A dynamic transactional model of parent-child interactions in autistic spectrum conditions.

Osborne, Lisa Anne

Osborne, Lisa Anne (2007) *A dynamic transactional model of parent-child interactions in autistic spectrum conditions..* thesis, Swansea University.
http://cronfa.swan.ac.uk/Record/cronfa42478

A Dynamic Transactional Model of Parent-Child Interactions in Autistic Spectrum Conditions

Lisa Anne Osborne

Submitted to the University of Wales in fulfilment of the requirements for the Degree of
Doctor of Philosophy

Swansea University

2007

Summary

This thesis examined relationships between parenting stress, parenting behaviours, and child behaviour problems in Autistic Spectrum Conditions (ASC).

Chapter 2 found gains in intellectual, educational, and adaptive behavioural, skills of young children with ASC receiving early teaching interventions. Intervention time-intensity impacted positively on child-outcome gains, but high parenting stress counteracted this effectiveness. Chapter 3 revealed that higher parenting stress was associated with greater child behaviour problems. Parenting stress at baseline was a stronger predictor of child behaviour problems at follow-up, than the reverse. In very young children, ASC severity was related strongly to parenting stress.

Chapters 4 and 5 explored why parenting stress had a negative impact. Chapter 4 found that, for parents of older children, parenting stress, communication, and limit setting interwove bidirectionally. In parents of younger children, these interactions were unidirectional; higher initial parenting stress resulted in poorer communication, but good initial limit setting resulted in lower parenting stress. Chapter 5 revealed that better parental limit setting at baseline produced fewer child behaviour problems at follow-up. Limit setting mediated the relationship between parenting stress and subsequent child behaviour problems.

Chapters 6 and 7 investigated early stress sources in parents of children with ASC. Chapter 6 gathered parents' perceptions of the diagnostic process, through focus groups. Parents wanted a quicker, easier, and more coherently-structured process, more information, and greater professional ASC training. Chapter 7 investigated impacts of ASC diagnosis on parenting stress. Parenting stress declined from when parents first noticed a problem, predicted by children's ASC severity, but failed to change once diagnosis had been received. This possible contra-indication for early ASC diagnosis warrants caution, and further investigation.

An empirically-based model of parent-child interactions was developed, which may contribute to inform theory, and aid practice, in this neglected area of ASC research, especially regarding teaching interventions, and parent support.

Declarations and Statements

This work has not previously been accepted in substance for any degree, and is not being concurrently submitted in candidature for any degree.

Signed .... (candidate)

Date ....30·04·08...

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed .... (candidate)

Date ....30·04·08...

STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

Signed .... (candidate)

Date ....30·04·08...

Contents

Acknowledgements

To embark on a Ph.D. is to undertake a journey of discovery. My eternal gratitude goes to Phil Reed who made it possible for me to conduct this research, and to pursue this degree. My deepest heartfelt thanks and appreciation go to Phil for his unending encouragement, unwavering belief, invaluable advice, patient help, and unerring guidance – my guiding light!

Many thanks to Louise McHugh, and to Jo Saunders, who very kindly agreed to supervise this Ph.D. when I really needed their help, and without whom it would not have been possible to submit this thesis. Their generous contributions, support, and comments are greatly appreciated.

Thank you to my dear parents, Margaret and Stuart Osborne, for their tremendous encouragement, interest and enthusiasm, and for their constant support every step of the way. My thanks also go to 'fellow traveller', Michelle Wright, and to Birgit Zybell, for their abiding friendship, wonderful confidence and belief, kind words, and for just always being there. Thanks to Lawrence Englesberg for being a good friend. My thoughts are always with Bubble who initially steered me towards this topic, and with Bedlam who sealed my interest and commitment. Both are missed terribly, and will always warm my heart with their memories.

I would like to acknowledge and thank the children, and their parents, for their kind participation in this research, as well as the teachers, schools, and Local Education Authorities who also kindly participated. Their participation was invaluable, and I appreciate it greatly. I could not have conducted this research without their help, and I enjoyed immensely talking with the parents, and hearing about the progress of their

children, they were an inspiration. I would like to take this opportunity to thank them for all of their questionnaire responses, and for the work and time that completing those questionnaires would have entailed.

I would also like to thank Mark Corness for his work as an Educational Psychologist in conducting some of the assessments of the children. Thanks are due to Emma Waddington, also a 'fellow traveller', for her help, support, and discussion. Thank you to Nikki Brown for her contributions, to Mike Connor, and to the Parent Partnership Officers in the participating Local Authorities, for their helpful suggestions, as well as to Melanie Brooks who helped to code and categorise some of the data reported in Chapter 6.

This research was funded and supported by grants from the South East Regional Special Educational Needs (SERSEN) Partnership, and The Disabilities Trust, to Phil Reed. Additional funding and support was provided by Wokingham Local Authority to Phil Reed, and by The Baily Thomas Charitable Fund to Phil Reed and myself. I would like to express my appreciation for this funding, and to Swansea University for providing a Staff Bursary to cover the fees for this doctoral degree.

To all mentioned above, a huge and sincere thank you! I could not have had better journey companions!

Publications and Conference Presentations Resulting from this Thesis

The data from Chapter 2 and Chapter 3 were first presented at the Second Conference of the European Association for Behaviour Analysis (EABA) in Gdansk, 2005. The data from Chapter 4 were initially presented at the Third Conference of the European Association for Behaviour Analysis (EABA) in Milan, 2006.

The research reported in several of the chapters of this thesis is now accepted for publication in a number of journals.

Chapter 2: Osborne, L.A., McHugh, L., Saunders, J., & Reed, P. (in press). Parenting stress reduces the effectiveness of early teaching interventions for Autistic Spectrum Conditions. *Journal of Autism and Developmental Disorders.*

Chapter 5: Osborne, L.A., McHugh, L., Saunders, J., & Reed, P. (in press). The effect of parenting behaviors on subsequent child behavior problems in Autistic Spectrum Conditions. *Research in Autism Spectrum Disorders.*

Chapter 6: Osborne, L.A., & Reed, P. (in press). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism.*

Chapter 7: Osborne, L.A., McHugh, L., Saunders, J., & Reed, P. (in press). A possible contra-indication for early diagnosis of Autistic Spectrum Conditions: Impact on parenting stress. *Research in Autism Spectrum Disorders.*

Chapter 8: Osborne, L.A. (in press). A dynamic transactional model of parent-child interactions. In P. Reed (Ed.), *Behavioral theories and interventions for autism.* New York: Nova Science Publishers.

The long and winding road.....

- Paul McCartney.

Chapter 1:

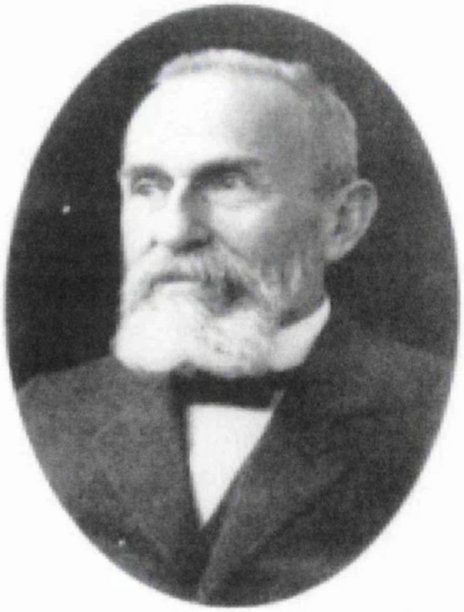
Introduction to, and Literature Review of, Autistic Spectrum Conditions, Interventions, and Parental Influences

1.0 Autistic Spectrum Conditions

Autistic Spectrum Conditions (ASC) are a collection of five developmental disorders (Autistic Disorder, Asperger's Syndrome, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified), which are typically characterised by deficits in social-emotional reciprocity. They comprise a wide spectrum of problems, including: impairment in social interactions, communication difficulties, limited spontaneous pretend and imaginative play, and restricted, repetitive, and stereotyped patterns of behaviours and interests.

1.1 History

The word "*Autism*" is derived from the Greek word "*autos*", meaning "*self*", and the study of Autism has a much longer history than is generally recognised, which stretches back to long before key figures, such as Leo Kanner (1943) and Hans Asperger (1944). The history of Autism is confused, in that, early on, the term was generally applied to patients suffering from Schizophrenia, although not exclusively so. Swiss Psychiatrist, Eugen Bleuler, (1911) first used the term "Autism" to describe patients with Schizophrenia who were living in a world of their own, and were self-absorbed, having minimal contact with others. Thus, in this context, the term "Autism" described, and encompassed, certain symptoms that were



strongly related to Schizophrenia (a term that Bleuler also coined in 1908). However, Bleuler employed this term of "Autism" to intonate a way of thinking that *everyone* engages in, which is disconnected from reality and the world in general, and is wholly concerned with self and self-related wishes. In 1911, Bleuler spoke at the Weimar Psychoanalytic Congress, and argued for two distinct modes of thinking, 'Logical' and 'Autistic'.

> *"...Bleuler conceived of autism not as a pathology confined to a special group of children but as a normal mode of thinking, found among children and adults alike. Autistic thinking, Bleuler claimed, is especially evident in dreams, in the pretend play of young children, in the reveries of normal adults, and in the fantasies and delusions of the schizophrenic."* (Harris, 2000, pp. 1-2.)

In addition to Bleuler, of course, there are several other researchers who worked in the field of early childhood problems, and who touched on areas related, or similar, to Autism. Some of these researchers appear to describe problems distinct from Autism (e.g., de Sanctis, 1906; Potter, 1933), and seem to be concerned primarily with Childhood Schizophrenia. Others studied childhood problems that appear to have specific, purely organic, causes. For example, Critchley and Earl (1932) worked in the area of Tuberous Sclerosis, a condition in which recognisable brain pathology occurs. However, this condition generates behaviour patterns that, in a large proportion of cases, are typical of Autism (Smalley, Tanguay, Smith, & Gutierrez, 1992). A very similar, and more recent, example of a physical disorder causing Autistic-like symptoms is Phenylketonuria. This is a metabolic disorder which, if it remains untreated with a special diet, results in behaviours that are Autistic in nature (Jervis, 1937).

However, there were three important figures, who worked within the developmental area, early in the twentieth century: Heller (1908), Yarmolenko (1926), and Tramer (1931). These are the pioneers who began to describe the symptomatologies, and conditions, which we would now recognise as Autistic Spectrum Conditions (ASC). These three figures firmly planted Autism in developmental study, and lead the way for later research into the 'pathway' of the development of Autism. Their works stand in contrast to the later, and more widely known, views that Autism is present from birth (e.g., Kanner, 1943), and so particularly merit some discussion here in a thesis concerned specifically with the transactional influences and impacts of parent-child interactions on the shifting, or dynamic, nature of Autistic behaviours.

1.1.1 Theodore Heller

Theodore Heller was an Austrian special educator, who identified, and described, a disorder, which he termed as "Dementia Infantilis" (1908), also known as Heller's Disease or Syndrome. Heller can be considered as a very important figure in the study of Autism, in that he specifically claims that Dementia Infantilis is quite distinct from other forms of childhood dementias (see Heller, 1930). There is now reason to regard Dementia Infantilis as synonymous with Childhood Disintegrative Disorder (CDD; Hendry, 2000), later termed "Disintegrative Psychosis of Childhood" by Rutter, Lebovici, Eisenberg, Snezhnevsky, Sadoun, Brook, and Lin (1969).

Heller's initial study, in 1908, was a report of Dementia Infantilis in six children (Kurita, 1989), which he later extended to observations of a total of twenty-eight children spanning from 1905 to 1930 (Malamud, 1959). Heller observed that these children exhibited age-appropriate development up to three or four years old, and then a dramatic change in their development would occur. A marked deterioration would be apparent, at this time, in the children's behaviours, moods, receptive and expressive language (which were often lost completely), and they tended to develop incontinence. While Heller maintained that intellectual functioning reduced, he noted that intelligent facial expressions did not diminish (Hendry, 2000). Zappert (1921) expanded on Heller's initial work, by being the first to postulate formal diagnostic criteria for Dementia Infantilis (see Table 1.1).

Table 1.1: Zappert's description of Dementia Infantilis.

1. The disease commences between the ages of 3 and 4.
2. Speech defect becomes noticeable at the onset of the disease and is progressive. Speech soon disappears altogether.
3. Restlessness, fear, and sometimes hallucinations occur as a rule at the beginning or, more rarely, during the course of the disease.
4. Intellectual deterioration progresses very rapidly, developing into full dementia.
5. The intelligent facial expression is preserved for a very long time, in spite of the dementia.
6. No neurological signs can be detected.
7. Physically, the child develops normally and shows no symptoms of any organic disease whatsoever.

Currently, Childhood Disintegrative Disorder (i.e. Dementia Infantilis) has a different diagnostic classification from Autism in the Diagnostic and Statistical Manual (DSM-IV), largely due to the single factor of age of onset (Volkmar & Rutter, 1995). However, although the DSM-IV implies that Autism is present earlier than CDD, given that the diagnosis of Autism is very difficult prior to the age of CDD onset (i.e. three years of age), and is practically impossible at birth, it seems probable that these two 'distinct' disorders are one, and the same. In fact, both Kurita (1989), and Hendry (2000), in reviews of the literature, suggest that a distinction should not be drawn between CDD and Autism. Hendry noted that:

> *"At this point, the variables...upon which CDD is currently distinguished from Autistic Disorder are not well substantiated...not enough information exists to justify it as a separate diagnostic category."* (Hendry, 2000, p. 88.)

1.1.2 Moritz Tramer

Heller is not alone in his work concerning the description of the developmental onset of symptoms relating to ASC. Moritz Tramer was a Swiss Psychiatrist, who outlined a novel special discipline which he termed "Child Psychiatry" (Stutte, 1975), and, in addition, he was the first to describe Elective Mutism (Tramer, 1934). Tramer, in 1931, studied and described a condition termed "Infantile Schizophrenia", albeit in only one child. However, this case history was exhaustive, and was based on daily records, as well as on medical and developmental observations. The psychosis became apparent in the child's third year, at which point the speech and language of the child underwent a dramatic deterioration from previously attained levels, rather like that described in CDD. However, in addition to the Mutism, Tramer describes the child as becoming 'isolated'. By the time the child had reached four, this regression had stabilised.

Tramer's description of this case study resembles Heller's accounts, and they both appear to be describing a set of symptoms that would be immediately recognisable as Autism, as we know it today. However, Tramer goes a little further, in that he not only refers to these behavioural manifestations as results of developmental maturation, but he also references a possible environmental trigger, namely, an upsetting incident involving a servant when the child was three years old. This is one case study only, and it is not known whether the child in question was indeed Autistic, as, later reported, he died at the age of twenty-two, and he appeared to suffer from Dwarfism, among other physical abnormalities (Tramer, 1943). However, it is of interest, for the current purposes, that Tramer does attempt to connect the child's condition to environmental and experiential events.

1.1.3 Avgusta Yarmolenko

Dating before Tramer (1931), and yet distinct from both Heller and Tramer, in that she more strongly considered environmental factors to be primary influences on the development of Autism, Yarmolenko is a key figure in Soviet Child Psychology, but she is almost entirely overlooked by Western Psychology. Avgusta Viktorovna Yarmolenko was a Psychologist in the Soviet Union, who worked in Child Psychology and Special Educational Needs. She was born in 1900, and most of her work in Autism was done very early on in her career, within the Pavlovian framework. In 1926, Yarmolenko wrote an important paper entitled: *Change of environment as a factor determining an anomaly of behaviour (autism in uncontrolled children).* In this paper, she uses the term "uncontrolled" to refer to children exhibiting characteristics similar to those regarded as Autistic nowadays. From this key paper, and from others (Yarmolenko, 1931; 1935a), it is possible to compile a list of characteristics and symptoms that are common to the children who she describes (see Table 1.2).

Table 1.2: Yarmolenko's list of characteristics of "uncontrolled" children, accompanied by modern parallels.

---

1. They exhibit inhibited behaviour; that is, a very limited and restricted repertoire of behaviours and responses (small behavioural repertoire and restricted imagination, Wing & Gould, 1979).
2. They exhibit "irradiated reactions" not in keeping with the nature of the stimulus, that is they display very idiosyncratic and inappropriate responses to the stimuli (stimulus over-selectivity, Lovaas & Schreibman, 1971, and weak central coherence, Frith & Happe, 1994; see also Wing, 1981).
3. They show very poor "static co-ordination" of hand movements (fine motor control), whereas, their "dynamic co-ordination" of active movements (gross motor control) are relatively better (as measured by the Gilliam Autism Rating Scale, 1995).

Yarmolenko (1926) links these characteristics, described in Table 1.2, to a series of repeated changes that occurred in the children's social environments, and in their social relations. At this point in time, she was heavily involved in studying children who had lived through the traumatic years of the Russian Revolution (i.e. 1917 onwards). Yarmolenko suggested that children need a settled and stable existence between certain critical ages, namely the "Transition Age" range, in order to learn about social relationships in an appropriate way. In a later paper, Yarmolenko (1935a) claims that some of the physical characteristics and behavioural symptoms (especially problems with motor skills and dyspraxia) of children with Autism or, as she calls them, "*Psychoneurotic children*" are not similar to those manifested in children with damage to, or diseases of, the nervous system. This claimed distinction implies that she is placing the causes of these physical characteristics and symptoms firmly in the environment, in other words, their motor skills are affected by learning. In fact, in later papers published in 1931, and in 1935b, Yarmolenko claimed that such low level motor abilities could be improved by systematic physical training.

1.2 Classic Descriptions of ASC

Prior to the classic work of Leo Kanner, and Hans Asperger, the conditions, that would now be termed ASC, had been regarded, and described, in the main, as developmental disorders, the onset of which would become apparent around the age of three. Up to this age, the child in question would appear to develop normally, and then, suddenly, typical development would halt, and rapidly deteriorate from this point onwards. The work of Kanner and Asperger altered this conception somewhat, but their works should still be viewed in the context of that previous research, as described above, which identifies ASC as relating to a very wide and diffuse range of symptoms and problems.

1.2.1 Leo Kanner

Kanner was a doctor working in Baltimore, USA, who wrote a seminal paper in 1943, often thought of as being the first to describe Autism. Here, he discussed the case histories of eleven children who displayed a "new" emotional disorder. According to Kanner, these children manifested a range of five diagnostic symptoms, including: extreme Autism (that is, the mode of thinking outlined by Bleuler), which is a profound aloneness, and an inability to form usual affective contact, and relationships, with other people: "*The outstanding, "pathognomonic", fundamental disorder is the children's <u>inability to relate themselves</u> in the ordinary way to people and situations from the beginning of life.*" (Kanner, 1943, p. 242). In addition, Kanner described symptoms of: anxious obsessiveness, especially involving preservation of environmental sameness and routine; stereotypy, that is, repetitive, ritualistic behaviours of elaborate kinds; and echolalia, mutism, or non-communicative, or non-inter-personal, vocalisations.

The last of the five diagnostic criteria, as outlined by Kanner, renders this condition distinct from Schizophrenia in a very important manner, namely, it allows its sufferers to maintain intelligent and purposeful interactions with objects, if not people, as inanimate objects pose no threat to the self-absorbed state. That is, Kanner described the studied children's fascination for objects, and noted that they handled objects well, displaying good fine motor skills. It is worth noting, however, that fine motor movements and skills are now a recognised area of profound weakness in many children diagnosed with ASC today (e.g., see Gilliam, 1995). Kanner also differentiated the disorder of Autism from Schizophrenia, in that he believed that Autism is innate, and present from birth, unlike Schizophrenia. Kanner (1943, p. 250) claimed that these eleven children are: "*...pure-culture examples of inborn autistic disturbances of affective contact.*".

In 1944a, Kanner wrote another paper reporting a series of twenty case studies. He described all twenty children as displaying indications of good cognitive intelligence, and, from infancy, they had shown a marked tendency to live within themselves. All of these children were obsessed with a desire for absolute uniformity of routine, and were extremely upset and distressed by any changes to these set habits. Kanner, in later years, developed his ideas on the causation of Autism, and moved away from his assertion that all Autism was innate, and present from birth. A return to Kanner will be later necessitated, in order to look at the shift in his opinions regarding the causal factors and aetiology of Autism, when examining the theories of Bruno Bettelheim.

1.2.2 Hans Asperger

Hans Asperger worked contemporarily with, but independently from, Kanner. Asperger was a Child Psychiatrist in Vienna, and used the term "*autistic psychopathy*", in 1944, to describe the social deficits in a group of boys whom he studied. In conducting this work, Asperger's frame of reference was heavily influenced by Bleuler's typology (Ehlers & Gillberg, 1993). He observed, in these young boys, a pattern of behaviours which were Autistic, and markedly deficient in social skills and inter-personal communication. However, these young boys appeared to have normally developing intelligence and language. Asperger asserted that these "*autistic psychopaths*" resembled the children described by Kanner (1943), but that they differed in three very important ways. Asperger omitted any mention of echolalia as a linguistic problem, but, instead, pointed out that the boys spoke like 'little adults', or "little professors". In addition, he noted that their motor activity was an issue, in that it was distinct from that of typically developing children, due to its clumsy, awkward, and exaggerated nature. Finally, Asperger claimed that such children first show symptoms during the third year of life. However, like Kanner's original theory, Asperger considered his syndrome to be genetically transmitted, as he noted that certain Autistic characteristics were evident across the generations of families when they were observed. Such Autistic trends were especially prevalent in the fathers of those with this syndrome. The similarities of, and differences between, Kanner's and Asperger's descriptions of what they each observed, in the children in their independent studies, are displayed below in Table 1.3.

Table 1.3: A comparison and contrast of Kanner's and Asperger's descriptions of their Autistic syndromes.

Characteristic	**Kanner**	**Asperger**
Speech	Poor, or absent	Good, but problems with the pronoun, "I"
Non-verbal Communication		Impaired
Social Interaction	Profoundly impaired	Profoundly impaired
Stereotypy or Repetitive Activities	Present	Present
Motor Skills	Good	Poor
Cognition	Good, but obsessive towards inanimate objects	Good, but obsessive towards inanimate objects

Asperger's work was not widely known until Lorna Wing later wrote about what she termed "Asperger's Syndrome", in 1981. Wing's "Asperger's Syndrome" is actually a modification of Asperger's original "autistic psychopathy", in that Wing notes a lack of interest in, and pleasure from, human company during the first year of life. There also occurs, according to Wing, a lack of 'urge' to babble and gurgle, accompanied by a lack of gesture, movement, smiling, and laughing in babies and toddlers with Autism. An eventual lack of speech results from these earlier marked deficits.

> "*Despite the eventual good use of grammar and a large vocabulary, careful observation over a long enough period of time discloses that the content of speech is impoverished and much of it is copied inappropriately from other people or books.*" (Wing, 1981.)

Wing mentions that Asperger described sufferers of his syndrome as having the capacity to be original and creative in a particular chosen field. Wing puts this down to a difference in the way that they think about things. She labels their thought processes as "*...confined to a narrow, pedantic, literal, but logical, chain of reasoning*". It is interesting that Wing claims that Autistic thought can be logical, as this view differs with that of Bleuler, who claimed that thought was either 'Autistic' or 'Logical'. This apparently subtle, but important, distinction actually takes the "Asperger's Syndrome" of Wing's well away from Asperger's original work, which was based heavily on Bleuler's original conception.

Also, regarding the point of creativity, Wing attributes the originality of thought of sufferers of Asperger's Syndrome to their unusual approach to subjects and topics. This arises from their tendency to select some arbitrary aspect of their chosen subject or topic as a starting point, which would be highly unlikely to occur to someone without this syndrome. Wing writes: "*Usually the result is inappropriate, but once in a while it gives new insight into a problem.*". The emphasis that Wing places on the inappropriateness, and unusual quality of approach to subjects and topics, taken by those with Asperger's Syndrome, links very coherently with the much earlier claims of Yarmolenko on this same subject. Yarmolenko talks about "*irradiated reactions*", those being behaviours that are not typically emitted in the presence of, or not in keeping with, the stimulus presented.

1.3 Contemporary Diagnostic Systems

The history and development of the description of Autistic symptomatologies have built over the years, and have lead to, and provided a context for, the present day understanding and definitions of ASC. In particular, there are two crucial contemporary sources for the key purposes of definition and diagnosis of ASC: the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association, and the International Classification of Diseases (ICD) of the World Health Organization. However, just as the previous characterisations of ASC reveal a wide and diffuse range of behavioural symptoms and characteristics, the current classifications, likewise, show a similar diversity in the symptoms attributed to ASC. Even when focusing on Autism itself (and not on Asperger's, CDD, etc.), although there are some similarities across the two classification systems, there are also some differences, and total agreement is not present regarding all of the symptoms taken to be critical for defining Autism. Hence, illustrating, even today, a width of definitional criteria.

1.3.1 DSM-IV Criteria for Autism

The items below reflect the criteria for labelling an individual as having Autism, taken from the Diagnostic and Statistical Manual of the American Psychiatric Association (4th Edition). These items suggest that there are three main areas of difficulty: (1) qualitative impairment in social interaction; (2) qualitative impairments in communication; and (3) restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities. In order to obtain a diagnosis of Autism, delays, or abnormal functioning, have to be seen in all of these three areas, with their onset being prior to the age three years. Each area lists a diverse set of symptoms, with a diagnosis being dependent on a total of six (or more) symptoms from these three main areas, with at least two symptoms being from qualitative impairment in social interaction, and at least one symptom from each of the other two areas. Additionally, the disturbance should not be better accounted for by either Rett's Disorder, or Childhood Disintegrative Disorder.

In terms of qualitative impairment in social interaction, this domain is described by the following symptoms: (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); and (4) a lack of social or emotional reciprocity.

For qualitative impairments in communication, there could be: (1) a delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gestures, or mime); (2) in individuals with adequate speech, marked impairments in the ability to initiate, or sustain, a conversation with others; (3) stereotyped and repetitive use of language, or idiosyncratic language; and (4) a lack of varied, spontaneous make-believe play, or social imitative play, appropriate to developmental level.

The domain of restricted, repetitive, and stereotyped patterns of behaviour, interests, and activities comprises: (1) encompassing preoccupation with one, or more, stereotypic and restricted pattern/s of interest, that is/are abnormal, either in intensity or focus; (2) apparently inflexible adherence to specific, non-functional routines or rituals;

(3) stereotypic and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements); and (4) persistent preoccupation with parts of objects.

1.3.2 ICD-10 Criteria for Autism

The International Classification of Diseases (10th Edition, World Health Organisation) classes Autism under the general area of Mental and Behavioural Disorders, and places it within 'Disorders of Psychological Development'. It stresses that the functions affected include: language, visuo-spatial skills, and motor coordination. The delay, or impairment, has been present from as early as it could be detected reliably, and will not diminish progressively as the child grows older. As with the DSM-IV, it suggests that onset is invariably during infancy, or childhood, that the impairment, or delay, in development of functions are strongly related to biological maturation of the central nervous system, and the disorder displays a steady course without remissions and relapse.

In the more specific description of 'Pervasive Developmental Disorders', it is suggested that abnormalities are a pervasive feature of the individual's functioning in all situations, and the ICD-10 highlights difficulties in: (1) reciprocal social interactions; (2) communication; and (3) restricted, stereotyped, repetitive repertoire of interests and activities. Childhood Autism is defined by: (a) the presence of abnormal or impaired development manifest before the age of three years; (b) abnormal functioning in all three areas of psychopathology; and suggests that (c) a range of other non-specific problems are common, such as: phobias, sleeping and eating disturbances, temper tantrums, and (self-directed) aggression.

1.4 Symptoms, Characteristics, and Problems

The previous sections concerning the history, and contemporary definitions, of ASC reveal just how this condition encompasses such a very wide, diverse, and diffuse range of difficulties and problems, hence, the current use of the term 'spectrum'. In fact, despite the detailed guidelines regarding the diagnosis of ASC, given both by the DSM-IV and ICD-10, the reality of this condition never fails to be complex and idiosyncratic. For instance, in addition to the core ASC criteria (e.g., stimulus over-selectivity, etc.), and many associated externalising child behaviour problems, there are sometimes sensory problems, and low IQ. Indeed, Lord and McGee (2001), in discussing the problems of researching ASC, have asserted that:

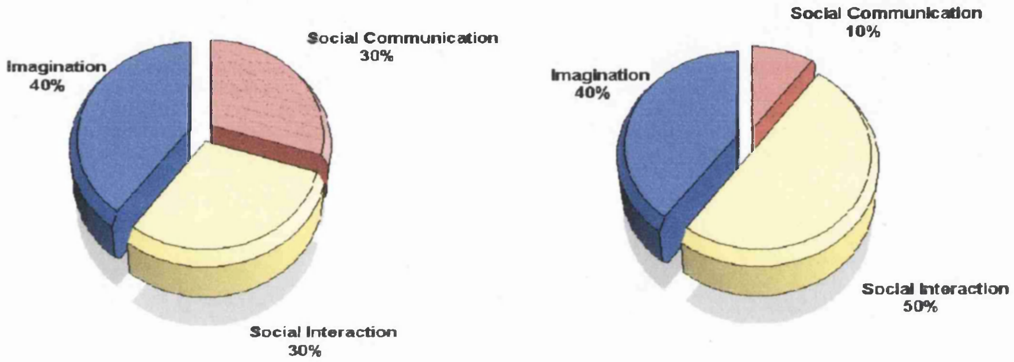
> "*If young children with autistic spectrum disorders were homogeneous in intelligence, behaviour, and family circumstances, and if researchers and educators could apply a uniform amount of treatment in nearly identical settings and life circumstances, then a standard, randomized group, clinical-trial research design could be employed to provide unequivocal answers to questions about treatments and outcomes. However, the characteristics of young children with autistic spectrum disorders and their life circumstances are exceedingly heterogeneous in nature. This heterogeneity creates substantial problems when scientists attempt to use standard research methodology to address questions about the effectiveness of educational treatments for young children with autistic spectrum disorders.*" (Lord & McGee, 2001, p. 193.)

It appears that no two cases of ASC are ever identical to one another, and that every instance of this condition seems, apparently, to be different and unique. This observation is consistent both with adopting the view of this condition as being a spectrum, and also with the original claim, made by Bleuler, that, rather than being an illness or disorder of a specific group of individuals, Autistic thinking is a form of thought that we all engage in from time to time. Hence, for Bleuler, Autism is a continuum on which we all can be placed:

> "*It is a mode of thought that is dominated by free association and wishful thinking. In logical or realistic thinking, by contrast, affective and emotional considerations are set aside, or tempered by an acknowledgement of what is rational and what is feasible. Bleuler acknowledged that autistic thinking can sometimes override logical thinking among normal adults.*" (Harris, 2000, p. 2.)

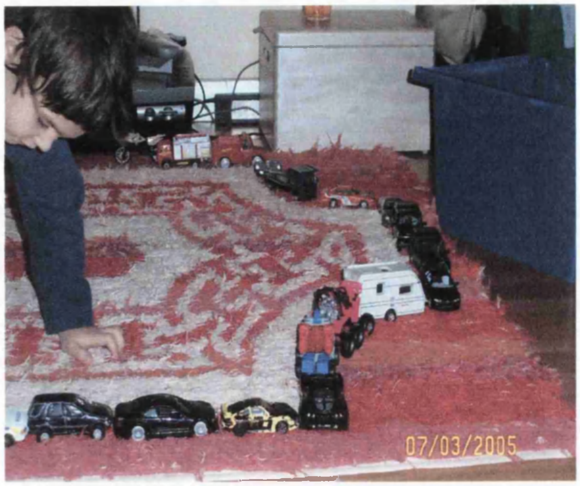
The assertion that 'everyone's Autism is different' can be illustrated by the following '*problems pie*' charts (Figure 1.1), based on Wing's triad of impairments, which illustrate how the behavioural profiles of individuals with ASC may be quite different from one another, even though they are made up of the same broad behavioural ingredients, but just in different quantities. The left panel of Figure 1.1 represents an individual with roughly equal amounts of difficulty in imagination, social communication, and social interaction, whereas the right panel depicts an individual with the same amount of difficulty with imagination, but with fewer social communication difficulties, and with many more difficulties in social interaction (e.g., behavioural problems).

Figure 1.1: The ASC problems pie.



The specific difficulties that each individual with ASC experiences, such as their range of particular interests, and the triggers for their behavioural problems, can, likewise, be very different from individual to individual. For example, O'Reilly, Richman, Lancioni, Hillery, Lindauer, Crosland, and Lacey (2000) describe one child's intense obsession with string, whereas the following quote from a mother, who participated in this current research, describes the idiosyncratic interests manifest in her son with ASC, and the impact of such intense interests on her son's behaviours:

"...he puts a great deal of concentration into it. He gets down low and, leaning over on all fours, looks from directly above to line them up. I have seen him do this with video cases as well. He also attempted it at Leisure Time, a kids' play-ground on the sea front. However, it was with several Little Tykes' Crazy Coupe cars that seat two toddlers up to about age four! He parked them along a fenced off area that had a two-story play house and was complete with circular traffic island and petrol pump! When I say parked, he actually reversed them in perfectly! Unfortunately, he wasn't the only child who wanted to play with these cars. He ran his younger brother over, and threw himself on the floor, smashing his head again and again on concrete, when another little boy dared to stroll over and drive off with one of approximately five cars. [He] went into instant panic, looking at me then the car, back to me, and just literally lets go, dropping to the floor, without a thought to put his hands out to stop himself! He then bangs his head two, maybe three, times before he feels it. This is the down side to all the wonderfully logical things he does and says!"



Moreover, there are times when individuals with ASC display talents and skills, rather than deficits. For example, the case of Nadia (aged 3 to 7 years), who was a child artist savant. Nadia subsequently lost her

special abilities, as she moved into a more formal educational setting, and as her language acquisition improved (Selfe, 1977). It should be noted that savant skills characteristically continue, rather than disappear, and, with continued use or practice, the special abilities either persist at the same level, or actually increase. In very few cases is there a trade-off of special skills or talents with the development of greater language abilities.

Of course, this situation poses some difficulties for researchers in this area, as suggested above by Lord and McGee (2001). It is actually quite unclear that there are any core, or central, uniquely specific deficits that produce, or define, ASC. Several investigators have suggested that ASC should be considered as a set, or range, of overlapping behaviours and difficulties, rather than being thought of as a disorder, or condition, that has a core problem.

This poses a particular difficulty for those attempting to develop causal theories of ASC, such as those researchers who postulate deficits in Theory of Mind (Baron-Cohen, Leslie, & Frith, 1985), and Central Executive Function (Frith & Happe, 1994), and who have recently stated that their previous attempts at a single explanation for Autism should be abandoned (Happe, Ronald, & Plomin, 2006).

This thesis is concerned, not with the causes of ASC, nor with its ‘central deficits’ (if there are any *per se*), but with the factors that may help those individuals with ASC. This approach may be more important in the light of the fact that around 500,000 families, in the U.K. alone, are affected by ASC, that is, about one person in every one hundred people has ASC (The National Autistic Society, 2005), and the prevalence of diagnosis of ASC is increasing worldwide (Chakrabarti & Fombonne, 2005). Boys are four times more likely to develop ASC than girls, and children with ASC are twenty times more likely to be excluded from school than children with other difficulties (The Disabilities Trust, 2005). So it appears now more important than ever to find effective practice concerning managing the symptoms and problems of ASC. This line of enquiry seems particularly timely, given that Autism can be associated with certain related problems, such as lower IQ, greater long-term care needs, increased unemployment, greater social isolation, and the development of subsequent mental disorders, such as depression.

The development of, and enhanced understanding of the factors that contribute to, effective teaching programmes would help to relieve the pressures on individuals with ASC, their families, and the many supporting agencies, and such an approach is now a United Kingdom governmental priority (DfES, 2002), with the hope that it will improve long-term prognosis for individuals with ASC.

2.0 Interventions

Given that educational and teaching interventions are a priority, coupled with the increase in diagnosis of ASC, there is a clear need to properly evaluate and rigorously assess interventions for ASC. Special attention should be given to the potential benefits of these interventions in terms of their impacts on the problems associated with ASC. This applies not only to the child outcomes in the intellectual, educational, and social domains, but also to the realm of the parental, and family, functioning and dynamics. Helping people with ASC to function more independently is very important for three main reasons. Firstly, it promotes their quality of life, increasing their options, and enhancing their skills. Secondly, it relieves some of the psychological, as well as some financial, strains on their families, by promoting a degree of self-sufficiency in those with ASC. Thirdly, it ultimately relieves some of the financial pressures on external supporting agencies and bodies, such as the National Health Service, Local Education Authorities, and Social Services.

There are many different forms of interventions for ASC, for instance: medical and pharmacological, nutritional and dietary, and educational and psychological. Treatments like the administration of the hormone, Secretin, and the use of Naltrexone, which is an opioid blocker, are examples of medical and pharmacological approaches. Gluten-free and casein-free diets are often prescribed for similar reasons as the opioid blockers. If gluten or casein cannot be digested completely by the body, then by-products, in the form of opioid compounds, can build up, and these can be hazardous to the brain, resulting in, or magnifying, autistic symptoms and behaviours. Another nutritional and dietary treatment is the administration of Dimethylglycine. This is technically a food, and this compound is found in tiny amounts in brown rice and liver, for instance. It resembles the water-soluble vitamins, like the B vitamins, and the major reason why this chemical is not classified as a vitamin in its own right is that there are no particular physical symptoms linked with a Dimethylglycine deficiency.

Although these various medical and pharmacological, and nutritional and dietary, treatments are quite common, they are not the focus of this thesis, and will not be covered here. This thesis is concerned with educational and psychological approaches to ASC. Educationally-based programmes are often the only form of intervention given to children with ASC, and are often the only form of support that their families receive (e.g., see Howlin & Moore, 1997). Often, these interventions are offered early in the child's development, and there is a perception that interventions offered earlier are more effective than those offered later (U.K. Department of Health, 2001).

A number of teaching interventions have been suggested as offering benefit to some children with ASC. Some of these interventions concentrate mainly on a child-centred approach. Some such interventions can be specifically targeted at improving particular skills, like the mathematical ability of children (e.g., Leader & Barnes-Holmes, 2001), and some are broader in scope (e.g., Lovaas, 1987). Applied Behaviour Analytic (ABA) approaches have been reasonably widely investigated (e.g., Eikeseth, Smith, Jahr, & Eldevik, 2002; Greer, Keohane, & Healy, 2002; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Lovaas, 1987; Smith, Annette, & Wynn, 2000). Other child-centred interventions include: the Treatment and Education of Autistic and Related Communication Handicapped Children programme (TEACCH; Schopler, 1997; Mesibov, 1997), Special Nursery provision (see Charman, Howlin, Berry, & Prince, 2004; Gabriels, Hill, Pierce, Rogers, & Wehner, 2001), Portage (e.g., Smith, 1999), Floortime (Greenspan & Wieder, 1997), and the Son-Rise Program®, amongst many others, and have all been offered as approaches to managing the problems associated with ASC. Some procedures focus more on the parents, and the family as a whole, such as EarlyBird (Shields, 2001), and such approaches are more 'holistic' in their management of the problems experienced when dealing with a child with ASC. There are many more teaching interventions for ASC than those few listed here, and there are many tools or techniques that are used in conjunction with teaching interventions. These additional tools usually target, and work on, communication and language, such as the Picture

Exchange Communication System (PECS), Speech and Language Therapy (SLT), and Makaton, which is a simple sign language, to name but a few.

2.1 History of Educational Treatments

Up to this point, coverage of the key historical figures in ASC has been presented (see Section 1), however, little detailed discussion has been offered regarding their views about the management and treatment of ASC. In terms of the figures, mentioned in the previous section, Heller (1930) stated that education could be employed as a therapy, but could achieve more success if Educators were to work alongside Physicians. Medical and educational co-operation, and overlap, would achieve better results to produce a therapeutic pedagogy. Tramer, being a Child Psychiatrist, must have believed in the power of treatment, but he does not appear to describe any treatment specific for ASC. Yarmolenko (1935b) claimed that clinical treatment could alleviate some of the fine motor problems in "psychoneurotic children", when she examined the exactness of their hand movements, when testing their "static" and "dynamic" muscular work.

Kanner (1944b) emphasised the role of education in the 'social therapy' of the "rejected" child. He claimed that a child, who is rejected at home, can gain acceptance at school, but only if the teachers are: understanding, do not share the family's attitudes towards the child, and are adequately prepared and trained to guide, and work with, the child and their problems. By 1955, Kanner was, however, less optimistic about treatment success (Kanner & Eisenberg, 1955). Kanner and Eisenberg studied the life histories of forty-two children, and treatment appeared to have little effect, if any at all. They found that a strong predictor of a poor prognosis for the child outcomes at adolescence was the severity of their language dysfunction in their pre-school years. Asperger (1941) was already heavily involved in the treatment of children who were damaged and scarred emotionally by the Second World War in Germany. In 1949, Asperger discussed the education of children with ASC. He remarked that, although fraught with difficulties, the typical "autistic psychopath" could be successfully helped and guided by expert Educators and psychotherapeutic treatments.

Returning to Kanner, his 'understanding teachers', as a helpful force, are the flip-side of his 'rejecting parents', which he suggested, at some points in his writings, as one possible cause of ASC. In this, he appears to be simply hoping that a reversal of the process that lead to the problem will work to undo the problem. It should be noted, however, that there is some ambiguity in Kanner's work regarding his views on the causes of ASC. Kanner, in 1943, claimed that ASC is innate, and that it is present from birth, and his view of possible organic factors did not alter throughout his work. However, over the years, his approach developed and allowed for multiple causes, some of which are environmental and experiential. For example, Kanner and Eisenberg (1956) noted that a clear distinction between "organic" (physiological and genetic) and "functional" (learned reactions) ASC cannot be maintained. Kanner and Eisenberg (1957) said that: "*Present knowledge leads to the inference that innate as well as experiential factors conjoin to produce the clinical picture.*" Thus, a brief survey suggests that education is the major solution proffered in the management and treatment of ASC, up to the mid-twentieth century.

2.2 Applied Behaviour Analysis

Much current debate has centred on Applied Behaviour Analysis (ABA). This approach was originally derived from the theoretical, and empirical, work of B.F. Skinner, and was initially extended to produce an intervention for children with ASC by C.B. Ferster. Since these early developments, a large number of differing ABA approaches have been outlined, for example, the 'Lovaas' approach (i.e. the UCLA Early Behavioural Intervention Programme; Lovaas, 1987), the Princeton Institute approach (McClannahan & Krantz, 1994), the Verbal Behaviour approach (Sundberg & Michael, 2001), and the Comprehensive Application of Behavior Analysis for Schooling (CABAS®) approach (Greer, 1997). Each one of these programmes is subtly different from one another in their specifics, but all adhere to the same basic shared principles of reinforcement and environmental management of behaviour.

These educational interventions are typically one-to-one teaching procedures (e.g., Lovaas, 1987), and are usually home-based, although they can be delivered effectively in school settings (e.g., Greer *et al.*, 2002). They often involve the parents, as well as adult helpers, or 'therapists', or teachers, using discrete-trial reinforcement-based methods, often referred to as Antecedent/Behaviour/Consequence (ABC). Any aggressive and self-injurious behaviours lead to 'time-out' from reinforcement, with the intention of extinguishing the unwanted and inappropriate behaviours through ignoring these behaviours, whenever safe to do so. Of course, there are a variety of systems that deliver such teaching techniques across the various ABA approaches, but all emphasise the basic need to manage behaviour by the careful analysis of the stimuli that control the behaviours.

It is often claimed that such teaching interventions work best when they are time-intensively delivered, and Lovaas (1987) suggested that forty hours per week is the ideal, and optimal, amount of time required (although this figure is the subject of some debate, see Reed, Osborne, & Corness, 2007a). An ABA session of a 'Lovaas-type' intervention, as typically delivered in a home setting, is two to three hours long in duration, and the numbers of tasks taught average from about eight to around fourteen per session, depending on the length of the session, and the abilities of the child. Each task will probably last for about five to ten minutes, and 'down time' rests, or intervals, between tasks will last for about five minutes each. During this 'down time' between tasks, the therapist makes notes regarding the last teaching task, and prepares for the commencement of the next task. It also serves as a rest period for the child, in which they can play, or just take a break. The curriculum overview, as suggested by Lovaas (1987), roughly divides into the stages, and goals, as shown in Table 1.4.

Table 1.4: Education curriculum suggested by Lovaas (1987).

Year 1: Aims to reduce self-stimulation and aggression, and aims to develop 'compliance' with commands, imitation, and play.
Year 2: Focuses on expressive language, and interactive play.
Year 3: Deals with emotional expression, pre-academic skills, and observational learning.

As noted above, a number of alternative behavioural interventions have been developed, and these ABA programmes can take a number of different forms (see Mudford, Martin, Eikeseth, & Bibby, 2001). Two of these approaches have received some detailed attention: the 'Verbal Behaviour' approach (Sundberg & Michael, 2001), and the CABAS® approach (Greer, 1997; Twyman, 1998). The Verbal Behaviour intervention is a discrete-trial approach to the treatment of ASC that focuses, primarily, on the development of verbal responses. This approach emphasises the development of verbal operants (i.e. functional language), rather than the development of words and their meanings (see Skinner, 1957). It also emphasises the independent training of speaker and listener repertoires.

The CABAS® approach provides teacher-training, supervisory support, and administrative support, to implement a teaching system (see Greer *et al.*, 2002). This system employs a combination of ABA technologies, which include direct instruction, precision teaching, and a personalised system of instruction for both staff-training and parent-training (see Keohane, 1997). The CABAS® approach stresses the importance of 'learn-units' (i.e. opportunities to learn), and emphasises the interaction of teacher and student as the unit of analysis, rather than focusing solely on the child's response to a discrete-trial prompt (Greer, 1997). That is, the child's success would be gauged by examining the number of question-response learn units that were correct, as a function of the total number of question-response learn units available. The CABAS® approach also has a specific curriculum (see Greer & McCorkle, 2003), which is quite different from the curriculum outlined by Lovaas, as described above in Table 1.4.

The initial results, reported by Lovaas (1987), concerning the outcome effectiveness of the ABA approach were remarkable. The children undergoing this approach made gains of up to 30 IQ points, and just under half of these children appeared to 'recover', that is, they were not noticeably different from typically developing children after three years of the intervention (the latter finding, however, is yet to be convincingly replicated, see Reed *et al.*, 2007b).

There have been a number of critiques of this initial piece of research (i.e. Lovaas, 1987) that have focused on problems, both with the internal, and external, validity of the study (e.g., Connor, 1998; Gresham & MacMillan, 1997; Mudford *et al.*, 2001). In terms of the internal validity of the Lovaas (1987) study, it should be noted that different IQ tests were used at baseline and at follow-up to assess the children's intellectual functioning, reducing the reliability of the measurements (Magiati & Howlin, 2001). Of course, this is not a problem unique to studies of the effectiveness of ABA approaches to ASC, but can be found in studies of the effectiveness of other approaches (e.g., Charman *et al.*, 2004).

In terms of the threats to the external validity of the Lovaas (1987) study, firstly, the reliance on IQ as a sole measure may be questioned, given that IQ is not necessarily the main problem in the functioning of children with ASC. Secondly, the sample chosen for the study reported by Lovaas (1987) were verbal, relatively high-functioning, participants, who may have performed equally well with any intervention with a reasonable time-input (such as some of those noted above). Finally, the study reported by Lovaas (1987) was a 'clinic-based' study (i.e. one conducted in a clinic, institution, or school), as opposed to a 'community-based' study (i.e. one conducted in the parents' home, etc.), and may not generalise to a majority of ABA interventions that are typically delivered in a home setting, compromising the usefulness of this study. This issue has been highlighted in a number of recent reports of home-based ABA programmes, which have questioned the extent to which the results of clinic-based assessments can be generalised to the types of ABA programmes that occur in the community (Mudford *et al.*, 2001).

Although several of these points of critique have been addressed in subsequent research, few, if any, studies have addressed them all in a single investigation. For example, both Eikeseth *et al.* (2002), and Howard *et al.* (2005), have used community-based, rather than clinic-based samples, and both have found ABA to be effective, but neither used the same tests at baseline and follow-up. Several of these criticisms were addressed by Reed *et al.* (2007b), who partially replicated the effectiveness of previous studies of clinic-based ABA programmes in a community-based sample, using the same tests at baseline and at follow-up, across a participant sample displaying a wide range of abilities and functioning levels.

2.3 TEACCH

The Treatment and Education of Autistic and related Communication handicapped CHildren (TEACCH) programme is a structured teaching method (Schopler, 1997). There is no specific content to the TEACCH method, as is also the case with ABA. Both TEACCH and ABA are approaches to teaching, and the contents are tailored to the individual needs of the child, depending on their strengths and difficulties. There is little direct empirical evidence relating to the outcome effectiveness of the TEACCH method, although, as it is a widely employed technique, it is described in some detail below.

It is important to keep in mind the individual requirements of children, and teachers must remember to structure and organise classroom life, in order that children expand their strengths, compensate for, and circumvent, their weaknesses, as well as improving on them. Individualisation is a key to effectively employing the three main features of TEACCH, namely: physical organisation, scheduling, and teaching methods. A teacher must always consider the individual strengths and needs of the children to be taught when planning and preparing their strategies for teaching. Teachers who use the teaching methods of prompts and reinforcement can only do so effectively if they assess and attend to the interests, learning styles, abilities, needs, and requirements of the individual children to be taught (see Mesibov, Shea, & Schopler, 2005).

The classroom environment is physically organised in a way that is designed to alleviate, or moderate, potential problems and difficulties. For example, the arrangement of the furniture in a classroom can help, or hinder, a child's independent functioning, and alter their ability to recognise, and comply with, rules and limits. The deficits of ASC can mean that a child can have organisational difficulties, and this will often result in their not knowing where to be at a given time, and how to get there using the most direct route available. A teaching environment can be structured to be less distracting, for instance, lighting, wall space, and displays, and mobile features can all be examined, and organised, so as to reduce any distraction and confusion. Due to difficulties in receptive language, children with ASC may often misunderstand, or fail to understand completely, directions or rules. The teacher can structure the environment in such a way as to offer clear visual cues to aid, and even enable, understanding. Materials should be clearly marked, labelled, or arranged in a way, and at a level, that a child can understand. Materials should be placed in the settings in which they will be used, thus, helping children to follow directions more easily, and complete tasks with more success. The whole classroom layout, both overall and detailed, must be taught to the child with ASC, in order that the teacher can effectively teach.

Time management is employed to give structure, order, and more stability, resulting in an enhanced sense of security. The elements of surprise and change can be disturbing to children with ASC, so familiar activities and regular routines are comforting and calming. Teaching must be well planned and scheduled, as a teacher must have a framework in order to teach children with ASC effectively. Teaching methods must be systematised and organised to obtain the best results, and teaching tasks need to be set up in a structured way for success. Timetables and routines give direction, and aid clarification, to classroom life, and school life as a whole. Structuring the environment in order to promote the acquisition of skills, and facilitating independence across all levels of abilities, are two basic principles of the TEACCH approach (Lord & Schopler, 1994).

2.4 'Eclectic' Approaches

Special Nursery provision is an 'eclectic' teaching approach to managing the problems associated with ASC. Such approaches are often referred to as 'eclectic' (e.g., Howard *et al.*, 2005), or 'generic' (e.g., Lovaas, 1987), programmes, as they do not follow a particular 'brand name' approach to education, but offer a variety of teaching methods (e.g., Picture Exchange System, activities drawn from the TEACCH model, Circle Time, Social Stories, etc.) that do not necessarily adhere to a single underlying philosophy.

Such 'eclectic' approaches, by their nature, vary, but one such programme was described by Reed *et al.* (2007b). In this 'eclectic' programme, each of the classes were small (about six to eight children), and each class was under the supervision of a teacher with postgraduate qualifications in teaching, and specialist training in Special Educational Needs. In addition to the teacher, each class had two or three learning support assistants, who would help to work with the children in small groups. Thus, most teaching was conducted in small groups, rather than individually (about four times as much group work as individual work). The intensity of the intervention (hours per week) was about sixteen hours per week (moderate, compared to a typical ABA programme). The children attended the nursery for a number of two to three hour sessions per week, depending on the severity of the child's ASC.

Typically, a session would start, and end, with the children in a group with the teacher at the front of the group. The teacher usually guided a song, or other introduction, and the children were encouraged to turn-take in answering their names, or responding, often involving doing an individual activity (e.g., picking up a name card, shaking an instrument, etc.), whilst the others were encouraged to respond and comment. A key feature was the use of materials, and methods, appealing to children with ASC, such as brightly coloured visual materials, glitter, water, paint, sand, or musical instruments. Much of the school's environment was, and many of the tasks given to the children were, presented in a highly structured method, as outlined by the TEACCH methodology (Mesibov, Schopler, & Hearsey, 1994).

Thus, the focus was on learning and motivation, developing shared attention, and participation (with support from up to two or three adults). Other sessions included a free choice of activities for the children, with adults focusing their support on individuals who are encouraged to work towards their learning objectives, and, all of the time, encouraging and prompting social interaction, turn-taking, shared attention, and commenting, in the children. Another session involves group outdoor activities, such as running across the playground, together in pairs, to practice physical coordination, and group participation, etc. Most of the reinforcers were social (e.g., 'good boy', or clapping, or having the opportunity to play with a desired toy, etc., but always in the context of the group).

This approach has the benefit of being reasonably cost-effective, in comparison to more time intensive approaches, such as ABA. However, Special Nursery provision appears to suffer from the problem of having an apparent scant evidence-base, with respect to its effectiveness in promoting children's intellectual, educational, and adaptive behavioural functioning. A number of studies have reported the effectiveness of Special Education provision, and, in particular, the effectiveness of the 'eclectic' approaches to teaching, frequently delivered to children with ASC. These 'eclectic' approaches are often studied in comparison to ABA intervention programmes. The results of such comparative studies almost universally show that ABA intervention programmes are more effective than the Special Education provisions (e.g., Howard *et al.*, 2005; Reed *et al.*, 2007b). However, these studies are approximately evenly split between those that find a slight improvement in functioning, and those that find little improvement, when examining the impacts of the Special Education programmes *per se*.

In the former 'improvement' category, four studies have reported a variety of differently sized gains for children with ASC in 'eclectic' placements. Sheinkopf and Siegel (1998) found a two point increase in IQ, over a year, in children in Special School provision. Eikeseth *et al.* (2002) found a four point improvement in IQ, over a year, following a Special Educational placement (using 1:1 techniques, such as TEACCH, and Sensory-Integration Therapy). However, there was no improvement in standardised adaptive behaviour, as measured by the Vineland Adaptive Behaviour Scales. Gabriels *et al.* (2001), in a retrospective, three-year, study of children with ASC undergoing an 'eclectic' approach to intervention, found a five point increase in IQ. In a study conducted in the U.K., Reed *et al.* (2007b) found that children with ASC in Special Nursery placements made a ten point gain in IQ, and a smaller, but statistically significant, gain in adaptive behavioural functioning, over a period of nine to ten months.

In contrast, four studies found no improvements in any functioning for children with ASC attending Special Nursery. Sallows and Graupner (1999) found a seven point decrease in IQ, over a period of a year. The remaining three studies, in this latter 'non-improvement' group, found no overall change in the standardised scores for children in Special Education placements with an 'eclectic' approach to teaching intervention. Howard *et al.* (2005) compared two groups of children with ASC, receiving either intensive, or non-intensive, 'eclectic' Special Education interventions. In neither case were there any changes in a variety of assessments of the children's intellectual abilities. Lovaas (1987) found no improvement for children undergoing "generic" educational interventions, over a three year period. Charman *et al.* (2004) found no improvements in adaptive behaviour scores, as measured by, amongst others, the Vineland Adaptive Behaviour Scales (see also Eikeseth *et al.*, 2002).

Given this failure to reliably document improvements in 'eclectic' programmes, there is little wonder that parents, when faced with such evidence, will argue strongly for the more expensive, and time-intensive, ABA approaches. Although the evidence-base with regard to such ABA interventions is certainly flawed (see Connor, 1998; Mudford *et al.*, 2001), at least it does have a platform of data from which to argue a plausible case.

2.5 Portage and Local Education Authority 1:1 Approaches

Portage is a home-based, 1:1 teaching programme, offered by numerous Local Education Authorities in the U.K, for pre-school children with Special Educational Needs. The Portage programme has been extensively used with children with developmental disabilities, as well as with children with many different physical disabilities (see Cameron, 1997). Although this intervention was not originally developed for children with ASC, it has been modified to accommodate children with ASC (see Reed, Gibson, & Osborne, 2000; Smith, 2000). This modification involves a slightly increased temporal input to the programme, and a focus on teaching and developing attentional responses, such as joint attention, and attention-sharing behaviours.

Portage is a relatively low time-intensity programme, with the majority of the work being conducted 1:1 with the child by parents, although there can (rarely) be some group work involved. The Portage programme is supervised by a trained Portage supervisor, who has graduate level qualifications, and who has attended training courses in the delivery of Portage. This programme, typically, follows a manual, written by the Portage Service who provides the programme and the supervisor. The supervisor visits the parents once a week, or fortnight, and parents are shown how to apply this system during these visits, so that they can work with the child between visits from the supervisor.

The Portage sessions conducted with the child are brief, usually about forty to sixty minutes per day, if the child has ASC (but they can be shorter in duration for other disorders). The sessions are scheduled for times when the parent believes that the child will be at their most receptive. Thus, the programme shares some common elements with more motivationally-oriented approaches, such as Floortime (Greenspan & Wieder, 1997). Typically, the parent will teach the child in a 1:1 situation, and will target several skills for teaching over each week. The child is taught new skills through the use of questions, tasks, prompts, and rewards. The skills to be taught are outlined, and categorised, in the Portage manual, and each individual skill acquired is used to build into larger, and more complex, behaviour responses over the course of the programme. Monitoring and evaluation of progress occurs during the visits by the supervisor.

Smith (2000) provided some data to suggest that Portage programmes can impact on the social development of children with ASC, and Reed *et al.* (2000) discuss some possible developments, and limitations, of this approach in the context of ASC. However, this approach, although commonly used in practice, suffers from a great paucity of empirical evidence regarding its effectiveness. In a recent study, Reed *et al.* (2007b) noted little impact of Portage on the intellectual, educational, and adaptive behavioural outcomes for children with ASC.

Alternatively, as well as Special Nursery provision, many Local Education Authorities offer their own forms of 1:1 intervention, often as an alternative to the more expensive, and time-intensive, ABA programmes. For example, the Parents of Autistic Children Training and Support (PACTS) scheme, previously run by Bexley Local Education Authority (see Reed *et al.*, 2007c, for a discussion), and the Scottish Centre for

Autism Preschool Treatment Programme (see Salt, Sellars, Shemilt, Boyd, Coulson, & McCool, 2001). Many of these Local Education Authority interventions offer a similar number of hours of teaching to that given in Special Nursery placements, and also offer a parental training programme, as suggested as important by other home-based interventions (see Section 2.6).

Both Eikeseth *et al.* (2002), and Howard *et al.* (2005), have described the effectiveness of time-intensive 'eclectic' approaches, offered within a Special Education placement, that also involve 1:1 teaching as part of the more general provision. However, there have been few evaluation studies of Local Education Authority 1:1 approaches, that are 'eclectic' in nature. One such programme evaluation was reported by Salt, Shemilt, Sellars, Boyd, Coulson, and McCool (2002). In this programme, children and parents visited a Nursery setting, for a short period of time (eight hours over every two weeks), and teaching work was conducted with the child (see Salt *et al.*, 2001, for full details). Using behavioural-based assessment tools (Vineland Adaptive Behaviour Scales), it was found that there was no increase in the standard scores over a period of eleven months. Thus, as with the study reported by Charman *et al.* (2004), mentioned above, there was some gain in behavioural ability, but no more than would be expected through normal changes in chronological age. This is, perhaps, not surprising, given the relatively small temporal input of the programme (around four hours per week).

2.6 Parent-Oriented Approaches

In addressing the problems, and related issues, produced by having a child with ASC, the role of the parents has recently come to the fore; for example, involving the parents with any interventions given to the child has been shown to be important (e.g., Schuntermann, 2002; Stoddart, 1999). Recent initiatives provide good examples of this movement: the EarlyBird scheme (Shields, 2001), and Portage programme (Smith, 2000; see Section 2.5), specifically highlight the need for parental involvement in helping the child with ASC. Recently, ABA programmes have also focused both on the need for parental involvement (e.g., Gabriels *et al.*, 2001; Luiselli, Cannon, Ellis, & Sisson, 2000; Harris, 1994), and on the impacts of the intervention on the family as a whole (Hastings & Johnson, 2001). Given these developments, there seems every reason to place the parents clearly in focus when framing an understanding of the impacts of ASC, and when considering the development of interventions for ASC.

Many of these more family-oriented interventions have noted improvements in children's behaviours, and functioning, as a result of a reduction in parenting stress, and an increase in parental coping abilities (e.g., Harris, Handleman, Arnold, & Gordon, 2000; Lovaas & Smith, 2003; Spaccarelli, Cotler, & Penman, 1992; see Brookman-Frazee, Stahmer, Baker-Ericzen, & Tsai, 2006, for a comprehensive review). There are several studies that suggest that teaching positive parenting skills to parents of children with ASC will subsequently reduce their children's challenging behaviours. For example, teaching parents 'mindful parenting', was shown to reduce aggression, non-compliance, and self-injury in their children, and promoted parental satisfaction with their parenting skills, as well as with their parent-child interactions (Singh, Lancioni, Winton, Fisher, Wahler, McAleavey, Singh, & Sabaawi, 2006).

Parent-centred approaches, such as EarlyBird, have targeted the parents directly, rather than the child, and appear to produce gains in children (see Joycelyn, Casiro, Beattie, Bow, & Kneisz, 1998; Sheilds, 2001). Jocelyn *et al.* (1998) reported the results of a randomised-controlled trial that evaluated a caregiver-based intervention programme for children with ASC, in community day-care centres, over a three month period. In this study, both parents and nursery staff were trained in the intervention programme. The children in the experimental group demonstrated greater gains in language abilities, and there were significant increases in parents' and nursery staff's knowledge about ASC, greater perception of control on the part of mothers, and greater parental satisfaction.

There are numerous other interventions that target the problems experienced by the parents of children with ASC, such as Behavioural Marital Therapy, Behavioural Family Therapy, and individualised intervention techniques to help families adapt to the chronic stress of living with a child with ASC (e.g., Cherry, 1989; Harris, 1984; 1994; Moes, 1995). Although several programmes have noted improvements in parental stress (e.g., Bitsika & Sharpley, 2000), others have noted less obvious benefits (Bitsika & Sharpley, 1999; Kuloglu-Aksaz, 1994). Despite such occasional negative reports, beneficial child outcomes, as a result of combating parental problems, such as stress, suggest that parental stress impacts on children's behaviours. Findings related to these various interventions suggest that improved parent-child interactions occur through promoting low stress in parents during those interactions, and through the development of more positive communication (e.g., Koegel, Bimbela, & Schreibman, 1996). Parents who receive support, that buffers stress, relate better, emotionally, to their children (Boyd, 2002). Thus, these interventions recognise how parental functioning may influence the behaviours of a child with special needs (Harris, 1994), and several studies have noted improvements in the children's behaviours, as a result of a reduction in parental stress, or improvements in communication and interactions (Engwall & Macpherson, 2003; Harris *et al.*, 2000; Lovaas & Smith, 2003).

Thus, it is now becoming more widely recognised that focusing purely on the impacts of interventions on children with ASC, neglects the important and key role that parents play in the management of their child's problems (Harris *et al.*, 2000). The importance of involving, and preparing, parents, in support of their child undergoing intervention and treatment across a range of conditions and illnesses, is gaining recognition. There is growing evidence that such family- or parent-oriented interventions show more robust and consistent benefits than purely patient- or child-focused interventions (see Martire & Schulz, 2007). Thus, a more parent-oriented approach is arguably required to gain a fuller understanding of the systems, dynamics, and mechanisms that are involved, and influential, in the development and treatment of the child with ASC.

3.0 Family Issues

There is relatively little current research on family influences on ASC, although this area of study is developing (e.g., see Section 2.6). This relative lack of contemporary study is potentially due to the reaction to Bruno Bettelheim's contentious views on the mothers of children with ASC. Bettelheim (1967) claimed that children with ASC had been raised in 'unstimulating' environments during the first few years of their lives, when their language and motor skills were developing (this view continued a tradition developed by Kanner, see Section 2.1). The nature of Bettelheim's claims lead many to believe that some blame was attributed to parents of children with ASC. This lead to strong feeling, and a backlash regarding the direction taken by subsequent research into the area of the family, and there was a reduction of the amount of investigation into the relationship between parental behaviours and the development of children with ASC. Recently, however, there has been some work on the influence of families, and, more specifically, parents, on ASC, and a re-emergence of interest in this area.

3.1 Historical Views on the Family and ASC

Kanner (1944a) reported on twenty cases of children, who, from infancy, were manifesting marked autistic tendencies. He noted that many of these children lived in families of high academic achievement. Out of the twenty, nine families were listed in the *Who's Who in America*, or in *American Men of Science*, or in both. It was suggested that it is possible that the preoccupation of such eminent academics was with abstract ideas, rather than with people and social relations. This characteristic could be pathologically exaggerated in their descendants, so that their children live within themselves, and show no interest in social relationships whatsoever.

This characteristic social disinterest could be either, or both, genetic or learnt. However, by 1949, Kanner was more clearly swayed in thinking that ASC is a learnt problem. He observed fifty-five children with ASC, and their parents, and noted that most of the children had been exposed to 'parental coldness', and a lack of 'affectionate warmth', from the beginning of life. Their parents tended to be obsessive, and displayed a mechanical attention to their child's physical needs, but not to their emotional and social requirements. The children withdrew from contact with people, but became affectionate towards objects, and obsessed about preserving sameness. Though intelligent, if they used language at all, they did so in a self-directed manner in order to entertain themselves, and not in an interpersonal and communicative way with others. Kanner claimed that the children sought solitude as a form of comfort and escape from their situation, and profoundly avoided all social contact. These observations of Kanner's correspond to those of Asperger (1944), especially regarding the social class of the families observed. Thus, for these two seminal figures in the field of ASC, the functional causes of ASC were primarily to do with the family, and the family dynamics at work.

This view of ASC as being family-related, and socially generated, along with the prevailing Freudian approach to treatment, as well as the salient research of the time on maternal care, deprivation, and attachment (Bowlby, 1951), ultimately lead to Bruno Bettelheim's controversial work and assertions. In 1967, Bettelheim, a Hungarian Freudian Psychologist, who emigrated to the U.S.A., wrote his book: *The empty fortress: infantile autism and the birth of the self.* This book was a case study of three children suffering from ASC, and it documents their Psychodynamic treatment. He wrote about the experiences of the staff members at the Sonia Shankman Orthogenic School in Chicago, of which he was the Director, and, despite wide-spread perceptions to the contrary, Bettelheim takes no explicit stand on the aetiology of the disorder of ASC in this book.

Bettelheim's earlier work provides the framework into which he fitted his study of the treatment of ASC. Bettelheim (1950) wrote a book, entitled: *Love is not enough; the treatment of emotionally disturbed children*, in which he describes the care offered at the Orthogenic School for emotionally-disturbed children. The school worked to restore a sense of security in children, whose parents were not capable of maintaining it, by deploying Psychoanalytic methods of treatment, and everyday activities, in order to reduce their anxieties and insecurities. Bettelheim's interest in the problems seen in children that directly resulted from problems of their parents, and their parents' ways of handling particular situations and activities, was later adapted to the study and treatment of ASC by Bettelheim.

3.2 Critiques of Family Causes of ASC

The perception of Bettelheim's work on ASC sparked a backlash that shifted the study of the causes of ASC from looking at environmental, experiential, and learnt influences, to examining organic, biological, and 'within-child' factors. This shift in focus has been welcomed, and embraced, by many people, as can be seen in the sentiments expressed on many websites dealing with ASC. For example, an anonymous writer states: "*Luckily, research has been shown that autism is a disease with biological causes, not social ones.*", on the Macalester University Psychology website. Similarly, Lorna Wing (1997) writes: "*Fortunately not everyone had faith in the theory of the emotional causes of autism.*".

Unfortunately, this resultant 'relief' appears to have been misplaced, in that, while it has served to relieve parents of feelings of guilt and blame, it has failed to lead to any substantial methods of management, and treatment, of the children's problems (see Section 2). Some of the backlash against Bettelheim appears to have been of a very personal kind. His book, *The empty fortress: infantile autism and the birth of the self*, was called: "*The empty book*", by his critics (see Gardner, 2000), and the infamous term "refrigerator mothers", that was so widely attributed to Bettelheim, does not appear to be present in any original sources by Bettelheim himself. He appears to have been a victim of a 'smear' campaign that challenged the whole environmental approach to ASC, and, if ousted, could be replaced by one purely focused on its biological origins.

More scientific, and legitimate, concerns were first expressed by Schopler (1971), who flagged the important issue of parents not being used as scapegoats. He questioned whether 'scapegoating' behaviour, as outlined by Allport regarding prejudice, was taking place in the study of ASC, and whether it was biasing attitudes against the parents of individuals with ASC. He warned that researchers, in this area, should be aware of, and on their guard against, such negative behaviour, and concluded that professionals should examine their motives in classifying parents as primary causes of ASC. This expression of concern was made at the time when ASC was beginning to be associated with genetic, constitutional, and biochemical pre-dispositions.

Bernard Rimland (1964), a Psychologist, and father of a boy with ASC, wrote a book, entitled: *Infantile Autism: The Syndrome and its implications for a neural theory of behaviour*, in which he argued that ASC was a biological disorder, not an emotional one. This book marked an enormous change in the way that ASC was perceived, and it impacted greatly on future treatments, and on the direction in which the study of ASC travelled. Once the floodgates were opened by Rimland for biological explanations of the aetiology, and nature, of ASC, numerous suggestions were made in the same biological, and 'within-child' vein.

For instance, a biological theory regarding ASC was proposed by Shattock and Lowdon (1991), who suggest that opioid peptides are involved in the development of ASC. They propose that some people have difficulty in breaking down casein (milk and dairy produce), or gluten (wheat and some other cereal products), during digestion. This inability to digest completely these compounds leads to excess amino acids (peptides) crossing into the brain, rather than being disposed of in the urine, and this interferes with normal brain function and activity. This build-up of such peptides results in autistic-like behaviours.

Rutter (2000) has argued for a strong genetic basis for ASC. As well as the purely genetic work that has been conducted in this area, it has been postulated that many autistic traits may have their roots in genetics. For example, Baron-Cohen, Wheelwright, Stott, Bolton, and Goodyer (1997) have argued, on the basis of a sample of 919 replies from parents of children with ASC, that fathers and grandfathers of children with ASC are far more likely to be engineers than the fathers and grandfathers of children without ASC. They suggest that there is, ultimately, a genetic basis for a cognitive phenotype, or certain cognitive approach, that predisposes a person to excel in engineering. Engineering, as an occupation, is over-represented in fathers and grandfathers of children with ASC, and, if that same predisposition to excel in engineering goes too far, it will result in ASC. Baron-Cohen and Hammer (1997) refer to this cognitive style as a reflection of the functioning of the 'male brain', which they believe is biologically determined. However, there is no way of knowing whether these traits are biologically, or environmentally, determined, and their findings have been disputed by many researchers (e.g., Gerrans & McGeer, 2003; Islam, 1998; Wolff, 1998).

In terms of the evidence for family and parent factors producing ASC, it is clear that much of the evidence is quite anecdotal in nature. This hypothesis has also been challenged on the basis of a few reports that have examined the social class and profession of the parents, as suggested by Kanner (1944a) and Asperger (1944; and, later, by Baron-Cohen *et al.*, 1997).

Ritvo, Cantwell, Johnson, Clements, Benbrook, Slagel, Kelly, and Ritz (1971), on the basis of previous studies' findings that parents of children with ASC were found to be more emotionally detached, more highly educated, and from higher socio-economic classes, than parents of typically developing children or parents of disturbed children, wanted to investigate these claimed differences. All admissions to a large metropolitan institution were assessed, and seventy-four children with ASC were matched for gender and age with children with various organic, neurotic, and behavioural problems. Parents' educations, and occupations, were used as variables to indicate social class, and the parents were evaluated for age, ethnic origin, social class, and religion. There were no indications apparent in the results of any differences between the parents of the children with ASC and the matched parents on any of the variables for social class. One finding that was statistically significant was that more mothers of children with ASC did not have employment.

Schopler, Andrews, and Strupp (1979), in a state-wide study of 522 families with children with ASC and related communication problems, found no difference in the severity of ASC between the high and low socio-economic status families. They found no significant difference in the cognitive potential of the children, nor did they find any difference in the complexity of their rituals and obsessive maintenance of sameness, but they did find that children from a higher social class had an earlier age of onset of ASC (although the reasons for this finding are unclear).

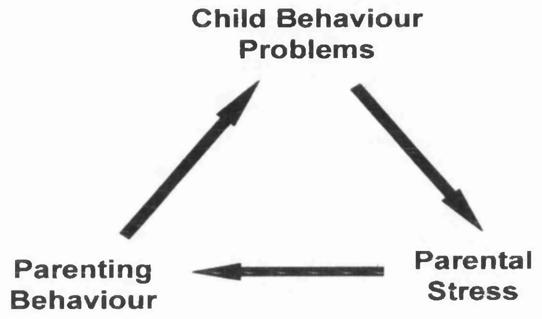
Despite the fact that both of these above studies did find a slight effect of social class, the findings have been used to dispute the importance of this influencing factor (see Frith, 1989; Wing, 1997). However, even if the claims of Frith and Wing were accepted, they still do not convincingly challenge the theory that there are differences in the parenting style of parents with children with ASC, irrespective of their high, or low, economic status. Bettelheim (1950) made the point that the central relationship between the parents and child is the key factor, and any early, and continuous, difficulties in this relationship could underlie the disturbance in the child. It is not the case, according to Bettelheim, that specific aspects of the child's behaviours are merely influenced by the occupations of the parents (a view more correctly attributable to Kanner). As will be seen in later sections of this thesis, there are numerous differences between parents of children with ASC, and parents of those without ASC, in terms of their parenting styles, levels of stress, coping strategies, and parenting behaviours. It is difficult to say whether the variations in these parental factors cause the ASC, or are caused by the severity of the ASC and its associated difficulties. Nevertheless, there is a question here to be acknowledged and addressed.

3.3 Contemporary Models of Parenting

There are numerous theoretical models proposed to explain parent-child interactions, which suggest that parental stress may influence parenting behaviours, which, in turn, will impact on child behaviour problems (e.g., Deater-Deckard, 1998; Hastings, 2002). Levels of parental stress may have an impact on behaviours of children with learning disabilities, and with ASC (see Section 2.6), and this finding has formed the basis of several theoretical models of parent-child interactions (e.g., Deater-Deckard, 1998; Hastings, 2002; but see Lazarus, 1991, for an alternative parental stress, and coping, model).

In the context of learning disabilities, Hastings (2002) presented a theoretical model of the relationships between child behaviour problems, parental stress, and parenting behaviour (see Figure 1.2). This theoretical model postulated that child behaviour problems influence levels of parental stress, which, in turn, impact on parenting behaviour. These parenting behaviours then subsequently feed back into child behaviour problems, thus, producing a cyclical model, displaying singular directionality of influence. Due to there being relatively little work conducted in this area, there is currently limited evidence to support, or reject, these suggested links between child behaviour problems, parental stress, and parenting behaviour, particularly concerning the dynamics within families of children with ASC. However, this theoretical model can be used as a potential springboard for research in this comparatively neglected area, and allows several key areas of potential parental influence, in the context of ASC, to be highlighted and examined (e.g., parental stress, and parenting behaviour).

Figure 1.2: Hastings' (2002) model.



In support of the use of this theoretical model, a number of studies show that child behaviour problems and parental stress do correlate (e.g., Baxter, Cummins, & Yiolitis, 2000; Hodapp, Fidler, & Smith, 1998; Stores, Stores, Fellow, & Buckley, 1998). However, Hastings (2002) claims that two further elements are necessary to substantiate his model. Firstly, the relationship between child behaviour problems and parental stress has to be demonstrated as non-spurious, in order to rule out the possibility of other factors, or confounds, having an influence on parental stress. Secondly, temporal precedence should be established for causal directionality, that is, it should be shown that the child behaviour problems precede the parental stress.

Several studies have presented data consistent with the view that child behaviour problems, and not other factors, are associated with parental stress (e.g., Donenberg &

Baker, 1993; Dumas, Wolf, Fisman, & Culligan, 1991; Floyd & Gallagher, 1997). These studies equated child behaviour problems across groups; including one developmentally disabled, and one not developmentally disabled, and they demonstrated that there were no differences in reports of parental stress across these behaviour problems groups. It should be noted that these previous studies all employed only parent ratings of child behaviour problems, and none of these studies employed independent ratings of child behaviour problems, such as made by teachers. This is important, as Lecavalier, Leone, and Wiltz (2006) noted that parents and teachers did not perfectly agree on the nature, and severity, of child behaviour problems. Although parental stress and parent-rated child behaviour problems made each other worse, over a period of a year, there was no such effect when teacher ratings of child behaviour problems were used. It may be that high levels of stress in parents are related to an alteration in their perception of the behaviours of their children (see Fong, 1991).

In addition, it is important to establish the temporal precedence between child behaviour problems and parental stress, in order to provide some evidence for possible causal directionality. Such evidence could be provided by using a longitudinal study design. Then, the correlations between child behaviour problems and parental stress at baseline, and at follow-up, could be used to examine temporal directionality. Hastings (2002) suggested that the correlation between child behaviour problems at baseline and parental stress at follow-up should be stronger than the correlation between parental stress at baseline and child behaviour problems at follow-up.

However, it should be remembered that this model was developed for learning disabilities, rather than for ASC, and it needs to be considered in the context of the literature on ASC (see below). The above discussion has focused on the methodological issues with regard to establishing the relationship between child behaviour problems and parental stress, as there is evidence to suggest that parental stress is important in the context of ASC, and there is little existing evidence for ASC, specifically, to illustrate these methodological points with reference to the other two links in this model.

4.0 Parenting Stress

Many reports have noted the high degree of stress that parents experience when dealing with their child's problems (e.g., Bebko, Konstantaraes, & Springer, 1987; Shuntermann, 2002). These high stress levels can produce a range of severe problems in the parents. Such problems include depression (Wolf, Noh, Fisman, & Speechly, 1989), and disruption in the context of family life (see Dunn, Burbine, Bowers, & Tantleff, 2001; but see Gabriels *et al.*, 2001). Freeman, Perry, and Factor (1991) found that parenting stress, which was related to specific child behaviours, was also correlated with general levels of parental stress. Koegel, Schreibman, O'Neill, and Burke (1983; see also Donenberg & Baker, 1993) draw a distinction between 'general stress' and 'situation-specific stress' in parents of children with ASC, and suggest that it is plausible that the latter may periodically occur, while finding no evidence of general stress levels being high. In this thesis, it is parenting stress (i.e. that stress related to the child, and parenting) that is the focus of examination.

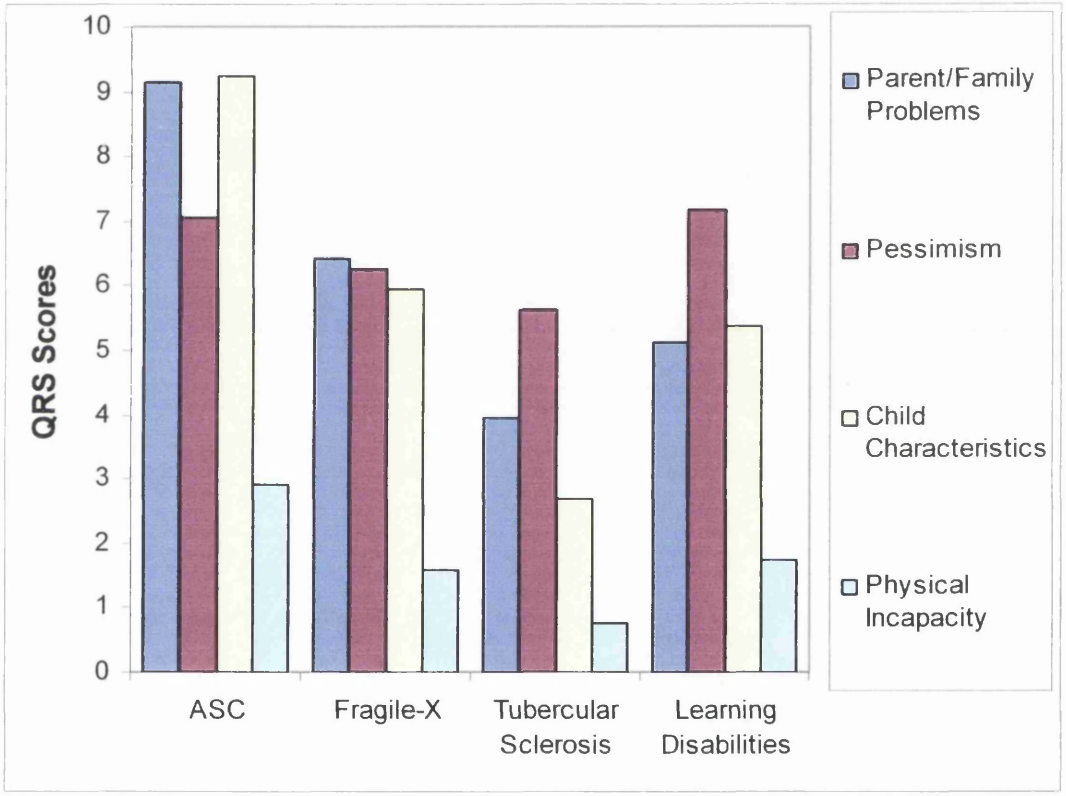
4.1 Levels of Parenting Stress

Levels of parenting stress are more highly pronounced in parents of children with ASC, compared to parents of children with almost any other type of disability or health problem (Blacher & McIntyre, 2006; Bouma & Schweitzer, 1990; Dunn *et al.*, 2001; Eisenhower, Baker, & Blacher, 2005; Koegel, Schreibman, Loos, Dirlich-Wilhelm, & Dunlap, 1992; Perry, Sarlo-McGarvey, & Factor, 1992; Weiss, 2002; but see Holroyd & McArthur, 1976). In a review of current research on parents of children with ASC, Pisula (2003) found that profound parenting stress is reported as being experienced by such parents. For example, Wolf *et al.* (1989; see also Fisman, Wolf, & Noh, 1989; Sander & Morgan, 1997) found greater stress levels, and more dysphoria and depression, in parents of children with ASC than in parents of children with Down's Syndrome, and in parents of children without a developmental disability. Similarly, Bouma and Schweitzer (1990) found that ASC contributed significantly more to family stress than did a chronic physical illness (Cystic Fibrosis). Perry *et al.* (1992) have also shown this to be the case, in comparison to Rett's Disorder.

These elevated levels of parenting stress in parents of children with ASC can be seen clearly by comparing the results of several studies that have all used a common measure of parenting stress (the *Questionnaire on Resources and Stress*; Friedrich, Greenberg, & Crnic, 1983). These various reports have studied parenting stress in the parents of children with: ASC (Osborne, McHugh, Saunders, & Reed, 2006), Fragile X Syndrome (Backes, von Gontard, Schreck, & Lehmkuhl, 2001), Tubercular Sclerosis (Backes *et al.*, 2001), and Learning Disabilities (Walden, Pistrang, & Joyce, 2000). The resulting levels of parenting stress (broken down by particular domains) can be seen in

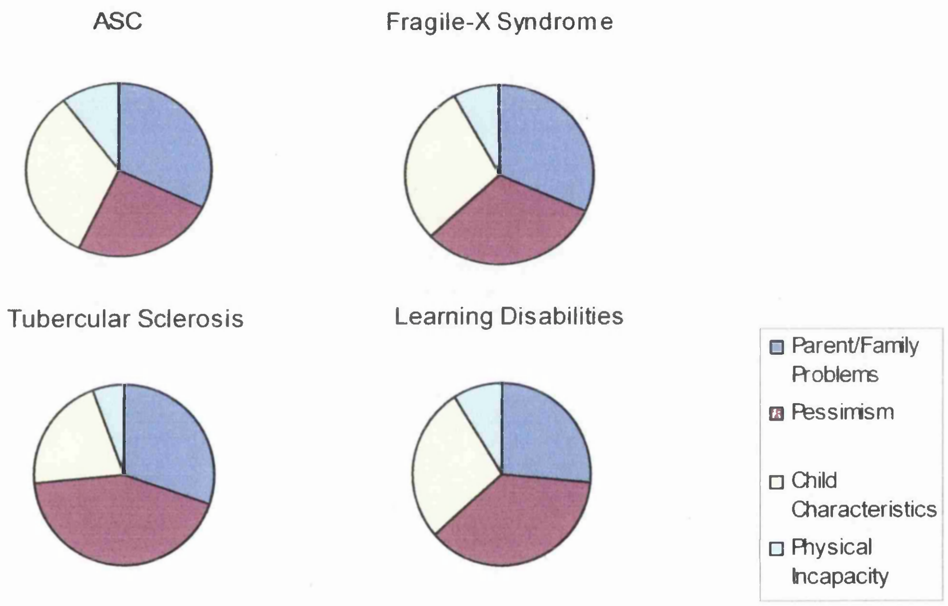
Figure 1.3, which shows consistently higher levels of parenting stress in parents of children with ASC, than in the parents of children with the other disorders, across almost all of the measured domains of parenting stress.

Figure 1.3: Stress levels of parents of children with various disabilities.



The distribution of parenting stress, across the four domains, in parents of children with each of the different disabilities, can be examined by noting the proportions of the total parenting stress, accounted for by each of the domains of parenting stress, which are shown in Figure 1.4.

Figure 1.4: Proportions of parenting stress for the sub-scales of the QRS for various disabilities.



4.2 Causes of Parenting Stress

It is reasonably clear that the personalities of parents of children with ASC are not different from the personalities of parents of children with other disabilities, and, indeed, with no disabilities (e.g., Koegel *et al.*, 1983). In fact, the only obvious characteristic that sets this group of parents apart from other parents is their extremely high levels of parenting stress (Blacher & McIntyre, 2006; Dunn *et al.*, 2001; Eisenhower *et al.*, 2005; Hastings & Johnson, 2001; Koegel *et al.*, 1992; Perry *et al.*, 1992; Weiss, 2002). A number of factors have been shown to be related to this elevated parenting stress, including the cumulative effect of long-term parenting a child with ASC (McAdoo & DeMyer, 1977), a number of parental characteristics, such as their coping strategies (Boyd, 2002), and the trigger of the diagnosis of ASC itself (Shuntermann, 2002).

The severity of the child's autistic symptoms is also associated with parental self-reports of stress, with higher levels of stress being reported by parents of children with severe behavioural problems (Bebko *et al.*, 1987; Hastings, 2003; Hastings, Kovshoff, Ward, degli-Espinosa, Brown, & Remington, 2005; Hastings & Brown, 2002; Hastings & Johnson, 2001; Konstantareas & Homatidis, 1989). Kasari and Sigman (1997) found that parents who reported greater levels of stress had children with ASC who were less responsive in social interactions with an experimenter, and less engaged during a social game with the parent. Fong (1991) noted trends toward higher levels of maladaptive behaviours in adolescents with ASC of highly stressed mothers.

Several other factors have been found to contribute towards the high levels of stress in parents caring for children with ASC. Boyd (2002), in a review of the literature, reveals that mothers of children with challenging behaviours, and those mothers who are under greater stress, are more likely to seek social support. Individuals without access to rich social networks tend to report more stress than individuals with good social support, which may be mediated by the parent-perceived expertise of those providing the assistance, and respite (Factor, Perry, & Freeman, 1990; Gill & Harris, 1991; Konstantareas & Homatidis, 1989; Sharpley, Bitsika, & Efremidis, 1997; Weiss, 2002).

Additionally, it appears that informal social support is a more effective 'stress-buffer' than formal support for mothers of children with ASC (Boyd, 2002; Hastings & Johnson, 2001).

The perceived presence of social support, along with hardiness, has been found to predict successful adaptation in parents (Weiss, 2002; Wolf *et al.*, 1989), and lack of 'hardiness', and low levels of social support, are predictive of poor adaptation, and worse coping with stress, leading to 'burnout' (Weiss, 2002), and predict depression and anxiety (Boyd, 2002). Maternal- and paternal-stress are associated with the depression of their partner (Hastings *et al.*, 2005). Stress levels may rise, thus, due to a temporary loss of external support from the partner (Hastings, 2003). Likewise, individuals who employ avoidant coping strategies in response to stress, tend to report more feelings of stress and mental health difficulties, compared to those who utilise positive reframing strategies (Dunn *et al.*, 2001; Hastings & Johnson, 2001; Hastings *et al.*, 2005).

4.3 Diagnosis of ASC and Parenting Stress

One area that would appear to have a high capacity for the production of stress in parents of children with suspected ASC is their contact and communication with professionals (Brogan & Knussen, 2003; Evans, Stoddart, Condon, Freeman, Grizzell, & Muller, 2001; Goin-Kochel, Mackintosh, & Myers, 2006; Randall & Parker, 1999). A key aspect of this contact and communication with professionals concerns the process of obtaining a diagnosis of ASC for their child (Brogan & Knussen, 2003; Goin-Kochel *et al.*, 2006; Howlin & Moore, 1997). For example, a large-scale survey by Howlin and Moore (1997) described the experiences of around 1,200 families with children with

ASC. Many of these families expressed an early sense of a problem (often by the age of eighteen months), and many sought help from their doctor when their child was as young as two years of age. However, the report indicated that a diagnosis was often not made until the child was six years old, potentially losing the important advantage of early educational intervention.

These findings have been mirrored in several other reports. For example, Goin-Kochel *et al.* (2006) conducted a web-based survey across five countries, and noted that parent satisfaction with the diagnostic process increased, the fewer professionals they needed to see in order to obtain a diagnosis for their child. Mansell and Morris (2004), in a postal survey of parents in one U.K. Local Education Authority, found that early, and speedy, diagnosis was a key contributor to reducing parental stress (see also Brogan & Knussen, 2003). Both Mansell and Morris (2004), and Oberhein (1996) found that, in general, parents thought that the diagnostic process was a slow, chaotic, and badly-handled procedure. These results are mirrored by those findings obtained from a small set of four interviews conducted with parents in Wales (Midence & O'Neill, 1999). In this study, parents reported difficulty in getting provision for their child, or, indeed, obtaining any form of help and support. However, several of these studies have noted that, on the positive side, the parents, generally, were very appreciative of the help that they did receive (Mansell & Morris, 2004; Oberhein, 1996), and reported relief at obtaining a diagnosis of ASC (Midence & O'Neill, 1999).

In another small-scale analysis, Bartolo (2002; see also Goin-Kochel *et al.*, 2006) noted that the manner of communication between professionals and parents was often problematic. These reported problems invariably revolved around discrepant approaches adopted by professionals across different sites. Other studies have highlighted points of discrepancy, and potential conflict, between the professionals and the parents. Grey (1993; see also Evans *et al.*, 2001, for similar findings) found that points of disagreement between professionals and parents included: the prospect of a cure, the nature of the child's affection, and the uniqueness of the child and how this is related to the possibility of institutionalisation.

Thus, diagnosis of ASC for a child is an extremely important event and issue in understanding the potential causes of child behaviour problems and prognosis, given its impact on parents (Dale, Jahoda, & Knott, 2006). Diagnosis could be treated, speculatively, as a traumatic event that could induce a state similar to that of Post Traumatic Stress Disorder in parents. Certainly, Klauber (1999) has noted that parents of children with ASC are hyper-vigilant, and sensitive, to feelings of persecution regarding their child's ASC, which would suggest an extreme state of anxiety in this context. This state appears to be present in the extended families of such parents, who also seem to have a proneness to anxiety (Klauber, 1999).

This area is important, as contact with professionals, especially regarding obtaining a diagnosis of ASC, most often comes prior to parents' engagement in a particular intervention programme for their child. If the contact with professionals has been particularly stressful, or aversive, this may lead to any subsequent teaching intervention being less successful than it might, otherwise, have been (Robbins, Dunlap, & Plienis, 1991), and may lead to negative feelings, and a lack of trust, concerning those professionals (Brogen & Knussen, 2003).

5.0 Parenting Stress and ASC

There have been numerous studies regarding the effectiveness of teaching interventions for ASC (see Section 2). However, parental factors may well influence the effectiveness of such teaching interventions, and studies that focus purely on the impact of teaching interventions in isolation on child outcomes neglect the key role that parents play in the management and treatment of the problems experienced by the child with ASC (see Section 2.6; Section 3.3).

There are two lines of evidence that point to the importance of studying the relationship between parents and the outcomes of teaching interventions for children with ASC. Firstly, parents' mental well-being, and related coping abilities, have been found to influence short-term, as well as long-term, outcomes of teaching intervention programmes (see Section 2.6). Secondly, the levels of stress experienced by parents of children with ASC are enormously high, compared to those experienced by parents of children with almost any other type of disability, or health problem (see Section 4.1). As a consequence, one parental variable that may affect a child's performance on a teaching intervention is the level of parenting stress.

5.1 Role of Stress in General Medical Conditions

The role of stress has been long acknowledged as a powerful force in many medical conditions, and has been shown to influence the outcomes and prognoses for various illnesses and disorders. In the general medical literature, Mazure (1995) claims that stress is a factor in both the development and exacerbation of psychiatric illness, and presents a collection of reviews that investigate stress, different responses to stress, and the interaction of stressors and psychiatric disorders, providing illness prevention strategies. Similarly, Melamed (1995) argues that stress management programmes can have a positive influence on immune system responses during treatment and recovery from illness, including life-threatening conditions, like liver transplantation, Stage II and Stage III breast cancer, and following diagnosis of HIV infection.

In childhood disorders, such as diabetes, there has been shown to be a relationship between poor symptom management (diabetic balance) and adverse psychosocial factors, such as family stress (Kaar, 1983; Viner, McGrath, & Trudinger, 1996), and that there is a relationship between illness and family stress (Piening, 1984; see Lloyd, Smith, & Weinger, 2005, for a review). In fact, high family life stress is strongly correlated with the symptoms of diabetes (Viner *et al.*, 1996). In addition, it has been suggested that the interactional styles within the family have an influence over somatic illness, and illness outcome (Tienari, Sorri, Lahti, Naarala, Wahlberg, Rõnkkö, Moring, & Pohjola, 1987; Wahlberg, Wynne, Oja, Keskitalo, Anais-Tanner, Koistinen, Tarvainen, Hakko, Lahti, Moring, Naarala, Sorri, & Tienari, 2000). These findings indicate that both physical illness and mental illness can be affected by family influences, such as stress, and interactional and communication styles.

Importantly, Warner and Pottick (2006) reported that nearly 40% of children under the age of six years old, who were admitted to mental health services, were identified as having psychiatric problems that stemmed from family stress. Moreover, Carlson-Green, Morris, and Krawiecki (1995) noted that the best predictors of both children's behaviour problems, and their adaptive behaviours, following intervention for paediatric brain tumours, were family and demographic variables, including family stress, maternal coping, and the number of parents present in the home.

5.2 Parenting Stress and ASC Outcomes

Given that parenting stress appears to be related to child outcomes (Section 5.1), and, given that many teaching interventions require long-term, time-intensive, and intrusive access to the family home (see Reed *et al.*, 2007b), and often recruit parents as therapists (Mudford *et al.*, 2001), it makes sense to investigate the influence of parenting stress on child outcomes from teaching intervention programmes for ASC. A study already mentioned above, relating to paediatric brain tumours (i.e. Carlson-Green *et al.*, 1995), has demonstrated a negative impact of parental stress on child outcomes following an intervention, but not in the context of teaching interventions for ASC.

However, similar findings have been noted for young children with ASC in a family-orientated training programme, reported by Robbins *et al.* (1991), in which they explored aspects of family functioning, as they related to the children's progress twelve months later. They found a strong relationship between mother-reported stress and child progress, and, in particular, they noted that high maternal stress can inhibit the success of early interventions.

In addition to the impacts on the child and the family, stress can impact negatively on the ability of the parents to engage with the child. Konstantareas and Homatidis (1992) examined the self-reported involvement of parents with their children. Parents of non-autistic, but mentally disabled children reported greater involvement with their children than did parents of children with ASC. This difficulty with involvement may also extend to the interventions given to the children (cf. Boyd & Corley, 2001). Other studies have noted that levels of maternal stress are associated with worse maternal well-being, and less engagement in treatments, or intervention programmes (Dale *et al.*, 2006). High maternal stress, as well as levels of support received from the intervention programmes, and the severity of the child's ASC, predict worse attributions of parental therapeutic self-efficacy (Hastings & Symes, 2002), and greater negative emotional reactions, and more threat-related appraisals to videotaped scenes of adolescents with ASC engaged in everyday activities (Fong, 1991). A relative lack of involvement and engagement with the intervention may exacerbate the stress-related problems experienced by the parents, and lead to the development of a 'vicious circle', or degenerative cycle.

5.3 Parenting Stress and Child Behaviour Problems

There is evidence that parenting stress correlates both with the symptoms of ASC, and with child behaviour problems, and it is important to be able to determine which of these factors is associated most strongly with such parenting stress. The main difficulty is that the severity of ASC symptoms and child behaviour problems also correlate with each other, rendering it difficult to separate these two factors (e.g., Eisenhower *et al.*, 2005; Gabriels, Cuccaro, Hill, Ivers, & Goldson, 2005).

Hastings and Johnson (2001; see also Tobing & Glenwick, 2002) report that higher levels of ASC symptomatology (i.e. "severity" of ASC; as measured by the Autism Behavior Checklist) were associated with higher levels of reported parenting stress, as measured by the Questionnaire on Resources and Stress. Similarly, Duarte, Bordin, Yazigi, and Mooney (2005) found that the strongest association in their study was between stress in mothers and having a child with ASC, although, maternal stress increased when the symptoms, poor expression of feeling and emotion, and little social interest, were more severe (see also Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Kasari & Sigman, 1997, regarding the effects of child levels of social skills as being a good predictor of maternal stress).

In contrast, several studies present data consistent with the view that child behaviour problems, and not other factors, such as the type of disability, or child adaptive behaviours, are associated with parental stress (e.g., Blacher & McIntyre, 2006; Donenberg & Baker, 1993; Dumas *et al.*, 1991; Floyd & Gallagher, 1997; Lecavalier *et al.*, 2006). For instance, Lecavalier *et al.* (2006) found that child behaviour problems were strongly associated with parental stress, especially a specific group of externalised behaviours, such as conduct problems (but adaptive skills were not associated with parental stress). Whereas, Tomanik, Harris, and Hawkins (2004) reported that both child maladaptive, and child adaptive, behaviours correlated with maternal stress. Konstantareas and Homatidis (1989) noted that the best predictor of stress in both parents was child self-abuse, and, for mothers, child hyper-irritability was associated with elevated stress scores. Gabriels *et al.* (2005) ascertained that parent ratings of their own stress levels were strongly correlated with repetitive behaviours of their children (repetitive behaviours being a form of behavioural problem for many children with ASC). Fong (1991) noted a trend towards higher levels of maladaptive behaviours in adolescents with ASC, whose mothers were highly stressed.

Noh, Dumas, Wolf, and Fisman (1989) found that stress levels were highest in parents of children with behaviour and conduct problems, and were slightly greater than those reported by parents of children with ASC. Pisula (1998; 2003) noted that behavioural disorders, and problems related to atypical child behaviours, were the main source of parental stress in mothers of children with ASC. In a ten-year longitudinal study, Gray (2002) noted that, generally, improvements were experienced by most parents of children with ASC in many aspects of their lives. However, less favourable outcomes were reported in families whose children showed violent and/or aggressive behaviour problems. The parents in these families continued to experience high levels of parental stress.

As noted in Section 3.3, several studies have equated child behaviour problems across groups, including one developmentally disabled and one not developmentally disabled, and demonstrated that there were no differences in reports of parental stress across these groups. For example, Donenberg and Baker (1993) compared children with ASC, children with externalising behaviours (e.g., hyperactivity and aggression) who did not have ASC, and typically developing children with no significant behaviour problems. They found similar higher child-related stress in the parents of the externalising children and in the parents of children with ASC, compared to the parents of the typically developing children. Dumas *et al.* (1991) studied reports of parenting stress, child behaviour problems, and dysphoria in families of children with ASC, behaviour disorders, Down's Syndrome, and typically developing children. Parents of children with ASC, and parents of behaviour-disordered children, reported experiencing higher levels of parenting stress than parents in the other two groups. Mothers of children with ASC, as well as mothers of behaviour-disordered children, experienced the highest levels of dysphoria. Although, it should be noted that the parents of the children with behaviour disorders reported that their children displayed more intense behavioural difficulties, which were greater in number, than those reported by the parents of all of the other children in the study, including those parents of the children with ASC.

Blacher and McIntyre (2006) found that neither maternal stress, nor depression, were related to the type of disability (intellectual disability, Cerebral Palsy, Down's Syndrome, and ASC), once differences in child behaviour problems were controlled for. Similarly, maternal stress has been found to be correlated with child behaviour problems, but not to correlate independently with adaptive behaviour, nor the symptoms of ASC (Hastings *et al.*, 2005). Hence, these studies indicate that the child behaviour problems are related to parenting stress, rather than the disability, disorder, syndrome, or condition.

However, this pattern of results is not found in every study, for example, Eisenhower *et al.* (2005) noted that the type of disability (especially ASC) accounted for maternal stress, even after controlling for levels of child behaviour problems. Thus, in some cases, the type of child disability can produce effects on parenting stress, even after differences in child behaviour problems, and cognitive levels, have been accommodated. In particular, Eisenhower *et al.* (2005) conclude that the behavioural differences manifested in children with ASC, compared to children with other disabilities (e.g., Down's Syndrome, Cerebral Palsy, and developmental disability), were paralleled by differences in parental stress, such that parents of children with ASC are at increased risk of higher stress, which is contributed to by the characteristics of the ASC itself, over and above any externalising child behaviour problems. Thus, while it appears that there is a large degree of evidence associating externalising child behaviour problems with parenting stress, the influence of the characteristics specific to the ASC itself cannot be ruled out as a factor associated with parenting stress.

Moreover, it remains unclear as to the temporal direction of the influence of these factors on one another. Although it has been widely assumed that child behaviour problems, and/or the ASC itself, impact on parenting stress (see Section 3.3), this view is not strongly supported in the literature (see Sections 5.1 and 5.2). Lecavalier *et al.* (2006) found that child behaviour problems and parental stress exacerbated each other over a period of one year. Thus, suggesting that this relationship is more complicated than the simple unidirectional relationship, as suggested by many models of parenting (see Hastings, 2002). It is worth noting that some studies have shown that significant levels of maternal stress during pregnancy and birth can be associated with ASC, suggesting that stress precedes later problems, and not the other way around (Beversdorf, Manning, Hillier, Anderson, Nordgren, Walters, Nagaraja, Cooley, Gaelic, & Bauman, 2005; Ward, 1990). Although, it may well be that pre-natal stressors could be quite different in nature from those experienced after the birth of the child. Due to the obvious difficulties involved in conducting longitudinal research, there are very few studies that have collected data from several different points across time, and that would allow indication of the temporal directionality of the relationship between parenting stress and child behaviour problems. In fact, where these studies do exist, they provide little evidence that child behaviour problems predict parenting stress, but rather they tend to indicate that the reverse relationship is stronger (e.g., Robbins *et al.*, 1991).

6.0 Parenting Stress and Parenting Behaviours

The reasons why high parenting stress levels have a negative impact on child behaviour problems (see Section 5.3), and predict worse intervention child outcomes (see Section 5.2), are currently unclear. There are, however, several possibilities that are worth some mention. On a purely speculative basis, it could be that children with ASC are sensitive to their parents' levels of emotional stress. Perhaps the presence of emotions, such as parenting stress and anxiety, can be sensed by children with ASC, even if they are not fully able to identify those emotional states (Hobson, Ouston, & Lee, 1989). In fact, some people with ASC can be described as over-sensitive to emotional disturbance (Grandin, 1990), and this sensitivity may upset their psychological and emotional equilibrium, and subsequently may affect their behaviours and outcomes. However, there remains very little evidence of any such over-sensitivity to parental emotion in children with ASC.

It could be argued that the parents of children with ASC tend to be more reactive, both in their responses to stressors, and in their parenting styles, which would lead to both high levels of parenting stress, and high resultant levels of child behaviour problems. However, this is unlikely, as there is very little evidence for this claim, and there is much research that shows no difference in the personalities, socio-economic statuses, and family backgrounds, of parents of children with ASC, compared to other sets of parents (e.g., Koegel *et al.*, 1983; but see Sanua, 1987).

Possibly the most likely suggestion is that the high levels of parenting stress trigger changes in the parents' ability to patiently accommodate, and respond to, their children's behaviour problems. McAdoo and DeMyer (1977) made the point that the continual stress of parenting a child with ASC may lead to changes in the personalities of such parents, and, if this were the case, these changes could have an effect on their parenting behaviours. Holroyd and McArthur (1976) found more family integration problems, reported by mothers of children with ASC, relative to mothers of children with Down's Syndrome. Certainly, Tienari *et al.* (1987) found that family interactional styles can have a predisposing influence to, and precipitate, somatic illness, as well as affecting illness outcome (see Section 5.1). However, over and above the extreme 'burden of care' placed on parents of children with ASC (see Section 4.1), little is known about their parenting behaviours, let alone whether these parenting behaviours are impacted on by parenting stress.

There is some, though still limited, evidence regarding parenting behaviours *per se*. Rodrigue, Morgan, and Geffken (1990) noted that mothers of children with ASC reported less parenting competence, and less family adaptability, than either mothers of children with Down's Syndrome, or mothers of children without developmental disability. Powers (2000) suggested that there are three common areas of parenting difficulty for parents of children with ASC. Firstly, there is a risk of over-involvement, or over-compensation, a suggestion supported by the findings of El-Ghoroury and Romanczyk (1999), who reported that parents initiate more play interactions and behaviours with their children with ASC than with their siblings. Secondly, Powers (2000) warned of the 'trap' of over-protectiveness of the child with ASC, or of affording too little autonomy for that child. Thirdly, Powers (2000) highlighted the risk of parental rejection of, or withdrawal from, children with ASC. Nevertheless, there is very little empirical evidence regarding such suggestions, at this point in time.

Similarly, there are few, if any, studies of the effects of parenting stress on the parenting behaviours of parents of children with ASC. There have been some investigations, however, of the effects of parenting stress on parenting behaviours in the general population. For example, Rodgers (1993; 1998) found that parenting stress directly, and indirectly, affected parenting behaviour in 85 mothers of young children in Head Start or Kindergarten. Likewise, Kotchick, Dorsey, and Heller (2005; see also Meyers & Miller, 2004), in a longitudinal study of 123 low-income, urban-dwelling, single mothers, noted that higher levels of neighbourhood stress had a relationship to greater psychological distress, and detrimental effects on psychological functioning, in the mothers. This subsequently went with less engagement in positive parenting practices, and resulted in poorer parenting over time. Webster-Stratton (1990) found that various stressors seriously disrupted parenting practices, by their influencing some parents to become more irritable, critical, and punitive, and these parenting behaviours, in turn, increased the likelihood that children would develop conduct problems.

Nevertheless, it should be noted that there is a mixed picture presented in this area of research, making more difficult any generalisations from the general population to parents of children with ASC. For example, Greenley, Holmbeck, and Rose (2006) reported variable effects of parenting stress on parenting behaviours, and adaptive parenting, in their study of parents of children with, and without, Spina Bifida. Levers and Drotar (1996), in a review of studies of family and parental functioning in caring for children with Cystic Fibrosis, noted higher levels of stress in parents of children with Cystic Fibrosis, compared to parents of healthy children, but they found that parenting behaviour, and family functioning, were similar in the two groups. Similarly, Nitz, Ketterlinus, and Brandt (1995) assessed the role of maternal stress, amongst other things, on the parenting behaviour of adolescent mothers of healthy infants. Their findings indicated that parenting stress *per se* did not significantly predict maternal behaviour.

7.0 Parenting Behaviours and Child Behaviour Problems

The above review has suggested that levels of parenting stress may impact on behaviours of children, and lead to subsequent worsening of child behaviour problems (Section 5.3), and poorer child outcomes following teaching interventions (Section 5.2). In order to explain these findings, it has been proposed that high levels of parenting stress can have an impact on subsequent parenting behaviours (Section 6), which, in turn, impact on child behaviour problems, and outcomes (Section 3.3). However, although high levels of parenting stress are associated both with subsequently higher levels of child behaviour problems, and with later changes in parenting behaviours, it is not known whether parenting behaviours are associated directly with subsequent child behaviour problems, and poorer outcomes. It could be that both parenting behaviours and child behaviour problems are jointly influenced by parenting stress, but that each of these are not directly impacted upon by one another (see Anthony, Anthony, Glanville, Naiman, Waanders, & Shaffer, 2005; Blader, 2006).

Unfortunately, there is virtually no evidence showing a direct link between parenting behaviours and child behaviour problems in the context of ASC. There are numerous intervention programmes that target the parents of children with ASC (see Section 2.6). Many of these interventions have noted improvements in the children's behaviours, and functioning, as a result of a reduction in parenting stress, and an increase in parental coping ability (e.g., Harris *et al.*, 2000; Lovaas & Smith, 2003; Spaccarelli *et al.*, 1992; see Brookman-Frazee *et al.*, 2006, for a comprehensive review). There are also several studies that suggest that teaching parenting skills to parents of children with ASC will reduce their children's challenging behaviours. For example, teaching parents 'mindful parenting' reduced aggression, non-compliance, and self-injury in their children (Singh *et al.*, 2006). Nevertheless, these results may not reflect a direct relationship between parenting behaviours and child behaviour problems, but could reflect the results of a reduction of parenting stress levels, which, in turn, could have impacted on both parenting behaviours and on child behaviour problems, but the latter challenging child behaviours may not have been affected directly via parenting behaviours.

There is, of course, a considerable literature on the effects of parenting practices and strategies in families of typically developing children. Fenning, Baker, Baker, and Crnic (2007) review this substantial literature, and suggest that the parent characteristics of 'warmth' and 'responsiveness' contribute to a more positive, and adaptive, parenting style which, in turn, facilitates a satisfactory social, and emotional, development in the child. On the other hand, low levels of manifest parental 'warmth' correlate with child behaviour problems, such as increased externalising behaviours (e.g., oppositional, and disruptive behaviours). Similarly, a lack of parental 'responsiveness', as seen in over-intrusive interventions, over-controlling, and harsh disciplinary, parenting styles, are, likewise, associated with child behaviour problems. Furthermore, Fenning *et al.* (2007) note that parental emotional expressiveness, in particular, high expressed frequencies of negative affect, especially anger, can act to inhibit empathic responding, reduce levels of emotional understanding, and increase the probability of prolonged and continuing behavioural problems in the child. However, the relevance of much of this parenting literature to the study of children with ASC might be questionable, as an often proposed mechanism for such links between parenting behaviours, and styles, and child behaviour problems, and outcomes, is that of imitation (e.g., Bandura, Ross, & Ross, 1961; Fenning *et al.*, 2007). Given the nature of the deficits involved in ASC, the extent to which such parenting findings can be generalised, or applied, to this specific population is unclear.

Some findings that could be relevant, especially as they involve teaching interventions, are those from research conducted on Head Start programmes, often involving socio-economically disadvantaged children. In a study by Siantz and Smith (1994), it was found that the parenting styles of the mothers of sixty, three to eight year old, children of Mexican American migrant farm-workers accounted for a significant proportion of the child behaviour problems, reported by the mothers. Similarly, Dumas and Wekerle (1995) noted some modest relationship between "dysfunctional parenting" and child behaviour problems. However, as these research studies were cross-sectional, and not longitudinal, temporal directionality between these two factors cannot be discerned (see also similar claims made by Jackson, 2000, and by Jackson & Huang, 2000, on the basis of other cross-sectional correlational studies).

On looking at the longitudinal effects of maternal anti-social behaviours, and parenting practices, on the behaviour problems of boys at risk of developing anti-social behaviours, Ehrensaft, Wasserman, Verdelli, Greenwald, Miller, and Davies (2003) noted that lower levels of maternal involvement, and monitoring, and higher levels of conflict between the mothers and sons, contributed to worse subsequent child behaviour problems seen one year later. Although the boys' behaviour problems were directly worsened by the conduct disorder problems of their mothers, it was established that the effect of parenting was even more contributive to the subsequent child behaviour problems. Similarly, Austin, Dunn, Johnson, and Perkins (2004) conducted a longitudinal study, which investigated the impact of families on the behaviour problems of children and adolescents with epilepsy. They found that parental confidence in managing discipline of their child at baseline was correlated with child behaviour problems at baseline, and also predicted these child behaviour problems at follow-up, twenty-four months later. Moreover, decreasing parental confidence in disciplining their child was related to an increase in child behaviour problems over time.

Thus, both the study by Ehrensaft *et al.* (2003), and that by Austin *et al.* (2004), highlight aspects of limit setting (i.e. monitoring, or managing discipline, see Gerard, 1994) as important parenting behaviours associated with reductions in future child behaviour problems. Of course, such behaviour management skills are also often emphasised in the context of training programmes for parents of children with ASC (e.g., Harris *et al.*, 2000).

8.0 Summary

The above review suggests that there are a number of important theoretical reasons for examining the relationships between parenting stress, parenting behaviours, and child behaviour problems in ASC samples. At this point, it should be noted that this thesis, in line with past practice in the field, will define these above mentioned factors by the various psychometric tests employed herein, and that have been designed, and widely used in the literature, to measure these parent/child factors. So, for example, parenting stress will be defined as measured by the *Questionnaire on Resources and Stress*, and so forth. The results of such examinations may have practical implications for the development of future interventions for ASC. In particular, there are needs to establish: firstly, whether high parenting stress levels impact negatively on child outcomes (Chapter 2); secondly, the nature of the relationship between parenting stress and child behaviour problems over time, in order to determine the temporal directionality of any such parent-child interactions (Chapter 3); thirdly, whether parenting stress impacts on parenting behaviours, and the types of parenting behaviours that are influential for subsequent child behaviour problems in the context of ASC (Chapter 4); fourthly, that the association between parenting behaviours and child behaviour problems is a direct one, and is not the by-product of both of these behavioural elements being impacted upon by additional factors, such as parenting stress (Chapter 5); and finally, whether the contact and communication experiences of parents with professionals leading up to, and during, the diagnostic process is of particular significance (Chapters 6 and 7).

Chapter 2:

Parenting Stress Reduces the Effectiveness of Early Teaching Interventions for Autistic Spectrum Conditions

Introduction

There have been numerous studies regarding the effectiveness of early teaching interventions for Autistic Spectrum Conditions (ASC; e.g., Eldevik, Eikeseth, Jahr, & Smith, 2006; Lovaas, 1987; Ozonoff & Cathcart, 1998; Reed, Osborne, & Corness, 2007b; Rogers, 1998; Sallows & Graupner, 2005; see Chapter 1). Intervention appears to be more effective if offered earlier, rather than remedially later, so the child's age at the start of an intervention may be one factor that influences outcomes (Rogers, 1998). However, as discussed in Chapter 1, parent factors, as well as child factors, may also influence the effectiveness of early teaching interventions, and child outcomes, and parental factors are the focus of the current chapter. For example, parents' mental well-being, family functioning (Harris, 1984), and levels of parental education, have been found to influence the short-term, as well as the long-term, outcomes of early teaching intervention programmes (Ozonoff & Cathcart, 1998). Moreover, studies that focus purely on the impact of early teaching interventions on child outcomes neglect the important role that the parents may play in the treatment of the problems experienced by the child (see Hastings & Johnson, 2001). One variable that may affect a child's performance on an early teaching intervention is that of the levels of parenting stress, as perceived, and reported, by the parents themselves.

There are two lines of evidence that point to the importance of studying the relationship between parenting stress and the outcomes of early teaching interventions for children with ASC. Firstly, levels of stress experienced by the parents of children with ASC are enormously high, compared to those experienced by parents of children with almost any other type of disability or health problem (Blacher & McIntyre, 2006; Bouma

& Schweitzer, 1990; Dumas, Wolf, Fisman, & Culligan, 1991; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Eisenhower, Baker, & Blacher, 2005; Koegel, Schreibman, Loos, Dirlich-Wilhelm, & Dunlap, 1992; Perry, Sarlo-McGarvey, & Factor, 1992; Pisula, 2004; Weiss, 2002; Wolf, Noh, Fisman, & Speechley, 1989). There is some limited evidence that such parenting stress has been found to impact on child outcomes following interventions. Robbins, Dunlap, and Plienis (1991) noted a strong relationship between mother-reported stress and the child progress, recorded twelve months later, in young children with ASC in a family-orientated training programme. Similar findings have been reported by Carlson-Green, Morris, and Krawiecki (1995) who noted that the best predictors of children's behaviour problems and adaptive behaviour, following intervention for paediatric brain tumours, were family and demographic variables, including family stress.

Secondly, there are numerous interventions that recognise how family functioning may influence the behaviours of a child with special needs (Harris, 1994), and several have noted improvements in the children's behaviours as a result of a reduction in parenting stress (e.g., Bitsika & Sharpley, 2000; Engwall & Macpherson, 2003; Harris, Handlemann, Arnold, & Gordon, 2000; Lovaas & Smith, 2003). Despite occasional negative reports (Bitsika & Sharpley, 1999; Kuloglu-Aksaz, 1994), beneficial child outcomes, as a result of combating parental problems, such as stress, suggest that parenting stress impacts on children's behaviours. A number of studies certainly show that child behaviour problems and parenting stress correlate with one another (e.g., Baxter, Cummins, & Yiolitis, 2000; Hodapp, Fidler, & Smith, 1998; Lecavalier, Leone, & Wiltz, 2006; Stores, Stores, Fellow, & Buckley, 1998).

Given that parenting stress appears to be related to child outcomes, and, given that many early teaching interventions require long-term, intensive, and intrusive access to the family home (see Reed *et al.*, 2007b), and often recruit parents as therapists (Mudford, Martin, Eikeseth, & Bibby, 2001), it seems important to investigate the relationship between parenting stress and the effectiveness of early teaching interventions. Specifically of interest is the influence of parenting stress on child outcomes produced by early teaching intervention programmes for ASC. Two studies already mentioned above (i.e. Carlson-Green *et al.*, 1995; Robbins *et al.*, 1991) have demonstrated a negative impact of parenting stress on child outcomes following an intervention, but not in the context of early teaching interventions for ASC, and replication and extension of these findings to this latter area would be an important development.

To these ends, the community-based study, reported in this chapter, examined the influence of early teaching interventions for ASC, as well as the dynamics between intervention time-input and parenting stress, on child outcomes across a wide range of measures. Of course, studying intervention intensity through quantity, as measured by time-input, does not reflect all of the possible aspects of an intervention (e.g., quality). However, although some have criticised the use of time-intensity as a measure (National Research Council, 2001), often no alternative metrics are suggested. In fact, there are very few measures of intensity of an intervention, other than time (but see Keohane, 1997), and few of these can easily be applied in a community setting. Moreover, time-input has been the subject of several recent reports (e.g., Eldevik *et al.*, 2006; Reed *et al.*, 2007a), so this metric (albeit not all encompassing) was used in this current chapter. A community-based sample was studied, rather than a clinic-based sample, to offer the greatest generality of the findings possible, as the home is where the majority of such programmes are conducted (Mudford *et al.*, 2001). Moreover, a range of similar 'non-brand name' early teaching interventions were studied, again to increase the generality of the findings. A wide range of child outcome measures were taken, including: intellectual functioning (Psycho-Educational Profile-Revised), educational functioning (British Abilities Scale), and adaptive behavioural and social functioning (Vineland Adaptive Behavior Scale), whereas, previous studies have often used IQ alone as an outcome measure (see Connor, 1998). The same psychometric child outcome measures were administered at baseline, and then, again, at follow-up, for all children after a nine to ten month period. Other studies have rarely used the same tests at baseline and at follow-up, and this limits their reliability (see Magiati & Howlin, 2001). The aim of the current chapter, therefore, is to examine the contribution, and possible detrimental impact, of levels of parenting stress on the outcomes of early teaching interventions for children with ASC.

Method

Participants

A total of 65 children with ASC (59 male and 6 female) were identified in conjunction with Local Education Authorities in the South East of England. All of the families of these children, who were contacted, agreed to participate in this study. Participants were selected on the basis of three criteria, the children had to be: 2:6 to 4:0 years old; at the start of their first teaching intervention; and independently diagnosed with ASC by specialist Paediatricians (typically using clinical judgement, supported by psychometric testing), following initial referral from a general medical practitioner. All diagnoses were made prior to participating in, and the commencement of, this study. In addition to these independent diagnoses of ASC, all of these children had a statement of Special Educational Needs related to their ASC from their Local Education Authorities.

These independent diagnoses were supported in the present study by the use of the Gilliam Autism Rating Scale (GARS), which allowed further independent assessment of the degree of their autistic severity. The GARS measure showed that the mean (standard deviation) of the overall GARS score for this sample was 93.8 (± 13.4), indicating that this sample was of a slightly milder than average autistic severity (the GARS has a standardised mean for all children with ASC of 100 ± 15 implying 'averagely autistic'; higher scores implying greater severity of problems, and lower scores implying milder severity of difficulties). The scores for the four sub-scales of the GARS, each representing a different aspect of the disorder, showed a similar pattern, in that all of these scores were slightly milder than the average. The sub-scales have a standardised mean of 10 (± 3), representing 'average severity'; higher scores implying greater severity, and lower scores implying less severe symptoms. The mean sub-scale scores were: Stereotyped Behaviours = 9.0 (± 2.6); Communication Problems = 9.8 (± 2.2); Social Interaction Problems = 8.4 (± 2.9); and Developmental Disturbances = 9.4 (± 1.9).

Interventions

In addition to the standardised measures, the teachers or tutors delivering the interventions were asked to complete a questionnaire concerning the nature of the intervention that the child was receiving. The teachers or tutors were asked to complete these forms at follow-up. These questionnaires were completed at the same time as the follow-up child assessments were made. Finally, the parents were also asked to complete a questionnaire at follow-up regarding the characteristics of the programmes that their children had experienced. From all of these questionnaires, the overall nature of the interventions received by the children could be documented (see Table 2.1).

Table 2.1: Description of interventions.

	Min.	*Max.*	*Mean (SD)*	*Stress r*
Intervention Hrs/Wk	2	40	15.6 (9.2)	- 0.044
1:1 Hrs/Wk	0	38	11.1 (9.5)	0.062
Group Hrs/Wk	0	22	4.9 (5.9)	- 0.069
Tutors	2	9	4.2 (1.6)	- 0.172
Family Hrs/Wk	0	13	2.6 (3.8)	- 0.016
Involved Family Hrs/Wk	1	13	4.9 (3.0)	- 0.125

Intervention Type	*N (%)*	*Total*	*N (%)*
Reinforcement	49 (75%)	1	21 (32%)
Special Nursery	36 (55%)	2	27 (42%)
Speech & Language	31 (48%)	3	16 (25%)
Parent Training	11 (17%)	4	1 (1%)

Table 2.1 displays the descriptive statistics for the interventions received by the children, focusing on the number of hours per week delivered by the intervention, broken down by hours provided in a 1:1 situation, or in a group setting. Additionally, the number of intervention hours per week delivered by parents is displayed, as is the number of tutors involved in delivering the intervention (including parents, if appropriate). The bottom panel of Table 2.1 shows the percentage of children receiving each of four broad types of teaching intervention (i.e. reinforcement-based, special nursery, speech and

language therapy, and parent training programmes), and the frequencies of children receiving one, or more, of these types of intervention.

These approaches were Local Education Authority responses to provision for children with ASC, and most programmes could be termed 'eclectic' interventions (for 51/65 children), in that they did not adhere to one particular form, or 'brand name', of intervention (often being the Local Education Authorities' own tailored approaches), and these approaches differed from authority to authority. Inspection of the bottom right panel of Table 2.1 shows that nearly 70% of children received at least two forms of teaching intervention.

The mean number of hours per week that the teaching interventions were given for was 15.6. Most of the children (75%) received an intervention that had a main focus of 1:1 teaching (receiving a mean of about 11 hours per week of this form of teaching) that was delivered by teachers, tutors, and/or parents. Many children (55%) received teaching in small groups (mean 5 hours per week), sometimes in addition to the above 1:1 based teaching, delivered by a teacher, tutor, and/or parents. In fact, most children (74%) received a mixture of both 1:1 and small group work, albeit in different proportions to one another.

Typically, there were four tutors involved in the delivery of these programmes, which could include the parents of the child. Although the teaching interventions did not necessarily require regular parental involvement as part of their remit, 53% of parents did become involved in delivering the teaching interventions for their children. The mean time of involvement in delivering the teaching interventions, when all parents were considered, was 2.6 hours per week. However, considering only the 53% of parents who chose to be involved in the delivery of the teaching interventions, their mean level of involvement was 5.0 hours per week. Some children (48%) were receiving speech and language therapy during the period of this study, for varying lengths of time (ranging from one or two visits in total from a trained Speech and Language Therapist, during the course of the study, to one or two hours per week). Many of the children (60%) were also on specific dietary interventions (e.g., gluten-free diets), and one child (1.5%) was undergoing a 'fringe' crystal intervention.

This variation in therapeutic approaches reflects the general 'eclectic' experience of the population being studied. This study was focused on the types of intervention that typically occur in the community for children with ASC, in order to increase its external validity, and, therefore, these interventions had a highly 'eclectic' nature. Nevertheless, the interventions described could be characterised by several common features, which are described below. Table 2.2 shows the range of, and mean, hours for each of the four broad types of intervention received by this sample. That is, of those who received the forms of teaching noted in this table, these data describe the typical levels of input. However, it must be emphasised that, given the 'eclectic' nature of the provision, any particular individual may have received more than one of these types of teaching intervention.

Table 2.2: Description of the temporal inputs (hours per week) of the four broad types of teaching interventions.

	Min.	*Max.*	*Mean*	*(SD)*
Reinforcement	1	35	13.5	10.7
Special Nursery	1	23	8.1	5.5
Speech & Language	1	3	1.2	0.7
Parent Training	1	10	4.2	2.3

Reinforcement-Based Interventions: These programmes all shared several key features. Most were home-based, and offered almost exclusively 1:1 teaching for the child with ASC, and the intensity (hours per week) of the interventions were typically quite high (see Table 2.2). Sessions would vary in length from about 30 minutes to three hours, and would comprise anything from one to 14 tasks per session, (depending upon the particular needs of the child). These tasks would last, typically, for about 5 – 10 minutes each, and would be repeated until some criterion performance was reached. Each task would be separated by a 5 – 10 minute break, or down-time. The programmes used an antecedent (question/task), behaviour (response), sometimes prompted, if necessary, and a consequence, procedure, as outlined in the various manuals. Reinforcement was usually a 'tangible', such as food, but could also be praise and activities, depending on what was effective with the individual child. No aversive stimuli were used in any of the programmes. All of these programmes were overseen by appropriately trained supervisors, or teachers, and the interventions were conducted by appropriately trained tutors, or parents, in accordance with the appropriate intervention manuals associated with the approach offered.

Special Nursery Placements: Each of the classes in the nursery provisions were relatively small, with about 6 to 8 children in each class. All curricula and practices had been approved by Ofsted reports (U.K. Government inspection reports that are given regularly to all schools). Each class was under the supervision of a teacher with postgraduate qualifications in teaching, and specialist training in Special Educational Needs. In addition to the teacher, each class had two or three learning support assistants, who would help to work with the children in small groups. Thus, most of the teaching was conducted in small groups, rather than individually (about four times as much group work as individual work).

The children attended the nursery for a number of 2 to 3 hour sessions per week, depending on the severity of the child's ASC (see Table 2.2 for the range of time-inputs). Typically, a session would start, and end, with children in a group, with the teacher at the front. The teacher usually guided a song, or other introduction, and the children were encouraged to turn-take in answering their names, or responding, often involving doing an individual activity (e.g., picking up a name card, shaking an instrument, etc.), whilst the others were encouraged to respond, and comment. A key feature was the use of materials and methods appealing to children with ASC, such as brightly coloured visual materials, glitter, water, paint, sand, or musical instruments. During all of this time, the adults encouraged, and prompted, social interaction, turn-taking, shared-attention, and commenting from the children. Much of the school environment, and many of the tasks given to the children, were presented in a highly structured manner, as outlined by the TEACCH methodology.

Speech and Language Therapy: This intervention was, of course, different across provision in public schools, and from private therapists, although many programmes have the same basic components. The therapy was usually delivered in the home, or a special class in the school. The children were usually in small groups (2 to 3), of similar age, and autistic severity, and the session would last from 30 to 60 minutes, once a week, or a fortnight. Where possible, the children were encouraged to have a few minutes of conversation, to loosen up their speech muscles, and promote social interaction. The rest of the session was spent performing an activity, such as playing a game, crafts, drawing, or singing. These activities focused on improving the children's communication skills, using several techniques, which were tailored to each individual's problem areas. The children sometimes used mirrors to look into their mouths as they practiced sounds, to ensure that their tongue, teeth, and lips, were used appropriately for speech sounds. A child's speech was sometimes recorded, and played back, so that the child could hear what he, or she, was saying.

At the end of the session, the children were usually given a reward for good behaviour. This could be a sticker, a pencil, or a small toy. They were also given worksheets to complete at home with their parents. The worksheets usually involved verbal interaction, through games and colouring activities. Parental involvement, and reinforcement, played an integral part in a child's progress.

Parent Training: Parent training was either provided by Local Education Authorities, or voluntary organisations, such as The National Autistic Society (NAS). Most programmes initially attempted to educate parents about the characteristics of a child with ASC, and then attempted to provide the parents with skills in order to help them manage their child's behaviours. For example, the EarlyBird Programme, provided by the NAS, is a three-month programme, which combines group training sessions for parents, with individual home visits, when video feedback is used to help parents apply what they have learned, whilst working with their child. In this programme, parents have a weekly commitment to a 2 hour training session, or a home visit, and to ongoing work with their child at home during a three-month programme. Such a model was similar to many Local Education Authority approaches, and those offered by several ABA-type programmes, whose main focus was, typically, on developing behaviour management skills in parents.

Measures

Gilliam Autism Rating Scale: The GARS (Gilliam, 1995) comprises four sub-scales, each describing behaviours symptomatic of ASC (*Stereotyped Behaviors*, *Communication, Social Interaction,* and *Developmental Disturbances*). The raw scores from these sub-scales can be converted into standard scores (mean = 10, standard deviation = 3). These sub-scales combine to give an overall *Autism Quotient*; higher scores meaning greater autistic severity (mean = 100 [average autistic severity], standard deviation = 15). In terms of assessing the probability that an individual has ASC, an *Autism Quotient* score of between 90 to 110 means an 'average' probability of ASC, a score below 89 means that there is a 'below average' probability of ASC, and a score below 79 means that there is a 'low' probability that the individual has ASC (Gilliam, 1995). The scale is appropriate for persons aged 3 to 22 years old, and is completed by parents, or professionals, in about 10 minutes. Its internal reliability (Cronbach's alpha) is 0.96, and it has high criterion validity with the Autism Behavior Checklist (0.94).

Psycho-Educational Profile – Revised: The PEP-R (Schopler, Reichler, Bashford, Lansing, & Marcus, 1990) is a developmental test designed for assessing both the typical strengths and characteristic weaknesses of children with ASC. The test measures functioning in seven developmental domains: *Imitation*, *Perception*, *Fine Motor Skills*, *Gross Motor Skills*, *Eye-Hand Coordination*, *Nonverbal Conceptual Ability*, and *Verbal Conceptual Ability*. The mental age required to perform these tests ranges from 1 to 72 months. The PEP-R also gives an overall developmental functioning score, that can be converted into an Overall score (e.g., [mental age/chronological age] x 100). The internal reliability of the PEP-R for children with ASC ranges from 0.85 (*Perception*) to 0.98 (*Cognitive Verbal Performance*), and it has high criterion validity with some other tests for intelligence, such as the Merrill Palmer Scale of Mental tests (0.85). The PEP-R was used, as its low floor, and high ceiling, made it appropriate to administer to the current sample both at baseline, and at follow-up. This avoids one major criticism of previous work that different tests are administered at these two times, reducing the reliability of the measure (Magiati & Howlin, 2001).

British Abilities Scale: The BAS II (Elliott, Smith, & McCulloch, 1996) is a battery of tests of cognitive abilities, which index educational achievement. It is suitable for use with children and adolescents from 2:6 to 17:11 years old. For the current purposes, the *Early Years Battery* was employed, which is designed for children under the age of 6 years. The present use of the test concerned educational achievement, so the *Verbal Comprehension*, *Early Number Concepts*, *Picture Matching*, and *Naming*

Vocabulary sub-scales were used. These sub-scales allow the calculation of a *General Cognitive Ability* scale (mean = 100, standard deviation = 15), which represents early educational achievement.

Vineland Adaptive Behavior Scale: The VABS (Sparrow, Balla, & Cicchetti, 1990) is a semi-structured interview, administered to a parent, or other caregiver, of the child. It can be used from birth to 5:11 years, making it suitable for the present cohort. The VABS assesses children's day-to-day adaptive functioning. Scores from four domains of adaptive behaviour were used in the present study (*Communication*, *Daily Living Skills*, *Socialization*, and *Motor Skills*). The raw scores can be converted to standard scores, and a *Composite Overall* score can be derived, based on the sum of the sub-scale standard scores (mean = 100; standard deviation = 15). The internal reliability of the *Overall Composite* score is 0.93.

Questionnaire on Resources and Stress: The Friedrich Short-Form of the QRS (Friedrich, Greenberg, & Crnic, 1983) is a 52-item, self-administered, true/false tool, designed to measure parental perceptions of the impact of a developmentally delayed, or chronically ill, child on other family members. The QRS-F consists of four sub-scales, which assess parental perceptions about: *Parent and Family Problems* – dealing with the impact that the disability has on family activities or relationships; *Pessimism* – related to parent depression; *Child Characteristics* – dealing with the impact of the child's problems on the family; and *Physical Incapacity* – which examines the family problems produced by the child not being able to perform certain activities for themselves. These scores summate to produce a *Total Stress Score* (0-52). Higher scores are indicative of greater perceived stress within the family, as perceived, and indicated, by the parents (but not, it should be noted, of a greater degree or number of actual stressors, see Dyson, Edgar, & Crnic, 1989). The internal reliability of the sub-scales, measured by Cronbach's alpha, ranges from: 0.77 (*Physical Incapacity*) to 0.85 (*Child Characteristics*), with the internal reliability of the *Total Stress Score* being 0.89. This tool has previously been employed for samples with ASC in assessing stress in parents (Hastings & Johnson, 2001), and so allows comparison with previous studies. The *Total Stress Score* from this scale has been shown to have good reliability and validity for research with parents of young children with ASC (Honey, Hastings, & McConachie, 2005).

Procedure

The children were identified by the Local Education Authorities, their parents were contacted, and, on choosing to participate, parental consent was received. The same tests were administered at baseline, and then, again, at follow-up, for all children and parents, after a nine to ten month period. Autistic severity (GARS), intellectual functioning (PEP-R), educational functioning (BAS), and adaptive behavioural and social functioning (VABS) were all measured. In addition, measures of self-reported parenting stress (QRS-F) were collected.

The children were visited by an Educational Psychologist, who was blind to the nature of the intervention, and to the levels of parenting stress, and the baseline child measures were taken (GARS, PEP-R, BAS, and VABS). Parents were contacted, at this time, and asked to complete the QRS-F questionnaires, and to give some background regarding their child, as well as a brief history of their child's provision, which they did independently. The questionnaires were sent out by post to the parents, along with an information letter, and a pre-paid, addressed return envelope. The information letter provided contact details, offering parents the opportunity to seek help and guidance, if required, regarding the completion of the questionnaires, however, it was extremely rare that any parents made contact in order to ask advice about answering specific questions. On completion, the parents used the pre-paid envelope to return the questionnaires. As an added incentive for returning this information, the parents were automatically entered into a prize draw, the winner of which received £50 for toys or books for their child. This incentive was specified in the information letter. If parents had not returned the questionnaires after a period of time, they were contacted, via telephone, and reminded, and given the opportunity to return the completed questionnaires.

After nine to ten months, the follow-up child measures were taken by the same Educational Psychologist. All parents, and the teachers and tutors delivering the interventions, were asked to complete separate questionnaires concerning the nature of the interventions, and to return them by post, as described above.

Results

Sixty-five children, satisfying the inclusion criteria, were divided into four groups based on their levels of intervention time-input, and on their parents' self-reported parenting stress levels. The interventions experienced by the children had a range of between 1.5 hours per week to 40 hours a week, with a mean (and standard deviation) of 15.6 ($\pm$ 9.2) hours per week. The mean of 15.6 hours per week was then used to divide the sample into low and high time-intensity groups. Those participants with less than

15.6 hours per week of intervention were placed in the low time-intensity groups, and those with more than 15.6 hours per week of intervention were placed in the high time-intensity groups. A categorical approach to analysing these data was taken, as there were too few participants to be confident in the results of a multiple regression procedure. Moreover, a regression approach would make theoretical assumptions about the linear relationship between variables, such as parenting stress and child outcomes, it would not pick up potential threshold-effects, or step-effects, in this relationship. A between-groups categorical approach is theoretically neutral with respect to this issue. A mean split procedure was adopted to produce the (lower and higher) categories for both variables. In the absence of any *a priori* reason for selecting the groups on any other grounds (e.g., at particular cut-off points for parenting stress), this approach was the most theoretically conservative.

Table 2.3: Numbers of participants with mean (standard deviation) for hours intervention received per week and total parenting stress (total QRS score).

	Group			
	Lower Time Lower Stress	Lower Time Higher Stress	Higher Time Lower Stress	Higher Time Higher Stress
N	25	20	9	11
Time (hrs/wk)	11.4 (2.8)	9.7 (5.9)	26.5 (5.0)	27.5 (8.3)
Range	3 – 15	1 – 15	20 – 34	16 – 40
Stress (Total QRS)	23.4 (5.3)	33.3 (4.7)	25.1 (4.4)	32.5 (4.1)

Table 2.3 shows the mean parenting stress and intervention time-inputs for the four groups. Table 2.4 shows the group-mean baseline levels for autistic severity (GARS), intellectual functioning (PEP-R), educational functioning (BAS), and adaptive behavioural functioning (VABS), for these four groups. These groups did not differ from one another on any of the baseline measures taken, *F*s < 1. It should also be noted that Table 2.1 shows that parenting stress was not statistically significantly associated with any of the intervention time-inputs measured in this study, suggesting that baseline parenting stress did not vary systematically with any aspect of the interventions measured.

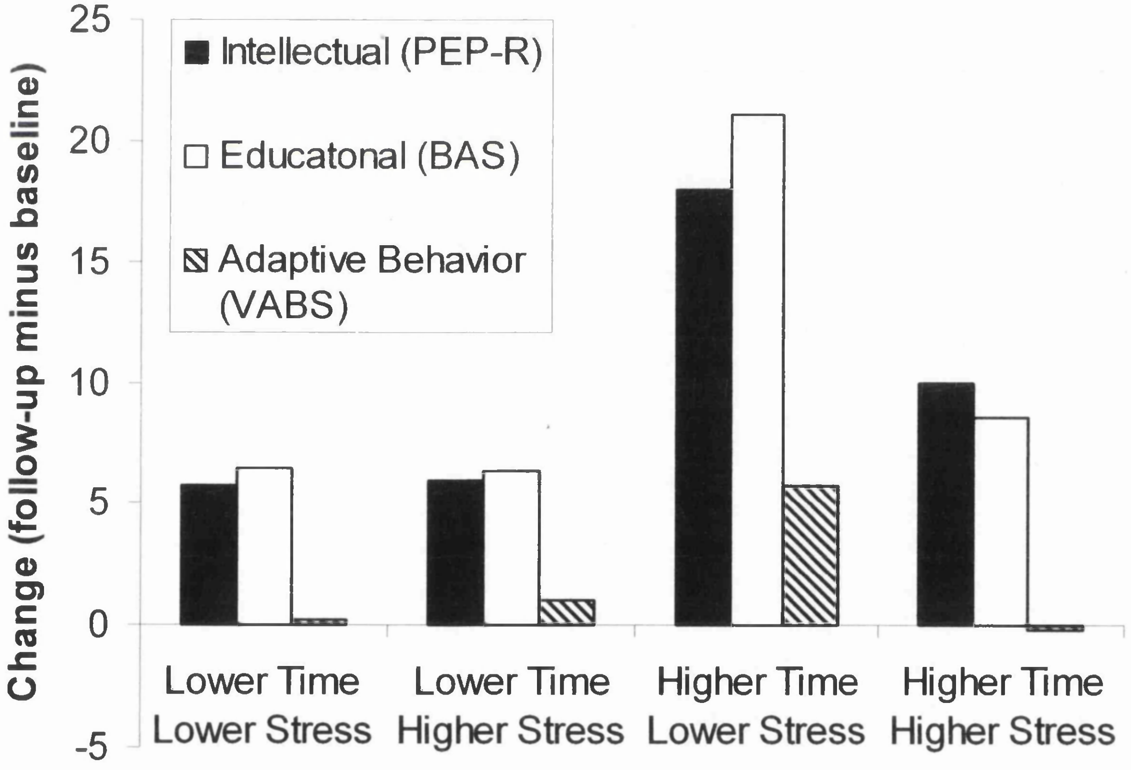
Table 2.4: Mean baseline measures scores (and standard deviations) for the four groups.

	Group			
	Lower Time Lower Stress	Lower Time Higher Stress	Higher Time Lower Stress	Higher Time Higher Stress
GARS	90.7 (19.8)	95.8 (11.8)	90.7 (13.7)	90.6 (19.0)
PEP-R	51.3 (11.9)	53.7 (22.1)	54.0 (12.2)	57.2 (20.2)
BAS (GCA)	53.4 (9.1)	56.8 (14.0)	57.7 (19.0)	59.3 (20.7)
VABS Composite	55.6 (4.7)	56.6 (6.2)	57.0 (6.6)	58.6 (11.0)

Note: Mean performance on all tests (except the GARS) for children without ASC is 100 (standard deviation = 15).

The children's scores for each of the three outcome measures at baseline were subtracted from their corresponding scores at follow-up assessment. The resulting differences represented for the three child outcome measures are displayed in Figure 2.1. Children receiving more intervention time-input had greater improvements across all of the three measures than children receiving less intervention time-input. Parenting stress did not impact on the gains made by children with lower intervention time-input, but the gains associated with greater intervention time-input were reduced by high levels of parenting stress.

Figure 2.1: Change scores (follow-up minus baseline) for child measures.



A two-factor multivariate analysis of variance (MANOVA), with intervention time-input (lower versus higher), and parenting stress (lower versus higher), as the two factors, was conducted on the data displayed in Figure 2.1. A Pillai's Trace Criteria was used as the most robust test statistic (Olson, 1979). This analysis revealed a statistically significant main effect of time-input, $F(3,59) = 3.44, p < 0.05$, a statistically significant main effect of parenting stress, $F(3,59) = 2.63, p < 0.05$, and a statistically significant interaction between these two factors, $F(3,59) = 3.28, p < 0.05$.

To analyse the interaction further, separate MANOVAs were conducted: firstly, on the effects of parenting stress on the two different intervention time-input groups (i.e. higher versus lower parenting stress for the lower intervention time-input groups, and higher versus lower parenting stress for the higher intervention time-input groups); and, secondly, on the effect of intervention time-input on the two different sets of parenting stress groups (i.e. higher versus lower intervention time-input for the lower parenting stress groups, and higher versus lower intervention time-input for the higher parenting stress groups).

The MANOVA conducted on the lower intervention time-input groups revealed no difference between the parenting stress conditions, $F < 1$, suggesting no impact of the level of parenting stress when the intervention time-input is lower. However, there was a statistically significantly lower level of functioning for the higher parenting stress group, compared to the lower parenting stress group, for the higher intervention time-input groups, $F(3,16) = 2.81, p < 0.05$, suggesting that parenting stress has a negative impact when intervention time-input is higher. Separate univariate analyses of variance (ANOVAs) conducted on the change scores for the individual measures (PEP-R, BAS, and VABS), for the groups experiencing higher intervention time-inputs, revealed that there was no statistically significant effect of parenting stress on intellectual functioning (PEP-R), $p > 0.20$, but there was a statistically significant effect of parenting stress in reducing educational functioning (BAS), $F(1,18) = 4.93, p < 0.05$, and on reducing adaptive behavioural functioning (VABS), $F(1,18) = 6.39, p < 0.05$.

The MANOVA conducted on the lower parenting stress groups revealed a statistically significant effect of intervention time-input, $F(3,30) = 4.65, p < 0.005$, suggesting that, at lower levels of parenting stress, higher intervention time-input programmes are more effective than lower intervention time-input programmes. Separate univariate ANOVAs conducted on the change scores for the individual measures (PEP-R, BAS, and VABS), for the lower parenting stress groups, revealed that higher intervention time-input statistically significantly improved intellectual functioning (PEP-R), $F(1,32) = 6.72, p < 0.05$, educational functioning (BAS), $F(1,32) = 12.28, p < 0.01$, and adaptive behavioural functioning (VABS), $F(1,32) = 5.68, p < 0.05$. However, there was no statistically significant effect of intervention time-input when the parenting stress levels were higher, $F < 1$, suggesting that higher levels of parenting stress counteract the benefits of higher intervention time-input.

Discussion

The study reported in this chapter demonstrated the effectiveness of early teaching interventions for children with ASC, with respect to gains in intellectual, educational, and adaptive behavioural and social skills. There was some evidence of a relationship between higher intervention time-input and greater child-outcome gains, suggesting that child outcomes may show greater improvements following more time-intensive interventions (see also Eldevik *et al.*, 2006; Lovaas, 1987; Reed *et al.*, 2007a). However, the results also suggest that early teaching interventions for ASC, especially those with higher time-input, are not so effective when parenting stress levels are higher (cf. Carlson-Green *et al.*, 1995; Robbins *et al.*, 1991).

In general, children who received more time-intensive interventions (i.e. higher time-input) demonstrated greater outcome improvements across measures of intellectual, educational, and adaptive behavioural and social, skills than children receiving lower time-intensive programmes. This is a finding that has been reported previously for Applied Behaviour Analytic (ABA) programmes (see Eldevik *et al.*, 2006; Reed *et al.*, 2007a), at least up to an optimal level of intervention time-input (see Reed *et al.*, 2007a). However, the present study additionally focused on a range of early teaching programmes that were not necessarily classifiable as ABA, and the current results extend the generality of those previous findings with respect to intervention time-input. The results of previous studies on the outcome effectiveness of non-ABA approaches have been mixed (cf. Charman, Howlin, Berry, & Prince, 2004; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Ozonoff & Cathcart, 1998), and obviously more investigation is required to isolate the effective parts of such teaching programmes (e.g., 1:1 teaching versus group teaching, etc.), which was not the purpose of the present study. However, that the findings, with respect to the effect of intervention time-input on child outcomes, remained similar, despite an increased variety of teaching programmes being studied, corroborates the suggestion that many early teaching interventions are influenced by the same factors (Dawson & Osterling, 1997).

Importantly, the current chapter found that the early teaching interventions studied produced fewer gains when parents reported higher feelings of parenting stress, especially when the teaching intervention had a higher time-input. In this finding, the present study produced similar results to those reported by Carlson-Green *et al.* (1995), and Robbins *et al.* (1991). Although neither of these latter two studies was concerned with early teaching interventions for children with ASC, they both found that higher levels of parenting stress impacted adversely on child outcomes. Combined with the current results, this suggests that parenting stress may be a key factor in determining the effectiveness of early interventions for children with ASC (although this may be limited to interventions with a higher time-input). In the present chapter, and in the two previous studies mentioned above, higher parenting stress at baseline was found to impact on child outcomes, measured some time later, so these studies, and the present chapter, provide more than correlational evidence for the relationship between high parenting stress and diminished child outcomes.

It may be worth noting that, in the current chapter, higher levels of parenting stress produced statistically significant negative effects on educational, and adaptive behavioural, functioning, but not on the measure of intellectual functioning. This may, of course, be an artefact of sample size, as there was a numerical reduction in the intellectual functioning gains, as a result of higher parenting stress. However, similar findings have been reported previously, in the context of recovery from paediatric brain tumour operations, where higher parenting stress was found to predict future child behaviour problems, as well as adaptive behavioural problems, but was not found to relate to the children's future intellectual functioning (Carlson-Green *et al.*, 1995). It is currently unclear what causes this apparent differential impact of higher parenting stress, but it is worth noting that two studies have now found the same effect.

Given the impact of parenting stress on child outcomes, a measure of parenting stress levels before the commencement of a teaching intervention may allow recommendations to be made for parents to seek out stress management, and reduction, programmes, or counselling, should they decide to follow time-intensive early teaching interventions for their child (e.g., Harris *et al.*, 2000; Lovaas & Smith, 2003). It could be argued, on the basis of these findings, that early teaching interventions should offer initial parenting stress management training, and/or counselling, in order to ensure their maximum effectiveness.

The channel through which parenting stress levels influence the outcomes of early teaching interventions for children with ASC is presently unclear. Higher levels of parenting stress may influence parenting behaviours, and styles, which, in turn, may impact on the child outcomes of early teaching interventions. It is also possible that different levels of parenting stress mean that early teaching interventions are conducted differently in the home (e.g., see Dale, Jahoda, & Knott, 2006; Hastings & Symes, 2002). For example, it may be that highly stressed parents are less likely to continue systematic intervention with their child when the teaching sessions are over for the day, making it less likely that these children will show generalisation gains, and so forth.

The current findings have some theoretical implications, as well as the practical ones for developing early teaching interventions for ASC. Previous research examining the behaviours of children with learning difficulties has suggested a link between child behaviour problems and levels of parenting stress (e.g., Baxter *et al.*, 2000; Hodapp *et al.*, 1998; Lecavalier *et al.*, 2006). However, much of this evidence is correlational, and does not allow any indication of the temporal directionality over time between these two factors. In the present chapter, the parenting stress at baseline was found to impact detrimentally on the later measured effectiveness of early teaching interventions, devised to manage the disorder (see also Carlson-Green *et al.*, 1995; Robbins *et al.*, 1991). That is, the association found in this present study is time-lagged, and baseline parenting stress cannot be caused by the child outcome gains, which are measured at a later point in time at the follow-up assessments. This effect would not be directly predicted by some theoretical models (e.g., Deater-Deckard, 1998; Hastings, 2002; see Chapter 1), which suggest the opposite direction of influence; that is, from child outcomes to parenting stress. Obviously, further work is necessary in this area, but the current results suggest, at the least, an additional source of influence in the relationship between parenting stress and children's behaviours. It might be that, as these theoretical models were devised for children with learning difficulties, and not for those with ASC, a different set of principles are in operation.

In summary, these findings suggest that levels of parenting stress should be taken into account when designing early teaching interventions for ASC. Helping parents of children with ASC to reduce their stress levels may, therefore, also aid the child to achieve greater outcome gains in time-intensive early teaching intervention programmes. Hence, it could be suggested that helping the parents could help the child.

Chapter 3:

The Relationship Between Parenting Stress and Behaviour Problems of Children with Autistic Spectrum Conditions Receiving Teaching Interventions

Introduction

As noted in the previous chapters, there has been relatively less research on family influences on Autistic Spectrum Conditions (ASC), over the past twenty years, than on many other aspects of ASC, although, recently, there has been an increase in the amount of recognition and investigation of the role of the family on ASC. In particular, the role of parenting stress and its relationship to child behaviour problems has received some attention in recent years (see Chapter 1). This present chapter focuses on two aspects of this area that have been subjects of some debate: firstly, whether parenting stress is strongly associated with child behaviour problems, over and above the severity of ASC symptoms; and, secondly, the temporal directionality of this relationship, that is, whether child behaviour problems precede parenting stress, or *vice versa*.

Levels of parenting stress are more highly pronounced in parents of children with ASC, compared to parents of children with almost any other type of disability or health problem (e.g., Blacher & McIntyre, 2006; Bouma & Schweitzer, 1990; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Eisenhower, Baker, & Blacher, 2005; Koegel, Schreibman, Loos, Dirlich-Wilhelm, & Dunlap, 1992; Perry, Sarlo-McGarvey, & Factor, 1992; Weiss, 2002; but see Holroyd & McArthur, 1976). In a review of current research on parents of children with ASC, Pisula (2003) noted that profound parenting stress is reported as being experienced by such parents. For example, Wolf, Noh, Fisman, and Speechley (1989; see also Fisman, Wolf, & Noh, 1989) found greater stress, and more dysphoria and depression, in parents of children with ASC than in parents of children with Down's Syndrome and in parents of children without a developmental disability.

Similarly, Bouma and Schweitzer (1990) found that ASC contributed significantly more to family stress than did a chronic physical illness (cystic fibrosis).

There have been a number of attempts to discover factors that are associated with this high level of parenting stress. From the current literature, it is somewhat unclear whether parenting stress is more strongly related to the severity and symptoms of the child's ASC, or to the child behaviour problems that commonly accompany ASC (e.g., externalising, disruptive, and aggressive behaviours). Certainly, severe symptoms in many medical conditions in children have been found to be related to high levels of stress in parents. For example, high family life stress is strongly correlated with the symptoms of diabetes (Viner, McGrath, & Trudinger, 1996). With respect to ASC, Hastings and Johnson (2001; see also Tobing & Glenwick, 2002) reported that higher levels of symptomatology and severity of impairment involved with ASC were associated with higher levels of reported parenting stress. Similarly, Duarte, Bordin, Yazigi, and Mooney (2005) found that the strongest association was between stress in mothers and having a child with ASC, and maternal stress increased when the symptoms, poor expression of feeling and emotion, and little social interest, were more severe (see also Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Kasari & Sigman, 1997, regarding the effects of child levels of social skills being a good predictor of maternal stress).

However, in addition to the severity of the symptoms of ASC, several reports have noted a relationship between parenting stress and child behaviour problems that are not directly related to ASC symptoms. A number of studies show that child behaviour problems and parenting stress do correlate (e.g., Baxter, Cummins, & Yiolitis, 2000; Hodapp, Fidler, & Smith, 1998; Stores, Stores, Fellow, & Buckley, 1998). Lecavalier, Leone, and Wiltz (2006) found that child behaviour problems were strongly associated with caregiver stress, especially a specific group of externalised behaviours, such as conduct problems. In this report, child adaptive skills were not associated with caregiver stress, whereas, Tomanik, Harris, and Hawkins (2004) noted that both child maladaptive, and child adaptive, behaviour correlated with maternal stress. Konstantareas and Homatidis (1989) noted that the best predictor of stress in parents was child self-abuse, and, for mothers, hyperirritability also was associated with elevated stress scores. Repetitive behaviours, being a form of behavioural problems in some children with ASC, Gabriels, Cuccaro, Hill, Ivers, and Goldson (2005) ascertained that parent ratings of their own stress levels were strongly correlated with repetitive behaviours in their children. Fong (1991) noted a trend toward higher levels of maladaptive behaviours in adolescents with ASC whose mothers were highly stressed.

Several studies present data consistent with the view that child behaviour problems are associated with parenting stress, over and above other factors, such as type of disability, severity of ASC, and child adaptive behaviours (e.g., Blacher & McIntyre, 2006; Donenberg & Baker, 1993; Dumas, Wolf, Fisman, & Culligan, 1991; Floyd & Gallagher, 1997; Lecavalier *et al.*, 2006). Noh, Dumas, Wolf, and Fisman (1989) found that stress levels were highest in parents of children with behaviour and conduct problems, and were actually slightly greater than those reported by parents of children with ASC. Pisula (1998; 2003) noted that behavioural disorders, and problems related to atypical child behaviours, were the main source of parenting stress in mothers of children with ASC. In a ten-year longitudinal study, Gray (2002) noted that, over time, general improvement was experienced by most parents of children with ASC in many aspects of their lives. However, less favourable outcomes were reported in families whose children showed violent and/or aggressive behaviour problems. The parents in these families continued to experience high levels of parenting stress.

Several studies have equated child behaviour problems across groups; and have used an approach which includes a group of developmentally disabled children and a group of children without developmental disabilities. These studies have demonstrated that there were no differences in reports of parenting stress across these groups, which were matched on behaviour problems, despite having differences in the levels and types of disorder. For example, Donenberg and Baker (1993) compared children with ASC, children with externalising behaviours (e.g., hyperactivity and aggression), and typically developing children with no significant problem behaviours. They found similar high child-related stress in the parents of the externalising children, and in the parents of children with ASC, compared to the parents of the typically developing children. Dumas *et al.* (1991) studied reports of parenting stress, child behaviour problems, and dysphoria in families of children with ASC, behaviour disorders, Down's Syndrome, and those of typically developing children. Parents of children with ASC, and parents of children with behaviour disorders, reported experiencing higher levels of parenting stress than parents in the other two groups, with mothers both of children with ASC, and behaviour disorders, experiencing higher levels of dysphoria. Although it should be noted that the parents of the children with behaviour disorders reported that their children displayed more intense behavioural difficulties, which were greater in number, than those reported by the parents of all other children in the study, including those parents of the children with ASC.

Blacher and McIntyre (2006) found that maternal stress, or depression, were not related to the type of disability (intellectual disability, cerebral palsy, Down's Syndrome, and ASC) once differences in child behaviour problems were controlled for. Similarly, maternal stress has been found to be correlated with child behaviour problems, but not to correlate independently with adaptive behaviour and the symptoms of ASC (Hastings, Kovshoff, Ward, degli-Espinosa, Brown, & Remington, 2005). Although, again, it should be noted that this pattern of results has not been found in every study. For example, Eisenhower *et al.* (2005) noted that the type of disability (especially ASC) accounted for maternal stress, even after controlling for levels of behaviour problems. Thus, in some cases, the child syndrome can produce effects on parenting stress, even after differences in child behaviour problems and cognitive levels have been accommodated. In particular, Eisenhower *et al.* (2005) conclude that the behavioural differences manifested in children with ASC, compared with children with other disabilities (e.g., Down's Syndrome, cerebral palsy, and developmental delay), were paralleled by differences in parenting stress, such that parents of children with ASC are at increased risk from high stress, which is contributed to by characteristics of the syndrome beyond the child behaviour problems.

Thus, there is evidence that both the symptoms of ASC, and child behaviour problems, are correlated with parenting stress, and it is important to be able to determine which of these factors is associated most strongly with such stress. The main difficulty is that the severity of ASC symptoms and child behaviour problems also correlate themselves (e.g., Eisenhower *et al.*, 2005; Gabriels *et al.*, 2005). Hastings (2002) claims that, to establish a relationship between child behaviour problems and parenting stress, this association has to be demonstrated as non-spurious to rule out the possibility of other factors, or confounds (e.g., ASC symtomatology), having an influence on parenting stress. Thus, while it appears that there is a large degree of evidence associating child behaviour problems with parenting stress, further replication that such problems predict parenting stress, over and above the level of severity of the syndrome, would be helpful. This represents one aim of the current chapter. In addition, it is possible to determine a tentative pattern to the differences in these reports. Studies that show a strong relationship between ASC severity and parenting stress are often conducted on younger children (e.g., Eisenhower *et al.*, 2005; Hastings & Johnson, 2001), and those that show child behaviour problems correlate most strongly with parenting stress often have a much wider range of ages of children (e.g., Dumas *et al.*, 1991; Lecavalier *et al.*, 2006). This might suggest that, early in the development of this parent-child dynamic interaction, parenting stress is focused on the ASC itself, but, later, its focus becomes concentrated on the child behaviour problems. The current chapter aimed to see whether this relationship pattern would be confirmed, or not.

In addition to establishing factors that are associated with parenting stress, a goal of this research is to attempt to provide evidence about the potential direction of such a relationship. Temporal precedence of one factor prior to another is a first step in attempting to establish causal directionality. For example, it is not known whether child behaviour problems precede parenting stress, or whether parenting stress precedes child behaviour problems. Many articles are written that implicitly suggest that the former scenario is the case; that is, that child behaviour problems precede, predict, or even cause parenting stress (e.g., Hastings, 2002; Hastings *et al.*, 2005). Although many of these claims are based solely on correlational, or regression, procedures conducted on data collected at one single point in time, whereas a minimum requirement would be that a relationship between factors across time is established. There are, of course, many potential explanations for a correlation between variables collected at the same time.

Due to the difficulties involved in conducting longitudinal research, there are relatively very few studies that have collected data from several different points in time, and which would allow indication of the temporal directionality of the relationship between parenting stress and child behaviour problems. In fact, these studies show little evidence that child behaviour problems predict parenting stress to any great degree, rather they tend to indicate the reverse relationship. For instance, Lecavalier *et al.* (2006) found that child behaviour problems and caregiver stress exacerbated each other over a period of one year. Robbins, Dunlap, and Plienis (1991) demonstrated that the learning progress of young children with ASC was less favourable in those children whose mothers self-reported high stress. Likewise, in Chapter 2, it was reported that parenting stress, measured at baseline, had a large detrimental impact on the later outcomes for children with ASC receiving various early teaching interventions. This relationship between parenting stress and subsequent child behaviours is not restricted to ASC. Carlson-Green, Morris, and Krawiecki (1995) found, in their work with children with heterogeneous brain tumours, that the best predictors of children's behaviour problems and adaptive behaviour included family variables, such as family stress and maternal coping (see also Warner & Pottick, 2006, for a discussion of psychiatric problems in young children that stem from family stress).

As it is important that temporal precedence between child behaviour problems and parenting stress needs to be established, in order to provide first evidence for causal directionality, this forms the second aim of the current chapter. Such evidence could be provided by using a longitudinal study design. Then, the correlations between the child behaviour problems and the parenting stress scores at baseline and at follow-up could be used to examine temporal precedence. There is little existing evidence to examine this for ASC, so this present chapter examines data from children with ASC and their families over an extended time period.

To summarise, the current chapter aims to examine the relationships of parenting stress to both ASC severity and to child behaviour problems, to ascertain whether these relationships evolve over time, and to establish whether there is any temporal precedence between these factors. To achieve these ends, two longitudinal studies were conducted in order to measure these factors in a range of differently aged children, using a range of measurement instruments to gain a greater degree of generality from the results.

Study 1

There were two main aims of the first study reported here. The first aim was to evaluate and assess the relationship between child behaviour problems and parenting stress, and the second aim was to ascertain and determine the possible, if any, temporal directionality of the dynamics between child behaviour problems and parenting stress. This first study examined these two aspects of family functioning and family dynamics in a cohort of young children with ASC who were receiving early teaching interventions. A lot of research includes young children with ASC as participants in the studies (e.g., Hastings *et al*., 2005), however, these younger participants only serve as a part of a much larger group of children with ASC with a wider age range (e.g., Lecavalier *et al*., 2006), and are seldom, if ever, analysed separately with respect to child behaviour problems and parenting stress. So there are few studies that report on very young children with ASC. Moreover, young children with ASC undergoing early teaching interventions are an important participant group in current research (e.g., Reed, Osborne, & Corness, 2007a; 2007b). If it is the case that parents of younger children are more stressed about the ASC, and its severity, than about the child behaviour problems, then this association should be revealed in this sample.

Additionally, it is rarely the case that differences between parent and teacher ratings of child behaviour problems are examined. Few researchers in this area have compared and contrasted parent and teacher ratings of behaviour problems in children with ASC, and related these different ratings to levels of parenting stress. One such recent study to elicit ratings both from parents and teachers was by Lecavalier *et al.* (2006). This report noted that, although there was some agreement between these ratings, parents and teachers did not perfectly agree on the nature and severity of child behaviour problems. Although parenting stress and child behaviour problems made each other worse over a period of a year, there was no such effect when teacher ratings were used.

Thus, the first study in this chapter elicited ratings of child behaviour problems both from parents and teachers at the start of a child's early teaching intervention programme (baseline), and, then again, after nine to ten months (follow-up). In addition, self-reported ratings of parenting stress were taken at baseline, and then at follow-up, as were independent assessments of the child's autistic severity, intellectual functioning, and adaptive behavioural functioning. This first study aimed to use the baseline measures to assess the relationship between child behaviour problems and parenting stress, when other factors were controlled for, and the relationship between baseline measures and follow-up measures to provide any possible evidence of temporal directionality of effect.

Method

Participants

A total of 65 children with ASC (59 male and 6 female) were identified in conjunction with Local Education Authorities in the South East of England. All of the parents of these children were contacted, and agreed to participate in the study. Participants were selected on the basis of three criteria, the children had to be: 2:6 to 4:0 years old; receiving an early teaching intervention; and independently diagnosed with ASC by specialist Paediatricians, following initial referral from an independent general medical practitioner. All diagnoses were made prior to participating in, and the commencement of, this study. In addition to these independent diagnoses of ASC, all of these children had a statement of Special Educational Needs related to their ASC from their Local Education Authorities.

These independent diagnoses were supported in the present study by the use of the Gilliam Autism Rating Scale (GARS), which allowed further independent assessment of the degree of their autistic severity. The GARS measure showed that the mean (standard deviation) of the overall GARS score for this sample was 91.9 (± 16.1), indicating that this sample was of a slightly milder than average autistic severity (the GARS has a standardised mean for all children with ASC of 100 ± 15 implying 'averagely autistic';

higher scores implying greater severity of problems, and lower scores implying milder severity of difficulties). The scores for the four sub-scales of the GARS, each representing a different aspect of the disorder, showed a similar pattern, in that all of these scores were slightly milder than the average. The sub-scales have a standardised mean of 10 (± 3), representing 'average severity'; higher scores implying greater severity, and lower scores implying less severe symptoms. The mean sub-scale scores were: Stereotyped Behaviors = 9.0 (± 2.6); Communication Problems = 9.8 (± 2.2); Social Interaction Problems = 8.4 (± 2.9); and Developmental Disturbances = 9.4 (± 1.9).

Measures

Gilliam Autism Rating Scale: The GARS (Gilliam, 1995) comprises four sub-scales, each describing behaviours symptomatic of ASC (*Stereotyped Behaviors, Communication, Social Interaction,* and *Developmental Disturbances*). The raw scores from these sub-scales can be converted into standard scores (mean = 10, standard deviation = 3). These sub-scales combine to give an overall *Autism Quotient*; higher scores meaning greater autistic severity (mean = 100 [average autistic severity], standard deviation = 15). The scale is appropriate for persons aged 3 to 22 years old, and is completed by parents or professionals in about 10 minutes. Its internal reliability is 0.96, and it has high criterion validity with the Autism Behavior Checklist (0.94).

British Abilities Scale: The BAS II (Elliott, Smith, & McCulloch, 1996) is a battery of tests of cognitive abilities, which index educational achievement, and intellectual functioning. It is suitable for use with children and adolescents from 2:6 to 17:11 years old. For the current purposes, the *Early Years Battery* was employed, which is designed for children under the age of 6 years. The present use of the test concerned intellectual functioning, and the *Verbal Comprehension*, *Early Number Concepts*, *Picture Matching*, and *Naming Vocabulary* sub-scales were used. These sub-scales allow the calculation of a *General Cognitive Ability* scale (mean = 100, standard deviation = 15), which represents early intellectual functioning.

Vineland Adaptive Behavior Scale: The VABS (Sparrow, Balla, & Cicchetti, 1990) is a semi-structured interview, administered to a parent, or other caregiver, of the child. It can be used from birth to 5:11 years, making it suitable for the present cohort. The VABS assesses children's day-to-day adaptive functioning. Scores from four domains of adaptive behaviour were used in the present study (*Communication*, *Daily Living Skills*, *Socialization*, and *Motor Skills*). The raw scores can be converted to standard scores, and a *Composite Overall* score can be derived, based on the sum of the sub-scale standard scores (mean = 100; standard deviation = 15). The internal reliability of the *Overall Composite* score is 0.93.

Conners' Rating Scale: The *Conners' Rating Scale-Revised* (CRS-R; Conners, 1997) assesses children (aged 3 to 17) for behavioural problems, hyperactivity, and attention-deficit disorder. There are two versions of the CRS-R; the *Parent Rating Scale* (completed by the parents or caregivers of the child), and the *Teacher Rating Scale* (completed by the teacher/tutor responsible for administering or supervising the intervention). The short versions of both forms were employed in this study, which take 5 to 10 minutes to complete. The short version of the CRS-R consists of 28 items for the teacher version, and 27 items for the parent version. Questions on both versions of the form consist of a *0* (*Not True at All*) to *4* (*Very Much True*) Likert-type scale. There are four sub-scales of the test: *Oppositional Behavior* – indicative of rule breaking, authority problems, and ease of anger; *Cognitive Problems* – indexing inattention, difficulty in organising work, or concentrating for sustained periods; *Hyperactivity* – suggesting difficulties in sitting still, restlessness, and impulsivity; and the *ADHD* index – identifies children likely to suffer from ADHD. The range of internal reliability of the sub-scales is from 0.77 to 0.96. Although not used primarily for ASC *per se*, this tool has been identified as important in the assessment of the effects of interventions for ASC on behavioural difficulties (see, Handen, Johnson, & Lubetsky, 2000).

Questionnaire on Resources and Stress: The Friedrich Short-Form of the QRS (Friedrich, Greenberg, & Crnic, 1983) is a 52-item, self-administered, true/false tool, designed to measure parental perceptions of the impact of a developmentally delayed, or chronically ill, child on other family members. The QRS-F consists of four sub-scales, which assess parental perceptions about: *Parent and Family Problems* – dealing with the impact that the disability has on family activities or relationships; *Pessimism* – related to parent depression; *Child Characteristics* – dealing with the impact of the child's problems on the family; and *Physical Incapacity* – which examines the family problems produced by the child not being able to perform certain activities for themselves. These scores summate to produce a *Total Stress Score* (0-52). Higher scores are indicative of greater perceived stress within the family, as perceived and indicated by the parents (but not, it should be noted, of a greater degree or number of actual stressors, see Dyson, Edgar, & Crnic, 1989). The internal reliability of the sub-scales ranges from: 0.77 (*Physical Incapacity*) to 0.85 (*Child Characteristics*), with the internal reliability of the *Total Stress Score* being 0.89. This tool has previously been employed for samples with

ASC in assessing stress in parents (Hastings & Johnson, 2001), and so allows comparison with previous studies. The *Total Stress Score* from this scale has been shown to have good reliability and validity for research with parents of young children with ASC (Honey, Hastings, & McConachie, 2005).

Procedure

The same tests were administered at baseline and then, again, at follow-up for all of the children, after a nine to ten month period. Intellectual functioning (BAS) and adaptive behavioural and social functioning (VABS) were measured. In addition, measures of child behaviour problems (Conners'), and family functioning were taken, concentrating on self-reported parenting stress (QRS-F). When identified, the children were visited by an Educational Psychologist, who was blind to the nature of the intervention and to the levels of parenting stress, and the baseline child measures were taken (GARS, BAS, and VABS). Parents were contacted and asked to complete a Conners' questionnaire about their child's behaviours, and a QRS questionnaire, and to give a brief history of the child's provision. At this time, the child's main teacher, or programme supervisor, was contacted and asked to complete a Conners' questionnaire on the child's behaviours, independently of the parents. After nine to ten months, the follow-up child measures were taken by the same Educational Psychologist. All parents, as well as the teachers and tutors delivering the interventions, were asked to complete separate questionnaires concerning the child's behaviour problems (Conners'). The parents also were asked to complete another QRS questionnaire, and the parents, and tutors, were asked to complete a questionnaire about the nature of the intervention itself.

Results and Discussion

Measures of parenting stress, using the total QRS score, were taken at baseline, which revealed a mean score of 28.1 (standard deviation = 6.6), and at follow-up, which revealed that total stress had fallen to 24.8 (± 7.6). A paired t-test conducted on these data revealed that this fall was statistically significant, $t(64) = 4.51, p < 0.001$. The autistic severity of the children, as measured by the total GARS score, was 91.9 (± 16.1) at baseline, and 90.9 (± 16.3) at follow-up, which was not a statistically significant change, $t < 1$. The children's intellectual functioning, as measured by the General Cognitive Ability score from the BAS, rose from 56.1 (± 14.4) at baseline, to 65.1 (± 18.9) at follow-up, a statistically significant increase, $t(64) = 6.75, p < 0.001$. The children's adaptive behavioural functioning, as measured by the VABS Composite score, rose only slightly from 56.6 (± 6.7) to 57.7 (± 8.4), and this change was not statistically significant, $p > 0.10$.

Table 3.1: Pearson's correlations between autistic severity (GARS), intellectual functioning (BAS), adaptive behavioural functioning (VABS), and parenting stress (QRS) at baseline (top panel), and at follow-up (bottom panel), in Study 1.

Baseline	GARS	BAS	VABS
QRS	0.295*	0.000	0.015
VABS	- 0.370**	0.485**	-
BAS	- 0.218*	-	-

Follow-up	GARS	BAS	VABS
QRS	0.186	- 0.126	- 0.065
VABS	- 0.351*	0.799**	-
BAS	- 0.263*	-	-

* $p < 0.01$, ** $p < 0.001$

Table 3.1 shows the correlations between these variables, and reveals that there were several statistically significant relationships between these factors, with the GARS score correlating with almost all of the variables, and the VABS Composite and BAS scores correlating strongly.

Table 3.2: Mean (and standard deviation) child behaviour problems at baseline, and at follow-up, as measured by the Conners' parent and teacher scales (population mean = 50, standard deviation = 10) in Study 1.

Parent Scale	Baseline	Follow-up	*t*(64)
Oppositional	56.9 (9.6)	53.0 (8.2)	3.25*
Cognitive	76.1 (11.1)	71.1 (10.4)	2.87*
Hyperactivity	65.7 (8.2)	62.3 (7.5)	3.60**
ADHD	69.9 (7.7)	64.9 (7.8)	4.98**
Teacher Scale	**Baseline**	**Follow-up**	***t*(64)**
Oppositional	67.3 (10.9)	60.9 (11.5)	5.24**
Cognitive	77.4 (14.0)	67.7 (13.2)	4.68**
Hyperactivity	66.5 (8.1)	59.8 (9.6)	7.53**
ADHD	66.4 (7.8)	60.1 (8.6)	7.62**

* $p < 0.01$, ** $p < 0.001$

The behavioural problems experienced by the children at baseline, and at follow-up, as measured by both the parents' Conners' rating scale, and the teachers' Conners' rating scales, are shown in Table 3.2. As can be seen from inspection of the parents' ratings, the child behaviour problems reduced across all four domains at follow-up, when compared to baseline. All of these change scores were statistically significant. This decrease over time was also true of the teachers' ratings of the child behaviour problems. Again, all of these change scores were statistically significant.

When the parents' ratings of the child behaviour problems at baseline were correlated with the teachers' ratings of the child behaviour problems at baseline, there were no statistically significant correlations: Oppositional Behavior, $r = -0.004$; Cognitive Problems, $r = -0.061$; Hyperactivity, $r = 0.174$; ADHD, $r = 0.201$, all $ps > 0.10$. This lack of statistically significant correlation at baseline was also noted, to a large degree, when the parents' and teachers' follow-up ratings of child behaviour problems were correlated: Oppositional Behavior, $r = 0.219$; Cognitive Problems, $r = 0.057$; and ADHD, $r = 0.136$, all $ps > 0.10$, apart from Hyperactivity, $r = 0.311, p < 0.01$, which was statistically significant.

There could be many reasons for this dichotomy of results in the ratings of child behaviour problems made by parents and teachers. Obviously, the children can behave quite differently in distinct contexts and surroundings, and their behaviour problems could vary greatly between the home environment and that of the school/intervention setting/context. Teachers may also place more structure upon the child, which can have a major influence on the child behaviours. It must be remembered that teachers are observing the children in relation to other children, whereas, the parents may often be focusing on that child and the ASC only. Even if siblings are involved, their experience is limited to those children, not a wider range of children with ASC and the behaviour problems that go with it. It may well be that the parents have different expectations regarding their children's behaviours from the teachers' expectations of those same children's behaviours. Additionally, the parents may well have a greater degree of 'personal investment' in their children's behaviour, compared to the teachers, and may rate their children's behaviour problems differently as a consequence. Whatever the explanation, while it is clear that the parents and teachers rate these child behaviour problems differently from one another, they both agree that the child behaviour problems are decreasing over time for this sample as a whole.

Table 3.3: Semi-partial correlations between autistic severity (GARS), intellectual functioning (BAS), adaptive behavioural functioning (VABS), and the four scales from the parent (top panel) and teacher (bottom panel) ratings of child behaviour problems (Conners'), and parenting stress (QRS) at baseline, and at follow-up, in Study 1.

Parent	Baseline	Follow-up
ASC (GARS)	0.330*	0.060
Intellectual (BAS)	- 0.026	- 0.027
Adaptive Behaviour (VABS)	0.132	0.054
Oppositional	0.166	0.304*
Cognitive	0.196	- 0.162
Hyperactivity	0.189	- 0.014
ADHD	- 0.200	0.237
Teacher	**Baseline**	**Follow-up**
ASC (GARS)	0.312*	0.126
Intellectual (BAS)	0.024	- 0.141
Adaptive Behaviour (VABS)	0.106	0.085
Oppositional	0.057	- 0.071
Cognitive	- 0.025	- 0.085
Hyperactivity	0.039	- 0.180
ADHD	- 0.043	0.236

* $p < 0.01$

The relationship between each of the child behaviour problems (as rated by the parents' Conners' scales) and parenting stress (the total QRS score) at baseline, and at follow-up, were calculated. As was the relationship between autistic severity (total GARS score), intellectual functioning (General Cognitive Ability score from the BAS), and adaptive behaviour (VABS Composite score), and parenting stress. Each of these relationships was assessed by semi-partial correlations between the target (child behaviour problems, autistic severity, intellectual functioning, and adaptive behaviour) and parenting stress, while controlling for the influence of the other variables. Semi-partial correlations were performed in preference to examining the standardised beta coefficients from a multiple regression, as the predictor variables were correlated with one another (see Table 3.1), and, in these circumstances, standardised beta coefficients are not an appropriate estimate of the individual contribution of predictor variables (Darlington, 1990; Howell, 1997).

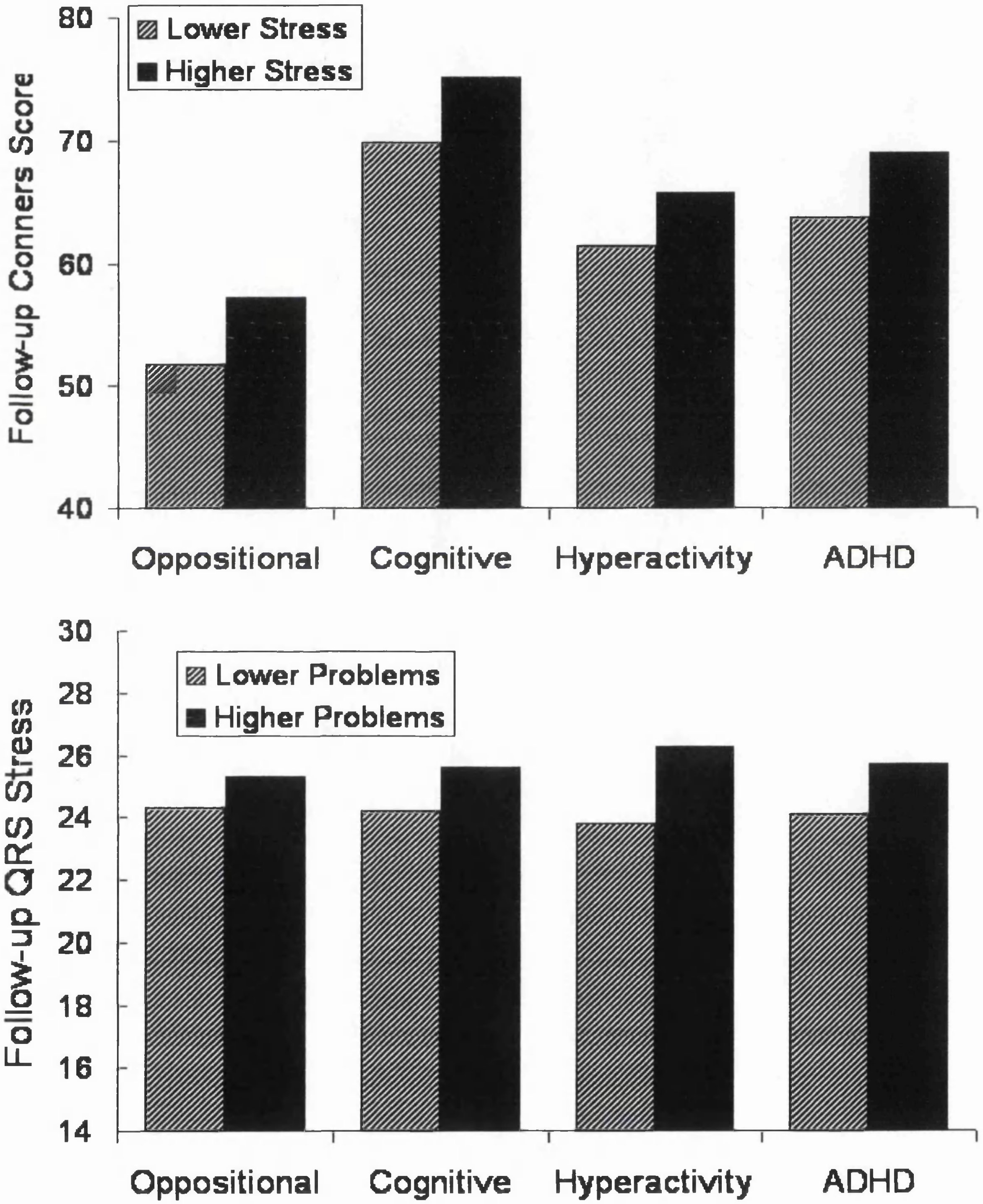
For the baseline measures, only the semi-partial correlation between autistic severity and parenting stress was independently statistically significant. There were no statistically significant semi-partial correlations between teacher-rated child behaviour problems and parenting stress, with only the relationship between autistic severity and parenting stress being independently significant.

However, at follow-up, the relationship between the parent-rated child behaviour problem of Oppositional Behavior was independently statistically significantly related to parenting stress (with autistic severity now not predicting parenting stress). Autistic severity was no longer an independent predictor of parenting stress in the context of the teachers' ratings of child behaviour problems.

These results replicate both sets of previous findings regarding the relationship between autistic severity, child behaviour problems, and parenting stress. At baseline, when the child was younger (and closer to the 'parental trauma' of diagnosis), autistic severity is the best predictor of parenting stress (see also Eisenhower *et al.*, 2005). However, at follow-up, when the child is somewhat older, parent-rated child behaviour problems are the best predictors of parenting stress (see also Donenberg & Baker, 1993; Dumas *et al.*, 1991; Floyd & Gallagher, 1997), when other factors, such as the child's autistic severity, and intellectual ability, are removed as potential influences.

The relationships between the parent-rated, and teacher-rated, child behaviour problems and parenting stress were quite different from one another (see also Lecavalier *et al.*, 2006). There are some plausible explanations for this effect. For instance, parents possibly could use both the Conners' questionnaire and the QRS to tap into the same, or similar, psychological and emotional resources, and so they are answering the two questionnaires in the same, or a similar, way. It would not be surprising, therefore, that high child behaviour problems would go very closely with high parenting stress. On the other hand, the teachers' answers cannot be related to parenting stress, as that is not generally known to them, and so they could be more objective regarding the child behaviour problems, and less connected to the parenting stress levels, of which they have little, if any, knowledge. However, this possible explanation does not explain why the relationship between parenting stress and child behaviour problems changes over time. Trying to delve into the mechanisms of how these questionnaires are used, and work, is difficult, and is speculative, but what is known is that these questionnaires do offer a high level of reliability and validity for the current purposes.

Figure 3.1: Results from Study 1. Top panel = effects of lower and higher parenting stress at baseline on child behaviour problems at follow-up. Bottom panel = effects of lower and higher child behaviour problems at baseline on parenting stress at follow-up.



To gain an indication of the possible temporal precedence between parenting stress and child behaviour problems, the sample was split into lower parenting stress (n = 45, mean QRS = 24.9 ± 4.9), and higher parenting stress (n = 20, mean QRS = 35.8 ± 3.7) groups at baseline, using a split at the mean QRS value. The parent-rated child behaviour problems at follow-up for the two groups are shown in the top panel of Figure 3.1. The impact of the two parenting stress groups on each of the parent-rated child behaviour problems was analysed using analyses of covariance (ANCOVAs) with the influence of ASC (GARS), intellectual functioning (BAS), and adaptive functioning (VABS) at baseline as covariates. These analyses revealed statistically significant effects of baseline parenting stress on: Oppositional Behavior, $F(1,60) = 7.53, p < 0.01$; Hyperactivity, $F(1,60) = 4.11, p < 0.05$; and ADHD, $F(1,60) = 4.35, p < 0.05$; but not on Cognitive Problems, $p > 0.10$.

Also, the sample was split into lower and higher parent-rated child behaviour problems at baseline, using a split at the mean for each child behaviour problem area, as measured by the Conners' scale. This produced a lower Oppositional Behavior (n = 41, mean = 51.5 ± 5.5), and a higher Oppositional Behavior (n = 24, mean = 66.3 ± 7.8) group; a lower Cognitive Problems (n = 39, mean = 68.8 ± 7.9), and a higher Cognitive Problems (n = 26, mean = 87 ± 3.5) group; a lower Hyperactivity (n = 41, mean = 61.1 ± 5.7), and a higher Hyperactivity (n = 24, mean = 73.6 ± 5.2) group; and a lower ADHD (n = 36, mean = 64.7 ± 5.2), and a higher ADHD (n = 29, mean = 76.4 ± 4.7) group. The effect of these groups on parenting stress at follow-up is shown in the bottom panel of Figure 3.1, and was analysed by ANCOVAs, with autistic severity (GARS), intellectual functioning (BAS), and adaptive behaviour (VABS) at baseline as covariates. There was no statistically significant effect of child behaviour problems at baseline on parenting stress at follow-up for any of the child behaviour problems, all *p*s > 0.10. These data corroborate findings reported in previous studies (e.g., Robbins *et al.*, 1991; see also Chapter 2) that show that initial parenting stress is negatively related to later child outcomes at follow-up.

In summary, these data show that there is a relationship between parenting stress and child behaviour problems, as has been found in many previous investigations. This relationship still holds even when the influence of other factors, such as the child's autistic severity, intellectual ability, and adaptive behavioural functioning are controlled for. However, this relationship appears to be confined to those child behaviour problems identified by the parent (perhaps in the home setting), and are not found when teachers' ratings of child behaviour problems are employed. Moreover, this relationship holds only as the child becomes older, and, when the child is younger, autistic severity appears to be more strongly related to parenting stress. The temporal directionality of the relationship between parenting stress and child behaviour problems appears to be from the baseline parenting stress to the subsequent child behaviour problems at follow-up, rather than *vice versa*, although this would require further evidential corroboration.

Study 2

In Study 1, the strongest predictor of parenting stress was found to change over time. At the start of Study 1, when the children were younger, autistic severity was associated with parenting stress most strongly, but, after nine to ten months, it was the child behaviour problems that were most strongly related to parenting stress. This result may help to resolve some discrepant findings in the literature. While most findings show a relationship between parenting stress and child behaviour problems (e.g., Dumas *et al.*, 1991; Lecavalier *et al.*, 2006), a few have noted a strong relationship between autistic severity and parenting stress (e.g., Eisenhower *et al.*, 2005; Hastings & Johnson, 2001). Study 1 offered a suggestion as to how to resolve this difference.

Study 2 employed a group of children with ASC who have a wider age range to those participating in Study 1, so as to allow previous studies that have examined the relationship between parenting stress and child behaviour problems to be replicated. Such studies have found that child behaviour problems, and not autistic severity, are most strongly associated with parenting stress (e.g., Dumas *et al.*, 1991; Lecavalier *et al.*, 2006).

Moreover, in Study 1, parenting stress appeared to predict later child behaviour problems, but not *vice versa*. This last finding corroborates the results from several studies that have noted such a relationship between parenting stress and child outcomes (e.g., Robbins *et al.*, 1991; Chapter 2), but that has not previously been reported in relation to child behaviour problems. Given this, it would be sensible to try to replicate these findings in a much more general population of children with ASC, with a wider range of ages, and also using a wider range of questionnaire measures, to ensure that the results are not purely specific to one sample of children with ASC, using just one particular set of questionnaire measures.

Method

Participants

A total of 83 children with ASC (75 male and 8 female) were identified in conjunction with Local Education Authorities in the South East of England. All of the parents of these children were contacted, and the parents of 72 children (70 male and 2 female) agreed to participate in this study (86%). Participants were selected on the basis of three criteria, the children had to be: 5:0 to 16:0 years old (mean = 8:8), undergoing a teaching/educational intervention, and independently diagnosed with ASC by specialist Paediatricians, as described in Study 1 of this chapter, with a statement of Special Educational Needs related to their ASC from their Local Education Authorities.

These independent diagnoses were supported in the present study by the use of the GARS, which allowed further independent assessment of the degree of their autistic severity. The GARS measure showed that the mean (standard deviation) of the overall GARS score for this sample was 89.0 (± 16.2), indicating that this sample was of a slightly milder than average autistic severity. The scores for the four sub-scales of the GARS, each representing a different aspect of the disorder, showed a similar pattern, in that all of these scores were slightly milder than the average. The mean sub-scale scores were: Stereotyped Behaviors = 8.1 (± 2.9); Communication Problems = 8.3 (± 3.2); Social Interaction Problems = 8.1 (± 3.2); and Developmental Disturbances = 8.6 (± 3.0).

Measures

The Gilliam Autism Rating Scale (GARS), British Abilities Scale (BAS; School Age Battery), Vineland Adaptive Behavior Scale (VABS), and Questionnaire on Resources and Stress (QRS), as described in Study 1 of this chapter, were employed in Study 2. In addition, a second measure of parenting stress (the Parenting Stress Index), and two measures of child behaviour problems (the Developmental Behaviour Checklist, and the Strengths and Difficulties Questionnaire), were employed to increase the generality of the measures and findings.

Developmental Behaviour Checklist: The extent of problem behaviours exhibited by each of the children was measured using the Parent Report version of the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1995). This rating questionnaire contains 96 individual items, which were derived from case files of children and adolescents with developmental disabilities. It is a behaviour-rating questionnaire developed upon, and standardised for, populations of children and adolescents with intellectual disabilities, and it has excellent psychometric properties; internal reliability = 0.94 (Einfeld & Tonge, 1995). The DBC gives a Total Problem Behaviour Score (with a score of 46, or greater, on this scale representing a clinically significant problem). There are also sub-scales for Disruptive/Antisocial Behaviour (score range 0 – 54), Self-Absorbed Problem Behaviours (score range 0 – 62), Communication Disturbance (score range 0 – 26), Anxiety (score range 0 – 18), and Social Relating Problems (score range 0 – 20). This scale has been used extensively for young people with ASC (e.g., Hastings *et al.*, 2001).

***Strengths and Difficulties Questionnaire*:** The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) is a brief behavioural screening questionnaire concerning 3 to 16 year olds. It exists in several versions to meet the needs of researchers, clinicians, and educationalists. The parent version includes 25 items, divided between 5 scales, all score ranges 0 to 10: emotional symptoms (norm = 1.9), conduct problems (norm = 1.6), hyperactivity/inattention (norm = 3.5), peer relationship problems (norm = 1.5), and pro-social behaviour. The first four sub-scales, when added together, generate a Total Difficulties Score (norm = 8.4; score range 0 – 40). The questionnaire correlates highly with the Rutter Child Questionnaires (Goodman, 1997).

Parenting Stress Inventory: The PSI (Abidin, 1995) is a 120-item parent report that measures stress in the parent in two major domains: child and parent characteristics. The child sub-scales are: adaptability, acceptability, demandingness, mood, distractibility/hyperactivity, and reinforcement of parent. The parent sub-scales are: depression, attachment, restriction of role, sense of competence, social isolation, spouse/partner relationship, and parent health. The sub-scales are combined into a Total Stress Score, as an overall indicator of parent-child relationship stress, and there is also a 19-item Life Stress scale. The internal reliability of the Total Stress Score is 0.95, and it has been used extensively in research into parenting stress.

Procedure

The same tests were administered at baseline, and then again, at follow-up, for all of the children, after a nine to ten month period. Intellectual functioning (BAS), and adaptive behavioural and social functioning (VABS), were measured. In addition, measures of child behaviour problems (DBC and SDQ), and family functioning were taken, concentrating on self-reported parenting stress (QRS-F; PSI). When identified, the children were visited by an Educational Psychologist, and the baseline child measures were taken (GARS, BAS, and VABS). Parents were contacted, and asked to complete the DBC and SDQ questionnaires about their child's behaviours, and the QRS and PSI questionnaires about their own stress. After about nine to ten months, the follow-up child measures were taken by the same Educational Psychologist. All parents were asked to complete the questionnaires concerning their child's behaviour problems (DBC and SDQ), and another QRS, and PSI, questionnaire about their own stress.

Results and Discussion

Measures of parenting stress, using the total QRS score, were taken at baseline, which revealed a mean total QRS score of 24.4 (± 9.3), and at follow-up, which revealed that the mean total QRS stress had fallen to 21.3 (± 7.5). A paired t-test conducted on these data revealed that this fall was statistically significant, $t(71) = 3.58, p < 0.001$. Measures of parenting stress using the total PSI were 290.6 (± 40.0) at baseline, and 275.6 (± 33.8) at follow-up, $t(71) = 3.68, p < 0.001$. All parents were over the 90th percentile in terms of parenting stress according to the PSI. However, Life Stress was only 8.9 (± 7.0) at baseline, and 8.9 (± 5.7) at follow-up, $t < 1$. These scores are lower than the 10th percentile, indicating that stress about events, other than parenting, was relatively low in this sample. The autistic severity of the children, as measured by the total GARS score, was 89.0 (± 16.2) at baseline, and 88.5 (± 16.3) at follow-up, which was not a statistically significant change, $t < 1$. The children's intellectual functioning, as measured by the General Cognitive Ability score from the BAS, rose from 62.5 (± 16.7) at baseline, to 72.5 (± 16.7) at follow-up, a statistically significant increase, $t(71) = 3.97$, $p < 0.001$. The children's adaptive behavioural functioning, as measured by the VABS Composite score, rose from 54.9 (± 17.2) at baseline, to 82.9 (± 19.8) at follow-up, $t(71) = 10.12$, $p < 0.001$. The correlations between all of these variables at baseline, and at follow-up, can be seen in Table 3.4.

Table 3.4: Pearson's correlations between autistic severity (GARS), intellectual functioning (BAS), adaptive behavioural functioning (VABS), and parenting stress (QRS and PSI) at baseline (top panel), and at follow-up (bottom panel), in Study 2.

Baseline	GARS	BAS	VABS	QRS
PSI	0.525**	- 0.240	- 0.018	0.727**
QRS	0.528**	- 0.196	- 0.151	-
VABS	- 0.087	0.173	-	-
BAS	- 0.086	-	-	-
Follow-up	**GARS**	**BAS**	**VABS**	**QRS**
PSI	0.257	- 0.059	- 0.264	0.788**
QRS	0.390**	- 0.209	- 0.453**	-
VABS	- 0.374**	0.271*	-	-
BAS	- 0.086	-	-	-

* $p < 0.01$, ** $p < 0.001$

Table 3.5: Mean (and standard deviation) child behaviour problems at baseline, and at follow-up, as measured by the Developmental Behaviour Checklist (DBC; top panel), and by the Strengths and Difficulties Questionnaire (SDQ; bottom panel), in Study 2.

DBC	Baseline	Follow-up	*t*(71)
Total	65.6 (25.5)	58.1 (20.4)	3.21*
Disruptive	19.0 (9.6)	16.4 (7.9)	3.39**
Self-Absorbed	19.6 (9.4)	17.3 (8.5)	3.24*
Communication	9.8 (5.0)	9.4 (4.1)	1.09
Anxiety	7.2 (3.5)	5.9 (2.3)	3.51**
Social Relating	6.5 (3.0)	5.3 (2.3)	3.21*
SDQ	**Baseline**	**Follow-up**	***t*(71)**
Total	19.9 (6.1)	18.2 (4.6)	3.35**
Conduct	2.8 (1.9)	2.7 (1.6)	< 1
Emotion	4.0 (2.6)	3.8 (1.9)	< 1
Hyperactivity	7.2 (1.8)	6.8 (1.8)	2.38*
Peer Problems	5.6 (2.2)	4.8 (1.9)	4.18**

* $p < 0.01$, ** $p < 0.001$

The child behavioural problems at baseline, and at follow-up, as measured by both the DBC, and the SDQ, are shown in Table 3.5. As can be seen from inspection of these data, parents rated their children as displaying high levels of behaviour problems on both scales at baseline. These child behaviour problems reduced across nearly all of the measured domains at follow-up, when compared to baseline, but remained well above norms for these scales. The total scores from both scales correlated highly with one another at baseline, $r = 0.696, p < 0.001$, and also at follow-up, $r = 0.681, p < 0.001$.

Table 3.6: Semi-partial correlations between autistic severity (GARS), intellectual functioning (BAS), adaptive behavioural functioning (VABS), and the sub-scales from the Developmental Behaviour Checklist (DBC), with parenting stress (QRS top panel, and PSI bottom panel) at baseline, and at follow-up, in Study 2.

QRS	Baseline	Follow-up
ASC (GARS)	0.133	0.093
Intellectual (BAS)	- 0.153	- 0.087
Adaptive Behaviour (VABS)	0.053	- 0.180
Behaviour (Total DBC)	0.222*	0.621**
ASC (GARS)	0.216	0.102
Intellectual (BAS)	- 0.126	- 0.094
Adaptive Behaviour (VABS)	0.056	- 0.073
Disruptive	0.426**	0.097
Self-Absorbed	- 0.096	0.367**
Communication	- 0.055	- 0.130
Anxiety	- 0.250	0.083
Social Relating	0.281	0.137

PSI	Baseline	Follow-up
ASC (GARS)	- 0.117	0.096
Intellectual (BAS)	- 0.150	- 0.102
Adaptive Behaviour (VABS)	0.120	- 0.150
Behaviour (Total DBC)	0.539**	0.500**
ASC (GARS)	0.075	0.090
Intellectual (BAS)	- 0.070	- 0.154
Adaptive Behaviour (VABS)	0.099	- 0.225
Disruptive	0.566**	0.404**
Self-Absorbed	- 0.078	0.105
Communication	0.060	- 0.283*
Anxiety	- 0.168	0.057
Social Relating	0.168	0.216

* $p < 0.01$, ** $p < 0.001$

The semi-partial correlations between parenting stress (as measured by the total QRS score, and the total PSI score), and each of the child behaviour problems (as rated by the DBC), autistic severity (GARS total score), intellectual functioning (BAS General

Cognitive Ability score), and adaptive behaviour (VABS Composite score), at baseline, are shown in Table 3.6. For both of these parent-stress measures, the semi-partial correlations between parenting stress and the total child behaviour problems from the DBC scale were independently statistically significant. In terms of the sub-scales, there was a statistically significant contribution of Disruptive Behavior. There were no statistically significant semi-partial correlations between parenting stress and autistic severity.

The semi-partial correlations between parenting stress (as measured by the total QRS and PSI scores), and each of the child behaviour problems (as rated by the DBC), autistic severity (GARS total score), intellectual functioning (BAS General Cognitive Ability score), and adaptive behaviour (VABS Composite score), at follow-up, are also shown in Table 3.6. The semi-partial correlations between parenting stress and the total child behaviour problems from the DBC scale were independently statistically significant for both parent-stress scales. In terms of the sub-scales, there was a statistically significant contribution of Disruptive Behavior (PSI), and Self-Absorbed Behavior (QRS), as well as Communication Problems for the PSI. There were no statistically significant semi-partial correlations between parenting stress and autistic severity.

The pattern of semi-partial correlations was broadly similar for the SDQ measure of child behaviour problems. At baseline (Table 3.7), there was an independent effect of total child behaviour problems (PSI), and a contribution from Conduct Problems (QRS and PSI), to parenting stress (however, the relationship between autistic severity and parenting stress was statistically significant also for the SDQ measure). At follow-up, there were independent effects of total child behaviour problems on parenting stress, as well as contributions from most sub-scales, but not from Conduct for the QRS, and not from Peer Problems for the QRS and PSI. Autistic severity was not statistically significantly related to parenting stress at follow-up.

Table 3.7: Semi-partial correlations between autistic severity (GARS), intellectual functioning (BAS), adaptive behavioural functioning (VABS), and the sub-scales from the Strengths and Difficulties Questionnaire (SDQ), with parenting stress (QRS top panel, and PSI bottom panel) at baseline, and at follow-up, in Study 2.

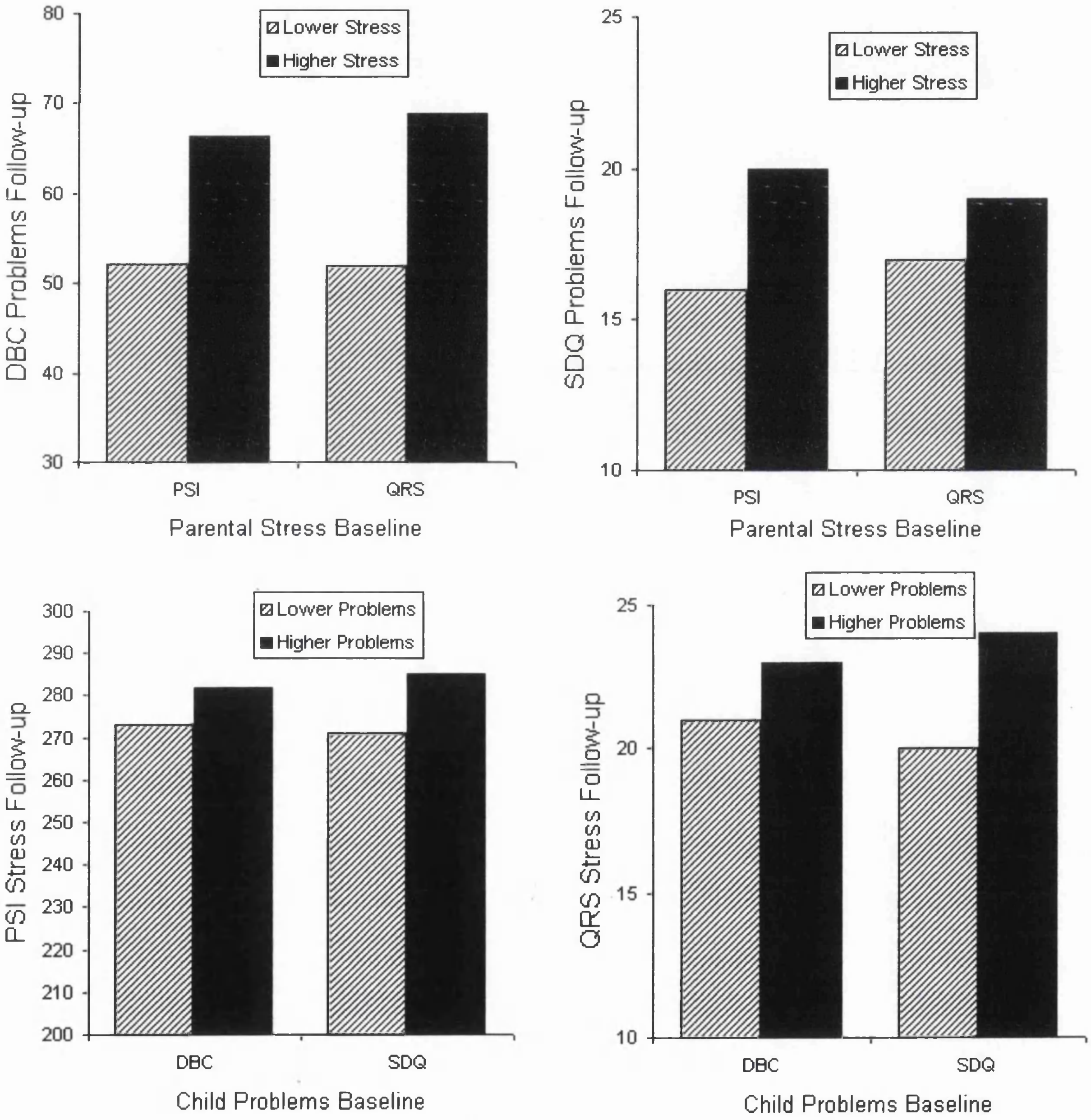
QRS	Baseline	Follow-up
ASC (GARS)	0.268*	0.180
Intellectual (BAS)	0.135	- 0.073
Adaptive Behaviour (VABS)	0.034	- 0.261
Behaviour (Total SDQ)	0.177	0.520**
ASC (GARS)	0.392**	- 0.085
Intellectual (BAS)	- 0.262	0.128
Adaptive Behaviour (VABS)	0.011	- 0.195
Conduct	0.447**	0.079
Emotion	0.075	0.262*
Hyperactivity	- 0.236	0.347**
Peer Problems	- 0.004	0.059
PSI	**Baseline**	**Follow-up**
ASC (GARS)	0.096	0.160
Intellectual (BAS)	- 0.060	- 0.126
Adaptive Behaviour (VABS)	0.082	- 0.224
Behaviour (Total SDQ)	0.483**	0.563**
ASC (GARS)	0.275*	0.117
Intellectual (BAS)	- 0.112	- 0.097
Adaptive Behaviour (VABS)	0.005	0.137
Conduct	0.548**	0.308**
Emotion	0.268*	0.231*
Hyperactivity	- 0.133	0.236*
Peer Problems	- 0.054	0.069

* $p < 0.01$, ** $p < 0.001$

In summary, these results show that there was a strong relationship between child behaviour problems and parenting stress in this sample of older children. This was especially pronounced for externalising and disruptive-type child behaviour problems, irrespective of the type of scale used to measure these behavioural factors. When using the SDQ, with the exception of autistic severity and parenting stress, measured by the QRS, and to a lesser extent by the PSI, at baseline, there was no strong relationship between autistic severity and parenting stress in this sample. Therefore, this study replicates, and corroborates, those previous reports that have established a relationship between child behaviour problems and parenting stress, when a sample of children of a wider age range is studied (e.g., Dumas *et al.*, 1991; Lecavalier *et al.*, 2006). This suggests that the findings from Study 1 (and a minority of other reports; e.g., Eisenhower *et al.*, 2005) may be restricted to a sample of younger aged children.

To gain an indication of the possible temporal precedence between parenting stress and child behaviour problems, the sample was split into lower and higher parenting stress groups, based on the total QRS score (lower stress, $n = 46$, mean QRS = 18.8 ± 5.4; higher stress, $n = 26$, mean QRS = 34.2 ± 5.7), and lower and higher parenting stress groups, based on the total PSI score (lower stress, $n = 42$, mean PSI = 265.3 ± 25.3; higher stress, $n = 30$, mean PSI = 325.9 ± 28.3), at baseline, using a split at the mean in both cases. The parent-rated child behaviour problems at follow-up, for both the DBC and SDQ total child behaviour problems scales, for the two parenting stress groups, are shown in the top panel of Figure 3.2. The impact of the two parenting stress groups on each of the parent-rated child behaviour problems at follow-up was analysed using an analysis of covariance (ANCOVA), with autism (GARS), intellectual functioning (BAS), and adaptive functioning (VABS) as covariates.

Figure 3.2: Results from Study 2. Top panels = effects of lower and higher parenting stress at baseline on child behaviour problems at follow-up. Bottom panels = effects of lower and higher child behaviour problems at baseline on parenting stress at follow-up.



There were statistically significant effects for the PSI baseline parenting stress on the DBC follow-up child behaviour problems, $F(1,67) = 3.14, p < 0.05$; the PSI baseline parenting stress on the SDQ follow-up child behaviour problems, $F(1,67) = 5.03, p < 0.05$; and the QRS baseline parenting stress on the DBC follow-up child behaviour problems, $F(1,67) = 3.78, p < 0.05$; but not for the QRS baseline parenting stress on the SDQ follow-up child behaviour problems, $F < 1$.

The sample was also split into lower and higher parent-rated child behaviour problems at baseline, for both the total DBC score (lower behaviour problems, $n = 51$, mean DBC = 52.7 ± 13.6; higher behaviour problems, $n = 21$, mean DBC = 97.0 ± 19.8), and the total SDQ score (lower behaviour problems, $n = 51$, mean SDQ = 16.9 ± 3.8; higher behaviour problems, $n = 21$, mean SDQ = 27.4 ± 3.3), using a split at the mean for each scale. The effect of these groups on parenting stress at follow-up is shown in the bottom panel of Figure 3.2, and was analysed by ANCOVAs, with autistic severity (GARS), intellectual functioning (BAS), and adaptive behaviour (VABS) at baseline as covariates. There were no statistically significant effects of child behaviour problems at baseline on parenting stress at follow-up, ps > 0.05.

These data corroborate what was apparent in Study 1 of this chapter, that the temporal directionality of this relationship appears to be from parenting stress at baseline to the child behaviour problems at follow-up. This relationship pattern was observed in the current sample, which had a much wider range of child ages than in Study 1, and which employed a wider range of measurement tools than Study 1. The fact that similar findings were noted, suggests that this dynamic is supported, and is one of some generality.

General Discussion

The two studies reported in this chapter examined the relationship of parenting stress to behaviour problems in children with ASC using longitudinal designs. The main questions under examination were whether parenting stress is most strongly associated with child behaviour problems, or with the severity of the ASC (about which there was some debate in the literature), and to establish the temporal directionality of this effect. The findings to emerge were that parenting stress is largely associated with child behaviour problems, rather than with the severity of the ASC, except in younger children where the reverse is the case. Also, it appears that parenting stress is a much stronger predictor of future child behaviour problems, than child behaviour problems are of higher levels of parenting stress later.

In terms of the relationship between parenting stress, child behaviour problems, and ASC severity, the current findings indicate that, for the most part, parenting stress is related to the severity of the child behaviour problems, over and above the impact of the severity of the ASC. In this, the current findings replicate much of the previous literature (e.g., Dumas *et al.*, 1991; Lecavalier *et al.*, 2006). However, in Study 1 of this chapter, it was found that earlier on in the relationship, the severity of the ASC, rather than the severity of the child behaviour problems, was associated most strongly to parenting stress. This latter finding has been noted by some researchers in previous studies (e.g., Eisenhower *et al.*, 2005; Hastings & Johnson, 2001). The current findings suggest that this apparent discrepancy may well be the result of children with ASC being studied at different stages in their development. Examination of the literature, in so far as this is possible, does indicate that, when younger children are involved, parenting stress is more related to the ASC severity (e.g., Eisenhower *et al*., 2005), but, as the children become older, parenting stress appears to be more related to the child behaviour problems. However, such cross-study comparison is difficult, not least, because the full age ranges of the children participating are sometimes not provided. The present two studies demonstrated this evolution within this one chapter, and may help to resolve some of the discrepancies in the literature on this topic.

It is possible that the reason for this change in the factors most strongly associated with stress in the parents is concerned with the impact of diagnosis on the parents, which tends to occur (although, not always) in younger, rather than older children. It is clear that diagnosis is a very traumatic event and experience for parents (see Chapter 6), and, in the immediate aftermath, it would be very surprising if this, and the associated focus on the child's ASC, were not critical factors in promoting high parenting stress levels. Obviously, many parents are fully aware of problems prior to the diagnosis, and there may well be a build-up of stress, which may peak at the point of diagnosis. From this point in time, the ASC may well be the focus of the parents, until the child behaviour problems start to take over as more of a focal point for the parents.

From the current data, it is not necessarily the severity of the child behaviour problems that grows over time (in fact, the severity is shown to reduce over time in both of the studies in this chapter). It may well be that the relative parental perception of the importance of the child behaviour problems, versus the severity of the ASC, or the accumulation of dealing with child behaviour problems over a prolonged period of time, all help to cause these child behaviour problems to become strongly associated with parenting stress when the child becomes older. It must be remembered that these measures are based on self-reports of parental perceptions of stress. So, even when the severity of child behaviour problems decreases over time, the parental accounts of their own stress levels appear to indicate that they are concentrating more on child behaviour problems as a source of their perceived stress, and this could be a cumulative effect.

The two studies reported in this chapter both additionally examined the temporal directionality of the relationship between parenting stress and child behaviour problems. The studies assessed whether one of these factors at baseline had a larger impact on the other at follow-up. It is often assumed that the relationship is from initial child behaviour problems to later parenting stress (e.g., Hastings, 2002). However, such theoretical models are almost entirely based on the results of correlational studies of data collected at one point in time, rather than being based on longitudinal data, such as those collected in this chapter. In fact, most studies in the literature that have examined the impact of parenting stress on subsequent child outcomes (e.g., educational, and adaptive behavioural, functioning) have suggested the opposite relationship, that is, that initial parenting stress has a negative impact on subsequent child outcomes (e.g., Robbins *et al.*, 1991; and see Chapter 2). Both of the current studies, reported here, confirmed that this relationship between initial parenting stress also holds for later child behaviour problems. The one other study which has adopted such a longitudinal approach (Lecavalier *et al.*, 2006) also found a relationship between initial parenting stress and subsequent child behaviour problems. However, this latter study also noted the converse relationship as well, a finding that was not found in this current chapter. Whether the relationship between child behaviour problems and subsequent parenting stress is confirmed, it is clear that there is ample evidence to suggest that initial parenting stress has an impact on subsequent child behaviour problems.

The reasons why initial parenting stress has a negative impact on later child behaviour problems, and child outcomes, can only be speculated on, at this point. There are, however, several possibilities that are worth some mention here, and certainly deserve some future investigation. On a purely speculative basis, it could be that children with ASC are sensitive to their parents' levels of emotional stress. Perhaps the presence of emotions, such as stress and anxiety, can be sensed by children with ASC, even if they are not fully able to identify those emotional states (Hobson, Ouston, & Lee, 1989). In fact, some people with ASC can be described as 'over-sensitive' to emotional disturbance (Grandin, 1990), and this sensitivity may upset their psychological and emotional equilibrium, and subsequently may affect their behaviours and outcomes.

It could be argued that the parents of children with ASC tend to be more reactive, both in their responses to stressors, and in their parenting styles, which would lead to both high levels of parenting stress and to high resultant levels of child behaviour problems. However, this is unlikely, as there is very little evidence for this claim, and there is much research that shows no difference in the personalities of parents with children with ASC, compared to other sets of parents (e.g., Koegel, Schreibman, O'Neill, & Burke, 1983). Moreover, the current findings showed that levels of general life stress were low in this group of parents. Thus, the only obvious factor that sets this group of parents apart is their extremely high levels of parenting stress (perhaps triggered by the diagnosis of ASC, and a cumulative effect of long-term parenting of a child with ASC).

Possibly the most likely suggestion is that the high levels of parenting stress trigger changes in the parents' ability to patiently accommodate and respond to their children's behaviour problems. McAdoo and DeMyer (1977) made the point that the continual stress of parenting a child with ASC may lead to changes in the personalities of such parents, and, if this is the case, these changes could have an effect on their parenting behaviours. Holroyd and McArthur (1976) found more family integration problems reported by mothers of children with ASC, relative to mothers of children with Down's Syndrome. Certainly, Tienari, Sorri, Lahti, Naarala, Wahlberg, Ronkko, Moring, and Pohjola (1987) found that family interactional styles can have a predisposing influence to, and precipitate, somatic illness, as well as affecting illness outcome. It may be the case that parenting stress impacts on the children's behaviours, which, in turn, feeds back into parenting stress, setting up a cyclical interaction over time. The current chapter found evidence of such an interaction, in that later, as opposed to earlier, child behaviour problems were reported as being strongly associated with parenting stress, and there is some evidence from other sources that this might be the case (e.g., Lecavalier *et al.*, 2006) This is clearly an area that requires further study within the present context.

In summary, the current chapter has allowed, and provided, some resolution of previously discrepant findings regarding the factors associated with parenting stress. It was noted that the severity of ASC is more strongly associated with parenting stress in parents of very young children (i.e. those below 4 years of age), but that child behaviour problems are more strongly correlated with parenting stress in parents of older children (i.e. those above 4 years of age). Additionally, it shows that parenting stress can negatively impact on later child behaviour problems.

Chapter 4:

Parenting Stress and Parenting Behaviours in Parents of Children with Autistic Spectrum Conditions

Introduction

In Chapters 2 and 3, it has been illustrated that parenting stress impacts on child outcomes, and on child behaviour problems, respectively. The reasons why initial high parenting stress levels predict worse intervention child outcomes, and have a negative impact on subsequent child behaviour problems, are currently unclear. One tentative suggestion is that the high levels of parenting stress trigger changes in the parents' abilities to patiently accommodate and respond to their children's behaviour problems. McAdoo and DeMyer (1977) made the point that the continual stress of parenting a child with Autistic Spectrum Conditions (ASC) may lead to changes in the personalities of such parents, and, if this is the case, these changes could have an effect on their parenting behaviours. In keeping with this suggestion, Holroyd and McArthur (1976) found more family integration problems reported by mothers of children with ASC, relative to mothers of children with Down's Syndrome. Likewise, Tienari, Sorri, Lahti, Naarala, Wahlberg, Ronkko, Moring, and Pohjola (1987) found that family interactional styles can have a predisposing influence to, and precipitate, somatic illness, as well as affecting illness outcomes.

As outlined in Chapter 1, there are numerous theoretical models proposed to explain parenting behaviours, which suggest that parenting stress may influence parenting behaviours, which, in turn, will impact on child behaviour problems (e.g., Deater-Deckard, 1998; Hastings, 2002). Levels of parenting stress may have an impact on behaviours of children with learning disabilities, and this has formed the basis of theoretical models of parent-child interactions (Deater-Deckard, 1998; Hastings, 2002; but see Lazarus, 1991, for an alternative stress and coping model). However, over and above the extreme "burden of care" placed on parents of children with ASC (e.g., Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005), little is known about parenting behaviours of parents of children with ASC, let alone whether they are impacted upon by parenting stress.

There is some, but still limited, evidence regarding parenting behaviours *per se*. Rodrigue, Morgan, and Geffken (1990) noted that mothers of children with ASC reported less parenting competence, and less family adaptability, than mothers of children with Down's Syndrome and mothers of children without developmental disability. Powers (2000) suggests that there are three common areas of parenting difficulty for parents of children with ASC. Firstly, the risk of over-involvement, or over-compensation, a suggestion supported by the findings of El-Ghoroury and Romanczyk (1999), who reported that parents initiate more play interactions and behaviours with their children with ASC than with their siblings. Secondly, Powers (2000) warns of the trap of over-protectiveness of the child, or affording too little autonomy for the child, and, thirdly, highlights the risk of parental rejection of, or parental withdrawal from, the child. Nevertheless, there is very little empirical evidence regarding such suggestions, at this point in time, and providing some illumination regarding parenting behaviours in parents of children with ASC is one aim of the current chapter.

There are few, if any, studies of the effects of parenting stress on parenting behaviours of parents of children with ASC. There have been some investigations of the effects of parenting stress on parenting behaviours in the general population. It is worth mentioning, here, that a few of these studies conducted on parents in the general population have used observational strategies, while more appear to have used self-report methods, in order to examine parenting behaviours. However, it is not clear whether the overall findings generated from these two disparate approaches actually differ greatly from one another. Rodgers (1993; 1998), using questionnaires, found that parenting stress directly, and indirectly, affected parenting behaviour in 85 mothers of young children in Head Start or Kindergarten. Likewise, Kotchick, Dorsey, and Heller (2005; see also Meyers & Miller, 2004), in a longitudinal study of 123 low-income, urban-dwelling, single mothers, using self-report questionnaires, found that higher levels of neighbourhood stress had a relationship to greater psychological distress, and detrimental effects on psychological functioning, in the mothers. This subsequently went with less engagement in positive parenting practices, and resulted in poorer parenting over time. In a review of the literature, Webster-Stratton (1990) notes that various stressors seriously disrupted parenting practices, by their influencing some parents to become more irritable, critical, and punitive, and these parenting behaviours, in turn, increased the likelihood that children would develop conduct problems.

However, it should be pointed out that there is a mixed picture presented in this area of research, making more difficult any generalisation from the general population to parents of children with ASC. For example, Greenley, Holmbeck, and Rose (2006), combining the approaches of observational and questionnaire assessments, reported variable effects of parenting stress on parenting behaviours and adaptive parenting in their study of parents of children with, and without, spina bifida. Levers and Drotar (1996), in a review of studies of family and parental functioning in caring for children with cystic fibrosis, noted higher levels of stress in parents of children with cystic fibrosis than compared to those of healthy children in the control groups, but they found that parenting behaviour and family functioning were similar in the two groups. Similarly, Nitz, Ketterlinus, and Brandt (1995) used questionnaires to assess the role of maternal stress, amongst other things, on the parenting behaviour of adolescent mothers of healthy infants. Their findings indicated that parenting stress *per se* did not significantly predict maternal behaviour. Thus, another aim of the current research, over and above documenting parenting behaviours in parents of children with ASC, was to assess the impacts of parenting stress on parenting behaviours. Should parenting stress be shown to impact on parenting behaviours, it may provide evidence regarding the relationship between parenting stress and subsequent child behaviour problems, and offer a potential mechanism by which this relationship operates.

Method

Participants

A total of 149 children with ASC (135 male and 14 female) were identified in conjunction with Local Education Authorities in the South East of England. Participants were identified on the basis of three criteria, the children had to be: 2:6 to 16:0 years old (mean = 6:0 ± 3.8), undergoing a teaching/educational intervention for ASC, and independently diagnosed with ASC by specialist Paediatricians, following initial referral from an independent general medical practitioner. All diagnoses were made prior to participating in, and the commencement of, this study. In addition to these independent diagnoses of ASC, all of these children had a statement of Special Educational Needs related to their ASC from their Local Education Authorities. All of the parents of these 149 children were contacted, and provided parental consent for their participation in the research. Of these 149 parents who initially agreed, and consented, to participate, 138 parents (130 with male children, and 8 with female children) completed the study (92.6%), rendering a very small attrition rate (7.4%).

The independent diagnoses were supported in the present study by the use of the Gilliam Autism Rating Scale (GARS), which allowed further independent assessment of the degree of their autistic severity. The GARS measure showed that the mean (standard deviation) of the overall GARS score for this sample was 90.7 (± 16.4), indicating that this sample was of a slightly milder than average autistic severity (the GARS has a standardised mean for all children with ASC of 100 ± 15 implying 'averagely autistic'; higher scores implying greater severity of ASC, and lower scores implying milder severity of ASC). The scores for the four sub-scales of the GARS, each representing a different aspect of the disorder, showed a similar pattern, in that all of these scores were slightly milder than the average. The sub-scales have a standardised mean of 10 (± 3), representing 'average severity'; higher scores implying greater severity, and lower scores implying less severe symptoms. The mean sub-scale scores were: Stereotyped Behaviors = 8.5 (± 2.8); Communication Problems = 8.9 (± 2.8); Social Interaction Problems = 8.2 (± 3.1); and Developmental Disturbances = 8.9 (± 2.6).

Measures

Gilliam Autism Rating Scale: The GARS (Gilliam, 1995) comprises four sub-scales, each describing behaviours that are symptomatic of ASC (*Stereotyped Behaviors, Communication, Social Interaction,* and *Developmental Disturbances*). The raw scores from these sub-scales can be converted into standard scores (mean = 10, standard deviation = 3). These sub-scales combine to give an overall *Autism Quotient*; higher scores meaning greater autistic severity (mean = 100 [average autistic severity], standard deviation = 15). The scale is appropriate for persons aged 3 to 22 years old, and is completed by parents, or professionals, in about 10 minutes. Its internal reliability is 0.96, and it has high criterion validity with the Autism Behavior Checklist (0.94).

British Abilities Scale: The BAS II (Elliott, Smith, & McCulloch, 1996) is a battery of tests of cognitive abilities, which index educational achievement and intellectual functioning. It is suitable for use with children and adolescents from 2:6 to 17:11 years old. This test allows the calculation of a *General Cognitive Ability* scale (mean = 100, standard deviation = 15), which represents intellectual ability.

Vineland Adaptive Behavior Scale: The VABS (Sparrow, Balla, & Cicchetti, 1990) is a semi-structured interview, administered to a parent, or other caregiver, of the child. It can be used from birth to 18:11 years, making it suitable for the present cohort. The VABS assesses children's day-to-day adaptive functioning. Scores from three domains of adaptive behaviour were used in the present study (*Communication*, *Daily Living Skills,* and *Socialization*). The raw scores can be converted to standard scores, and a *Composite Overall* score can be derived, based on the sum of the sub-scale standard scores (mean = 100; standard deviation = 15). The internal reliability of the *Overall Composite* score is 0.93.

Questionnaire on Resources and Stress: The Friedrich Short-Form of the QRS (Friedrich, Greenberg, & Crnic, 1983) is a 52-item, self-administered, true or false, tool, designed to measure parental perceptions of the impact of a developmentally delayed, or chronically ill, child on other family members. The QRS-F consists of four sub-scales, which assess parental perceptions about: *Parent and Family Problems* – dealing with the impact that the disability has on family activities or relationships; *Pessimism* – related to parent depression; *Child Characteristics* – dealing with the impact of the child's problems on the family; and *Physical Incapacity* – which examines the family problems produced by the child not being able to perform certain activities for themselves. These scores summate to produce a *Total Stress Score* (0-52). Higher scores are indicative of greater perceived stress within the family, as perceived and indicated by the parents (but not, it should be noted, of a greater degree or number of actual stressors, see Dyson, Edgar, & Crnic, 1989).

The internal reliability of the sub-scales ranges from: 0.77 (*Physical Incapacity*) to 0.85 (*Child Characteristics*), with the internal reliability of the *Total Stress Score* being 0.89. This tool has previously been employed for samples with ASC in assessing stress in parents (e.g., Hastings & Johnson, 2001), and so allows comparison with previous studies. The *Total Stress Score* from this scale has been shown to have good reliability and validity for research with parents of children with ASC (Honey, Hastings, & McConachie, 2005).

Parent-Child Relationship Inventory: The PCRI (Gerard, 1994) is a 78-item self-administered tool to assess parents' attitudes towards parenting and their parenting behaviours. The items are selected to measure a wide variety of parenting dispositions and behaviours. All of the items have a Likert-type, 4-point response format: strongly agree, agree, disagree, and strongly disagree. There are seven scales, which each produce a standardised T-score (mean = 50, standard deviation = 10), where high scores reflect positive orientations and "good parenting" behaviours. According to Gerard (1994), T-scores above 40 are indicative of "good parenting" behaviours and skills. Whereas, T-scores of less than 40 indicate problems in the particular domain reflected by that scale, and T-scores less than 30 suggest serious problems in that domain. The seven scales are: *Parental Support*, *Satisfaction with Parenting*, *Involvement*, *Communication*, *Limit Setting*, *Autonomy*, and *Role Orientation*. To check the validity of the protocol, there is a 5-item *Social Desirability* scale, which, if scores are low (9 or less), indicates that the parent responses are unrealistically positive regarding the parent-child relationship.

Due to the fact that the current study was concerned only with parenting behaviours, it seemed inappropriate to examine the *Parental Support*, *Satisfaction with Parenting*, and *Role Orientation* scales. These scales do not deal with parenting behaviours *per se*, but with the parental perceptions of the level of emotional and social support received, the amount of pleasure and fulfilment derived, and their attitudes towards gender roles, respectively. The four remaining scales all dealt with parenting behaviours, and each assessed different aspects of this parenting behaviour. The *Involvement* scale consists of 14 items that examine the parental interaction with, and parental knowledge of, their child (e.g., "*I am very involved with my child's sports or other activities*", "*I spend very little time talking with my child*"). The *Communication* scale contains 9 items that assess the effectiveness of parental communication with their child (e.g., "*My child generally tells me when something is bothering him or her*", "*If I have to say no to my child, I try to explain why*"). The *Limit Setting* scale consists of 12 items that concentrate on parental disciplining of their child (e.g., "*I sometimes give in to my child to avoid a tantrum*", "*I often lose my temper with my child*"). The *Autonomy* scale contains 10 items that evaluate the parental ability to promote independence in their child (e.g., "*I worry a lot about my child getting hurt*", "*I have a hard time letting go of my child*").

The internal reliability (alpha coefficients) of the four scales used ranged from 0.76 (*Involvement*) to 0.88 (*Limit Setting*), and they had a mean test-retest reliability of 0.81. Also, the PCRI has good correlation with other instruments that measure parenting behaviours (see Coffman, Guerin, & Gottfried, 2006; Gerard, 1994). Heinze and Grisso (1996) reviewed the PCRI, amongst other instruments of parenting capacity, and their results lead them to conclude that the PCRI was a useful measure for child custody hearings, in abuse cases, and in divorce mediations. The PCRI has been utilised in various research settings, for instance, in order to assess outcome effectiveness of various interventions, such as the Family Mentoring Program, and has been found to be a useful measure for such purposes (e.g., Barron-McKeagney, Woody, & D'Souza, 2002).

Procedure

The children were identified by the Local Education Authorities, were contacted, and, on choosing to participate, parental consent was received. The same tests were administered at baseline, and then, again, at follow-up, for all children, after a nine to ten month period. Autistic severity (GARS), intellectual functioning (BAS), and adaptive behavioural and social functioning (VABS) were measured. In addition, measures of self-reported parenting stress (QRS-F), and self-reported parenting behaviours (PCRI) were collected.

The children were visited by an Educational Psychologist, who was blind to the levels of parenting stress, and to parenting behaviours, and the baseline child measures were taken (GARS, BAS, and VABS). Parents were contacted, at this time, and asked to complete QRS-F and PCRI questionnaires, and to give some background regarding their child, as well as a brief history of their child's provision, independently. The questionnaires were sent out by post to the parents, along with an information letter, and a pre-paid, addressed return envelope. The information letter provided contact details, offering parents the opportunity to seek help and guidance, if required, regarding the completion of the questionnaires, however, it was extremely rare that any parents made contact in order to ask advice about answering specific questions. On completion, the parents used the pre-paid envelope to return the questionnaires. As an added incentive for returning this information, the parents were automatically entered into a prize draw, the winner of which received £50 for toys or books for their child. This incentive was specified in the information letter. If parents had not returned the questionnaires after a period of time, they were contacted, via telephone, and reminded, and given the opportunity to return the completed questionnaires.

After nine to ten months, the follow-up child measures were taken by the same Educational Psychologist. All parents were asked to complete the QRS-F and PCRI questionnaires again, and to return them by post, as described above.

The scores from these follow-up assessments were compared with those from the baseline assessments in order to ascertain the relationship between the measures of parenting stress and parenting behaviours over the nine to ten month period. On scoring the PCRI questionnaires, two questionnaires were found to have scores on the *Social Desirability* scale that indicated unrealistically positive depictions of their parent-child relationships (one baseline, and one follow-up). These two complete sets of PCRI scores were removed, as the *Social Desirability* scale indicated that they had questionable validity, and they were replaced by mean substitutions, based on the mean of the rest of the sample.

Results

Table 4.1: Mean (standard deviation) scores for child measures, parenting stress, and parenting behaviours, at baseline, and at follow-up.

Baseline	**Overall**	**2-3**	**4-6**	**7-11**	**12+**
N	*138*	*47*	*47*	*25*	*19*
Age	6.0 (3.8)	2.7 (0.5)	4.9 (0.9)	8.6 (1.6)	13.6 (1.3)
GARS	90.7 (16.4)	92.5 (11.9)	89.8 (21.1)	94.5 (13.7)	83.7 (14.4)
BAS	68.6 (20.5)	57.1 (14.4)	63.2 (20.6)	86.3 (11.4)	87.4 (13.7)
VABS	55.5 (12.7)	57.2 (6.8)	56.4 (12.9)	51.2 (12.7)	55.4 (20.8)
QRS-F	26.3 (8.4)	29.2 (5.9)	24.3 (8.8)	26.1 (8.6)	24.2 (10.4)
INV	45.7 (9.0)**	46.6 (8.1)*	44.1 (10.0)**	46.2 (8.7)*	46.5 (8.8)
COM	34.5 (8.9)**	31.5 (7.5)**	34.7 (9.3)**	35.4 (7.6)**	40.2 (9.7)**
LIM	47.9 (6.9)**	48.3 (6.7)	49.0 (7.7)	46.6 (7.0)	46.3 (5.1)**
AUT	49.8 (6.0)	48.7 (6.4)	50.4 (5.9)	50.2 (5.3)	50.1 (6.1)
Follow-up	**Overall**	**2-3**	**4-6**	**7-11**	**12+**
GARS	94.7 (13.3)	95.5 (11.8)	92.5 (16.8)	94.5 (12.5)	93.1 (11.2)
BAS	70.8 (18.9)	65.8 (18.4)	62.5 (20.4)	88.5 (15.2)	87.4 (12.1)
VABS	63.8 (19.9)	58.5 (7.4)	70.0 (21.6)	65.4 (6.6)	67.1 (21.9)
QRS-F	23.1 (8.0)	25.7 (7.8)	22.6 (8.3)	20.1 (5.7)	22.2 (8.9)
INV	44.1 (6.9)**	44.2 (7.2)**	45.1 (7.8)**	42.2 (4.9)**	44.3 (8.5)*
COM	35.7 (7.6)**	31.0 (6.3)**	37.0 (7.5)**	39.2 (6.3)**	39.6 (6.9)**
LIM	48.4 (6.7)*	47.5 (7.5)	49.5 (6.9)	50.1 (4.2)	45.4 (4.6)**
AUT	50.8 (7.3)	50.3 (8.1)	51.5 (7.9)	50.0 (4.8)	51.4 (7.4)

*$p < 0.01$, **$p < 0.001$

Table 4.1 displays the mean scores representing the three child characteristics (i.e. autistic severity, general cognitive ability, and adaptive behavioural functioning), parenting stress levels, and parenting behaviours at baseline, and at follow-up. These data are presented for the sample as a whole, and for four different age groups of children. Inspection of these data at baseline show that, in terms of child characteristics, the overall GARS score was slightly milder than average for children with ASC, and this score did not differ by a great degree across the four age groups, $p > 0.05$. The BAS *General Cognitive Ability* score was much lower than the average for the general population, indicating a high degree of intellectual impairment, but this score was higher in the two older groups of children than in the two younger groups, $F(3,134) = 27.86, p < 0.01$. The VABS *Overall Composite* score was very low for this sample, and it was similar across all groups, $p > 0.05$.

The parenting stress score (QRS-F) was high for the sample, and this score was particularly high in the parents of the children in the youngest age group, but reduced in the parents of the children in the three older age groups. This difference was statistically significant, even when the influences of the three child characteristics were controlled for by an analysis of covariance (ANCOVA), $F(3,131) = 2.71, p < 0.05$.

In terms of parenting behaviours, the *Involvement* score was statistically lower than the general population mean, but it was constant across the four age groups, $F < 1$. The *Communication* score was much lower than the general population mean (a score below 40 indicates problems in a particular parenting behaviour domain, Gerard, 1994), but this score increased across the four age groups, even when controlling for the three child characteristics scores by an ANCOVA, $F(3,131) = 2.76, p < 0.05$. The *Limit*

Setting score was lower than the general population mean overall, but this overall difference was largely due to the parents of the older age group of children having a low score. However, there was no statistically significant difference across the four age groups for this score, $F < 1$. The *Autonomy* score was not different from the general population mean, and it showed no change across the four age groups, $F < 1$.

Correlations between parenting stress and each of the four parenting behaviours at baseline were conducted, and these revealed statistically significant negative relationships between parenting stress and: *Involvement*, $r = - 0.339, p < 0.001$, *Communication*, $r = - 0.406, p < 0.001$, and *Limit Setting*, $r = - 0.469, p < 0.001$, but not with *Autonomy*, $r = - 0.104$.

Inspection of these data at follow-up shows a broadly similar pattern of results to that seen at baseline. There were no statistically significant changes in the child functioning measures (GARS, BAS, VABS) at follow-up, compared to baseline, $ps > 0.05$. Comparing across the different age groups at follow-up, only the BAS *General Cognitive Ability* measure differed statistically significantly, $F(3,134) = 4.78$, $p < 0.05$. Parenting stress remained high at follow-up, and this score was not statistically significantly different from baseline, $p > 0.05$. Parenting stress reduced as the age of the child increased (even when controlling for the three child characteristics by an ANCOVA), $F(3,131) = 2.75, p < 0.05$.

The follow-up parenting behaviours showed a close similarity to their baseline scores. Comparing parenting behaviours at baseline to parenting behaviours at follow-up, there was a striking consistency across these scores. In no case was there a statistical difference between the baseline score and the follow-up score, all $ps > 0.10$. Also, there were strong correlations between the baseline score and the follow-up score for each of the four parenting behaviours: *Involvement*, $r = 0.478, p < 0.001$, *Communication*, $r = 0.579, p < 0.001$, *Limit Setting*, $r = 0.480, p < 0.001$, and *Autonomy*, $r = 0.359, p < 0.001$. At follow-up, *Involvement*, *Communication*, and *Limit Setting* scores were lower than the general population mean (although it should be noted that the *Communication* score was the only one that was particularly low). Parenting behaviours also displayed a similar pattern across the age groups at follow-up, as detailed for the baseline. There were statistically significant increases in the *Communication* score across the ages, even when controlling for the three child characteristics by an ANCOVA, $F(3,131) = 6.75, p < 0.001$, and there was a statistically significant decrease in the *Limit Setting* score across the age groups, $F(3,131) = 2.75, p < 0.05$, even when the three child characteristics were controlled for by an ANCOVA.

At follow-up, there were statistically significant negative correlations between parenting stress and: *Involvement*, $r = - 0.233, p < 0.001$, *Communication*, $r = - 0.418, p < 0.001$, *Limit Setting*, $r = - 0.487, p < 0.001$, and *Autonomy*, $r = - 0.227, p < 0.01$.

Table 4.2 presents the results from a series of semi-partial time-lagged correlations between parenting stress at baseline and parenting behaviours at follow-up, and between parenting behaviours at baseline and parenting stress at follow-up, removing the influences of the three child characteristics at baseline (i.e. autistic severity, general cognitive ability, and adaptive behavioural functioning).

Table 4.2: Semi-partial time-lagged correlations between parenting stress and parenting behaviours, with autistic severity, intellectual functioning, and adaptive behaviour, at baseline, controlled for.

Overall	**Stress to Parenting**	**Parenting to Stress**	**Statistically Stronger Correlation**
INV	- 0.365 **	- 0.225*	Stress to Involvement *
COM	- 0.335 **	- 0.202*	Stress to Communication *
LIM	- 0.459 **	- 0.421**	
AUT	- 0.066	- 0.189	
2 - 3			
INV	- 0.378**	- 0.235	Stress to Involvement *
COM	- 0.321*	- 0.047	Stress to Communication **
LIM	- 0.234	- 0.398**	Limit Setting to Stress *
AUT	- 0.163	- 0.257	
4 - 6			
INV	- 0.154	- 0.124	
COM	- 0.330**	- 0.326**	
LIM	- 0.374**	- 0.350**	
AUT	- 0.084	- 0.208	
7 - 11			
INV	- 0.234	- 0.206	
COM	- 0.384*	- 0.453*	
LIM	- 0.229	- 0.490*	
AUT	- 0.011	- 0.243	
12 +			
INV	- 0.183	- 0.286	
COM	- 0.321*	- 0.332*	
LIM	- 0.497*	- 0.608*	
AUT	- 0.137	- 0.113	

*$p < 0.01$, **$p < 0.001$

Semi-partial correlations were performed, in preference to examining the standardised beta coefficients from a multiple regression, as the predictor variables were correlated with one another, and, in these circumstances, standardised beta coefficients are not an appropriate estimate of the individual contribution of predictor variables (Darlington, 1990; Howell, 1997). Moreover, semi-partial correlations are a more conservative, and cautious, estimate of the relationship than are partial correlations, and are to be preferred for this reason (Tabachnick & Fidell, 1989). These correlations were conducted to establish whether there were any indications of temporal precedence, and directionality, between parenting stress and parenting behaviours.

In terms of the semi-partial time-lagged correlations for the overall sample (for which the age of the child was also removed as an influencing factor, in addition to the three child characteristics measures), there were statistically significant relationships between baseline parenting stress and: *Involvement*, *Communication*, and *Limit Setting* parenting behaviours at follow-up. In addition, there were also statistically significant relationships between the parenting behaviours of *Involvement*, *Communication*, and *Limit Setting* at baseline and parenting stress at follow-up. When comparing these correlations, it was found that the relationships between baseline parenting stress and follow-up *Involvement*, and between baseline parenting stress and follow-up levels of *Communication*, were stronger than the relationships between the baseline parenting behaviours and follow-up parenting stress. This comparison between these correlations was conducted, as outlined by Howell (1997), to ascertain statistically significant differences between the pairs of related correlations.

These overall semi-partial time-lagged correlations obscure some differences in these correlations as the children become older. For the youngest group of children, there were statistically significant negative relationships between baseline parenting stress and follow-up *Involvement*, and follow-up *Communication*, but a statistically significant negative relationship between baseline *Limit Setting* and follow-up parenting stress. In the three older age groups of children, the tendency was for there to be statistically significant negative relationships between baseline parenting stress and follow-up *Communication*, and follow-up *Limit Setting*, and also between baseline *Communication*, and baseline *Limit Setting*, and follow-up parenting stress. The parenting behaviours related to *Involvement*, and *Autonomy*, did not enter into statistically significant relationships with parenting stress in the three older age groups of children.

Discussion

This research has examined the relationship between parenting stress and parenting behaviours in parents of children with ASC. This relationship was examined, because relatively little is known about the types of parenting behaviours that are exhibited by parents of children with ASC, and whether these parenting behaviours differ in any way from those of parents in the general population. Moreover, it has been suggested that the levels of parenting stress experienced by parents of children with ASC will impact on their parenting behaviours, which will, in turn, impact on child behaviour problems (e.g., Hastings, 2002). This would provide a mechanism that explains the findings that high parenting stress is associated with poorer intervention outcomes for children with ASC (Robbins *et al.*1991; Chapter 2), and with higher subsequent levels of child behaviour problems (Lecavalier *et al.*, 2006; Chapter 3).

The current research revealed that parenting behaviours, as measured by the PCRI self-report questionnaire, in parents of children with ASC, were slightly lower than the mean levels of self-reported parenting behaviours seen in the general population. However, these levels of parenting behaviours, although statistically significant, were only slightly attenuated, relative to the general population, and, according to Gerard (1994), would not be classified in a clinical, or a social care, context as problematic. Indeed, most of the parenting behaviours fell into the 'normal', and 'typical', range that is taken to reflect "good parenting" (see Gerard, 1994). The one exception to this general finding was that the parents' self-reported communication with their children, on average, was in the problematic range for parenting behaviour (i.e. showed a T-score of below 40). This area was also found to be rated highly as a concern of parents of adolescents with ASC in a study by Fong, Wilgosh, and Sobsey (1993), when they identified a number of consistent themes of concern, expressed by parents, that emerged from interviews. However, given the nature of ASC, especially given that communication disturbance is one of the definitive elements in the diagnosis of ASC (see DSM-IV), this finding is to be expected, and may well be indicative of the child's difficulties, rather than being a reflection of any particular characteristic of the parenting behaviours for this group of parents. Thus, this finding should not be taken to be particularly surprising.

The parenting behaviours of this sample were reasonably consistent over time. The parenting behaviours at follow-up were not different from, and were strongly correlated with, those at baseline. A finding that suggests highly consistent parenting practices in this group. This was also reflected when the parenting behaviours were studied across the four age groups of children in this sample. There were very few changes in parenting behaviours as a result of the age of the child. The one exception to this latter finding was that of self-reported communication; which improved as the age groups of the children became older, suggesting an improvement in this aspect of parenting behaviours over time. Again, this finding may well reflect the development of the child, as much as changes in the behaviours exhibited by the parents. Taken together, these findings suggest that this sample does not differ from the general population regarding parenting behaviours. This result parallels previous studies concerning the similarities of the personality traits of parents of children with ASC to parents in the general population (e.g., Koegel, Schreibman, O'Neill, & Burke, 1983).

The one exceptional aspect concerning parents of children with ASC is that they report extremely elevated levels of parenting stress. In this respect, the current chapter corroborates many earlier demonstrations of very high levels of parenting stress in parents of children with ASC (e.g., Blacher & McIntyre, 2006; Dunn *et al.*, 2001; Eisenhower *et al.*, 2005). These particularly high levels of parenting stress could be responsible for any slight differences observed in self-reported parenting behaviours in this sample, compared to parents in the general population, and these elevated parenting stress levels could permeate these differences in parenting behaviours. Indeed, Hastings (2002; see also Deater-Deckard, 1998) postulated, in a theoretical model concerning parents of children with general developmental disabilities, that high levels of parenting stress impact adversely on subsequent parenting behaviours. The current results partly corroborate this suggested link between parenting stress and parenting behaviours, in the context of ASC, but the findings that have emerged also imply a far more complicated, and subtle, interaction between parenting stress and self-reported parenting behaviours, as indicated by the above review of the existing literature (cf. Kotchick *et al.*, 2005; Levers & Drotar, 1996; Meyers & Miller, 2004).

There was clear evidence that high levels of parenting stress were associated with lower scores for many aspects of self-reported parenting behaviour. However, such correlations do not allow any indication of the temporal directionality of this relationship. That is, such correlations at baseline, and at follow-up, merely show an association, and do not allow any indication that either parenting stress or parenting behaviours preceded one another. Evidence concerning temporal precedence came from the time-lagged correlations employed in this research. These demonstrated a somewhat more complex, but still consistent, and clearly interpretable, picture of the relationship between these factors.

In general, there was a statistically significant bidirectional relationship between parenting stress and self-reported parenting behaviours concerning: involvement with the child, communication with the child, and limit setting for the child (but not for promoting the child's autonomy). This suggests that parenting stress and some parenting behaviours closely interact with one another across time. Such a finding was similarly revealed for the bidirectional relationship between parenting stress and child behaviour problems by Lecavalier *et al.* (2006). However, it should be noted that, although these factors clearly do have a bidirectional interaction, the effect of earlier parenting stress on later parenting behaviours does display a more pronounced relationship, in some instances (i.e. for involvement, and for communication), than the converse temporal relationships.

Moreover, inspection of the data for the four different age groups of children reveals a very clear pattern of results. In the three older age groups of children, there are consistent bidirectional relationships between self-reported communication and parenting stress, and between self-reported limit setting and parenting stress. These relationships suggest that low levels of parenting stress precede better parenting behaviours and skills, and also that better parenting behaviours and skills precede subsequent lower levels of parenting stress. However, in the youngest age group of children, the relationships between parenting stress and self-reported parenting behaviours are all unidirectional; but these relationships appear to operate in different temporal directions for different parenting behaviours. For involvement, and for communication, high initial levels of parenting stress precede poorer subsequent parenting behaviours and skills in those domains. However, for limit setting, good initial skills in this domain of parenting behaviour precede subsequently lower levels of parenting stress.

These findings partly support the theoretical model outlined by Hastings (2002), but also present a considerably more complicated picture than is suggested by Hastings (2002). It is a set of relationships, however, that might be predicted, in that it would not be unexpected, or surprising, if parents withdrew, either physically or emotionally, from a highly stressful situation, perhaps as a form of defence mechanism, or as a coping strategy (Powers, 2000). Repetti and Wood (1997) discuss workload stress-induced behavioural and emotional withdrawal of parents from their children, such as less speaking to, and fewer expressions of affection towards, their children during parent-child interaction. Such parental withdrawal could be exacerbated by the typical tendency of the child with ASC to display deficits in social responsiveness, and a reduced capacity for reciprocity. This would possibly reduce a parent's experience of reinforcement from their child, especially given that there appears to be a significant correlation between perceived child attachment and parental gratification (Hoppes & Harris, 1990). This parental withdrawal would also make sense, given the extreme levels of parenting stress experienced by parents of children with ASC (see also Blacher & McIntyre, 2006; Dunn *et al.*, 2001; Eisenhower *et al.*, 2005), and it could help to alleviate some of the strain that they must experience (Powers, 2000). Such a parental coping mechanism, however, would have a detrimental impact on certain parenting behaviours, such as involvement, and communication, with a child. In contrast, the ability to set limits for a child, early on in a child's development, could have beneficial consequences for later parenting stress, and could also be regarded as a successful parenting strategy to be adopted in a highly stressful parenting situation. Thus, the relationships between parenting stress, parental coping, and parenting behaviours clearly warrant further exploration.

In terms of the practical implications of these current findings for the early treatment of ASC, to focus purely on the impact of any early intervention neglects the important role that parents play in the management of their child's problems. The present findings suggest that intervention programmes that focus on providing parents with behaviour management skills (e.g., Harris, Handlemann, Arnold, & Gordon, 2000; Lovaas & Smith, 2003) will have benefit to both the child and the parent. Moreover, reductions in parenting stress, as a consequence of better limit setting skills, may subsequently feed into promoting other successful parenting behaviours and skills, through the reduction of the parenting stress that attenuates abilities in such domains as involvement and communication. However, it is clear that early interventions should also focus on the reduction of parenting stress at their commencement, as this may allow development of better parenting behaviours and skills subsequently. Numerous intervention programmes target the parents of children with ASC, and have noted improvements in the children's behaviours and functioning as a result of the parents' reduction in stress, and their increase in coping ability (e.g., Harris *et al.*, 2000; Lovaas & Smith, 2003; see Blacher, Neece, & Paczkowski, 2005, for a review).

There are a couple of limitations to this study that should be mentioned. Firstly, caution needs to be used when extrapolating from any particular sample to the whole population of parents of children with ASC. It may be that parents who volunteer for such research studies display different characteristics to those who do not volunteer. For example, volunteers may have higher levels of parenting stress than those who do not volunteer. The fact that the numbers of participants decrease as the children become older, and that parenting stress also decreases as the children become older, may fit with this suggestion. However, self-selection of participants is a limitation and difficulty of all such community-based studies, and this problem is not specific to this particular research. It should be mentioned that very few of the identified families refused to participate, suggesting that self-selection was not a major problem in this study.

Secondly, the measure of parenting behaviours used was a self-report questionnaire measure, and, as such, could be taken to reflect parents' perceptions, descriptions, and accounts of their parenting behaviours, rather than being a direct observational measure of those parenting behaviours themselves. Nevertheless, the use of self-report questionnaire measures reflects the more typical, and common, approach deployed to assess parenting behaviours and styles across a range of different populations (e.g., Kotchick *et al.*, 2005; Meyers & Miller, 2004). This provides the advantage of allowing for some direct comparison, and contrast, with those previous studies, and those diverse populations. Moreover, it is actually unclear whether there would be any difference if direct observation, compared to self-report, assessment of parenting behaviours were adopted. Further research that employs direct observation could help to corroborate these self-report findings, although this former approach would severely limit the sample size, relative to the latter self-report questionnaire method employed in this current research. It should be acknowledged that the PCRI, although a well-standardised, reliable, validated, and widely used measure for parents of typically developing children, has not been formally validated for use with parents of children with ASC. However, the present results show little difference between the current parent sample, and those parents of typically developing children reported by Gerard (1994). This indicates that the PCRI may well be quite appropriate for use with a sample of parents of children with ASC. Further research that employs a range of additional measures of these parenting behaviours and child behaviour problems would help to corroborate and systematically replicate the current findings.

Thus, the relationships between parenting stress and self-reported parenting behaviours have been established by the current chapter, to some degree. These may provide tentative evidence to explain previous findings regarding the impact of parenting stress on child outcomes (Robbins *et al.*, 1991; Chapter 2), and on child behaviour problems (Lecavalier *et al.*, 2006; Chapter 3). Moreover, these relationships between parenting stress and self-reported parenting behaviours may well be entirely consistent with the development of adaptive behavioural strategies adopted by parents in order to deal with their extreme levels of parenting stress, and with the long-term strain that this stress can produce. It is certainly not suggested that ASC is caused by parenting stress, nor by parenting behaviours, but that helping parents to manage their parenting stress more effectively may enhance their parenting behaviours and skills, and, hence, promote their successful management of their child's behaviour problems.

Chapter 5:

The Effect of Parenting Behaviours on Subsequent Child Behaviour Problems in Autistic Spectrum Conditions

Introduction

Levels of parenting stress impact on behaviours of children with Autistic Spectrum Conditions (ASC). It is well established that there is a strong association between parenting stress and child behaviour problems (Baxter, Cummins, & Yiolitis, 2000; Hodapp, Fidler, & Smith, 1998; Lecavalier, Leone, & Wiltz, 2006; Stores, Stores, Fellow, & Buckley, 1998). Recent evidence suggests that high initial levels of parenting stress can lead to subsequently poorer child outcomes following early teaching interventions (Robbins, Dunlap, & Plienis, 1991; Chapter 2), and a worsening of child behaviour problems (Lecavalier *et al.*, 2006; Chapter 3).

In order to explain these findings, it has been proposed that high levels of parenting stress can have an impact on subsequent parenting behaviours, which, in turn, impact on a child's behaviour problems, and outcomes. This suggestion has formed part of several theoretical models of parenting (e.g., Deater-Deckard, 1998), which have been applied in the context of developmental and learning disabilities (Hastings, 2002). There is some evidence to support the suggestion that parenting stress impacts on parenting behaviours for parents within the general population (Kotchick, Dorsey, & Heller, 2005; Meyers & Miller, 2004; Rodgers, 1993; 1998), and also for parents of children with ASC, in particular (see Chapter 4). The latter longitudinal research studied the relationship between parenting stress and parenting behaviours in a sample of 138 parents of children with ASC, over a nine to ten month period of time. Parenting stress and some parenting behaviours, namely, involvement with the child, communication with the child, and limit setting for the child, closely interacted bidirectionally with one another over time.

However, although high levels of parenting stress are associated both with subsequently higher levels of child behaviour problems, and with later changes in parenting behaviours, it is not known whether parenting behaviours are associated directly with subsequent child behaviour problems, and poorer outcomes. It could be that both parenting behaviours and child behaviour problems are jointly influenced by parenting stress, but that each of these are not directly impacted upon by one another (see Anthony, Anthony, Glanville, Naiman, Waanders, & Shaffer, 2005; Blader, 2006). Thus, it is necessary to identify and establish the channels, or mechanisms, of influence that may possibly be involved between parenting behaviours and child behaviour problems.

Unfortunately, there is virtually no evidence showing a direct link between parenting behaviours and child behaviour problems in the context of ASC. There are numerous intervention programmes that target the parents of children with ASC. Many of these interventions have noted improvements in the children's behaviours, and functioning, as a result of a reduction in parenting stress, and an increase in parental coping ability (e.g., Harris *et al.*, 2000; Lovaas & Smith, 2003; Spaccarelli, Cotler, & Penman, 1992; see Brookman-Frazee, Stahmer, Baker-Ericzen, & Tsai, 2006, for a comprehensive review). There are several studies that suggest that teaching parenting skills to parents of children with ASC will reduce their children's challenging behaviours. For example, teaching parents 'mindful' parenting reduced aggression, non-compliance, and self-injury in their children, and promoted parental satisfaction with their parenting skills, and their parent-child interactions (Singh, Lancioni, Winton, Fisher, Wahler, McAleavey, Singh, & Sabaawi, 2006). Nevertheless, these results may not reflect a direct relationship between parenting behaviours and child behaviour problems, but could reflect the results of a reduction of the parenting stress levels, which, in turn, could have impacted on both parenting behaviours and on child behaviour problems, but the latter challenging behaviours may not have been affected via parenting behaviours directly.

There is, of course, a considerable literature on the effects of parenting practices and strategies in families of typically developing children. Fenning, Baker, Baker, and Crnic (2007) review this substantial literature, and suggest that the parent characteristics of 'warmth' and 'responsiveness' contribute to a more positive, and adaptive, parenting style which, in turn, facilitates a satisfactory social, and emotional, development in the child. On the other hand, low levels of manifest parental 'warmth' correlate with child behaviour problems, such as increased externalising behaviours (e.g., oppositional and disruptive behaviours). Similarly, a lack of parental 'responsiveness', as seen in over-intrusive interventions, over-controlling, and harsh disciplinary parenting styles, is, likewise, associated with child behaviour problems. Furthermore, Fenning *et al.* (2007) note that parental emotional expressiveness, in particular, high expressed frequencies of negative affect, especially anger, can act to inhibit empathic responding, reduce levels of emotional understanding, and increase the probability of prolonged and continuing behavioural problems in the child. However, the relevance of much of this parenting literature to the study of children with ASC might be questionable, as an often proposed mechanism for such links between parenting behaviours, and styles, and child behaviour problems, and outcomes, is that of imitation (e.g., Bandura, Ross, & Ross, 1961; Fenning *et al.*, 2007). Given the nature of the deficits involved in ASC, the extent to which such parenting findings can be generalised, or applied, to this specific population is unclear.

Some findings that could be relevant, especially as they involve teaching interventions, are those from research conducted on Head Start programmes, often involving socio-economically disadvantaged children. In a study by Siantz and Smith (1994), it was found that the parenting styles of the mothers of 60, 3-8 year old, children of Mexican American migrant farm-workers accounted for a significant proportion of the child behaviour problems, reported by the mothers. Similarly, Dumas and Wekerle (1995) noted some modest relationship between "dysfunctional parenting" and child behaviour problems. However, as these research studies were cross-sectional, and not longitudinal, temporal directionality between these two factors cannot be discerned (see also similar claims made by Jackson, 2000, and by Jackson & Huang, 2000, on the basis of other cross-sectional correlational studies).

On looking at the longitudinal effects of maternal anti-social behaviour, and parenting practices, on behaviour problems in boys at risk of developing anti-social behaviours, Ehrensaft, Wasserman, Verdelli, Greenwald, Miller, and Davies (2003) noted that lower levels of maternal involvement, and monitoring, and higher levels of conflict between the mothers and sons, contributed to worse subsequent child behaviour problems seen one year later. Although the boys' behaviour problems were directly worsened by the conduct disorder problems of the mothers, it was established that the effect of parenting was even more contributive to the subsequent child behaviour problems. Similarly, Austin, Dunn, Johnson, and Perkins (2004) conducted a longitudinal study which investigated the impact of families on behaviour problems of children and adolescents with epilepsy. They found that parental confidence in managing discipline of their child at baseline was correlated with child behaviour problems at baseline, and also predicted these behaviour problems at follow-up, 24 months later. Moreover, decreasing parental confidence in disciplining their child was related to an increase in child behaviour problems over time. Thus, both the study by Ehrensaft *et al.* (2003), and that by Austin *et al.* (2004), highlight aspects of limit setting (i.e. monitoring, or managing discipline, see Gerard, 1994) as important parenting behaviours associated with reductions in future child behaviour problems. Of course, behaviour management skills are also often emphasised in the context of training programmes for parents of children with ASC (e.g., Harris *et al.*, 2000).

The above review suggests that there are a number of important theoretical reasons to examine the relationship between parenting behaviours and child behaviour problems in an ASC sample. These findings may also have practical implications, and applications, for the development of future interventions for ASC. In particular, there is, firstly, a need to establish a relationship between parenting behaviours and child behaviour problems over time, in order to determine the temporal directionality of any such parent-child interactions and relationships. Secondly, there is the need to identify which types of parenting behaviours are influential for subsequent child behaviour problems in the context of ASC. Finally, it is important to demonstrate that the parenting behaviours and child behaviour problems association is a direct one, which is not the product of both of these behavioural elements being impacted upon by additional factors, such as parenting stress. To achieve these ends, a longitudinal study was conducted in order to measure the family factors operational, across a range of children with ASC, and their parents.

Method

Participants

A total of 83 children with ASC (75 male and 8 female) were identified in conjunction with Local Education Authorities in the South East of England. All of the parents of these children were contacted, and 72 parents (70 with male children, and 2 with female children) agreed to participate in the study (86%). Participants were identified on the basis of three criteria, the children had to be: 5:0 to 16:0 years old (mean = 8:8), undergoing a teaching/educational intervention for ASC, and independently diagnosed with ASC by specialist Paediatricians, following initial referral from an independent general medical practitioner. All diagnoses were made prior to participating in, and the commencement of, this study. In addition to these independent diagnoses of ASC, all of these children had a statement of Special Educational Needs related to their ASC from their Local Education Authorities.

These independent diagnoses were supported in the present study by the use of the Gilliam Autism Rating Scale (GARS), which allowed further independent assessment of the degree of their autistic severity. The GARS measure showed that the mean (standard deviation) of the overall GARS score for this sample was 89.0 (± 16.2), indicating that this sample was of a slightly milder than average autistic severity. The scores for the four sub-scales of the GARS, each representing a different aspect of the disorder, showed a similar pattern, in that all of these scores were slightly milder than the average. The mean sub-scale scores were: *Stereotyped Behaviors* = 8.1 (± 2.9); *Communication Problems* = 8.3 (± 3.2); *Social Interaction Problems* = 8.1 (± 3.2); and *Developmental Disturbances* = 8.6 (± 3.0). The intellectual functioning of the children was assessed at baseline by the British Abilities Scale, which revealed a mean *Cognitive Ability Score* at baseline of 80.3 (± 18.4). Similarly, the Vineland Adaptive Behavior Scale *Overall Composite* score for these children was 54.7 (± 16.4) at baseline.

Measures

Gilliam Autism Rating Scale: The GARS (Gilliam, 1995) comprises four sub-scales, each describing behaviours that are symptomatic of ASC (*Stereotyped Behaviors, Communication, Social Interaction,* and *Developmental Disturbances*). The raw scores from these sub-scales can be converted into standard scores (mean = 10, standard deviation = 3). These sub-scales combine to give an overall *Autism Quotient*; higher scores meaning greater autistic severity (mean = 100 [average autistic severity], standard deviation = 15). The scale is appropriate for persons aged 3 to 22 years old, and is completed by parents, or professionals, in about 10 minutes. Its internal reliability is 0.96, and it has high criterion validity with the Autism Behavior Checklist (0.94).

British Abilities Scale: The BAS II (Elliott, Smith, & McCulloch, 1996) is a battery of tests of cognitive abilities, which index educational achievement and intellectual functioning. It is suitable for use with children and adolescents from 2:6 to 17:11 years old. This test allows the calculation of a *General Cognitive Ability* scale (mean = 100, standard deviation = 15), which represents intellectual ability.

Vineland Adaptive Behavior Scale: The VABS (Sparrow, Balla, & Cicchetti, 1990) is a semi-structured interview, administered to a parent, or other caregiver, of the child. It can be used from birth to 18:11 years, making it suitable for the present cohort. The VABS assesses children's day-to-day adaptive functioning. Scores from three domains of adaptive behaviour were used in the present study (*Communication*, *Daily Living Skills,* and *Socialization*). The raw scores can be converted to standard scores, and a *Composite Overall* score can be derived, based on the sum of the sub-scale standard scores (mean = 100; standard deviation = 15). The internal reliability of the *Overall Composite* score is 0.93.

Questionnaire on Resources and Stress: The Friedrich Short-Form of the QRS (Friedrich, Greenberg, & Crnic, 1983) is a 52-item, self-administered, true or false, tool, designed to measure parental perceptions of the impact of a developmentally delayed, or chronically ill, child on other family members. The QRS-F consists of four sub-scales, which assess parental perceptions about: *Parent and Family Problems* – dealing with the impact that the disability has on family activities or relationships; *Pessimism* – related to parent depression; *Child Characteristics* – dealing with the impact of the child's problems on the family; and *Physical Incapacity* – which examines the family problems produced by the child not being able to perform certain activities for themselves. These scores summate to produce a *Total Stress Score* (0-52). Higher scores are indicative of greater perceived stress within the family, as perceived and indicated by the parents (but not, it should be noted, of a greater degree or number of actual stressors, see Dyson, Edgar, & Crnic, 1989).

The internal reliability of the sub-scales ranges from: 0.77 (*Physical Incapacity*) to 0.85 (*Child Characteristics*), with the internal reliability of the *Total Stress Score* being 0.89. This tool has previously been employed for samples with ASC in assessing stress in parents (e.g., Hastings & Johnson, 2001), and so allows comparison with previous studies. The *Total Stress Score* from this scale has been shown to have good reliability and validity for research with parents of children with ASC (Honey, Hastings, & McConachie, 2005).

Parent-Child Relationship Inventory: The PCRI (Gerard, 1994) is a 78-item self-administered tool to assess parents' attitudes towards parenting and their parenting behaviours. The items are selected to measure a wide variety of parenting dispositions and behaviours. All of the items have a Likert-type, 4-point response format: *strongly agree*, *agree*, *disagree*, and *strongly disagree*. There are seven scales, which each produce a standardised T-score (mean = 50, standard deviation = 10), where high scores reflect positive orientations. The seven scales are: *Parental Support*, *Satisfaction with Parenting*, *Involvement*, *Communication*, *Limit Setting*, *Autonomy*, and *Role Orientation*. To check the validity of the protocol, there is a 5-item *Social Desirability* scale, which, if scores are low (9 or less), indicates that the parent responses are unrealistically positive regarding the parent-child relationship.

Due to the fact that the current study was concerned with the impact of parenting behaviours, it seemed inappropriate to examine the *Parental Support*, *Satisfaction with Parenting*, and *Role Orientation* scales. These scales do not deal with parenting behaviours *per se*, but with the parental perceptions of the level of emotional and social support received, the amount of pleasure and fulfilment derived, and their attitudes towards gender roles, respectively. The four remaining scales all dealt with parenting behaviours, and each assessed different aspects of this parenting behaviour. The *Involvement* scale consists of 14 items that examine the parental interaction with, and parental knowledge of, their child (e.g., "*I am very involved with my child's sports or other activities*", "*I spend very little time talking with my child*"). The *Communication* scale contains 9 items that assess the effectiveness of parental communication with their child (e.g., "*My child generally tells me when something is bothering him or her*", "*If I have to say no to my child, I try to explain why*"). The *Limit Setting* scale consists of 12 items that concentrate on parental disciplining of their child (e.g., "*I sometimes give in to my child to avoid a tantrum*", "*I often lose my temper with my child*"). The *Autonomy* scale contains 10 items that evaluate the parental ability to promote independence in their child (e.g., "*I worry a lot about my child getting hurt*", "*I have a hard time letting go of my child*").

The internal reliability (alpha coefficients) of the four scales used ranged from 0.76 (*Involvement*) to 0.88 (*Limit Setting*), and they had a mean test-retest reliability of 0.81. Also, the PCRI has good correlation with other instruments that measure parenting behaviours (see Coffman, Guerin, & Gottfried, 2006; Gerard, 1994). Heinze and Grisso (1996) reviewed the PCRI, amongst other instruments of parenting capacity, and their results lead them to conclude that the PCRI was a useful measure for child custody hearings, in abuse cases, and in divorce mediations. The PCRI has been utilised in various research settings, for instance, in order to assess outcome effectiveness of various interventions, such as the Family Mentoring Program, and has been found to be a useful measure for such purposes (e.g., Barron-McKeagney, Woody, & D'Souza, 2002).

Strengths and Difficulties Questionnaire: The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) is a brief behavioural screening questionnaire for 3 to 16 year olds. It exists in several versions to meet the needs of researchers, clinicians, and educationalists. The parent version includes 25 items, divided between 5 scales, all score ranges are from 0 to 10: *emotional symptoms* (norm = 1.9), *conduct problems* (norm = 1.6), *hyperactivity/inattention* (norm = 3.5), *peer relationship problems* (norm = 1.5), and *pro-social behavior*. The first four sub-scales, when added together, generate a *total difficulties score* (norm = 8.4; score range 0 – 40). Scores in the *total difficulties score* between 0 and 13 are in the normal range, scores between 14 and 16 are deemed to be borderline, and scores of 17 to 40 are abnormal. The questionnaire correlates highly with the Rutter Child Questionnaires (Goodman, 1997).

Procedure

The children were identified by the Local Education Authorities, were contacted, and, on choosing to participate, parental consent was received. The same tests were administered at baseline, and then, again, at follow-up, for all children, after a nine to ten month period. Autistic severity (GARS), intellectual functioning (BAS), and adaptive behavioural and social functioning (VABS) were measured. In addition, measures of self-reported parenting stress (QRS-F), self-reported parenting behaviours (PCRI), and the parents' assessments of the child behaviour problems (SDQ) were collected.

The children were visited by an Educational Psychologist, who was blind to the levels of parenting stress, and to parenting behaviours, and the baseline child measures were taken (GARS, BAS, and VABS). Parents were contacted, at this time, and asked to complete QRS-F, PCRI, and SDQ questionnaires, and to give some background regarding their child, as well as a brief history of their child's provision, which they did independently. The questionnaires were sent out by post to the parents, along with an information letter, and a pre-paid, addressed return envelope. The information letter provided contact details, offering parents the opportunity to seek help and guidance, if required, regarding the completion of the questionnaires, however, it was extremely rare that any parents made contact in order to ask advice about answering specific questions. On completion, the parents used this pre-paid envelope to return the questionnaires. As an added incentive for returning this information, the parents were automatically entered into a prize draw, the winner of which received £50 for toys or books for their child. This incentive was specified in the information letter. If parents had not returned the questionnaires after a period of time, they were contacted, via telephone, and reminded, and given the opportunity to return the completed questionnaires. After nine to ten months, all parents were asked to complete the QRS-F, PCRI, and SDQ questionnaires again, and to return them by post, as described above.

The scores from these follow-up assessments were compared with those from the baseline assessments in order to ascertain the relationship between the measures of parenting behaviours and child behaviour problems over the nine to ten month period. On scoring the PCRI questionnaires, two questionnaires were found to have scores on the *Social Desirability* scale that indicated unrealistically positive depictions of their parent-child relationships (one baseline, and one follow-up). These two complete sets of PCRI scores were removed, as the *Social Desirability* scale indicated that they had questionable validity, and they were replaced by mean substitutions, based on the mean of the rest of the sample.

Results

Table 5.1: Means (standard deviations) for child behaviour problems, parenting stress, and parenting behaviours.

Measure	*Baseline*	*Follow-up*	*Correlation*	*t-test*
Child Problems	19.9 (6.1)	18.2 (4.6)	0.680***	3.35***
Parenting Stress	24.4 (9.3)	21.3 (7.5)	0.642***	3.58***
Involvement	44.0 (9.7)	43.4 (6.9)	0.496***	< 1
Communication	36.5 (8.9)	38.3 (6.6)	0.615***	2.10*
Limit Setting	46.8 (6.7)	48.8 (5.6)	0.562***	2.87**
Autonomy	50.5 (6.1)	51.5 (7.6)	0.226	1.07

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 5.1 shows the mean (standard deviation) for the total parenting stress (QRS-F), parenting behaviours (PCRI), and total child behaviour problems (SDQ), at both baseline, and at follow-up. These data at baseline show high levels of parenting stress, as measured by the QRS-F, and high levels of child behaviour problems, the mean of the latter score being in the abnormal range at both baseline and at follow-up. The broad pattern of data was similar at follow-up, with most of the scores showing some improvement (i.e. fewer child behaviour problems, less parenting stress, and improved scores in the parenting behaviour domains). Parenting stress and child behaviour problems showed statistically significant improvements, as did the *Communication* and *Limit Setting* scales for parenting behaviours. These parenting behaviour scores were, however, consistent across participants, all, with the exception of the *Autonomy* scale, showed statistically significant correlations between baseline and follow-up.

Table 5.2: Correlations between parenting stress and child behaviour problems and parenting behaviours at baseline, and at follow-up.

Baseline	***INV.***	***COM.***	***LIM.***	***AUT.***
Parenting Stress	-0.434***	-0.424***	-0.552***	-0.018
Child Problems	-0.143	-0.115	-0.545***	-0.151
Follow-up	***INV.***	***COM.***	***LIM.***	***AUT.***
Parenting Stress	-0.094	-0.257*	-0.427***	-0.124
Child Problems	-0.306***	-0.130	-0.422***	0.068

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 5.2 shows the correlations between the four parenting behaviour scales of the PCRI and the total parenting stress score (QRS-F), and the total child behaviour problems score (SDQ), at both baseline and at follow-up. These data show a reasonably consistent pattern of results across baseline and follow-up. The parenting behaviour of *Limit Setting* strongly correlated negatively with parenting stress (QRS Total), and also with child behaviour problems (SDQ Total), at both baseline and follow-up. The *Communication* scale of the PCRI correlated negatively with parenting stress, but not with child behaviour problems, at baseline and at follow-up. The *Autonomy* scale did not correlate with either parenting stress, or with child behaviour problems, at either baseline or at follow-up. The one inconsistent result was that the *Involvement* scale only correlated negatively with parenting stress at baseline, and only with child behaviour problems at follow-up. Parenting stress correlated positively with child behaviour problems at both baseline, $r = 0.515, p < 0.001$, and at follow-up, $r = 0.525, p < 0.001$.

Table 5.3: Semi-partial time-lagged correlations between parenting behaviours (PCRI) at baseline and child behaviour problems (SDQ) at follow-up, and child behaviour problems at baseline and parenting behaviours at follow-up (with autistic severity, intellectual functioning, adaptive behaviour, and parenting stress partialled out).

Parenting Behaviour	***Parenting to Child Problems***	***Child Problems to Parenting***
Involvement	-0.126	-0.207
Communication	0.008	0.034
Limit Setting	-0.333***	-0.175
Autonomy	-0.043	0.029

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 5.3 presents the results from a series of semi-partial time-lagged correlations between parenting behaviours (PCRI) at baseline and child behaviour problems (SDQ Total Score) at follow-up, and between child behaviour problems at baseline and parenting behaviours at follow-up, removing the influences of the three child characteristics, namely, autistic severity (GARS Overall), intellectual functioning (BAS General Cognitive Ability), and adaptive behavioural functioning (VABS Composite), and parenting stress (QRS Total). Semi-partial correlations were performed, in preference to examining the standardised beta coefficients from a multiple regression, as the predictor variables were correlated with one another, and, in these circumstances, standardised beta coefficients are not an appropriate estimate of the individual contribution of predictor variables (Darlington, 1990; Howell, 1997). Moreover, semi-partial correlations are a more conservative, and cautious, estimate of the relationship than are partial correlations, and are to be preferred for this reason (Tabachnick & Fidell, 1989). These correlations were conducted to establish whether there were any indications of temporal precedence, and directionality, between parenting behaviours and child behaviour problems. Of these semi-partial time-lagged correlations, only that between *Limit Setting* at baseline and child behaviour problems at follow-up was statistically significant.

Figure 5.1: Mediation analysis of the relationship between baseline parenting stress, baseline limit setting, and follow-up child behaviour problems.

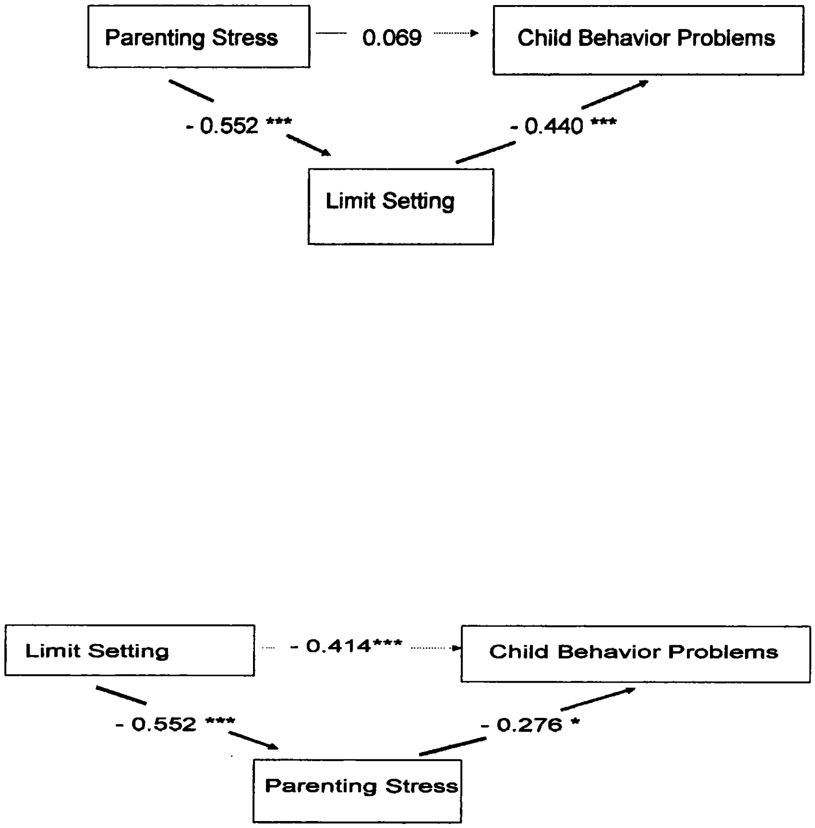


Figure 5.1 shows the results of two mediational analyses conducted on these data. The relationship between parenting stress, *Limit Setting* (as the only important parenting behaviour established above), and child behaviour problems was analysed, as suggested by Miles and Shevlin (2001). The top panel of Figure 5.1 shows that there were significant negative relationships between parenting stress and *Limit Setting* at baseline, and between *Limit Setting* at baseline and child behaviour problems at follow-up. However, when *Limit Setting* was used as a mediator of the relationship between parenting stress at baseline and child behaviour problems at follow-up, this direct relationship virtually disappeared. In contrast, when parenting stress was used as a mediator of the relationship between *Limit Setting* at baseline and child behaviour problems at follow-up, there remained a strong relationship between these two variables.

Discussion

The current research aimed to explore the relationship between parenting behaviours in parents of children with ASC, and child behaviour problems. Such a link has been suggested a number of times in the theoretical literature (e.g., Deater-Deckard, 1998; Hastings, 2002), but, so far, there has been little empirical evidence to support it, especially in regard to ASC. There was a relationship between parenting behaviour and subsequent child behaviour problems, but only for the parenting behaviour of limit setting. The better the limit setting of the parents at baseline, the fewer child behaviour problems were noted at follow-up. Finally, the parenting behaviour of limit setting was found to mediate the relationship between parenting stress and subsequent child behaviour problems.

It has been suggested that parenting behaviours will be linked to child behaviour problems (e.g., Deater-Deckard, 1998; Hastings, 2002). This is not an unreasonable claim, although there is surprisingly little empirical evidence to support it. There have been some demonstrations of this link in the general population (e.g., Ehrensaft *et al.*, 2003; Fenning *et al.*, 2007), but this present research was the first demonstration of a clear link, in a sample of children with ASC and their parents, that showed that this link was not impacted upon by other factors (such as the severity of the child's ASC, the child's intellectual functioning, the child's adaptive behaviour, or the parents' levels of parenting stress).

Moreover, the current study used a longitudinal design, which allowed the temporal precedence, and directionality, of this link between parenting behaviours and child behaviour problems to be established. In this regard, the current study found that limit setting by parents at baseline was associated with fewer child behaviour problems at a later point in time. To this extent, the present research is one of the first studies to give some empirical support to theoretical models of parenting, especially in a population with a developmental disability, like ASC. The particular parenting behaviour that appears to be of uppermost importance, in this regard, is that of limit setting (i.e. greater parental limit setting -> fewer child behaviour problems).

This finding that earlier effective limit setting by parents is the best predictor of fewer later behaviour problems in children with ASC is a simple, but, nevertheless, interesting result. It corroborates similar findings from a range of other samples of children (e.g., Austin *et al.*, 2004; Ehrensaft *et al.*, 2003), regarding the importance of behaviour management strategies, monitoring children's behaviours, and parental confidence in providing discipline. It should be mentioned that this finding does not conflict with claims that parental 'warmth' and 'responsiveness' are important characteristics, and that harsh disciplinary parenting styles are counter-productive (Fenning *et al.*, 2007). Firstly, limit setting is not necessarily at odds with a 'warm' parenting style, and secondly, it is unclear how such attitudes in the parents as 'warmth' would directly impact on children with ASC, if not through parenting behaviours. The importance of limit setting, in the context of this sample with ASC, may have wider implications for the prevention of behaviour problems in children in other educational and family settings.

This finding of a relationship between parenting behaviour and subsequent child behaviour problems may provide a mechanism as to how high parenting stress produces poorer child outcomes resulting from undergoing teaching intervention programmes (Robbins *et al.*, 1991; Chapter 2), and also more extreme child behaviour problems (Lecavalier *et al.*, 2006; Chapter 3). It may be that, if parenting stress impacts on parenting behaviours, which the current study evidentially demonstrated (see also Chapter 4), and, if these parenting behaviours impacted on child behaviour problems, then this would provide a channel or route via which parenting stress could impact on child behaviour problems and child outcomes in children with ASC. The limited literature to date does suggest that parenting stress can impact on parenting behaviours (e.g., Kotchick *et al.*, 2005; Meyers & Miller, 2004; Chapter 4), and that parenting behaviours can impact on child behaviour problems (Ehrensaft *et al.*, 2003; Fenning *et al.*, 2007, as well as the current chapter), and on child outcomes (Robbins *et al.*, 1991; Chapter 2).

Taken together, the above studies support a number of theoretical models of parenting behaviours. However, the current research also demonstrated, through mediational analyses, that parenting behaviours mediated the effects of parenting stress on subsequent child behaviour problems, but that parenting stress did not greatly affect the impact of parenting behaviours. These data also support the above suggestions regarding theoretical models of parenting, although they should be treated with some caution for two reasons. Firstly, previous studies have found a direct link between parenting stress and child behaviour problems (Anthony *et al.*, 2005; Blader, 2006), although not in a sample of children with ASC. Given that one of the core definitional and diagnostic characteristics of ASC is a difficulty with accurately interpreting emotional states in others (e.g., Hobson, Ouston, & Lee, 1989), this difference between the present study and those studies of Anthony *et al.* (2005), and Blader (2006), may not be surprising. Secondly, a mediational analysis that studied parenting stress, parenting behaviours, and child behaviour problems at three time points, instead of the current two, would add significantly to this analysis. However, given that Chapter 4 has established a bidirectional interaction between parenting stress and parenting behaviours, in a sample of parents of children with ASC, then there is evidence to support such a temporal relationship, independent of the data reported in the present study.

In terms of the implications, and practical applications, of these current findings for the intervention and treatment of ASC, focusing purely on the impact of any intervention or treatment neglects the important role that parents play in the management of their child's behaviour problems and difficulties. The present findings suggest that intervention programmes that focus on providing parents with behaviour management skills (e.g., Harris *et al.*, 2000; Lovaas & Smith, 2003) will have benefits for both the child and the parents. However, it is clear that interventions should focus also on the reduction of parenting stress at their commencement, as this may allow development of better parenting behaviours and skills subsequently. Numerous intervention programmes target the parents of children with ASC, and have noted improvements in the children's behaviours, and functioning, as a result of the parents' reduction in stress, and their increase in coping ability (see Blacher *et al.*, 2005, for a review).

There are several limitations to the present research that should be mentioned. The limitations regarding parents who volunteer for such research studies, and the self-report measure of parenting behaviour, as discussed in Chapter 4, would both similarly apply to the current study. Additionally, the current study was conducted on a relatively older sample of children (5 to 16 years old). The results may not be the same in a younger sample of children with ASC. For example, in a younger sample of children with ASC, the parenting stress is affected by different variables than in an older sample (e.g., autistic severity has a greater impact on parenting stress in parents of younger children with ASC than it does in parents of older children with ASC; Dumas, Wolf, Fisman, & Culligan, 1991; Eisenhower *et al.*, 2005; Hastings & Johnson, 2001; Lecavalier *et al.*, 2006; Chapter 3). Therefore, the generalisability of the current study needs to be treated with caution. An older sample of children with ASC was employed in the current study, as it was thought that, in the parents of such older children, the relationship between levels of parenting stress and parenting behaviours may have had time to settle and develop, whereas the relationship between these factors may well be in greater flux in parents of a younger sample of children with ASC.

In summary, the current findings are some of the first to demonstrate that parenting behaviours directly impact on subsequent child behaviour problems in children with ASC, and that this relationship appears to mediate the impact of parenting stress on child behaviour problems. It should be reiterated that it is certainly not suggested that ASC is caused by parenting behaviours, nor by parenting stress, but that helping parents to manage their parenting style and parenting behaviours, as well as their parenting stress, may enhance their management of their child's behaviour problems. The parents should be included in any intervention programme or treatment designed to address the difficulties experienced by children with ASC.

Chapter 6:

Parents' Perceptions of Communication with Professionals During the Diagnosis of Autistic Spectrum Conditions

Introduction

In addressing the issues and problems produced from having a child on the Autistic Spectrum, the importance of the parent cannot be underestimated, and this has recently come to the fore, and has been addressed in the previous chapters. For example, the importance of involving the parents with the interventions given to the child has been recognised (e.g., Schuntermann, 2002; Stoddart, 1999). Recent initiatives provide good examples of this movement: the EarlyBird Scheme (Shields, 2001), and Portage programmes (Reed, Gibson, & Osborne, 2000; Smith, 1999), specifically highlight the need for parental involvement in helping the child with an Autistic Spectrum Condition (ASC). Applied Behaviour Analytic programmes also have focused recently on both the need for parental involvement (e.g., Gabriels, Hill, Pierce, Rogers, & Wehner, 2001; Luiselli, Cannon, Ellis, & Sisson, 2000), and the impact of the intervention on the family as a whole (Hastings & Johnson, 2001). Given these developments, there seems every reason to place the parent in focus when framing an understanding of the impact of ASC, and when considering the development of interventions for ASC.

Many reports have noted the high degrees of stress that the parents experience when dealing with the needs of the child with ASC (e.g., Bebko, Konstantaraes, & Springer, 1987; Blacher & McIntyre, 2006; Schuntermann, 2002). These stress factors can produce a range of severe problems for the parents, such as depression and dysphoria (Wolf, Noh, Fisman, & Speechley, 1989), and disruption in the context of family life (see Dunn, Burbine, Bowers, & Tantleff, 2001; but see Gabriels *et al.*, 2001). A number of studies have shown that, relative to the parents of children with other forms of learning difficulties, levels of stress, and stress-related problems, are greater for parents of children with ASC. For example, Perry, Sarlo-McGarvey, and Factor (1992) have shown this to be so in comparison to Rett's Disorder, and this is also shown to be the case in comparison to parents of children with Down's Syndrome (Sander & Morgan, 1997; Wolf *et al.*, 1989).

In addition to the impact on the individual parent, and on the family as a whole, high levels of stress can impact negatively on the ability of the parent to engage with their child with ASC (Chapters 4 and 5). This difficulty with parenting may also extend to the interventions given to the children (cf. Boyd & Corley, 2001), and may exacerbate the stress-related problems experienced by the parent, and lead to the development of a 'vicious circle', or degenerative cycle (Lecavalier, Leone, & Wiltz, 2006; Chapters 3 and 4). Certainly, pre-intervention parental stress levels are negatively related to the success of early teaching interventions (Robbins, Dunlap, & Plienis, 1991; Chapter 2).

One area that would appear to have a high capacity for the production of stress in parents of children with suspected ASC is their experience of communication with professionals (Brogan & Knussen, 2003; Evans, Stoddart, Condon, Freeman, Grizzell, & Muller, 2001; Goin-Kochel, Mackintosh, & Myers, 2006; Randall & Parker, 1999). A key aspect of this contact and communication with professionals concerns the process of getting a diagnosis of ASC for their child (Brogan & Knussen, 2003; Goin-Kochel *et al.*, 2006; Howlin & Moore, 1997). For example, a large scale survey by Howlin and Moore (1997) described the experiences of around 1,200 families with children with ASC. Many of these families expressed an early sense of a problem (often by the age of 18 months), and they sought help from their medical practitioner when the child was as young as two years of age. However, the report indicated that a diagnosis was often not made until the child was six years old, losing the potential advantage of early diagnosis, and, hence, access to important early educational intervention. These findings have been mirrored in several other reports. For example, Goin-Kochel *et al.* (2006) conducted a web-based survey across five countries, and noted that parent satisfaction with the diagnostic process rose, the fewer professionals they needed to see in order to obtain a diagnosis. Mansell and Morris (2004), in a postal survey of parents in one U.K. Local Authority, found that early and speedy diagnosis was a key contributor to reducing parental stress (see also Brogan & Knussen, 2003).

Given the above findings that high parental stress can inhibit the success of early teaching interventions (e.g., Robbins *et al.*, 1991; Chapter 2), the contact and communication experiences of parents with professionals leading up to, and during, the diagnostic process may be of particular importance. Contact with professionals, especially concerning diagnosis of ASC, most often comes prior to the parents' engagement with a particular intervention programme. If the contact with professionals has been particularly stressful, or aversive, this may lead to any subsequent teaching intervention being less successful than it might, otherwise, have been (see Chapter 2), and also may lead to negative feelings and lack of trust concerning those professionals (Brogen & Knussen, 2003). Unfortunately, there has been relatively little work that has directly addressed parental communication with professionals concerning the diagnosis of ASC, and its follow-up (e.g., Hecimovic, Powell, & Christensen, 1999, reflect this situation in their use of the term "forgotten" to describe members of families, other than the children with ASC).

Both Mansell and Morris (2004), and Oberheim (1996), each surveyed over 100 parents in a single Local Authority in the U.K. (a different Local Authority in each case), and they each found that, in general, parents thought that the diagnostic process was a slow, chaotic, and badly-handled procedure. These results are mirrored by those findings obtained from a small set of four interviews conducted with parents in Wales (Midence & O'Neill, 1999). In this study, parents reported difficulty in getting provision for their child or, indeed, obtaining any form of help or support. However, several of these studies have noted that, on the positive side, the parents, generally, were very appreciative of the help that they did receive (Mansell & Morris, 2004; Oberheim, 1996), and reported relief at obtaining a diagnosis of ASC (Midence & O'Neill, 1999). Similarly, in another small-scale analysis, Bartolo (2002; see also Goin-Kochel *et al.*, 2006) noted that the manner of the communication between professionals and parents was often problematic. These reported problems invariably revolved around discrepant approaches adopted by professionals across different sites. Still other studies have highlighted points of discrepancy and potential conflict between the professionals and the parents themselves. Grey (1993; see also Evans *et al.*, 2001, for similar findings) found that points of disagreement between parents and professionals included: the prospect of a cure, the nature of the child's affection, and the uniqueness of the child and how this is related to the possibility of institutionalisation.

Thus, a picture emerges in which it is acknowledged that the parent may play a pivotal role in the prospects for the child with ASC, and that those parents can suffer from many stressors and stress-produced forms of psychological distress and anxiety. This parent stress may have a negative impact on the prospective outcomes of the child with ASC. Many of these early stressors revolve around the communication and contact with professionals over the period of time in which a diagnosis of ASC is sought and obtained (Goin-Kochel *et al.*, 2006; Mansell & Morris, 2004; Oberheim, 1996). However, there has been relatively little research effort devoted to discovering, and learning about, the parents' perceptions of the processes involved in obtaining a diagnosis of ASC for their child, and of the help and support that they received from various professionals. The study, reported in this current chapter, aimed to survey parental perceptions of the diagnostic process across a number of Local Authorities in South East England, and attempted to elicit opinions about what would make the process better from their perspective.

Method

Participants

Groups of parents were recruited as participants from five Local Authorities in the South East of England. These participants were selected randomly by the Local Authorities from lists of parents, who fulfilled the criteria outlined below, which were supplied to the Parent Partnership Officers in those Local Authorities. The parents were written letters inviting them to attend focus group interviews to discuss their experiences of obtaining ASC diagnoses for their children. The participants received no payment for their involvement in this research, however, they were offered help with travelling expenses to and from the interviews, and with childcare for the duration of their participation in the focus group interviews.

There were fifteen focus group interviews conducted, three focus groups in each of the five Local Authorities. In each Local Authority, one focus group comprised parents of pre-school aged children, one comprised parents of primary school aged children, and one comprised parents of secondary school aged children. Thus, there were five focus group interviews for each of these three groups of parents. There were, in total, seventy parents included in this study (fifty-six mothers and fourteen fathers), with an age range of twenty-five to fifty-five years. There were eighteen parents of pre-school aged children (thirteen mothers and five fathers), twenty-nine parents of primary school aged children (twenty-six mothers and three fathers), and twenty-three parents of secondary school aged children (seventeen mothers and six fathers). The numbers of parents in each focus group are shown in Table 6.1.

Table 6.1: Numbers of participants in each focus group interview session.

Pre-school Children	**Primary-aged Children**	**Secondary-aged Children**
3 females, 1 male	7 females, 1 male	2 females, 1 male
3 females	2 females, 1 male	4 females
2 females, 1 male	6 females	2 females, 1 male
3 females, 2 males	5 females, 1 male	7 females, 3 males
2 females, 1 male	6 females	2 females, 1 male

The criteria for inclusion of a parent in this study were that their child's diagnosis had been made not less than six months before the focus group interviews were held, and not more than seven years before the focus group interviews were held.

Focus Group Interview Sessions

Each focus group interview was conducted by a trained moderator. The focus group interviews were structured by a scripted set of instructions concerning the conduct of the focus group interview sessions. This script also specified the questions to be asked, and the prompts to be used, in order to elicit opinions and experiences from the participants (see Appendix 6.1 for the full script). This procedure ensured that identical questions were asked in every focus group interview, under the same conditions. Table 6.2 displays the general sense of the questions that were asked by the moderator during the focus group interviews.

Table 6.2: Questions asked during the focus group interview sessions.

---

1. Who made the diagnosis?
   Which factors lead them to make the diagnosis?
2. What types of support, advice, and information were you given about understanding the nature of autism?
3. What did you find helpful about the process of getting the diagnosis?
   What could have been improved about the diagnostic process?
4. What types of help have you been offered by the professional services?
5. At what stage do you feel the information about the various types of professional help would, ideally, have been given to you?
6. What support and professional help do you currently receive?
7. How could communication between the professionals and yourselves be made better?
   What would be your preferred method of communication?
8. What professional help, ideally, would you have liked to receive?

The lengths of the focus group interview sessions varied, depending on the numbers of participants involved. The shortest focus group interview session lasted for approximately forty minutes, and the longest session lasted for approximately one hundred and twenty minutes.

The Content Analysis

The focus group interview sessions were audio-tape recorded, and, subsequently, these audio-tape recordings were typed into transcripts. These transcripts of the focus group interviews were then subjected to a content analysis. The phases of the content analysis employed were conducted in line with the recommendations made by Vaughn, Schumm, and Sinagub (1996). These phases are outlined in Table 6.3.

Table 6.3: Phases in the content analysis (after Vaughn et al., 1996).

1. Identification of key themes or 'big ideas' within the data, following reading and re-reading of each transcript.
2. Identification and highlighting of units of information (phrases and/or sentences) relevant to the research purposes.
3. Selection of category headings to sort and group these units of information.
4. Units of information are coded, according to category headings, to enable most of the units to be placed within a category.
5. Negotiation between the researchers to agree the category headings that most economically accommodate the relevant units of information.
6. Categories generated in the first phase of data analysis are reviewed and revised.

After transcription of the audio-taped focus group interviews, the participants' statements were broken down into the smallest units of information that would bear interpretation. Those statements containing more than one unit of information were divided into separate units. A sample of the focus group interview transcripts were selected (one from each of the different child age groups). Category headings were generated from this sample for each question, in order that all of the units of information, extracted for each question, could be categorised according to the theme headings for that question. The category headings summarised the perceptions of the participants concerning each of the issues asked about in the focus group interviews. After all of the units of information were placed into these categories by one assessor, the list of category headings and the transcripts were passed to a second assessor, who was blind to the specific categorisations of the units of information made by the first assessor. The second assessor read, and categorised, the units of information to enable an objective check to be made, and to allow agreement, on the unitisation process, and on the reliability of the categorisation.

Reliability

To verify the reliability of the coding of the results, a Cohen's Kappa analysis was used for inter-rater reliability. For these purposes, 40% of the data were rated by two assessors. A high mean level of reliability (0.81) was identified between their separate judgements across the questions. These figures ranged from a low of 0.76 for Question 8, to a high of 0.98 for Question 1, with all other values falling between these two extreme values.

Results

In total, approximately 18,000 statements (units of information) were made in response to the questions asked during the focus group interview sessions. The final sets of agreed categories, or themes, are shown in Tables 6.4 to 6.11. To illustrate these categories, or themes, some selected *verbatim* quotes are provided.

Who Made the Diagnosis, and Which Factors Lead Them to Make the Diagnosis?

Table 6.4: Percentages of responses to Question 1: "Who made the diagnosis? Which factors lead them to make the diagnosis?".

Who made the diagnosis?

	Pre-school	Primary	Secondary
Medical Practitioner	53	52	61
Speech & Language Therapist	17	24	7
Psychologist	30	24	32

Which factors lead them to make the diagnosis?

	Pre-school	Primary	Secondary
Behaviour Problems	21	23	22
Developmental Differences	27	7	12
Cognitive Impairments	5	8	9
Language	16	19	28
Perseveration	16	12	10
Hyperactivity	5	3	5
Poor Co-ordination	0	3	5
Social Behaviour	0	18	9
Poor Sleep	5	6	0
Placidity	5	1	0

The responses of the parents of the three different child age groups to the first question are displayed in Table 6.4. The upper panel of Table 6.4 shows the breakdown of who made the diagnoses for this sample. Inspection of these data shows that, for all three groups of parents, the most common route for diagnosis was by a medical practitioner, most often a General Practitioner, but sometimes a specialist: "*Dr. A from B Hospital diagnosed my son, and just went by the notes and meeting my son, and couldn't understand why he hadn't been diagnosed years ago*". However, problems were noted also by other professionals (e.g., Speech and Language Therapists, and Psychologists), with approximately the same probability as medical practitioners. It should be noted that several of the respondents may have been interpreting this question as being about who first suggested that there may be an ASC, rather than who made the official diagnosis: "*we eventually started to hear the words 'Asperger's' or 'Asperger's Syndrome' bandied about, it was first floated as an idea by a friend of ours who was a school teacher*".

Inspection of the lower panel of Table 6.4 shows the main factors that prompted the diagnoses. For the two groups of parents with the older-aged children, these factors mainly fall into the typical symptoms of ASC: behavioural impairments: "*terrible tantrums, if things aren't in a special organised way*"; language problems: "*where he had actually in the past been fine with regard to he had labels for things, he knew the names for things, we suddenly found that conversation wasn't developing*", "*his speech wasn't very good*"; and perseverative or repetitive behaviours: "*because of the stereotypic playing*", "*needs very structured routines for everything*", "*flaps his hands*", "*terrible trouble changing clothes, he keeps wearing the same clothes all the time, doesn't like different clothes, doesn't like new shoes*". For the pre-school aged children, another key indicator of a problem appeared to be differences between the developmental progress of the child and their peers: "*the whole basis of my argument seemed to sort of fall on the fact that I had three children that were in one direction, or like each other in many respects, and one child that was significantly different*". Strikingly, impairments in social behaviours were only noted as a major factor by the parents of primary-aged children: "*doesn't like going out to play*", "*can't mix very well*", "*doesn't give good eye contact*", and did not receive great mention from the parents of the children in the other two age groups. This finding may appear to be somewhat unusual, but may simply reflect the fact that the younger children were not yet of an age where social interactions were a main concern, although, in the absence of further data, undue speculation may be unwise.

What Types of Support, Advice, and Information Were You Given About Understanding the Nature of Autism?

Table 6.5: Percentages of responses to Question 2: "What types of support, advice, and information were you given about understanding the nature of autism?".

	Pre-school	**Primary**	**Secondary**
None / Very Little	32	30	25
Leaflets / Books	16	17	16
Professional Advice	30	33	29
Self	22	20	30

Table 6.5 displays the responses to the question regarding the types of support that the participants were offered regarding the nature of ASC. These data show that a high proportion of all participants' responses (around a quarter to a third in all groups) reflected their perceptions that they had not been given any help, support, or advice about the nature of ASC: "*I must say, it was a bit of a shock to start with, didn't know what it meant, or how it was*", "*we were really left with this title and no information at all*", "*as far as education goes, absolutely nothing, so there's been no information whatsoever*". The responses that indicated that some help and advice had been received were divided between information received from professionals, such as teachers and Psychologists: "*she did offer me some books when the day that she diagnosed my son*", which was usually highly appreciated by the participants: "*had quite a few leaflets at the time that were very helpful, very helpful*", "*Dr. C told us of books to buy to help to understand him, and told us to get in touch with the autistic society*"; and information obtained by the participants themselves: "*we've really had to find it out for ourselves, I think*", "*it was really something that we did*"; usually from libraries: "*read a couple of books that are around*", "*I think I went to the library and looked in a medical dictionary under autism*"; or from the internet: "*using our own resourcefulness, I suppose, we went to the internet, and tried to locate publications*". The latter form of information tended to produce negative reactions from, and further worry for, the participants, due largely to its 'negative' nature. Somewhat fewer of the responses indicated that any form of leaflet, or booklet, had been provided for the participants at the time of diagnosis.

What Did You Find Helpful, and What Could Have Been Improved, About the Diagnostic Process?

Table 6.6: Percentages of responses to Question 3: "What did you find helpful about the process of getting the diagnosis? What could have been improved about the diagnostic process?".

What did you find helpful about the process of getting the diagnosis?

	Pre-school	Primary	Secondary
Relief / Confirmation	19	44	52
Altered Expectations	4	11	6
Nothing	50	11	25
Understanding / Support	27	34	17

What could have been improved about the diagnostic process?

	Pre-school	Primary	Secondary
Standardisation and Speed	25	44	47
Offer of Support and Help (Counselling and Services)	18	20	16
Information About Organisations and Services	24	19	21
Information on Impact of Autism / What to Expect	27	14	8
Practical Information on How to Deal With Child	6	3	8

The responses to Question 3, which concerned the helpfulness of the diagnostic process, and its shortcomings, are displayed in Table 6.6. This question provoked the most emotional set of responses from the participants, and their answers were often accompanied by strong affect. The top panel of Table 6.6 displays responses to the part of the question regarding what was helpful about the diagnostic process. Inspection of these data reveals that half of the responses made by the parents of the pre-school aged children suggested that nothing was helpful about the process of getting a diagnosis: "*I don't feel I came away knowing anything about autism*", "*the manner in which the diagnosis was given to us would have been, I suppose, in one sense, quite cold and calculating, it sort of accounted this is the problem, that's it, goodbye*", "*anything that people could say to me wouldn't have been helpful, I wanted my son back*". This response may reflect the relative contiguity in time of the diagnosis with the focus group interview sessions. Although between 10% and 25% of responses from the participants in the other two groups also expressed this view, this percentage is substantially less than for the parents of the younger-aged children, who have had their diagnosis, generally, closer in time to the focus group interview sessions than the former two groups.

When the participants reported that something was positive about the diagnostic process, this typically concerned their feelings of relief that they were correct in their suspicions that something was wrong with their child's development: "*relief, yes, yes, I mean, I'd been battling for years*", "*we were relieved*", "*there's a kind of relief*", "*our suspicions, as being those that actually live and bring up our child, were actually founded, that we weren't sort of quite mad or paranoid*"; and that they were not merely 'bad parents': "*I mean, because we couldn't say what it was before, and we kept getting blamed*", "*it took the blame off me, if that makes sense*", "*I hated, I mean, it's awful to be labelled more or less a bad mother for all these years of your life when you've tried so hard to do the right thing for your child*", "*it did help me, if it didn't help my son*", "*what* *was helpful, just knowing, just knowing really*". A smaller proportion of the participants' responses concerned the increase in understanding of the problems that the parents faced: "*now we can explain to people 'cos why he won't go out to play*"; and the increase in support that this diagnosis could afford their child: "*it's a bit like, you know, playing the Asperger's card almost, my son's got this, therefore, give me whatever I need*", "*we managed to get some extra disability ... I know money isn't everything, we have to take my son everywhere, he can't go anywhere on his own, he's eleven now, he can't even walk down the road on his own*", "*we've got that extra money, if nothing else*".

The lower panel of Table 6.6 shows the participants' views on what could be improved about the diagnostic process. Across all three age groups, a view often expressed was that more offers of support and help could have been made at the time of diagnosis. Many of the parents' responses stressed that it was important that they received information about various organisations and services that could be of help to them: "*information is given, and choices are available*", "*more information*". In fact, 24% of all of the responses made by the parents of pre-school aged children concerned receiving information about services and early interventions available for their child. For the parents of the youngest children, it was important to receive information about what to expect as a consequence of their child having ASC: "*will he ever be able to work?*", "*is there any chance for this child to have a future, or they going to have to be cared for, for the rest of their lives?*", "*the school perhaps could be a bit more educated*". Perhaps not surprisingly, this need for information about what to expect declined in the parents of the older children. Most strikingly, however, was that close to 50% of the responses from the parents of the older children suggested that the most important improvements that could be made concerned the speed and standardisation of the diagnostic process. The speed of diagnosis, in particular, was a major concern, with many responses expressing concern that it was far too slow: "*the diagnosis comes in too late*", "*I'm very, very bitter at the delay that we've had with our son*", "*the sooner you get in, the further you get*", "*all you get is delay, after delay, after delay*". Additionally, it was often expressed that there was no clearly delineated process, or channel, for obtaining the diagnosis: "*I felt it was really by pure chance that I got the diagnosis*", "*there was nothing automatic about that*", "*something more automatic should have taken place*", "*there is a need for agencies to work together, so that referrals are dealt with*". Relatively few of the statements made in response to this question were concerned with the need to gain practical information on how to deal with a child with ASC.

What Types of Help Have You Been Offered by the Professional Services?

Table 6.7: Percentages of responses to Question 4: "What types of help have you been offered by the professional services?".

	Pre-school	**Primary**	**Secondary**
Respite Care	2	1	7
Reviews With Professional	5	9	4
Educational Help	21	28	28
Community Nurse / Worker Visits	4	5	10
Intervention Packages (Portage, EarlyBird, etc.)	27	6	10
Medical Help	5	11	10
Nothing / No Offers	36	40	31

Table 6.7 shows the responses to the question regarding the types of professional help that the participants perceived themselves to have been offered. One striking feature of these data that deserves immediate comment is that between 30% and 40% of the responses suggested that the participants felt that they had received no offers of help: "*overall, we didn't receive any*", "*well, we actually didn't have any help offered at all*", "*they said they just couldn't do anything, because they didn't have time, once he'd got the diagnosis*", "*we were just left really*", "*it got so bad that the autistic society stepped in and said, you know, this family is just going to fall to pieces, someone's going to get seriously hurt*", "*since my son's been diagnosed, I haven't had any help from anyone*".

Around 30% of the responses in the group of parents of pre-school aged children mentioned that they had received offers of some form of intervention package: "*Speech Therapy*", "*Portage service*". The offer of an intervention package was replaced by advice from teachers: "*and since she's been at the school, they've been very helpful, they've taught me a lot about the autism*", "*I found that I got a lot of support from the Special Educational Needs Co-ordinator*"; and by offers of placements in schools: "*this family needs help, what about D?; ...a specialised unit for children with emotional behaviour problems to do with some kind of disorder, not all autistic, but my son was there for that reason*"; as the prime forms of help noted by the parents of the older children groups. This change in the prime form of help offered between pre-school aged children and the older children most likely reflects the forms of help currently being made available to the parents, depending on the age of their child, rather than reflecting any change in practice over time, as most parents appeared to interpret the question in the former manner.

This educationally-based help was appreciated a great deal by the parents, who spoke highly of this help when it was provided: "*they have helped him*", "*I think, now, we seem much more hopeful for the future*", "*they really have been very helpful, the school, and my GP has been very good as well*", "*you'll get very helpful people like the headmaster at E ...and, you know, the Special Needs lady at F ...were just brilliant, but, I think, a lot of the time, you know, people have to really shout and scream*".

At What Stage do You Feel the Information About the Various Types of Professional Help Would, Ideally, Have Been Given to You?

Table 6.8: Percentages of responses to Question 5: "At what stage do you feel the information about the various types of professional help would, ideally, have been given to you?".

	Pre-school	**Primary**	**Secondary**
Immediately / Directly After Diagnosis	84	67	35
After Some Months	8	3	12
Phased / Follow-up Information	8	30	53

Responses to Question 5, concerning when information about help should have been given, are shown in Table 6.8. These data are relatively straightforward, in that parents for the two youngest age groups (pre-school and primary) overwhelmingly wanted all of the information to be made available to them immediately at the time of diagnosis: "*I think when they sort of, maybe, start doing tests to determine whether a child has autism, or whatever, maybe, give you some more information then, be more* *open*", "*right from the start when you first sort of suspect something may be wrong, then*", "*tell you right at the start, more fully, more openly, tell you more about it*", "*if I'd been pointed towards Asperger's and autism, and read it, I would have known that's what my son had*", "*more or less, straight away, I think*", "*straight away*", "*immediately*". This was true, even when the parents recognised that they may not be able to take in all of this information immediately after the diagnosis: "*it would've been helpful just to have a very generalised, not a deep, I don't know I could have coped with loads and loads of leaflets*", "*it's very difficult to assimilate a diagnosis of autism*". However, these parents felt that the fact that they had such information at hand, should they need it, would be a great benefit to them: "*give us some leaflets of different things about children with difficult problems, and let me read them*", "*it should be there all the time, whether you need it, or not, before you get to that stage [breaking point]*". In contrast, the parents of the older children produced a different pattern of responses to this question. This group of parents suggested that the introduction of information about help should be phased over a period of time after the diagnosis: "*Probably, I'm still learning about things, but everything I learn about usually helps*", "*it doesn't have to ever stop, does it, it could be ongoing*". This pattern of results actually reflects concerns of these parents about issues, such as school transitions, especially those issues revolving around leaving school, which may not impact immediately on parents of younger children.

What Support and Professional Help do You Currently Receive?

Table 6.9: Percentages of responses to Question 6: "What support and professional help do you currently receive?".

	Pre-school	Primary	Secondary
None	31	36	44
Disability Allowance	5	0	4
Intervention Packages	39	4	11
Medical / Nurse Visits	5	20	4
Educational	20	33	29
Respite	0	7	8

In response to Question 6 about the types of professional help and support currently received (see Table 6.9), about 40% of the responses of the parents of pre-school aged children concerned early-intervention packages: "*ABA, Applied Behavioural Analysis, it used to be known as Lovaas*", "*from this EarlyBird programme we're doing, at the moment*", "*the Hannon programme, which is very similar to the EarlyBird*". A further 20% of the responses of this group concerned educational help received from specialist teachers, or nursery placements: "*the only real support I feel we're getting is through people like the [nursery] group*", "*you get so much support there*". This help was well received among the parents, and shows a strong picture of early help being offered. The picture changes somewhat for the two groups of parents of the older children, in that they do not mention intervention packages to the same extent as parents of pre-school aged children. About a third of the responses from the groups of parents of the older children concerned the help that they received from schools and teachers: "*the special school that my daughter goes to*". This help was, similarly, positively viewed, as in the group of parents of the youngest children. That the proportion of responses falling into this category was similar across all three groups suggests a consistency in the degree of help and support offered through educational authorities, and by educational professionals, over the course of the children's development. However, it should be noted that a high proportion of the responses from parents of the older children also suggested that the participants felt that they received no professional help or support: "*I'm absolutely desperate for respite care, and I'm not receiving it*", "*I'm trying to find avenues in order to get more help*", "*it's that bad, it's that isolating, and I feel that shoved out of society*", "*there's not enough real help*".

How Could Communication Between the Professionals and Yourselves be Made Better, and What Would be Your Preferred Method of Communication?

Table 6.10: Percentages of responses to Question 7: "How could communication between the professionals and yourselves be made better? What would be your preferred method of communication?".

	Pre-school	Primary	Secondary
Restructured Service	18	24	35
More Access to Professionals	13	33	24
Greater Flexibility of Groups	3	13	5
Support Groups and Meetings	51	18	23
Newsletter	8	1	10
Face-to-Face / Home Visits	7	11	3

Question 7 concerned the participants' suggestions about how to improve communication with professionals. Their responses to this question are displayed in Table 6.10. These results reveal a wide range of suggestions for improving the nature, and manner, of the communication between professionals and parents. Many responses of the parents of the youngest children indicated that these participants felt that greater opportunity to contact support groups: "*I feel quite lucky, because I did have that group for parents of newly diagnosed children*", or to talk to other parents in a similar situation to themselves: "*I would have loved just to have had some, to have met other parents*", "*not just to have come away and be left, and not know anybody else, no other mothers, nobody else, with children with autism*", "*if parents like ourselves could make up a pack that could be handed out for future parents*", would be of great benefit. Although, many suggested that it would be helpful if a professional attended such groups, this was not universally thought to be necessary. Many other responses to this question involved the need to gain more access to professionals. This was expressed through the desire to have queries answered in a shorter space of time by professionals: "*it's still slightly bizarre or surreal in my own mind, because I rang this number, which I thought would be answered immediately, and I was told that I was in a queuing system, could I be patient and wait, while this adolescent was waving a knife in front of me*", and by the possibility of being able to contact the professionals more easily and more often: "*quite often, it's very difficult to get hold of consultants*", "*I don't also think it's really the doctors' fault, I don't think they've got the time*", "*they haven't got enough Child Psychiatrists*", "*Social Services, I think, they need more people*", "*they need to be more available*".

A strong view, articulated by the respondents, was that communication could be made easier by restructuring the services provided: "*looking back, I sometimes wonder if my GP could have been more involved ...a GP is much more accessible, they're local*". This view became more pronounced in the parents of the older children. Many participants felt that there was little continuity, or communication, between the various services and authorities involved: "*I find it very frustrating how Social Services, Health, and Education ...all work very much independently of one another*", "*they are very guarded in sharing information, and they're very reluctant to actually get around the same table*". For example, the diagnosis was generally medical in nature, but the help offered was largely educational. The need for a more coherent service and system, involving Health, Education, and Social Services, was often stressed: "*the sooner the three work together, the better it would be*", "*tri-agency alliances are a must*", "*a joint file, not each and everyone keeping their own individual files*". One means by which this could be facilitated was thought to be by the appointment of a 'key worker' for the parents: "*if there was somebody standing beside the parent, speaking on their behalf*", "*to help the parent access Education, Health*". This 'key' person was suggested to act as a point of contact for the parents throughout their involvement with the various services. Such a 'key worker' was suggested to be somebody who could have quick access to the child's records, and who could give information about the appropriate agencies: "*someone who is able to communicate between the agencies*", "*a liaison officer who could have said 'OK, right, you go here for this, and here for that'* ", "*as a passer-on of information*", "*to co-ordinate what was happening in all the other areas*".

What Professional Help, Ideally, Would You Have Liked to Receive?

Table 6.11: Percentages of responses to Question 8: "What professional help, ideally, would you have liked to receive?".

	Pre-school	**Primary**	**Secondary**
Support Group for Parents	8	5	10
Educational	10	18	13
Whole Family Support (e.g., Groups, Counselling)	16	12	16
Practical Training Programme for Parents	16	21	5
Training for Professionals to Increase Understanding	14	11	27
Information	30	27	6
Professional to Regularly Assess Child	6	3	10
Respite	0	3	13

Table 6.11 displays the results of the responses to Question 8, about the types of professional help that would have, ideally, been received. There were a great many forms of professional help that the participants would, ideally, have wished to have received. These ranged from further information: "*I didn't realise he could have had help*", "*I would have benefited from someone coming round ...and telling me 'don't expect this too soon', or 'don't expect that behaviour'*", suggested by many of the responses from the parents of the younger children, to greater training for professionals, suggested by all of the groups, especially the secondary group: "*that sort of expertise is really wonderful, if you can access it*", "*mainstream nursery schools with inadequately educated assistants*", "*who haven't any idea about autism*". This latter suggestion typically involved the need for greater awareness in medical practitioners and teachers regarding the problems of

ASC: "*more professional help, more understanding*", and many calls were made for more open-mindedness in professionals about possible causes and treatments of ASC: "*a general openness all round*", "*rather than actually judging that person ...to actually stop and listen*", "*a much more open approach, and a much more honest approach*". Finally, parents of the older children often suggested that respite would be of great benefit to them: "*people who would befriend him ...like a buddy system, where people would befriend and actually just sort of spend time ...and actually take him outside the family environment ...it alleviates some of the burden from me and my wife, and particularly my other children*".

Discussion

One of the major objectives of this research was to investigate the ways in which communication concerning ASC, and its diagnosis, could be facilitated between parents and professionals. This present study was an attempt to further discern, and bolster, the findings from previous investigations regarding how parents view the diagnostic process concerning ASC (e.g., Brogan & Knussen, 2003; Goin-Kochel *et al.*, 2006; Howlin & Moore, 1997). It also attempted to advance this literature by discovering how the parents feel that this diagnostic process could be improved. In addition to enhancing communication and contact with the professionals, this information is potentially important in reducing stress in the families of children with ASC. As discussed above, such parental stress may have a negative impact on the prognosis for any early teaching intervention programmes for children with ASC (Robbins *et al.*, 1991; Chapter 2).

The perceptions of the parents from the present study can be summarised in the following manners. At the time of diagnosis, most of the parents wished for a quicker and easier process (see also Goin-Kochel *et al.*, 2006; Mansell & Morris, 2004). In particular, they would prefer the procedure to have a more coherent structure and content (see also Goin-Kochel *et al.*, 2006). Additionally, they requested greater professional awareness of, and training about, ASC, in particular regarding the information that professionals possess, and the interpersonal skills of some professionals (as also reported by Brogan & Knussen, 2003; Evans *et al.*, 2001). The idea of broad information sheets, or pamphlets, to be provided at the time of diagnosis, would be of value to many parents, especially to combat negative information provided from other sources (e.g., the internet, cf. Huws *et al.*, 2001). After a period of adjustment and consolidation, following the initial diagnosis of ASC, many of the parents suggested that they would appreciate being given more information regarding the range of interventions and educational programmes available for their children. This change over time in the perceptions of the parents of what they feel would be of benefit to them may well reflect this process of adjustment and adaptation after receiving the diagnosis. Dale (1996) and Hornby (1995) have both likened the effect of receiving an ASC diagnosis for a child to a bereavement, and an analysis of the literature on coming to terms with this latter process may help to shed some insight into the needs of parents of children with ASC following the diagnosis of their child.

In terms of the practical help and support that they would like to receive, many parents suggested that they would benefit from knowledge of, and contact with, support groups (see also Huws *et al.*, 2001). For the benefit of the interventions and educational programmes that they have been offered, the parents would like better trained, and well-informed, teachers and professionals working within the Local Authorities, and also they felt that they would benefit from a list of reputable private providers of interventions and educational programmes. The development of stronger links between professional agencies was reported as an important aspect needed to more readily facilitate the help and support that parents could be offered and given. For example, the diagnosis of ASC is made within a medical context, but subsequent help is provided, mainly, through educational channels. One suggestion about the way in which this enhanced communication between the different professional agencies could be facilitated was by the provision of a 'key-worker' to co-ordinate the work of these different agencies, which accords with suggestions made in the *National Autism Plan for Children* (NAS, 2003).

The information from this research may well be important in forming the basis for action to help parents of children with ASC, and steps are being taken to develop consistent information sheets across the South East region of England (see SERSEN website). However, these current findings also allow comparison with previous investigations of parental views and perceptions of the diagnostic process for ASC, and subsequent professional provision (e.g., Goin-Kochel *et al.*, 2006; Midence & O'Neill, 1999; Oberheim, 1996). In all of these studies, a clear message that emerges is that parents are dissatisfied with the speed, ease, and coherence of the diagnostic process. Thus, the major findings of the previous studies are replicated in the current study's results. Obviously, this is an area that still requires much work, as these findings span a decade of research.

The parents in the present study offered some suggestions as to what would improve their perceptions and experiences of the diagnostic process. These suggestions made by the parents deserve serious consideration. A common view was that a support group, or some counselling, may well be beneficial. There is some evidence on the effectiveness of such support groups, and of counselling, however, it is not as positive as many of the parents may hope. For example, Bitsika and Sharpley (1999) noted that general counselling produced only a slight improvement in the well-being of parents, but these gains were not consistent across all parents. In fact, such counselling sessions were found to be much more helpful if they were coupled with specific behaviour management training (Bitsika, & Sharpley, 2000; see also Sharpley, Bitsika, & Efremidis, 1997). The results of such studies should be used to tailor any programmes produced in response to parental demands and suggestions.

Of course, there are a number of limitations to the present study that need to be discussed. The size and representativeness of the participant sample have to be considered. The current study involved seventy parents, which is a large number of participants for a focus group study, but is still a relatively small number, compared to the number of parents of children with ASC, in total. Despite these reservations, it should be noted that there was a reasonable consistency between the perceptions of the various focus groups. Moreover, the size of this current study is larger, in terms of the number of Local Authorities involved, than many previous studies of a similar design, and also is larger, in terms of the numbers of parents interviewed, than some previous research. As the participants in this present research were volunteers, their representativeness of parents, in general, may be an issue that limits the generality of the conclusions that may be drawn from these data. It may be that, although the parents were randomly selected for invitation to attend the focus groups, there may well be an element of self-selection concerning those who actually chose to attend. For example, it could be that those who attended felt more strongly (either positively, or negatively) about the diagnostic process than those who chose not to attend. Finally, as with any analysis of interview-based, or focus-group, data, these perceptions and opinions should be considered as a measure of the strength of feeling about particular issues, and should not be regarded as an indication of their frequency in the general population. Although this is a limitation regarding the use of qualitative methodology, studying the effect of diagnosis would be extremely difficult prospectively, and only can realistically be achieved retrospectively, and/or through qualitative means.

Appendix 6.1: Moderators' Script for Interviews

Introduction

After an initial meeting period (perhaps ten to fifteen minutes over tea or coffee), the introduction allows the Moderator to outline the scope and purposes of the Focus Group, and the guidelines for participation. Take about five minutes to do this.

Welcome

"Welcome and thank you for coming to this Focus Group. We are very happy that you are able to help us, because all of your points of view are important to us. We know that you are busy, and we greatly appreciate your contribution to this project. This interview is not a test, nor should it in any way be viewed as a series of questions with right or wrong answers. We are very interested in what you think and feel, and we want to know your opinions on these issues. We are seeking to elicit your considered points of view and an account of your experiences. You do not need to agree with the opinions of others, although there may be times when you do, and it is appropriate for you to let us know that as well."

"I should point out that this group discussion is being audio-taped, so that it can be written into a transcript later. I would like to assure you that you will be assigned false names for the purposes of transcription and data analysis, so that you will remain anonymous. Once transcribed, the tape will be destroyed."

Purposes

"The purpose of this Focus Group interview is to determine your experiences of getting a diagnosis of autism, and the help that has been given since that diagnosis."

"We would like to know what information you were given, whether it was helpful, and what was done after the diagnosis was given."

"Your views and feelings about how helpful you found the process, and what could have been done to improve the situation, would be particularly welcome."

Guidelines

"There are a few guidelines that I would like to ask you to follow during the Focus Group interview."

"Firstly, you do not need to speak in any particular order. When you have something to say, please do so."

"Secondly, please do not speak while somebody else is talking. Sometimes, the issues get emotional, and it is tempting to 'jump in' when somebody is talking, but we ask you to refrain from doing so."

"Thirdly, remember that there are many people in the group, and that it is important that we obtain the points of view of each of you."

"Fourthly, you do not need to agree with what everyone, or anyone, in the group says, but you do need to state your view points without making any negative comments or 'put downs'."

"Finally, because we have only a limited amount of time together, occasionally, I may need to stop and redirect our discussion."

"Do you have any questions?...... O.K., let's begin."

Warm Up

This provides an opportunity for general questions and relaxation. Allow each participant about a minute to address these warm-up questions.

"You may have had a chance to meet each other already, and to ask each other some questions. However, it would be very helpful if we could all introduce ourselves. I'll start. My name is ....., and I'm involved in autism through my work as ......"

Go around the group, and get everybody to introduce themselves, and their interest in, and connection to, the topic. While they introduce themselves, make a 'table map' of where the participants are seated to help you identify them during the discussion.

The Questions

Here, the Moderator will go around the group members, collecting all their opinions. Try to vary the order in which the group members are asked the questions. It is of help if you can refer to the person by name when you are asking them a question. If somebody's answer appears to be difficult to hear, then summarise what they have just said, and ask them if that summary is correct.

Allow about five to ten minutes for each question. Do not discourage people from returning to the topic, once everybody has had a chance to answer, but remember that there are quite a lot of questions to get through. If somebody does not understand a question, then try to prompt them, using the prompts provided. It is very important, however, to stick as closely to the script as possible, so that all of the Focus Groups elicit the same information, and the analysis can be applied consistently.

"Now we have had a chance to introduce ourselves, I would like to start hearing your opinions on a number of issues concerned with your experiences of getting a diagnosis, and what happened afterwards. I will ask a question, and then go around the table, one person at a time, getting your opinions and ideas."

"Could you say who made the diagnosis, and which factors lead them to make the diagnosis? Let's start with ..... " (Go around the group, "*Now, what about you, ...?*".)
PROMPT: "*What were the symptoms that seemed most important during the diagnosis*"

"What types of support, advice, and information were you given about understanding the nature of autism?" (Go around the group, but in a different order from above.)
PROMPT: "*Perhaps you were given some leaflets, or a list of useful books?*"

"It would be very useful to know what you found helpful about the process of getting the diagnosis. When everybody has had a chance to answer that question, I would like to get your views about what could have been improved about the process. First of all, what was helpful about the process? " (Go around the participants.) "*Now, what could have been improved about the diagnostic process?*" (Go around the participants again.)

"*Since the diagnosis, what types of help have you been offered by the professional services (for example, by Education, Health, or Social Services)? Could you say also when you were offered this help?*" (Go around the participants, vary the direction.)
PROMPT: "*Have you been offered special education programmes, medical treatment, or respite, for example?*"

"*We would be very interested to know at what stage you feel the information about the various types of professional help you have mentioned would, ideally, have been given to you?*" (Go around the participants.)
PROMPT: "*Would you have liked all the information at the time of the diagnosis, or would it have been better to receive the information some time after the initial diagnosis?*"

"*What support and professional help do you currently receive?*" (Go around the participants in the opposite direction.)
PROMPT: "*For example, does your child receive any particular educational help, or medical treatment, or do you receive respite?*"

"*How could communication between the professionals and yourselves be made better? What would be your preferred method of communication?*" (Go around the participants.)
PROMPT: "*For example, would you like to have regular support group meetings, or a newsletter?*"

"*Finally, what professional help, ideally, would you have liked to receive? This help may be part of an intervention for the child, or may be provided for the family as a whole.*"
(Go around the participants.)
PROMPT: "*Would the best help be concerned with your child's academic skills and behaviour, or would you find help with coping with the difficulties yourself most useful.*"

Wrap Up

Here, the Moderator will attempt to identify the major themes of the participants' responses, and will organise these in a summative manner. Also, the Moderator will aim to ensure that any controversial points that were not completed are recognised.

"Unfortunately, we are close to being out of time. Once the interview gets started, it moves at a fast pace, and there is less time to express your points of view than we would like. Let me attempt to summarise the key ideas I have heard ..... "

"There were several topics that we touched upon that we were not able to complete discussing during this Focus Group. These seemed to be ..... "

Participant Check

Here, how each participant feels about selected issues can be verified.

"Let me identify some key discussion points, then I would like to find out how each of you feel about them, by checking with each participant. At this point, I'm not looking for further discussion, just a general idea of how many of you feel a particular way."

Closing Statements

"As we come to a close, I need to remind you that the audiotape will be transcribed. You will be assigned false names for the purposes of transcription and data analysis, so that you will remain anonymous, and then the tape will be destroyed. We ask that you respect the right of each member of the group to remain anonymous, and refrain from discussing the comments of the group members outside the group. Are there any questions that I can answer?"

"This was a very successful Focus Group interview. Thank you for your valuable contribution to this project. Your honest and forthright responses will be an enormous asset to our work. The results of this project will be fed back to you. "

"Again, we very much appreciate your involvement. Thank you."

Chapter 7:

A Possible Contra-indication for Early Diagnosis of Autistic Spectrum Conditions: Impact on Parenting Stress

Introduction

Early diagnosis is a common goal in the management of many medical conditions, and the associated early treatment leads to enhanced outcomes, and better long-term prognoses. The same is true for the diagnosis of Autistic Spectrum Conditions (ASC) in children. It is often suggested that intervention for ASC is more effective if offered early, rather than remedially later (Lovaas, 1987), and such assumptions and suggestions produce pressure for earlier diagnosis of ASC. However, the diagnosis of mental problems can have dichotomous and paradoxical effects. For example, people diagnosed with schizophrenia can have poorer probability of remission than those with no such label (Bentall, 1990). In paediatric cases, the impact of diagnosis is also often seen in the parents, and, through their influence, affects the children. Although an early diagnosis of ASC can facilitate access to services (Gillman, Heyman, & Swain, 2000), and enhance treatment prognosis for the child (Lovaas, 1987), it may be the case, as described in Chapter 6, that the diagnosis of ASC may possibly produce elevated levels of stress in the parents.

As discussed in the previous chapter, one area that has a high capacity for producing stress in parents of children with ASC is their experience of communication with professionals, and a key aspect of this communication concerns the process of getting a diagnosis (Goin-Kochel, Mackintosh, & Myers, 2006; Howlin & Moore, 1997). In Chapter 6, it was discovered that issues, such as the speed of diagnosis (Mansell & Morris, 2004), the chain and coherence of referral through the system (Goin-Kochel *et al.*, 2006), the help offered to parents at the time of diagnosis (Chapter 6), and the communication styles of the professionals involved in the diagnostic process (Bartolo, 2002), may all be implicated in the development of stress in parents during the diagnostic process. Resultant, and often heightened, parental stress was impacted further by the fact that many parents felt that they were given no help and advice following diagnosis.

Contact with professionals concerning diagnosis of ASC in children often comes prior to engagement in treatment programmes. If the contact has been stressful, this may lead to subsequent treatment being less effective and successful (see also Brogen & Knussen, 2003). In terms of treatment outcomes, Robbins, Dunlap, and Plienis (1991) noted a strong relationship between mother-reported stress and the child progress, recorded twelve months later, in young children with ASC in a family-orientated training programme. Similar findings have been reported by Carlson-Green, Morris, and Krawiecki (1995), who noted that the best predictors of children's behaviour problems and adaptive behaviour, following intervention for paediatric brain tumours, were family and demographic variables, including family stress. Such a finding was also reported in Chapter 2, regarding the negative impact of parenting stress on outcomes following early teaching interventions for children with ASC. High levels of stress in the parents also can have detrimental impacts on the children in terms of behaviour problems (e.g., Lecavalier, Leone, & Wiltz, 2006; Chapter 3).

In order to explain these findings, it has been proposed that high levels of parenting stress impact negatively on subsequent parenting behaviours, which, in turn, impact on a child's behaviour problems, and outcomes. There is some evidence to support this suggestion for parents within the general population (Kotchick, Dorsey, & Heller, 2005; Meyers & Miller, 2004; Rodgers, 1993; 1998), and also for parents of children with ASC, in particular (Chapters 4 and 5).

Thus, a picture emerges in which it is acknowledged that the parent plays a pivotal role in the prospects for the child with ASC, and that those parents suffer from high levels of stress, which have, in turn, a negative impact on the prospective outcomes of their children. Many of the early stressors may revolve around communication and contact with professionals over the critical period of time in which a diagnosis of ASC is sought and obtained. Given that high parenting stress can inhibit the effectiveness and success of treatment, the experiences of parents during the diagnostic process may be of particular importance. However, importantly, there has been relatively little research effort devoted to discovering, and learning about, the impacts of the diagnosis of ASC for the child on the levels of stress in the parents.

Method

Participants

A total of 149 children with ASC (135 male and 14 female) were identified in conjunction with Local Education Authorities in the South East of England. The identified children were between 3 and 16 years of age, at the time of the study, and previously had been independently diagnosed with ASC by specialist Paediatricians, following initial referral from an independent general medical practitioner. All diagnoses were made prior to potentially participating in, and the commencement of, this study. In addition to these independent diagnoses of ASC, all of these children had a statement of Special Educational Needs related to their ASC from their Local Education Authorities.

All of the parents of these 149 children were contacted, and, of these, the parents of 85 children (comprising 83 male children, and 2 female children) agreed (57%

agreement rate), and they provided parental consent for their own, and for their child's, participation in this research. All of the parents who agreed, and consented, to participate, completed the study. The children who participated had a mean age of 8:8 years.

The independent diagnoses were supported in the present study by the use of the Gilliam Autism Rating Scale (GARS), which allowed further independent assessment of the degree of their autistic severity. The GARS measure showed that the mean (standard deviation) of the overall GARS score for this sample was 90.5 (± 15.7), indicating that this sample was of a slightly milder than average autistic severity. The scores for the four sub-scales of the GARS, each representing a different aspect of the disorder, showed a similar pattern, in that all of these scores were slightly milder than the average. The mean sub-scale scores were: *Stereotyped Behaviors* = 8.0 (± 3.0); *Communication Problems* = 5.2 (± 4.5); *Social Interaction Problems* = 7.7 (± 3.1); and *Developmental Disturbances* = 9.0 (± 3.0). The intellectual functioning of the children was assessed by the British Abilities Scale, which revealed a mean *Cognitive Ability Score* of 68.1 (± 22.6). Similarly, the Vineland Adaptive Behavior Scale *Overall Composite* score for these children was 55.2 (± 14.0).

Measures

Gilliam Autism Rating Scale: The GARS (Gilliam, 1995) comprises four sub-scales, each sub-scale describing behaviours that are symptomatic of ASC (*Stereotyped Behaviors*, *Communication, Social Interaction,* and *Developmental Disturbances*). The raw scores from these sub-scales can be converted into standard scores (mean = 10, standard deviation = 3). These sub-scales combine to give an overall *Autism Quotient*; higher scores meaning greater autistic severity (mean = 100 [average autistic severity], standard deviation = 15). In terms of assessing the probability that an individual has ASC, an *Autism Quotient* score of between 90 to 110 means an 'average' probability of ASC, a score below 89 means that there is a 'below average' probability of ASC, and a score below 79 means that there is a 'low' probability that the individual has ASC (Gilliam, 1995). The scale is appropriate for persons aged 3 to 22 years old, and is completed by parents, or professionals, in about 10 minutes. Its internal reliability is 0.96, and it has high criterion validity with the Autism Behavior Checklist (0.94).

British Abilities Scale: The BAS II (Elliott, Smith, & McCulloch, 1996) is a battery of tests of cognitive abilities, which index educational achievement and intellectual functioning. It is suitable for use with children and adolescents from 2:6 to 17:11 years old. This test allows the calculation of a *General Cognitive Ability* scale (mean = 100, standard deviation = 15), which represents intellectual ability.

Vineland Adaptive Behavior Scale: The VABS (Sparrow, Balla, & Cicchetti, 1990) is a semi-structured interview, administered to a parent, or other caregiver, of the child. It can be used from birth to 18:11 years, making it suitable for the present cohort. The VABS assesses children's day-to-day adaptive functioning. Scores from three domains of adaptive behaviour were used in the present study (*Communication*, *Daily Living Skills,* and *Socialization*). The raw scores can be converted to standard scores, and a *Composite Overall* score can be derived, based on the sum of the sub-scale standard scores (mean = 100; standard deviation = 15). The internal reliability of the *Overall Composite* score is 0.93.

Questionnaire on Resources and Stress: The Friedrich Short-Form of the QRS (Friedrich, Greenberg, & Crnic, 1983) is a 52-item, self-administered, true or false, tool, designed to measure parental perceptions of the impact of a developmentally delayed, or chronically ill, child on other family members. The QRS-F consists of four sub-scales, which assess parental perceptions about: *Parent and Family Problems* (total possible = 20) – dealing with the impact that the disability has on family activities or relationships; *Pessimism* (total possible = 12) – related to parent depression; *Child Characteristics* (total possible = 14) – dealing with the impact of the child's problems on the family; and *Physical Incapacity* (total possible = 6) – which examines the family problems produced by the child not being able to perform certain activities for themselves. Higher scores are indicative of greater perceived stress within the family, as perceived and indicated by the parents (but not, it should be noted, of a greater degree or number of actual stressors, see Dyson, Edgar, & Crnic, 1989). The internal reliability of the sub-scales ranges from: 0.77 (*Physical Incapacity*) to 0.85 (*Child Characteristics*). This tool has previously been employed for samples with ASC in assessing stress in parents (e.g., Hastings & Johnson, 2001), and so allows comparison with previous studies.

Procedure

The parents of the children, initially identified by the Local Education Authorities, were contacted, and, on choosing to participate, parental consent was obtained. Autistic severity (GARS), intellectual functioning (BAS), and adaptive behavioural and social functioning (VABS) were measured for all children. In addition, measures of self-reported parenting stress (QRS-F), and a brief history of the child's problems and treatments, were collected.

The children were visited by an Educational Psychologist, who was blind to the levels of parenting stress, and the child measures were taken (GARS, BAS, and VABS). Parents were contacted, at this time, and asked to complete the QRS-F, and to give some background regarding their child, such as the age of their child when they first noticed a problem, and the age of their child at diagnosis, as well as a brief history of their child's provision, which they did independently.

The questionnaires were sent out by post to the parents, along with an information letter, and a pre-paid, addressed return envelope. The information letter provided contact details, offering parents the opportunity to seek help and guidance, if required, regarding the completion of the questionnaires. However, it was extremely rare that any parents made contact in order to ask advice about answering specific questions. On completion, the parents used the pre-paid envelope to return the questionnaires. As an added incentive for returning this information, the parents were automatically entered into a prize draw, the winner of which received £50 for toys or books for their child. This incentive was specified in the information letter. If parents had not returned the questionnaires after a period of time, they were contacted, via telephone, and reminded, and given the opportunity to return the completed questionnaires.

Results

Table 7.1 displays the mean (and standard deviation) for the children's levels of autistic severity (GARS), and adaptive behavioural functioning (VABS), along with the mean age (in months) at which the parents first noticed that their child had a problem, and the mean age (in months) at which the diagnosis was received. From these data, it can be seen that the autistic severity of the children was slightly milder than average, but that their adaptive behavioural functioning was very low (in the bottom 1% of the general population). The mean age at which the parents reported first noticing a problem was about 21 months (range: birth to 72 months), and the mean age at which a diagnosis was received was about 45 months (range: 16 to 192 months), with an average period between noticing and diagnosis of 24.3 months (± 27.7; range: 1 to 144 months).

Table 7.1: Mean (and standard deviation) for the children's autistic severity (GARS), adaptive behavioural functioning (VABS), and ages in months at the time of the parents' first noticing a problem, and at diagnosis, parenting stress levels, and the correlations between these variables.

		GARS	VABS	Noticing	Diagnosis
QRS Stress	Mean	89.5 (15.7)	55.2 (14.0)	21.4 (11.1)	45.6 (31.8)
Family	8.4 (5.3)	0.180	0.027	- 0.041	0.011
Pessimism	7.1 (1.9)	0.230**	0.037	- 0.076	0.050
Child	7.9 (2.8)	0.353***	- 0.062	- 0.056	- 0.227*
Incapacity	2.0 (1.7)	0.285***	0.033	- 0.092	- 0.285**

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table 7.1 also shows the mean levels of parenting stress, reported by the parents, and the correlations between these parenting stress levels, and both: the two child characteristics, and the temporal details of noticing and diagnosis, as noted above. From these correlations, it can be seen that autistic severity had statistically significant correlations with all of the parenting stress sub-scales, except for the *Parent and Family Problems* sub-scale. The greater the autistic severity, the greater the parenting stress.

However, only the parenting stress relating to *Child Characteristics*, and to the child's *Physical Incapacity*, had statistically significant correlations with the age at which the child was diagnosed. The younger the child at diagnosis, the higher the parenting stress levels. No stress sub-scale was related to the age of the child at which their parents first noticed a problem.

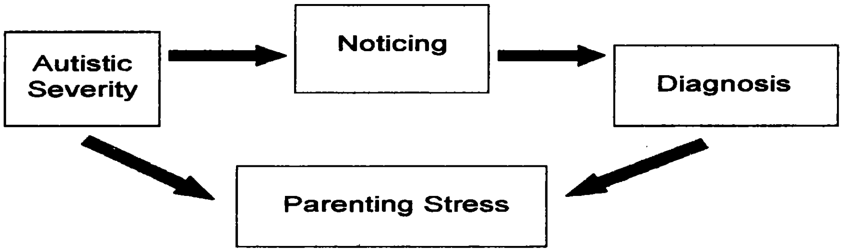
Table 7.2: Standardised beta coefficients for the predictions of the children's ages at the time of the parents' first noticing a problem with their child, at the time of diagnosis, and for parenting stress levels.

Prediction					
Noticing		Diagnosis		Child Characteristics Stress	
GARS	-0.300**	GARS	-0.017	GARS	0.367***
VABS	-0.025	VABS	-0.164	VABS	0.024
Child	0.054	Child	-0.190	Noticing	0.170
		Noticing	0.514***	Diagnosis	-0.237**
Noticing		Diagnosis		Physical Incapacity Stress	
GARS	-0.283**	GARS	-0.011	GARS	0.349***
VABS	-0.023	VABS	-0.133	VABS	0.157
Incapac.	0.008	Incapac.	0.214	Noticing	0.140
		Noticing	0.506***	Diagnosis	-0.262**

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$

Table 7.2 shows the standardised beta coefficients from a series of multiple regressions. These attempted to identify the independent contributions of the child's autistic severity, the child's adaptive behavioural functioning, and the age of the child at which the parents first noticed a problem, to the diagnostic process, and to the resulting parenting stress. Only the parenting stress relating to *Child Characteristics*, and to the child's *Physical Incapacity*, were studied, as these were the only sub-scales that had statistically significant correlations with the other measures in this study. Both the analysis using parenting stress relating to *Child Characteristics*, and the analysis using parenting stress relating to the child's *Physical Incapacity*, showed highly similar results to one another (and a schematic representation of these results is displayed in Figure 7.1).

Figure 7.1: A schematic representation of the interactions between autistic severity, parents' first noticing a problem with their child, receiving a diagnosis, and parenting stress.



The only statistically significant independent predictor of the age of the child at which the parents first noticed a problem was autistic severity; the greater the autistic severity, the younger the child was when a problem was first noticed. The adaptive behavioural functioning of the child, and parenting stress, made no statistically significant contributions to the age of the child at which a problem was first noticed.

The only statistically significant independent predictor of age at which the child was diagnosed with ASC was the age of the child at which the parents first noticed a problem. The younger the child was when the parents first noticed a problem, the younger the child was at diagnosis. The child's autistic severity, their level of adaptive behavioural functioning, and the level of parenting stress made no statistically significant contribution to predicting the age of the child at diagnosis.

When parenting stress was the variable to be predicted, both the autistic severity of the child (the greater the autistic severity, the greater the parenting stress), and the child's age at diagnosis (the younger the child at diagnosis, the greater the parenting stress), made statistically significant independent contributions to the level of parenting stress. The child's adaptive behavioural functioning, and the age of the child when the parents first noticed a problem, did not independently statistically significantly predict parenting stress.

Table 7.3: Standardised beta coefficients for the predictions of parenting stress levels by: autistic severity (GARS), the time between first noticing a problem and the measurement of parenting stress, and the time between diagnosis and the measurement of parenting stress.

	Child Characteristics	Physical Incapacity
GARS	0.307**	0.266**
Noticing – Test	-0.290*	-0.370**
Diagnosis – Test	0.021	0.008

** $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$*

Table 7.3 shows the independent effects of the children's autistic severity, the passage of time from the parents' first noticing a problem, and the passage of time from the point of diagnosis of ASC, on the current levels of parenting stress. As the children's adaptive behavioural functioning showed no statistically significant relationship to any other variable in the preceding analyses, it was not included in this analysis. The mean length of time between the parents' first noticing a problem with their child, and the time at which their parenting stress levels were measured, was 53.6 months (± 45.6; range: 1 to 144 months). The mean length of time between receiving the diagnosis, and parenting stress levels being measured, was 29.4 months (± 32.7; range: 1 to 132 months).

The standardised beta coefficients from the multiple regressions reveal that autistic severity predicted levels of both types of parenting stress; the higher the autistic severity, the higher the parenting stress. There was a statistically significant negative relationship between the passage of time from the parents' first noticing a problem to their current levels of parenting stress. The longer the period of time since a problem was first noticed, the lower the parenting stress. However, the length of time since receiving the diagnosis bore no relationship to the current levels of parenting stress.

The above pattern of results implies that, the shorter the period of time between parents first noticing a problem with their child and receiving the diagnosis, the higher will be the current parenting stress levels. This implication was confirmed by two separate correlations, which showed statistically significant negative correlations between the noticing to diagnosis time period and current levels of parenting stress relating to *Child Characteristics*, $r(83) = -0.239, p < 0.05$, and parenting stress relating to the child's *Physical Incapacity*, $r(83) = -0.291, p < 0.01$.

Discussion

The current chapter investigated the impact on parenting stress of a diagnosis of ASC in children. Parenting stress has been implicated as a factor important in managing this condition. Moreover, there is increasing pressure to provide early diagnosis of ASC, despite a lack of evidence relating to the impact of such an early diagnosis on the parents. The present study noted a clear route to getting a diagnosis, in that the child's autistic severity, unsurprisingly, predicted the parents' first noticing a problem with their child. It was the age of the child at which the parents first noticed a problem, rather than the child's autistic severity, that subsequently predicted getting an earlier diagnosis.

In terms of parenting stress, the autistic severity of the child was related directly to this factor, a finding that has been noted previously (Eisenhower, Baker, & Blacher, 2005; Chapter 3). However, a novel, and potentially important, finding to emerge from this study, albeit one that will require caution, and replication, is that earlier diagnosis may be detrimental to levels of parenting stress, which subsequently can have a negative effect on children's behaviour problems (Lecavalier *et al.*, 2006; Chapter 3), and on their treatment outcomes (Robbins *et al.*, 1991; Chapter 2). Moreover, it was found that, while parenting stress declined over time from the point at which they first noticed a problem with their child, it failed to change by any significant degree once the diagnosis of ASC had been received. Thus, one interpretation of these results is that the levels of parenting stress appear to be fluid until the point of diagnosis, which appears to have the effect of crystallising these levels of parenting stress, in that they did not systematically decline over time, once the diagnosis had been received.

It was also found that shorter periods of time between parents initially noticing a problem with their child, and the child receiving an ASC diagnosis, were associated with higher levels of current parenting stress. This effect was independent of the severity of the child's ASC. Thus, the longer the period of time between initially noticing a problem and receiving a diagnosis of ASC, the lower the levels of parenting stress. This indicates that parenting stress levels may have had an opportunity to decrease from the point at which the parents had first noticed a problem with their child, before diagnosis occurred.

Given that the current findings provide a possible contra-indication for early diagnosis of ASC, in terms of its potential effects on the stress reported by parents, this is an issue that warrants caution, tentative discussion, and, certainly, further investigation. As found previously, the reason why parenting stress is important is that it can impact on the management of the child's condition (Lecavalier *et al.*, 2006; Robbins *et al.*, 1991; Chapters 2 and 3). Of course, for physical illnesses, such as cancers, early diagnosis and treatment are critical, as they lead to a better prognosis. However, for mental illnesses, this simple relationship may not always necessarily hold, and such a 'common sense' approach may sometimes be detrimental in this context. For example, it has been suggested that 'labelling' is not necessarily always helpful for some mental problems (Bentall, 1990). This issue is more complex still in paediatric cases, where the impacts of an early diagnosis, and the accompanying 'label', are felt by the parents, as well as by the child, and have secondary implications for the outcome prognosis for that child.

It must be acknowledged that many qualitative reports, in this area, have noted that, when asked directly, parents of children with ASC often say that they want an early and speedy diagnosis (e.g., Goin-Kochel *et al.*, 2006; Chapter 6). In contrast, the implication of the findings from this chapter are that parents, for whom a longer period of time elapses before they receive a diagnosis of ASC for their child, perhaps during which time they can receive help, display lower self-reported stress levels. However, it may be that what parents are implying by their responses, in such qualitative studies, is that they want to be reassured that they are not 'bad' parents (Williams, 2006), and to be supported and assured that they are not alone (Chapter 6), as well as gaining access to services for practical help that a formal diagnosis facilitates (see Gillman *et al.*, 2000).

The implications of the current findings must be weighed in terms of their potential impact on current, and future, diagnostic practice and service provision. To the extent that early diagnosis crystallises levels of parenting stress, such a strategy should be treated with some caution, and two possible alterations to practice could be considered. Firstly, there is no clear and obvious reason why a formal diagnosis should have to precede access to support, and services, for parents, and their children with ASC. For instance, it is recognised by the Welsh Assembly Government, in their recent document, *The Autistic Spectrum Disorder Strategic Action Plan for Wales* (2007), that there should be no requirement of a formal diagnosis of ASC in order for parents to receive help and support, as well as services, in managing the problems experienced by their children. The proposed policy is that, if there is a specific behavioural problem, then that problem is treated with no contingent necessity of a prior specific diagnosis. Similarly, Lauchlan and Boyle (2007) conducted a literature review, and, on the basis of this, suggest that, while it may be easier to respond where there is a clearly diagnosed need, there are many children who may not necessarily satisfy the full criteria for a diagnostic 'label', but who still require access to enhanced support, and service provision. Thus, the use of 'labels' appears to be more unhelpful, than helpful. In the light of the current findings, reported in this chapter, this approach may well alleviate much of the parenting stress, which the formal diagnosis appears to do little, if anything, in itself, to reduce.

Secondly, enhanced management of parenting stress should be an increasing feature of many interventions for children with ASC problems. For example, Baker-Ericzen, Brookman-Frazee, and Stahmer (2005) suggest such modifications as increasing family support, and incorporating parental interventions, for those parents with elevated levels of stress, in early intervention programmes for children with ASC. Findings related to these various interventions suggest that improved parent-child interactions occur through promoting low parenting stress (e.g., Koegel, Bimbella, & Schreibman, 1996; Chapters 4 and 5). Parents who receive support, which buffers stress, relate better, emotionally, to their children (Boyd, 2002). Thus, interventions that target the problems experienced by the parents of children with ASC, such as behavioural marital therapy, behavioural family therapy, and individual intervention techniques to help families adapt to the chronic stress of living with a child with ASC (Cherry, 1989; Harris, 1994), have been developed with some success. In this context, Bouma and Schweitzer (1990), and Hastings and Johnson (2001), discuss the implications of family stress for the development of family interventions, and home-based behavioural intervention programmes, when looking at chronic physical illness (cystic fibrosis), and psychological disorders, such as ASC, respectively.

For such a potentially contentious topic, the limitations of this study should be discussed, so that future work can further explore these important issues. The limitations regarding the representativeness of parents who self-selectively volunteer for such research studies, and the generalisability of the subsequent results, that were initially discussed in Chapter 4, would similarly apply to the current study. Additionally, it should be acknowledged that the present study used a retrospective approach, and a correlational design. Although it is difficult to envisage any other practical type of study design for this particular topic, this does produce issues regarding the interpretation of the data that should be mentioned. Early diagnosis is not the only factor responsible for parenting stress, and that needs to be addressed when intervening in cases of ASC. For example, individuals without access to rich social networks tend to report more stress than individuals with good social support, which may be mediated by parent-perceived expertise of those providing the assistance and respite (Factor, Perry, & Freeman, 1990; Gill & Harris, 1991; Konstantareas & Homatidis, 1989; Sharpley, Bitsika, & Efremidis, 1997; Weiss, 2002). Lack of 'hardiness', and low levels of social support, are predictive of poor adaptation and worse coping with stress, leading to 'burnout' (Weiss, 2002), and these factors predict depression and anxiety (Boyd, 2002). Likewise, individuals who employ avoidant coping strategies in response to stress tend to report more feelings of stress and mental health difficulties, compared to those who utilise positive reframing strategies (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings & Johnson, 2001). Maternal-stress and paternal-stress are associated with the depression of their partner (Hastings, Kovshoff, Ward, degli-Espinosa, Brown, & Remington, 2005), and parenting stress levels may rise due to a temporary loss of support from their partner (Hastings, 2003).

Hence, there are many factors that arguably could impact upon the levels of post-diagnosis parenting stress. However, it should be noted that these same factors would also impact on the levels of post-noticing parenting stress, but parenting stress levels still decline from the time of first noticing a problem, but do not systematically reduce after the diagnosis is received. Moreover, it is unlikely that the passage of time, in itself, is responsible for these results. For instance, it could be claimed that parenting stress levels would reduce naturally to a floor over time after parents have initially noticed a problem with their child, and this would happen, irrespective of whether, or not, a formal diagnosis is received. However, this is unlikely for two reasons: firstly, parenting stress does not reach a floor, and remains exceptionally elevated in parents of children with ASC (Blacher & McIntyre, 2006); and secondly, there was a wide range of temporal intervals between first noticing and diagnosis in the current study, making appeal to 'natural' processes in the reduction of parenting stress levels less convincing.

In summary, the current findings suggest that, in itself, early diagnosis may not necessarily be helpful to parents of children with ASC, unless it is coupled with support for those parents. At the very least, this contra-indication requires further investigation. In terms of policy, the present results imply that early access to services, and provision, for individual problems, and early emerging difficulties, are much more important (and, indeed, are potentially less harmful) than an early formal diagnosis of ASC, without accompanying support for parents, and children, alike.

Chapter 8:

A Dynamic Transactional Model of Parent-Child Interactions

1.0 Summary

This thesis identified a number of important theoretical reasons for examining the relationships between parenting stress, parenting behaviours, and child behaviour problems in Autistic Spectrum Conditions (ASC) samples. These reasons revolve around ascertaining whether these three family-centred parent-child elements interact with, or impact on, one another, and, if so, how, and what the nature, and degree, of such influences would be. Moreover, it was of interest to discover whether such family factors impacted on the effects of teaching interventions for children with ASC. As such, the results of these examinations may have some practical implications for the development of future teaching interventions for ASC, especially regarding parent training, counselling, and support.

1.1 Aims

The review of the literature, presented in Chapter 1, suggested that there was a need, firstly, to establish whether high parenting stress levels impact negatively on child outcomes during, and following, teaching interventions for children with ASC, which was addressed in Chapter 2. Secondly, it was thought important to determine the nature of the relationship between parenting stress and child behaviour problems over time, in order to determine the temporal directionality of any such parent-child interactions. A further issue, arising in relation to this question, was whether parenting stress was most strongly associated with the severity of the ASC, or with the severity of the child behaviour problems. These two topics were tackled in Chapter 3.

Chapter 4 grappled with the third, and next, identified area of enquiry, that is, whether parenting stress impacts on parenting behaviours, and the types of parenting behaviours that are influential for subsequent child behaviour problems, in the context of ASC. Fourthly, it was considered important to assess whether any association between parenting behaviours and subsequent child behaviour problems is a direct one, and not simply a by-product resulting from these two behavioural elements being impacted upon by additional factors, such as parenting stress. Chapter 5 examined this area of concern.

A fifth realm of investigation was how, and from where, parenting stress levels initially emerge, and whether parents' contact, and communication experiences, with professionals leading up to, and during, the diagnostic process is of particular significance in the generation of such parenting stress, in the context of ASC. To wrestle with these questions, Chapter 6 dealt with the subject matter of parental experiences, and perceptions, of the diagnostic process, and systems, when trying to obtain a diagnosis of ASC for their child. Furthermore, Chapter 7 extended this investigation, and examined the additional, and related, influences of both the initial emergence and parental noticing of problems with the child, and of the ASC diagnosis concerning the child, on the parents' levels of stress.

It was hoped that these interconnected investigations, conducted in this thesis, would provide some clarification of, and even answers for, these related areas of enquiry. Furthermore, it was hoped that an empirically-based model of the interrelationships between all of these family elements could be developed, on the basis of any findings that had emerged, and that this model may contribute to inform theory, aid practice, and promote further development of previous ideas, and notions, in this, somewhat, neglected field, in the context of ASC.

1.2 Thesis Results

The first empirical chapter of this thesis, Chapter 2, presented the results from a community-based study, which examined the influences of early teaching interventions on sixty-five young children who had been diagnosed with ASC. In addition, this study explored the dynamics between the time-intensity of the early teaching interventions (hours per week), and the levels of parenting stress, on child outcomes, when measured nine to ten months after the interventions had first commenced. The intellectual, educational, and adaptive behavioural and social, functioning of the children were all measured. The children in this study were divided into four groups, based on both the levels of time-intensity of their interventions, and on their parents' levels of stress. The study found that there were gains in the intellectual, educational, and adaptive behavioural and social, functioning of the children over the nine to ten month period of assessment, and that there was a positive relationship between the time-intensity of the early teaching interventions and the child outcome gains. However, more importantly for the purposes of this thesis, it was noted that high levels of parenting stress counteracted the overall effectiveness of the early teaching interventions. Children whose parents reported higher levels of stress made fewer outcome gains, even when engaged in higher time-intensity interventions, than the children whose parents reported lower levels of stress. This finding, that higher levels of stress in parents could have detrimental effects on early teaching intervention outcome effectiveness for children with ASC, acts as a fulcrum for the subject matter, and development, of this thesis.

Findings of a similar detrimental relationship between high levels of stress in parents, and the development of subsequent child behaviour problems, were obtained in the pair of studies reported in Chapter 3. This chapter presented the results from two longitudinal studies, involving a total of one hundred and thirty-seven children, and examined the interaction between stress in parents and the behaviour problems in children with ASC. Study 1 focused on the effects of these family dynamics in very young children, while Study 2 employed a wider range of child ages. Both of these studies assessed levels of stress in parents, and child behaviour problems, at two points in time, separated by about ten months. Both studies noted that, in general, higher levels of self-reported stress in parents were strongly associated with higher reported levels of child behaviour problems, even when other factors, such as the severity of the child's ASC, and the child's intellectual functioning, were controlled for. However, Study 1 found that, when the children were very young (2:6 to 4:0 years old), their severity of ASC was related most strongly to levels of stress in parents. In addition, both Study 1 and Study 2 found that stress levels in parents at baseline were a stronger predictor of child behaviour problems at follow-up, than the reverse relationship. Thus, children with ASC, of all ages, whose parents initially reported higher levels of stress, displayed more behaviour problems about ten months later, than did those children whose parents initially reported lower levels of stress.

The next two chapters (Chapters 4 and 5) explored potential mechanisms, and influences, whereby high parenting stress may have a negative impact on child outcomes and child behaviour problems, specifically via the possible impact of parenting stress on parenting behaviours. Chapter 4 examined the relationships between parenting stress and parenting behaviours in one hundred and thirty-eight parents of children of various ages with ASC, over a period of nine to ten months. Apart from the parents' communication with their child being attenuated, relative to that of parents of typically developing children, which might be expected, there were no obvious major areas of parenting weakness in this sample. Parenting stress was found to closely interact with the parenting behaviours of involvement, communication, and limit setting over the time period of this study. For the parents of the older children (i.e. those children aged above four years), parenting stress and the parenting behaviours of communication, and limit setting, interwove bidirectionally to improve, or exacerbate, each other. However, in the sub-set of the parents of the younger children (i.e. those children aged below four years), the interaction between parenting stress and parenting behaviours was not bidirectional, but was unidirectional; higher initial levels of parenting stress were found to result in less subsequent involvement, and poorer communication, with the child. In contrast, within this sub-set of parents, good initial parenting skills in limit setting resulted in subsequently lower levels of parenting stress. These findings suggest that the relationship between parenting stress and parenting behaviours evolves, that is, develops, and alters, over time.

The relationships noted in Chapter 4 could enhance understanding, and form the basis of a possible explanation, concerning the impact of parenting stress on child behaviour problems, and outcomes, as mediated by parenting behaviours. The research reported in Chapter 5 explored the relationships between parenting behaviours (which are impacted upon by parenting stress), in parents of children with ASC, and subsequent child behaviour problems. The sample deployed in Chapter 5 consisted of seventy-two children with ASC (aged from five to sixteen years old), and their parents, who were assessed over a period of nine to ten months. The results of this study noted a relationship between parenting behaviours and subsequent child behaviour problems, but only for the parenting behaviour of limit setting. It was found that, the better the limit setting abilities of the parents at baseline, the fewer the child behaviour problems reported at follow-up, nine to ten months later. Importantly, the parenting behaviour of limit setting was found to mediate the relationship between parenting stress and subsequent child behaviour problems.

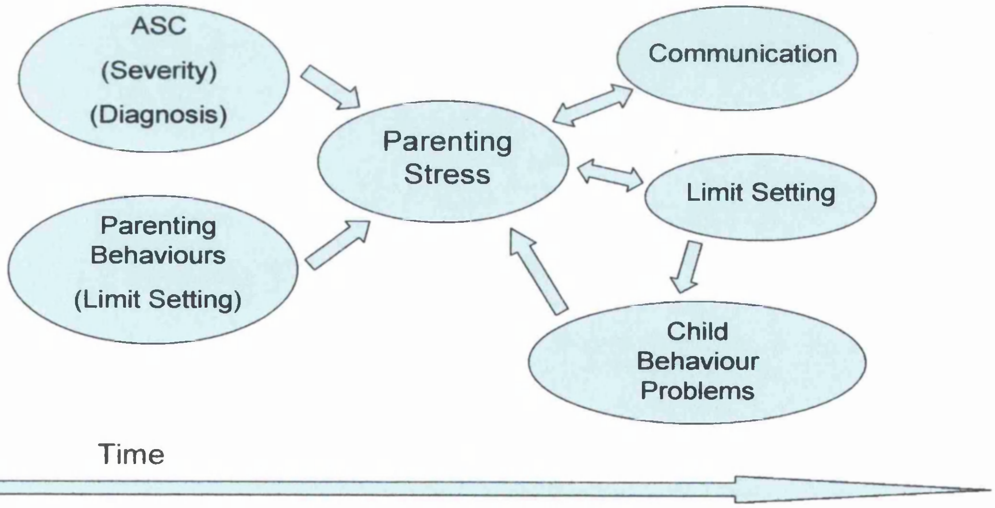
The final two empirical chapters (Chapters 6 and 7) of this thesis sought to investigate potential sources of early stress in parents of children with ASC, as parenting stress appears to trigger changes in parenting behaviours that lead to subsequent child behaviour problems. One obvious source of initial stress for parents of children with ASC is the experience of seeking, and obtaining, a diagnosis of ASC for their child, and their contact and communication with professionals involved in this diagnostic process. In order to gain the views of parents concerning their perceptions, and experiences, of the process of getting a diagnosis of ASC for their child, Chapter 6 presented the findings from fifteen focus groups, conducted across a range of locations in South East England. These focus groups were split into separate sets of parents of pre-school, primary-aged, and secondary-aged, children who had received an ASC diagnosis. The analyses of these focus groups showed that, at the time of diagnosis, most of the parents involved in this study wished for a quicker and easier process. In particular, they would have preferred the procedure to have had a more coherent structure and content. They also requested greater professional training regarding ASC, especially concerning the level of information about ASC that some professionals possess, and the interpersonal skills of some professionals. The idea of general information sheets that could be provided to parents, at the time of diagnosis, was suggested, and agreed to be of value, especially in order to combat negative information obtained from other sources.

The final empirical study, reported in this thesis (Chapter 7), investigated the impact of an ASC diagnosis for children on the levels of parenting stress in their parents. The parents of eighty-five children with ASC (aged from three to sixteen years) completed measures of their parenting stress, and gave a brief history of their child and their child's diagnosis. The children were assessed for their severity of ASC, and for their adaptive behavioural functioning. The results revealed that the severity of a child's ASC predicted that their parents would first notice a problem at an earlier stage in that child's development. The speed at which parents first noticed a problem with their child, rather than their child's severity of ASC, predicted obtaining an earlier diagnosis of ASC. While the severity of a child's ASC was related directly to parenting stress, a somewhat surprising finding to emerge from Chapter 7 was that an earlier diagnosis may be detrimental to levels of parenting stress. While parenting stress declined over time from the point at which the parents had first noticed a problem with their child, it failed to change by any significant degree, once the diagnosis of ASC had been received. Given this possible contra-indication for early diagnosis of ASC, this finding warrants some caution, and further investigation, in this area.

2.0 A Dynamic Transactional Model of Parent-Child Interactions

The results from the six empirical chapters presented in this thesis, which are summarised in Section 1.2, in addition to the context of the previous background literature, are graphically crystallised and depicted in an empirically-based model shown in Figure 8.1. The model presents the relationships between the various elements of parent and child behaviours and interactions involved in parenting a child with ASC.

Figure 8.1: A dynamic transactional model.



The model presented in Figure 8.1 is particularly complex, involving multiple elements, and their interactions, which alter over time, and which are triggered by different stimuli at different points in the child's development, and in the parent's experience of that development. It should be noted that "parent-child interactions" refer only to the relationships between those elements represented in Figure 8.1; namely, those between a child's ASC severity, parenting stress, parenting behaviours, and child behaviour problems. The two terms used to describe the model, "dynamic" and "transactional", are explained and discussed below, and act to place this model within a behavioural framework.

2.1 Dynamic Model

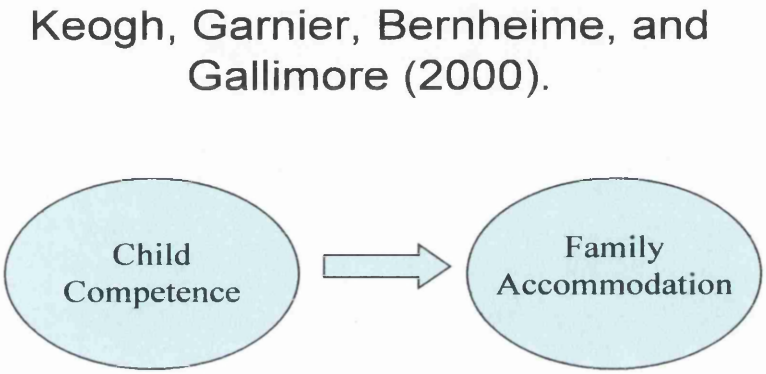
This model has been termed "dynamic", in order to indicate the movement, change, and flux of the relationships presented. That is, what is true for the younger children with ASC and their parents, is not necessarily true for the older children with ASC and their parents, and *vice versa.* In some sense, this model, therefore, could be classed as a 'developmental' model; one that seeks to encapsulate and depict the alterations in processes, and the changes in parent-child interactional behaviours, that occur as the child grows older. However, although this model may be viewed as 'developmental', in this sense, it should not be taken to imply that this is a model concerning 'developmental maturation'. This model does not present a picture of set developments within a child, based purely on changes that come about as a result of innate catalysts, such as are often postulated in typical 'stage' models of development (e.g., Brainerd, 1978, for a comprehensive critique of such 'stage' models). These models, typically characterised, for example, by Piagetian theories (Piaget, 1954), are often postulated in the area of ASC (e.g., Frith & Frith, 2003), and are related to the age of a child, such as Theory of Mind accounts of ASC (e.g., Baron-Cohen, Leslie, & Frith, 1985; Leslie, 1991).

Rather, what is intended by this model is to display a representation of complex mechanisms, and interactive components, that are triggered by environmental and experiential events, which are compatible with a behavioural interpretation. That is, the interactions that occur, and that drive the model, will depend on the behaviours, and events, that are most salient at a particular time in the development of a child. Parent and child behaviours feed into each other, and particular relationships between these behaviours will build up to influential capacities over time, creating different patterns of triggering at different points in time.

2.2 Transactional Model

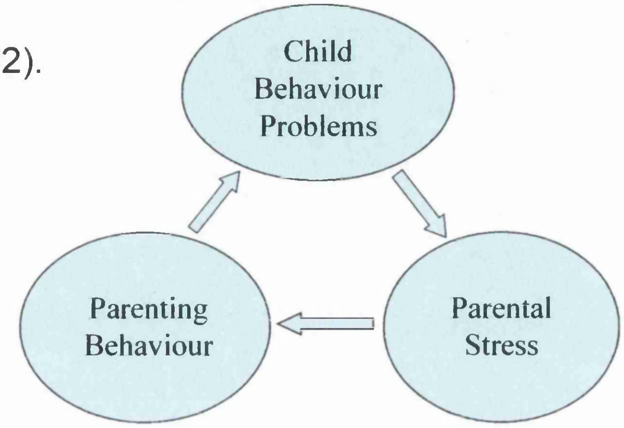
This model has been termed "transactional", in order to encompass the various multiple bidirectional interactions involved between the many elements present. Models that are composed entirely, or largely, of one-way interactions could be termed 'unidirectional'. There are some examples of such models in the developmental area. For instance, the model presented by Keogh, Garnier, Bernheime, and Gallimore (2000; see Figure 8.2) could be referred to as a 'child-driven' unidirectional model, in that a child's competences determine and produce accommodation for those abilities, or deficits, by the family, but influence does not act in the reverse direction.

Figure 8.2: A simple unidirectional model.



A somewhat more complicated, and triangular, model is the theoretical model of parent-child relationships for learning disabilities, presented by Hastings (2002; see also Deater-Deckard, 1998; see Figure 8.3). As discussed in Chapter 1, this model shows three elements impacting upon each other, in a linear fashion. According to Hastings' model (2002), child behaviour problems impact on parental stress, which, in turn, impacts on parenting behaviour, which, in turn, impacts on child behaviour problems. Thus, the direct effect of each element upon the next element in line is one way, and so is unidirectional, and, if this model were not 'triangular' in structure, then it could not be said to be transactional in any sense.

Figure 8.3: A mediated transactional model.



Hastings (2002).

Thus, although in Hastings' (2002) model, one element does impact on another directly (e.g., parental stress impacts directly on parenting behaviour), the reverse relationship between these elements is not direct, but, rather, this reverse relationship is mediated. For example, the relationship between two elements (e.g., the impact of parenting behaviour on parental stress) is always mediated by a third element (e.g., child behaviour problems). In this sense, this model could be termed a 'mediated transactional' model.

There are many instances of models, in the behavioural literature, that may be deemed to be 'fully transactional' in their structure. For example, in the field of marketing, Foxall (1999) proposed a behavioural model, whereby the behaviour of the marketer acts as a discriminative stimulus (Sd) for the consumer, and the subsequent behaviour of the consumer acts as an Sd for the marketer's subsequent behaviour. These two behaviours could be said to 'interlock', and to be 'fully transactional' (see Figure 8.4).

Figure 8.4: A fully transactional model.

Marketer

$$\begin{tikzcd}
 & Sd \arrow[r] & Rm \arrow[r] \arrow[d] & S^{R/A} \\
S^{R/A} & Rc \arrow[l] \arrow[u] & Sd \arrow[l] &
\end{tikzcd}$$

Consumer

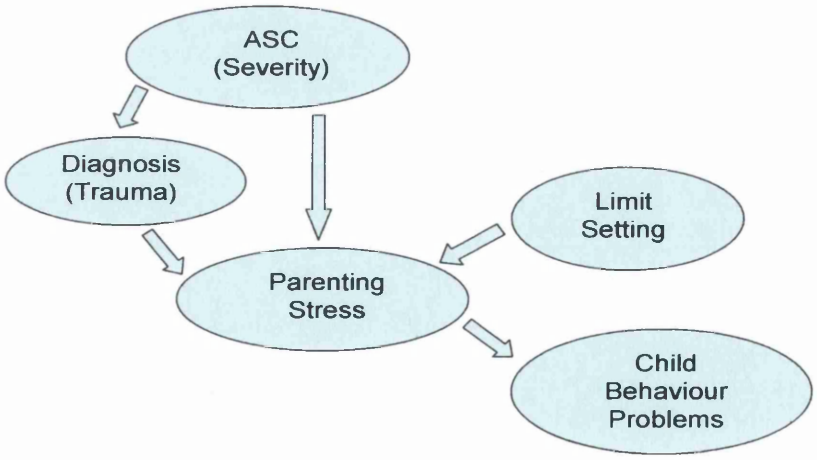
Foxall (1999).

In the field of educational interventions that have been widely used for children with ASC, the concept of the 'learn unit' also could be said to be 'fully transactional'. The behaviour of the teacher acts as an Sd for the behaviour of the child, and the child's subsequent behaviour acts as an Sd for the teacher's subsequent behaviour, and so on (see Greer, 2002; Keohane, Greer, & Ackerman, 2007).

2.3 The Model for Younger Children

In order to untangle some of the complexities of the current model, presented in Figure 8.1, it is necessary to break the model down into two separate parts, based on the different ages of the children represented on the timeline of this model. By breaking down this model into two separate parts (for younger and older children with ASC), it may be easier to see how, and when, different processes 'kick in' in order to determine, or trigger, behaviours (as mentioned in Section 2.1). This present section examines the interactions between the elements for younger children (below the age of four years), when the initial signs, and early problems, of ASC are first becoming apparent to the parents, and when diagnosis is usually sought and obtained. This part of the model is represented in Figure 8.5.

Figure 8.5: Model part for younger children and their parents.



The key elements, at this stage of the timeline of the model, are the severity of the child's ASC, the process of seeking and obtaining a diagnosis, the parents' ability to limit set for their child, and the levels of parenting stress. At this stage, it appears that the severity of the child's ASC has an impact, both directly, and indirectly, on the levels of parenting stress. In Chapter 3, it was noted that, for younger children (between 2:6 and 4:0 years old), there was a strong direct relationship between the severity levels of the ASC and the levels of parenting stress. This relationship was stronger, at those young ages, than that between the levels of child behaviour problems and parenting stress. Although there has been some debate about the relative strengths of these relationships (see Chapter 1), this finding does correspond to several other reports that have sampled very young children, and which have found the level of ASC to be a very strong predictor, at such young ages, of parenting stress (Duarte, Bordin, Yazigi, & Mooney, 2005; Eisenhower, Baker, & Blacher, 2005).

Many reasons could be postulated for this finding; for instance, when a child is very young, child behaviour problems (e.g., externalised behaviours) may not be particularly salient, or troublesome, for a parent (as the child is smaller, less strong, and aggressive behaviours are easier to restrain). As a child grows older, larger, and stronger, such behaviours become more difficult to manage and control, and the relationship between child behaviour problems (e.g., aggressive and externalising behaviours) and parenting stress will become more closely bonded. However, when a child is very young, those behaviours that are more integrally associated with the core problems of ASC (e.g., weak social interaction, poor eye contact, etc.) will be more immediate, and salient, concerns for parents.

As noted in Chapter 7, these ASC-related behaviours often alert parents initially to notice a problem with their child, and prompt parents to seek help and advice, and to obtain a diagnosis concerning these problems. While the levels of parenting stress appear to reduce from the point at which parents first notice a problem, the point of diagnosis, itself, is strongly correlated with future levels of parenting stress, and this traumatic event appears to 'set', or 'crystallise', these levels of parenting stress. Previous studies also have reported a relationship between obtaining a diagnosis of ASC, and levels of stress in parents (e.g., Schuntermann, 2002). This may be due to the difficulties involved in obtaining a diagnosis, and due to experiences of contact and communication with professionals involved in the diagnostic process and system, as suggested in Chapter 6 (see also Brogan & Knussen, 2003; Evans, Stoddart, Condon, Freeman, Grizzell, & Muller, 2001; Goin-Kochel, Mackintosh, & Myers, 2006).

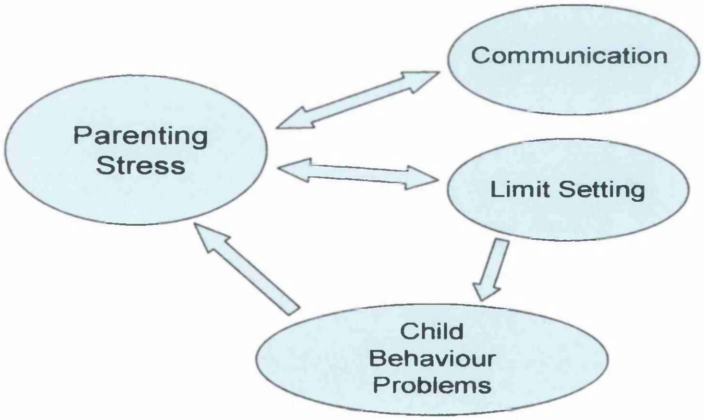
Thus, there are two factors that appear to increase levels of parenting stress in the parents of younger children (often, just recently diagnosed) with ASC: the severity of the ASC, and the diagnosis of ASC. A third factor, that of the parents' skills in limit setting for their child, was also shown, in Chapter 4, to be connected with levels of parenting stress. The better a parent's limit setting behaviours, the lower their subsequent levels of parenting stress were found to be, and, of course, the worse their abilities to limit set for their child, the higher were their subsequent levels of parenting stress. Although not previously noted in an ASC sample, there is some additional evidence for this relationship in the general population (Kotchick, Dorsey, & Heller, 2005; Meyers & Miller, 2004).

These factors all contribute to the initial production, and continual generation, of parenting stress. In turn, this factor of parenting stress was associated with more exacerbated child behaviour problems (see Chapter 3). For this younger age group, it is not yet determined whether this relationship is a direct one, or whether it is mediated through parenting behaviours, as the sample used in Chapter 5 did not include very young children. However, it is established that child behaviour problems become more strongly associated with parenting stress as children grow older. This relationship becomes stronger, over time, than that between a child's ASC severity and parenting stress (see Chapter 3). This finding is consistent also with that noted in the literature for slightly older children of around four years and above (see Blacher & McIntyre, 2006; Lecavalier, Leone, & Wiltz, 2006), and Lecavalier *et al.* (2006) have previously noted a bidirectional relationship between parenting stress and child behaviour problems for such a sample.

2.4 The Model for Older Children

The part of the model that deals with children with ASC as they get older (i.e. above four years old), and their parents, is a little less complicated than the part of the model that applies to younger children. Firstly, this is because the initial powerful effects of undergoing the diagnostic process, and obtaining such an ASC diagnosis (see Chapter 6), although not necessarily dissipated over time (see Chapter 7), are no longer present and ongoing in the environment of the child and parents. Secondly, it should be noted that the effects of the core ASC behaviours do not exert a major influence on parenting variables, such as parenting stress and parenting behaviours, at this point in a child's development (Blacher & McIntyre, 2006; Donenberg & Baker, 1993; Floyd & Gallagher, 1997; Lecavalier *et al.*, 2006; Chapter 3). Rather, the key behaviours of the child that are important, at this stage, are their behaviour problems, such as externalising, anti-social, and aggressive behaviours, for reasons discussed in Section 2.3. Thus, the major components of the part of the model for older children are parenting stress, parenting behaviours (communication and limit setting), and child behaviour problems. The relationships between these components for older children are seen in Figure 8.6.

Figure 8.6: Model part for older children and their parents.



The evidence presented in this thesis suggests that the relationships between these three elements are straightforward. As noted in Chapter 4, the levels of parenting stress impact upon the types of parenting behaviours that are utilised. In particular, high levels of parenting stress are associated with subsequently lower abilities to communicate with, and limit set for, a child with ASC. Also, it was noted in Chapter 4, that the reverse relationships were relatively strong. That is, parental levels of communication, and limit setting skills, are related to subsequent parenting stress: the better these parenting skills, the lower the subsequent parenting stress. Such findings have not previously been reported in an ASC sample, but there is evidence from the general population of broad links between parenting stress and parenting behaviours that supports this current model (Kotchick *et al.*, 2005; Meyers & Miller, 2004).

Chapter 5 noted that there was then a relationship between parental limit setting for a child with ASC, and subsequent behaviour problems displayed by that child. However, there were found to be no relationships between other forms of parenting behaviours measured here and subsequent child behaviour problems. Moreover, the limit setting behaviour of parents was found to be the variable that mediated the relationship between parenting stress and child behaviour problems. Of course, the fact that the parenting behaviour of communication did not impact on subsequent child behaviour problems could reflect the specifics of this sample of children with ASC, and for whom communication may not be a prime concern. This finding may not necessarily generalise to samples that are more able linguistically.

3.0 Implications and Practical Applications

The findings discussed in Section 1, and the resulting empirically-based model presented and outlined in Section 2, of this chapter have a number of theoretical implications, and possible practical applications, that merit brief discussion.

3.1 Relationship to Other Models of Parenting

There have been numerous models of parenting, and parent-child interactions, relating to various conditions, disorders, and disabilities (e.g., Hastings, 2002; Keogh *et al.*, 2000), as well as to typically developing children and their parents (e.g., Deater-Deckard, 1998). There are probably too many such models to list and review here, but some of the more pertinent models have been mentioned in this thesis (e.g., see Chapter 1).

A difference between the model presented in Section 2 of this chapter, and many of the previous models (e.g., Hastings, 2002; Keogh *et al.*, 2000), is that these previous models tend to be unidirectional in their proposed interchanges between the elements therein, whereas, the currently proposed model is much more 'fully transactional', in that it postulates a mutual bidirectional exchange between many of the elements involved. Moreover, many of the previous models cannot be said to be truly 'developmental' in nature, as they do not propose that these exchanges modify as a child grows older. Rather, they tend to propose a static situation with regard to the manners in which the various components relate to one another. The current model attempts to accommodate, and describe, developmental changes, by reference to the most environmentally salient events, and states, that fuel and propel the interchanges between the components at particular times in a child's development.

These theoretical differences, noted above, were discussed in Sections 2.1 and 2.2. However, there are also empirical reasons presented in this thesis that separate the current model from most previous models. In particular, previous models tend to suggest that it is the child's behaviour problems that trigger parenting stress (e.g., Deater-

Deckard, 1998; Hastings, 2002), or that lead to family accommodation concerning those child competencies, or behavioural problems and deficits (e.g., Keogh *et al.*, 2000). The parenting stress, in many of these models, then impacts on parents' ability to parent. That parenting stress impacts on the ability to parent is also part of the current model, at least for older children (see Chapter 4), and has been noted in the general literature (Kotchick *et al.*, 2005; Meyers & Miller, 2004; see also Chapters 1, 4, and 5). However, the current thesis found very little evidence that it is the child behaviour problems that impact on parenting stress, but, rather, it found a large amount of evidence that the impact was in the opposite direction (Chapters 2 and 3), and perhaps mediated through parenting behaviours (Chapter 5).

For instance, one link in Hastings' (2002) theoretical model (i.e. child behaviour problems impacting on parental stress) would imply that temporal precedence is from child behaviour problems to parental stress. If this hypothesis of causal directionality were true, then the relationship between child behaviour problems at a baseline measurement and parental stress at a follow-up measurement would be stronger than the relationship between parental stress at baseline and child behaviour problems at follow-up. However, in Chapter 3, it was found that the relationship between child behaviour problems at baseline and parenting stress at follow-up was not statistically significant, and was weaker than the relationship between parenting stress at baseline and child behaviour problems at follow-up. This latter relationship was statistically significant. Hence, regarding this link in Hastings' (2002) theoretical model, it would appear that the temporal directionality, as indicated by the data in Chapter 3 (and also in Chapter 2), runs in opposition to that put forward in Hastings' (2002) model, as well as in many other similar models (e.g., Deater-Deckard, 1998; Keogh *et al.*, 2000).

This contrary evidence relates only to that link in Hastings' (2002) model between child behaviour problems and parental stress. This model was offered as a theoretical account for learning disabilities, as a whole, and was not intended specifically for ASC. Nevertheless, it has served as a useful device for focusing attention on the specifics of the complex interactions between parenting stress levels, parenting behaviours, and child behaviour problems, when applied to ASC. Furthermore, Hastings (2002) suggested that two tests were necessary in order to substantiate this model. Firstly, that the relationship between child behaviour problems and parental stress had to be demonstrated as non-spurious to rule out the possibility of other factors, or confounds, having an influence on parental stress. Secondly, that temporal precedence needed to be established for any suggestion of causal directionality to be supported. In claiming that these two aspects needed examination, Hastings (2002) proposed rigorous criteria against which to substantiate his model, and, indeed, any future models.

Hence, the current model proposed in this thesis, which places more emphasis upon the impacts of parents' behaviours on their child's behaviours, than the other way around, represents something of a return to the earlier behavioural models, for example, as suggested by Ferster (1961). This change in conception may help to mark a turning of the tide in terms of the ways in which disorders, such as ASC, are being approached (see also Drash & Tudor, 2004, for a similar argument), and this sea change is due to pivotal and prominent work within the behavioural field (e.g., Lovaas, 1987; Greer, 2002), which has placed the emphasis on environmental, rather than within-child, factors.

3.2 Developing Interventions

In terms of the practical implications of these current findings for the treatment of ASC, it may be noted that focusing purely on the impact of any intervention on the child (see Chapter 1) neglects the important role that parents play in the management of their child's problems. There is increasing research on the effects of ASC on family functioning (e.g., Eisenhower *et al.*, 2005; Hastings & Brown, 2002; Hastings & Johnson, 2001; Mash & Johnston, 1983), and growing amounts of research on the influences of the family, and parents, on the child with ASC (see Blacher, Neece, & Paczkowski, 2005, for a review), especially concerning their effects on the child's behaviour problems and outcomes following intervention (e.g., Lecavalier *et al.*, 2006; Robbins *et al.*, 1991). In the current thesis, for example, Chapter 2 highlighted, in the context of early teaching intervention programmes, the influence of parenting stress on child outcomes. Thus, the results of this thesis may have implications for, and be consistent with, the development of interventions for parents, in order to enhance their adaptive behavioural strategies, to more effectively deal with their extreme parenting stress levels.

As noted in Chapter 1, there are many interventions now targeted at the parent, rather than the child. However, the results of the current research help to identify the specific aspects that such interventions should target. The present findings, especially from Chapter 5, suggest that intervention programmes that focus on providing parents with enhanced behaviour management skills (e.g., Harris, Handlemann, Arnold, & Gordon, 2000; Lovaas & Smith, 2003) will have benefits for both the parent and the child. In particular, those programmes that aid the parent to limit set more effectively may help to reduce subsequent child behaviour problems, and also to reduce parenting stress. Moreover, reductions in parenting stress, as a consequence of better limit setting skills, may subsequently feed into promoting other successful parenting behaviours, such as involvement and communication, which high parenting stress otherwise attenuates (see Chapter 4).

However, it is clear that interventions should focus also on the reduction of parenting stress at their commencement, as this may allow development of better parenting behaviours and skills, subsequently. Numerous intervention programmes target parents of children with ASC, and note improvements in the children's behaviours and functioning as a result of parents' reductions in stress, and increases in their coping abilities (e.g., Harris *et al.*, 2000; Lovaas & Smith, 2003; see Blacher, Neece, & Paczkowski, 2005, for a review).

In addressing the issues and problems resulting from having a child with ASC, the importance of the parent cannot be underestimated. As noted above, in the context of developing interventions, the importance of involving the parents with the interventions given to the child has been recognised (e.g., Schuntermann, 2002; Stoddart, 1999). However, the parental, and family, influences that contribute to the effectiveness of interventions should continue to be documented and assessed, to gain a more complete picture of the influencing factors on child behaviour problems, and on child outcomes (see Harris, 1984; 1994; Harris *et al.*, 2000; Lovaas & Smith, 2003; Robinson & Anderson, 1983).

It is of essential importance to highlight the ethical implications embedded in this area of parenting and ASC, and to emphasise that the re-focus on the parents' role in managing ASC, and in promoting intervention outcomes, should not be misunderstood, and taken to imply that the parent is being held responsible, or blamed, for the original development of the child's ASC. This is not a return to any view that suggests that such responsibility, or blame, is attributed to the parent. It is not intended to heap further burdens upon parents who are already struggling with their child's problems, but, rather, to point to ways in which parents may be helped and supported to manage the problems of their child. "*Blame is for God and little children*"; as this Dalton Trumbo quote implies, it is neither relevant, nor meaningful, to use such terms as "blame", and to apportion it is not helpful or constructive (see also B.F. Skinner's *Beyond Freedom and Dignity* for a similar analysis).

The various theories regarding the possible causes of ASC, like most other theories, are greatly influenced by the times in which they are postulated. These theories, and especially those that relate to the impact of parental care, are often conceived, in the first place, as a result of their political, social, and economic contexts (e.g., see the debate regarding the post-war political agenda that helped to promote and encourage the notion of maternal deprivation, Bowlby, 1951). Theories come in waves, and each wave seems to react to, or against, whatever has preceded it. Depending on the requirements of the time in question, certain theories will be favoured more than others, and, as public, political, and scientific opinions change, some theories will fall out of favour, and be replaced by others. The social climate determines what is 'in', and what is 'out', but this will fluctuate, and is never constant. Hence, many theories of ASC are agenda-driven and agenda-laden, and these alter over time to fulfil the requirements, or fit the needs, of their socio-political times. The current model views parental factors as one of potentially many factors that influence the behaviours of a child with ASC, and not as the 'cause' of the ASC.

On the other hand, certain 'within-child' causal theories of ASC may diminish feelings of guilt in parents, reduce panic, and alleviate blame. However, although rendering 'more digestible' the causal theories of ASC, and readily reducing some of the certain anguish and anxiety of parents, such 'within-child' views will not, on their own, offer any real assistance, in practical terms, in managing the inherent problems of having a child with ASC. Such causal theories may inform, educate, and comfort parents, families, and the public in general, but they cannot help in practical ways to manage behaviours that are deemed inappropriate, anti-social, and even damaging. Nor can 'within-child' causal theories actively promote other behaviours that are regarded as appropriate. In contrast, if identification can be made of some child problems resulting from parenting stress and parenting behaviours, then this knowledge will aid both the child and the parents. To aid and support parents to help their children is not to blame those parents!

3.3 Diagnostic Practice

There are also implications for diagnostic practice, and the role that the process of diagnosis may play in generating parenting stress. The impact of the diagnosis on parenting stress was studied in Chapter 7, and parents' perceptions of the diagnostic process were documented in Chapter 6. Combined with the findings from the other chapters, these results suggest that the period of diagnosis may be critical in producing, and setting, parenting stress levels, and that high parenting stress has a subsequent negative impact on child outcomes and behaviours.

While there is increasing pressure to provide early diagnosis of ASC, there is a lack of evidence relating to the impact of early diagnosis on parents. Chapter 7 suggested that early diagnosis may not necessarily be helpful to parents if they already experience high levels of parenting stress. This creates a tension, as it is often assumed that intervention for ASC is more effective if offered early, rather than remedially later (Lovaas, 1987), and such suggestions produce pressure for earlier diagnosis of these conditions. However, as mentioned in Chapter 7, the diagnosis of mental problems can have unexpected effects (see Bentall, 1990, for a discussion relating to 'labelling' and schizophrenia).

In cases of ASC, the impact of a diagnosis can often be seen in parents (Chapter 7), and this impact, in turn, will affect the children. Thus, although an early diagnosis of ASC may facilitate access to services, and enhance treatment prognosis for the child, the diagnosis of ASC can contribute to the production of extreme levels of stress in parents. These high levels of stress in parents have been shown to have detrimental impacts on children, in terms of treatment outcomes (e.g., Robbins *et al.*, 1991; Chapter 2), and behaviour problems (e.g., Lecavalier *et al.*, 2006; Chapter 3). Thus, parents play a pivotal role in the prospects for the child with ASC, but these parents suffer from extreme levels of stress, which can be heightened by the diagnostic process, and which have, in turn, a negative impact on the prospective outcomes for the child with ASC.

As shown in Chapter 6, many of the early stressors experienced by such parents revolve around communication and contact with professionals during the critical period of time in which a diagnosis of ASC is sought and obtained. Such contact often comes prior to engagement in treatment programmes, and, if this contact has been stressful or aversive, it may well lead to less success in the subsequent treatment. Hence, as high parenting stress can inhibit the effectiveness of such treatments, the communication experiences of parents with professionals during the diagnostic process may be of particular importance.

Given this situation, there is a very clear need to provide further empirical evidence regarding the impacts of diagnosis on parents, and how this process could be made less stressful for parents whose children are undergoing such a diagnosis. One way forward may be to uncouple diagnosis (or a statement of Special Needs) from accessing help, support, and intervention for children with ASC. Of course, if ASC is not regarded as a unitary disorder, but rather as a set of conditions, composed of a collection of behaviours, then help can be directed at those specific behaviours, as and when needed, rather than at a disorder, as a whole. Such a philosophy underlies much of the applied behavioural interventions for ASC, and has recently been suggested as a policy to be adopted by the Welsh Assembly Government (Welsh Assembly Government's *The Autistic Spectrum Disorder Strategic Action Plan for Wales*, 2007).

3.4 Poverty and Economic Deprivation

If ASC is approached in the manner suggested in Section 3.3 of this chapter (see also Chapter 1), namely, as a collection of behavioural difficulties, rather than as a disorder *per se*, it could be argued that ASC can be seen to share some similarities with a number of other problem areas. The practical implications that can be derived from adopting this approach, and from the current model of parent-child interactions, could then be generalised to some of these other areas of concern. One such area, which is of long-term and continuing significance, is that of economic deprivation and poverty, and its immediate, and lasting, impacts on children. Comparing the natures, and the approaches to alleviating the effects, of ASC and poverty may lead to possibly enhanced mutual informing and understanding. There are three points that could be made in this regard.

Firstly, it would not be sensible to suggest that poverty, or economic deprivation, presented a single, or unique, profile of difficulties for the children who experience them. Neither could it be said that there is one single cause of poverty. Nevertheless, attempts are often made to counteract the various serious impacts of poverty on children who experience such economic deprivation problems, and such attempts are often made governmental priorities. Similarly, as argued above, it should not be thought necessary to provide evidence for a single cause of ASC, and, indeed, such a search may be fruitless. Despite this, numerous interventions have been developed for ASC (see Chapter 1). In both cases, a search for a single cause may be distracting from the search for remedies for the effects of the problems.

Secondly, there have been numerous initiatives aimed at helping children in poverty, or in areas of economic deprivation, to overcome the often debilitating effects of such deprived conditions on their learning and behaviours. Many of these initiatives are aimed at younger children, and can be called 'early interventions' (e.g., Head Start, Sure Start, etc.). The links to early teaching interventions for ASC (e.g., Lovaas, 1987; outlined in Chapter 1) are obvious, and have, importantly, not gone unnoticed by prominent researchers and investigators in the field of ASC. In a recent interview, Greer ("*The Unorthodox Behaviorist*", 2007) makes a clear link between the effects of ASC and the impacts of poor, deprived, environments, especially in terms of their influences on language acquisition and development:

> "*...they may have had thousands fewer language interactions than their peers. Other research shows that the teacher then speaks to them less than to the other kids, because she doesn't know how to deal with them, and then the kid misbehaves to get attention. By fourth grade, he's in special ed, and by 14, she's pregnant, and it's a generational repeat. And it's absolutely about poverty, not race. There were plenty of black families in the higher-income group that Hart and Risley studied and plenty of whites in the welfare group.*" (Greer, 2007.)

If this is the case, then early teaching interventions could be applied to aid the development of economically deprived children, of which, of course, there have been numerous examples. However, few of these examples, such as Head Start or Sure Start, have the strong empirical investigative foundations, and developed knowledge regarding their effectiveness, that many of the behavioural teaching interventions for ASC possess. Given this, the attempts to alleviate, and reverse, the effects of poverty could benefit greatly from the field of behavioural interventions for ASC.

Thirdly, this argument is mainly based on similarities in the effects of economically deprived environments, and of ASC, on language acquisition and development. However, the similarities may go much further than this, and may well involve the area of parenting practices. In fact, much of the evidence that helps to support the current model of parent-child interactions in ASC comes from studies of parenting in economically deprived families and neighbourhoods. For instance, as noted in Chapter 4, there have been some investigations of the effects of parenting stress on parenting behaviours in economically deprived populations. Rodgers (1993; 1998) found that parenting stress directly, and indirectly, affected parenting behaviours in mothers of young children in a Head Start programme. Likewise, Kotchick *et al.* (2005; see also Meyers & Miller, 2004), in a longitudinal study of low-income, urban-dwelling, single mothers, noted that higher levels of neighbourhood stress had relationships with greater psychological distress, and with detrimental effects on psychological functioning, in these mothers. This subsequently went with less engagement in positive parenting practices, and resulted in poorer parenting over time. Similarly, it was noted in Chapter 5 that Ehrensaft, Wasserman, Verdelli, Greenwald, Miller, and Davies (2003) examined the long-term effects of maternal anti-social behaviours, and parenting practices, on behaviour problems in boys at risk of developing anti-social behaviours. They found that lower levels of maternal involvement, and monitoring, and higher levels of conflict between the mothers and sons, contributed to worse subsequent child behaviour problems, seen one year later. This overall pattern of results from economically deprived families reflects the pattern of results found in the current investigation of ASC. Thus, it is clear that there are real opportunities, and fruitful possibilities, to be had from a cross-fertilisation, and mutual informing, of these two disparate areas.

4.0 Limitations and Future Research

As with all research, there are areas that should be acknowledged as limitations to the generality of the results, and which may inform any ongoing, or future, work in the field. Several of these limitations are general in their nature, and could be applied to many of the empirical chapters reported in this thesis. These more general limitations are discussed below, and relate to participant selection, assessment of various behaviours of the participants, and the need to explore additional areas of behaviour. Many of these general limitations are characteristic of all 'real world' research, and, to some extent, community-based research needs to be pragmatic in its approach, and to acknowledge the difficulties in controlling all possible variables.

4.1 Participant Selection

There are a couple of limitations to the empirical work reported in this thesis that should be mentioned, with respect to the selection, and possible characteristics, of the participants involved. These limitations may affect the generality of the extrapolation of these current findings to other samples. Firstly, of course, caution needs to be exercised when extrapolating from any particular sample to the whole population of parents of children with ASC. In all of the present empirical chapters, the samples of parents, and their children, studied were always volunteers. It may be that parents of children with ASC who volunteer for such research studies display different characteristics to those who do not volunteer. Consequently, the findings from the current empirical chapters may be somewhat biased in their findings. However, self-selection of participants is a recognised limitation, and an acknowledged difficulty, of all such community-based studies, and this problem is not specific to this particular research. Such participant self-selection would have been the case in the vast majority, if not all, of the studies cited in this thesis. Moreover, it is not clear how this limitation could be overcome, short of coercion. Such studies depend on the voluntary participation of those involved, and participants cannot be forced to take part against their wishes. To the extent that all studies in this area have this same constraint, the findings generated by the current thesis are perfectly generalisable to the background literature cited here.

It should be mentioned that very few of the families, identified as possible participants by their Local Education Authorities, actually refused to participate in the studies reported here. In each of the present empirical chapters, the attrition rates for the participants (including those who did not volunteer when initially contacted) were low for the area, and, in some cases (e.g., Chapter 2), were almost at zero levels. This suggests that self-selection was not a major problem in these studies, and that most parents, when contacted, chose and agreed to participate. Importantly, the initial contact with these parents was based solely on the characteristics of their children, not on the basis of any parental characteristics likely to contribute to their subsequent participation.

The second participant-related issue regarding possible characteristics that might have implications for the generality of these findings, and which future research could address, is that of the impacts of the demographic characteristics (e.g., age, ethnicity, marital status, religion, socio-economic status, etc.) of the parents involved. Unfortunately, few measures of these variables were taken in the current studies, and there is no way, with sufficient accuracy, to identify precisely the social or economic background, for example, of each individual participant.

It is not known precisely how demographic factors, such as these mentioned above, may impact on the current results. Although, as discussed in Chapter 1, parents' age, ethnicity, marital status, religion, and socio-economic status appear to have little impact on the probability of having a child with ASC (Ritvo, Cantwell, Johnson, Clements, Benbrook, Slagel, Kelly, & Ritz, 1971), Dumas and Wekerle (1995) looked at differences between high and low socio-economically disadvantaged families, and they found that, in the high disadvantaged group, there was a relationship between stress and parenting, but this relationship was not found in the less disadvantaged families. It is highly likely that parents from higher socio-economic backgrounds may have access to greater levels of support, in that they may be able to afford to 'buy in' help, perhaps in the form of home interventions, perhaps with greater access to day care, professional support, respite, and facilities, such as private special nurseries. In addition, such parents may be in a position to provide greater amounts of educational materials for their child (e.g., books, puzzles, toys, computers, and even extra rooms in the family home in which to hold home-based interventions, etc.).

While there is little direct evidence bearing on this demographic issue that would allow assessment of its impacts, the discussion in this chapter (Section 3.4) would imply that poverty and economic deprivation are associated with greater parental stress, and can act as a break on the developmental progress of a child. Moreover, the previous studies, reviewed in Chapter 1, concerned with the impact of special nursery on child outcomes, that have shown such placements to be effective for children with ASC (e.g., Charman, Howlin, Berry, & Prince, 2004; Reed, Osborne, & Corness, 2007b), have all been conducted within areas of relatively high socio-economic status, which might impact on those child outcomes. Hence, this is an area that will require further investigation.

4.2 Measures of Parenting Behaviours

One of the central themes of this current research, and of the empirically-based model that arises from this work, concerns parenting behaviours. As such, it is important to be able to assess such parenting behaviours accurately and objectively. It should be noted that the measure of parenting behaviours, used in this thesis (e.g., the Parent-Child Relationship Inventory, PCRI), was a self-report measure. On the one hand, the PCRI is a well-standardised, reliable, validated, and widely used measure (see Chapters 4 and 5 for full discussions of this measure's psychometric properties). On the other hand, it has to be acknowledged that such a measure suffers from two potential problems. Firstly, it does produce a measure of parents' self-reported perceptions of their own parenting abilities, rather than a direct measure of these behaviours. Secondly, although well-standardised for the general population, it has had limited use with the ASC population. Thus, further research that employs a range of additional measures of these parenting behaviours would help to corroborate, and systematically replicate, the current findings.

The degree to which the PCRI could be shown to correlate with other measures of parenting behaviours for this ASC sample would be an important finding. It may be that parental perceptions of their own behaviours, and those of their child, are affected by factors, such as the high levels of parenting stress that they experience. For instance, Fong (1991) noted that highly stressed mothers reported more threatening appraisals, based on video-taped scenes of adolescents with ASC engaged in everyday activities, than did low stress mothers. This might imply, simply, that highly stressed parents rate the same behaviours differently to low stress parents (albeit sometimes more accurately linked to child behaviours, see Kasari & Sigman, 1997). However, the parenting reactions of the highly stressed mothers, studied by Fong (1991), based on their assessments, were subsequently different to those of the low stress mothers, the former having more negatively emotional responses. Such differences in their subsequent reactions (i.e. in their parenting behaviours and interactions with their children) to their appraisals may lead to differences in their perceptions, and reporting, of their own parenting behaviours.

A study, in which the PCRI were to be used alongside direct observation and rating of parenting behaviours of these parents, would also add to the evidence concerning the validity of the PCRI for this sample. Moreover, direct observation of the parenting of children with ASC could help to corroborate the findings reported in this thesis. Although, it should be mentioned that this latter, more direct, approach would severely limit the sample size, relative to the method employed in this research. Moreover, this observational approach would not appear to be highly feasible, or viable, given the range of parenting behaviours, and the time course of the study, needed, and such an approach would be highly intrusive and invasive for the parents and families involved. Indeed, the invasiveness of such a direct and intrusive observational procedure may well lead to changes in the parenting behaviours being observed, as parents may show some reactivity to the process of being observed while parenting their children.

4.3 Role of Coping Strategies

One area of parenting that was not measured in the current research was that of coping, namely, the strategies employed in order to deal with, and counteract, the parenting stress experienced, and adopted to handle stressful parenting situations. Neither the parents' abilities to cope with the high levels of parenting stress that they reported, nor their coping strategies, were assessed in this thesis. Both of these aspects, of course, could have moderated the effects of parenting stress. This is clearly an area that could be investigated in subsequent work, and the impacts of parents' coping strategies and abilities could be incorporated in to the model of parent-child interactions postulated in this thesis.

One practical reason why parental coping was not assessed in the current studies was, simply, that the parents participating in these studies were already being asked to complete a large number of questionnaires, and to ask them to fill in additional measures could have seriously jeopardised the return rate of data. Additionally, the inclusion of yet another variable (i.e. coping) would have resulted in a substantial loss of statistical power, and reliability, given the present sample sizes (which were reasonably high, by the norms, for this field, and which were appropriate for the number of variables assessed).

Certainly, in models that examine the effects of stress, both degrees of coping ability, and different strategies of coping, are often thought of as important moderators, and/or mediators, of the effects of stress. For example, there has been work using the Double ABCX model for parents of children with ASC (Bristol, 1987), which suggests that coping strategies impact on the behaviours that stressful situations will produce. Some models of parenting incorporate coping strategies into their descriptions of the parenting process (e.g., Kurtz & Derevensky, 1994; Lazarus, 1991), and, in an extension to the basic theoretical model presented by Hastings (2002), parental coping with stress was added as a factor, although very limited evidence was presented in support of this addition of coping.

In terms of what is known about the coping strategies used by parents of children with ASC, research indicates that parents deploy a variety of coping strategies to deal with their child's ASC, including support from family and friends (Marcus, 1977), the use of service providers (DeMeyer, 1979), and religion (Gray, 1994). Hastings, Kovshoff, Brown, Ward, Degli Espinosa, and Remington (2005) documented four coping dimensions: active avoidance coping, problem-focused coping, positive coping, and religious/denial coping, and they suggested that reliance on 'avoidance' coping is detrimental, and should be decreased, if possible, and that increasing the use of 'positive' coping strategies may be beneficial.

However, the results from two other studies suggest that this advice may not be entirely appropriate, or, at least, may be over simplistic. Firstly, Gray (2006) noted that parental coping strategies change over time. As time passes, fewer parents cope via reliance on service providers, family support, social withdrawal, and individualism, and more parents cope via religious faith, and other emotion-focused strategies. These results support other research on parental coping that indicates the benefits of more emotion-focused coping strategies. For example, Waddington and Reed (2007) noted greater intellectual, and educational, gains for children with severe ASC, whose parents used passive reappraisal coping strategies, rather than active, or confrontive, coping strategies.

This work on parent coping ties in with intervention studies that have shown that teaching parents 'mindful parenting' reduced aggression, non-compliance, and self-injury in their children, and promoted parental satisfaction with their parenting skills, as well as with their parent-child interactions (Singh, Lancioni, Winton, Fisher, Wahler, McAleavey, Singh, & Sabaawi, 2006). A related area that may warrant some study in this ASC context is that of Acceptance and Commitment Therapy (ACT; Hayes, 1994; Hayes, Strosahl, & Wilson, 1999). ACT was originated, in part, to help people who suffer chronic levels of distress, which have debilitating effects on their functioning across many aspects of their lives. Traditional threads of Psychotherapy were designed to decrease the intensity, and frequency, of aversive affect and cognition, and ACT was developed as an alternative to these more traditional approaches. Rather than attempting, directly, to decrease such aversive feelings, emotions, and thoughts, ACT focuses on increasing behavioural effectiveness, regardless of the presence of unpleasant feelings and thoughts. Given the persistent high levels of stress in parents of children with ASC, and, given the apparent improvements for children associated with parental passive reappraisal coping strategies, ACT, in this context, may be beneficial, and is certainly worthy of future investigation in relation to possibly aiding this population.

5.0 Beyond the Empirical Analysis of ASC: Philosophical Analogies

As a consequence of a background in Philosophy, and how it relates to Education, it is tempting to briefly explore some particular philosophical writings, and theories, that may have unexpected bearing on, and pertinence for, the area of ASC. There has been much written on the Philosophy of Mind, and its obvious connections with the Theory of Mind, and there seems little reason to 'rehash' this topic when it has been covered so extensively, and proficiently, in the context of ASC by so many (e.g., Gallagher, 2004; Gipps, 2004). A more unusual approach is to see whether the concept of 'privacy' has any part to play in the understanding of ASC, and how, and why, ASC is problematic. This discussion follows from what may be regarded as a somewhat paradoxical finding from the current thesis. That is, despite the core conception of ASC as being disorders in which social interaction does not typically occur (DSM-IV; ICD-10), some of the emerging problems of the child with ASC may be related to problems with, essentially, social contact with their parents. A brief discussion of the philosophical arguments surrounding the effects of too little, and too much, privacy may help to illuminate this paradox in a different light.

Philosophically, the term 'privacy' has many varied uses, and its meaning alters according to its usages in moral and ethical, governmental and constitutional, and legal and legislative contexts. In these latter legal and legislative domains, the concept of 'privacy' is connected with concealment, and forbidden knowledge; those opinions, views, facts, and secret spheres deemed distinct and separate from others, and over which state or government control, interference, intrusion, and scrutiny would be regarded as wholly inappropriate. Hence, 'privacy' can be taken to mean the opposite to public, and such a view may be traced to Aristotle (*Politics*, Book 1), who distinguished between the public and political arena, and the private, domestic, and family sphere. As such, privacy has been argued to be a principle and a right, most famously by Warren and Brandeis (1890), in "*The Right to Privacy*", in which they acknowledge and recognise: "*...the right to be let alone...*", and "*...the right to one's personality...*".

Stemming from these jurisprudence aspects of privacy, the term 'privacy' can encompass solitude, restricted access, and seclusion. This notion of privacy may offer an appropriate analogy for ASC, given its role in regulating social exposure, which is a core deficit in, and issue for, ASC. In these aspects, the meaning and importance attached to privacy in a philosophical context can be seen to offer an analogy of the descriptions of autism offered by Kanner (1943):

"There is from the start an extreme autistic aloneness that, whenever possible, disregards, ignores, shuts outs anything that comes to the child from the outside. Direct physical contact or such motion or noise as threatens to disrupt the aloneness is either treated "as if it weren't there" or, if this is no longer sufficient, resented painfully as distressing interference." (Kanner, 1943, p. 242.)

If it were to be postulated that privacy, just like ASC, has a spectrum, and that each person can be placed somewhere on that spectrum – some higher, and some lower, along its continuum – then it is possible to argue that individuals with ASC are at one extreme end of the privacy spectrum. Individuals with ASC can be characterised as being so far away from the social world, and from community life, that they are dwelling in their own 'private world', and that they are a 'community of one'. As the Greek root of Autism, 'autos', meaning 'self', implies, individuals with ASC are dwelling deep within themselves, locked inside their selves (see Kanner, 1943). Such a suggestion of a spectrum of privacy is not totally novel. Bleuler (1911), for example, made a similar claim regarding the degree to which people engage in self-related, and self-directed, wishes (see Chapter 1). Such heightened privacy would, as predicted by Wittgenstein's arguments in the *Philosophical Investigations*, regarding "private language", severely reduce a person's ability to acquire and develop language. If people with ASC were to be characterised as inhabiting a 'community of one', then it is not surprising that such individuals often display impaired language skills, or no language at all.

Ideas of a continuum or spectrum have also been expressed and developed by researchers associated with Behavioural Psychology, such as Meehl (1962) in relation to schizophrenia and schizotypy. Notions of a spectrum of behavioural traits shared by all, whether they are related to schizophrenia, or to ASC, allow the development of more inclusive arguments regarding the impact of the environment on individuals. It should not be taken that the concept of 'privacy' is being used in a way to suggest a central deficit in ASC, rather the impact of violations of privacy norms may allow some greater insight and understanding of the issues surrounding, and faced by, persons with ASC. The analogy of 'privacy', as discussed in Philosophy, may be regarded as such an attempt, and may relate empirical research findings to a more intuitive understanding from which people may gain insight. The inclusivity of this approach could enhance empathy and sympathy, as it draws on our own experiences in order to illustrate the concepts and facets arising from the empirical research.

In this thesis, it has been shown that some specific aspects of parenting are important to help children with ASC (see Chapter 5). However, there is a further issue of *how* such specifics are delivered, namely, parenting style. It has been noted that a lack of parental responsiveness, culminating in 'over-intrusive' parenting, can be problematic for some populations of children (e.g., borderline intellectual functioning, i.e. an IQ of between 71 and 84); over-controlling, and harsh disciplinary, parenting styles have been shown to lead to increased 'disturbed' behaviours from the child (Fenning, Baker, Baker, & Crnic, 2007). If an individual is high in privacy (such as a child with ASC), then they may well reach such a point of being over-intruded upon at an earlier stage, in other words, they have a lower privacy threshold. The impact of a lack of privacy is a key topic in the philosophical literature concerning this concept. Privacy can offer safety, immunity from invasion, and the promise of security. It can afford a chance to enjoy one's own company, and to be alone with one's own thoughts; privacy can deliver some peace and quiet, time to think, and it can free us from the judgements and interruptions of others.

Schoeman (1984) presents an anthology of philosophical dimensions of privacy, in which many authors suggest that privacy is a basic need of all of us to stop and retreat from the social world, and spend some time in our own skins, private and alone. We can recharge our batteries, as it were, and then, when refreshed and replenished, we can re-enter the social fray. The need for privacy can be shown to apply, not only to human animals, but to non-human animals also. Indeed, there is extensive research, both experimental in the laboratory, and ethological in the field, that illustrates that privacy is not a species-specific requirement, but that it is a fundamental necessity that stretches right across the animal world. For instance, recent research published in *Animal Behaviour*, in an article by Sherwin (2007), describes how laboratory mice, living in an enriched, and social, environment, pressed a lever in order to gain access to a chamber in which they could spend some time on their own. Thus, it was reinforcing for these mice to be alone for a while, and to be 'private'. Alan Westin (1967), in his survey of animal studies, demonstrated that privacy is not a predilection, and desire, of human animals alone, but of other species too.

Returning to the present discussion, in order to place this within a philosophical context, George Steiner (1998) claimed that we all need privacy, indeed he deemed it an integral part of one's humanity. He characterised its value as the: "*...most precious right – the right to a private life of feeling.*" (p. 76). Indeed, he went on to say:

> "*This is the most dangerous aspect of all. Future historians may come to characterize the present era in the West as one of a massive onslaught on human privacy, on the delicate processes by which we seek to become our own singular selves, to hear the echo of our specific being. This onslaught is being pressed by the very conditions of an urban mass-technocracy, by the necessary uniformities of our economic and political choices, by the new electronic media of communication and persuasion, by the ever-increasing exposure of our thoughts and actions to sociological, psychological, and*

> *material intrusions and controls. Increasingly, we come to know real privacy, real space in which to experiment with our sensibility, only in extreme guises: nervous breakdown, addiction, economic failure. Hence the appalling monotony and publicity – in the full sense of the word – of so many outwardly prosperous lives. Hence also the need for nervous stimuli of an unprecedented brutality and technical authority."* (Steiner, 1998, p. 76.)

In support, he pointed out how the withholding of privacy can be, and has been, on countless occasions, used as a form of torture. Thus, the disabling of privacy can be used as a systematic and purposeful withholding of a requirement as essential as social contact for human beings. As an example, Steiner explicitly described how, during the Holocaust, the Nazis used such a torture technique in their concentration camps (work and death camps) to persecute, and dehumanise, their prisoners. This lack of privacy is more than a mere function of the organisation, and machinery, of a concentration camp. The deprivation of privacy is a classic tool of persecution, and genocide, or of 'ethnic cleansing', as it is termed nowadays. The restriction of the basic need for periods of privacy is implemented as a form of torture, in much the same way that the restricting of social interaction is used as a form of torture in the guises of isolation and solitary confinement. To take away a person's access to privacy is to render them less than human, to treat them like cattle, and to hinder their ability to think their own thoughts. In fact, Falzon (2007, p. 92) highlights: "*The role of depersonalisation or dehumanisation in making possible the systematic exploitation and mistreatment of entire peoples...*". Also, to deprive someone of their privacy is an effective way of gaining control and power over that person, a means of stripping them of their individuality, their uniqueness. This technique can be used on a small scale, like reading someone's diary, or on mass, but it is always about the same thing, namely, to invade. The invasion of someone's privacy is the breeching of social boundaries, and lines of intimacy, that we draw around ourselves, and that define our personhood (e.g., personal freedom, and personal space; see Reiman, 1976, for a discussion of these issues). This process of invasion then devalues, dehumanises, and objectifies. For the person with ASC, this point may be reached much more rapidly than for those further along the privacy spectrum, with the resultant impact on their behaviours.

Thus, privacy is generally regarded as an important, and positive, aspect of our functioning, and even as a fundamental necessity (but see Feminist arguments, MacKinnon, 1989). However, it is possible that too much privacy may produce problems in its own right, and ASC could be argued as being the converse of over-social exposure, the opposite of being deprived of privacy (i.e. an excess of privacy). Thus, this discussion of privacy as an analogy for ASC is rendered as a tool by which to enhance understanding of the problems faced by those with ASC. It is an attempt to bridge the gulf that separates them from us, and *vice versa*, and not an argument in support of the 'right' to be autistic.

One example of a problem that may emerge from being forced into a private situation, that of social isolation, is that an inability to interact with others in a social community reduces the ability of the individual, thus deprived, to maintain their own identity. Much behaviour that defines an individual as being a particular person comes from their social interactions with others; an inability to emit such behaviours will reduce the concept of 'self' that a person possesses. The effects of a reduction in the range of sensory and social contacts on behaviour can be seen in two examples, the impact of sensory deprivation, and the impact of institutionalisation (and social isolation). Both of these phenomena have surprising similarities to the behaviours seen in individuals with ASC.

In terms of the effects of prolonged sensory deprivation, and impoverished environmental stimulation, often resulting from prolonged solitary confinement (and so related to institutionalisation), loud noises and bright lights, and the hustle and bustle of busy activity, as experienced outside the deprivation, are confusing, disorientating, terrifying, and even painful. The senses appear to be unable to deal with, and make sense of, the over-stimulation of this outside world, as if there has been a narrowing, or shrinking, of the capacity of the senses. Sensory perception has been reduced, altered in some way, so that perception of one thing at any one time becomes more than enough to deal with; attention zeros in, and concentrates on, that one thing, then further focuses down to just details of that one thing, and then down further to only one single detail. This over-selection may be produced, as an attempt to handle any more than single details at any one time would result in 'overload'.

The phenomenon of institutionalisation manifests itself to the detriment of autonomy, and quality of life; in a restriction of activities and interests, stereotypic behaviours, repetitive mannerisms; and in a decrease in confidence, and an inability to function, especially socially (see Fleck, Wagner, Wagner, & Dias, 2007). The idea of release from confinement conjures up, not elation and hope, but fear, self-doubt, trepidation, and feelings of insecurity. Exposure anxiety, phobias like agoraphobia, and fear of change and novelty, all combine to limit inquisitiveness, curiosity, and adventurousness.

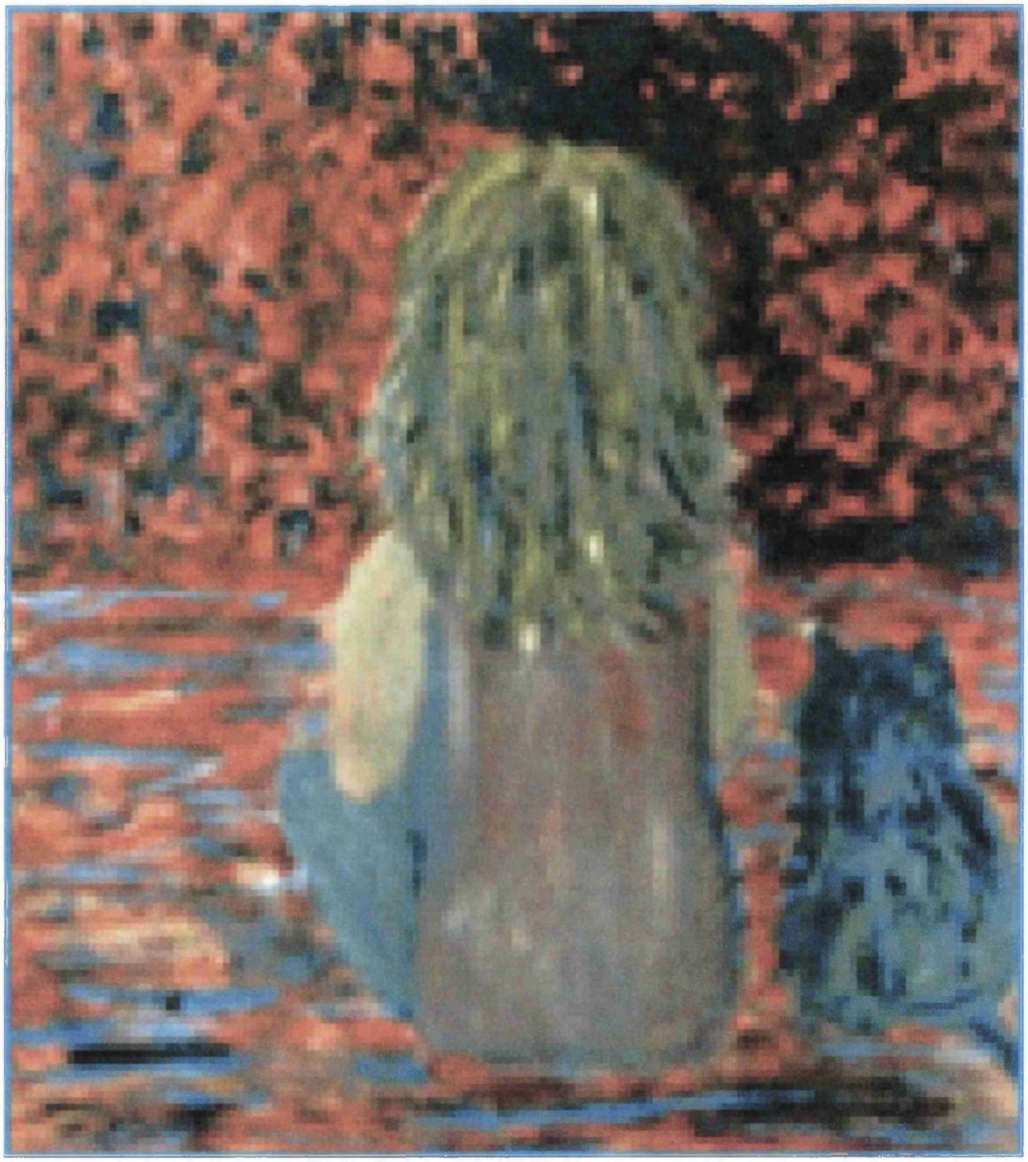
If such an analogy were made for ASC, it would help to explain the common inability of children with ASC to initiate play, to utilise creativity, inventiveness, and imagination. Institutionalisation restricts and reduces repertoires of behaviours and interests, as well as damaging the breadth of ability to cope in, and adapt to, unfamiliar and novel situations. Communication skills suffer also, and can deteriorate dramatically over time. Timing can become awkward, stilted, and impaired, and width of vocabulary can be damaged, so that the same words or phrases can end up being repeated over and over, like echolalia. Emotional affect, facial expression, eye contact, and body language can all be negatively impacted; gross and fine motor skills can be affected, and clumsiness and a lack of coordination, like dyspraxia, can result from long-term confinement. Such a sparseness of skills, especially social skills, would lead to problems of depression and anxiety, which are often seen in adolescents and adults with ASC, as they are required to enter more into the social world, and have greater social contact.

These behaviours that result from such processes of removal from a wider range of social activity are classic characteristics of ASC, and they express a lack of flexibility, variability, and adaptability. In attempting to discover why, and how, there is a reduction in the behavioural repertoire, it must be acknowledged that there is a reduction in the experience of reinforcement, which produces obvious analogies with Ferster's writings on this subject in the areas of ASC and depression. Stimulation is shut off and blocked, reinforcement is limited, and there is a starvation of reward. This is the other extreme from withholding privacy, for that shuts one off from oneself and from one's own private world, whereas ASC, like institutionalisation, is the 'flipside' of that process, as it shuts one off from others and from the public world. Of course, this would prove problematic for individuals with ASC, and especially for those, such as parents and family, who are around them, and this could lead to increases in stress, as seen in the current thesis (Chapter 3).

Most individuals with ASC could be said to have suffered a 'withdrawal' at such a young age that they never, in fact, properly entered the social world, a state of affairs alluded to by Kanner (1943). Thus, not all children with ASC can accurately be said to have 'retreated', or 'withdrawn', as they always 'dwelt' in their own private world (the possible exception being those with Childhood Disintegrative Disorder). Nevertheless, the behavioural characteristics of ASC (see DSM-IV; Chapter 1) could be said to mirror what happens when privacy goes too far.

Bettelheim referred to the "empty fortress", but what if the fortress is not empty, but occupied, and the "fortress" be regarded as a prison? Contact, interaction, and communication are difficult from the outside in, and also from the inside out, resulting in frustration on both sides, especially where severe language difficulties are present. In the case of ASC, frustration and alienation can increase parental stress, and anxiety, for the parents 'trapped' on the outside; and, for the child 'trapped' on the inside, frustration can result in temper tantrums, and aggression, from the child, rendering social contact increasingly aversive and difficult. This is privacy as a 'prison', and with confinement, especially long-term confinement, comes increased social isolation, alienation, and institutionalisation. If one's world is a tiny cell, one focuses more and more on the detail of, and within, that cell. If one's world is one's self, then one fixates on the minutiae of experience and life within one's self, and self-stimulation, in one form or another, becomes vital. If your prison is not a walled cell, but your own skin, your own sensory experiences, and those resulting from contact with your immediate environment, are your only sources of stimulation. The world within your skin, and immediately outside your skin, is all that exists for you in any real sense.

In summary, the current thesis suggests a model, in which initial ASC problems, and the diagnosis of ASC, generate extremely high levels of parenting stress, which, in turn, impact on subsequent parenting behaviours, and, through this mediation, influence child behaviour problems. Such behaviour problems of the child then evolve into a more salient focus for parenting stress, as time passes, and, then, possibly feed back into parenting stress, creating a cyclical effect. This model clearly requires further testing, but, hopefully, provides some direction for future research, and discussion, in this area.



The Wall (2003) by Donna Williams.

References

Abdin, R.R. (1995). *Parenting Stress Index.* Odessa, Fl.: Psychological Assessment Resources.

Anthony, L.G., Anthony, B.J., Glanville, D.N., Naiman, D.Q., Waanders, C., & Shaffer, S. (2005). The relationships between parenting stress, parenting behaviour and preschoolers' social competence and behaviour problems in the classroom. *Infant and Child Development*, **14**, 133-154.

Aristotle. *The Politics.* B. Jowett, rev. J. Barnes (in *The Complete Works of Aristotle*, vol. 2. Princeton, 1984).

Asperger, H. (1941). Zur Erziehungstherapie in der Jugendfuersorge. / Educational treatment in the care of youth. *Monatsschrift fuer Kinderheilkunde*, **87**, 238-248.

Asperger, H. (1944). Die 'aunstisehen Psychopathen' im Kindesalter. *Archiv fur Psychiatrie und Nervenkrankheiten*, **117**, 76-136.

Asperger, H. (1949). Bild und soziale Wertigkeit der autistischen Psychopathen. / The aspects and social significance of autistic psychopaths. *Proceedings International Orthopedics Congress II, Amsterdam*, 257-269.

Austin, J.K., Dunn, D.W., Johnson, C.S., & Perkins, S.M. (2004). Behavioral issues involving children and adolescents with epilepsy and the impact of their families: Recent research data. *Epilepsy and Behavior*, **5**, 33-41.

Backes, M., von Gontard, A., Schreck, J., & Lehmkuhl, G. (2001). Parental stress and coping in families with fragile X boys. *Gene Function & Disease*, **2**, 151-158.

Baker-Ericzen, M.J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, **30**, 194-204.

Bandura, A., Ross, D., & Ross, S.A. (1961). Transmission of aggression through imitation of aggressive models. *Journal of Abnormal and Social Psychology,* **63**, 575-582.

Baron-Cohen, S., & Hammer, J. (1997). Is autism an extreme form of the “male brain”? *Advances in Infancy Research,* **11**, 193-217.

Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a ‘theory of mind’? *Cognition,* **21**, 37-46.

Baron-Cohen, S., Wheelwright, S., Stott, C., Bolton, P., & Goodyer, I. (1997). Is there a link between engineering and autism? *Autism,* **1**, 101-109.

Baron-McKeagney, T., Woody, J.D., & D’Souza, H.J. (2002). Mentoring at-risk Latino children and their parents: Analysis of the parent-child relationship and family strength. *Families in Society,* **83**, 285-292.

Bartolo, P.A. (2002). Communicating a diagnosis of developmental disability to parents: Multiprofessional negotiation frameworks. *Child Care, Health and Development,* **28**, 65-71.

Baxter, C., Cummins, R.A., & Yiolitis, L. (2000). Parental stress attributed to disabled family members: A longitudinal study. *International Journal of Disability Research.*

Bebko, J.M., Konstantaraes, M.M., & Springer, J. (1987). Parent and professional evaluations of family stress associated with characteristics of autism. *Journal of Autism and Developmental Disorders,* **17**, 565-576.

Bentall, R.P. (1990). *Reconstructing schizophrenia.* London: Routledge.

Bettelheim, B. (1950). *Love is not enough; the treatment of emotionally disturbed children.* New York: Free Press.

Bettelheim, B. (1967). *The empty fortress: infantile autism and the birth of the self.* Oxford: Free Press of Glencoe.

Beversdorf, D.Q., Manning, S.E., Hillier, A., Anderson, S.L., Norgren, R.E., Walters, S.E., Nagaraja, H.N., Cooley, W.C., Gaelic, S.E., & Bauman, M.L. (2005). Timing of parental stressors and autism. *Journal of Autism and Developmental Disorders*, **35**, 471-478.

Bitsika, V., & Sharpley, C. (1999). An explanatory examination of the effects of support groups on the well-being of parents of children with autism: I: General Counselling. *Journal of Applied Health Behaviour*, **1**, 16-22.

Bitsika, V., & Sharpley, C. (2000). Development and testing of the effects of support groups on the well-being of parents of children with autism-II: Specific stress management techniques. *Journal of Applied Health Behaviour*, **2**, 8-15.

Blacher, J., & McIntyre, L.L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual and Developmental Disabilities*, **50**, 184-198.

Blacher, J., Neece, C.L., & Paczkowski, E. (2005). Families and intellectual disability. *Current Opinion in Psychiatry*, **18**, 507-513.

Blader, J.C. (2006). Which family factors predict children's externalizing behaviors following discharge from psychiatric inpatient treatment? *Journal of Child Psychology and Psychiatry*, **47**, 1133-1142.

Bleuler, E. (1911). Dementia Praecox oder die Gruppe der Schizophrenien. *Deuticke.* Leipzig.

Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*, **46**, 722-730.

Bowlby, J. (1951). Maternal care and mental health. *Bulletin of the World Health Organization*, **3**, 355-533.

Boyd, B.A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism & Other Developmental Disabilities,* **17**, *208-215.*

Boyd, R.D., & Corley, M.J. (2001). Outcome survey of early intensive behavioral intervention for young children with autism in a community setting. *Autism*, **5**, 430-441.

Brainerd, C.J. (1978). The stage question in cognitive-developmental theory. *The Behavioral and Brain Science*, **12**, 173–213.

Bristol, M. M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the Double ABCX Model. *Journal of Autism and Developmental Disorders,* **17**, 469-486.

Brogan, C.A., & Knussen, C. (2003). The disclosure of a diagnosis of an autism spectrum disorder. *Autism*, **7**, 31-46.

Brookman-Frazee, L., Stahmer, A., Baker-Ericzen, M.J., & Tsai, K. (2006). Parenting interventions for children with autism spectrum and disruptive behaviour disorders: Opportunities for cross-fertilization. *Clinical Child and Family Psychology Review*, **9**, 181-200.

Butow, P.N., Kazemi, J.N., Beeney, L.J., Griffin, A., Dunn, S.M., & Tattersall, M.H.N. (1996). When the diagnosis is cancer: patient communication experiences and preferences. *Cancer*, **77**, 2630-37.

Cameron, R.J. (1997). Early intervention for young children with developmental delay: The Portage approach. *Child: Care, Health & Development*, **23**, 11-27.

Carlson-Green, B., Morris, R.D., & Krawiecki, N. (1995). Family illness predictors of outcome in pediatric brain tumors. *Journal of Pediatric Psychology*, **20**, 769-784.

Chakrabarti, S., & Fombonne, E. (2005). Pervasive developmental disorders in preschool children: Confirmation of high prevalence. *American Journal of Psychiatry,* **162**, 1133-1141.

Charman, T., Howlin, P., Berry, B., & Prince, E. (2004). Measuring developmental progress of children with autism spectrum disorder on school entry using parent report. *Autism,* **8**, 89-100.

Cherry, D.B. (1989). Stress and coping in families with ill or disabled children: application of a model to pediatric therapy. *Physical & Occupational Therapy in Pediatrics*, **9**, 11-32.

Coffman, J.K., Guerin, D.W., & Gottfried, A.W. (2006). Reliability and validity of the parent-child relationship inventory (PCRI): evidence from a longitudinal cross informant investigation. *Psychological Assessment*, **18**, 209-214.

Conners, C.K. (1997). *Conners' parent rating scale.* Pearson Assessment.

Connor, M. (1998). A review of behavioural early intervention programmes for children with autism. *Educational Psychology in Practice, 14,* 109-117.

Critchley, M., & Earl, C.J.C. (1932). Tuberose sclerosis and allied conditions. *Brain*, **55**, 311-346.

Dale, M. (1996). *Working with families of children with special needs: Partnership and practice.* London: Routledge.

Dale, E., Jahoda, A., & Knott, F. (2006). Mothers' attributions following their child's diagnosis of autistic spectrum disorder: Exploring links with maternal levels of stress, depression and expectations about their child's future. *Autism*, **10**, 463-479.

Darlington, R.B. (1990). *Regression and linear models.* New York: McGraw-Hill.

Dawson, G., & Osterling, J. (1997). Early intervention in autism: Effectiveness and common elements of current approaches. In Guralnick (Ed.), *The effectiveness of early intervention: Second generation research*, (pp. 307-326). Baltimore: Brookes.

Deater-Deckard, K. (1998). Parenting stress and child adjustment: Some old hypotheses and new questions. *Clinical Psychology: Science and Practice*, **5**, 314-332.

DeMeyer, M.K. (1979). *Parents and children in autism.* Washington, DC.: V.H. Winston & Sons.

De Sanctis, S. (1906). Sopra alcune varieta della demenza precoce. *givista Airgentale Di Freniatria E Di Acina Legale*, U, **1**, 1-165.

Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV). Arlington, Va.: American Psychiatric Association.

Department for Education and Skills. (2002). *Good autism practice pointers.* Nottingham: DfES.

Department of Health (2001). *The mental health policy implementation guide*. London: Department of Health.

Donenberg, G., & Baker, B.L. (1993). The impact of young children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology*, **21**, 179-197.

Drash, P.W., & Tudor, R.M. (2004). An analysis of autism as a contingency-shaped disorder. *The Analysis of Verbal Behavior,* **20**, 55-62.

Dumas, J.E., & Wekerle, C. (1995). Maternal reports of child behavior problems and personal distress as predictors of dysfunctional parenting. *Development and Psychopathology*, **7**, 465-479.

Dumas, J.E., Wolf, L.C., Fisman, S., & Culligan, A. (1991). Parenting stress, child behaviour problems, and dysphoria in parents of children with autism, Down syndrome, behaviour disorders, and normal development. *Exceptionality,* **2**, 97-110.

Dunn, M.E., Burbine, T., Bowers, C.A., & Tantleff-Dunn, S. (2001). Moderators of stress in. parents of children with autism. *Community Mental Health Journal*, **37**, 39-52.

Durate, C.S., Bordin, I.A., Yazigi, L., & & Mooney, J. (2005). Factors associated with stress in mothers of children with autism. *Autism*, **9**, 416-427.

Dyson, L., Edgar, E., & Crnic, K. (1989). Psychological predictors of adjustment of siblings of developmentally disabled children. *American Journal of Mental Retardation*, **94**, 292-302.

Ehlers, S., & Gillberg, C. (1993). The epidemiology of Asperger syndrome: A total population study. *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, **34**, 1327-1350.

Ehrensaft, M.K., Wasserman, G.A., Verdelli, L., Greenwald, S., Miller, L.S., & Davies, M. (2003). Maternal antisocial behavior, parenting practices, and behavior problems in boys at risk for antisocial behavior. *Journal of Child and Family Studies*, **12**, 27-40.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism. *Behavior Modification*, **26**, 49-68.

Einfeld, S.L., & Tonge, B.J. (1995). *Manual for the Developmental Behaviour Checklist*. Monash: UNSW-Monash University.

Eisenhower, A.S., Baker, B.L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behaviour problems, and maternal well-being. *Journal of Intellectual Disability Research*, **49**, 657-671.

Eldevik, S., Eikeseth, S., Jahr, E., & Smith, T. (2006). Effects of low-intensity behavioral treatment for children with autism and mental retardation. *Journal of Autism and Developmental Disorders*, **36**, 211-224.

El-Ghoroury, N.B., & Romancyzk, R.G. (1999). Play interactions of family members towards children with autism. *Journal of Autism and Developmental Disorders*, **29**, 249-258.

Elliot, C.D., Smith, P., & McCulloch, K. (1996). *British Ability Scales II.* Windsor: NFER-Nelson.

Engwell, P., & Macpherson, E. (2003). An evaluation of the NAS EarlyBird programme. *Good Autism Practice*, **4**, 13-19.

Evans, M., Stoddart, H., Condon, L., Freeman, E., Grizzell, M., & Mullen, R. (2001). Parents' perspectives on the MMR immunisation: a focus group study. *British Journal of General Practice*, **51**, 904-910.

Factor, D.C., Perry, A., & Freeman, N. (1990). Stress, social support, and respite care use in families with autistic children. *Journal of Autism and Developmental Disorders*, **20**, 139-146.

Falzon, C. (2007). *Philosophy goes to the movies: An introduction to philosophy.* London: Routledge.

Fenning, R., Baker, J., Baker, B., & Crnic, K. (2007). Parenting children with borderline intellectual functioning. *American Journal on Mental Retardation*, **112**, 107-121.

Ferster, C.B. (1961). Positive reinforcement and behavioral deficits of autistic children. *Child Development*, **32**, 437-456.

Fisman, S.N., Wolf, L.C., & Noh, S. (1989). Marital intimacy in parents of exceptional children. *Canadian Journal of Psychiatry*, **34**, 519-525.

Fleck, M.P.A., Wagner, L., Wagner, M., & Dias, M. (2007). Long-stay patients in a psychiatric hospital in Southern Brazil. *Rev. Saúde Pública.*

Floyd, F.J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*, **46**, 359-371.

Fong, P.L. (1991). Cognitive appraisals in high- and low-stress mothers of adolescents with autism. *Journal of Consulting and Clinical Psychology*, **59**, 471-474.

Fong, L., Wilgosh, L., & Sobsey D. (1993). The experience of parenting an adolescent with autism. *International Journal of Disability, Development, and Education*, **40**, 105-113.

Foxall, G.R. (1999). The marketing firm. *Journal of Economic Psychology*, ***20***.

Freeman, N.L., Perry A., & Factor, D.C. (1991). Child behaviours as stressors: Replicating and extending the use of the CARS as a measure of stress. *Journal of Child Psychology and Psychiatry*, **32**, 1025-1030.

Friedrich, W.N., Greenberg, M.T., & Crnic, K. (1983). A short-form of the questionnaire on resources and stress. *American Journal of Mental Deficiency*, **88**, 41-48.

Frith, U. (1989). *Explaining the enigma.* Oxford: Blackwell.

Frith, U., & Frith, C.D. (2003). Development and neurophysiology of mentalizing. *Philosophical Transactions of the Royal Society London – Series B: Biological Sciences*, **358**, 459-473.

Frith, U., & Happe, F. (1994). Autism: Beyond "theory of mind". *Cognition*, **50**, 115-132.

Gabriels, R.L., Cuccaro, M.L., Hill, D.E., Ivers, B.J., & Goldson, E. (2005). Repetitive behaviors in autism: Relationships with associated clinical features. *Research in Developmental Disabilities*, **26**, 169-181.

Gabriels, R.L., Hill, D.E., Pierce, R.A., Rogers, S.J., & Wehner, B. (2001). Predictors of treatment outcome in young children with autism. *Autism*, **5**, 407-429.

Gallagher, S. (2004). The interpersonal and emotional beginnings of understanding: A review of Peter Hobson's The cradle of thought: Exploring the origins of thinking. *Philosophy, Psychiatry, & Psychology*, **11**, 253-257.

Gardner, M. (2000). The brutality of Dr. Bettelheim. *Skeptical Inquirer*, Nov.

Gerard, A.B. (1994). *Parent-child relationship inventory (PCRI) Manual.* Los Angeles, CA: Western Psychological Services.

Gerrans, P., & McGeer, V. (2003). Theory of mind in autism and schizophrenia: A case of over-optimistic reverse engineering. In B. Repacholi, & V. Slaughter (Eds.), *Individual differences in theory of mind: Implications for typical and atypical development. Macquarie monographs in cognitive science*, (pp. 271-303). New York: Psychology Press.

Gill, M.J., & Harris, S.L. (1991). Hardiness and social support as predictors of Psychological discomfort in mothers of children with autism. *Journal of Autism and Developmental Disorders,* **21**, 407-416.

Gilliam, J.E. (1995). *Gilliam Autism Rating Scale*. Austin, TX: Pro-Ed.

Gillman, M., Heyman, B., & Swain, J. (2000). 'What's in a name? The implications of diagnosis for people with learning difficulties and their family carers. *Disability & Society,* **15**, 389–409.

Gipps, R. (2004). Autism and intersubjectivity: Beyond cognitivism and the theory of mind. *Philosophy, Psychiatry, & Psychology*, **11**, 195-198.

Goin-Kochel, R.P., Mackintosh, V.H., & Myers, B.J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism*, **5**, 439-451.

Goodman, R. (1997). The Strengths and Difficulties Questionnaire: A research note. *Journal of Child Psychology and Psychiatry*, **38**, 581-586.

Grandin, T. (1990). Needs of high functioning teenagers and adults with autism: Tips from a recovered autistic. *Focus on Autistic Behavior*, **5**, 16.

Gray, D.E. (1993). Negotiating autism: Relations between parents and treatment staff. *Social Science and Medicine*, **36**, 1037-1046.

Gray, D.E. (1994). Coping with autism: Stresses and strategies. *Sociology of Health and Illness*, **16**, 275-300.

Gray, D.E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability*, **27**, 215-222.

Gray, D.E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research*, **50**, 970-976.

Greenley, R.N., Holmbeck, G.N., & Rose, B.M. (2006). Predictors of parenting behavior trajectories among families of young adolescents with and without spina bifida. *Journal of Pediatric Psychology,* **31**, 1057-1071.

Greenspan, S.I., & Wieder, S. (1997). Developmental patterns and outcomes in infants and children with disorders in relating and communicating: A chart review of 200 cases of children with autistic spectrum diagnoses. *Journal of Developmental and Learning Disorders,* **1**, 87-141.

Greer, R.D. (1997). The Comprehensive Application of Behavior Analysis to Schooling (CABAS®). *Behavior and Social Issues*, **7**, 59-63.

Greer, R.D. (2002). *Designing teaching strategies: An applied behavior analysis systems approach.* London: Elsevier.

Greer, R.D. (2007). *The unorthodox behaviorist.* Teachers' College, Columbia University. Press Room Article, published: *06/04/2007.*

Greer, R.D., Keohane, D.D., & Healy, O. (2002). Quality and comprehensive applications of behavior analysis to schooling. *The Behavior Analyst Today*, **3**, 3-15.

Greer, R.D, & McCorkle (2003). *Preschool Inventory of Repertoire for Kindergarten*, unpublished manuscript.

Gresham, F. & MacMillan, D. (1998). Early intervention project: Can its claims be substantiated and its effects replicated?' *Journal of Autism and Developmental Disorders*, **28**, 5-13.

Handen, B.L., Johnson, C.R., & Lubetsky, M. (2000). Efficacy of methylphenidate among children with autism and symptoms of attention-deficit hyperactivity disorder. *Journal of Autism and Developmental Disorders*, **30**, 245-255.

Happe, F., Ronald, A. & Plomin, R. (2006). Time to give up on a single explanation for autism. *Nature Neuroscience*, **9**, 1218-1220.

Harris, P.L. (2000). *The work of the imagination.* Malden, MA: Blackwell Publishers.

Harris, S.L. (1984). The family of the autistic child: A behavioral-systems view. *Clinical Psychology Review*, **4**, 227-239.

Harris, S.L. (1994). Treatment of family problems in autism. In E. Schopler & G.B. Mesibov (Eds.), *Behavioral issues in autism* (pp. 161-175). New York, NY: Plenum Press.

Harris, S.L., Handleman, J.S., Arnold, M.S., & Gordon, R.F. (2000). The Douglass Developmental Disabilities Center: Two models of service delivery. In J.S.Handleman & S.L.Harris (Eds.), *Preschool Education Programs for Children with Autism (2nd ed.),* (pp. 233–260). Austin, TX: Pro-Ed.

Hastings, R.P. (2002). Parental stress and behaviour problems of children with developmental disability. *Journal of Intellectual and Developmental Disability,* **27,** 149-160.

Hastings, R. (2003). Brief report: Behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, **33**, 99-104.

Hastings, R.P., & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation*, **107**, 222-232.

Hastings, R.P. & Johnson, E. (2001). Stress in U.K. families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorders,* **31,** 327-336.

Hastings, R.P., Kovshoff, H., Brown, T., Ward, N.J., Espinosa, F.D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, **9**, 377-391.

Hastings, R.P., & Symes, M.D. (2002). Early intensive behavioral intervention for children with autism: parental therapeutic self-efficacy. *Research in Developmental Disabilities*, **23**, 332-341.

Hayes, S.C. (1994). *Acceptance and change: Content and context in psychotherapy.* Reno: Context Press.

Hayes, S.C., Strosahl, K., & Wilson, K.G. (1999). *Acceptance and Commitment Therapy: An experimental approach to behavior change*. New York: Guilford Press.

Hecimovic, A., Powell, T.H., & Christensen, L. (1999). Supporting families in meeting their needs. In D.B. Zager (Ed.), *Autism, identification, education, and treatment,* (pp. 261-299). Mahwah: Erlbaum.

Heinze, M.C., & Grisso, T. (1996). Review of instruments assessing parenting competencies used in child custody evaluations. *Behavioral Sciences and the Law*, **14**, 293-313.

Heller, T. (1908). Cited in Volkmar, F.R. (1992). Childhood disintegrative disorder: Issues for DSM-IV. *Journal of Autism and Developmental Disorders*, **22**, 625-642.

Heller, T. (1930). Ueber die Dementia infantilis. / Concerning infantile dementia. *Zeitschrift-fuer-Kinderforschung*, **37**, 661-667.

Hendry, C.N. (2000). Childhood disintegrative disorder: Should it be considered a distinct diagnosis? *Clinical Psychology Review*, **20**, 77-90.

Hobson, R.P., Ouston, J., & Lee, A. (1989). Naming emotion in faces and voices: Abilities and disabilities in autism and mental retardation. *British Journal of Developmental Psychology*, **7**, 237-250.

Hodapp, R.M., Fidler, D.J., & Smith, A.C.M. (1998). Stress and coping in families of children with Smith Magenis syndrome. *Journal of Intellectual Disability Research*, **42**, 331-340.

Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal of Mental Deficiency*, **80**, 431-436.

Honey, E., Hastings, R.P., & McConachie, H. (2005). Use of the Questionnaire on Resources and Stress (QRS-F) with parents of young children with autism. *Autism*, **9**, 246-255.

Hoppes, K., & Harris, S.L. (1990). Perceptions of child attachment and maternal gratification in mothers of children with autism and Down syndrome. *Journal of Clinical Child Psychology*, **19**, 365-370.

Hornby, G. (1995). Fathers' views of the effects on their families of children with Down syndrome. *Journal of Child and Family Studies*, **4**, 103-117.

Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the U.K. *Autism*, **1**, 135–162.

Howard, J.S., Sparkman, C.R., Cohen, H.G., Green, G., & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities*, **26**, 359-383.

Howell, D.C. (1997). *Statistical methods for psychology*. New York: Duxbury.

Huws, J., Jones, R.S., & Ingledew, D.K. (2001). Parents of children with autism using an e-mail group: A grounded theory study. *Journal of Health Psychology*, **6**, 569-584.

International Classification of Diseases (ICD). Geneva: World Health Organization.

Islam, Y. (1998). Is there a link between engineering and autism?: Commentary. *Autism*, **2**, 98.

Jackson, A.P. (2000). Maternal self-efficacy and children's influence on stress and parenting among single black mothers in poverty. *Journal of Family Issues*, **21**, 3-16.

Jackson, A.P., & Huang, C.C. (2000). Parenting stress and behavior among single mothers of preschoolers: The mediating role of self-efficacy. *Journal of Social Service Research*, **26**, 29-42.

Jervis G. (1937). Phenylpyruvic oligophrenia: introductory study of 50 cases of mental deficiency associated with excretion of phenylpyruvic acid. *Archives of Neurology and Psychiatry*, **38**, 944.

Jocelyn, L.J., Casiro, O.G., Beattie, D., Bow, J., & Kneisz, J. (1998). Treatment of children with autism: A randomized controlled trial to evaluate a caregiver-based intervention program in community day-care centers. *Journal of Developmental and Behavioral Pediatrics*, **19**, 326-334.

Kaar, M.L. (1983). Clinical course of diabetes in children: With special reference to factors affecting metabolic control. *Acta Universitatis Ouluensis*, **100**.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, **2**, 217-250.

Kanner, L. (1944a). Early infantile autism. *Journal of Pediatrics*, **25**, 211-217.

Kanner, L. (1944b). The role of the school in the treatment of rejected children. *Nervous Child*, **3**, 236-248.

Kanner, L. (1949). Problems of nosology and psychodynamics of early infantile autism. *American Journal of Orthopsychiatry*, **19**, 416-426.

Kanner, L., & Eisenberg, L. (1955). Notes on the follow-up studies of autistic children. In P.H. Hoch, & J. Zubin (Eds), *Psychopathology of childhood*. (pp. 227-239). Oxford: Grune & Stratton.

Kanner, L., & Eisenberg, L. (1956). Child psychiatry. Mental deficiency. *American Journal of Psychiatry*, **112**, 531-534.

Kanner, L., & Eisenberg, L. (1957). Early infantile autism, 1943-1955. *Psychiatric Research Reports*, **7**, 55-65.

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders*, **27**, 39-57.

Keogh, B.K., Garnier, H.E., Bernheimer, L.P., & Gallimore, R. (2000). Models of child family interactions for children with developmental delays: child-driven or transactional? *American Journal of Mental Retardation*, **105**, 32-46.

Keohane, D.D. (1997). *A functional relationship between teachers' use of scientific rule governed strategies and student learning*. Doctoral Dissertation.

Keohane, D.D., Greer, R.D., & Ackerman, S. (2007). Conditioned observation for visual stimuli and rate of learning. *Paper presented at the Third Conference of the International Association for Behavior Analysis, Beijing, China.*

Klauber, T. (1999). The significance of trauma and other factors in work with the parents of children with autism. In A. Alvarez & S. Reid (Eds.), *Autism and personality: findings from the Tavistock autism workshop* (pp. 33-48). Florence, KY: Taylor & Frances/Routledge.

Koegel, R.L., Bimbella, A., & Schreibman, L. (1996). Collateral effects of parent training on family interactions. *Journal of Autism and Developmental Disorders*, **26**, 347-359.

Koegel, R.L., Schreibman, L., Loos, L.M., Dirlich-Wilheim, H., & Dunlap, L. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders*, **22**, 205-216.

Koegel, R.L., Schreibman, L., O'Neill, R.E., & Burke, J.C. (1983). The personality and family interaction characteristics of parents of autistic children. *Journal of Consulting and Clinical Psychology*, **51**, 683-692.

Konstantareas, M.M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry*, **30**, 459-470.

Kotchick, B.A., Dorsey, S., & Heller, L. (2005). Predictors of parenting among African American single mothers: Personal and contextual factors. *Journal of Marriage and Family*, **67**, 448-460.

Kuloglu-Aksaz, N. (1994). The effect of informational counseling on stress level of parents of children with autism in Turkey. *Journal of Autism and Developmental Disorders*, **24**, 109-110.

Kurita, H. (1989). Heller's syndrome as a type of pervasive developmental disorder. *Journal of Mental Health*, **35**, 71-81.

Kurtz, L., & Derenvensky, J. L. (1994). Adolescent motherhood: An application of the stress and coping model to child rearing attitudes and practices. *Canadian Journal of Community Mental Health*, **13**, 5–24.

Lauchlan, F., & Boyle C. (2007). Is the use of labels in special education helpful? *Support for Learning*, **22**, 36–43.

Lazarus, R. (1991). *Emotions and adaptations*. New York: Oxford University Press.

Leader, G., & Barnes-Holmes, D. (2001). Establishing fraction-decimal equivalence using a respondent-type training procedure. *Psychological Record*, **51**, 151-165.

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, **50**, 172-183.

Leslie, A.M. (1991). Theory of mind impairment in autism. In A. Whiten (Ed.), *Natural theories of mind: Evolution, development, and simulation of everyday mindreading.* Cambridge, MA: Basil Blackwell.

Levers, C.E., & Drotar, D. (1996). Family and parental functioning in cystic fibrosis. *Journal of Developmental and Behavioral Pediatrics*, **17**, 48-55.

Lloyd, C., Smith, J., & Weinger, K. (2005). Stress and diabetes: A review of the links. *Diabetes Spectrum*, **18**, 121-127.

Lord, C., & McGee, J. (2001). *Educating children with autism.* Washington, DC: National Academy Press.

Lord, C., & Schopler, E. (1994). TEACCH services for preschool children. In S.L. Harris & J. S. Handleman (Eds.), *Preschool education programs for children with autism* (pp. 87-106). Austin, TX: Pro-Ed.

Lovaas, O.I. (1987). Behavioral treatment and normal educational functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, **55**, 3-9.

Lovaas, O.I., & Schreibman, L. (1971). Stimulus overselectivity of autistic children in a two stimulus situation. *Behaviour Research and Therapy*, **9**, 305-310.

Lovaas, O.I., & Smith, T. (2003). Early and intensive behavioral intervention in autism. In E. Kazdin & J. R. Weisz (Eds.), *Evidence-based psychotherapies for children and adolescents* (pp. 325-340). New York: Guilford.

Luiselli, J.K, Cannon, B., Ellis, J.T., & Sisson, R.W. (2000). Home-based behavioral interventions for young children with autism/pervasive developmental disorder: A preliminary evaluation of outcome in relation to child age and intensity of service delivery. *Autism*, **4**, 426-438.

MacKinnon, C. (1989). *Toward a feminist theory of the state*. Cambridge: Harvard University Press.

Magiati, I., & Howlin, P.A. (2001). Monitoring the progress of preschool children with autism enrolled in early intervention programmes: Problems in cognitive assessment. *Autism*, **5**, 399-406.

Malamud, N. (1959). Heller's disease and childhood schizophrenia. *American Journal for Psychiatry*, **116**, 215-218.

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: access to information and use of service. *Autism*, **8**, 387-407.

Marcus L. (1977). Patterns of coping in families of psychotic children. *American Journal of Orthopsychiatry,* **47**, 383-399.

Martire, L.M., & Schulz, R. (2007). Involving family in psychosocial interventions for chronic illness. *Current Directions in Psychological Science*, **16**, 90-94.

Mash, E.J., & Johnston, C. (1983). Parental perceptions of child behavior problems, parenting self-esteem, and mothers' reported stress in younger and older hyperactive and normal children. *Journal of Consulting and Clinical Psychology*, **51**, 86-99.

Mazure, C.M. (1995). *Does stress cause psychiatric illness?* Washington, DC: American Psychiatric Association.

McAdoo, W.G., & DeMeyer, M.K. (1977). Research related to family factors in autism. *Journal of Pediatric Psychology*, **2**, 162-166.

McClannahan, L., & Krantz, P. (1994). The Princeton Child Development Institute. In S. Harris & J. Handleman (Eds.), *Preschool education programs for children with autism*. Austin, TX: Pro-Ed.

Meehl, P.E. (1962). Schizotaxia, schizotypy and schizophrenia. *American Psychologist,* **17**, 827-838.

Melamed, B.G. (1995). The interface between physical and mental disorders: The need to dismantle the biopsychosocialneuroimmunological model of disease. *Journal of Clinical Psychology in Medical Settings*, **2**, 225-231.

Mesibov, G. (1997). Formal and informal measures on the effectiveness of the TEACCH programme. *Autism*, **1**, 25-35.

Mesibov, G.B., Schopler, E., & Hearsey, K.A. (1994). Structured teaching. In E. Schopler, & G.B. Mesibov (Eds.), *Behavioral issues in autism*. (pp. 195-207). New York, NY: Plenum Press.

Mesibov, G.B., Shea, V., & Schopler, E. (2005). *The TEACCH approach to autism spectrum disorders.* New York: Kluwer Academic/Plenum.

Meyers, S.A., & Miller, C. (2004). Direct, mediated, moderated, and cumulative relations between neighborhood characteristics and adolescent outcomes. *Adolescence*, **39**, 121-144.

Midence, K., & O'Neill, M. (1999). The experience of parents in the diagnosis of autism: A pilot study. *Autism*, **3**, 273-285.

Miles, J., & Shevlin, M. (2001). *Applying regression & correlation: A guide for students and researchers*. London: Sage.

Moes, D. (1995). Parent education and parenting stress. In R.L. Koegel & L.K. Koegel (Eds.), *Teaching children with autism: Strategies for initiating positive interactions and improving learning opportunities* (pp. 79-93). Baltimore, MD: Paul Brookes.

Mudford, O.C., Martin, N.T., Eikeseth, S., & Bibby, P. (2001). Parent-managed behavioral treatment for preschool children with autism: Some characteristics of U.K. programs. *Research in Developmental Disabilities,* **22,** 173-182.

National Autistic Society (2003). *National autism plan for children (NAPC).* London: The National Autistic Society.

National Autistic Society. (2005). *How many people have autistic spectrum disorders?* London: The National Autistic Society.

National Research Council (2001). *Educating children with autism.* Committee on Educational Interventions for Children with Autism, Canada.

Nitz, K., Ketterlinus, R.D., & Brandt, L.J. (1995). The role of stress, social support, and family environment in adolescent mothers' parenting. *Journal of Adolescent Research,* **10**, 358-382.

Noh, S., Dumas, J.E., Wolf, L.C., & Fisman, S.N. (1989). Delineating sources of stress in parents of exceptional children. *Family Relations: Journal of Applied Family and Child Studies,* **38**, 456-461.

Oberhein, D. (1996). *The support needs of adults and children with autism and their carers in Kent.* Gillingham: The Kent Autistic Trust.

Olson, C.L. (1979). Practical considerations in choosing a MANOVA test statistic. *Psychological Bulletin,* **83**, 579-586.

O'Reilly, M.F., Richman, D., Lancioni, G., Hillery, J., Lindauer, S., Crosland, K., & Lacey, C. (2000). Using brief assessments to identify specific contexts for problem behavior maintained by positive and negative reinforcement. *European Journal of Behavior Analysis,* **1**, 135-142.

Osborne, L.A., McHugh, L., Saunders, J., & Reed, P. (2006). Stress and parenting behaviour in parents of children with autistic spectrum disorders. *Third Conference of the European Association for Behaviour Analysis, Milan.*

Ozonoff, S., & Cathcart, K. (1998). Effectiveness of a home program intervention for young children with autism. *Journal of Autism and Developmental Disorders*, **28**, 25 -32.

Perry, A., Sarlo-McGarvey, N., & Factor, D.C. (1992). Stress and family functioning in parents of girls with Rett syndrome. *Journal of Autism and Developmental Disorder*, **22**, 235-248.

Piaget, J. (1954). *Intelligence and affectivity: Their relationship during child development.* Palo Alto, CA: Annual Review, Inc.

Piening, S. (1984). Family stress in diabetic renal failure. *Health and Social Work*, **9**, 134-141.

Pisula, E. (1998). Stress in mothers of children with developmental disabilities. *Polish Psychological Bulletin*, **29**, 305-311.

Pisula, E. (2003). Parents of children with autism – review of current research. *Archives of Psychiatry and Psychotherapy*, **5**, 51-63.

Pisula, E. (2004). Stress and depression in mothers and the behavior of children with autism in the strange situation. *Przeglad Psychologiczny*, **47**, 291-304.

Potter, H.W. (1933). Schizophrenia in children. *American Journal of Psychiatry*, **12**, 1254-1270.

Powers, M.D. (2000). Children with autism and their families. In M.D. Powers (Ed.), *Children with autism: A parents' guide*, (pp. 119-153). Bethesda, MD.: Woodbine House.

Randall, P., & Parker, J. (1999). *Supporting the families of children with autism.* Chichester: Wiley.

Reed, P., Gibson, E. & Osborne, L.A. (2000). Portage as a potential intervention for autism. *International Portage Newsletter.*

Reed, P., Osborne, L.A., & Corness, M. (2007a). Relative effectiveness of different home-based behavioral approaches to early teaching intervention. *Journal of Autism and Developmental Disorders*, **37**.

Reed, P., Osborne, L.A., & Corness, M. (2007b). The real-world effectiveness of early teaching interventions for children with autistic spectrum disorders. *Exceptional Children*, **73**.

Reed, P., Osborne, L.A., & Corness, M. (2007c). Effectiveness of special nursery provision for children with Autistic Spectrum Conditions. *Autism.*

Reiman, J. (1976). Privacy, intimacy, and personhood. *Philosophy and Public Affairs*, **6**, 26-44.

Repetti, R.L., & Wood, J. (1997). Effects of daily stress at work on mothers' interactions with preschoolers. *Journal of Family Psychology*, **11**, 90-108.

Rimland, B. (1964). *Infantile autism: The syndrome and its implications for a neural theory of behavior.* East Norwalk: Appleton-Century-Crofts.

Ritvo, E.R. Cantwell, D., Johnson, E., Clements, M., Benbrook, F., Slagle, S., Kelly, P., & Ritz, M. (1971). Social class factors in autism. *Journal of Autism and Childhood Schizophrenia*, **1**, 297-310.

Robbins, F.R., Dunlap, G., & Plienis, A.J. (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention*, **15**, 173-184.

Robinson, E.A., & Anderson, L.L. (1983). Family adjustment, parental attitudes, and social desirability. *Journal of Abnormal Child Psychology*, **11**, 247-256.

Rodgers, A.Y. (1993). The assessment of variables related to the parenting behaviour of mothers with young children. *Children and Youth Services Review*, **15**, 385-402.

Rodgers, A.Y. (1998). Multiple sources of stress and parenting behavior. *Children and Youth Services Review*, **20**, 525-546.

Rodrigue, J.R., Morgan, S.B., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology*, **19**, 371-379.

Rogers, S. J. (1998). Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child Psychology*, **27**, 168-179.

Rutter, M. (2000). Genetic studies of autism: From the 1970s into the millennium. *Journal of Abnormal Child Psychology*, **28**, 3-14.

Rutter, M., Lebovici, S., Eisenberg, L., Snezhnevsky, A.V., Sadoun, R., Brook, E., & Lin, T. (1969). A triaxial classification of mental disorder in children. *Journal of Child Psychology and Psychiatry*, **10**, 41-61.

Sallows, G.O., & Graupner, T.D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation*, **110**, 417-438.

Salt, J., Sellars, V., Shemilt, J., Boyd, S., Coulson, T., & McCool, S. (2001). The Scottish Centre for Autism pre-school treatment programme: I. A developmental approach to early intervention. *Autism*, **5**, 362-373.

Salt, J., Shemilt, J., Sellars, V., Boyd, S., Coulson, T., & McCool, S. (2002). The Scottish Centre for Autism pre-school treatment programmme: II. The results of a controlled treatment outcome. *Autism*, **6**, 33-46.

Sanders, J.L., & Morgan, S.B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behavior Therapy*, **19**, 15-32.

Sanua, V.D. (1987). Standing against an established ideology: Infantile autism, a case in point. *Clinical Psychologist*, **40**, 96-100.

Schoeman, F. (1984). *Philosophical dimensions of privacy: An anthology.* Cambridge: Cambridge University Press.

Schopler, E. (1971). Parents of psychotic children as scapegoats. *Journal of Contemporary Psychotherapy*, **4**, 17-22.

Schopler, E. (1997). Implementation of TEACCH philosophy. In D.J. Cohen & F.R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 767-795). New York: Wiley.

Schopler, E., Andrews, C.E., & Strupp, K. (1979). Do autistic children come from upper middle class parents? *Journal of Autism and Developmental Disorders*, **9**, 139-152.

Schopler, E., Reichler, R., Bashford, A., Lansing, M., & Marcus, L. (1990). *Psychoeducational Profile* (rev.). Austin, TX: Pro-Ed.

Schuntermann, P. (2002). Pervasive developmental disorder and parental adaptation: Previewing and reviewing atypical development with parents in child psychiatric consultation. *Harvard Review of Psychiatry*, **10**, 16-27.

Selfe L. (1977). *Nadia: A case of extraordinary drawing ability in an autistic child.* London: Academic Press.

Sharpley, C.F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress anxiety, and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability*, **22**, 19-28.

Shattock, P., & Lowdon, G. (1991). Proteins, peptides and autism: II. Implications for the education and care of people with autism. *Brain Dysfunction*, **4**, 323-334.

Sheinkopf, S.J., & Siegel, B. (1998). Home-based behavioral treatment of young children with autism. *Journal of Autism and Developmental Disorders*, **28**, 15-23.

Sherwin, C.M. (2007). The motivation of group-housed laboratory mice to leave an enriched laboratory cage. *Animal Behaviour*, **73**, 29-35.

Shields, J. (2001). The NAS EarlyBird programme: Partnership with parents in early intervention. *Autism*, **5**, 49-56.

Siantz, M.L.de-L., & Smith, M.S. (1994). Parental factors correlated with developmental outcome in the migrant Head Start child. *Early Childhood Research Quarterly*, **9**, 481-503.

Singh, N.N., Lancioni, G.E., Winton, A.S.W., Fisher, B.C., Wahler, R.G., McAleavey, K., Singh, J., & Sabaawi, M. (2006). Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism. *Journal of Emotional and Behavioral Disorders*, **14**, 169-177.

Skinner, B.F. (1957). *Verbal behavior*. New York: Appleton Century Crofts.

Skinner, B.F. (1971). *Beyond freedom and dignity*. Indianapolis, IN.: Hackett Publishing.

Smalley, S.L., Tanguay, P.E., Smith, M., & Gutierrez, G. (1992). Autism and tuberous sclerosis. *Journal of Autism Developmental Disorders*, **22**, 339-55.

Smith, T. (1999). Outcome of early intervention for children with autism. *Clinical Psychology: Science and Practice*, **6**, 33-49.

Smith, T.G., Annette, D., & Wynn, J.W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation*, **105**, 269-285.

Spaccarelli, S., Cotler, S., & Penman, D. (1992). Problem-solving skills training as a supplement to behavioral parent training. *Cognitive Therapy and Research*, **16**, 1-17.

Sparrow, S., Balla, D., & Cicchetti, D. (1990). *Vineland Adaptive Behavior Scales*. Circle Pines: American Guidance Service.

Steiner, G. (1998). *Language and silence: Essays on language, literature, and the* inhuman. New Haven: Yale University Press.

Stoddart, K.P. (1999). Adolescents with Asperger syndrome: Three case studies of individual and family therapy. *Autism*, **3**, 255-271.

Stores, R., Stores G., Fellows, B., & Buckley, S. (1998). Daytime behaviour problems and maternal stress in children with Down syndrome, their siblings, their non intellectually disabled and other intellectually disabled peers. *Journal of Intellectual Disability Research*, **42**, 228-237.

Stutte, H. (1975). History of the term "child psychiatry". *Acta Paedopsychiatrica: International Journal of Child and Adolescent Psychiatry*, **41**, 209-215.

Sundberg, M.L., & Michael, J. (2001). The benefits of Skinner's analysis of verbal behavior for children with autism. *Behavior Modification*, **25**, 698-724.

Tabachnick, B.G., & Fidell, L.S. (1989). *Using multivariate statistics.* New York: Harper Collins.

The Disabilities Trust (2005). *Prevalence and effects of autism.*

Tienari, P., Sorri, A., Lahti, I., Naarala, M., Wahlberg, K.E., Rönkkö, T., Moring, J., & Pohjola, J. (1987). Family environment and the etiology of schizophrenia; implications from the Finnish adoptive family study of schizophrenia. In H. Stierlin, F.B. Simon, & G. Schmidt (Eds.), *Familiar realities.* New York: Brunner/Mazel.

Tobing, L.E., & Glenwick, D.S. (2002). Relation of the Childhood Autism Rating Scale-parent version to diagnosis, stress, and age. *Research in Developmental Disabilities*, **23**, 211-223.

Tomanik, S., Harris, G.E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disabilities*, **29**, 16-26.

Tramer, M. (1931). Die Entwicklungslinie eines psychotischen Kindes. / The development curve of a psychotic child. *Archives Suisses de Neurologie*, **27**, 383-392.

Tramer, M. (1934). Elektiver Mutismus bei Kindern. *Z Kinderpsychiatric*, **1**, 30.

Tramer, M. (1943). Tagebuch ueber ein geisteskrankes Kind. / Diary on a psychotic child. *Zeitschrift fuer Kinderpsychiatrie*, **10**, 115-121.

Twyman, J.S. (1998). The Fred S. Keller School. *Journal of Applied Behavior Analysis*, **31**, 695-701.

Van Krevelen, D.A. (1971). Early infantile autism and autistic psychopathy. *Journal of Autism and Childhood Schizophrenia*, **1**, 82-86.

Vaughn, S., Schumm, J.S., & Sinagub, J. (1996). *Focus group interviews in education and psychology*. Thousand Oaks, CA: Sage.

Viner, R., McGrath, M., & Trudinger, P. (1996). Family stress and metabolic control in diabetes. *Archives of Disease in Childhood*, **74**, 418-321.

Volkmer, F.R. & Rutter, M (1995). Childhood disintegrative disorder: Results of the DMS-IV autism field trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, **142**, 1450-1452.

Waddington, E.M., & Reed, P. (2007). Comparison of the affects of mainstream and special school placements on outcomes in children with ASD: An archive-based analysis. *Submitted for publication.*

Wahlberg, K.E., Wynne, L.C., Oja, H., Keskitalo, P., Anais-Tanner, H., Koistinen, P., Tarvainen, T., Hakko, H., Lahti, I., Moring, J., Naarala, M., Sorri, A., & Tienari, P. (2000). Thought disorder index of Finnish adoptees and communication deviance of their adoptive parents. *Psychological Medicine*, **30**, 127-136.

Walden, S., Pistrang, N., & Joyce, T. (2000). Parents of adults with intellectual disabilities: Quality of life and experiences of caring. *Journal of Applied Research in Intellectual Disabilities*, **13**, 62-76.

Ward, A.J. (1990). A comparison and analysis of the presence of family problems during pregnancy of mothers of "autistic" children and mothers of normal children. *Child Psychiatry and Human Development*, **20**, 279-288.

Warner, L.A., & Pottick, K.J. (2006). Functional impairment among preschoolers using mental health services. *Children and Youth Services Review*, **28**, 473-486.

Warren, S., & Brandeis, L. (1890). The Right to Privacy. *Harvard Law Review*, **4**, 193-220.

Webster-Stratton, C. (1990). Stress: A potential disruptor of parent perceptions and family interactions. *Journal of Clinical Child Psychology*, **19**, 302-312.

Weiss, M.J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, **6**, 115-130.

Welsh Assembly Government (2007). *The autistic spectrum disorder strategic action plan for Wales*. Cardiff: Welsh Assembly Government.

Westin, A. (1967). *Privacy and freedom*. New York: Atheneum.

Williams, J. (2006). Learning from mothers: how myths, policies, and practices affect the detection of subtle developmental problems in children. *Child: Care, Health, and Development*, **33**, 282-290.

Wing, L. (1981). Asperger's syndrome: a clinical account. *Psychological Medicine*, **11**, 115-129.

Wing, L. (1997). The history of ideas on autism. *Autism*, **1**, 13-23.

Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders*, **9**, 11-29.

Wittgenstein, L. (1953). *Philosophical investigations*. G.E.M. Anscombe & R. Rhees (Eds.), G.E.M. Anscombe (trans.). Oxford: Blackwell.

Wolf, L.C., Noh, S., Fisman, S.N., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders*, **19**, 157-166.

Wolff, S. (1998). Is there a link between engineering and autism?: Commentary. *Autism*, **2**, 96-97.

Yarmolenko, A.V. (1926). Change of environment as a factor determining an anomaly of behavior (autism in uncontrolled children). *Voprosy Izucheniya i Vospitaniya Lichnosti/Problems in the Study and Education of Personality*, **1**, 38-46.

Yarmolenko, A.V. (1930). *Obsledovanie dvisheniy normalnikh i anormalnikh detey. / A study of the movements of normal and abnormal children.* Oxford, England: Gosudarstvennoe Medizinskoe Izdatel.

Yarmolenko, A.V. (1935a). The exactness of hand movements in psychoneurotic children. *Novosti Psikhonevrologii Detskogo Vozrasta*, 129-138.

Yarmolenko, A.V. (1935b). The motor sphere of psychoneurotic children. *Novosti Psikhonevrologii Detskogo Vozrasta*, 149-167.

Zappert, J. (1921). Dementia infantilis (Heller). / The infantile dementia of Heller. *Zeitschrift fuer Kinderpsychiatrie*, **4**, 161-169.