning autistic spectrum disorder. Um, at that stage, Will was actually diagnosed at a well-known hospital because we had a lot of problems getting a diagnosis locally, from round here. We went through all the semantic-pragmatic, um, communication, speech and language type disorders, but nobody would actually put there finger on it when it was completely obvious, to us really, that he was on the autistic spectrum. So we went up to the hospital, saw the specialist when Will was four and a half and she diagnosed, and she said that Will would present, she could see that he would present later on as Asperger’s, though it’s quite hard to define I think, what’s high functioning and what’s Asperger’s, you know, but she felt he would make progress and would, had, had a lot of potential. And so obviously, his education at that point was really key as to where we would place him and what sort of support he would have.

Um, my older son Stan, has recently, well in the last year or so, had some psychiatric difficulties, so we actually went through the NHS to get him a referral, but it was such an absolute shambles, the process and the er, completely, I don’t know, insensitive assessment of us as a family, that we decided that we would go privately and we paid for a psychiatrist to see Stan and then he’s subsequently had counselling sessions, and really the outcome is that they think Stan is on the autistic spectrum as well, but he has an Asperger’s, a mild Asperger’s and associated mental health problems um, around, sort of obsessive, obsessive-compulsive disorder, but he’s a very bright lad. He’ll hopefully be going to university this year, but the dilemma we face with our older boy is that he’s going off to university, he struggles socially, um, he knows himself he has difficulties, but the dilemma we have is, do we formally recognize it with the university, with people who may be student, you know, counselors or people who are there for the students. Do we do that? Do we go down that track? Which Stan doesn’t actually want to do, but my feeling is that we’ve got so much ahead of us in the future which it could all go horribly wrong for Stan, and so far we’ve protected him, but in the big wide world, he will be extremely vulnerable I think. Um, but it’s again, it’s what Stan wants for himself, how far do we take the fact that he has an Asperger related disorder? I don’t know.
So, at the moment, we, we’re just seeing how it goes, knowing I think that he’s not going to go to university and it’ll all be happily ever after. So, so, we have our own set of problems with Stan, but with Will, maybe I should do them one at a time, would that be easier?

I3: Yes, let’s just start at the beginning, when did you first think there was something?

P3: With Will?

I4: A difficulty yes

P4: Well, with Will, we felt, um, um, I think it was probably around 14 months really, because until then, he’d been a really good baby, in contrast to Stan who had always been a horrendous baby, he’d always been up and about all the time, but, Will was a very settled baby. He’d been born abroad, we lived in Europe for seven years, he was born there, but we came back to England quite soon. And Will, he seemed to sleep for very long periods, um, he, he was born a bit premature and he had problems feeding in the first few months, so he was a bit of a scrawny baby, but then he seemed to almost take on too much so he became almost very over-weight at about 6 months, so, his, his, kind of, you know, we, we had kind of issues in that way, we were concerned that he wasn’t feeding, and then he was eating too much, but over all, he was a very settled baby who slept for long periods, but by about fourteen months he started to, um, well, he wasn’t sitting, he didn’t sit up until he was 10 months. He didn’t walk until he was sixteen months, but then my older son didn’t either and so we didn’t think that was a problem. But he didn’t seem to have much speech and then he started about flapping of his hands, when he could walk which was sixteen months, seventeen months, he was walking up and down, rhythmically, um. His eye contact was quite poor, I think he never really responded very well to nursery rhymes, so if you’d sit him on your knee, he would um, not engage with you, whereas Stan, the older one always did, I always got feedback.

So, I had, I had in a way, a kind of marker. I think people who’ve got a first child, you’re not really sure what you’re looking at, but certainly with Will, quite early on, and this was before MMR, actually, I thought there was something amiss. Then he had the MMR, erm, but I can’t say like other parents say, that ‘there was a change’, there wasn’t particularly, he sailed through that, didn’t have any kind of response, never had any particular bowel issues, you know, gastric problems, or anything, although I will say he’s got a, he does have a tendency towards constipation, but I think that’s very typical of autistic, quite a lot of autistic kids. But he didn’t have the same sort of things related to MMR. So he, he, eighteen months, he was I would say, fairly clearly autistic, flapping, up and down, spinning, no speech, um, really, you know, by about two then, people were starting to get a bit alarmed. The health visitor started to be a bit, to suspect something was wrong, although we did, and we talked about it, um
Did you think it was autism?

P5: Erm, I don’t suppose I really knew enough about it, I suppose at that stage you always think ‘well, there’s something wrong’, but you, I couldn’t, I felt the flapping and the spinning and the ups, the going up and down was, I didn’t know enough at that stage. I think if I knew then what I know now, I’d definitely spot it, but I think it was all, you were waiting for the professionals to kind of go ‘well, let’s go for assessments, lets have a look at what’s going on’. And the health visitor, um, and also to say I hadn’t had much contact with autism really, I didn’t know what it, what it really looked like, you know, so I had, there was nobody in the family, or anything, so that I could gauge it

We had a health visitor who was, um, quite strange really. She had her own set of problems. She um, she had a lot of personal problems herself and she would sometimes come to the house sometimes and sit for two and a half hours talking about her issues, and, while it was all very nice, I used to think it was quite inappropriate that she never used to talk very much about Will, although I suppose she had enough about her to refer us to the pediatrician, um. In fact, no she didn’t. She referred us to the local speech and language therapist to start with, who work locally in the, in the, in this area. And she was just abysmal, that’s all I can say, is that she came, she did assessments on Will, but again, it was highly inappropriate she would stay for long periods, she’d talk quite a lot to me, but she wouldn’t really focus on what the issues were. And after about 6 months of all of this, we got, we just said ‘look we’ve got to be referred to the pediatrician’ so then she referred us, I remember now, she referred us on to the pediatrician and Will was seen by a pediatrician at the hospital on his third birthday

Now by that stage, Will had come on quite a bit, he was saying isolated words, erm, you got some eye contact, but not very good, and you got some, fleeting, attention, but not good, unless you could engage him, and you had to be more, and more and more creative to actually get him engaged in anything. Um, I was working at this time, I was always working part-time as a health professional, um, and I think I carried quite a lot of guilt because, as I wanted to work, I felt it was important for me to kind of, go out and work. We were finding it increasingly difficult to get nursery places and to get child care support for Will because his behaviour was so different really to other children his age. And he was in a, a private nursery in the town, but really, not doing very well, and the nursery staff there were quite, upset, that he was, he was behaving, quite differently to the others

Anyway, on his third birthday, we saw the pediatrician, she went through the regime of getting out little figures and asking Will to pour a cup, you know get a figure to pour a cup of tea and all this, which he did, and he carried out the tests
quite well actually, so much so in fact that she put in her report 'this child is definitely not autistic. Great!

So we thought ‘ah, well, that’s not’ because other people, other professionals around us were saying that they actually thought he was, but she put it in black and white and we still have that letter, that he isn’t, or wasn’t, so. But, she said he did have some sort of semantic pragmatic difficulties, but the fact that he could actually get a figure to pour a cup of tea, meant that he had some insight, some sort of social awareness. So, um, she then referred us to the speech therapist and the psychologist, so we went through a stream of professionals. I think at one point I counted how many there were and it was about eighteen people who were involved at that particular time. Ranging from speech therapists, psychologists, educational psychologists, um, pediatrician, because by then I wanted to put Will as well, in some sort of specialist nursery situation. So I moved him to a speech and language group, a specialist speech and language group, some way away, I don’t know if you know it? But it was a specialist nursery where he had a lot of speech and language input. So, there were the staff there as well, and there were, there were just masses of people who were involved in assessing and um, thinking where we go from here:

Um, and we didn’t really get a diagnosis, we did get help, I think they were quite quick, we were very fortunate in that, in those days, it was like ten years ago, there wasn’t the rush of kids that there are now with this sort of difficulty. I think that has happened in the last ten years, but Will was one of the first I think. There were other children like him, but he was one of the first to be, um, although a few were coming through, to be seen to be statemented quite early, because I think now it is a real hassle to get statemented. But they seemed to, that didn’t seem to be an issue, we had the ed psych round and we got the statement through quite quickly, because it was seen that Will had needs that weren’t really being met, um, in, in, in, I mean obviously he was in a speech and language nursery, but he needed much more than that. So when he was four he was offered a place in a specialist nursery, speech and language nursery

I6: So was this on the strength of the statement?

P6: Yes, it was really, and the fact Will, a statement came through when Will was nearly four, he then was named a nursery place at a speech and language pre-school, it was like a pre-school language unit, and Will’s behaviour was like, I mean, they very quickly recognized that he needed one to one, because he would go running off across the field. But what they saw, very often we would get professionals saying to us ‘this is what Will is like’ but sometimes we saw a different Will at home. What they were saying he couldn’t do, we knew full well he could do, so we knew within Will there was an element of choice. He was choosing not to respond to maybe the speech therapist at the nursery, but he would respond at home. So we could then, at that stage we could give Will instructions to go and get something and he would do it, whereas when we told
the speech therapist that at the nursery, she would say 'absolutely impossible' he can't do that. And we would say 'yes he can, because he actually does it'.

But it was, we really felt not heard at that stage. We felt the professionals were doing their assessments and we were not really being listened to. Um, and we are quite able parents, I might say, you know we kind of are quite clued up, and we’d read a lot of books and we knew what we were doing, but we really didn’t feel that we were listened to. Um, though I think they were getting the message that we weren’t certainly going to allow just anything to happen to Will, we, we, because we then pushed for a diagnosis, we said we wanted to go to the London hospital, we’d heard of the specialist who’s a pediatrician who we knew that she would do, I’d spoken to her on the ‘phone, and she would do a 3 hour session, assessment, look at Will, the psychologist would see him, the speech therapist would see him, and by the end of the morning she would give us a diagnosis and that is exactly what happened. And we went to the hospital and she did say by the end of the morning ‘yes, he is on the autistic spectrum’. And although we knew it, it was very difficult actually, it was very hard to kind of accept that, the words

(CRYING)

It just felt really awful. I mean we just knew, our future, I mean even though we knew it, it was just the future was, just, difficult

I remember standing under the clock at Waterloo, you know, we came out at Waterloo, we just looked at each other, you know, my husband came with me, and we just thought, you know ‘how hard it was’

17: Do you want me to turn the tape off?

P7: Yes

I8: Sorry, you were saying about how you bury so much

P8: I just think you bury so much, um, with all the practicalities, you know, you’re just carrying on. A time like that makes you take stock of where you are at, and, and how difficult it's going to be.

Um, but we’ve always been optimistic, we’ve always carried that optimism, um, sorry were you going to say something?

I9: I was just, just going to say, it's sort of a double edged sword isn’t it, sort of wanting to know

P9: Yeah

I10: But then the pain of knowing
We needed to know, we needed to know. Because as the specialist has said, you know, what’s going to be really key for Will, is the support he gets. Um, so we were then armed with a diagnosis. She was absolutely brilliant, I think of all the people I have ever met, and we were only talking about this the other day, myself and my husband, and we were saying, you know, out of all the professionals that we have met, who would we rate, kind or really rate? And we would rate her as being the one person who gave us the truth when everybody else had hedged. She gave us the truth but she did it in such a way that was, it was very sensitive, it was very optimistic, very positive, and what she did for us in a practical sense was wrote a very full and comprehensive assessment that gave all the professionals working with Will, and us, and everybody, guidelines as to how to go forward and that was extremely useful because on the basis of that Will got a one to one, um, support.

And the next stage was, of course, deciding on the school, ‘where does Will go to school?’ And, I remember a fairly junior ed psych, she’s actually, I’ve seen her recently actually and she’s much more kind of established now, but at that stage she hadn’t come across many children like Will I don’t think and she came to see us, and she said she really felt Will needed to go to the specialist autistic school, and we said ‘okay, we’ll go and have a look’, and we went and had a look, I think it was the only school we looked at, I think there is another but that wasn’t being mentioned. Um, we went to the school, but to me it just seemed like complete chaos, it was very noisy, a lot of children there who were far more severe than Will was, children who were incontinent, children who were banging their heads against the wall, who needed a lot of therapy, a lot of input, and we didn’t really see Will in that category. We, we, we saw Will as a child who had got difficulties, um, we had, we had with a lot of effort got him toilet trained, he was starting speaking, and we just felt he would be one of the more able. And we felt the school really wanted him because they wanted more able children in there to get balanced, to strike a balance, and we could see that, but at the end of the day we felt it wasn’t what we wanted, so we looked at the local infant school just round the corner here, where Stan our older son had been through, and of course he was now at junior school, and, ***** was on the governors there, and we had quite a good relationship with the school and we said ‘what about, would they consider taking Will?’ and they said ‘yes’ they would ‘with one to one support’.

Um, and they knew nothing at all about autism, very little, he was the only statemented child in the school, he was the only child really with any level of special need that had been recognized. And it was great really because the teacher who took him on was the special needs coordinator as well, and she was actually doing, she was doing a masters in special needs education, so she selected Will as her kind of study, and went out and she found out so much about autism and she did her study on him, and that was great because, kind of, she learnt a lot, and we learnt a lot.
We knew that everybody working with Will had to be trained, and at that stage there wasn’t any outreach, or there was minimal outreach, um, so we asked education to pay for training, and I fixed up, I sorted out the training for the staff which was down in, in fact in a school which is for Asperger’s children, but they do training for parents and the professionals, and I managed to secure a few hundred pounds from education to get people off to do training. Um, I took ownership of that because I knew it wasn’t going to happen unless I did that. The school were great, you know, they all went along, the head teacher went, the special needs coordinator, Will’s helpers went, and they were all really keen to go.

And he had a very good experience, I think, in infant school, I mean there were ups and downs, but he was integrating and he was doing quite well, um, but then it came to middle school level, because it wasn’t a straight through school, and he had to move, and we could see that by the time he got to seven, eight I think he was then because he was in the first lot that moved on, um, we just knew that he was needing to move away from one to one, but he needed a much more of a unit type situation because just being thrown into junior school would be very difficult. But the county said ‘no’ he had to go on to junior as he was, with a one to one, and we said ‘well no, I don’t think so’. So, we went and round and looked at possibilities. We looked at a couple, one of which had a special needs unit. We liked the other one, and Will had an assessment there, and the head teacher at the time, um, had said that he would accept Will, but the local authority were saying that they didn’t want to pay. They didn’t want Will to go to that school.

So we appointed a barrister, who is great actually, he fights quite hard for families, and he does it, although he is a very respected barrister, he does things at a lowish rate for families, I think, because he only charges you basically for the days he works on the case, so it was possible to appoint him, and he did, we did masses, we had to do as parents, masses and masses of work. We had together papers, the files are still upstairs, we must have about three massive files on the information we had to get together to go to tribunal, and the barrister, we sent everything to him, and he was really great. And he wrote loads of letters on our behalf, and we were about three days away from tribunal, and um, the um, authorities said ‘no, you’re okay, can have your place’. But then we had a real blow, because the school decided they didn’t want Will after all. And they wrote to us to say that on balance, although they had assessed him and they’d accepted him, they felt he wouldn’t fit in with the other boys in the school at that time.

What we didn’t know then was that the headmaster was under er, under um, what’s the word? Well very shortly after, he was suspended, for, for physical assault, on two boys at the school. So we were very pleased that we didn’t send Will there in the end!

But at the time I thought I thought this headmaster was a bit dodgy actually, and he’d, he’d been very, he’d been saying things to us and then obviously he’d then written to us, and we’d complained about him, this was before he was suspended,
we complained about him to the governors, that we’d been led down this path, and that we were suddenly disappointed, even though the authority had agreed to pay, and it was just a nightmare. Anyway, in the end the school said ‘no, they weren’t going to accept Will’, so we went for the other school, mainstream junior school, but it had a unit, and Will went there, and he was given a place there. Of course, the authority were happy because they didn’t have to pay out for the other one.

I11: Was the other one private?

P11: Yeah, yeah. So it was all a bit of a mess. It was an absolute mess. But in the end we got Will into the mainstream junior, and for the first couple of years he did extremely well there, and there was a fantastic special needs coordinator who knew exactly what he needed. And she really like Will as well, and I think it took, you know, she made special, she really did work hard to try to integrate him. But then she left the school. And with her went the whole specialist knowledge. And they appointed somebody who really didn’t have a clue about autism and how to set things up, and it just went from bad to worse. And Will’s behaviour went, and well obviously he was getting older so, maybe it should be attributed to him getting older, he was about 10 at this stage, but, he just, he then started getting very challenging. Throwing things around in the classroom, uncooperative and the teachers wanted him out all the time, they didn’t want him in their classroom, and I was forever being called up by the school to go in, and to, to deal with any crisis. You know, that was quite, that was very frequent.

I remember one time, I was in the middle of an assessment myself, *, doing assessment somewhere, and I was called by my work ‘could I call Will’s school urgently’. And he’d done something, he’d thrown something at a teacher, and for them it was quite major. And I had to absolutely drop everything in the middle of an assessment with a family of somebody I was seeing. Um, I had to more or less finish it off very quickly, apologize, rush off to Will’s school, go in there and find the whole thing in chaos. They couldn’t manage it, they really hadn’t dealt with the issues and they weren’t dealing with the forerunner to this sort of behaviour, you know, they were just being, managing the behaviour when it happened, but not actually seeing what were Will’s triggers, what was making him go like this

And the last year was just really bad at that school, it was just really awful for Will, and for us, because there were just countless times when he was throwing a wobbly and the school didn’t know how to respond. So then

I12: How did you feel about that?

P12: It was awful because, the teacher that as I say was really good left, and we were trying really hard to work with the new teacher who came in, who really didn’t have it, and you know, and, and also with the therapists who didn’t seem to be
getting anywhere, and Will’s behaviour just seemed to be going downhill, and we were working very hard with him every evening, because he would come home with masses of homework every night, because he wasn’t doing anything at school. And we would sit with him for an hour or two every night, to try and work through things, because we felt he could do it, he’s perfectly able for his age to do Maths and English, but he just didn’t want to do it at school, he just didn’t like the environment.

And the worst thing, the really worst situation was the last day he was in that school, because he’d been given a part in the school play, the last day, the leavers’ play, and he’d gone into school and he’d got a bit of a wobbly tooth, and I remember looking, and I was in the hall, and I was a bit apprehensive about how he was going to be anyway, and I looked straight across and I could see him starting to agitate about this tooth. And instead of, I suppose they, they handled it quite badly, because he was starting to get upset, and they just took him out. And by taking him out of the situation and taking him, you know, into the playground, he then erupted because he was going to miss his part in the play. So he starts screaming and went hysterical and all the audience could hear it. It was really awful, he missed his part in the play, because somebody else stood in and did his part because he was in such a state, and I then went into the classroom afterwards, well I left the hall, I was just, I couldn’t even watch the end of the play, it was just so upsetting. And I went into the classroom where he was being held, and he was being held, because they just didn’t know how to control him. Um, and he was just distraught that he had missed his part, this was his last day, he was a failure, and everything was sort of really bad for him and he was leaving under this black cloud, and things had been so bad and that really epitomized the whole situation and the school were just powerless to do anything, you know they just didn’t know.

So I just put, put him in the car and took him home. Um, and it was really bad, that was a bad day, but the worst thing was there was no plans for where to send him, because nobody had come up with any ideas about what school he should go to next. We’d been through loads of secondary schools, we’d been to schools to look at them, ordinary mainstream secondary schools to integrate him, but nobody, just nobody wanted him. Even units like the specialist speech and language unit had been out to see Will at school and they’d seen what his behaviour was like and nobody, I mean we must have had about five rejections, and we’d even been into schools pleading to give him a chance. We said ‘please can you integrate him, please can you, we can put together an individual package to make it work’, but nobody would take him on except to say that ‘this child is out of control’ and needed a specialist environment.

I13:  But he was only out of control once he hadn’t had the sympathetic...?

P13: He was out of control because of the, yeah. Because of the change that had happened and because, the lack of expertise, and the lack of, I suppose Will did
have a chance to integrate, but nobody really took it seriously, nobody really knew what they were doing in terms of integration. Um

I14: But things had been okay whilst he’d had that, interested and sympathetic

P14: Yeah, yeah, that’s right, that’s exactly right. And the teacher who’d been there who was good, she was quite a powerful personality, and what she had, she obviously had at her fingertips, methods of how to work with kids like Will. She also had, a fearsome sort of reputation with the rest of the staff. She would say to them ‘you will take this child with, in the rest of your class, never mind you can’t cope with them’. ‘We will make sure that he is in that class and he integrates’. And so the class teachers, sort of, they were all pleased to see the back of her actually, the rumours were that they were glad that she had gone, but it was because she was so powerful as an individual and that she knew what she wanted for each child, she was determined, and she knew what she wanted and that just came across, you know, to us parents as a very kind of, you know she was very good, but in her absence, and in the absence of any kind of coordinated plan, Will went to pieces, and we were very angry about that as parents.

We really thought about legal action, actually, we thought he’d been really let down by the system, so much so that his chances of integration at secondary level were zilch. Nobody wanted him. Um, so then, um, he was out of school basically, we had nowhere to send him. I had to leave work, I had to get a special dispensation from work to, to take three months off so that I could kind of work with Will at home. Um, and then we had another blow. Because what was being suggested was the special school, which I mentioned earlier about their training for people which is very good, but the school is a very long way away, and the principal of that school and one other, which are two schools owned by a private concern that runs schools for kids with Asperger’s, Tourette’s, high functioning autistic disorders, she came to see Will and said ‘I’ve got just the school for you Will and you are going to love it there’.

So a day’s assessment was fixed up, she wasn’t the head, she was the principal over the two schools, but the head of this particular school, we met, Will went for the day, we were told it was almost certain when he got to that stage he would get a place. And the head decided she wouldn’t accept him. After seeing him for a day. Even though he had been assessed by the principal of the two schools. She wouldn’t accept him. She felt he wasn’t right for that school, even though, she said ‘he wouldn’t fit into a peer group’ and I said ‘well what Asperger’s kid fits into a peer group? For god’s sake, that’s what the whole problem is’. But she er, oh, oh, I had so many, arguments, well with her, and with the principal who first assessed Will and I said ‘I just, I can’t believe this is happening, we’ve again been lead down a path to say Will will be accepted, and then at the 11th hour, they’ve turned round and said no’. And didn’t really have any good reason, so, then we looked at the second school where Will is now. They assessed him, said ‘he is a lovely boy, we can do a lot for him, we’ll take him’ and they took him, but he
didn’t actually start until, I can’t remember now, probably near enough Christmas of, after he’d left school, so, yeah

I15: So it was quite a while

P15: He was home for about three months, yeah. Mm. And in that time he had five hours a week offered, from somebody who really had never worked with autistic kids before. It was just somebody from the bank of home educators, home teachers, from the county, who knew nothing. So I’d really carried the weight, carried the bulk of all of that

I16: How were you feeling then?

P16: Oh awful! Really. I mean looking back on it now, it was, it was just such an uncertain time, you know, it was horrible, what was hanging over me, we didn’t know what the future was, all we could see was Will milling around at home. I didn’t know what to do with him, well, we had to, we had to structure his day, but he was just bored. It was a very uncertain time, and very stressful, very stressful, yeah. And at that time, my older son was starting to have mental health problems, so he was having obsessive, um, difficulties, a lot of guilt, a lot of, well mental health, real mental health issues about himself. Not so much around Will, although I’m sure that’s played it’s part in Stan’s problems, but I think Stan then started to display quite difficult behaviours which lead to us seeing a psychiatrist for him, um, but I had Will at home as well, at that period. It was very difficult

I17: It must have been. Do you think it affected your relationship with your husband?

P17: Um, I think it’s, it’s always been really difficult for us as a couple, um, and as a family, because, um, you know, it’s always, we’ve always been under strain. Um, and we’ve always had to, you know, not only were we working at work, we were working at home almost full time in trying to achieve, you know, trying to get the best outcome for both Stan and Will, and um, it’s an enormous pressure. And we don’t have family, my family, I’m one of a big family, I’ve got eleven brothers and sisters, but they all, they all live in a different part of the country, nine of them do anyway, with my, my mum’s still alive. Um, and they have been good and come down from time to time, but generally, they are not here, so we haven’t had family support. And my husband’s family do not live near either, he’s just got one brother and his dad, and you know, they’ve never really been very supportive, so, we haven’t had anybody. I’ve got good friends, I’ve got a lot of friends in this area, but as a family. When Will was little it wasn’t too bad, but I think, as he’s got older, people don’t really want you to be part of their social circle. I think there’s a very strong, I think some of it, and it’s not fair to say completely because, some of it is that I’m, we’re very conscious, as a family, that Will will go running upstairs and go through their drawers and rooms and want to know everything about everything in their house. Which is uncomfortable for

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anybody, and you’ve got to have very good friends for them to actually put up with that.

Um, but from their part, I could see that one or two of those experiences with Will, and we were like crossed off the list. And they were happy to see me

I18: Yes, yes

P18: You know, I had plenty of friends who would see me for a coffee, or say, or try and, almost in their own minds, make up for it in that way, or invite us round for dinner as a couple. But as a family, we were clearly struck off the list in terms of Will never got any party invitations after he, after he was beyond about six I don’t think. Um, we weren’t invited on walks, we weren’t invited on camping weekends, we weren’t, you know, it’s endless the things that people do that we were not part of

I19: Barbecues

P19: Barbecues, things like that and you know, things that we were always concerned as well that if Will got bored, he’d open the gate and he’d be off. And we were always watching him, and we were always, always conscious. You know, and now we’re, I suppose now Will’s older, we’ve kind of accepted that that’s just the way it is. But we’re definitely not part of the same sort of social scene that people are, my friends are. And it gets harder. Actually. I think it does get harder because, I used to be so full of optimism, optimism for the future, and we’d got, we’d made such good progress with Will in the early years, that I used to, as a parent, go and talk to parents of newly diagnosed, you know, parents of newly diagnosed children, and I was always really fired up with optimism, and, you know ‘you can go out there, you can do things, you can fight the system, you can get what you need for your child’ but I actually nowadays, now that I, Will has got older, and we still, we’re set with them, we’re just faced with another set of problems.

The reality that it doesn’t go away, is, is quite hard because you, you know, and I don’t want to talk to parents now almost. I do talk to parents, but I almost feel guilty that I’ve got a child of thirteen who’s still autistic. Do you know what I mean? It’s really hard. Because I think when they are three and four, you don’t really want to see them when they’re thirteen, you don’t really want to know that at thirteen, you’re still fighting. You want to know that you’re fighting now, but your child is going to be okay, they are going to be okay, but and that actual, when people say they come to terms with it, people say ‘yes, you have’, but you don’t come to terms with it. I think I’ve only just, I’m only just coming to terms with it. That Stan, you know Will, and Stan as well, Will is thirteen years on and I’ve struggled for all these years and I think it’s only now that I can see, that I can accept the future. I know what the future is, now, and I didn’t then, and I don’t think I would have wanted to know, then. That’s just my view, but um
I20: That’s interesting

P20: I just feel that, I have a friend in the village who has a son who’s four, who’s autistic, and she’s very, she’s great, and we’re very good friends, and she seeks me out a lot when she does have problems, and, you know, all sorts of struggles they’ve had, very similar to us. But I almost feel guilty talking about Will and I almost, not hide Will away as such, but I feel awkward that, and I feel awkward talking about the problems we still have because I’m very sensitive to her feelings with a child of four. Do you know what I mean?

I21: Don’t want to sort of make things look bleak

P21: I don’t want to make things look bleak for her, no, I, I, don’t. And I don’t want her to think that you know, ten years on she will still be battling the authorities the same way we are, because we still are. It’s not plain sailing where he is now. I feel that the school, although they are a specialist school, don’t really have, um, a very effective plan in place for Will. We’ve had to go into the school and set up a holistic development plan with them. Because we don’t feel they’ve actually got to grips with his, his needs, um, and we, we feel a sense of urgency now, that we’ve really got to address his behaviour, he’s still quite challenging and very angry. And we’re just now saying this has got to be addressed at thirteen because in ten years time, at twenty-three, we may have an adult who is completely out of control, or who is in residential care, or who is in, um, you know, getting in and out of trouble with the police because he can’t control his anger. So those sorts of things are issues for us now, as he’s approaching adolescence and adulthood, whereas, obviously at three or four, we had no idea that all of that sort of stuff was going to be ahead. And, um, that’s why it’s difficult, that’s why it’s difficult I think, difficult for me to talk to parents, sometimes. I still do, but I’m very careful, I’m very careful. Mm

Yeah, so as a family it’s been tricky, anyway, and our relationship, I think has suffered. I think it has really suffered. Um, to the point where you know, we, we, we’ve discussed separation, we’ve discussed um, each living, you know, having obviously, one of us moving out. We never quite come to the conclusion about which one it should be! Um, but we still get through. We carry on, you know, we just, um, to have two children with real difficulties, to actually split up would just exacerbate the situation I think, and I don’t think I could live with the impact of that on either of them. And I think they are very sensitive to the rows and stuff, and any tension. Will is enormously sensitive to tension, he just wants a quiet life, completely. And any sign of distress or upset or arguments, he goes over board. He gets really upset. So the impact of him on our, you know, feelings of, our own feelings as a couple is just, um. You know, sometimes you just want to say ‘well lets just have a quiet life, lets just sweep all of the stress and everything under the carpet, and have a glass of wine and put our feet up and watch the telly’
which is what we do, a lot of the time, just to completely relax, you know, to kind of switch off from it all.

You know, but yes, it's not been easy, you know. I think my husband is, and he recognizes it in himself, he, he has, um, he's quite intolerant, he's got, he's quite impatient, he doesn't always see things from other people's points of view. Um, he, he, er, he doesn't really think he's classic Asperger, although I've often accused him of it. I think he thinks he's more somewhere along those lines, but not really

I22: This is your husband, you think is autistic?

P22: This is my husband, yes I do. Yeah. He's a **************

I23: Right

P23: So he has, that sort of profile, um, very single minded, very bright. Always been into ******* research, um, he now manages projects but he used to build *******, you know, build equipment to ******* Um, so he's very bright and he's, um, I think, I, I just think, he's got a real short fuse, you know, so, so that's lead to a lot of tension as well. And family holidays, are an absolute... I don't know why we still have them quite honestly. I really don't know why we have family holidays. Because they are always a nightmare. Every single holiday period is an absolute nightmare.

And I, I think it's because, and it's not just going on holiday, um, I think it, it's actually everybody being together. Four people, three of which, and I don't know if, I don't think I class myself in there, although I might be! I don't know! Living all these years with a, a, you know, three of which have specific difficulties, is quite tough. And they all bounce off each other, you know, the actual all trying to keep it all under a, keep a lid on it all. Um, it's difficult as a family. Um, it works much better if we've got a routine, and if we're busy. So, if my husband's at work, I'm at work, Stan's at college, Will's at school, and we just have limited amounts of time together, it kind of, it kind of works. Um, but again, you're not fitting into the profile of the family, you know

I24: It's not what you expected

P24: No! And when people say. No it's not what I expected at all. And when people say to me they've had 'oh a lovely holiday' or whatever, I think to myself, I don't really know what one of those is. And I don't. But it would be nice, to have a holiday, without any mishaps. So, so for holidays, I have to start planning for them months in advance, because I know they're an absolute disaster unless I do. So, for example support for Will. I have to look at what clubs are around, but he doesn't really fit in anywhere. Because he doesn't really see himself as special needs. So he, we have to send him to things like disability challengers, which I
do occasionally. He looks around at kids in wheelchairs, or kids who have other
difficulties and he thinks ‘why am I here?’ You know ‘I’m fine’. Everybody else
is like, you know, but he’s fine! He sort of sees himself as fine

I25: Yes

P25: So, he then questions, but he’s END OF TAPE
Really, the ideal situation for Will is a one to one support worker who
understands him and can go with him to things. Um, and I’ve just actually, um,
for the first time, I’ve requested a social worker so that I could have a carer’s
needs assessment. Um, Will is obviously coming up to transition, so I felt he
needed a social worker any way. I, I’ve been his carer for so long, I thought he
needed somebody independent. But from my point of view, I had a carer’s needs
assessment which meant I was eligible for a direct payment of money, um, which
I’ve just got and that will be paid into an account and that will pay for support for
Will in the holidays, because it’s horrendously expensive. I mean, to get a
support worker for a day, which I did I think, the last holidays. It cost me a
hundred pounds just for the support worker, and then I had to pay like for the
theme park where they went and the trans, and the mileage and all the snacks and
everything, so it cost me near enough, two hundred pounds. For a day, because
he needed one to one support, so, but I was at work, so it was like 8 in the
morning, or half 8 ‘til 5 or whatever. Anyway, it worked out at near enough two
hundred pounds

So anyway, I thought ‘I really can’t be paying that sort of money for him’, so I’ve
got some money through a direct payment, for, and. I feel, it really, you know, I
tell a lot of careers that they can do this. I mean, I know the system because I
work with it in, because I work with *********, so, I know the system in side
out, so I knew I could make use of it. Though there are many more people out
there, I also feel a bit guilty at taking it, because I know that we are, compared to
a lot of people, we are, we’re okay financially, but still it does still bite into the
finances when you’ve got to pay for special needs support. But I tell as many
carers as I can that they’ve just got to go and do this, and get a payment, in their
own right, for respite care. Um, and just to get it recognized, because there are so
many people out there who are not getting what they should be getting

I26: It sounds as though you feel that people, lots of people are struggling due to lack
of information and lack of awareness

P26: Yeah! Oh God’! Tremendously. I mean I’m on the ******** national helpline,
so I get a lot of calls from people who, who just don’t know where to go. They
just do not know where to go. They maybe get handed a booklet, they are
diagnosed you know, locally or whatever, they are handed a booklet, and that’s it.
And they are told to go to a library. Or to go buy some books, and go and buy
Tony Attwood’s book on Asperger’s, and that’s, you know, the number of people
who tell me that they are merely sent out to buy books, is just terrible. And they
don’t have access to a pack, like a pack of information on what they should, you
know, like where they should go. It’s my view, and I think it’s the view of a lot
of parents, that there should be a key worker system, so when you have a child
who is diagnosed, with autism, um, or any special need really, you should have
somebody identified. In whatever discipline, it doesn’t really matter that much. It
can be health, it could be social services, it could be, whoever you are in contact
with, but one person is your coordinator and key worker and they will pull
together a plan, and they will look at any issues as they come up and they will
advise and support, and a lot of people are doing that informally, you know,
health visitors and social workers are doing it informally, but there’s nothing
actually formal for parents

I27: So it’s the luck of the draw as well isn’t it

P27: Yes

I28: As well, as to how much understanding they have about autism and, what it

P28: Yeah, of the, the, do you mean the key worker or the parent?

I29: Yes, the keyworker or whoever, to, you know, as to how much understanding, or
personal interest I suppose they have in autism and knowing

P29: Yeah, I think you do certainly need to know, you need to be clued up on the
condition and also where people go. And you can’t do all the legwork for them,
you’re never going to be able to do that. But you could actually go with people
to reviews, um, be a bit of an advocate, um, help people out with the benefits side
of things, because they are entitled to disability living allowance, and a lot of
parents don’t know that, don’t know that they are entitled to mileage if they are
taking their child to a specialist nursery of whatever. I didn’t know about it,
nobody told me, it was ages before I found out that I could actually claim mileage
for taking Will to the specialist speech and language unit. Um, there’s all sorts of
thinks out there, there’s again direct payments, not just for carers but also for
children now, that can be administered by parents, so if you want to get care
services, you can actually get a sum of money in an account and spend it, but it’s
audited, you know, by your social worker, but that’s possible. Um, there’s loads
of things, the disability discrimination act now covers children, covers all sorts of
things, and the carers and, you know, disabled children’s bill, there’s lots of
things backing up where parents can get support and get, you know, resources.
And also, not only that, they can fight the discrimination that they come across
from schools, for example

I mean I met a woman recently, locally, whose child has been excluded from
school at lunchtimes, and you know, because he’s seen to be different, he’s
waving a fork around or something, and they’ve excluded him on the basis that
he’s unpredictable, and that’s completely against the, you know, that’s
discrimination. The parents could fight that very hard on legal grounds. They’d have to know that. I mean we saw it all the time with Will, he was excluded all the time from after school clubs, they didn’t want him because they didn’t have the support and they would say ‘no he can’t join in’ so he never went to an after school club, unless I went and stood on the side lines if he wanted to say do sports or something, they would only let him if I was there. And then I would kind of go rushing over or something and then he’d miss his transport home, of course, and so then there would be no provision. That sort of thing. Parents don’t really realize that they can really fight against, and they need an advocate, every parent I think needs a key worker or an advocate, somebody on their side. It’s too ad hoc. And so, I just really feel for parents. I feel very sorry that they are in, you know, in horrendous, some of them are in terrible situations. You know, people who’ll ring me and they’ve got maybe three or four children on the autistic spectrum, you know, and you just think ‘how on earth do they cope’. When they don’t have anything, really. Don’t have any support. Um, so yes, I consider us as fortunate in lots of ways in that we do have skills, we do have means, we do have ways of fighting, we are fighters, we don’t sit back and accept, I suppose, what’s handed out, we question everything and we’re Will’s, we’re his assets, real assets I think, for his future, because, and I think my work in ******** |s really helpful, I can see what resources there are out there, I’m constantly in contact with agencies, I work a lot with brain injury, um so I know, there are very similar issues for people with brain injury as with Asperger’s quite often, and I think I kind of know what’s out there and what’s possible and I know, I’ve got an insider view, if you like, yeah

I30: Yeah. I’m just curious, when you say about people with brain injuries, do you think, do you see that there’s a difference in the way people are treated, whether they’ve got Asperger’s or brain injury

P30: Yes, yes. Definitely. I mean people with brain injury have got a recognized track of resources and funding, they come through physical disabilities budget, because it’s an injury, so they then go through that, have access to assessment, um, anything to meet their needs. Obviously, there’s always arguments around what’s to be provided, but it’s provided in the main. People with Asperger’s, they are not recognized, they don’t fit into any category at all at the moment. Learning disabilities won’t touch them because Asperger’s, people with Asperger’s have an IQ over 80 or whatever, so learning disability will only look at people with a low IQ. Mental health do not see Asperger’s as coming under their umbrella, obviously there are mental health problems associated from time to time which they will address through treatment, but they don’t by and large, will not pay for any provision. So as it stands at the moment, people with Asperger’s Syndrome do not get a service. They don’t get a service. And that’s a real problem. Nationally as well, not just locally, er, but where we stand now with Will, is very difficult. There’s no way I’m going to say he’s Asperger’s, he’s down on the disability register as autistic spectrum disorder, and I would say to any parent, so not put Asperger’s, if the child is young and diagnosed with Asperger’s, although
that's an accurate diagnosis to a certain extent, almost better is autistic disorder, high functioning autistic disorder, because they may just, may just squeeze into recognition on the register, and secondly, some sort of provision. Although the high functioning bit is again, is again a bit, a bit, I don’t know, it could exclude them from the learning disability service. I don’t know where they’d fit. To be quite honest with you, it’s a real worry to me about the future for Will, because although he’s not seen as Asperger, I can see, I can see very clearly, eighteen plus, if he is in need, of any kind of supported living, or any sort of supported employment situation, quite honestly, I can’t see where he will get it from, unless the criteria change.

Because if the county are recognizing now, they have actually appointed somebody to do a project, a project manager to look into the whole autistic kind of er, um services really

I31: Do you think parents of Asperger’s, autistic children, are treated differently from the parents of say brain-injured children?

P31: I, I think it depends, because some autistic children are seen as having learning difficulties, and therefore, um, get a service, and I wouldn’t say they’d treated any differently, they would get a social worker probably assigned to them, they would have specialist help. I think where the problem lies is when they are deemed to be higher functioning, and they don’t actually, I mean I know of a single parent who has two sons and her younger son, and she’s got massive difficulties, you know, just in coping with the two boys, both with difficulties, but then neither of them fit into the learning disabilities scheme because they are both high functioning, one has mental health problems, one has Asperger’s. And what I’m saying really, why I’m quoting that example, is because the younger son is getting a service from learning disabilities at the moment because of the just, because of the problems that he has, but what she’s getting from the professionals working for him is them saying ‘we shouldn’t really be doing this, you know, we shouldn’t be providing this to him, but we are doing this as an exception, but we shouldn’t be because he doesn’t fit our criteria’. But there’s nowhere else she could go.

I32: So how do you think people see the parents of autistic children, how do you think you are perceived?

P32: Um, I think we are seen as very troublesome. We’re seen, we as parents, from our point of view, we are always treading a fine line between getting the backs up of professionals, but making it very clear to them that we’re not, we’re not, we want the best for Will. We’re not interested in shoddy practice, at all. We want the best for him, you know, the most informed practice that will help him, um. But at the same time I think you can go too far in pushing for your child so that you get their backs up, and then your child goes to the bottom of the pile, and I know that happens, um, and I’m very conscious of the fact that we can alienate ourselves as parents, by being too aggressive and too strident. And that’s quite
hard as we are actually quite strident! We are quite strident people. Um, but we are always very aware that that’s a line that you tread with professionals, and it really is a line, you tread. And it’s not just me, I think every parent will say that in that they are almost scared, you are almost scared of any kind of backlash if you go too far. So you are always trying to keep people sweet, but at the same time you are always trying to, to almost get into their minds ‘if it was your child, what would you do?’ And I quite often use that method. I quite often say to professionals ‘look if he was your son, you know, what would you do?’ And they go ‘yeah, dead right, we’d do exactly the same as you’re doing’. And I say ‘well try and look at it from that point of view, try and imagine that it was your son with all these difficulties, what would you do?’ And they would fight tooth and nail. And as we do, you know. But I think you’ve almost be, get on the human side, of things, with professionals, you’ve got to really relate to them as equals, but from a human point of view, rather than it being a battle. Because battles are just very, very wearing for every body

I33: It sounds as though (inaudible)

P33: Oh yeah, yeah. I mean I think that, there’s not enough resources to go, I mean we all know that, the resources are limited, and er, people to an extent have to fight, but I don’t think that they have to fight to the extent that they do in this county. I think other counties get it, get it much better. You only have to look at the tribunal rate in this and the next county, they are the highest. They take parents to the wire time and time again in this area, whereas in other counties they seem to dispel that sort of thing early on, maybe they have better systems in place in their education, you know, the way they are set up, um, maybe they have more inspired, more creative people who are leading, um, planning, you know, educational and social planning. I think you do see a difference in different parts of the country where you live, and, I don’t think people have it so hard as they do here. I do think this county is a hardnosed county, but not very informed. And parents, and parents can recount such horrible ‘phone calls that they have with, you know, not so much with professionals very often, but sometimes it can be even the receptionist or somebody who is consistently refusing to listen to them. So it’s tough. Mm

I34: So, could we talk about just a couple of things we haven’t covered directly, did you have any particular thoughts on what causes autistic disorders?

P34: I think it’s genetic, to be quite honest. I don’t think it’s MMR. That’s not to say I don’t think there’s some value in the MMR, I think it’s genetic, I think there are some strands in you know, you can look, I can just see it really, genetically, and not just um, my husband’s side, but I think from my side of the family, I think there are, my sister, my eldest sister who has had very serious mental health problems in the past which were possibly related to schizophrenia, and I do have a cousin who was, was labeled as schizophrenia, although now he’s like in his sixties now, but I would probably say that if he, if he had his time again, he may
be seen as autistic or you know, he has sort of learning disabilities and mental health problems, so, he’s my mum’s brother’s son, so he’s a first cousin. Um, so, I think it’s just an unfortunate coming together of genetic, you know, bits and pieces, that, that have made, that have come out in Will, and in Stan to an extent

I35: And what would you say is the worst thing about being the parent of an autistic child?

P35: Oh, God! Loads! The worst thing? The worst thing? Some of the, I should think social isolation. I think you feel cut off, from, other families, unless they’ve got an autistic child! You know, I do think people band together if they are in the same boat. So, social isolation. I think, um, stress. Just really family stress, and the, um, just the day to day difficulties, not having a proper holiday, for example. ALWAYS having to face endless, you know, difficult situations really, always problems, never, nothing ever really straightforward. I think the er, the uncertainty about the future, is, is always in your mind, you know, you know that, I mean I know that at least one of my sons is probably not going to be independent, and he’ going to need life long support, and so that’s really difficult as well. Yeah. Can we stop for a minute?

I36: Is there anything else you’d like to say?

P36: I think we’ve covered most things. Er, I think we’ve got a long way to go, really, in understanding autism, you know, and in, in, professionals and working together, in any body understanding where it comes from, um, what’s the best way of managing and helping children with autistic difficulties, and getting fairly slick assessments and planning in place, because at the moment, it’s all over the place and, I think, you know, ten years on I’ve been kind of seeing it and I don’t really think much progress has been made, in terms of helping parents through those early stages, getting comprehensive single assessments in place so parents don’t have to deal with masses of professionals. Um, and just in the general long term planning for these children, because I feel that the parents are so often at the mercy of professionals who don’t really have any, enough information, don’t really have the training and they don’t know, they don’t have the skills and the methods and everything that, especially if the push is to integrated these children which it is very often. I really don’t think the mainstream schools have it together, they do not have the knowledge base and the skill base to be able to offer a sort of effective plan for these children and service. I think we’re still very much in infancy, and I just think they’ve got to work together, the organisation, the education, social services, health, have got to work together in a much more coordinated way to provide for these parents so that they are not feeling that they’ve got to do it themselves.

Because at the moment, the parents really feel isolated, they feel that there’s nobody, and I think that that is such a common theme that I hear, just on the helpline when I take calls. Such a common theme is isolation, and just feeling
very kind of er, I don’t know, very, just very let down if you like by the services. There’s so much mediocrity out there, which is such a shame, yeah

I37: And so much pressure on relationships as well

P37: Yeah, yeah, yeah definitely, yeah. Big, big area, but er, you know. I, I just think that’s just a symptom, isn’t it? Of the, you know, people not being helped, at an early enough stage, and people not being given enough support, you know, is that you know, the consequences are really very wide. And I think it does affect relationships. I mean I don’t many people who are still together, actually, with autistic kids. I think we’re probably one of the few couples I know of, I would say most of the people I know are on their own. Or separated, you know, live, still both have contact, but they’ve divorced, separated or divorced. So I think there’s a lot of that. Okay?

I38: Is there anything else?

P38: Oh yeah, one other thing I think is that, um, parents are seen as difficult, being difficult, and I think at the back of the professional’s minds, certainly, I’ve certainly seen it, what’s going on in their mind is ‘are these parents on the autistic spectrum as well?’ very often, that’s what comes out of it. And I think they, they also, labeling you as, as maybe somebody who has caused, somehow caused the difficulties that your child is having, so, they’re presenting with challenging behaviour, ‘there are difficulties at home’, or you know, you know. That’s so difficult to take as a parent. And there’s two, actually just two things that come to mind that I’ll say before we finish, um.

One is that one evening I went to a talk, Will was about 7, and a psychologist, a well known and well respected educational psychologist in this area, came to give a talk, and she very quickly got on to parenting skills. Saying that, telling us basically that the fact that we hadn’t, possibly hadn’t spoken to our child in the same way, hadn’t rocked them, hadn’t, maybe they’d been second children and we were busy with our first children and we weren’t kind of giving the attention that we should have done. The strong implication in her talk was ‘refrigerator mother’, STRONG implication. And I was so angry about what she was saying that I actually stood up and I walked out. And I said to her before I went ‘I though this sort of thing had gone out in the dark ages’ and the fact that she was sitting there talking about parenting skills and telling us that we hadn’t done this and we hadn’t done that, and that may be, could have been a result of our child being. Yeah, I won’t tell you who it is, but, anyway. I walked out of that talk.

Another talk I went to, this was as a professional, and I went to a course, a day’s course on autism, and I felt ‘well I’ll go, just to see’. And there was a very, very strong implication through the whole thing, it was, it was for professionals, they didn’t expect anybody to be there probably who was a, had any direct relationship to autism like me, as a carer. And, er, there was a very, very strong theme that
parents had to be handled carefully, because it was probable that they had autistic disorders as well. I stood up and actually gave a speech, I think, at the end to tell them what I thought about them. But um, there was a very, very strong ‘be very careful when you talk to these parents, don’t say too much, be aware that they’re probably like their children, um, you know, don’t give them too much information was really the strong theme going through it all and just always be aware that they could be kind of psychologically affected as well’ um, you know, in the sense that they are not quite compus mentus. And that was a very strong theme that came through, and I was disgusted that that sort of, um, that sort of teaching was being given to professionals. And, er, I mean, that’s not to say, as I said earlier I think there are genetic components, but I don’t think that you should, as professionals they should automatically assume that parents have got something wrong with them as well, because they are coming in on a premise that is very misleading. And it will lead them to treating the parents, you know, in a, in a kind of demeaning manner. Which is what happens. I think, not always, but I think it is there. And that there is a very strong element as seeing parents as being, not just difficult, but also as having something wrong with them as well. So, er, that’s a real sad state of affairs

One more thought, I have seen um, there are some mums, and dads, obviously, who are very stressed, but um, in my experience I’ve seen one or two mums who have really gone under with all the pressure. And one mum in particular, she was so low, she’d fought for years and years for her daughter, and she, I think she got bronco-pneumonia, and she just got so low in herself that she was admitted to hospital, but she was in hospital for 3 months, and that was with just physical illness, obviously she had a lot of emotional problems and anxieties, but I mean physical health problems associated with the caring role really, she was just um, just so worn out, completely drained, and to this day now, when I see her around, she has had to really take a back step, you know, she is now accepting much more that you know, her daughter may not have everything that her daughter needs through them fighting. But you know, they’ve had to come to terms with that because they are just so completely worn out. And I think, you know as a parent you’ve got to really look after your self. And um, make time out, take time out, make, you know, have treats, just do things that are pleasurable. Um, because it’s just, you know, if you don’t, you can become really, really ill, physically and mentally

I39: And you find that daily swimming

P39: Yeah, I go swimming almost every day, I go swimming every day and I go to aerobics twice a week and try to get out and about, see my friends, make time, even though I know I’m busy I seem to have this sort of inside me that says ‘right stop’. And if it’s all becoming too much, to just do something that’s pleasurable and something that’s for me and to put everything to one side for a little while and then get on with. And I’m very fortunate in that I’ve got good family in another part of the country and I go to spend time with them, and I’ve got friends I see
and just generally chill out a bit, and have a good time. And I think you’ve got to do that, or you do not survive as a carer. The stresses and strains are just too much, too much, and you need to find those little windows, time for yourself. And not feel too guilty about it, because the big thing is guilt, the biggest thing right through, for me, and I know for other parents I’ve spoken to, it’s, it’s guilt. Particularly, with kids with autism. Because you always feel you can go that extra mile and it might make a difference, because it’s such an unknown, I mean you don’t really know what’s going on within, in the brain, within the mind of an autistic child. And you know that with a lot of it there’s an element of choice, they’re choosing to do what they do. Um, particularly the high functioning ones, you know, they. There’s so much untapped potential, I think, in high functioning kids, that you’ve really, as a parent, you feel ‘if you just did this, and if you just did that, if you just did the other’ it may make a massive difference to their future, and you’ve got that hanging over you the whole time. That’s in your head the whole time. It’s this ‘if only I did a bit extra, if only I do a bit more working with professionals, working with the child’ that you’ll make such a difference. But you’ve sometimes just got to stop, because that pursuit of getting it right, that pursuit of wanting it to be all okay, can lead to you going under. Um, it’s a balance, it’s a real balance between, you know, trying to do what you can, but at the same time recognizing you own personal limitations.

And in the absence of professionals who are on your side, who are fighting for you, then you are, there’s a real danger that people can go under, so. I try to keep my head above water. Literally! Literally! I try to swim everyday and keep fit and try and keep healthy. Mm. Not easy. Hmm
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References


Bromley, J., Hare, D., Davison, K. & Emerson, E. (2002) 'The Health and Social Care Needs of Families and/or Carers Supporting a Child with Autistic Spectrum Disorders' for Manchester Health Authority (CAMHS) and the Joint Commissioning Team for Learning Disabilities. Manchester: NHS.


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Table 1: Participant Information
An investigation of factors influencing depression and anxiety in parents of children with autistic spectrum disorder, and implications for therapy

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Abstract

This investigation compared levels of depression and anxiety in 184 parents of children with an autistic spectrum disorder, 176 parents of children with Down's syndrome and 106 parents of children with no disorder. Experiences of parenting, attitudes to parenting and levels of locus of control were also examined in order to look for associations with depression and anxiety, and consider implications for therapy. Levels of anxiety and depression were highest in parents of children with an autistic spectrum disorder and associated with more negative experiences, more positive attitudes and lower levels of locus of control. The findings were interpreted within the framework of Hobfoll's (1989) Conservation of Resources framework and a holistic, or eclectic approach to therapy was proposed.

Key words: Autistic spectrum disorder; Down's syndrome; Anxiety; Depression; Control
Introduction

Autism

Since autism was first identified by Kanner in 1943, this condition affecting relationships, behaviour, learning and communication, has remained the focus of considerable interest, research, myth and speculation, as seen in both the scientific and popular press (Hamlyn-Wright, 2001). In Kanner's original article outlining his observations and ideas, he wrote "All of our patients have come of highly intelligent parents ...in the whole group there are very few really warm-hearted fathers and mothers" and suggested "...the question arises whether or to what extent this fact has contributed to the condition of these children...?" (Kanner, 1943, p.250). Whilst this tentative query based on his clinical encounters was not invalid, the notion that the autistic child's difficulties were due to a lack of parental warmth soon took root and grew, and the term "refrigerator parents" became widely used to describe this group (Bettleheim, 1959, p.389).

Early psychoanalytic theories of autism also described autistic children who had turned inward to survive because their parents were un-nurturing, cold, distant and aloof, and parents continued for several decades to be blamed for their child's disorder in both the literature and clinical practice (Hamlyn-Wright, 2001). Nowhere was it suggested that the causal route might be different and that these parents could have become 'frozen' as a result of the particular demands and difficulties that parenting an autistic child placed upon them. For example, on the basis of Hamlyn-Wright (2004) it seems possible that these parents may in fact have been very tired, depressed and worried about their child and perhaps, on the basis of their child's behaviour, concerned about how others might perceive them and react.

The first research to challenge the notion of parental blame was by Rimmland (1964). His work demonstrated that many of the so-called 'damaging' parents had other perfectly normal children, and also that many of the autistic children went on to develop epilepsy, thus indicating a link between psychology and neurology. However, it was not until the 1980's, when cognitive psychology was found to be a salient dimension for the
understanding of autism that the emphasis on parental blame began to subside. A study by Baron-Cohen, Leslie and Frith (1985) proposing that the autistic child lacks a Theory of Mind, that is, a cognitive mechanism allowing the representation of mental states, created a sudden and intense interest in the autistic brain. By the end of the 20th century, neurobiological and genetic factors were also being considered and making contributions to the picture. However, whilst parents were no longer explicitly blamed for their child’s disorder, a review of the literature relating to autism showed an almost complete lack of consideration for the parents’ perspective and exploration of their subjective experiences and needs (Hamlyn-Wright, 2001).

This continuing bias in the literature is highlighted in a review of the research on behalf of the steering group from the National Autistic Society and Parents’ Autism Campaign for Education (Charman & Clare, 2004) which concluded that the distribution of research on autism published in the last five years (n = 1,222) as indexed by the ISI author count, was: 52% symptoms; 20% intervention; 18% causes; 4% diagnosis; 4% family and services, and 2% epidemiology. These findings, in conjunction with the fact that autism is now more common (1:110) than previously recognized (Wing & Potter, 2002), suggest that considerably more needs to be done in terms of looking at the families of autistic children, with a view to offering support (Wing & Potter, 2002).

The nature of the literature since 2001 does suggest that investigators have started looking more at the type of emotional and dynamic issues relevant to Counselling Psychology. This change in focus is of particular importance due to the common finding that parents of children with developmental disabilities are more at risk of suffering from depression and psychological distress than parents of children with no developmental disorder (Abelson, 1999; Olsson & Hwang, 2001; Beck, Hastings, Daley & Stevenson, 2004). It seems vital therefore, to try to understand the specific nature and processes of the difficulties that these parents face, in order to provide the appropriate support. Also, as parents of children on the autistic spectrum have traditionally been blamed for their child’s disorder, this may be an indication that they have rather different needs from parents of children with other developmental disorders.
Down's syndrome

Down's syndrome is a congenital disorder affecting cognitive development, first described in 1866 by British physician John Langdon Down. It is caused by the presence of an extra twenty-first chromosome, which emerges as a triplet instead of a pair (Lejeune, 1959). Around 1:1000 babies are born with Down's syndrome each year (Down's Syndrome Association, 2004), but unlike children on the autistic spectrum, children with Down's syndrome have physical characteristics, which make their disorder quite apparent. They tend to have a short broad neck and be of below average height and have a small head, which is flattened at the back. Their eyes usually slant upwards and have folds in the corners, and their hands are often short and square with short fingers (Kendal & Hammen, 1995). Individuals with Down's syndrome regularly score in the sub-average range on measures of intellectual ability, although there is considerable variability, and physical and emotional development is slow (Down's Syndrome Association, 2004). They may also have a number of medical problems including heart and intestinal defects and difficulties with vision and hearing, and like any individuals with a learning disability, children with Down's syndrome may have emotional and behavioural problems also (Kendal & Hammen, 1995).

Whilst there are broad similarities between children with autistic spectrum disorders and Down's syndrome in so far as both have a form of developmental disorder associated with cognitive impairment, there are a number of important differences that may impact upon parents' experiences and the ways in which they are seen and responded to. For example unlike Down's syndrome, an autistic spectrum disorder is generally an unseen disability and when an autistic child has an emotional or behavioural outburst, it is often seen not in light of their disability, but as a reflection of the parents' parenting skills (Gray, 2003). Children with Down's syndrome tend to be immediately and easily recognizable, and thus allowances are often made for their behaviour (Gray, 2003). Also, unlike children with an autistic spectrum disorder, they almost always receive a diagnosis within two weeks of birth, and sometimes even before birth, and parents are offered information, support and advice before leaving the hospital (Quemby, 1995). At no time
has it been suggested that parents of children with Down's syndrome might be directly responsible for their child's condition due to the ways in which they relate to their child, although it has been linked to maternal age (Hecht & Hook, 1996). There are also important differences in the ways in which children with Down's syndrome relate to others. In particular, they are generally far more amenable to positive social interaction than children with an autistic spectrum disorder, although as with any disorder, individual differences remain (Kendal & Hammen, 1995).

Conservation of resources

One framework from which to examine possible differences in psychological health between parents caring for children with different developmental disorders is the Conservation of Resources theory (Hobfoll, 1989). This proposes that a significant loss of resources, an inability to acquire resources, or a significant investment of resources with no reward, results in stress and anxiety. In this instance, resources can be physical, psychological or symbolic in nature and thus have an internal (for example, loss of self-esteem) or external (for example, loss of social support) effect on the individual. Hobfoll (1991, 1998) also outlines the notion of resource loss spirals. He suggests "...those who experience loss will be increasingly vulnerable to stress. Original resource levels, that may even have been adequate to combat earlier threats or experiences, become deplete. New loss events or threats then strike a weakened individual, who no longer has the armamentarium necessary to offset further loss. To the extent this continues or where stressors are intense, loss spirals will increase in velocity." (Hobfoll, 1991, p189).

Hobfoll's (1991, 1998) theory of resource spirals suggests a useful way to explain how disorders that manifest through stress and anxiety, particularly in relation to parents of children with a developmental disorder, may be triggered and maintained. For example, there may be a number of factors, such as loss of self-esteem, loss of social support, loss of control or loss of financial means associated with having a child with a developmental
disorder which impact upon well-being, and there may also be important differences in these factors according to the child's disorder.

**Recent Research**

A phenomenological study by Hamlyn-Wright (2004) sought to identify the significant issues for parents of children on the autistic spectrum, and the themes that arose from the data reflected a number of consistent problems. Most parents reported difficulty in obtaining a diagnosis, with the process often taking several years, involving a multitude of professionals and causing much frustration and distress. Having achieved a diagnosis, many parents then experienced feelings of bereavement, such as anger, guilt and loss, but many also felt a sense of relief too. Most parents also described a seemingly endless 'battle' or 'fight' with 'the system' in order to acquire what they deemed to be the appropriate information, funding, education, integration and support for their child. They also described feelings of isolation and exclusion, and recalled incidents where they felt they were seen as 'difficult' or a 'bad parent'. Most also reported strains upon relationships with family, partners, professionals or peers, as a result of the difficulties associated with their child on the autistic spectrum, and many described exhaustion, lack of support, feelings of loss of control over their lives, and 'struggling to cope' too. Notably, apart from having to 'fight the system' these themes appear to be consistent with the focus of much of the recent research.

For example, the issue of diagnosis has recently attracted some investigative attention. A study by Nissenbaum, Tollefson and Reese (2002) looked at the impact of diagnosis on families and professionals, finding that parents often experienced relief on the basis that the problems they faced were not due to any lack of parenting skills, and that they now had an explanation for themselves and others as to why their child exhibited unusual behaviours. Some parents in the study, however, did not believe the diagnosis, becoming

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8 Some parents also discussed both positive and negative effects upon siblings, but this aspect is beyond the scope of the current study.
angry and questioning the professional’s ability, and it was found that the reactions of those who suspected their child had autism were significantly more positive than those who did not. Many of the parents had worries about how close relatives and friends would react to the diagnosis, and many of the parents and their families, in keeping with other work (Hamlyn-Wright, 2004) reported going through a grieving process. Importantly, it was found that regardless of their reaction, families did not feel that a diagnosis of autism influenced their interactions with their child.

A study by Gray (2003) looked at the impact that children with Asperger’s syndrome had on the family and found the median age of diagnosis to be nine years, meaning an exceptionally long referral process involving a large number of contacts with professionals in the struggle to find an accurate diagnosis. Most often it was mothers who had this responsibility and they perceived several negative effects associated with the failure of health care workers to make a quick diagnosis. Firstly, they had the difficulty of relating complicated and often inaccurate information to their husbands, and secondly, the absence of an accurate diagnosis exposed many of them to charges of incompetence by health care workers, as well as their husbands and other family members. Gray (2003) also found that mothers in particular, experienced considerable guilt and depression about their child’s disability and that diagnosis meant they also experienced a number of additional domestic tasks relating to treatment and education issues.

Brogan and Knussen (2003) investigated satisfaction with disclosure of the diagnosis of an autistic spectrum disorder, finding 55 percent indicated that they were satisfied or very satisfied with the disclosure. Parents were more likely to be satisfied if they gave positive ratings about the professional and the quality of the information provided; if they had been given written information and the opportunity to ask questions, and if their early suspicions had been accepted by professionals. Those gaining higher satisfaction scores were more likely to have been given the diagnosis of Asperger’s syndrome (as opposed to autism); to have had a definite diagnosis; and to have children who were not currently in an educational placement, underlining the importance of the interaction between parent
and professional during the disclosure interview, and the need for early and accurate
diagnosis. These studies suggest that the process of obtaining a diagnosis of an autistic
spectrum disorder can be an extremely stressful and protracted experience, and that the
way in which parents react may be mediated in part by the nature of the experience, as
well as their own cognitive appraisals.

Parental stress and social support are also factors that have been examined. A study by
Hasting and Johnson (2001) found that parents of children with an autistic spectrum
disorder reported more stress than parents of children with other developmental disorders.
They proposed that this might be due to the effects on the parent of the autistic child’s
withdrawn or socially challenging behaviours. However, a study of 58 parents with an
autistic child by Dunn, Burbine, Bowers and Tantleff-Dunn (2001) looked at moderators
of parental stress and found that the relationship between stressors and negative outcomes
was moderated by social support and the nature of their coping style. This poses the
question ‘why should it be that parents of children with an autistic spectrum disorder
have less social support and a less effective coping style?’

From a slightly different perspective, Abelson (1999) conducted an investigation to
identify the respite care needs of families with children with disabilities and the ways in
which a lack of respite impacts upon these families. In doing so, he identified factors
associated with parenting in general as well as stressors that are strictly related to
parenting an autistic child. These specific stressors were: isolation from the community
and family events; infrequency (or more usually, a total lack) of holidays; the passing up
of employment opportunities; marital conflicts and financial strains (tied in with missed
employment opportunities). Apart from financial strains, each of these factors is in
keeping with recent findings, such as Hamlyn-Wright (2004), and all of the factors seem
to fit within the Conservation of Resources theory framework.

The idea that having a child with an autistic spectrum disorder has the potential to place
financial strains upon parents is supported, however, by the findings of a ten-year
longitudinal study by Gray (2002a). This investigation found that parents of children
with autism often experience serious limitations in their career options, or have to give up their jobs completely. In keeping with other studies (Hasting & Johnson, 2001), this study also found that forms of emotional distress such as depression and anxiety are common among parents of children on the autistic spectrum. In a separate study, Gray (2002b) found that depression is more common in mothers than fathers, and that mothers tend to feel more stigmatized by their autistic child (particularly if they have aggressive or violent children). It was proposed that this might be attributed to the fact that mothers are more involved in their child’s daily activities and are more often the parent that takes the child on public outings. On this basis, and in keeping with other work (Hamlyn-Wright, 2004), it also seems reasonable to propose that the way in which parents of children on the autistic spectrum feel they are perceived and treated by others, on the strength of their child’s behaviour (DSM IV, APA, 1994) could be an important factor in terms of their well-being.

Indeed, Gray (2002b) also outlines five coping strategies that families with an autistic child tend to use to avoid stigmatization, each associated with restricting social interaction. The first strategy involves limiting the flow of information about the child in order to pass as a ‘normal’ family; the second strategy is to avoid excessive involvement with organizations that provide services for autistic individuals; the third is to limit public outings for the entire family, having people to the house less and opting for solitary outdoor family activities such as hiking or picnicking. The fourth strategy, linked with the first, is ‘selective disclosure’ which restricts who information is passed to, and the fifth is to only socialize with friends and family sensitive to the child’s condition. Gray (2003) cites religion as a further important coping strategy.

A study by Boyd (2002) also looked at coping strategies in mothers of children on the autistic spectrum and concluded that a sense of coherence is a key personality component, which affects coping ability. According to Boyd (2002), a sense of coherence consists of three components. The first component, ‘comprehensibility’ refers to the ability to view the world as structured and consistent, because if an individual is able to see structure in the world, they are less likely to feel as if the events that happen to
them are completely out of their control, and this sense of having some amount of control is important in effective coping. The second component, 'manageability' refers to an individual’s view about available and obtainable resources, because if a person has a sense that there are various resources, which can feasibly be accessed, they are much more likely to feel as if they are equipped to cope with the situation at hand. The third and last component of a sense of coherence, 'meaningfulness', refers to a person’s sense of their life (Boyd, 2002). These ideas fit well with both psychodynamic (Kohut, 1977) and cognitive theories (Young et al., 2003) of the self and the ways in which an individual comes to view the world.

_Locus of control_

Boyd’s ideas also fit well with earlier psychological research relating to locus of control, which is a concept that may also have bearing on the difficulties experienced by parents of children on the autistic spectrum. In addition, they fit well with Conservation of Resources theory and the notion of resource loss spirals. White’s (1959) examination of non-homeostatic needs and drives, identified a basic need to confirm a sense of personal competence. That is the need to feel capable and able to understand, predict and control the world, rather than feel at the mercy of external forces (Rubin & McNeil, 1983). The need for control is closely linked to the need to be free from the controls and restrictions of others and for an individual to dictate their own actions and not be dictated to. According to Brehm (1966), when a person’s freedom is threatened, they tend to react by reasserting their freedom, a process he termed _psychological reactance_. According to Seligman, (1975), when people initially expect to have control over the outcomes of their actions, the first experience is likely to produce reactance, but further bad experiences are likely to result in _learned helplessness_. Seligman (1975) also suggested that human depression can be explained in terms of _learned helplessness_ – the original anxiety being replaced by a state of inaction, or inhibition of coping behaviour (Seligman, 1975).
Seligman (1975) attributes learned helplessness to a loss of control, and it seems likely that the types of difficulty experienced by parents of children on the autistic spectrum, such as difficulty in obtaining a diagnosis, difficulty retaining a job and social isolation and stigmatization are all factors likely to result in learned helplessness, and thus a loss of control. There are important individual differences in how control is perceived, and Rotter (1966) proposed the locus of control concept to refer to relatively stable beliefs about what controls events in an individual’s everyday life and how they are reinforced for their actions. Johnson and Sarason (1978) devised a scale, based on Rotter’s (1966) Locus of Control Scale, called the Life Events Scale and found that life events stress was more closely related to psychiatric symptoms, in particular anxiety and depression, among people rated high on external locus of control than among those rated as high on internal locus of control. External locus of control is a tendency to attribute successes and failures to fate, luck and powerful others, whilst internal locus of control is a tendency to attribute such events to one’s own efforts and behaviour. This suggests that levels of depression and anxiety in parents with children on the autistic spectrum may be associated with external locus of control, which in turn may be linked to their experiences of parenting.

Therapeutic approach

These ideas have important implications for therapy. Traditionally, parents of children with an autistic spectrum disorder9 have been conceptualized within a psychoanalytic (Bettelheim, 1956) or psychodynamic framework and Object Relations theory in particular, which is essentially an interpersonal approach, does provide a salient lens through which to look at how parents relate to their child and others (Hamlyn-Wright, 2004). However, if it is hypothesized that the parenting of a child on the autistic spectrum might trigger parents to present in a certain way (that is, with low affect) as a result of their specific experiences and difficulties, it raises the question as to whether an

9 In keeping with the current terminology used by the National Autistic Society, children with autism and Asperger’s syndrome will be referred to as being on the autistic spectrum, or having an autistic spectrum disorder.
alternative approach might be more appropriate. For example, the cognitive behaviour approach, which addresses processing biases and distortions and is consistently found to be useful in treating anxiety and depression, could prove to be more effective. According to Beck's cognitive specificity hypothesis (Beck et al., 1979), depressed clients have a different cognitive profile from those with other psychiatric problems, showing primarily themes of loss, defeat and failure in their cognitive content. Newman and Borkovec (2002) also highlight the fact that anxiety is a common symptom associated with all mood disorders (the principle component being apprehensive expectation) and that research suggests worry prevents emotional processing (Newman & Borkovec, 2002, p.151). It seems possible therefore, that in the light of the notions of learned helplessness, locus of control and Hobfoll's (1991, 1998) theory of resource loss spirals, that cognitive behavioural therapy could be a particularly useful approach for treating the parents of children on the autistic spectrum.

Alternatively, the humanistic approach could also be very helpful as it places high value on the individual's experiences and his or her subjective reality, taking into account the influence of the environment and context. The approach sees each person as having an innate potential for personal development and growth, dependent on the basic need for positive regard (Rogers, 1951), and that physical and psychological difficulties arise from insufficient approval. It operates on the premise that self-concepts, attitudes and behaviour can be modified or transformed through the use of the core conditions namely, genuineness, empathy and unconditional positive regard, factors that may have particular salience for parents of children on the autistic spectrum in light of their unique experiences. The humanistic approach also places equality within the therapeutic relationship at its heart, as well as the development of the individual's ability to accept responsibility for their own life and trust in their own inner resources, thus increasing their sense of value, and most importantly, their sense of control.
Research aims

On the basis of the previous research, which indicates that parents of children with developmental disabilities are more at risk of suffering from depression and psychological distress than parents of children with no developmental disorder (Abelson, 1999; Olsson & Hwang, 2001; Beck, Hastings, Daley & Stevenson, 2004), and that parents of children with autism report more stress than parents of children with other developmental disorders (Hasting and Johnson (2001), the current study aims to investigate the relationship between depression, anxiety and locus of control in parents of children on the autistic spectrum, in order to gain a better understanding of their difficulties, processes, coping strategies and therapeutic needs. Additionally, the study sought to examine parents’ experiences, attitudes and beliefs in relation to general parenting and parenting a child with a disorder, and to identify factors (such as isolation, support and diagnosis, as well as marital and employment status) that may influence levels of anxiety, depression and locus of control, and also have bearing on the nature of the therapeutic approach. In order to establish factors unique to parents of children with an autistic spectrum disorder, the study makes comparisons with two other groups: the parents of non-disordered children and children with an alternative developmental disorder (Down’s syndrome).

Hypotheses

1. Parents of children with a developmental disorder will be significantly more depressed and anxious than parents of children with no disorder.
2. Parents of children with an autistic spectrum disorder will be significantly more depressed and anxious than children with Down’s syndrome.
3. There will be significant differences between groups in parents’ experiences, and depression and anxiety will be significantly associated with parents’ experiences of disorder.
4. There will be significant differences between groups in parents' locus of control, and locus of control will be significantly associated with levels of depression and anxiety.

5. There will be significant differences between groups in parents' attitudes to parenting and attitudes to parenting a child with a developmental disorder.

6. There will be significant differences between groups in employment and marital status.

7. There will be experiences that are significant predictors of anxiety and depression in parents of children with autistic spectrum disorders.

**Method**

**Design**

The hypotheses were tested by means of an independent groups questionnaire design where the main variable was disorder with three levels: no disorder, autistic spectrum disorder and Down's syndrome. The predictors were levels of depression; levels of anxiety; locus of control; experiences of parenting and attitudes to parenting.

**Recruitment**

Participants for this study were parents of children with: no disorder, an autistic spectrum disorder and Down’s syndrome. The only exclusion criteria were: being under 18 years old or having been, or currently being, treated by the NHS for a psychiatric illness. Participants were recruited by post through two co-educational mainstream independent schools and one co-educational mainstream local authority infant school, three regional branches of the National Autistic Society and the national Down’s Syndrome Association.
Cohen (1998) suggests that with a standard \( \alpha \) level of 0.05 and using the recommended power of 0.8, 783 participants are required to detect a small effect size \( (r = .1) \) and 85 participants are required to detect a medium effect size \( (r = .3) \). On the basis of Cohen (1998), 500 questionnaires were sent to each group (total \( n = 1500 \)).

**Measures**

The questionnaire booklet consisted of demographic questions relating to the participant’s self (such as age, education and marital status) and child or children (such as age and diagnosis), which could be continued on a separate sheet if necessary. Experiences were measured using a specially constructed questionnaire based on the literature (as discussed in the introduction). Part 1 of the questionnaire\(^{10}\) (Experiences of parenting a child with a disorder), was only completed by parents of children with a disorder. It consisted of 9 items relating to experiences of diagnosis, and parenting a child with a disorder, for example, Item 2: “Obtaining a diagnosis took a long time”. The order of the items was randomized and they were presented on a 6-point Likert scale\(^{11}\) ranging from 1 = *Strongly Agree* to 6 – *Strongly Disagree*. Scores ranged from 9 –54. The higher the total score, the more positive the parenting experiences. Items 1, 3 and 5 were reverse scored.

Part 2 of the Experiences scale\(^{12}\) was for all participants and the 14 items related to general experiences of parenting, such as levels of support; ways in which they feel they are seen by others; experiences of professionals and relationship with their child. For example, Item 6: “I get little support with childcare from my family and friends” and Item 14: “My experiences with health professionals concerning my child have always

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\(^{10}\) Internal consistency reliability of this scale (Experiences Part 1, Items 1 – 9) was analyzed. Cronbach \( \alpha = 0.93 \). (Nunally (1978) suggests that an alpha co-efficient of 0.65 is acceptable indicating that the internal reliability of the dimensions is good).

\(^{11}\) A 6-point Likert scale was used throughout the study, apart from on the Locus of Control Scale, in order to facilitate either ‘positive’ or ‘negative’ responses.

\(^{12}\) Internal consistency reliability of this scale (Experiences Part 2, Items 10 – 24) was analyzed. Cronbach \( \alpha = 0.78 \).
been positive”. The order of the items was randomized and they were presented on a 6-point Likert scale ranging from 1 = *Strongly Agree* to 6 – *Strongly Disagree*. Scores ranged from 14 – 84. The higher the total score, the more positively parents rated their experiences. Items: 11, 13, 14, 15, 22 and 24 were reverse scored.

Locus of control was measured using a 20 Item scale drawn from the International Personality Item Pool (Goldberg, 1999; IPIP, 2002). This included items relating to belief in luck and control by powerful others, for example, Item 11: “I believe that my success depends upon ability rather than luck” and Item 4: “I believe the world is controlled by a few powerful people”. The order of items was randomized and on the basis of Goldberg (1999) they were presented on a 5-point Likert scale ranging from Very Inaccurate (scored as 1) to Very Accurate (scored as 5) allowing for a ‘neither accurate or inaccurate’ response. Scores ranged from 20 – 100. The higher the score, the greater the internal locus of control.

Attitudes to parenting and disorder were measured using a second purpose built questionnaire based on the literature (as discussed in the introduction). This questionnaire had two parts. Part 1 consisted of 4 items relating to Attitudes to parenting, for example Item 3: “Parents are to blame for children who scream in the supermarket”. The order of items were randomized and they were presented as a 6-point Likert scale ranging from 1 = *Strongly Agree* to 6 – *Strongly Disagree*. Scores ranged from 4 – 24. The lower the total score, the more negative the attitude to parenting.

Part 2 consisted of 6 items relating to Attitudes to parenting a child with a developmental disorder, for example Item 2: “Parents of children with Down’s syndrome are more likely to feel stressed and depressed than parents of children with an autistic spectrum disorder”. The order of items were randomized and they were presented as a 6-point Likert scale ranging from 1 = *Strongly Agree* to 6 – *Strongly Disagree*. Scores ranged from 4 – 24. The lower the total score, the more negative the attitude to parenting.

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13 Internal consistency reliability of this scale (Locus of control) was analyzed. Cronbach’s alpha, $\alpha = 0.89$.

14 Internal consistency reliability of this scale (Attitudes Part 1, Items 1 – 4) was analyzed Cronbach $\alpha = 0.26$. After Item 4 was excluded, $\alpha = 0.46$.

15 Internal consistency reliability of this scale (Attitudes Part 2, Items 5 - 10) was analyzed. Cronbach $\alpha = 0.54$. After Items 8 and 9 were excluded, $\alpha = 0.70$. 

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Likert scale ranging from 1 = *Strongly Agree* to 6 = *Strongly Disagree*. Scores ranged from 6 – 36. The lower the total score, the more negative the attitude to the developmental disorder.

Levels of anxiety and depression were measured using the Hospital Anxiety and Depression Scale (Zigmund & Snaith, 1983). This is self-report tool designed to examine levels of depression and anxiety in non-psychiatric populations (Herrmann, 1997). It consists of 14 statements (7 relating to anxiety and 7 to depression) to which the respondent chooses one of the four responses that best represents how they have felt over the past few weeks. Responses are graded on a 4-point Likert scale 0 – 3. Scores range between 0 and 21 with higher scores indicating higher levels of anxiety and depression.

The Hospital Anxiety and Depression Scale has been used extensively in research on a wide variety of issues and with parents of children with a child with an autistic spectrum disorder (Hastings, 2003; Beck, Hastings, Daley & Stevenson, 2004). It has been shown to have good internal reliability on both dimensions (Anxiety: $\alpha = 0.76 - 0.82$; Depression $\alpha = 0.72 - 0.77$, Crawford, Henry, Crombie & Taylor, 2001; Martin & Thompson, 2000).

**Procedure**

Preliminary approval was sought from schools, regional branches of the National Autistic Society and the Down’s syndrome Association. Ethical approval of the protocol for the study was sought and obtained from the University of Surrey Ethics Committee (Appendix A). Particular consideration was given to the fact that there was some potential for the area under research (child disorder) to cause distress, and therefore, the covering information sheet (Appendix B) included a small section advising of this and suggesting whom participants should contact in this event. A pilot study was then conducted in order to assess the potential response rate and identify any difficulties with

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16 Internal consistency reliability of this scale (The Hospital Anxiety and Depression Scale) was measured using Cronbach’s alpha. Anxiety: $\alpha = 0.80$; Depression: 0.75.
the questionnaire. On the strength of the findings, the Attitude scales were shortened and condensed. The written decision from the University of Surrey Ethics Committee and the finalized research pack were shown for approval to the head teacher of each school and also to the appropriate representative of each society and association prior to distribution.

Class teachers distributed questionnaires at random to children in all age groups to take home to their parents by 'satchel post', in order to protect anonymity and confidentiality. Participants were also selected at random from members’ mailing lists by the Down’s Syndrome Association and the regional branches of the National Autistic Society, and each institution distributed questionnaires themselves by post, again to protect confidentiality and anonymity. Each participant was sent an A4 envelope containing an information sheet (Appendix B) and a questionnaire booklet (Appendix C) with a stamped addressed envelope in which to return the questionnaire. The information sheet provided general background information on the study (including exclusion criteria) and an explanation about the research and that it was designed to look at parents’ experiences and attitudes in relation to parenting and the effects of parenting on well-being. In addition, participants were informed that the University of Surrey Ethics Committee had approved the protocol for the study, and contact numbers were provided for participants to call in the event that they should have any questions or experience any distress.

Analytic Strategy

Group comparisons between parents of children with no disorder, parents of children with an autistic spectrum disorder, and parents of children with Down’s syndrome were made using a series of one-way analysis of variance (ANOVA) and t-tests. Correlation coefficients were used to examine the level of association between variables linked to anxiety; depression; locus of control and Chi-square tests were used to look for differences in marital status, employment status and education. Regressions were also used to examine which factors predicted anxiety and depression. All regressions used the
default of \( p < 0.05 \) to enter and \( p < 0.10 \) to leave the model (as recommended by Field, 2005).

Results

A total of \( n = 466 \) completed questionnaires were returned by post directly to the researcher by the specified deadline, indicating a response rate of 31.5\%, \( n = 106 \) from parents of children with no disorder; \( n = 184 \) from parents of children with an autistic spectrum disorder; \( n = 176 \) from parents of children with Down’s syndrome. A total of 439 females and 27 males participated in the study, with a mean age of 43.4 years. Preliminary analyses were conducted to check for normality, validity and reliability and to ensure parametric assumptions were met. Table 1 describes the number of participants in each group; the mean age of participants; participants’ mean number of children, and the number and percentage of female and male participants.

Table 1. Demographic information

<table>
<thead>
<tr>
<th></th>
<th>Number of Participants</th>
<th>Mean Age (SD)</th>
<th>Mean Number of Children (SD)</th>
<th>Number of Female Participants (Percentage)</th>
<th>Number of Male Participants (Percentage)</th>
</tr>
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<tbody>
<tr>
<td>No Disorder</td>
<td>106</td>
<td>43.6 (5.72)</td>
<td>2.1 (0.71)</td>
<td>102 (96.2%)</td>
<td>4 (3.8%)</td>
</tr>
<tr>
<td>Autistic Spectrum Disorder</td>
<td>184</td>
<td>44 (7.66)</td>
<td>2.2 (0.85)</td>
<td>165 (93.5%)</td>
<td>11 (6.5%)</td>
</tr>
<tr>
<td>Down’s Syndrome</td>
<td>176</td>
<td>42.6 (6.92)</td>
<td>2.6 (1.28)</td>
<td>172 (93.8%)</td>
<td>12 (6.3%)</td>
</tr>
</tbody>
</table>
Differences between groups on levels of depression and anxiety

A series of independent-samples t-tests was used to examine mean differences between groups on levels of depression and anxiety (see Table 2). On average, parents of children with a developmental disorder experienced significantly higher levels of depression than parents of children with no disorder ($t(256) = -8.11, p<0.001$). Parents of children with a developmental disorder also experienced significantly higher levels of anxiety than parents of children with no disorder ($t(239) = -4.24, p<0.001$).

Table 2. Mean depression and anxiety scores for non-disordered and disordered groups

<table>
<thead>
<tr>
<th></th>
<th>Mean depression scores</th>
<th>Mean anxiety scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>No disorder</td>
<td>3.36 (SD 2.83)</td>
<td>7.08 (SD 3.09)</td>
</tr>
<tr>
<td>Disorder</td>
<td>6.26 (SD 4.22)</td>
<td>8.68 (SD 4.36)</td>
</tr>
</tbody>
</table>

Parents of children with an autistic spectrum disorder had significantly higher levels of depression than parents of children with Down’s syndrome ($t(354) = 6.03, p<0.001$), and higher levels of anxiety than parents of children with Down’s syndrome ($t(358) = 5.6$, $p<0.001$). (See table 3).

Table 3. Mean depression and anxiety scores for autistic spectrum and Down’s syndrome groups

<table>
<thead>
<tr>
<th></th>
<th>Mean depression scores</th>
<th>Mean anxiety scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autistic spectrum disorder</td>
<td>7.47 (SD 4.32)</td>
<td>9.89 (SD 4.28)</td>
</tr>
<tr>
<td>Down’s syndrome</td>
<td>4.92 (SD 3.70)</td>
<td>7.41 (SD 4.09)</td>
</tr>
</tbody>
</table>
A one-way between groups analysis of variance was conducted to explore the impact of disorder on experience of general parenting (as measured by Part 2 of the Experiences scale). Participants were grouped as no disorder, autistic spectrum disorder and Down's syndrome. There was statistical difference in Experience scores for the three groups ($F(2, 463) = 107.5$, $p < 0.001$). Post-hoc comparisons using the Tukey HSD test indicated that the mean score for parents of children with no disorder ($M = 69.61$, $SD = 9.64$) was significantly higher (indicating more positive experiences) than the mean scores of parents of children with an autistic spectrum disorder ($M = 51.54$, $SD = 10.18$) and parents of children with Down's syndrome ($M = 61.24$, $SD = 10.92$). Post-hoc comparisons using the Tukey HSD test indicated that the mean score of parents of children with an autistic spectrum disorder ($M = 51.54$, $SD = 10.18$) was also significantly lower (indicating more negative experiences) than the mean scores of parents of children with Down's syndrome ($M = 61.24$, $SD = 10.92$).

To further explore the differences in experiences of parenting a child with a developmental disorder, an independent-samples t-test was conducted to compare differences in experiences between the Down's syndrome and autistic groups using Part 1 of the Experiences scale. Parents of children with an autistic spectrum disorder experienced significantly more negative experiences ($M = 31.43$, $SD = 0.45$) than parents of children with Down's syndrome ($M = 38.99$, $SD = 0.44$, $t(358) = -12.16$, $p<0.001$).

**Associations between parents' experiences of disorder and depression and anxiety**

The relationship between parents' experiences of having a child with a disorder (as measured by Part 1 of the Experiences scale) and depression were explored using Pearson product-moment correlation coefficient. There was a negative relationship\(^\text{17}\) between

\(^{17}\) Cohen (1998) suggests the following guidelines: $r = .10$ to $.29$ or $r = -.10$ to $-.29$ small 
$r = .30$ to $.49$ or $r = -.30$ to $-.49$ medium
$r = .50$ to $1.0$ or $r = -.50$ to $-1.0$ large
experiences of disorder and depression in parents of a child with an autistic spectrum disorder \( (r = -0.31, n = 184, p<0.001) \), and parents of a child with Down’s syndrome \( (r = -0.44, n = 176, p<0.001) \), indicating more negative experiences of parenting being associated with higher levels of depression. There was a negative relationship between negative experiences of parenting a child with a disorder and anxiety \( (r = -0.21, n = 184, p<0.004) \) in parents of children with an autistic spectrum disorder and a negative relationship \( (r = -0.33, n = 176, p<0.001) \) in parents of children with Down’s syndrome, indicating that higher levels of anxiety are associated with more negative experiences of parenting.

**Differences between groups in locus of control**

A one-way between groups analysis of variance was conducted to explore the impact of parenting a child with a disorder on locus of control. Participants were grouped as no disorder, autistic spectrum disorder and Down’s syndrome. There was statistical difference in locus of control scores for the three groups \( (F (2, 463) = 11.59, p < 0.001) \). Post-hoc comparisons using the Tukey HSD test indicated that the mean score for parents of children with no disorder was significantly higher (indicating greater locus of control) than the mean scores of parents of children with an autistic spectrum disorder and parents of children with Down’s syndrome. Post-hoc comparisons using the Tukey HSD test indicated that the mean score of parents of children with an autistic spectrum disorder was also significantly lower than the mean scores of parents of children with Down’s syndrome, indicating that parents of children with an autistic spectrum disorder have lower levels of internal locus of control than the other two groups (see Table 4.).
Table 4. Mean locus of control scores

<table>
<thead>
<tr>
<th></th>
<th>Mean locus of control scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>No disorder</td>
<td>77.72 (SD 12.06)</td>
</tr>
<tr>
<td>Autistic spectrum disorder</td>
<td>71.01 (SD 11.69)</td>
</tr>
<tr>
<td>Down’s syndrome</td>
<td>75.64 (SD 12.75)</td>
</tr>
</tbody>
</table>

Correlation between locus of control and depression and anxiety

The relationship between locus of control and depression was explored using 3 separate Pearson product-moment correlation coefficients on each disorder group. There was a negative relationship between the two variables in parents of children with no disorder (r = -0.58, n = 106, p<0.01), parents of children with an autistic spectrum disorder (r = -0.58, n = 184, p<0.01) and parents of children with Down’s syndrome (r = -0.54, n = 176, p<0.01), with lower internal locus of control being associated with more depression.

The relationship between locus of control and anxiety was explored using 3 separate Pearson product-moment correlation coefficients on each disorder group. There was a negative relationship between the two variables in parents of children with no disorder (r = -0.50, n = 106, p<0.01), parents of children with an autistic spectrum disorder (r = -0.42, n = 184, p<0.01) and parents of children with Down’s syndrome (r = -0.52, n = 176, p<0.01), with lower internal locus of control being associated with more anxiety.

Differences between groups in attitudes to parenting

A one-way between groups analysis of variance was conducted to explore the impact of disorder on Attitudes to parenting (as measured by Part 1 of the Attitudes scale). Participants were grouped as no disorder, autistic spectrum disorder and Down’s
syndrome. There was statistical difference in attitudes to parenting scores for the three groups (F (2, 463) = 12.69, p < 0.001). Post-hoc comparisons using the Tukey HSD test indicated that the mean score for parents of children with an autistic spectrum disorder (M = 14.96, SD = 2.48) was significantly higher than the means score of parents of children with no disorder (M = 13.31, SD = 2.90) and the mean score of parents of children with Down's syndrome (M = 14.44, SD = 2.79). Post-hoc comparisons using the Tukey HSD test indicated that the mean score of parents of children with Down’s syndrome was significantly higher than the mean score of parents of children with no disorder, although significantly lower than the parents of children with an autistic spectrum disorder, indicating that parents of children with a developmental disorder have a statistically more positive attitude to parenting.

Differences between groups in attitudes to parenting a child with a disorder

A one-way analysis of variance was conducted to explore the impact of disorder on Attitudes to parenting a child with a disorder (as measured by Part 2 of the Attitudes scale). Participants were grouped as no disorder, autistic spectrum disorder and Down’s syndrome. There was statistical difference in attitudes to parenting a child with a disorder scores for the three groups (F(2, 463) = 5.69, p<0.001). Post-hoc comparisons using the Tukey HSD test indicated that the mean score for parents of children with an autistic spectrum disorder (M = 20.63, SD = 3.04) was significantly higher than the means score of parents of children with no disorder (M = 19.44, SD = 3.08) and the mean score of parents of children with Down’s syndrome (M = 19.86, SD = 3.17). Post-hoc comparisons using the Tukey HSD test indicated that the mean score for parents of children with an autistic spectrum disorder was significantly higher than the mean scores of parents of children with Down’s syndrome and parents of children with no disorder, indicating that parents of children with an autistic spectrum disorder have a statistically more positive attitude to parenting a child with a disorder. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for parents of children with no disorder was statistically lower than that of parents of children with an autistic spectrum disorder.
and parents of children with Down’s syndrome, indicating that parents of children with no disorder have a statistically more negative attitude to parenting a child with a developmental disorder.

Differences between groups in marital and employment status

Chi-square analyses, using 2 separate 3 x 2 contingency tables, were conducted to look for differences between groups in marital and employment status. There was no statistical difference between groups in marital status, $\chi^2(2) = 0.06$, $p>0.05$. Eighty-nine per cent of parents of children with no disorder, 81.5% of parents of children on the autistic spectrum, and 78.4% of parents with children with Down’s syndrome, were married. There was a significant difference however, between groups in employment status $\chi^2(4) = 15.70$, $p<0.005$. Thirty-four percent of parents of children with no disorder, 47.8% of parents of children with an autistic spectrum disorder, and 31.3% of parents of children with Down’s syndrome were full-time homemakers.

Factors predicting levels of depression in parents of children with an autistic spectrum disorder

Stepwise multiple regression analysis was used to investigate factors predicting depression in parents of children with an autistic spectrum disorder. The final model to emerge from the stepwise analysis contains only two significant predictor variables ($F(2,181) = 65.36$, $p<0.001$): locus of control and experiences of parenting (as measured by Part 2 of the Experiences scale) which is 42% of the variance explained (see Table 5).
Table 5. Factors predicting levels of depression in parents of children with an autistic spectrum disorder

<table>
<thead>
<tr>
<th>Step 1: Locus of control</th>
<th>R</th>
<th>R²</th>
<th>AR²</th>
<th>B</th>
<th>β</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Locus of control</td>
<td>.58</td>
<td>.34</td>
<td>.34</td>
<td>-.22</td>
<td>-.58*</td>
<td>93.32</td>
</tr>
<tr>
<td>Exp. of parenting</td>
<td></td>
<td></td>
<td></td>
<td>-.13</td>
<td>-.03*</td>
<td></td>
</tr>
</tbody>
</table>

*p<0.001

Factors predicting levels of anxiety in parents of children with an autistic spectrum disorder

Stepwise multiple regression analysis was used to investigate factors predicting anxiety in parents of children with an autistic spectrum disorder. The final model to emerge from the stepwise analysis contains only two significant predictor variables (F(2,181) = 29.54, p<0.001): locus of control and experiences of parenting (as measured by Part 2 of the Experiences scale) (see Table 6).

Table 6. Factors predicting levels of anxiety in parents of children with an autistic spectrum disorder

<table>
<thead>
<tr>
<th>Step 1: Locus of control</th>
<th>R</th>
<th>R²</th>
<th>AR²</th>
<th>B</th>
<th>β</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Locus of control</td>
<td>.42</td>
<td>.18</td>
<td>.17</td>
<td>-.15</td>
<td>-.42*</td>
<td>39.48</td>
</tr>
<tr>
<td>Exp. of parenting</td>
<td></td>
<td></td>
<td></td>
<td>-.12</td>
<td>-.29*</td>
<td></td>
</tr>
</tbody>
</table>

*p<0.001
Discussion

The aim of the study was to investigate whether parents of children with an autistic spectrum disorder have higher levels of depression and anxiety than parents of children with no disorder and parents of children with an alternative developmental disorder and, if so, to try to establish factors accounting for this in order to identify and understand their needs. The results indicate that, in keeping with previous findings, parents of children with a developmental disorder do have significantly higher levels of depression and anxiety than parents of children with no disorder. They also show that parents of children on the autistic spectrum have significantly higher levels of depression and anxiety than parents of children with an alternative developmental disorder, and this gives rise to the question ‘why’?18

The previous research highlights the idea that a number of different factors and processes may be involved. Whilst feelings of loss and bereavement are a common reaction to the diagnosis of a child’s illness or disorder (Osborne & Coyle, 2002), this study proposes that parents of children with an autistic spectrum disorder face a number of additional difficulties that may be uniquely associated with their child’s specific disorder, and that these difficulties have a cumulative and negative affect on their well-being. For example, parents may face lengthy and complex difficulties associated with the process of obtaining a diagnosis (Gray, 2003), and may face social isolation, difficulty in taking holidays, financial strains and marital conflict (Abelson, 1999). They may also have to give up their jobs (Gray, 2002a) and cope with being stigmatized (Gray, 2002b), or seen as a ‘bad parent’ (Hamlyn-Wright, 2004), as well as cope with the direct difficulties associated with their child’s behaviour (Hastings & Johnson, 2001). Furthermore, parents may find themselves lacking in adequate social support (Boyd, 2002).

Overtime, the particular difficulties that parents of children on the autistic spectrum face may accumulate and impact upon one another, resulting in a sense of loss of control,

18 Whilst it is possible that depressed and anxious parents may be more likely to give birth to a developmentally disordered child, it should be remembered that these were non-clinical groups and most had other non-disordered children.
(Rotter, 1966) and thus, learned helplessness (Seligman, 1975), ideas which also fit well with the notion that a sense of coherence is an important factor in coping (Boyd, 2002). In keeping with Conservation of Resources theory (Hobfoll, 1989), these particular difficulties and processes can be conceptualized as a series of resource loss spirals, which leave parents feeling depleted and out of control, and lead to increased levels of depression and anxiety. If this is indeed the case, it would seem reasonable to expect that parents of children on the autistic spectrum would have significantly lower levels of internal locus of control, which in this study they did.

Locus of control is a concept that has long been associated with depression (Seligman, 1975; Johnson and Sarason, 1978) and this study found significant differences in levels of locus of control between all three groups. Parents of children with an autistic spectrum disorder scored lower on internal locus of control than parents of children with Down’s syndrome, who in turn scored lower than parents of children with no disorder. It was also found that lower levels of internal locus of control were significantly associated with higher levels of both depression and anxiety in parents of children with an autistic spectrum disorder. These findings lend support to the idea that there are specific factors associated with parenting a child with a developmental disorder, in particular autistic spectrum disorder, which may affect parents’ psychological processes and well-being. Therefore, on the basis that it has never been suggested that internal locus of control arises as a result of depression, it seems logical to look at parents’ experiences in order to identify factors that might account for the findings.

Significant differences were found between all groups in general experiences of parenting. Parents of children with an autistic spectrum disorder had more negative experiences of parenting than the other two groups, and they also had more negative experiences of parenting a child with a disorder than parents of children with Down’s syndrome. In contrast, however, they had a more positive attitude to parenting (including parenting a child with a developmental disorder) than the other two groups. Whilst this last finding could be interpreted as a defensive method of coping, the use of such a strategy would then imply a greater need and/or ability to do so. In keeping with Hobfoll
(1989) though, this distinct difference observed between parents' attitudes and their experiences could be a source of dissonance, or more importantly depression.

In this study, experiences were also significantly associated with locus of control and levels of depression and anxiety in all three groups, and locus of control and experiences both predicted anxiety and depression in the parents of children with an autistic spectrum disorder. This tends to lend weight to the idea that it is the specific nature of parents' experiences associated with parenting a child with an autistic spectrum disorder which result in increased levels of depression and anxiety in this group. Looking at the conservation of resources framework proposed by Hobfoll (1989), it could be conceived that the need for extra resources, above those utilized for general parenting, accounts for the increased levels of anxiety and depression seen in the parents of developmentally disordered children. Therefore, it would seem that parents of children with an autistic spectrum disorder in particular, are evidencing resource loss spirals.

From a cognitive perspective, it may also be that difficult life events, such as having a child with a developmental disorder, triggers early negative schemas (Young et al., 2003), but what the findings of this study suggest is that there may be very different triggering factors in the two disorder groups. In order to examine stressful factors specifically associated with parenting a child with a disorder, the Experiences of disorder questionnaire examined issues such as difficulty in obtaining a diagnosis, difficulty in going out with their child, the quality of the relationship, difficulties in caring for the child and meeting his or her needs, as well as social support. The general Experiences of parenting scale which, was administered to all groups, again contained items relating to support and difficulty in caring for their child, but also items associated with isolation, relationships with professionals, the school and Education Authority, and the need to have someone else to talk to. Additionally, there were items relating to how parents feel others see them, for example, as a 'bad parent' or 'troubemaker'. Each of the items on the Experiences scales was designed to tap into experiences that might deplete resources, effect control, or trigger negative schemas, and lead to isolation, thus influencing anxiety.
and depression, and these results have important implications in terms of therapy and practice.

Difficulty in going out with a child on the autistic spectrum (due to their behaviour and the reactions of others) and obtaining a diagnosis are common themes in the autistic spectrum literature and it may be that these particular experiences tap into early negative schemas regarding 'being different', 'failure', 'not being good enough', and 'not having needs met' (Young et al., 2003). It could also be however, that difficulties in obtaining a diagnosis affect coping style in the ways described by Boyd (2002), whereby lack of structure and resources result in reduced 'comprehensibility' and 'manageability', leading to less sense of control, which would fit well with current findings, particularly in relation to lower levels of locus of control in this particular group. It could also perhaps explain the discrepancy between the optimistic explanatory style necessary for these parents to persevere in obtaining a diagnosis and 'fighting the system' (Hamlyn-Wright, 2004) and locus of control scores.

The findings from this study suggest, therefore, that there are a number of factors to consider when thinking about therapy for the parents of children on the autistic spectrum, who are a group of parents more likely to experience depression and anxiety than others. They have a number of unique difficulties associated with caring for their child including difficulty in accessing diagnosis and resources, as well as social isolation and stigmatization, or being seen 'as a bad parent'. Their financial resources are also likely to be diminished by not being able to work, and these factors together may have a strong impact on their ability to cope (Boyd, 2002; Gray, 2002). Whilst parents' difficulties in relation to their child may activate early maladaptive schemas, it may also be that their specific problems are very realistic problems of living, which in turn may be felt more acutely by those who are generally used to feeling capable and in control.

The conservation of resources model would suggest that the parents of children on the autistic spectrum are especially likely therefore, to find themselves in resource loss spirals, whereby one loss of resource leads on to another, resulting in anxiety and
depression. On this basis, it is proposed that a holistic or eclectic approach to therapy might be the most effective for this particular group, incorporating elements from different therapeutic regimes to address the perceived and actual loss of physical, psychological, social and symbolic resources, in order to improve coping. For example, cognitive behavioural therapy could be an extremely useful approach for addressing parents' maladaptive schemas and helping them to develop positive coping strategies, and encouraging them to interact and find social support, in order to regain vital lost resources. In addition, the humanistic approach may be beneficial in improving the self-concept and internal locus of control. A more dynamic approach might provide parents with valuable insight, as well as understanding and awareness of the ways in which they interact with others, and the nature of their relationships with their child and family, which could then be translated into wider social contexts. Family therapy could be another useful option to address dynamics, and an existential-phenomenological approach may help parents to cope with thoughts and feelings about the meaning of their situation. What seems to be of most importance, however, is that parents receive prompt and effective treatment in order to empower them to be able to provide optimum care and attention for their child.

In conclusion, this study highlights the need for Counselling Psychologists in practice to be aware that parents of children with an autistic spectrum disorder are a group who are at special risk of developing depression and anxiety, and this may be linked to processes associated with loss of resources and control arising from specific nature of their experiences. Also, that a holistic or eclectic approach to therapy may be most appropriate. However, the study has two major limitations, the first is that the number of participants needed for the study (783) on the strength of the power calculation was not reached, thus limiting the generalisability. The second is that because the study was cross sectional and as such scores on the measures (for example, the Hospital Anxiety and Depression Scale and the Locus of Control scale) had not been collected before the participants had a child, causality could not be established. This last aspect of the study suggests a useful direction for future research. Importantly, however, this is not to
suggest that parents are in any way to blame for their child’s difficulties (as has been the case in the past), but to look for useful ways in which to intervene and help.
References


APPENDIX A

18 April 2005

Ms Sarah Hamlyn-Wright
Department of Psychology
School of Human Sciences

Dear Ms Hamlyn-Wright

Investigating potential factors influencing depression, stress and uptake therapy in parents of children on the Autistic Spectrum and parents of children with Down's Syndrome (EC/2005/15/Psych)

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 18 April 2005

The list of documents reviewed and approved by the Committee is as follows:-

Document Type: Application
Dated: 07/02/05
Received: 10/02/05

Document Type: Insurance Proforma
Received: 10/02/05

Document Type: Research Proposal
Received: 10/02/05

Document Type: Appendix 1: Preliminary Draft of Questionnaire
Received: 10/02/05

Document Type: Appendix 2: Information Sheet for Participants
Received: 10/02/05

Document Type: Appendix 3: Consent Form
Received: 10/02/05

Document Type: Your Response to the Committee's Comments
Dated: 13/03/05
Received: 01/04/05

239
This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research, and with the conditions set out below:

- The Committee ask that the fourth sentence of the fifth paragraph of the Information Sheet is amended to read "In this event you may wish to (rather than 'should') contact someone for support".

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected, with reasons.

I would be grateful if you would confirm, in writing, your acceptance of the conditions above.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethic Committee
    Dr J Ellis, Supervisor, Dept of Psychology
APPENDIX B

INFORMATION SHEET FOR PARTICIPANTS

“Factors influencing well-being in parents of children with developmental disorders”

I am a mature student in my final year of doctoral training as a Counselling Psychologist at the University of Surrey. I am currently conducting research looking at the experiences of parents and how these might affect well-being. I am particularly interested in looking for differences between the experiences, well-being and attitudes of parents with children on the autistic spectrum and parents of children with Down’s syndrome, compared to those of parents whose children do not have a pervasive developmental disorder.

I am, therefore, seeking parents (aged 18 years or over) who have not been, or not currently being, treated by the NHS for any psychological disorder and who have a child with a developmental disorder, or no disorder to participate in this study. This involves no more than completing the enclosed questionnaire and returning it to me, by Monday, 5th June, 2005, in the pre-paid addressed envelope provided.

You are under no obligation to participate. There are no consequences if you do not participate and you do not have to justify your decision. If you do not wish to take part, please send the incomplete questionnaire back to me in the pre-paid addressed envelope provided. If you do decide to participate, your responses will remain entirely anonymous. You cannot be identified by the data (so please do not put your name on the questionnaire). All information provided will be held and processed in the strictest confidence, and in accordance with the Data Protection Act (1998).

Please answer the questions as honestly as possible. There are no right or wrong answers, so do not feel you have to spend too much time on each one. If at any time you feel worried or upset about completing the questionnaire, do not feel you have to continue. In this event, you may wish to contact someone for support. Either the society or association who distributed the questionnaire; your GP; a friend or health visitor; or me (Sarah Hamlyn-Wright), on the telephone number below.

If you have any questions, again, feel free to contact me on the telephone number below. On completion of the study, I will be happy to provide you with general feedback on the project upon request. Thank you in anticipation.

Sarah Hamlyn-Wright, Psychology Department, University of Surrey
Tel: [redacted]

MATERIAL REDACTED AT REQUEST OF UNIVERSITY
APPENDIX C

Please complete the following demographic information, ticking or filling the boxes

Marital Status:  Married □  Single □  Divorced □  Widowed □  Co-habiting □

Age: □  Gender:  Female □  Male □

Education:  GCSE □  A Level □  Degree □

Occupation: □

Number of Children: □

CHILD NO: 1 (ELDEST)

Age: □  Gender:  Female □  Male □

Diagnosis:  Down’s Syndrome □

Asperger’s Syndrome □  High Functioning Autism □

Low Functioning Autism □  None of the above □

Awaiting diagnosis of □

Age of Child when Difficulties First Suspected: □  Not Applicable: □

Age of Child at Diagnosis: □  Not Applicable: □

Does this child live with you?  Yes □  No □
CHILD NO: 2

Age: □  Gender:  Female □  Male □

Diagnosis:  Down’s Syndrome □
Asperger’s Syndrome □
High Functioning Autism □
Low Functioning Autism □
None of the above □
Awaiting a diagnosis of □

Age of Child when Difficulties First Suspected: □  Not Applicable: □
Age of Child at Diagnosis: □  Not Applicable: □

Does this child live with you?  Yes □  No □

CHILD NO: 3

Age: □  Gender:  Female □  Male □

Diagnosis:  Down’s Syndrome □
Asperger’s Syndrome □
High Functioning Autism □
Low Functioning Autism □
None of the above □
Awaiting a diagnosis of □

Age of Child when Difficulties First Suspected: □  Not Applicable: □
Age of Child at Diagnosis: □  Not Applicable: □

Does this child live with you?  Yes □  No □
*IF YOU HAVE MORE THAN 3 CHILDREN, PLEASE CONTINUE PROVIDING THE SAME INFORMATION AS ABOVE FOR EACH CHILD, ON A SEPARATE SHEET.

*IF YOU HAVE MORE THAN ONE CHILD WITH A DISORDER, YOU MAY PROVIDE SEPARATE ANSWERS FOR EACH OF THESE CHILDREN TO ANY OF THE FOLLOWING QUESTIONS, IF YOU FEEL IT IS NECESSARY OR APPLICABLE.

The following 9 questions relate to your experiences as the parent of a child/children with an Autistic Spectrum Disorder (ASD) or Down's Syndrome (DS). Please circle the number that most accurately represents your experience. Please leave blank if your child has neither of these disorders.

1 = Strongly agree
2 = Moderately agree
3 = Slightly Agree
4 = Slightly Disagree
5 = Moderately disagree
6 = Strongly disagree

1. I found obtaining a diagnosis easy.......................... 1 2 3 4 5 6
2. Obtaining a diagnosis took a long time.......................... 1 2 3 4 5 6
3. I have found that having a diagnosis makes things easier........ 1 2 3 4 5 6
4. Being given a diagnosis was upsetting.......................... 1 2 3 4 5 6
5. I have a warm relationship with my child with ASD/DS........... 1 2 3 4 5 6
6. I find it harder to deal with my child with ASD/DS’s needs compared to my other children.......................... 1 2 3 4 5 6
7. I get little support from other parents of children with ASD/DS..... 1 2 3 4 5 6
8. I find it difficult to get the help I need from the NAS/DSA19........ 1 2 3 4 5 6
9. I find my child with ASD/DS ‘very hard work’.......................... 1 2 3 4 5 6

19 National Autistic Society; Down’s Syndrome Association
The following 15 questions relate to your experiences as a parent and are for all participants. Please circle the number that most accurately represents your experience.

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>10. I think others sometimes see me as a 'bad parent'.......................</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>11. I have a warm relationship with my child..................................</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>12. I get little support with childcare from my family and friends........</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>13. I get a lot of support with childcare from a partner...................</td>
<td>1 2 3 4 5 6</td>
<td></td>
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<tr>
<td>14. My experiences with health professionals concerning my child have always been positive</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>15. I would find it easy to ask for counselling/therapy....................</td>
<td>1 2 3 4 5 6</td>
<td></td>
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<tr>
<td>16. In the past I have found it difficult to get support from the Education Authority</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>17. I have always found the school supportive...............................</td>
<td>1 2 3 4 5 6</td>
<td></td>
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<tr>
<td>18. I find my child 'very hard work'...........................................</td>
<td>1 2 3 4 5 6</td>
<td></td>
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<tr>
<td>19. I think professionals sometimes see me as 'a troublemaker'............</td>
<td>1 2 3 4 5 6</td>
<td></td>
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<tr>
<td>20. As a parent sometimes I feel isolated.....................................</td>
<td>1 2 3 4 5 6</td>
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<tr>
<td>21. Counselling/therapy is not for me..........................................</td>
<td>1 2 3 4 5 6</td>
<td></td>
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<tr>
<td>22. I think other parents know how I feel....................................</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>23. I sometimes wish I had someone else to talk to..........................</td>
<td>1 2 3 4 5 6</td>
<td></td>
</tr>
<tr>
<td>24. I enjoy going out with my child.............................................</td>
<td>1 2 3 4 5 6</td>
<td></td>
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</tbody>
</table>
Below are phrases describing people's behaviours. Please use the rating scale to describe how accurately you think each statement describes you. Describe yourself as you generally are now, not as you wish to be in the future. Describe yourself as you honestly see yourself.

Please read each statement carefully, and then fill in your response.

<table>
<thead>
<tr>
<th>I like to take responsibility for making decisions</th>
<th>Very Inaccurate</th>
<th>Moderately Inaccurate</th>
<th>Neither Accurate nor Inaccurate</th>
<th>Moderately Accurate</th>
<th>Very Accurate</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel up to any task</td>
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<tr>
<td>I believe some people are born lucky</td>
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<tr>
<td>I believe that the world is controlled by a few powerful people</td>
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<td>I come up with good solutions</td>
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<td>I habitually blow my chances</td>
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<td>I act comfortably with others</td>
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<td>I feel my life lacks direction</td>
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<tr>
<td>I feel comfortable with myself</td>
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<td>I just know that I will be a success</td>
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<tr>
<td>I believe that my success depends upon ability rather than luck</td>
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<tr>
<td>I see difficulties everywhere</td>
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<tr>
<td>I dislike taking responsibility for making decisions</td>
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<tr>
<td>I love life</td>
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<tr>
<td>I dislike myself</td>
<td></td>
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<tr>
<td>I am less capable than most people</td>
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<tr>
<td>I feel that I am unable to deal with things</td>
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<tr>
<td>I make a decision and move on</td>
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<tr>
<td>I take the initiative</td>
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<tr>
<td>I believe that unfortunate events occur because of bad luck</td>
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</tbody>
</table>

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The following four questions relate to your opinions about parenting. Please circle the answer that most accurately reflects your opinion. There are no ‘correct’ or ‘incorrect’ answers.

1 = Strongly agree  
2 = Moderately agree  
3 = Agree  
4 = Disagree  
5 = Moderately disagree  
6 = Strongly disagree  

1. ‘Difficult’ children have ‘difficult’ parents.............................................1  2  3  4  5  6
2. Therapy is for parents who can’t cope.............................................1  2  3  4  5  6
3. Parents are to blame for children who scream in the supermarket......1  2  3  4  5  6
4. Parents are excluded if their child behaves ‘differently’.....................1  2  3  4  5  6

The following six questions relate to your opinions about developmental disorders. Please circle the answer that most accurately reflects your opinion. There are no ‘correct’ or ‘incorrect’ answers.

1 = Strongly agree  
2 = Moderately agree  
3 = Agree  
4 = Disagree  
5 = Moderately disagree  
6 = Strongly disagree  

5. Parents of children with Down’s syndrome are more likely to need therapy than parents of children with an autistic spectrum disorder.................................................................1  2  3  4  5  6
6. Parents of children with Down’s syndrome are more likely to feel stressed or depressed coping with their children than parents of children with an autistic spectrum disorder.................................................................1  2  3  4  5  6
7. Parents of children with an autistic spectrum disorder are more likely to have time for therapy than parents of children with Down’s syndrome.................................................................1  2  3  4  5  6
8. Parents of children with an autistic spectrum disorder have to ‘fight harder’ than parents of children with Down’s syndrome.................................1  2  3  4  5  6
9. Having a child with an autistic spectrum disorder makes you isolated more than having a child with Down’s syndrome.................................1  2  3  4  5  6
10. Autistic spectrum disorder is better understood than Down’s syndrome.................................................................1  2  3  4  5  6
Please answer the following questions, ticking the boxes corresponding with your answers.

**I feel tense or 'wound up'**
- □ Most of the time
- □ A lot of the time
- □ From time to time, occasionally
- □ Not at all

**I feel as if I am slowed down**
- □ Nearly all the time
- □ Very often
- □ Sometimes
- □ Not at all

**I still enjoy the things I used to enjoy**
- □ Definitely as much
- □ Not quite so much
- □ Only a little
- □ Hardly at all

**I get a sort of frightened feeling like 'butterflies' in the stomach**
- □ Not at all
- □ Occasionally
- □ Quite often
- □ Very often

**I get a sort of frightened feeling as if something awful is about to happen**
- □ Very definitely and quite badly
- □ Yes, but not too badly
- □ A little, but it doesn't worry me
- □ Not at all

**I have lost interest in my appearance**
- □ Very definitely and quite badly
- □ I don't take as much care as I should
- □ I may not take quite as much care
- □ I take as much care as ever

**I can laugh and see the funny side of things**
- □ As much as I always could
- □ Not quite as much now
- □ Definitely not so much now
- □ Not at all

**I feel restless as if I have to be on the move**
- □ Very much indeed
- □ Quite a lot
- □ Not very much
- □ Not at all

**Worrying thoughts go through my mind**
- □ A great deal of the time
- □ A lot of the time
- □ Not too often
- □ Very little

**I look forward with enjoyment to things**
- □ As much as I ever did
- □ Rather less than I used to
- □ Definitely less than I used to
- □ Hardly at all

**I feel cheerful**
- □ Never
- □ Not often
- □ Sometimes
- □ Most of the time

**I get sudden feelings of panic**
- □ Very often indeed
- □ Quite often
- □ Not very often
- □ Not at all

**I can sit at ease and feel relaxed**
- □ Definitely
- □ Usually
- □ Not often
- □ Not at all

**I can enjoy a good book or radio or television programme**
- □ Often
- □ Sometimes
- □ Not often
- □ Very seldom
***THANK YOU VERY MUCH INDEED FOR TAKING THE TIME AND THE TROUBLE TO PARTICIPATE IN THIS RESEARCH STUDY***

ETHNICITY

It would be useful if you could read and complete the following information about yourself. This information will not be used to identify you in any way but it will help with data analysis.

Choose one section from (a) to (e) and then tick the appropriate category to indicate your ethnic background.

(a) White:
  British
  Irish
  Any other white background please write below

(b) Mixed:
  White and Black Caribbean
  White and Black African
  White and Asian
  Any other mixed background please write below

(c) Asian or Asian British:
  Indian
  Pakistani
  Bangladeshi
  Any other Asian background please write below

(d) Black or Black British:
  Caribbean
  African
  Any other background please write below

(e) Chinese or other ethnic group:
  Chinese
  Any other please write below
APPENDIX D

Instructions for Authors

Journal of Autism and Developmental Disorders

General

Online Manuscript Submission

Publication Policies

Manuscript Style

Illustration Style

Submission of Accepted Manuscripts

Page Charges

Springer Open Choice

General

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http://iadd.edmgr.com
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Manuscript Style

Type double-spaced, and submit the original and three copies (including copies of all illustrations and tables). Academic affiliations of all authors and the full mailing address of the one author who will review the proofs should be included. Unless a self-addressed stamped envelope is enclosed, manuscripts cannot be returned.

A 120-word abstract is to be provided.

Illustration Style

Tables should be numbered and referred to by number in the text. Each table should be typed on a separate sheet of paper and should have a descriptive title.

Illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of arabic numerals. Photographs should be large, glossy prints, showing high contrast. Drawings should be prepared with India ink. Either the original drawings or good-quality photographic prints are acceptable. Identify figures on the back with author’s name and number of the illustration. Each figure should have an accompanying caption. The list of captions for illustrations should be typed on a separate sheet of paper. Electronic artwork submitted on disk should be in the TIFF or EPS format (1200 dpi for line and 300 dpi for half-tones and gray-scale art). Color art should be in the CYMK color space. Artwork should be on a separate disk from the text, and hard copy must accompany the disk.

Submission of Accepted Manuscripts

After a manuscript has been accepted for publication and after all revisions have been incorporated, manuscripts should be submitted to the Editor’s Office as hard copy accompanied by electronic files on disk. Label the disk with identifying information — software, journal name, and first author’s last name. The disk must be the one from which the accompanying manuscript (finalized version) was printed out. The Editor’s Office cannot accept a disk without its accompanying, matching hard-copy manuscript.

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APPENDIX E

Reflections on the use of self

As the parent of a 27-year old 'child' with Asperger's syndrome, my interest in autistic spectrum disorders has been long-standing. However, my interest in researching the impact of this disorder on parents was stimulated in the first instance by my curiosity about the term 'refrigerator parents' which simply did not ring true for me, and by meeting other parents whilst conducting previous research.

I noticed that in keeping with the view that there is a genetic component associated with autistic spectrum disorders, there were a few parents who seemed to be somewhat socially unskilled, but despite this they also appeared to be very keen to meet their child's needs. I was particularly struck by the sensitivity of a great number of the parents and their drive and determination to try to obtain the appropriate diagnosis, education and support for their child, as well as to try to adapt and make the best of the situation for their family. Alongside this purposeful behaviour however, I sensed a great deal of tiredness, sadness and feelings of frustration, anger and disempowerment which did not appear to result from their child's behaviour or their relationship with their child, but arising from the reactions of others and the difficulties associated with accessing resources. There also seemed to be a lot of worry about their child's future, and what would become of him or her when they were no longer there to care for them, to 'fight' for them and protect them.

This led me to wonder what was going on for these parents and how they coped, particularly as so many of them seemed to be socially restricted and only able to leave the house when their partner returned from work, due to the difficulties in taking their child out or leaving them with a non-family member. Reflecting on my own situation, I often felt very lucky as I have rarely been restricted, but many of the difficulties and emotions that parents faced, particularly in relation to obtaining a diagnosis, thinking about how others view them on the strength of their child's behaviour, worries about their child 'fitting in' at school and the future, were echoes of my own. I realize that this may also
have been part of my motivation to explore this particular area, and I recognize that my own particular method of coping is to attempt to understand and to rationalize.

What I found myself dwelling upon was the effect that having a child on the autistic spectrum has on the parent, rather than vice versa as very much considered in the past, and I was struck by how little there is about this in the literature. Personally, I feel that having a child ‘on the spectrum’ has helped me to grow and change over the years, making me in some ways more tolerant, and in other ways less so, and it has certainly heightened my awareness of others as I have had to develop the ability to be able to stop and process things on behalf of my child, or see things ‘through his eyes’. On a more negative side, I recognize there have been times when I have been angry and frustrated on behalf of my child and the lack of understanding I have met in others, and this has at times made me feel very low. What I questioned was why exactly it was that I felt this way, and how it was I dealt with it.

I also thought about how capable many of the parents seemed and yet how despondent they were about their experiences of the services that they were offered and the reactions of others. By participating in research most felt they were trying to bring about change, although this often felt like an extra burden on me, or responsibility, which at times I really struggled with in order to remain objective. However, it also seemed to suggest an optimistic explanatory style and good internal locus of control, which did not seem to fit with their hopelessness about ‘the system’ (that is the health, welfare and education system) and their child’s future. I decided to investigate this further in order to gain better understanding of the impact of their experiences on their attitudes, processes and needs, in order to try to conceptualized how they could best be helped.

As this research has personal relevance for me, in order to try to reduce bias, I have tried to remain mindful of the ways in which my own experiences and framework may have shaped the ideas and interpretation. In order to do this, I have sought the help of my supervisor and taken time for personal reflection, and hope that as a result I have been successful in producing a balanced piece of work.