DOCTOR OF PHILOSOPHY

Sensory perceptual experiences in autism

O'Neill, Meena

Award date:
2001

Awarding institution:
University of Wales, Bangor

Sensory Perceptual Experiences In Autism

Meena O'Neill

Thesis submitted for the degree of PhD
University of Wales, Bangor
2001

Summary

This study represents the first qualitative investigation of the phenomenology of unusual sensory-perceptual experience in autism drawn from a body of exclusively first-hand accounts of individuals with autism. A primary aim was that of discovery: an attempt to explore and articulate the nature and impact of unusual sensory-perceptual experience in individuals with autism as represented, in the main, by individuals with autism themselves.

A general review of the relevant autism literature sets the context for this investigation (Chapter 1). The first stage involved a pilot study in which published first-hand accounts by people with autism were analysed thematically (Chapter 2). This analysis confirmed unusual sensory-perceptual experiences as a salient theme and supported the case for more research into these phenomena. Chapter 3 describes the general methodology (Grounded Theory) that was used in the next three studies (Studies 2, 3, and 4) to investigate sensory-perceptual phenomena.

Chapter Four then presents the main study (Study 2) of the thesis. This study involved a series of interviews with individuals with autism, and the development of a theoretical integration derived from these accounts. The study generated a model for understanding the phenomenology of these sensory-perceptual experiences that centred on the concept of an inefficient and disordered attention system. This model is based on four key constructs: Disordered Attention Beam; Perseverative Bias; Sensory Based World, and Hypersensitivity. Variation in sensory-perceptual experience between participants was understood in terms of unique dimensional combinations of each of these elements.

Chapter Five presents the third study that involved interviews with parents of individuals with autism. These parental accounts were interrogated with a view to further theoretical development, and in particular to check if these would confirm, deny or further develop the essential elements of the model generated in Study 2. A similar process was undertaken in Chapter Six (Study 4) using the published first hand account literature as a data source and in Chapter Seven (Study 5) using the analysis of feedback gathered from a wider group of individuals with autism in a validation study. Chapter Eight presents the integration of the findings from these different data sources. The model developed in Study 2 was modified in the light of this integration. The limitations of the study and the clinical and theoretical implications of the findings are discussed.

Overall the investigation provides evidence that sensory-perceptual phenomena are significant in the life-experience of people with autism, and that an understanding of these phenomena is important in achieving a full understanding of the behaviour, psychological states and social functioning of individuals with this condition.

Acknowledgments

There are many people I would like to thank for helping me to produce this thesis. First I would like to thank my supervisor Dr. Robert Jones. I am indebted to Robert for many things: for support and guidance throughout the research process, for bolstering me when anxiety and exhaustion threatened to overwhelm me, and for seemingly endless patience and optimism. I would like to thank Professor Elizabeth Newson and Professor John Newson for their generosity and trust in facilitating this research. I would like to thank the individuals with autism and their families who made me welcome in their homes and who generously gave of their time and experiences. In similar vein I would like to thank the individuals with autism who offered feedback and comment on my developing analysis, and the authors of published accounts who have publicly shared their stories. In particular I would like to thank Dr. Temple Grandin whose courage and assertiveness inspired the topic for this research. I would like to thank Dr. Karen Henwood who acted as second supervisor during her time at Bangor, for her helpful guidance in relation to the process of undertaking qualitative research.

There are many others whom I wish to thank: Dr. Steve Noone for sharing the confessional at AFINABAIT meetings, and Robert again for acting as patient confessor; Jaci Huws, Sheila Barrett, and Stuart Wholmsley for their helpful observations and support; Sharon Fraser in roles too numerous to mention; Dr. Geraint Ephraim; Linda Molloy; Ann Fadden; Hilary Moore and many other colleagues and friends who have given support along the way. Last, but by no means least, I thank my family, my husband Ian and my daughters Rachel and Aine for sacrificing so much precious time together and for continuing to love me through it all.

Contents

General Introduction

What is Autism?

An evolving concept

Autism is a behaviourally defined and life-long developmental disorder that is among the most intensively researched and best validated of all developmental disabilities (Rutter & Schloper, 1987). Nevertheless our understanding of the disorder remains incomplete and is constantly evolving in the light of new research approaches and findings (Bailey, Phillips & Rutter, 1996). This changing and evolving understanding of the condition has been traced back over the centuries and reflects the dominant models for understanding human behaviour that have characterised different cultures and times including magical and religious models for explaining unusual behaviour (Frith, 1989; Wing, 1996).

Wing (1996) traces current conceptualisations back to the eighteenth and nineteenth centuries and the emergence of a medical model for understanding unusual or abnormal behaviour in children. She points out that Maudsley (1867), in detailing medical case descriptions of children that we might now recognise as autistic, introduced the notion that psychosis could occur in children. A general assumption continued into the first half of the twentieth century that the aberrant presentation of these and other unusual children represented early onset of adult-type psychosis. At the same time, the movement towards the categorisation of children according to IQ was also strong and undoubtedly many of these unusual children were grouped within the categories of intellectual retardation prevalent at the time.

The major influence on our current understanding of autism as a separate syndrome comes from work in the 1940's and the publication of two seminal papers, one by Leo Kanner in 1943, and the other by Hans Asperger, in 1944. Neither were apparently aware of the other at the time of publication but both used the word 'autism' or 'autistic' to describe groups of children whom they had met in their respective practices and whom they felt shared certain characteristics which did not seem to fit any diagnostic classifications available up to that point. Both argued that the condition they described represented a major developmental disorder. Kanner's paper, based on his work in America and published in English, was entitled 'Autistic disturbances of affective contact'. The English translation of the title of Asperger's paper, based on his work in Austria and published in German, is 'Autistic Psychopathy in childhood'. This choice of the word autistic, previously used by Bleuler, 1916, to describe the social withdrawal frequently seen in adults with schizophrenia, reflected the conviction of both authors that social disturbance was central to the disorder in the children they saw.

Kanner's Autism

Kanner's (1943) paper introduced the term 'early infantile autism' to describe the characteristic features shared by the children he saw. These features included the following:

> "Extreme autistic aloneness". Kanner identified a profound lack of affective contact with others which he saw as originating very early in life.
> "Anxiously obsessive desire for the preservation of sameness". Kanner noted that the children were extremely upset by disruption of routines or surroundings.
> "Limitation in the variety of spontaneous activity". Kanner observed the limited way in which the children related to the world and the repetitive nature of movements, interests and verbalisations.
> "Delayed echolalia". Those children who were not mute, repeated language they heard to indicate needs, but not to share ideas and feelings. This included the repetition of 'you' to refer to themselves and 'I' to refer to the other person.
> "Good cognitive potentialities". Kanner noted good rote memory, dexterity in spinning and manipulating objects and good skills in completing puzzles and felt that these skills represented evidence of good or even superior intelligence. Kanner also noted that the children looked normal and commented on their 'intelligent physiognomies'.
> "Oversensitivity to stimuli". Kanner observed negative reactions to certain noises and had food fads and other problems with food.
> " Highly intelligent families". Kanner observed that all the children he saw had able, intellectual parents.

Kanner (1943) also noted certain common associated features which included impaired non-verbal communication, clumsiness in gross motor movements in some of the children, stereotypies, temper tantrums and aggression. Subsequently he distilled this list of features to what he considered were the essential or core elements: autistic aloneness and obsessive insistence on sameness. The other symptoms he considered were secondary to these primary problems (e.g. problems in communication) or, alternatively were not specific to autism (e.g. stereotypies). Kanner (1943) felt that the behavioural syndrome he had identified was different from other childhood disorders and that it was present very early in life. In his early paper he was clearly of the view that autism was an organic or biological disorder:

> '...these children have come into the world with innate inability to form the usual, biologically provided affective contact with people"(Kanner, 1943, p. 250)

However Kanner also observed a characteristic of 'coldness' in the parents of many of these children and later leaned towards an emphasis on the contributory role of emotionally 'cold parenting' in line with the influence of psychoanalytic thinking at the time (Kanner, 1949).

Asperger's Syndrome

Asperger descriptions are, in general, strikingly similar to those of Kanner and like Kanner he uses the word autism to describe the condition. Although Asperger (1944) did not list essential criteria he highlighted the following aspects of behaviour:

> Disturbance in social relating. Asperger considered that this was the central and fundamental impairment underlying the condition. Asperger identified extreme ego-centrism and a disturbance in the child's understanding of and emotional connectedness to others.
> Life-long condition, present from the second year of life. Asperger considered that the characteristics of the disorder were present from the second year of life and persisted throughout the lifespan.
> Abnormal non-verbal communication. Asperger highlighted disturbance in eye gaze, facial expression and gestural communication.
> Abnormalities in the way language is used. Asperger highlighted difficulties in the use of and understanding of what are now termed the 'pragmatics' of language: tone, inflexion, timing etc. In addition, he noted idiosyncratic and literal use of language.
> Unusual preoccupation with special interests and/or unusual skills such as rote memory or calculation skills which may co-exist with significant learning difficulties and problems in concentrating and learning from others.
> Genetic influences. Asperger noted that the disorder he described was predominantly a 'male' disorder and noted a high incidence of similar behavioural traits in the parents and families of these children.
> Stereotypic movements, positive response to routine and distress at change.

Both Kanner and Asperger identified a disturbance of social relating as central to the disorder they described and both identified it's onset early in life. In addition, both identified problems in language use, non-verbal communication and repetitive behaviour. Where differences in emphasis exist, such as in the emphasis given to impaired non-verbal communication, these are largely due to the older age and better language levels of the children seen by Asperger (Wing, 1991).

Both Kanner and Asperger differentiated the autistic disorder they described from schizophrenia. There are also a small number of significant differences in their

accounts. Asperger identified both fine and gross motor clumsiness as a characteristic of the children he encountered whereas Kanner identified his children as showing unusual dexterity in fine motor movement. Kanner presumed normal intellectual ability on the basis of 'islets of ability' whereas Asperger saw that the condition occurred across the ability range.

Post Kanner: Early clarifications

Kanner's paper, in English, proved highly influential in the US and Britain and was a dominant influence in thinking about autism up until the 1980's (Kanner, 1943). Asperger's paper on the other hand did not have an immediate impact and it was not until 1981 that it was translated into English and began to significantly influence thinking about autism (Wing, 1981). Nevertheless, despite it's impact, the early history of Kanner's syndrome was also characterised by confusion about terminology and the nature of the disorder.

Because of the association of the term autism with schizophrenia and earlier notions of childhood psychosis, the disorder was labelled in various ways such as childhood schizophrenia, infantile psychosis and infantile autism. There was confusion about the nature of the disorder and whether it reflected an emotional disturbance, mental illness or organic disability. For example, autism was included as a subgroup of schizophrenia in ICD-8 (1967) and as a childhood psychosis in ICD-9 (1978). Much of the clinical and research effort in the 1960's, 1970's and indeed into the 1980's focused on differentiating autism from other conditions, in refining diagnostic criteria and sifting essential from non-essential features in Kanner's description, in establishing prevalence and in clarifying the organic nature of the disorder.

A major clarification took place with the work of Kolvin and colleagues in 1971 (Kolvin, Ounstead, Richardson & Garside, 1971) who clearly demonstrated the distinction between childhood autism and schizophrenia in terms of age of onset and general cognitive level thus establishing autism as a disorder of early development and not a mental illness. Furthermore, a growing body of work over these decades clearly established the organic basis to the disorder. Autism was linked to multiple organic aetiologies such as tuberous sclerosis (Hunt & Dennis, 1987) and congenital rubella (Chess, Korn & Fernandez, 1971); a clear link was established with learning disabilities (Clark & Rutter, 1977) and epilepsy (Rutter, 1970) and evidence of a genetic component was established through confirmation of sex linkage (Lord & Schopler, 1987), familial loading (Smalley, Asarnow, & Spence, 1988) and concordance in monozygotic twins (Folstein & Rutter, 1977). Similarly, the work of a number of clinicians, aimed at sifting and refining the diagnostic features highlighted by Kanner, converged to establish broad agreement about the essential diagnostic features of the condition. These centred on three core features: impaired communication, impaired social relating, and rigidity of

thought and behaviour, with evidence of onset of these impairments before the age of 30-36 months (Newson, 1977; Rutter1978).

Triad of impairments

These clinical formulations of core diagnostic features were given empirical support by Wing and Gould (1979). In a study which marked another major development in the evolving conceptualisation of autism Wing and Gould reported on the outcome of an epidemiological survey of children under the age of 15 years who lived in the Camberwell area of London. They screened all children under the age of 15 in the borough who had any kind of physical or learning disability or abnormality of behaviour who had come to the attention of social, educational or health services. Children were selected from this group if they had severe learning disabilities, and/or if they showed one of the following: social impairment, verbal and non-verbal language impairment and repetitive or stereotyped activities. This selected group were then observed and tested, and their parents or carers interviewed about their development and behaviour using a structured schedule designed for the purpose (Wing & Gould, 1978). On the basis of their social behaviour two groups emerged: a group who showed normal social interaction for their mental age and a socially impaired group. There were significant differences in the communication and play behaviours of the two groups. The sociable group had a very much lower incidence of repetitive and stereotyped behaviour and all showed evidence of symbolic play where this would be expected on the basis of mental age. In contrast, the profile of the socially impaired group indicated very high levels of language and communication impairments and stereotyped and repetitive behaviour, and absence or severe impoverishment in symbolic play at mental ages where this might be expected. Wing and Gould (1979) concluded: "all the children with social impairments had repetitive, stereotyped behaviour and almost all had absence or abnormalities of language and symbolic activities. Thus the study shows a marked tendency for these impairments to occur together" (p.25). Wing and Gould (1978) introduced the term 'triad of impairments' to describe this co-occurrence of impairments in sociability, communication, and imagination associated with rigid and repetitive behaviour. This study and a parallel study among adults in a mental handicap hospital (Shah, Holmes & Wing, 1982) confirmed that autism was indeed an identifiable syndrome characterised by a triad of core difficulties.

In addition, the study also introduced the notion of 'the autistic continuum' with 'Kanner's autism' as a subgroup of a wider disorder. Among the 'triad' group, Wing and Gould had clearly identified individuals with typical Kanner's autism, fulfilling his criteria. But there were more who clearly showed the triad of impairments but who did not precisely fit Kanner's criteria. These included children with quite severe learning disability and a few more able children. Wing and Gould found no clear boundaries

between the Kanner group and the others and as a result introduced the idea of autism as a continuum disorder with the Kanner group as one subgroup. The Kanner group tended to be associated with mild-moderate learning disability whereas the 'triad' occurred across the ability range, including children with severe and profound learning disability.

A further contribution of this study was that it demonstrated the changing developmental manifestation of autism across the different ability ranges and across age-span and introduced the notion of fluid sub-groupings. These sub-groupings were: an aloof group as described by Kanner; a passive group characterised by passivity in the face of social approaches by others but without any real interest or initiation of contact; an active but odd group who showed active interest in and initiation of social approaches to others but in an inept and non-reciprocal manner. Thus Wing and Gould's study highlighted variability in the way that the core impairments of autism could be manifested and demonstrated it's incidence in individuals across the ability range including those with severe learning disability. This study heavily influenced thinking in relation to the concept of autism and the concept of both 'triad' impairments and the autistic continuum was reflected in the DSM 111-R diagnostic criteria. Triad impairments continue to form the basis for the diagnosis of autism in DSM IV and ICD-10 today. Explaining the co-occurrence of triad impairments has also been instrumental in driving theoretical explanations of the disorder in the intervening decades (Baron-Cohen, 1995; Happé, 1994a).

Autism spectrum disorders

Wing (1988), arguing the existence of the essential triad of impairments across developmental age and IQ, introduced the concept of autistic spectrum disorders to include Asperger or high-functioning individuals at one end and severely or profoundly disabled individuals at the other. In support of her argument Wing cited the co-occurrence in twins and siblings of Asperger's syndrome and more classic autism; the changing presentation across the life-span so that in early years a child may show signs of classic autism but later on may present as a more able 'Asperger 'type; and the difficulty in differentiating the disorders in terms of aetiology or other factors. The concept of autistic spectrum disorders has had widespread clinical impact, especially in the UK. A number of more recent studies have provided additional support for the conceptualisation of autism as a spectrum disorder with lower and higher ability subgroups (Waterhouse, Morris, Allen, Dunn, Fein; Feinstein, & Rapin, 1996). Although Asperger syndrome has been included within DSM IV and ICD 10 as one of the pervasive developmental disorders which includes autism, a diagnostic distinction between autism and Asperger syndrome has been maintained within these classification systems. This issue will be explored further in Chapter 4.

Epidemiology

Research aimed at establishing the prevalence figures for autism has reflected changing conceptualisations of the disorder and differing diagnostic criteria. A number of early studies reported prevalence rates for classic or Kanner's autism of 4-5 per ten thousand (Lotter, 1966). Wing and Gould (1979) cited prevalence rates of 21 per 10,000 arising from the wider definition of autism in the Camberwell study, but have subsequently cited figures as high as 50 per 10,000 to include Asperger individuals at the upper end of the autistic spectrum (NAS, 1997).

In a review of a number of prevalence studies, Fombonne (1999) cited a median figure of 7.2 per 10, 000 for prevalence studies conducted since 1989 using narrow definitions of the disorder, and figures of around 15 to 21 per 10,000 for the wider category of pervasive developmental disorders. There is some evidence that prevalence rates differ according to the age range sampled, and in a more recent study of young children aged between 2.5 and 6.5 years, Chakrabarti and Fombonne (2001), using DSM IV criteria, reported rates of 16.8 per 10,000 for autistic disorder and 45.8 per 10,000 for other pervasive developmental disorders. If one approximates Wing's notion of autistic spectrum disorder with the category of pervasive developmental disorders in DSM IV, this suggests an approximate prevalence figure of 62 per 10,000 for this age range. The extent to which these changing figures represent methodological differences between studies, increased awareness and better diagnostic practice among clinicians, or represent a rising incidence of autism remains unclear.

In keeping with both the observations of Kanner and Asperger, studies have consistently demonstrated the sex-linked nature of autism with boys outnumbering girls by 3-4 to 1, rising to 5-10/1 at higher ability levels (Lord & Schopler, 1987; Siegel, 1996). Estimates of the degree of association with general learning disability have also varied according to differing conceptualisations of the disorder. Previously it was estimated that 75-80% of individuals with autism also had an additional learning disability but with the inclusion of the more able, Asperger group within the definition, this estimate has reduced to approximately 50%. In the Chakrabarti and Fombonne (2001) study just under 26% of the children with PDD were considered to have an additional learning disability although the young age of the sampled population suggests a cautious interpretation of this finding.

Biological factors

Both environmental and genetic factors have been implicated in the aetiology of autism although the precise mechanisms are poorly understood (Cook, 2001). Autism has been associated with a range of medical and genetic conditions including congenital rubella (Chess, 1977), encephalitis, tuberous sclerosis (Hunt & Dennis, 1987; Smalley, 1988), and fragile X (Gillberg & Wahlstrom, 1985). There is an increased association with pregnancy and birth complications (Folstein & Rutter, 1977) although the nature of this association is unclear (Goodman, 1990). A number of possible autism 'susceptibility' genes have been identified which require further investigation (Rutter, 2000) and there is evidence from both genetic screening and cognitive screening studies of a broader autism phenotype (Bailey et al., 1995; Bolton, MacDonald, Pickles & Rios, 1994). A number of researchers have suggested that a combination of genetic susceptibility and some form of pre- or post-natal insult may interact to produce the full-blown behavioural syndrome (Trottier, Srivastava & Walker, 1999).

Psychological theories

While much of the story of autism at a biological level continues to unfold, psychological theories of autism have attempted to explain the key deficits in the autistic mind that give rise to the observable behavioural deficits by which the disorder is defined. Much psychological theorising has been characterised by a search for a single psychological deficit or dysfunctional mechanism which would account for each of the 'triad' impairments (Happé, 1994a) and by a dichotomy between theorists who seek explanation in terms of 'cognitive' processes and those who see 'affective' processes as critical. In keeping with wider trends in developmental research increasingly theorists are seeking integration of both cognitive and affective processes within a developmental psychopathology framework (Tager-Flusberg, 2001; Mundy & Neal 2001). In addition, there is growing recognition that multiple deficits may be implicated at the psychological level (Happé, 1994a; Baron-Cohen & Swettenham, 1997). These attempts at integration are at an early stage and to date the dominant psychological theories can be located within either cognitive or affective models. Three cognitive theories are currently dominant: Theory of Mind (Baron-Cohen, Leslie & Frith, 1985), Executive Dysfunction (Ozonoff, Pennington & Rogers, 1991 ; Russell, Saltmarsh & Hill, 1999) and Central Coherence (Happé, 1999a). Theorists who propose a primary problem in affective mechanisms include Hobson (1993) and Mundy and colleagues (Mundy, 1995; Mundy & Markus, 1997).

Theory of mind

Normal social functioning is characterised by an intuitive understanding of the mental states of others. 'Theory of mind' (ToM) is the term used by cognitive developmental

researchers to refer to this ability to attribute independent mental states to self and others in order to predict and explain other peoples' behaviour. According to Leslie (1987) this ability arises from an innate and discrete cognitive mechanism that allows the typically developing infant to separately track physical and mental states, an ability that he terms 'metarepresentational capacity'. This cognitive or 'theory of mind mechanism' is said by proponents to underlie the development of pretence and later, theory of mind.

In the clinical literature on autism, lack of social empathy was well documented (Newson, 1977). Diminished or absent pretend play in children with autism was also well documented (Wing & Gould, 1979; Wulff, 1985). Building on this work, Baron-Cohen, Leslie and Frith (1985) hypothesised that meta-representational capacity may be deficient in autism. These authors tested this hypothesis using a False-Belief task (a task that requires subjects to recognise a character's false belief) called the Sally-Ann task (Wimmer & Perner, 1983) which is reliably passed by 4 years in normal children. Eighty percent of a group of children with autism with a mental age of greater than 4 years failed this task, in comparison with only 14% of a group of children with Down syndrome of slightly lower mental age. The vast majority of the children with autism failed to understand that someone can have a false belief about the world that is different from the physical reality, and this was taken as evidence for an autism-specific deficit in mentalising or 'mindblindness'.

In the 'strong' form of this theory, proponents argued that this failure was the primary cognitive deficit in autism and accounted for the core triad impairment of impaired social relating, communication and imagination (Baron-Cohen, 1989a). Repetitive and rigid behaviour was explained as a secondary effect resulting from the child's attempts to deal with a frightening and confusing social world (Baron-Cohen, 1989b; Carruthers 1996).

Subsequently this theory was tested and supported in a wide range of studies using a variety of different approaches and using other control groups. For example, language-impaired controls have been used to rule out language deficit as the reason for failure (Leslie & Frith, 1988). Proponents of ToM cite a wide range of evidence to support the specific prediction of the theory that on tasks and skills that do not require the ability to 'mind-read' individuals with autism should be unimpaired, while on tasks that do require this ability they should be clearly impaired relative to controls (see Baron-Cohen & Swettenham, 1997; 2001 for review of this area).

Attwood (1988) found that children with autism were impaired in the use of gestures that influence mental state (e.g. gestures of comfort or consolation) while unimpaired in the use of gestures to influence behaviour (e.g. indicating "go away"). Baron-Cohen (1989c) found that use and understanding of pointing for the sake of sharing attention (protodeclarative pointing) is impaired while pointing to express need

is not (protoimperative pointing). Tager-Flusberg (1993) summarises evidence of specific impairments in communication that support the prediction that people with autism have difficulty in those aspects of language that require appreciation of the speaker's thoughts or intentions. Others have argued that failure on false-belief tasks does not reflect a problem in mentalising but reflects deficits in other abilities tapped by these tasks. For example, Russell, Mauthner, Sharpe and Tidswell (1991) propose that failure on false-belief tasks is due to a specific difficulty in overcoming the perceptual salience of the object in the real location: inability to disengage from the object. In order to counter arguments such as this, a variety of other studies designed so that a test of the ability to mentalise could be readily compared with very similar tasks not requiring this ability have been carried out. Sodian and Frith (1992) found that children with autism have impaired capacity to understand deception (manipulating beliefs) while succeeding on tasks such as sabotage (manipulating behaviour). Children with autism have been also found to be unimpaired in understanding 'false photographs' (i.e. answering questions about a non-current state of the world) but impaired in understanding false-beliefs (Leslie & Thaiss, 1992).

The accumulating evidence has been widely accepted as robustly demonstrating a finding of 'mindblindness' as a strong feature of autism (Baron-Cohen & Swettenham, 1997, Happé 1994b; Tager-Flusberg, 2001). However, increasingly researchers have questioned its centrality as an explanatory mechanism for the behavioural symptomology of the disorder (Happé, 1999a). This criticism has centred primarily on the questions of universality, specificity and primacy. From the first studies it was clear that a minority of people with autism were able to pass classic 'first-order' theory of mind tasks (Baron-Cohen et al. 1985). Subsequently, several researchers found evidence that a proportion of high-functioning individuals also passed 'second -order' theory of mind tasks (Ozonoff, Pennington, & Rogers, 1991; Happé 1994a). ToM proponents have responded by suggesting that those who pass may be 'hacking out' a solution through unusual means (Frith, Morton & Leslie, 1991) and/or that the findings reflect 'ceiling effects' on the tests used (Baron-Cohen & Swettenham, 1997). More complicated 'third-order' ToM tests such as 'The Strange Stories' task (Happé, 1994 c) and 'adult' tests of ToM such as 'The Reading the Mind in the Eyes'(Baron-Cohen, Jolliffe, Mortimore & Robertson 1997) task have been devised. These tasks have demonstrated impaired performance in many who pass second-order ToM tasks. Nevertheless it seems clear from the literature that some individuals with autism do acquire the ability to think about their own and other's mental states (Frith, Happé & Siddons, 1994). Baron-Cohen and Swettenham (1997) argue that a 'delay' hypothesis would still allow ToM to be considered a primary factor since the ability to mentalise may not have been present at a critical time in development.

Other studies have emerged that have cast doubt on the uniqueness of ToM deficits to autism. Children and adults with general learning disability without autism (Zelazo, Burack, Benedetto, & Frye, 1996); oral deaf children (DeVilliers, & DeVilliers, 2000); and blind children (Brown, Hobson, Lee & Stevenson, 1997) also fail ToM tasks at a higher frequency than would be expected on the basis of their chronological and mental age. Perhaps the most telling difficulties have arisen for a strong version of the ToM hypothesis in relation to the issue of primacy.

A number of researchers have argued that ToM cannot account for the earliest signs of autism. Mundy and Sigman (1989), for example, have pointed out that children with autism show impaired joint attention, that emerges before pretence and mentalising ability. Indeed, Baron-Cohen, Allen and Gillberg (1992) themselves found evidence of joint attention and joint referencing deficits in children later diagnosed as autistic. Baron-Cohen and Ring (1994) modified their model in order to account for this finding by suggesting that mentalising deficits may be secondary to an earlier emerging impairment in the capacity to build 'triadic relationships'. They proposed the notion of an 'Eye Direction Detector' that normally develops very early in infancy and that feeds information to a 'Shared Attention Mechanism' that lies behind the development of joint attention skills and later theory of mind. They suggested failure in this mechanism in autism thus depriving the child of the foundations for development of mentalising ability (Baron-Cohen & Ring, 1994). Others have dismissed this account on the grounds that it fails to take account of the affective component of joint attention and early child-caregiver interaction (Mundy, Sigman & Kasari, 1993) and these issues will be explored below in reviewing affective theories. Evidence of other cognitive deficits such as executive dysfunction and weak central coherence have also been demonstrated in autism thus presenting competing or complementary explanations for the behavioural characteristics in autism (Ozonoff et al., 1991; Happé, 1999a).

Executive Dysfunction

Executive function (EF) is an "umbrella term for the mental operations that enable an individual to disengage from the immediate context in order to guide behaviour by reference to mental models or future goals" (Hughes, Russell & Robbins, 1994 p. 477) or "the ability to maintain an appropriate problem-solving set for attainment of a future goal" (Welsh & Pennington, 1988, p. 201). Executive or 'supervisory' function (Norman & Shallice, 1980; 1986) is associated with a large area of the brain, the pre-frontal cortex, that encompass many functionally and anatomically distinct sub-regions and their connections with other brain regions. Included in this set of mental operations are the abilities to: disengage from the external context; inhibit inappropriate responses; generate and plan sequences of willed actions; sustain an appropriate cognitive set for staying on -task; monitor own performance and make use of feedback and flexibly shift

attentional set. Stated more simply, executive function is conceived of as the mechanism that enables an individual to shift attention flexibly, to inhibit prepotent responses, to generate goal directed behaviour and to solve problems in a strategic way.

A number of researchers have proposed that dysfunction in executive processes may be a core or even primary explanatory factor underlying the behavioural impairments in autism. This 'Executive Dysfunction' (EDF) theory of autism was first suggested by Damasio and Maurer (1978). They observed that the characteristic behaviours of individuals with autism are similar to the symptoms shown by patients with injuries to the frontal lobes of the brain. Since that time a considerable number of researchers have found that adults, adolescents and older children with autism perform poorly on a range of executive tasks (see Pennington & Ozonoff, 1996 for review). The most frequently used tasks have been the Wisconsin Card Sorting test (WCST) and the Tower of Hanoi (TOH) and to a lesser extent the Stroop test. These tasks are taken to tap slightly different functions: flexibility, planning and working memory, and inhibition of prepotent behaviour respectively.

Rumsey (1985) and Rumsey and Hamburger (1988, 1990) carried out the first controlled studies of EF in adults with autism, demonstrating impaired performance on the WCST relative to normal and dyslexic controls. Prior and Hoffman (1990) were the first to explore EF in autistic children. These authors found that, relative to control groups matched on mental and chronological age, the autistic group were impaired on the WCST and a maze test, showing deficits in planning and the use of feedback to flexibly shift problem-solving strategies. The key study in prompting the current wave of interest in executive dysfunction as the primary causal dysfunction in autism was that of Ozonoff, Pennington and Rogers (1991). These authors compared high-functioning children and adolescents with autism with matched clinical and non-clinical controls on a number of tasks: first and second order theory of minds; emotion perception tasks, and executive function tasks (WCST; TOH). They found that performance on the executive function tasks was the best predictor of group membership, with performance on ToM tasks the next best predictor. In this study, 96% of the HFA group performed worse than controls on executive function tasks, 86% performed worse than controls on second-order ToM tests. Thus EF deficits were present even in more able individuals who passed second-order theory of mind tests. Ozonoff and colleagues therefore suggested that an EDF hypothesis offered better potential than the ToM hypothesis as the primary deficit in autism.

Executive functioning deficits have since been demonstrated in a large number of studies with older children, adolescents and adults. In their 1996 review of the area, Pennington and Ozonoff found that individuals with autism were significantly impaired on twenty-five of the thirty-two EF tasks used in the fourteen studies they reviewed. In addition, studies involving the siblings (Ozonoff, Rogers, Farnham & Pennington 1993;

Hughes, Plumet and Leboyer, 1999) and parents (Hughes, Leboyer, & Bouvard, 1997; Piven & Palmer, 1997) of children with autism, have also demonstrated evidence of elevated levels of EF impairments relative to controls. In studies exploring the links between EDF and key behavioural symptoms of autism significant relationships have been demonstrated between EF performance and joint attention and social interaction skills (Mc Evoy, Rogers & Pennington, 1993), imitation (Rogers, Bennetto, Mc Evoy & Pennington, 1996), pretend play (Jarrold, 1997), repetitive behaviour (Turner, 1997) and ToM (Ozonoff et al 1991). At a theoretical level a number of researchers have elaborated the mechanisms through which EF could cause these behavioural deficits and poor performance on ToM tasks (Ozonoff, 1995; Harris, 1993; Hughes & Russell, 1993; Jarrold, 1997, Turner 1997; Russell & Hill 2001).

As an alternative explanation of links with ToM, Baron-Cohen and Ring, (1994) have suggested that ToM ability may be sub-served by the pre-frontal cortex, potentially linking it to EF deficits through proximity of the neural structures involved. Bishop (1993) supports the idea of a common physical cause, affecting adjacent brain areas, causing both types of psychological impairment.

A problem for the EDF theory of autism is that EF deficits have also been found in a range of other developmental disorders including ADHD (Chelune, Feruson, Koon & Dickey, 1986); conduct disorder (Lueger & Gill, 1990); and Tourette Syndrome (Incagnoli & Kane, 1981). As a result, a particular research focus in recent years has been to investigate the component elements of this multi-component construct in order to identify the exact nature of executive dysfunction in autism and to see if this is different from other control groups. There has been acknowledgement that the WCST and the TOH tasks are somewhat crude measures of different aspects of executive function and attempts have been made both to refine and to simplify these tasks and to use an information-processing approach to deconstruct executive processes into their subcomponent parts (Ozonoff, Strayer, Mc Mahon & Filloux, 1994).

Hughes, Russell and Robbins (1994) used simplified but more component specific versions of both the WCST and the TOH tasks, the Intradimensional/Extradimensional Shift task (ID/ED) and the Tower of London (TOL) tasks. They compared the performance of learning disabled autistic individuals and age - and ability- matched controls. Hughes et al. (1994) found that autistic children had specific problems in flexibility (i.e. attentional set-shifting and planning). Autistic children also showed recurrent perseveration but this was not specific to autism but was shared with learning disabled controls. Ozonoff et al. (1994) used a Go-NoGo paradigm to examine two component processes, flexibility and inhibition, that are often entangled in standard EF tasks. They found that for individuals with autism, motor inhibition was intact, there was a moderate impairment in inhibiting pre-potent responses

and greatest impairment in cognitive flexibility (i.e. shifting of cognitive set) relative to controls.

Ozonoff and Strayer (1997) used the negative priming task (Tipper, 1985) and found that relative to controls, individuals with autism, were not impaired on this test of inhibition. Attempts have also been made to directly compare the performance of individuals with autism to that of other clinical groups where executive deficits have been found. Ozonoff and Jensen (1999) compared the performance of autistic children to two other clinical groups in which executive deficits have been found, an ADHD group and a Tourette's Syndrome group and also to a non-clinical control group. They used the WCST, the TOH, and the Stroop Test and found that the autistic group and the ADHD group showed a different pattern of impairments on these tasks. The autistic group demonstrated significant difficulties with the WCST and the TOH, thought to indicate flexibility and planning problems and not on the Stroop, relative to the other groups. Conversely, the ADHD group had difficulties with the Stroop task and not the WCST or the TOH, whereas the Tourette's Syndrome group did not show deficits on the measures relative to controls. Ozonoff and Jensen (1999) suggest that different clinical groups can be differentiated on the basis of their executive profiles and suggests that future research should look more closely at more fine-grained comparisons of patterns of executive deficits between different clinical groups.

More recently, a number of studies have shown mixed results with regard to the presence of specific executive deficits in very young children with autism thus posing a challenge to the primacy of executive dysfunction as the underlying deficit in autism. An early study by Mc Evoy, Rogers and Pennington (1993) investigated EF in young children aged 3-7 years using more age-appropriate tests drawn from the primate and human infant literature. These included a Piagetian A-not B task, a delayed response task, and a spatial reversal task. Significant group differences were found on the spatial reversal measure between the children with autism and developmentally delayed and normal control groups. The pattern of errors indicated that the children with autism had difficulty shifting set and made more perseverative errors thus mirroring deficits found in older individuals. However, subsequent studies by Wehner and Rogers (1994) and Griffith, Pennington, Wehner and Rogers (1999) failed to find evidence of EDF in young children. Griffith et al. (1999) examined EF across a broad range of tasks in children younger than previous studies (mean age, 51 months). They found no significant differences between children with autism and matched developmentally delayed controls although both were below expectations relative to normally developing children. These findings suggest that autism-specific impairments (as opposed to those linked only to developmental delay) in EF may emerge later in development. The authors concluded that their findings seriously challenge the primacy of EDF in explaining the behavioural characteristics of autism. It may be, however, that if EDF is

viewed as one of a number of deficits that underlie autism, it could still be genuinely primary but come to the fore at a different period of development than other causal deficits (Hughes, 2001).

In summary, it would appear then that there is substantial evidence of EDF impairment in older children, adolescents and adults with autism and that the specific pattern of impairment is different to that found in other clinical conditions. However, EDF has not been demonstrated in young children with autism and therefore the nature of the relationship between EDF and autism remains to be clarified.

Central coherence

'Central coherence' (CC) is the term used by Frith (1989) to describe the normal cognitive process by which high-level meaning is derived through the integration of otherwise fragmented information from the environment. Frith (1989) proposed that normally there is a strong tendency to process incoming information in a global way, taking account of context in the search for meaning. Frith proposed that an impairment in this drive for central coherence ('weak central coherence') could account not only for the impairments in autism but also for the preserved and even superior skills found among this population. A general feature of the theory is the idea that a full understanding of autism can only be achieved by addressing both 'asset' and 'deficit' skills. This theory which has its origins in the work of Hermelin and O'Connor (1970) was first proposed by Frith (1989) and has subsequently been developed and modified by Frith and Happé (1994) and Happé (1999a).

Frith (1989) argued that the processing style of individuals with autism emphasises detail at the expense of context and 'global' meaning. She based this theory on both clinical descriptions in the literature and the results of a series of research studies. Going back to Kanner (1943), a frequent clinical observation has been that individuals with autism show a marked interest in and ability to detect details and parts, while failing to attend to the 'gestalt' or 'essential gist' (Wing, 1969). In relation to empirical investigation, WCC theory predicts intact or enhanced performance where attention to local information is advantageous and poor performance on tasks requiring the recognition of global features or integration of stimuli within context. One test that has been used to investigate the former has been the Embedded Figures Test (EFT). This test involves spotting a hidden figure among a larger meaningful figure. Shah and Frith (1983) found that the performance of children with autism on the Embedded Figures Test (EFT) was significantly superior to matched learning disabled controls and normally developing children. This finding has subsequently been confirmed in both learning disabled and high-functioning adults with autism by Jolliffe and Baron-Cohen, (1997).

The Block Design sub-test of the Wechsler Intelligence Scales (Wechsler, 1981) has also been used by Frith and colleagues on the basis that it has strong Gestalt qualities and success on the test requires the ability to see parts over the whole. Individuals with autism have consistently been shown to show superior performance on this sub-test relative to performance on other sub-tests (Lockeyer & Rutter, 1970, Prior, 1979), a fact that is interpreted by Frith as due to precedence of local over whole processing. On the basis of WCC theory, Shah and Frith (1993) predicted that normal, but not autistic, subjects would show enhanced performance from pre-segmentation of the block designs. As predicted, individuals with autism did not show the advantage that the learning disabled and normal control subjects gained when using the pre-segmented designs and they showed superior performance only with whole designs. The diminished disadvantage in processing inverted faces which is shown by individuals with autism relative to controls (Hobson, Ouston & Lee, 1988) is also considered by Frith to reflect the reduced impact of disrupted configural processing compared to controls. Frith and Snowling (1983) tested the prediction that individuals with autism would show poor performance on tests that required the processing of information in context using a test involving disambiguation of homographs. Compared to normal and dyslexic controls of the same reading age, autistic children more frequently failed to take account of the full contextual meaning of the sentence in which the homograph was embedded.

Frith (1989) proposed that WCC could account for both triad deficits and the preserved and superior skill performance in autism. In relation to triad deficits, Frith argued that an inability to integrate the disparate and complex pieces of information typical of social interaction could easily give rise to a mentalising deficit. Similarly, being unable to extract the 'gist' from a speech stream would give rise to communication difficulties and prevent the individual from understanding the intentional aspects of communication. Frith (1989) argued that repetitive behaviours are normally inhibited by the same central control processes that are responsible for bringing coherence to experience, and would therefore persist where these central processes are weak. Subsequent investigation by Happé (1991a;1997) challenged this causal relationship. Using a test of pronunciation of homographs embedded within sentence contexts, Happé (1991) compared different groups of individuals with autism- those who failed first-order ToM, those who passed first-order ToM, and those who passed second-order ToM- with normal controls. Happé predicted, on the basis that weak central coherence underlies ToM, that only those individuals who were unable to pass ToM would show a deficit on the homographs test, whereas those who passed second-order ToM would perform at a level comparable to normal controls. Happé (1991/1997) found that regardless of ToM ability all individuals with autism showed deficits on the homograph task. As a result, Happé (1994b) concluded that WCC and ToM were

independent and that both deficits were present in autism. She proposed that these deficits represent impairment in two different cognitive systems: one a modular system dedicated to processing mental state information and the other a wider, distributed system or 'cognitive style' that influences the manner in which all types of information is processed and all levels of processing from perceptual to conceptual.

Subsequently evidence in support of WCC in autism has continued to accumulate. A 'perceptual bias' to local processing has been demonstrated using visual illusion tasks (Happé, 1996) and canononical dot counting (Jarrold & Russell, 1997). Unusually high occurrences of absolute pitch in autism (Heaton, Hermelin & Pring, 1998) and reduced susceptibility to visually-induced motion (Gepner, Mestre, Masson & de Schonen, 1995) have also been interpreted as evidence of local bias in perceptual processing (Happé, 1999a). Enhanced recognition of objects from detail despite poor integration of object parts (Jolliffe & Baron-Cohen, 2001), and enhanced facility for copying 'impossible' figures (Mottron, Belleville & Menard, 1999) have also supported the WCC hypothesis. Evidence for a detail-focused cognitive style in parents of children with autism has also been found (Baron-Cohen & Hammer, 1997). Happé (1999a) suggests that WCC reflects the spontaneous or automatic processing style of individuals with autism but can be overcome in situations with clear instructions to attend for gestalt or global meaning.

Nevertheless, some negative findings have been suggested (Plaistead, O'Riordan & Baron-Cohen 1998). Plaistead (2001) has argued that the evidence for a WCC hypothesis can better be accounted for in terms of a modified and refined conceptualisation. Plaistead proposes that individuals with autism are unable to integrate information because of a failure to recognise the similarities between stimuli or situations, and conversely, that they show enhanced recognition of unique features. What is clear is that many questions remain to be investigated in relation to the WCC hypothesis (Happé, 1999a) including questions about the general population variance in CC, the specificity of WCC to autism compared to a range of other clinical groups, and its relationship to other deficits such as EF. To date the WCC hypothesis has primarily been regarded as an explanation for 'non-triad' deficits and skills while ToM and EF have remained the major cognitive theories in relation to 'triad ' deficits.

Failure in Affective Intersubjectivity

Hobson (1983, 1993) proposes that autism is primarily a disorder of affective and social relations, with the majority of other cognitive and behavioural deficits arising from this basic failure in 'interpersonal relatedness'. Hobson presents his theory as an elaboration of Kanner's (1943) proposal that 'these children have come into the world with innate inability to form the usual, biologically provided affective contact with people' (p. 250).

Hobson (1993) accepts the existence of deficits in areas such as mentalising and weak central coherence but argues that there is a developmental path to these deficits arising from a more fundamental problem in affective intersubjectivity with other people. Hobson suggests that more basic psychological explanations such as attentional or perceptual -motor deficits either singly or in combination may lead to disrupted capacity for intersubjective engagement but argues that this failure in intersubjectivity is the final common pathway to autism. This failure disrupts early processes of interaction and joint attention, and thus, children with autism do not receive the necessary social experiences in infancy and early childhood to develop the cognitive structures for social understanding. In Hobson's (1983) account, emotional signalling and responsiveness is a key element in the 'constitutional components' necessary for interpersonal relatedness and knowledge of persons and this has generated a series of investigations of this area by Hobson and colleagues.

Weekes and Hobson (1987) found evidence of reduced salience attached to emotional expression in children with autism. Children with autism matched pictures of people by criterion of type of hat in preference to emotional expression. This was in contrast to controls where the reverse matching preference operated. Hobson (1986a) compared autistic children and normal and learning disabled controls on a task that required matching a drawn or photographed facial expression of emotion to enacted gestures, vocalisations or emotion-provoking situations. He found that children with autism were less able to match appropriate facial expressions to their correct counterpart. In a related study, Hobson (1986b) confirmed that children with autism had difficulties in matching different expressions of emotion even where these did not involve processing of facial features and expressions. Ozonoff et al. (1991) also found evidence of emotion-perception deficits in individuals with autism, although these were not as widespread as either ToM or EF deficits. Regardless of level of emotion-perception ability, however, there is evidence that individuals with autism go about emotion-perception tasks differently from controls (Hobson, Ouston & Lee, 1988).

Other researchers have found differences between people with autism and controls in relation to their bodily expressions of emotion. Ricks and Wing (1975) suggested that autistic children tend only to show extremes of expression, sometimes inappropriate to the social situation. Macdonald et al. (1989) found differences in both emotion recognition and expression between autistic and normal adults and Yirmiya, Sigman, Kasari and Mundy (1989) found differences in facial expression of emotion between autistic, developmentally delayed and normal subjects. More recently, Hobson and Lee (1999) have shown that children and adolescents with autism have difficulty imitating the emotional style (harsh or gentle) with which actors executed actions but not in the imitation of goal-directed actions per se. Hobson and Lee have interpreted this finding as evidence that individuals with autism do not spontaneously engage with the

emotional expressiveness of other people in the way that non-autistic matched controls do.

While there is considerable evidence that individuals with autism show differences and deficits in emotion perception, expression and imitation, the primacy of these affective deficits is difficult to either prove or disprove at an empirical level given the age at which autism is diagnosed. They might equally well be regarded as a consequence of a primary cognitive deficit. Research that has aimed to investigate the earliest markers of autism offers some support that differences in emotional and social relating are present within the first two years of life. Joint attention deficit is the most robust of these findings (Mundy & Sigman, 1989; Cox, Klein, Charman, Baird, Baron-Cohen, Swettenham, Wheelwright, & Drew, 1998) but a range of other social deficits have also been found. This evidence is also relevant to a consideration of the theoretical account presented by Mundy and colleagues (1989, 1995, 2001) and will therefore be considered in the account of the latter theory.

Transactional Social-Orienting Model of Autism

Like Hobson, Mundy (1995) has proposed a primary affective impairment in autism and there are clear similarities and areas of overlap between the two accounts. The affective theory presented by Mundy and colleagues has been presented in a number of evolutions, most recently in an account that emphasises the transactional and dynamic effects on development of a primary disturbance in 'social orienting' response that is present at birth or very early in development. In an early exposition in response to the emergence of the ToM hypothesis, Mundy and Sigman (1989) pointed out that children with autism show delayed and deficient joint attention behaviours, behaviours that develop prior to the emergence of pretence in the normally developing child, thus making it likely that autism must result from a deficit other than an inability to metarepresent.

They argued that a purely cognitive explanation such as that proposed by Baron-Cohen (1995) fails to take account of the emotional and affective quality of the 'jointness' or sharing that occurs in joint attention behaviours and which differentiate these behaviours from requesting skills that are impaired to a much lesser degree. Indeed Mundy and Sigman (1989) pointed out that the primary purpose of joint attention behaviours appears to be to *share* the experience of an event or object with others. Both early and subsequent versions of Mundy's theory rests on the evidence for a very specific pattern of social-communication impairments rather than generalised social deficits in autism. Where Hobson (1993) emphasises disrupted perception of affect, Mundy and Sigman (1989) and Mundy (1995) emphasise disrupted expression of affect in the evidence for their account and, in particular, deficits in the initiation of joint attention bids shown by children with autism (Mundy & Sigman, 1989). These

joint attention bids involve the spontaneous use of eye contact and gestures to show objects to others, or to share the experience of an event with others, and deficits in initiating these bids have been shown to be a robust and enduring deficit among children with autism at all levels of ability (Mundy, Sigman, & Kasari, 1993). Relatively less impaired is the use of eye contact and gestures to regulate the behaviour of others for more instrumental purposes such as requesting aid in obtaining objects. Deficits in responding to the joint attention bids of others have also been found but this has proved to be a less enduring deficit among older or more developmentally able children with autism (Dilavore & Lord, 1995).

The significance of this deficit in initiating joint attention is highlighted in studies that have found joint attention deficits to be among the most reliable early diagnostic indicators of autism (Baron-Cohen, Cox & Charman 1996) and in studies which have empirically linked measures of joint attention behaviours to parent reports of symptom severity of overall social disturbance in children with autism (Mundy, Sigman & Kasari, 1994). Individual differences in joint attention skill development have also been shown to be important short- and long-term prognostic indicators for cognitive, language and social development among children with autism (Sigman & Rushkin, 1999).

Deficits in other aspects of 'social orienting' have also been found. Swettenham et al. (1998) found that 20-month-old infants subsequently diagnosed with autism at 42 months, displayed far less 'social orienting' (such as spontaneous gaze shifts between objects and people) than did normal controls. Analysis of family videotape records have shown evidence of disturbance in joint attention and social orienting in children later diagnosed with autism (Osterling & Dawson, 1994). Klin (1991) found that the typical preference for speech and speech like sounds, normally present in the first months of life, was absent in all of his sample of children with autism. This preference was, however, present in all of the developmentally delayed matched control sample. In a further study Dawson, Meltzoff, Osterling, Rinaldi and Brown (1998) examined patterns of orienting to social stimuli and orienting to non-social stimuli in matched samples of autistic, Down syndrome and normal children in naturalistic settings. These authors found that children with autism had deficits relative to the other groups in orienting to both sorts of stimuli. Their impairment in orienting to social stimuli was more severe than their impairment orienting to non-social stimuli. In addition, individual differences in difficulty with social orienting, but not non-social orienting, were significantly related to joint attention behaviours. Leekam and Moore (2001), on the basis of experimental investigation of orienting response to both social and non-social stimuli in pre-school children with autism, have suggested that a failure to orient to people at a dyadic level, may underlie later difficulties with triadic joint attention.

Based on this research evidence and theoretical models derived from normal development, Mundy and Neal (2001) argue that joint attention deficits in children with autism reflect a basic failure in the normal preparedness to spontaneously orient to and process social information. This starts the child on a developmental trajectory in which experiences of, and opportunities for, social information processing are reduced and, perhaps through compensatory mechanisms, non-social information processing is overemphasised (Mundy, 1995). In turn, this disruption in early experiences negatively impact on subsequent neuronal, social and cognitive development and further removes the child from the normal developmental trajectory. An important part of this theory is that early experience drives a substantial portion of postnatal brain development and that disruption of these experiences will produce secondary neurological effects. Mundy and Neal (2001) argue that targeted early intervention that allows a degree of compensation in these early experiences, may lessen the degree of subsequent disruption.

Mundy and Neal (2001) suggest that this failure in social orienting may arise from an 'error in social reward sensitivity' but concede that the neurological mechanisms that lead to this are poorly understood at this time. They do, however, provide some converging evidence that functionally integrated neurological sub-systems may be organised around the regulation of social-emotional approach behaviour. Mundy and Neal (2001) argue that their model predicts that disruption in both neuronal growth in specific areas and disruption in neuronal pruning would result from the dynamic effects of the early neuropathology that underlies the failure in social orienting. Furthermore, they predict that targeted early intervention should lead to a reduction in these secondary outcomes. With regard to neuronal pruning, for example, they predict that successful early intervention would lead to lower brain volumes than is typical for individuals with autism. (Increased brain volume has been found by a number of researchers, Piven et al.1995; Piven, 1996, Bailey et al., 1995).

Whereas the evidence for early social and affective deficits in autism is mounting, many aspects of Mundy and Neal's model remain speculative. At the psychological level there is difficulty in generating detailed and verifiable predictions from their model given that autism is not yet reliably diagnosed until the age of about two years and yet investigation of social responding in the early infancy period is critical to a full exposure of the theory. However, a major contribution of this model, and to a lesser extent that of Hobson (1993), is in emphasising the active role of the infant in garnering experiences critical for subsequent development and in emphasising the transactional and dynamic nature of both typical and atypical development. These issues are critical to future theory building and research aimed at achieving a full understanding of autism.

[1]Unusual sensory-perceptual responding in autism

It is clear from this review of the literature that the major thrust of psychological research in the past two decades has centered on the triad of impairments that currently form the basis for diagnosis. As we have seen, however, both Kanner and Asperger also identified a number of non-triad aspects of behaviour and skills. One of the most fascinating of these is the presence of unusual sensory responding and preoccupations. The remainder of this thesis will focus on an analysis of this area and we will begin with a specific literature review of the more limited range of research that has been carried out on this topic.

Both Kanner and Asperger commented on the unusual sensory reactions and preoccupations of the children they observed and this feature was included by Kanner (1943) as one of the central features of the disorder.

> He kept throwing things on the floor, seeming to delight in the sounds they made. (Kanner, 1943, describing Donald).

> 'Over-sensitivity and blatant insensitivity clash with each other. Here are some examples. In the sense of taste we find almost invariably very pronounced likes and dislikes. The frequency of this phenomenon provides yet more proof of the unity of the type. There is often a preference for very sour or strongly spiced food such as gherkins or roast meat. Often there is an insurmountable dislike of vegetables or dairy produce. It is no different with the sense of touch. Many children have an abnormally strong dislike of particular sensations, for example, velvet, silk, cotton wool or chalk. They cannot tolerate the roughness of new shirts or of mended socks. Cutting fingernails is often the cause of tantrums. Washing water too can often be a source of unpleasant sensations and hence, of unpleasant scenes. In the hospital we have observed hypersensitivity of the throat which was so strong that the daily routine inspection with the spatula became an increasingly difficult procedure. There is hypersensitivity too, against noise. Yet the same children who are often distinctly hypersensitive to noise in particular situations, in other situations may appear to be hyposensitive. They may appear switched off even to loud noises' (Asperger, 1944).

Subsequent clinical accounts also noted a range of abnormal sensory reactions commonly found in this group (Goldfarb, 1961; Wing, 1966) and these included attempts to delineate the theoretical significance of these behaviours (Bergman & Escalona, 1949) and recommendations for treating this aspect of autistic symptomology

---

[1] See O'Neill and Jones (1997) for an earlier version of this review.

(Delacato, 1974). Diagnostic significance was attached to this aspect of the behaviour of children with autism in international classification systems until 1980. 'Unusual sensory responses' was included as one of the diagnostic criteria for an assessment of autism in DSM-11 and although omitted in DSM 111 for the diagnosis of infantile autism, was included for the diagnosis of the closely linked "Childhood Onset Pervasive Developmental Disorder (COPDD). 'Unusual sensory responses' has been omitted as a diagnostic feature in subsequent editions of these classification systems. With the growing influence of Wing's 'triad of impairments' this aspect of autistic behaviour has subsequently been down-played in both the clinical and research psychological literatures. Currently, consideration of unusual sensory reactions and preoccupations do not feature strongly in much mainstream diagnostic or intervention practice or in theoretical accounts of the disorder. Nevertheless, a small clinical and empirical literature does exist in relation to this aspect of behaviour.

Clinical studies

Prevalence. A number of early studies provide evidence to suggest that unusual sensory responses are present in the majority of children with autism. Wing (1969) reported abnormalities in response to sound and abnormal body movements in 80% of a group of children with autism. Ornitz, Guthrie and Farley (1978) surveyed parents of children under the age of 4 years subsequently diagnosed with autism, and parents of age-matched typically developing controls, using a written developmental inventory. Unusual sensory reactions strongly differentiated the groups with over 70% of the autistic group reported as showing unusual sensory responses. These unusual responses were reported across auditory, visual, tactile, vestibular and pain modalities by the parents of the autistic group and these included behaviours indicative of hyporeactivity, hypersensitivity and heightened awareness of sensory stimuli

Orntiz et al. (1978) found that in particular the category 'Ignores Sounds' was strongly related to abnormal social relating behaviours such as ignoring people, and being emotionally hard to reach. Volkmar, Cohen, and Paul (1986), using the same inventory on an independent sample of autistic children, found that 81% of parents reported that their child 'Ignores Sounds', 51% reported a disturbed reaction to certain noises, and 56% were preoccupied by textures. Dawson (1983), in a retrospective interview with parents of high-functioning adults with autism, reported that 80% recalled some type of anomalous response to sensory stimuli during their son or daughter's childhood.

Dahlgren and Gillberg (1989) used a retrospective parent report developmental questionnaire to investigate early symptoms of autism with parents of very young children with autism (under 3 years). Abnormal response to sound was reported by 100% of parents as having been present in the first two years of the child's life. With

one exception, more recent studies within the psychological literature have focused on 'sound sensitivity' alone, prompted by anecdotal claims of the success of Auditory Integration Training (AIT) as a treatment for autism and/or sound sensitivity specifically. Sound sensitivity has come to be used to describe a range of abnormalities that include hyperacute hearing of sound, distressed reaction to certain sounds, failure to react to sound and preoccupation with particular sounds. Bettison (1996) found that 65% of the parents of autistic children reported mild to severe distress reactions in their children in the presence of some sounds. In addition, marked individual differences in sound sensitivity were noted.

Rimland (1990) reported that 40% of the 12,000 families who had completed a standard symptom inventory on their children indicated that sound sensitivity was a feature of their child's reactions. In a recent study addressing sensory responding across the modalities, Talay-Ongan and Wood (2000) found significant differences between a group of children with autism and an age-matched normal control group on 45 out of 54 behaviours considered to represent abnormal sensory-perceptual processing

Other evidence with regard to the prevalence of specific forms of unusual sensory responding in autism has come from the Occupational Therapy literature. Building on the work of Ayres (1979), a number of investigators have explored the prevalence of either modality specific 'sensitivities', most commonly tactile or vestibular sensitivity, or a more general cross-modality construct of 'sensory sensitivity' in clinical populations. Kientz and Dunn (1997) using a parent questionnaire measure found that behaviours representing sensory sensitivity were reported in 50% of their sample of children with autism aged between 3 and 10 years. Modality specific 'tactile defensiveness' has also been reported as occurring in a significant proportion of children with autism (Ayres & Tickle, 1980). There is clear evidence from this literature that abnormal sensory-perceptual responding is not unique to autism. Problems such as tactile defensiveness, abnormal pain perception and sound sensitivity have also been found in other clinical groups including those with learning disability (Biersdorff, 1994).

Although there is considerable evidence to suggest that unusual sensory responding may be more prevalent among individuals with autism, a recurring observation in both the psychological and occupational therapy literatures is the high level of within group variability in these sensory behaviours (Bettison, 1996; Kientz & Dunn, 1996). Within subject variability in sensory-perceptual responding has also been documented (Rincover, Newsom, Lovaas & Koegel, 1977). The mechanisms underlying this variability are not yet understood and the manner in which individual children manifest sensory abnormalities has not been systematically investigated.

Developmental manifestation. In general only very limited evidence exists with regard to the developmental course of unusual sensory responding across the lifespan. There is increasing evidence to suggest that sensory abnormalities are manifested very early in development and that they are amongst the most diagnostically relevant features at this early age. Dalgren and Gillberg (1989) found that unusual sensory reactions, and abnormal response to sound in particular, strongly discriminated children with autism from learning disabled and typically developing controls matched for age, sex, and IQ). Social, communication (as opposed to language only) and play-behavioural abnormalities were also strongly discriminating features.

Lord (1995) found that unusual sensory behaviour and lack of orientation to voice were among the behaviours that differentiated 2-year old children with a later diagnosis of autism from a group with other developmental disorders. Other evidence has come from studies using home movies to identify early markers of autism. Osterling and Dawson (1994) compared the behaviour of normally developing and autistic children in home videos of their one year birthday parties. The groups showed significant differences on four behaviours that included unusual responses to auditory stimuli such as failure to orient to name and covering ears with hands. Baranek (1999) also analysed home videos of infants between the age of nine and twelve months. She compared videos of 11 children with autism, 10 children with other developmental disabilities and 11 typically-developing children. Baranek found that sensory-perceptual and sensory motor features in the tactile, auditory and visual domains differentiated the groups, as did other markers in social responsiveness.

The evidence with regard to the long-term developmental course of unusual sensory abnormalities is limited. In mixed learning disabled populations there is evidence that tactile defensiveness is linked to developmental age, and attenuates over the course of development (Baranek & Berkson, 1994). These authors noted abnormal response to sound as significantly more common in children (30%) than in adults (3%) in a mixed disability population that included individuals with autism. However, in the Talay-Ongan and Wood (2000) study the authors reported evidence of increased sensory sensitivity in older compared to younger children with autism, which they attributed to the older childrens' increased ability to articulate their sensory problems.

Experimental studies

There is also a limited body of experimental work which has addressed sensory-perceptual responding in individuals with autism. Some early work derived from the behaviour analysis literature has demonstrated unusual sensory preferences.

Metz (1967) studying stimulus-seeking behaviour found that children with autism preferred higher levels of sound for various types of auditory material including music and speech than did learning-disabled non-autistic children. Frankel, Freeman,

Ritvo, Chickamin and Carr (1976) found that for children with autism, specific frequencies of a flickering stimulus had reinforcing value whereas non-autistic learning-disabled children showed no such preferences. In a related study, Freeman, Frankel and Ritvo (1977) also found that the frequency of vestibular stimulation was significant for children with autism but not for the learning disabled controls. Using a different paradigm, Hermelin and O'Connor (1970) found that children with autism fail to show the normal modality dominance of auditory over visual information.

Abnormal responses to sensory stimuli have been shown in studies utilising a range of indices. Condon (1975), using sound-film microanalysis, found evidence of delayed and multiple response to sound in autistic-like children. This included response to their own speech as well as to the speech of others. However, this finding has not been replicated. Hermelin and O'Connor (1970) reported differences in behavioural and physiological responses to both visual and auditory stimulation in autistic subjects when compared with matched normal and learning-disabled controls. The findings with regard to response to sound were particularly interesting in that the autistic subjects showed more cortical responsiveness but fewer behavioural orientation responses to auditory stimuli than the other groups.

In addition, a body of early psychophysiological studies, reviewed by James and Barry (1980) and Dawson and Lewy (1989), had also indicated unusual response to sensory stimuli, interpreted as providing support for abnormal orienting and habituation to sensory stimuli in individuals with autism. Courchesne, Akshoomoff and Townsend (1990) summarised a number of event-related potential (ERP) studies that have found abnormal 'late' processing of auditory stimuli as indexed by the P300 or Pb component. Similarly, Lincoln, Courchesne, Harms and Allen (1995) found evidence in event-related brain potential experiments of failure to normally process auditory stimulus intensity among autistic and receptive developmental language disordered individuals compared to normal controls. More recently, Muller, Behen, Rothermel, Chugani, Muzik, Manger and Chugani (1999) using PET scan procedures, found reduced cerebellar activation to non-speech sounds, and a trend towards reduced activation of the auditory cortex during acoustic stimulation in a sample of high-functioning autistic adults compared to age-matched normal controls.

Event-related potential findings such as those by Courchesne and colleagues are in the main considered to reflect attentional processing components, and the focus of subsequent research has switched to investigation of the range of attentional capacities in individuals with autism (Allen & Courchesne, 2001). As a result of this and the wider emphasis on triad impairments which has previously been described, wide-ranging and systematic investigation of unusual sensory-perceptual responding has been neglected. A similar pattern can be seen in the evolution of theoretical understandings of autism. A number of early theories were strongly influenced by findings of unusual sensory

responding and processing. Building on the arousal theory of Hutt, Hutt, Lee and Ousted (1965), Ornitz and Ritvo (1968) proposed that autism is characterised by fluctuations between states of over- and under-arousal which results in a failure to modulate sensory intake adequately and an unstable perceptual experience. These authors proposed that the child's sensitivity and attention to stimuli fluctuate, depending on arousal level. Ornitz (1985) saw 'the autistic disturbance of sensory modulation and motility' as the primary symptom with other symptoms such as social and communication deficits the result of dysmodulation of sensory input. His neurophysiological model of autism implicated a dysfunction of the neuronal networks in the brainstem and diencephalon that are involved in the initial processing of sensory input. This subcortical dysfunction of sensory processing assumed that distorted sensory information, when relayed to higher centres, became distorted information.

Building also on arousal theories of autism, and introducing the notion of 'optimal levels of stimulation' for information processing, Dawson and Lewy (1989) proposed that children with autism have biologically-based deficiencies in arousal modulation which directly affect attention to and processing of social and non-social information. These authors proposed that children with autism have a narrower band of optimal stimulation, so that stimuli which would elicit an orienting response in normal individuals, elicit instead an 'aversive' response in individuals with autism, thus accounting for many aspects of unusual sensory responding. In particular, Dawson and Lewy (1989) proposed that children with autism have a lower than normal threshold for an aversive response to stimuli that are unpredictable and novel, hence accounting for the social relating difficulties since people are inherently unpredictable.

Additional findings which are relevant to the issue of sensory-perceptual responding in autism concern the underlying integrity of the sensory systems themselves. Increased rates of deafness, similar to those found in learning disabled populations (3.5%), and highly elevated levels of hyperacusis (almost 1 in 5 individuals) have also been reported in autism (Rosenhall, Nordin, Sandstrom, Ahlsen & Gillberg, 1999). Increased rates of deafness may be due to the strongly associated learning disability and/or to the increased rates of recurring otitis media frequently found in autism. The finding with regard to hyperacusis provides reliable evidence of hyperacuity which is one of the features of abnormal responding to auditory stimuli reported in the clinical literature. Reasons for the elevated levels of hyperacusis are not understood.

Methodological Limitations

In the clinical literature relating to basic perceptual processes, there is not an agreed taxonomy of what constitutes sensory-perceptual abnormality with different behaviours being assigned different interpretations in different studies. A frequent limitation in the experimental studies reviewed here is a failure to consider developmental and

maturational effects in sample and control group selection. Studies have focused on a limited number of modalities and the full range of sensory -perceptual abnormalities have not been investigated. Diagnostic criteria were often imprecise. More fundamentally however, these studies, by virtue of typically being carried out in tightly controlled environments far from the buzzing confusion of the real world, tell us only what autistic subjects can do, as opposed to what they usually do, how they can function as opposed to how they may typically function. Given what is known about the impact of environmental manipulations such as degree of structure and predictability on autistic behaviour (Olley & Reeve, 1997), ecological validity may be a critical issue in the investigation of unusual sensory-perceptual responding.

The salience of sensory-perceptual phenomena

Because of the limited extent and shortcomings of the research to date, it is difficult to evaluate the significance of sensory-perceptual phenomena in autism. Although the literature review presented here suggests that sensory-perceptual experiences are an important and perhaps neglected aspect of our understanding of autism, some very basic questions remain regarding the impact these phenomena have on the lives of people with autism themselves. We do not know how common these experiences are, how central they are experientially, how they relate to other impairments, nor indeed how specific they are to autism. Providing answers to these and other questions will require a concerted research effort utilising a combination of investigative strategies encompassing behavioural, psychophysiological, neurophysiological and self-report measures. The theoretical implications remain unclear with major theorists disagreeing as to the significance of sensory phenomena and as to whether they are best explained by higher (Frith & Baron-Cohen, 1987) or lower level (Ornitz, 1989; Dawson & Lewy, 1989) perceptual processes. At this stage it would appear that until we have answers to at least some of the above questions 'grand' theories which attempt to account for these abnormalities may be as yet premature.

In particular, more rigorous approaches to self-report data drawing on a range of quantitative and qualitative research methods, may be the most fruitful and logical place to start in terms of informing and generating hypotheses for the wider research effort. It is only by applying the range of scientific methodologies available that we will come to a full understanding of the significance of these sensory-perceptual phenomena.

Much 'first-wave' research (Briere, 1992) remains to be carried out to delineate the nature of the phenomenon, to accurately identify its prevalence within the spectrum, and to map out the extent to which it is central or peripheral to the nature of the disorder. There is increasing evidence from the neuroanatomical field, for the existence of deficits linked to sensory processing, and at least one investigator has called for more research on sensory-perceptual abnormalities (Tribe, 1992).

The voice of people with autism. One valuable source of evidence which has largely been ignored in the search for understanding the nature of autism is the perspective of people with autism themselves. Apart from a number of published individual case study descriptions, only a small number of 'insider' studies have been carried out, and these have offered an interesting perspective on the relative salience of various triad and non-triad features in the experience of living with autism.

Cesaroni and Garber (1991), for example, reported on two firsthand accounts from verbal, high-functioning individuals with autism, which were generated through participant observation, informal and formal interviews and analysis of art work, poems and essays. Five themes were identified in the analysis: sensory processing, stereotypical behaviours, social interaction, empathy and memory. Olney (2000) drew on published parent autobiographical accounts and a number of published accounts by people with autism themselves. Based on thematic analysis of these texts the author identified six major themes: sensation; attention; emotion; communication; rituals, repetition and rhythm; and sensory manipulation. As in the Cesaroni and Garber study, the feature of disrupted sensory perception was found to be both common and central in the accounts analysed.

Whelan (1996) reported on a questionnaire survey of thirty individuals with autism. Survey questions primarily related to sensory-perceptual experiences across the modalities, with some additional questions addressing memory, behaviour, relationships and movement. Aberrant sensory-perceptual experiences were identified by a very significant majority of those surveyed. However, the reliability of this study, and to a lesser extent the Olney study, is significantly undermined by the inclusion of accounts generated through the use of Facilitated Communication. At least half of those surveyed in the Whelan (1996) study were facilitated speakers, while Olney (2000) included an autobiographical account generated through Facilitated Communication. Facilitated communication has been seriously undermined in a series of studies which have pointed to 'facilitator' authorship of the facilitated message (see Mostert, 2001 for review) and this means that the greatest caution must be exercised when interpreting the findings from these studies.

Because of the limited nature of the evidence so far, it is difficult to evaluate the salience of unusual sensory-perceptual phenomena in the lived experience of individuals with autism. Significant questions remain as to how common aberrant sensory-perceptual are among individuals with autism, and over the extent to which these phenomena are subjectively perceived as central within the wider experience of living with autism. Before embarking on detailed research into the nature and extent of these problems for a doctoral thesis, it was first necessary to determine whether or not these experiences were sufficiently salient and common in people with autism to warrant doctoral research.

The increasing number of published and other first-hand accounts (e.g. internet, conference presentations) by individuals with autism offered a useful starting point for further investigation of this issue. A pilot study involving a systematic review of these accounts offers one way of gathering preliminary evidence as to the salience and nature of sensory-perceptual phenomena in the lives of people with autism. If unusual sensory-perceptual experiences are described as significant in these accounts it would suggest that these phenomena should be investigated in more detail.

Study 1 of this thesis will, therefore, describe a systematic review of this published first-hand account literature. In keeping with a number of other chapters in the thesis, the report of the study will begin with a short section, written in the first person, called process issues. Here some issues central to the decision to regard the first-hand literature as a study in itself, rather than part of a general introduction are discussed in more detail.

STUDY 1

[2]Sensory-Perceptual Experience in Autism: A Pilot Study

"All the behavior modification in the world is not going to stop an autistic child from screaming when a noise hurts his ears" (Grandin, 1992b).

Process Issues

Although my own clinical experience suggested that sensory-perceptual phenomena might be an area worth investigating, I was unsure as to whether or not these were a sufficiently salient and common experience in people with autism to warrant doctoral research. I decided therefore to conduct a small pilot study to address this question and this pilot study forms the basis of the current chapter. I decided to analyse existing published autobiographical and other first-hand accounts to examine whether these phenomena had been reported in the literature in detail. The primary goal of this pilot study was to determine if there was a case for more research into these phenomena in autism. During the planning stages of this pilot investigation, it became clear that this was an essential first step in the research process as a whole and could not merely be included as a part of a general literature review. Rather, it would involve a number of clear stages, centring on the completion of a scholarly review of the first-hand account literature. These stages were:

1) A careful reflection on the reasons behind the desire to study sensory-perceptual phenomena in detail. This would include the background to the study and a clear statement as to how these phenomena came to interest me.
2) The completion of a scholarly review of the first-hand account literature.
3) The public presentation of the findings of the review at conferences and meetings. The review was designed to act as a stimulus for comment from clinicians and people with autism themselves.
4) The review would be submitted to the most prestigious journal in the field (Journal of Autism and Developmental Disorders) and careful note would be taken of the editor's comments and referee's opinions in guiding future research.
5) Finally, the information from all these sources would be used to determine the final shape of the studies that might combine to form the thesis as a whole. At this stage it was possible that the results of the review would suggest that this was <u>not</u> an avenue worth pursuing and that the sensory-perceptual experiences

---

[2] The results of this study were presented and discussed in an earlier summary in O'Neill and Jones (1997).

of people with autism were not regarded as sufficient to warrant doctoral research.

The pilot study

Published autobiographical and other first-hand accounts offer a rich and valuable source of insight into nature and subjective experience of a range of disabling conditions and mental health problems (e.g. Bliss, 1980). Within the autism literature there was at the time of this pilot study a considerable number of published first-hand accounts. These included published autobiographies (some written with the support of a co-writer), published Conference papers, autobiographical accounts published in professional journals and autism society newsletters, extracts from first-hand accounts published by researchers and clinicians in professional journals or as part of a thesis, and firsthand accounts included in other publications such as books written by parents of individuals with autism. In order to evaluate the significance of sensory-perceptual phenomena in the lives of people with autism as a legitimate focus of research, I decided to review these accounts for descriptions of sensory-perceptual problems and preoccupations.

In constructing the review a number of decisions had to be made. Firstly, it was decided that, as a preliminary analysis, the review should focus on some basic questions. The first was to identify whether or not these phenomena were spoken about by a large enough sample of individuals. Although no formal limit was decided upon in advance, if only two or three accounts were found, this would not suggest that these phenomena were widespread enough to merit more detailed examination. A second question involved the involvement of different modalities. My existing knowledge of the subject suggested that unusual sensory-perceptual experiences might well be reported in relation to hearing and touch but I was interested to know if other modalities might also be involved. I therefore decided to group the data using different sense modalities as headings. Finally, it was decided to articulate any cautions and limitations that were inherent in this type of analysis. As a stimulus for further comment, these caveats were important in eliciting negative as well as positive responses.

The methodology used for the review was, therefore, closely dictated by the purpose of the study. The central question would be "Is there a case for further researching these phenomena" rather than any attempt to integrate or synthesise the contents of the accounts or form a theoretical model of these experiences. It was felt to be too early in the research process for such integration and therefore a simple 'trawl' of the accounts seemed preferable to using a more formal 'thematic' analysis such as grounded theory.

As planned, the pilot study formed the basis of a review, which was submitted to the Journal of Autism and Developmental Disorders for publication and was accepted with only minor amendments (O'Neill & Jones, 1997).

Method

The following sources were searched for autobiographical and other first-hand accounts:

Publications of major Autism Societies and Organisations (e.g. National Autistic Society, American Society for Autism).

Psychological literature: Journals, Books and Theses via databases such as PSYCLIT, BIDS, and MEDLINE.

This process yielded the following list of 18 published textual accounts and one animated film narrated by people with autism that describes aspects of their experience:

1. Bemporad, J. (1979) Adult recollections of a formerly autistic child. *Journal of Autism and Developmental Disorders*, 9, 179-197.
2. Carpenter, A. (1992). Autistic Adulthood: A Challenging Journey. In E. Schopler G. B. Mesibov (Eds.), *High-Functioning Individuals with Autism*, New York: Plenum Press.
3. Cesaroni, L. (1990). *Exploring the experience of Autism through first-hand accounts from high-functioning individuals with autism.* Master's Thesis, University of Toronto.
4. Cesaroni, L., & Garber, M. (1991). Exploring the Experience of Autism Through First-Hand Accounts. *Journal of Autism and Developmental Disorders*, 21, 3.
5. Dawson, M. (1983). *Personal accounts: able autistic people's memories and perceptions of their life experiences.* Preliminary Report to DHSS
6. Grandin, T. (1984). My experiences as an Autistic Child and Review of Selected Literature. *Journal of Orthomolecular Psychiatry*, 13, 144-174.
7. Grandin, T. (1989). An Autistic Person's View of Holding Therapy. *Communication*, 23, 75-78.
8. Grandin, T. (1990). Recognizing Faces is Difficult. *The Advocate*, 22, (2&3), Summer/Fall, p. 6.

9. Grandin, T. (1990). Sensory problems in autism. In *Proceedings of Annual Conference of the Autism Society of America*, Buena Park, California.
10. Grandin, T. (1992). An inside view of autism. In E.Schopler and G. Mesibov (eds.), *High-functioning autism*. New York: Plenum.
11. Grandin, T. (1992). Calming Effects of Deep Touch Pressure in Patients with Autistic Disorder, College Students and Animals. *Journal of Child and Adolescent Psychopharmacology*, 2, 63-72.
12. Grandin, T., & Scariano, M. (1986). Emergence: Labelled autistic. Novato CA: Arena.
13. Miedzianik, D. (1986). *My autobiography*. Nottingham: University of Nottingham, C.D.R.U.
14. Volkmar, F., & Cohen, D. (1985). The experience of infantile autism: A first-hand account by Tony W. *Journal of Autism and Developmental Disorders*, 15, 47-54
15. White, B. B. & White, M. S. (1987). Autism from the inside. *Medical Hypotheses*, 24, 223-229.
16. Williams, D. (1992). *Nobody Nowhere*. London: Doubleday.
17. Williams, D. (1994). Somebody Somewhere. London: Doubleday.
18. Zoller, D. (1989). *Wenn isch mit euch reden konnte*. Bern:Scherz Verlag. (Introduction translated by Annie Humphreys, Autism Research Unit, Sunderland Polytechnic, 1990)
19. *A is for Autism*- a short film produced by the British Film Institute with animated drawings and narration by able autistic people including D. White and Temple Grandin. (Main focus is on unusual sensory experiences and 'obsessional'/stereotypic behaviour).

In addition the following parental account contained quotes from her autistic daughter:
Stehli, A. (1990). *The sound of a miracle: A child's triumph over autism.* New York; Doubleday.

The accounts of these authors were analysed for the following:

-presence or absence of references to unusual or abnormal sensory-perceptual functioning

- all descriptions of sensory-perceptual problems, fascinations, skills and deficits
- all descriptive accounts of the perceived cause, trigger, context, course and impact of these phenomena .

These phenomena were then summarised according to type and modality.
Where a number of accounts by the same author were reviewed, references to sensory-perceptual phenomena were summarised together under the author heading.

Results

All but two accounts made reference to some aspect of unusual sensory-perceptual experience. The following quotes illustrate some of the range of experiences described.

Sound

> "My hearing is like having a hearing aid with the volume control stuck on 'super loud'. It is like an open microphone that picks up everything. I have two choices: turn the mike on and get deluged with sound, or shut it off..." (Grandin, 1992a, p. 16).

> "Another trick which my ears played was to change the volume of sounds around me. Sometimes when other kids spoke to me I could scarcely hear them and sometimes they sounded like bullets" (White & White, 1987, p. 224).

> " My father's girlfriend had a high-pitched voice that hurt my ears, and my body language must have made her feel like she had the plague. I discovered I could use cotton wool in my ears in order to try to tolerate the pitch and intonation of her voice but it still set my nerves on end so that I kept feeling I was going to explode" (Williams, 1994, p. 42).

> "The sound was the only thing that drove me crazy...sound was going on all the time. It was hard to get away from it. With the other things I could look down, or walk away. But I could always hear the blood in my veins and my own breathing" (Stehli, 1991, p. 189).

Vision

> "Bright lights hurt my eyes...I also remember one Christmas when I got a new bike for a present. It was yellow. I would not look at it. Extra red was added to the colour making it look orange, and it blurred upwards making it look like it was on fire " (Attwood, 1993, p. 40)

> "My eyesight blurred several times that day and once I could see no more than a yard in front...I broke my collarbone falling off a radiator. My eyes were

showing a wide windowsill where the radiator was and I sat down falling off instantly" (White & White, 1987, p. 225).

Smell

"...and smells like deodorant and aftercare lotion, they smell so strong to me I can't stand it, and perfume drives me nuts" (Stehli, 1991, p. 187).

Touch

"When I was a child I craved the feeling of being hugged but then I withdrew because I was overwhelmed by the tidal wave of sensation" (Grandin, 1992a, p. 18).

Other sensory difficulties

Several accounts made reference to general sensory overload and difficulties in attending and making sense of stimulation received through more than one channel at a time:

" Fabrics dangled in front of me in my dark cupboard, the security of my chosen darkness. Here the bombardment of bright light and harsh colours, of movement and blah-blah-blah, of unpredictable noise and the uncontrollable touch of others were all gone .... Here, there was no final straw to send me from overload into the endless void of shutdown" (Williams, 1994, p. 22).

In addition some first-hand accounts refer to multi-channel receptivity and/or difficulties in identifying the channel or modality through which sensory input is coming in the first place:

" Sometimes the channels get confused , as when sounds come through as colour. Sometimes I know that something is coming in somewhere, but I can't tell right away what sense it's coming through" (Cesaroni & Garber, 1991, p. 305).

Individual Variability in Sensory problems

While a description of sensory perceptual abnormalities was common to the accounts outlined above there was nevertheless considerable variation in the manner and extent to which individuals experienced these difficulties. For example Grandin, (1986; 1992a) referred primarily to problems with sound and touch whereas White and White (1987) described, in addition, difficulties in visual processing. Neither describes the level of extraordinary auditory and visual hyper-acuities described by Stehli (1991) or the multichannel receptivity described in Cesaroni and Gaber (1991). The account by Williams (1994) placed her sensory difficulties within the context of a much wider and

pervasive deficit in processing and integrating information from all sources, both internal and external, including awareness of hunger, pain, heat or cold.

Central to Autistic Experience

Despite individual variation between authors in the range and severity of sensory abnormalities, they were nevertheless described in many of these accounts as central to the autistic experience, subjectively standing alongside other impairments such as social and communication difficulties. They were portrayed as contributing to high levels of distress, fear, anxiety, and as disrupting daily life and social functioning:

> " It is the perceptual disturbance which bothers me. I see and hear too much and therefore I need more peace than other people. Sometimes everything upsets me... No one knows what it means to be disturbed in perception...In those days I had no happiness, cried mostly, often bellowed like an animal. On the other hand, I was without feelings. I felt no love, touch was unpleasant; it was so indefinite, not really there. I cannot describe it at all" (Zoller, 1989, in Gillingham, 1991, p. 24).

The Paradox: Sensory Fascinations and Stereotypies

It seemed clear from the accounts described that sensory-perceptual abnormalities were experienced by the individuals concerned as contributing to high levels of stress and anxiety. Analysis of these accounts also suggests an apparent paradox, however; on the one hand these unusual sensory experiences were described as a source of pain and distress, and yet on the other, sensory events and experiences were also sometimes described as a source of pleasure and safety:

> "I used to love it. It had always come to rescue me and take me away from an incomprehensible world, where once having given up fighting for meaning, my senses would stop torturing me as they climbed down from overload to an entertaining, secure, and hypnotic level of hyper. This was the beautiful side of autism. This was the sanctuary of the prison" (Williams, 1994, p. 112-113).

Discussion

The results of this review confirmed that sensory-perceptual problems, fascinations and related phenomena were reported in the vast majority of published first-hand accounts analysed. It also confirmed that these phenomena were experienced across all modalities, In addition, in many of these accounts they were portrayed as significant in

the subjective experience of living with autism. In particular, the results of the review offered confirmation that further investigation of these phenomena was warranted.

The review also raised a number of cautions with regard to sensory-perceptual phenomena. The first arose around an assumption of universality in these experiences. It was noteworthy that in two of the accounts analysed there was no reference to these phenomena (Miedzianik, 1987; Carpenter, 1992). The second arose from an awareness of the dangers of assuming that these published accounts were representative of the experiences of people with autism in general. Individuals who publish autobiographical accounts could generally be regarded as exceptional in terms of their general ability and, in particular, in their ability to articulate their experiences. Their experiences may or may not be representative of individuals with autism who are less articulate. Thirdly, a number of these accounts (e.g. Bemporad, 1979; Cesaroni, 1990; Volkmar & Cohen, 1985) were the outcome of lengthy contacts between the autistic individual and a non-autistic author, or, as in the case of Grandin and Scariano (1986), were co-authored accounts. This raised the possibility that what is presented may have been influenced by interpretation or selection by others, thus producing a biased or misleading picture of the actual extent and significance of the sensory-perceptual abnormalities described.

These cautions highlight a very real danger: that a very small number of prolific writers may come to influence our understanding of the autistic experience in a potentially unbalanced and unrepresentative manner. This led then to an important starting point for investigation in this area. Many people with autism who publish accounts of their lives report sensory-perceptual phenomena as a significant aspect of their life experience. Would a sample of people with autism drawn from a normal clinical population report similar experiences and if so what could we learn about the nature of these experiences from talking with them?

Dissemination

The findings of the review were presented at an international autism conference jointly organised by the National Autistic Society and the Autism Research Unit at the University of Sunderland. This was chosen because it is an annual conference attended by clinicians, researchers, parents and people with autism. Feedback at this stage was primarily from clinicians, researchers and parents. The feedback could be summarised as an exhortation to continue research into these issues. In general, there was a sense that that these issues were regarded as important coupled with a shared sense of the absence of clear understanding of the nature of these phenomena.

The findings of the review were also presented to a group of parents of school-aged children with autism in North Wales. The feedback here was that the descriptions resonated very much with their observations of their own children. The parents felt that

the presentation helped them understand aspects of their children's behaviour. Once again there seem to be strong encouragement to continue with further investigation into these phenomena.

A summary of the findings in relation to challenging behaviour was presented at a 'round table' discussion about new developments in understanding challenging behaviour held in Manchester. The audience consisted mainly of clinical psychologists and front-line staff working with people with learning disabilities. Again the contents of the paper elicited strong interest.

Finally, a number of eminent clinicians and researchers were contacted individually (Uta Frith, Rita Jordan and Elizabeth Newson) and the contents of the review were discussed with them. These discussions confirmed the view that this was a neglected topic and merited further investigation.

One of the conclusions to emerge from this feedback was the fact that although there was a clear mandate to research these phenomena in more detail, there was an absence of a theoretical framework within which to work. Most clinicians and researchers were interested in the phenomena but did not see it as falling clearly within any of the pre-existing theories of autism. This was in keeping with my own feelings when reviewing the clinical and experimental literature for the review. What was needed was a 'first wave' research investigation. Later research might be in a position to conduct theoretically-driven investigations, but I saw a clear need to begin the research process by attempting to articulate the nature of the phenomena themselves.

Conclusions

It was clear from the findings of this pilot study that sensory-perceptual phenomena were a sufficiently salient and common experience in people with autism to warrant doctoral research. I was encouraged by the positive response to the review article and the individual responses to the conference presentations to attempt to examine these phenomena in more detail. The further lines of enquiry were decided upon at this stage and remained constant throughout the time scale of the investigation. At the heart of the investigation would be a series of interviews with people with autism themselves. I would also, where possible, interview the parents of these individuals. My plan was to construct a theoretical integration of any themes that might emerge from the interviews with the people with autism (Study 2) and later to interrogate the parental accounts to see if these would confirm or deny aspects of this theoretical integration (Study 3). I would then return to the published first-hand accounts and check the theoretical integration against the existing literature using a more formal qualitative methodology than that undertaken in the present pilot study (Study 4). It was also decided to present the theoretical integration to individuals with autism (Study 5).

At this stage I had thought that I might return to the individuals interviewed in Study 2, but I subsequently decided to use the internet as a way of expanding the range of feedback. At this stage, however, I had answered my first basic question: there was a case for more research into sensory-perceptual phenomena in autism. The next chapter, therefore, will outline the general methodology used throughout these subsequent studies.

General Methodology : Chapter 3

> A distinction in research is between that which is concerned with *verification* and that which is concerned with *discovery*. In the former type, theory serves as a framework to guide verification. In the latter, theory is in the 'jottings in the margins of ongoing research', a kind of research in which order is not very immediately attained, a messy, puzzling and intriguing kind of research in which the conclusions are not known before the investigations are carried out.
> (Gherardi and Turner, 1987, p.12, quoted by Pidgeon, 1996).

Introduction

This chapter describes the general methodology used throughout the remaining studies outlined in this thesis. Although each study required a slightly different approach to data gathering and analysis, there were many commonalties in the methodologies used and it is these commonalties that are described here. In particular, each study used a qualitative approach, although the particular research question dictated the specific approach used. The chapter begins with a general discussion about the qualitative research paradigm before moving on to outline the procedures used in the different studies reported in the thesis.

Why Qualitative Research?

The decision to approach the aims of this investigation using a qualitative research methodology was based on a number of factors. As a result of the investigations carried out in Study 1 it was clear that sensory-perceptual phenomena in autism are poorly understood both at the descriptive and theoretical levels. In particular, the phenomenology of sensory-perceptual experience in autism had not been adequately explored and articulated in existing psychological literature. The psychological and behavioural correlates, and developmental course of sensory problems and fascinations remained under-researched. Qualitative approaches are particularly suited to aims of 'discovery' and to exploring and defining the territory in areas where there is little or inadequate existing research (Barker, Pistrang & Elliot, 1994). Furthermore, a central aim of qualitative research is to represent the experiences and actions of people in relation to specific situations or processes. This fitted with the researcher's clinical orientation and concern to understand the 'lived experience' of individuals with autism as it pertained to sensory-perceptual phenomena. Qualitative methodology was consistent with the researcher's value base in that it privileges effective listening to and representation of the realities and concerns of individuals as the basis for theoretical understanding and action. This is considered especially relevant in the field of learning and developmental disability where there is relatively little research which is explicitly driven by the concerns of the disabled individuals themselves and where traditionally the

voice of disabled adults and children is rarely heard (Sinason, 1992). A desire to engage meaningfully with individuals with autism in 'co-discovery' using a qualitative methodology was consistent with the researcher's motivation in pursuing the research topic.

Why Grounded Theory?

One important approach to qualitative research is that of 'Grounded Theory'. This methodological approach was first developed by Glaser and Strauss (1967) at a time when social science research was dominated by quantitative approaches which focused on the verification of a relatively small number of 'grand' theories. Glaser and Strauss (1967) argued that a critical and important first stage of the research process was being overlooked: the discovery of concepts and hypotheses relevant to the topics under research. They developed grounded theory method as one way of addressing this issue. Grounded theory method has subsequently been developed and expounded by a number of qualitative researchers (Glaser & Strauss, 1967; Strauss & Corbin, 1990; Charmaz, 1995; Henwood & Pidgeon, 1995). Consequently it is best understood as a strategic approach to conducting qualitative research which is characterised by a number of core characteristics and principles, the application of which can (and should) be adapted in order to meet the particular requirements of each research undertaking. The central aim of grounded theory is to generate theoretical understanding that is grounded in the data and not from pre-determined theory or hypotheses. Theoretical understanding requires the researcher to move beyond the descriptive to a more conceptual and abstract account of the data. In particular, grounded theory emphasises the development of conceptual understanding which reflects the variations and complexities of the experiences under investigation in the contexts where they typically or naturally occur (Harre & Secord, 1973). These characteristics suggested grounded theory as an appropriate method to the particular aims of this research investigation. In particular, a move beyond a purely descriptive account to a more conceptual understanding of the processes underlying sensory-perceptual experience was considered necessary in terms of enhancing our understanding of sensory-perceptual phenomena and in generating possible directions for future research in this area. Furthermore grounded theory methodology is now well established within psychology research practice, and it has been used in areas such as cognitive science (Pidgeon, Turner, & Blockley, 1991) and social psychology (Currie, 1988). It's utility has been particularly demonstrated in the clinical and health research literatures (Dingwall, 1992) and within disability research (Clegg, Standen, & Jones, 1996; Hallberg & Carlsson, 1993; Wholmsley, 1999). It is increasingly applied within the field of autism and has been used to investigate both parent experiences (Midence & O'Neill, 1999; Huws, Jones & Inlgedew, 2001) and the experiences of individuals with autism themselves (Jones & Meldal, 2001).

Principles of Grounded Theory

A number of core principles are emphasised in grounded theory research and these are highlighted by proponents as critical to the differentiation of grounded theory methodology from other forms of thematic or content analysis. These principles represent a set of inductive strategies for analysing data. These include:

(i) theoretical sensitivity on the part of the researcher. This refers to the ability to recognise what is important in the data and to give it meaning. Within grounded theory it has two main sources. The first is from the professional knowledge and experience of the researcher in the field under investigation, and the second is from the use of recommended analytic and questioning strategies in coding and interacting with the data. An example of the latter would be the use of the 'Paradigm model' (Strauss & Corbin, 1990) to assist the researcher in discovering and articulating links between categories to enhance theoretical understanding

(ii) creation of analytic codes and categories developed from the data, not from pre-conceived hypotheses. This requires careful and methodical interaction between the researcher and the text so that coding of the data and the analytic concepts which arise from it are true to and accurately represent the experiences and variability of the phenomenon which is being investigated. This requires for example an attitude of scepticism about analytic categories which have been developed and continually seeking to verify these against the data. The process of coding and data analysis will be described in more detail below

(iii) an iterative process of data collection and data analyses. Because grounded theory aims to achieve theoretical understanding of the phenomenon under study, moving between data analysis and data collection allows the researcher to pursue emerging concepts and categories in new data sources and this flexibility is seen as an important aspect of the grounded theory approach. The analysis of subsequent data becomes more focused in challenging and developing the accuracy and properties of emerging concepts.

(iv) adherence to the constant comparative method. This involves systematic comparison of data and concepts in order to enhance understanding of variation and complexity. Transcripts are compared with each other, concepts are checked against instances of data, and concepts are compared with other concepts. It is a basic and essential component of the coding process and of the development of increasing conceptual understanding of the data. This method of systematic comparison is also seen as a valuable tool in increasing the validity of emerging understanding. In particular, searching for data that does not fit the emerging

categories 'negative case analysis' is useful as a control against premature conclusions, and, in developing the analysis further.

(v) theoretical sampling. Theoretical sampling is a process of checking and developing emerging understanding against new data. Analyses and emerging categories are tested and developed by either returning to the original participants to explore these emerging interpretations or by theoretical sampling of new data sources. For example one may wish to check in a new data source if there is evidence that a particular category is relevant and if so if it is different in any way from existing conceptualisation of that category. Data sets may be drawn from any relevant source. Glaser and Strauss(1967) and later Strauss and Corbin (1990) explicity encourage the use of archival and other textual materials, and the use of a combination of sources and data types.

(vi) use of memos to assist in and clarify the analytic process. Memos record the researcher's thinking about the data, about codes and categories and the relationships between them. They can be used to record comments, hunches, explanations or links with the literature. As well as externalising the research process, memos can assist the researcher in keeping track of the analysis and stimulate further analysis.

Essentially, the range of strategies outlined above provide the researcher with a framework for moving from a body of unstructured material to the generation of conceptual understandings and links that illuminate the phenomenon under scrutiny.

Data collection and storage

Textual data in grounded theory can take a number of forms including interviews, documentary records (e.g. clinical notes), and published or archived material (e.g. autobiographies). Most commonly however, textual data are generated by interviewing. The aim of interviewing is to generate a 'rich' set of materials which represent the central experiences of participants in relation to the issue which is being investigated. Typically interviews are fully transcribed and appropriately labelled. A number of software packages which assist in the storage and handling of qualitative data are now available (NUD*IST; Ethnograph) or data may be handled in hardcopy format by copying, cutting and pasting using indexing systems.

Data Analysis

The process of making sense of unstructured textual data begins with an initial level of analysis, variously referred to in different methodological accounts as 'open coding' (Strauss & Corbin, 1990) or initial coding (Charmaz, 1995). This process of coding is open-ended. The researcher works carefully and methodically through the text to be

analysed, generating labels or codes to describe the relevant phenomena and concepts represented in the text.

When this process is complete, analysis moves to a more refined and abstract level where these initial codes are reviewed and 'opened up' to reveal their essential features, similarities and differences so that they can be located within 'higher level' or more abstract categories. This process of analysis involves a balance between abstract and conceptual interpretation of the text, and the requirement that the codes and emerging categories should 'fit' the data (i.e. provide a recognisable description). 'Success in generating theory that is well grounded in the data therefore depends upon maintaining a balance between the full use of the researcher's own subjective understanding and the requirement of fit'(Pidgeon & Henwood, 1996, p. 87). These higher level categories or 'focused codes' (Charmaz, 1995) are defined and their essential features identified.

Grounded theorists recommend the systematic use of questioning tactics to interrogate or 'open up' the data when engaged in this coding and analytic process: Charmaz (1995) identifies a number of basic questions which are helpful when engaged in this process and these are summarised in Table I

Table 1: Questions to facilitate coding (Charmaz, 1995)

Basic questions when coding
1. What process is at issue here?
2. Under what conditions does this process develop?
3. How does the participant think, feel and act while involved in this process?
4. When, why and how does this process change?
5 What are the consequences of the process?

The next stage in the analytic process is the further development and refining of categories and the delineation of links between categories. This process is described as 'axial coding' by Strauss and Corbin (1990) and they set out a framework which they term 'the paradigm model' to assist in this process of systematic analysis. In simplified

terms this involves looking at the categories and the data they represent utilising the following framework:

(A) Causal conditions	>	(B) Phenomenon >
(C) Context	>	(D) Intervening
Conditions	>	
(E) Action/Interaction sequences	>	(F) Consequences

The final stage in data analysis involves commitment to a core category or central story line which best represents relationships between the categories and which provides a theoretical account of the data.

Credibility in Qualitative research

The notion of credibility in qualitative research has been the subject of considerable debate (Holliday, 2001). Issues of reliability and validity are common to both quantitative and qualitative approaches but the ways in which these are expressed and the mechanisms by which they are addressed are necessarily influenced by the differing purposes of enquiry and the nature of the data. There are now widely recognised procedures within the field of qualitative research to address these issues (Holliday, 2001). With regard to reliability, two strategies are common: making explicit the 'context' of the data collection (Kirk & Miller, 1986) and the use of low inference descriptors (Seale, 1999). With regard to interview generated text, making explicit the context of the data involves presenting clear description of the participants involved, and the nature of the process and questioning which led to generation of the text, thus allowing the reader to make judgements about the context and boundaries of the investigation. The use of low inference descriptors involves the presentation, within the research report, of extensive, verbatim data accounts to illustrate the concepts and categories developed thus allowing the reader to evaluate the adequacy or 'reliability' of the researcher's analysis of the data.

The term 'validity' in qualitative research is taken to refer to ' the extent to which an account accurately represents the social phenomena to which it refers' (Hammersley, 1990, p. 57). Because the development of a systematic qualitative methodology to ensure validity of outcomes was one of the key aims of Glaser and Strauss (1967) in developing the grounded theory method, particular aspects of grounded theory methodology are widely considered as integral to the issue of validity in qualitative research. In particular, the constant comparative method and the issue of theoretical sampling described above are proposed as essential aspects of a wider strategy to ensure valid outcomes, since these strategies involve the systematic interrogation of text and

data sources for variation and difference in emerging concepts. Additional forms of validation have also been suggested as particularly appropriate to qualitative research. Denzin (1970) proposed a strategy of 'triangulation' i.e. the use of multiple data sources or methods as part of the research methodology to allow for a comprehensive treatment of the issue under investigation. Triangulation of data sources involves investigation of a given phenomenon from the point of view of different groups. The use of multiple data sources allows for the identification of similarities and differences between accounts and different vantage points. However, a number of researchers (Fielding & Fielding, 1986) have argued that any process of triangulation needs to be done carefully, recognising the 'situated' or context bound nature of each different data source, and avoiding the temptation to 'adjudicate' between different accounts. Bearing these concerns in mind however, it is argued that the investigation of different perspectives widens and deepens the generated account of a given phenomenon, thus adding to its validity (Denzin, 1970).

A second and long-standing strategy to support outcome validity in qualitative research is that of respondent validation (Miles & Huberman, 1994). This is a process of bringing research findings back to participants to get their views on the extent to which the research account fits with and represents their experience. This is viewed as a useful strategy to ensure 'goodness of fit' between the researcher's emerging theoretical understanding and the reality of participants' experiences on which the understanding is based.

The Present Study

In addition to investigating the occurrence of sensory-perceptual phenomena in a sample of individuals with autism from a clinical sample, a primary purpose of this research enquiry was to develop an account of the phenomenology of sensory-perceptual experience in autism with a view to informing both future research and clinical practice. While a feature of qualitative enquiry (and grounded theory research in particular) is that the nature and course of the research may change and develop over time in response to emerging concerns and findings (Charmaz, 1995), the basic structure of the research design was conceived as a whole. The research enquiry was designed to utilise a grounded theory approach which particularly emphasised the principles of 'triangulation', 'theoretical sampling' and 'respondent validation' as key elements in developing a rounded and valid account of the phenomenon being investigated.

Overall the studies reported in the thesis comprised a series of linked grounded theory studies using multiple data sources: interviews with individuals with autism (Study 2), interviews with the parents of these individuals (Study 3), analysis of published first-hand accounts of individuals with autism (Study 4), and respondent validation of the analytic account developed from the individual interviews (Study 5).

The use of these multiple data sources combined opportunities for both triangulation and theoretical sampling. Opportunities for triangulation were provided by exploring sensory perceptual phenomena from the perspectives of both individuals with autism, of their parents and of different 'groups' of individuals with autism. Opportunity for theoretical sampling was provided by investigating the extent to which emerging conceptual understandings developed in study 2 were relevant to the analysis of the additional data sources provided by studies 3, 4 and 5.

Summary of Research Design Sequence:

Step 1: Study 2: Interviews with individuals with autism drawn from a clinical sample and development of an emergent analytic account of sensory-perceptual phenomena using grounded theory methodology.

Step 2: Study 3: Interviews with parents of participants in study 2 and the development of conceptual understanding of sensory-perceptual phenomena from this perspective. This involved exploration of the extent to which emerging categories from study 2 agreed with parental accounts and also involved the identification of new understandings suggested by this data source.

Step 3: Study 4: Analysis of sensory-perceptual experience in autism as represented in published first-hand accounts of individuals with autism using grounded theory method. This was different to the pilot study outlined in Study 1 in that it involved exploration of the extent to which emergent understandings developed in study 2 were relevant to or dissonant from this data set. It also involved the identification of additional perspectives of sensory-perceptual phenomena as warranted by these accounts.

Step 4: Study 5: Feedback of the emergent understandings arising from Study 2 to original participants and other individuals with autism with a view towards developing the analysis further in the light of their feedback.

Step 5: Integration of the findings from Studies 2, 3, 4, and 5.

Step 6: Interrogation of existing theoretical literature in autism in light of findings arising from Step 5.

The first step in this sequence was regarded both as the most important and the most difficult. Previous research (e.g. the accounts outlined in Study 1) had reported the views of quite able people with autism. Prior to the present study, no previous investigation using an in-depth interview approach to this client group had been reported without an extensive clinical or therapeutic contact between the researcher and the participant. The most basic and, perhaps most valuable question that the present research asked involved was whether or not it was possible for a clinical sample of people with autism to respond to a detailed interview-based research protocol. A great deal of planning and background research was required to design such an interview protocol and this is described in the next chapter.

Study 2

Introduction

Study 1 has established that, in individuals represented in published first-hand accounts, unusual sensory-perceptual phenomena are a salient aspect of the experience of living with autism. The aims of the study reported in this chapter were three-fold: to explore the extent to which a lengthy and detailed face to face interview is useful as an approach to investigating sensory-perceptual experience in a clinical sample of people with autism, to investigate the extent to which unusual sensory-perceptual experiences of the sort described in published first-hand accounts are also reported by these individuals, and, finally to explore the phenomenology of these experiences. In order to achieve these aims the decision was made to interview people with High-Functioning Autism and Asperger's Syndrome about their sensory-perceptual experiences.

Why High Functioning Autism/Asperger's Syndrome?

The decision to select more able individuals with Autism and Asperger's Syndrome, rather than a sample drawn from across the ability ranges, was made for a number of reasons. Published first-hand accounts are by individuals at the more able end of the autistic spectrum. Even within this more able group they are considered to be among the 'elite' or most successful cases in terms of social adjustment and of intellect (Happé, 1991b) and it is unclear as to how far their experiences are 'typical' of the wider group of people who receive a diagnosis of High-Functioning Autism or Asperger's Syndrome. A clear aim of the investigation is to establish if unusual sensory-perceptual experiences of the sort described in published accounts are also described by individuals drawn from a clinical sample who may be considered more typical or representative of the vast majority who receive these diagnoses.

Secondly, another central aim of the study is to explore the phenomenology of sensory-perceptual experience in autism. A key aim of this research is therefore to achieve a detailed description and understanding of sensory-perceptual phenomena from an 'insider-perspective'. This includes knowledge of the ways in which these experiences impact on the behaviour and psychological states of those who experience them, how these change over the course of development and, what factors may impinge on this process. Interviewing is the most common, and, the preferred approach to the generation of 'rich description' in grounded theory and seemed therefore to be the obvious approach of choice for such an objective. Nevertheless, because of the nature of the disability, the extent to which an interview approach would be successful with individuals with autism was uncertain. No published studies using an interview approach to research with this client group could be located within the literature other

than those accounts described in Study 1, where there was some form of clinical or therapeutic contact over an extended period of time with more able individuals.

Interviews based on one-off or a small number of contacts were considered more likely to prove productive with more able individuals than with individuals with additional learning disabilities. More able individuals were considered more likely to have the memory, cognitive and verbal capacities necessary to recall and articulate their sensory-perceptual experiences. A mixed ability group more 'representative' of the autistic spectrum and weighted towards the majority of individuals with autism who also have a learning disability was considered less likely to be able to provide the detailed articulation of experience which the study aims to achieve. Nevertheless, it was hoped that the accounts generated by more able individuals would prove helpful in sensitising future research to factors and behavioural indicators relevant to exploring sensory-perceptual phenomena across the wider spectrum.

In addition, a number of researchers have highlighted the benefits of using samples of more able individuals with autism or Asperger's Syndrome to further our understanding of the disorder. They have argued that this offers an opportunity to investigate 'pure' autism that is not confounded by the presence of additional learning disability (Rumsey, 1992). This issue is relevant to our understanding of sensory-perceptual phenomena in autism since there is evidence that sensory problems are also present in other clinical groups including those associated with a degree of learning disability (Biersdorff, 1994).

Autism/Asperger Debate

The most commonly used diagnostic systems for the classification of autism are the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM IV; American Psychiatric Association, 1994) and the International Classification of Diseases, 10th Revision (ICD -10; World Health Organisation, 1992). Within these systems Autism and Asperger's Syndrome are classified as separate disorders within the wider category of Pervasive Developmental Disorders. There is considerable overlap between the diagnostic criteria for both conditions with the major distinguishing feature for Asperger's Syndrome being the absence of any early cognitive delay or early language delay or abnormality. However, this distinction has caused widespread unease, and the validity of Asperger's Syndrome as a distinct entity from High-Functioning Autism has been challenged for a number of years (Frith, 1991). Wing (1998) observes that DSM IV criteria do not include abnormal language use, which was considered by Hans Asperger to be a defining feature of the disorder. Attempts to distinguish Asperger's Syndrome from High-Functioning Autism on a range of indices such as motor clumsiness (Ghaziuddin, Tsai & Ghaziuddin, 1994; Marjiviona & Prior, 1995; Volkmar & Klin, 1998) visuo-spatial function (Marjiviona & Prior, 1995; Klin,Volkmar,

Sparrow, Cicchetti & Rourke, 1995); theory of mind (Prior, Dahlstrom & Squires, 1990) and executive function (Miller & Ozonoff, 2000) have also failed to demonstrate reliable findings across studies. In a review and discussion of this issue, Schopler (1998) has argued strongly that the validity of Asperger's Syndrome as a separate disorder has not been demonstrated. Of the fourteen contributors to the book edited by Schopler, Mesibov and Kunce(1998) to address the issue, Schopler found that only two were of the opinion that High-Functioning Autism and Asperger's Syndrome are separate conditions, with six supporting the view that there is no distinction, and six of the view that the argument remains ambiguous. In clinical practice in Britain and Ireland, it is the researcher's experience that the term Asperger's Syndrome can be used quite loosely, frequently assigned to any high-functioning individual with autism regardless of early language and cognitive development. It is also the researcher's view that a reliable distinction has not been demonstrated between High-Functioning Autism and Asperger's Syndrome. For this reason, the criteria for selecting participants for inclusion in the study included the diagnosis of *either* High-Functioning Autism or Asperger's Syndrome according to DSM IV criteria. In addition the generic term 'autism' is used frequently throughout the thesis to refer to both conditions in preference to the more cumbersome term 'High-Functioning Autism and Asperger's Syndrome'.

The interview process

The dilemma of structure

The issue of 'structuring' or 'direction' of the research interview in qualitative research, and in grounded theory in particular, is a controversial one. A number of researchers argue against any form of 'structuring' of the research conversation because of the danger of 'leading' participants in preconceived directions or imposing unwarranted assumptions on the experiences under investigation (e.g. Clegg, Sheard, Cahill & Osbeck, 2001). Others have taken a less trenchant and more pragmatic view, acknowledging that the use of semi-structured interview may usefully serve specific purposes and have beneficial outcomes under certain circumstances (Charmaz, 1990). Regardless of stance on this issue, grounded theory requires the researcher to remain vigilant to the danger of loaded questioning and/or being constrained by pre-formulated questioning when interviewing participants in a research investigation.

For the purposes of this research the decision was taken to use a semi-structured interview protocol to assist in the research interview. This decision was taken for a number of reasons but primarily because of the nature of the memory demands placed on participants drawn from this client group in exploring the phenomena in question. A number of studies have found evidence of specific memory impairments in autism that have a bearing on any investigation which uses retrospective self-report of individuals'

personal experiences. Free recall has been shown to be impaired (Boucher, 1981) but intact functioning has been shown on cued recall using a range of cues including 'leading question' cues (Boucher & Lewis, 1989). Others have also observed that individuals with autism appear to perform poorly on memory tasks where little support is provided at test, and perform well where retrieval cues are provided (Bowler, Mathews & Gardner, 1997). Furthermore, using Tulving's distinction of episodic (memory for personal experiences such as events at a particular time and place) and semantic memory (general world knowledge and facts about the world), a number of studies have suggested that episodic memory is impaired in autism (Bowler, Gardiner & Grice, 2000).

Millward, Powell, Messer and Jordan (2000) suggest that it is personal episodic memory or recall of self-experienced events that are significantly impaired in autism, relative to recall of observed events experienced by others. In the light of this research, an interviewing strategy which allowed for a degree of support for recall of personal experience was considered necessary in exploring the extent to which individuals with autism could talk about past and current sensory-perceptual experience.

There is some preliminary research using a descriptive experience sampling and interview technique that suggests that able individuals with autism do not introspect or report inner experiences in the same way as 'non-autistic' subjects (Hurlburt, Happé & Frith, 1994). Whereas non-autistic subjects report inner experience in four major ways: verbal inner experience; visual images; unsymbolised thinking; and feelings; these authors found that the three autistic subjects in their study reported inner experience in terms of visual images only and did not describe feelings, verbal inner experience or unsymbolised thinking. These findings suggest that individuals with autism may have difficulty in spontaneously reflecting on feelings. For this reason also it was considered necessary to allow for specific questions on the emotional aspects of the subjective experience of sensory-perceptual phenomena where these were not spontaneously reported.

A semi-structured format was also seen as helpful to the researcher. Because it was intended that the research interviews should comprehensively explore sensory-perceptual functioning across all modalities, the breadth of issues, which might potentially be covered, was substantial. A degree of 'preformulated' aide memoir to support the interviewer was therefore seen as helpful, especially in early interviews.

Design of interview protocol

In order to orient participants to their childhood memories and experiences a number of the initial questions in the interview were included with this orientation purpose in mind. These questions are Parts 1-3 of the Autobiographical Memory Interview by Koppelman, Wilson and Baddeley (1990). These covered the different stages of

childhood (pre-school years, junior school years and high school years) and involve a combination of factual autobiographical questions (e.g. name of school-semantic memory) and a question involving recall of one particular event from that time period (episodic memory).

In structuring the interview protocol, sensory-perceptual experience in each modality is explored in turn: sound, vision, touch, taste, smell and proprioception. Within each modality a range of experiences and behaviours are explored as appropriate to the individual participant. The behaviours/experiences, which are included in the protocol, are based on a review of a number of sources of published material in relation to sensory -perceptual functioning.

These include:

- the phenomena reported in first-hand accounts in Study 1,
- a review of the item content of previous measures used in investigating sensory responding in autism including items drawn from the Occupational Therapy literature.

These were:

Sound Sensitivity Questionnaire (Bettison, 1996)

TIE: Touch inventory for school-aged children., (Royneen, 1990)

Sensory History Questionnaire, (Ayres, 1979)

Tactile Defensiveness Rating Scale for Pre-schoolers (Royneen, 1987)

- behaviours or experiences identified as potentially linked to aspects of aberrant sensory-perceptual experiences such as stereotyped behaviours or fears
- general or non-modality specific phenomena identified from the range of sources reviewed.

The protocol was constructed so that questions about each modality were initially broad and exploratory, gradually 'funnelling' to reflect a greater degree of specificity in question content (see Appendix 1). More specific questions about particular experiences and behaviour could be used with discretion. A quote from a published autobiographical account was included at the end of questioning about each modality. This could be used where the researcher considered that it might be useful as a concrete example of the type of phenomena being explored.

Nevertheless, while the structure and content of the protocol were carefully thought out it was not felt that the interview should be constrained by it. It was envisaged that the order, language and content of questions would be adapted as appropriate to ensure that interviews were conducted in a flexible and responsive manner. It was also envisaged that the content and structure might change as the research progressed. Feedback about the content and length of the interview was

explicitly sought from participants in the early interviews to inform subsequent interviews.

Approaching the interview

Grounded theory draws on a range of skills that are integral to clinical work: skills of rapport building, interviewing, interpretation and the ability to integrate and refine conceptually different strands of information that build an understanding of a particular phenomenon. This also helps to make grounded theory an appropriate method in clinical research. Kvale (1992) identified two key elements in a qualitative interview: the interview as 'a construction site for knowledge' and the interview as 'an inter-change of views.' The key task of the researcher is to reveal participants' knowledge, understanding and relationship with the topic under investigation. This requires sensitivity to the relative power positions of the interviewee and researcher and any particular issues which may pertain to the articulation and discovery of knowledge between them.

Interviewing people with autism presents specific challenges in this regard. There is only a very sparse clinical literature (Hare & Flood, 2001; Hare & Paine, 1997) to guide the process. A search of the major research databases (PsycInfo; Web of Science; Medline) did not identify a single article which addressed the issue of interviewing individuals with autism for the purposes of research. Therefore the clinical researcher brings to the process their own assumptions about potential pitfalls and limitations in conducting the research interview, based on their own experience with people with autism and the general clinical literature. Similarly the participants will have their own experiences of interviews with 'professionals' which will impact on the research process.

These issues were pertinent to the whole research process. The researcher's major concern was that the well-being of participants would not be compromised in any way by involvement in the research process. This was particularly a concern given that the majority of participants were young adults. The researcher's clinical experience suggested that this is often a difficult period in the lives of individuals with autism as they struggle to come to terms with the fact and nature of their disability, at a time also when a wish to 'fit in' may also be at it's strongest. Fluctuation in acceptance of an Autism/Asperger label and fluctuation in mood and anxiety levels are common. For this reason the researcher decided, in consultation with the clinician from who's caseload participants were drawn, that the invitation to participate in the research should be channelled through the parents of research participants (all but one of the research participants lived at home). The researcher felt that parents would be in the best position to judge the appropriateness and timing of the request depending on their son's mood and anxiety state.

METHOD

Data collection phase

Participants

Recruitment

Ethical guidance and approval for the study was obtained from two sources: University of Wales, Bangor, School of Psychology Ethics Committee (see Appendix 2) and The National Autistic Society Ethical Review Board.

Participants were recruited from the national caseload of an eminent psychologist in the field of autism in Britain who has for many years provided diagnostic and intervention services to children and adults with autism. This psychologist identified potential participants from her caseload who fulfilled the following criteria

- had a firm diagnosis of Autism (High-Functioning) or Asperger's Syndrome
- were aged sixteen or over
- were aware of their diagnosis
- were considered capable of giving informed consent

The psychologist then made contact by telephone with the parent(s) of these potential participants to seek their permission for their contact names and addresses to be forwarded to me. This was for the purpose of my writing to them with an invitation to participate in the study.

Where approval was given an approach was made in writing to each participant via their parent(s). This initial approach included an introductory letter, (Appendix 3) information sheet (Appendix 4) and response slip (Appendix 5). All participants who were contacted returned a response slip in the affirmative. Further contact was made by phone to discuss the requirements of participation in the study further and to respond to any queries. An invitation to the parents of these participants to participate in a parent interview study (Study 3) was made simultaneously. Written consent (Appendix 7) was also required prior to interview. All participants approached by the researcher went on to participate in the study.

Six of the seven participants were recruited in this way. The seventh participant, also known to the psychologist, was recruited indirectly as a result of this process, having heard of the study by word of mouth and having expressed interest in participating in the research. Again the procedure involved the provision of written information about the study to the participant and his parents, and written consent was provided prior to interview.

Participants interviewed

Seven participants with a diagnosis of High-Functioning Autism or Asperger's Syndrome were interviewed. In the case of six of the seven individuals these diagnoses were confirmed by examination of each participant's case file using DSM IV diagnostic criteria. Access to the case file was not possible in the case of the seventh participant but he had a long-standing diagnosis of High-Functioning Autism by a well known psychiatrist and researcher in the area of autism. All participants were male. The absence of a female participant reflected the preponderance of males over females on the clinical caseload. This is in keeping with studies which suggest that High-Functioning Autism and Asperger's Syndrome may be between five (Lord & Schopler, 1987) and ten times (Siegel, 1996) more prevalent in boys than in girls with ratios in clinical studies as high as 10-15: 1 (Wing, 1981; Gillberg, 1989). The participants ranged in age from just under sixteen years to forty-four years. In order to assist the reader in 'locating' the sample within the wider population of people with autism a brief outline of each participant is presented as follows:

> Participant A was aged eighteen years old at the time of interview. He lived at home with parents, sister and brother and attended a Further Education College. His had a strong interest in pop music and showed considerable knowledge about chart statistics.
>
> Participant B was aged 23 years old at the time of the interview. A chemistry graduate, he lived independently and ran his own business as a Children's Entertainer. He was also an occasional speaker at autism conferences.
>
> Participant C was aged almost eighteen at the time of interview. He attended a further Education College and lived at home with his parents and younger brother who also had a diagnosis of Asperger's Syndrome. He showed a strong interest in buses, bus routes and trains.
>
> Participant D was aged seventeen at the time of interview. He attended a mainstream school and was taking a number of A-levels with a view to pursuing a degree in computing or Maths at University. He lived at home with his mother.
>
> Participant E was aged forty-four at the time of interview. He lived on his own and worked as a lecturer and research statistician.

Participant F was just under sixteen years old (due to an oversight in relation to month of birth) and the youngest of those interviewed. He attended mainstream school and lived with his parents and sister.

Participant G was seventeen and lived at home with his parents and younger sister. He attended a mainstream school where he was taking A-levels with a view to studying at University.

Interview Process

Participants chose the location of the interview. Six of the interviews took place in the participants' homes and one interview at the participants' work. All participants were interviewed alone, in a private area, to ensure privacy and confidentiality, to minimise distraction and to avoid unnecessary disturbance of the interview process. Each interview lasted between one and two and half-hours. The length of the interview was carefully negotiated with each participant, both in discussion in advance of the interview and by checking during the interview. Participants were aware that they could interrupt or terminate the interview at any time if they wished. At the outset of each interview, the purpose of the research was explained again and participants' questions were answered. Similarly, at the end of each interview participants were offered the opportunity to comment on or ask questions about the interview and the general research aims. All participants were given a contact number for the researcher to allow for further contact in relation to the interview if participants wished to do so. In addition, all participants and their parents were contacted within a week of the interview to thank them for their participation and to deal with any questions or difficulties which might have arisen as a result of the interview. No problems were identified by either participants or their parents as a result of the interview.

Each interview was audiotaped in full for later transcription. Although using an interview protocol formulated in advance of the interviews as a guide, the interviews were not rigidly constrained. The researcher used a range of clinical and interview skills to support participants in speaking freely and to explore issues of interest in a flexible manner. There was considerable variation between participants in the extent to which they were able to engage in free-flowing conversation, and as a result some interviews reflected more of a 'question and answer' format than others. This is reflected in the variation in the duration of interviews between participants.

The researcher also completed a 'reflexive log' after each interview that summarised her overall impressions of how the interview had gone and an impressionistic summary of the major issues that had emerged. This log had a number of purposes. One was to provide an opportunity for reflection on the researchers skills in the interview itself. Another was to provide a record of the 'feel' and content of the

interview as an aid to the analytic process and to identify issues for further exploration. An example of one of these reflexive memos is contained in Appendix 8 .

Interviews were conducted in a staggered manner over a ten-month period. Preliminary analysis and reflection on early interviews influenced subsequent interviews by suggesting areas of interest to be explored.

Data Preparation: transcription and storage

The content of one interview (Participant A) was lost due to equipment failure, leaving a total of six interviews available for transcription. All six interviews were transcribed in full. Interview tapes were repeatedly listened to following transcription to ensure that the researcher was fully conversant with the meanings and nuances of the transcribed material. Each interview was clearly and anonymously labelled and saved as a separate document in text format suitable for importation into QSR NUD*IST 4 software package. NUD*IST (Non-numerical Unstructured Data * Indexing Searching and Theorising) is a computer package designed to aid researchers in handling non-numerical and unstructured data in qualitative analysis. In this research because of the large volume of textual data generated, the software was used primarily as an aid to efficient management of the documents, the indexing/coding system, and the linking and storage of memos generated throughout the analysis.

Data analysis phase

Data analysis involved a number of steps culminating in the production of an analytic account which is presented in the results section of this chapter. These steps were conducted within, and informed by, the principles of grounded theory methodology that was set out in Chapter 3. These steps can be summarised as follows:

Step 1: Preliminary analysis and coding. The analysis began after the first three interviews had been transcribed. Each transcript was read thoroughly a number of times and the audio recording listened to check for clarity of meanings. A general overview and summary of initial thoughts and documentation of possible emergent themes was produced for each transcript. This allowed for basic comparative impressions of the three interviews. (This preliminary analysis then influenced subsequent interviews, with a similar process occurring between each interview). These three transcripts were the subject to initial coding according to modality: sound, vision, touch, taste, smell and proprioception. A number of other more general preliminary cross-modal codes were also generated and these included synaesthesia, repetitive behaviour, first memory, favourite activities, fears, and least/most preferred sense.

Step 2: Coding of initial three transcripts. The data within each modality were coded in turn following the grounded theory procedure of open coding. Open coding

involved detailed line by line analysis of the text and the generation of a lengthy list of primarily descriptive codes to represent the data. After open coding a process of examining and clustering codes into more conceptual categories was undertaken. The use of NUD*IST software allowed for easy movement between the codes and the relevant data instances which they represented, thus facilitating this analytic process.

Step 3: Transcripts for the final three interviews were then coded, again into the major modality and general codes. Data within each modality were then coded in turn using the conceptual categories developed from the analysis of the initial three transcripts to aid analytic thinking. This process also involved an openness to new codes and ideas within this data. Where new codes emerged the researcher returned to the previous transcripts to check for relevance, and in this way a 'flip-flop' between earlier and later transcripts and conceptualisations was an important aspect of the analytic process. By this stage the analysis had yielded a considerable number of descriptive/ conceptual categories within each modality and these are documented with illustrative verbatim data in Appendix 9. A summary of these individual categories, by modality, and a number of cross-modality categories (a total of 36 categories were generated in this way) are summarised below in 'Results section 1'.

Step 4: The next step in the analytic process involved comparing and clustering these categories. These categories were then further reviewed and analysed using the paradigm model from Strauss and Corbin (1990) into a total of 17 'higher - order' categories.

Step 5: The final step involved the development of a core category and sub-categories which integrated these 'higher-order' categories, and the writing of the analytic account which is presented below in 'Results Section 2'.

Results

The 'results' or outcome of the analysis will be presented in two sections. Section One contains a summary of the categories that emerged from Steps 1-3 of the analytic process. This represents a summary of the individual modality categories and a number of cross-modality categories. (See Appendix 9 for summary with illustrative verbatim data). Section Two contains an account of the analytic model, which has been developed to represent the accounts of sensory-perceptual phenomena generated in the study. The results are presented in this way in order to make the analytic process of moving from interview text to analytic account transparent.

Results Section 1

Sound

Distorted sound

This category relates to descriptions by participants of an experience of sound as distorted, blurred or confusing. In the absence of 'active listening' or effortful concentration on an event or activity a number of participants describe their experience of the sound environment as distorted and without meaning. This experience is described as unpleasant or as a source of distraction or nuisance. Emotional states of worry or anxiety and/or noisy environments exacerbate this experience. It may be experienced as part of sensory overload. One participant describes this difficulty in making sense of sound as part of a wider problem in the automatic processing of all incoming information when not actively concentrating on an event or situation.

Distractibility

This category relates to participants' descriptions of difficulties in achieving or maintaining concentration on specific events or tasks because of distraction or interference by the wider auditory environment. It is variously described as being 'open' to all sensory events when not actively engaged in an activity or as a difficulty in screening out background sound in order to focus on one aspect of the sound environment. This category contrasts sharply with participants' description of a state of intense absorption in an activity in which they are very difficult to distract.

Factors which accentuate this distractibility include anxiety, sustaining attention over long periods or situations of high cognitive demand. Unexpected or unfamiliar sounds may be particularly distracting. Internal thoughts may also be distracting. This distractibility may lead to a need to deliberately shut out all sound from outside. Participants' descriptions suggest a sense of being at the mercy of this susceptibility to distraction which may be accepted phlegmatically or lead to anticipatory anxiety which in turn feeds into a spiral of distractibility in certain situations.

Failure to hear or register sound

This category encompasses participants' descriptions of failure to, or delay in, hearing sound around them. In sharp contrast to descriptions of distractibility, participants describe the experience of being so engrossed in thoughts or activities that they fail to or are delayed in hearing sound. This includes quite dramatic examples of failure to respond to sound including a lack of startle response to very sudden loud sound.

Participants locate this phenomenon in an attentional framework rather than at the level of the mechanics of hearing. The effect of intense absorption may be described in terms of an altered state of consciousness akin to intense daydreaming. In this state

distractibility is very much reduced. Participant descriptions suggest that intense absorption and failure/delay in hearing sound arises involuntarily as a result of active engagement in an activity and is especially pronounced in childhood: In certain circumstances participants also describe a deliberate 'switching off' or blocking out of background sound in order to achieve this state of perceptual awareness with regard to sound. This is described as a mechanism to deal with a confusing auditory environment, to minimise distraction from the auditory environment, to enhance selective attending to one event or activity or to cope with other aversive sounds or unwanted intrusions. This is achieved through a variety of strategies including deliberately focusing on one sound or activity, physically blocking out sound (e.g. fingers in ears) or cognitive strategies to 'switch off' background sound.

Effortful 'Interpretative Attending'

This category refers to participant descriptions of needing to effortfully concentrate or deliberately focus on sound in order to make sense of it. Participants' accounts explicitly and repeatedly refer to the need for active listening or deliberate and effortful concentration in order interpret, make meaning from, and efficiently respond to the auditory environment. This can be conceptualised as a necessary action or strategy to deal with the subjective experience of phenomena such as those outlined above and as representing an underlying impairment in the 'automatic' ability to selectively and flexibly attend to auditory information. A number of participants particularly highlight difficulties in following others' speech and the role of others in facilitating this process of interpretative attending.

Hyper-acuity

This category refers to participant descriptions of 'hyperacuity' or exceptional hearing, either as a general characteristic or in relation to specific sounds or qualities of sound. This includes descriptions of hearing at a lower volume, at greater distance and a greater range of sound frequency than others and the experience of loud sounds as 'too loud'. It also includes descriptions of exceptional capacity to detect barely audible sounds which have a particular salience for the individual e.g. sound associated with a special interest. Hyperacuity is primarily described as a childhood phenomenon but may in the case of some individuals continue into adolescence and adulthood.

Problematic hyper-sensitivity (sound)

This category relates to participants' descriptions of 'unpleasant' hyper-reactivity/ hypersensitivity to particular sounds or qualities of sound. These sounds can produce high levels of anxiety or distress. A number of specific attributes associated with these sounds, either on their own or in combination can be identified from participants' accounts. These include loud sounds, unpredictable or unexpected sounds, high-pitched or reverberating sound and sounds associated with negative or aversive experiences.

Participants describe a range of physical and feeling states associated with these problematic auditory experiences. These include irritation, discomfort, hurt, dislike, upset, tension, anxiety, aversion, fear, goosepimples, or shock reflecting variation in the way in which and in the degree to which different sounds were felt to be aversive. In two accounts a distinction is made between physical hurt (e.g. earache) and the internal or mental pain associated with these sounds. Participants' behavioural responses to these aversive experiences included crying and other signs of upset, fingers/hands over ears, running, escape and avoidance of the situation. Repetitive or stereotypic behaviours may also be used to shut out unpleasant sound. Participant accounts suggest considerable variation between individuals in the impact of these problematic experiences on their lives and social functioning. This spanned circumscribed distress limited to the immediate situation; anticipatory fear and anxiety, or, avoidance of social situations and activities associated with the aversive sound. Problematic hypersensitivity is most marked in childhood but may, for some, continue in attenuated form into adulthood. Gradual familiarisation and/or increasing ability to make sense of and predict events are identified as factors which contribute to these hypersensitivities becoming less of a problem. Where problems continue they may be managed in a more socially acceptable way.

Perseveration

This category refers to participants' descriptions of a perseverative, 'repeating' or 'sticking' quality to the experience of certain sounds (both real and imagined) and thoughts. Certain sounds are described as mentally echoing, ringing or reverberating. Thoughts may stick in the mind and become difficult to dislodge. This perseverative experience impacts on sensory-perceptual experience in a number of ways: it adds to the unpleasant impact of aversive sounds because these are experienced as 'multiple exposures'; it may 'drown out' other incoming sound; and it may exacerbate the impact of distracting sounds or thoughts.

A-social, sensory world

This category refers to an experience of the world which is primarily physical or sensory-based. Participants' descriptions suggest an experience of the world in which awareness is primarily centered on the sensory or physical attributes of the environment and events within it. This has the quality of a naive or developmentally young view of the world: a world in which auditory events are a source of intense curiosity, wonder or pleasure with interest and exploration primarily driven at this level and not in a shared social experience. This sensory focus is associated with an 'in the moment' awareness in which there is an absence of a search for meanings and connection, of shared social understanding, and an absence of reflection on experience other than at a very basic level (e.g. association). This focus on sensory-based activity and detail is described as at the expense of all other aspects of the environment including people.

Concrete worldview

This category refers to a framework for interpreting and responding to the world which is rooted in the physical and concrete, eschewing abstract, social or reflective interpretations or strategies. The physical or sensory experience-based experience described by participants is associated with a primarily concrete way of interpreting, managing and responding to events around them. 'Mental' events or thoughts may be ascribed a 'physical' interpretation. Sensory or attentional 'blocking' or physical escape from the situation is used as a means of dealing with a range of unwanted events or situations including unpleasant sensory events and unwanted social demands and experiences.

Fascinations (sound)

This category relates to participants' descriptions of sound as a source of enjoyment, comfort or fascination. Echoing a sense of immersion in a sensory based world participants' accounts indicate that auditory events were a source of considerable pleasure in childhood. All participants described some type of fascination with sound or sounds in childhood. A number of specific attributes, either singly or in combination were identified by individual participants as underlying the appeal of these sounds. Repetitiveness, predictability, and softness/quietness were identified. Sounds associated with obsessional interest, sounds generated through repetitive or stereotypic behaviours, sounds associated with relaxation or pleasant situations or sounds that were part of a pleasurable multi-sensory experience were also described. In some cases these sounds were enjoyed opportunistically, in others these sounds were actively sought out. In some situations intrusion or interruption of individuals while they were engaged with these fascinations provoked anger, irritation or a sense of loss.

Vision

A-social sensory world

This category refers to participant descriptions of a primary orientation of awareness and interest in the physical and sensory as opposed to the social world. Intellectual interest and exploration are described as being grounded in the physical rather than the social or meaning based world of ideas. This is contrasted with the 'normal' orientation to people and the social world. There is some suggestion that an absence of, or difficulty with, an orientation to people causes this orientation to the physical-sensory world.

Orientation to repetition and pattern

A key aspect of this orientation to the physical and sensory world are participants' descriptions of an attentional orientation to repetitive, predictable pattern and symmetry within the visual field. All but one participant describes being drawn to or fascinated by visual events that contain these elements. There is a strong sense from participant accounts of a subjective experience of cognitive congruence or emotional pleasure in visual stimuli which possess these characteristics. Parallel to this sense of congruence, participants describe a sense of dissonance or irritation where disruption of repetition, pattern or symmetry occurs within the visual environment. A number of participants describe a difficulty in disengaging from these stimuli. This in turn can distract from other events and sources of information and can lead to negative social consequences for the individual.

Pattern and Intense Absorption

This category relates to descriptions of subjectively experienced altered states of awareness when engaged with repetitive, predictable visual stimuli or dynamic pattern. Participants describe a process of intense absorption in these events which impacts on awareness of the wider environment around them. This is described in various ways: a pleasurable intense absorption akin to a hypnotic effect; a dissociative type experience; an experience of awareness being somewhere other than in the real world. Interruption of this state may be perceived as jarring or aversive or as coming back or waking up to the 'real' world. Intense absorption may arise from a gradual, involuntary entrapment by dynamic pattern or repetitive stimuli. This is most likely when not actively concentrating on other tasks or activities. It may also be more actively sought out through engagement with particular activities (e.g. spinning top) in order to achieve a sense of relaxation or a sense of power and control. Conscious efforts may be needed to avoid getting drawn into these stimuli. This gets easier with age.

Preferring the familiar

This category relates to descriptions of a preference for the familiar and a discomfort with change in the visual environment. This preference for the familiar is described as a more pronounced feature in childhood which attenuates with age, and with efforts to become more adaptable.

Visual fascinations

This category relates to additional aspects of the visual environment which are described as a source of particular pleasure or fascination. These are idiosyncratic to the individual and include streetlights or other 'artificial' light, straight lines, telegraph pylons or poles and tiny details of the physical or natural world such as leaves and ants.

One participant indicated a reluctance to dissect the nature of the appeal of these events with the implication that cognitive understanding or analysis might in some way undermine their pleasurable impact. Another participant describes an emotional attachment to small objects or 'treasures'. Loss of these objects may provoke an intense emotional reaction, leading to social difficulties.

Unpleasant Visual Events

This category relates to participants' accounts of visual events which provoked a degree of displeasure, dislike or anxiety. These include disrupted pattern or symmetry, sharp objects, butterflies and moths (also fear of contact with these) and objects disliked because of their association with another unpleasant experience. Reactions ranged from a sense of dissonance at interrupted pattern, to panic and distress which provoked a need to escape from the situation. Lack of reflection or 'in the moment' awareness was identified by one participant as contributing to the extent of his fear of butterflies. In general participants describe these reactions in the past tense and largely as childhood phenomenon. Where they persist they do so in a greatly attenuated form.

Distractibility

This category refers to descriptions of distractibility by the wider visual environment. This includes being aware of and distracted by events in peripheral vision or particular sorts of stimuli including repetitive pattern (already described), lights or shiny objects. Awareness of, or being distracted by, events in peripheral vision may lead to misinterpretation of these events e.g. seeing things that are not there and a sense of vision 'playing tricks'. Individuals may be more susceptible to being distracted in situations in which they are not actively engaged in an activity or where motivation is poor.

Hypersensitivity

This category refers to a concept of hypersensitivity or heightened reactivity to specific properties of stimuli in the visual environment that was described by one participant. Stimuli are experienced as over-intense akin to the experience of sound as too loud. These include bright light or colour, sharp contrast and flashing bright lights which may be perceived as echoing internally. This hypersensitivity is described as having curtailed social opportunities and as contributing to a sense of 'difference' from others.

Specific aptitudes and deficits

This general category relates to descriptions of specific visual aptitudes and deficits. It includes difficulties in the judgement of distance, size, depth and height. Difficulties in judging the size of distant objects is related to the 'literal' interpretation of them as small. Judgement of local depth and height, and problems with eye-motor co-ordination are also described. Consequently walking and moving around may require active concentration. Fear of heights and going down escalators is also described.
One participant describes a tendency to see in 2-D and a difficulty with visuo-spatial tasks such as Embedded Figures. However, other participants describe a particular aptitude for Embedded Figures and spatial judgement.

Touch

People touch

This category relates to participant descriptions of their experience of different forms of social or 'people' touch: physical contact and interaction with people as distinct from objects. This includes affectionate touch, playful touch or other forms of social or functional touch. A number of participants describe affectionate touch as difficult, overwhelming, unpleasant and as a result this was avoided where possible. This problem with affectionate touch may be described as part of a wider problem in dealing with people. Confusion or difficulty with the emotional content of affectionate touch is identified by a number of participants. Being in control of the encounter is identified as important in mediating the extent to which affectionate touch can be tolerated.
Difficulties in dealing with some aspects of playful touch were also described. Tickling may be experienced as unpleasant or 'tolerated' rather than enjoyed. Other playful contact such as rough and tumble play were not experienced as a problem. A number of participants also describe difficulties with other forms of physical contact such as accidental touch and/or other social touch such as shaking hands. Factors such as increased social awareness may lead to greater efforts to tolerate physical contact. In addition, motivation for romantic relationships impacts on the experience of affectionate touch.

Tactile hyper-sensitivities

This category relates to participants' descriptions of their experiences of aspects of non-social touch (i.e. tactile reactions to materials, objects and other non-social events). It includes tactile sensations which are subjectively perceived by participants as problematic or unpleasant and experiences of perceived hypersensitivity. All participants described some form of sensitivity to non-social tactile sensation including particular fabrics and materials, new or particular types of clothing or footwear or body care routines. These sensitivities were a greater problem in childhood. In addition to tactile hypersensitivity a number of accounts suggest that other considerations may also contribute to difficulties: unfamiliarity of new clothes or change in clothing; effort involved in putting on types of clothing or footwear, inability to dismiss or ignore 'minor' irritations and the social interaction demands of tasks such as having hair cut.

Food Dislikes

This category relates to descriptions of foods which were strongly disliked. Several participants describe a dislike of certain food primarily on the grounds of texture. This includes dislike of foods which 'look' solid but are in fact mushy (e.g. cooked vegetables); or foods which have an 'in-between' consistency (i.e. are not properly solid or properly liquid). New or unfamiliar foods may also be problematic for some individuals. These dislikes are primarily a phenomenon of childhood. An increased desire to 'fit in' socially is one factor in this development.

Tactile Fascinations

This category relates to tactile-based fascinations or activities which were enjoyed primarily for their tactile sensation. These fall into two categories: those that produced a sense of comfort or security, and those which were associated primarily with a sense of purely aesthetic pleasure or enjoyment. These include deep-pressure touch such as being tightly wrapped or covered; the feel of satin-like labels or ribbons; and the tactile sensation of particular surfaces such as smooth, polished wood.

Smell

Hyper-reactivity to smell

This category refers to very strong or intense reactions to smells or odours. A number of participants considered themselves to have a heightened sensitivity to smell or problematic sensitivity to certain odours. These included aversive reaction to the smell of perfume, deodorants, after-shave or sweet cloying smells, cigarette smoke, eggs and disinfectants. The impact of these sensitivities varied from a circumscribed unpleasant feeling which was not expressed behaviourally to avoidance of people or places associated with the unpleasant experience. Hyper-reactivity to smell may continue past childhood for some individuals but may be managed in more acceptable ways.

Hypo-reactivity to smell

This category relates to descriptions of under-reactivity to or lack of awareness of smell. A number of participants recalled situations in which they were unaware of smells or types of smell of which other people were aware.

Evocative smell

This refers to descriptions of olfactory experience impacting on or being influenced by the context or situations with which it is associated. Two participants explicitly refer to strong associations between smell and it's associated contexts: emotional response to situations can be strongly influenced by smell including those of which the individual is not consciously aware: the emotional context can affect how smell is evaluated as either pleasant or unpleasant.

Taste

Preferring the familiar

This refers to descriptions of taste as influenced by familiarity and change. A number of participants described a childhood concern for familiarity and sameness and a difficulty in negotiating change, variety or the unfamiliar. This included familiar/unfamiliar tastes and combinations of foods.

Social influences

This relates to descriptions of social influences on taste. Social reaction may contribute to the maintenance of unusual food preferences in childhood. However, a wish to fit in may also lead to trying new foods and taste as an adolescent/adult.

Body Awareness

Variable Experience of Pain

This category refers to descriptions of variable pain experience. This variability ranges from descriptions of 'normal' pain reactions to apparent hypo-reactivity in some situations to hyper-reactivity in other situations. In addition, confusion or lack of clarity over whether a particular sensation is pain or not is described. Social experiences and mood state may affect pain perception.

Hypo-reactivity

This category refers to descriptions of under-reactivity to pain. Attentional awareness is described as one factor in under-reactivity to pain. It may be necessary to 'see' damage or injury in order to become aware of painful sensation. Distraction by other events or thoughts may block awareness of pain, or individuals may actively screen out pain from attentional awareness. Labelling or recognition of sensation as pain may also be impaired.

Hyper-reactivity to pain

This category relates to descriptions of over-reactivity to pain. Hyper-reactivity is described in relation to specific forms of pain experience (e.g. pain associated with needles or pain associated with particular areas of the body such as the mouth). Poor memory is identified as one factor which contributes to a difficulty in correctly labelling pain and illness and as a consequence minor symptoms may be perceived as overwhelming or frightening.

Hypo-reactivity to temperature, hunger and thirst

This category relates to descriptions of under-detection of temperature, hunger and thirst. These are described by one participant. This hypo-reactivity is described as a significant source of risk to health and safety. Perception of temperature improves with age but difficulties with recognition of hunger and thirst remain. However, the individual uses more effective strategies to manage eating and drinking in order to minimise the impact of this difficulty. This hypo-reactivity is attributed to a failure to recognise and correctly label internal body sensation.

Muscle Tension

This refers to descriptions of chronic high levels of muscle tension and is described by one participant only. In addition to feeling anxious and a difficulty in relaxing, this tension is described as having led to recurring headaches and sinus problems. It is also described as contributing to an odd gait and posture which compounded his social

difficulties. This problem has been overcome to a considerable degree through use of Alexander technique and massage.

Manneristic and Repetitive Motor Behaviour

This category relates to descriptions of repetitive or ritualistic behaviours involving body movement or activity with or without objects. These include arm and hand flapping or jerking, running to and fro, self-spinning, facial tics, teeth grinding, and fidgeting or fiddling with or without objects. These are described as occurring spontaneously and naturally, often without conscious awareness and may, for some, be more likely if nervous, anxious, agitated or excited. The concurrent affective experience described while engaged in these behaviours varied from individual to individual, ranging from a neutral experience to a pleasing or positive experience including a calming effect. One participant indicates purposeful engagement in repetitive motor movements as a way of calming himself. Conversely, active inhibition of these behaviours could be difficult and in itself cause agitation. A number of participants describe a growing awareness of the negative social impact and consequences of manneristic behaviours. A desire to fit in and not come across as weird may lead to active suppression and control of these behaviours. With age and effortful practice this suppression may become more automatic, although for some it may continue to be difficult.

Across - modality codes

Individual variability

This category represents variability between individual participants in a number of dimensions of their sensory-perceptual experience. It includes: variability in modality preferences and strengths; in the range of phenomena identified; in the extent to which individual participants perceived these experiences to be significant or problematic in their lives, and in the extent to which participants perceived their sensory-perceptual experiences as setting them apart or as representing 'difference' from others. Aspects of this variability are represented throughout the individual codes described in Appendix 9.

Vagaries of attention

This category relates to perceived degree of control over attention and sensory-perceptual experience. An underlying theme throughout participant accounts is that of a diminution of full or automatic control over the focus of attention and sensory-perceptual experience: a sense of being at the mercy of the vagaries of their sensory-perceptual system. This is evident across the modalities.

As a result there is a strong theme of effortfulness in managing and coping with these experiences to achieve a more reliable system. This is described at a number of

levels including trying to manage the system in a moment by moment sense, effortfulness in developing strategies to compensate for lack of reliability in sensory perception, and effortfulness in inhibiting and overcoming negative social consequences.

Emotion

This category relates to the perceived impact of emotional factors on sensory-perceptual experience. Emotion was strongly identified by one participant as a source of variability in his sensory-perceptual experience and as contributing to a sense of unreliability in the working of basic sensory perceptual processes. Anxiety and worry were identified as playing a role in how sensory events are perceived, in vulnerability to distraction and in the extent to which background sound interferes with concentration to tasks. This can lead to a spiral of negative effects where anticipation of these effects leads to further anxiety which in turn impacts negatively on sensory-perceptual experience. In other situations where emotional state is more relaxed, information processing and the ability to process information across modalities is described as more efficient. Emotion was also identified by a number of participants as a factor in the perception of specific sounds as pleasant or unpleasant through a process of association. Sounds associated with situations, contexts or memories where participants experienced positive emotions were perceived as pleasurable or pleasant. On the other hand sounds associated with situations or events or memories which provoked negative emotions such as anger, annoyance or sadness were perceived as unpleasant or aversive.

Developmental processes and change

This category relates to participant accounts of the developmental course of sensory-perceptual experiences. A process of change in sensory-perceptual experience is reflected in all participant accounts. The specific developmental course of different aspects of sensory-perceptual experience and the factors which are identified as influencing vary from participant to participant. Overall a general theme in participant accounts is that of some degree of attenuation (but not always) in problematic experiences and in sensory fascinations with age. A number of factors are identified as contributing to this change including reduced hyperacuity, improved memory, increasing skill in semantic processing and the labelling and recognition of events. Increasing social awareness is described as leading to more appropriate management of sensory-perceptual experience.

Specific perceptual aptitudes and deficits

This category refers to particular perceptual skill 'aptitudes' or 'deficits' which are identified by participants. A number of participants make references to their visual perceptual skills in judging distance and/or size or depth/height. Two participants

describe difficulties in judging size and distance. One participant identifies a problem in that he tends to see in 2-D. In contrast other participants describe themselves as having a particular aptitude for these skills. In contrast to his poor visual skills, one participant identifies auditory memory and recognition skills as an area of strength.

Results Section 2

The Analytic Account

In my analysis the core analytic concept around which I have made sense of participants' accounts of their sensory-perceptual experience is that of a 'Disordered Attentional System'. This concept is rooted in participants' own descriptions of attentional problems. In describing their experiences participants made use of terms such as concentration, attention and focus and these terms were invoked as explanatory concepts in understandings of specific sensory-perceptual phenomena. However, I developed the concept to reflect my analytic understanding of an inefficient or disordered attentional mechanism which I suggest underlies the sensory experiences described by participants.

This core concept might be encapsulated by the following statement:
The central theme permeating participants' accounts of their sensory experiences is that of a disordered attentional system. The attentional system is disordered in several key aspects:

(1) an impaired and poorly refined attention beam which without effortful management oscillates erratically between a state of over-narrow and a state of over-wide focus;
(2) a bias to repetition and sameness in the attentional system. This predisposes towards the maintenance of attention to whatever is within current focus resulting in a lack of flexibility in switching attention. This bias also privileges specific stimulus characteristics;
(3) an a-social attentional orientation to the physical and sensory world. This is a physical, sensory-based experience associated with a non-reflective, 'in the moment' experience and a concrete, physical world view;
(4) perceptual hypersensitivity which leads to exceptional capacity to detect or excessive reactivity to particular types of sensory events in one or more modalities.

The extent or degree of impairment in the working of the attentional system and in each of its constituent aspects is conceptualised as falling along a continuum of disorder with each individual participant affected to differing degrees. Specific perceptual skill aptitudes and deficits also contribute towards variability in individual experience. The working of the system is subject to a number of influences. Emotional state is identified as a key factor impacting on the working of the system. Developmental factors such as age, memory and learning are also highlighted: with increasing age, maturation and learning the system becomes more reliable. Because of the disordered

nature of the attentional system participants may perceive to differing degrees a lack of control and mastery over basic perceptual processes.

Disordered Attentional Beam

This category refers to the researcher's analytic concept of a poorly refined attentional beam which is felt to underlie participants' descriptions of a number of sensory-perceptual phenomena. This beam can be conceptualised as a spotlight, the intensity and breadth of which will determine what sensations and sensory events enter one's awareness or attentional focus. The absence of smooth, automatic narrowing and widening of this beam is considered a barrier to efficient processing, meaning making, and responding to significant events within the sensory environment. This may include 'internal', body related sensation as well as external events.

The researcher's analytic understanding of participants' accounts suggest that automatic working of this beam is poorly refined, and that without effortful and deliberate management on their part, the beam oscillates inefficiently along a continuum between two extreme states: a state of too wide and diffuse a focus and a state of over-narrow focus. This conceptualisation of a continuum derived initially from the concept of a state of over-narrow attentional focus. This was based on participants' understanding of phenomena related to lack of responsivity to events around them, phenomena such as 'failure to hear sound' which were attributed to intense concentration or focus in an activity. These descriptions resonated with the concept of 'over-selective attending' which has been investigated within the research literature in autism and which may be conceptualised as arising from an over-narrowly focused attention beam.

However, several other phenomena described by participants, such as distractibility and sensory distortion, contradicted this idea of over-selective attending and seemed to suggest an opposing concept, that of difficulty in selectively attending, conceptualised as an overly-wide attention beam. Thus, the concept of a dynamic but inefficient attentional beam which oscillates between these states was developed. Furthermore, within this framework, the recurring theme in participant accounts of effortfullness in making sense of or in disengaging from particular events within the sensory environment was felt to reflect a problem in the automatic working and adjustment of this attentional beam.

The degree of impairment in the efficient working of this attentional beam and the extent to which individuals operate at extreme ends of the continuum is posited as one source of variation and individual difference in sensory-perceptual experience.

'Too wide beam'

As described, in the 'too wide' state the attention beam is conceptualised as being too wide and diffuse resulting in difficulty in efficiently processing sensory information within the environment. An alternative conceptualisation is that of an impairment in the ability to selectively attend to particular events by filtering out extraneous and peripheral sensation in order to effectively process or make meaning of these events.

A number of the sensory-perceptual phenomena described by participants are considered to reflect this overly wide attentional beam and an attendant difficulty in automatic, efficient narrowing of focus to enable effective selective attending to specific events. Distortion and confusion of sound and vision, difficulties described in the automatic processing of incoming information from the environment, susceptibility to distraction by the visual and auditory environment, sensory overload and the inability to screen out background sensory stimulation are conceptualised as reflecting this overly wide attentional beam. This diffusely focused beam is linked in participant accounts to situations in which they are not actively concentrating suggesting a failure in the 'automatic' focusing of the attentional beam.

This 'openness' to the wider sensory environment is conceptualised as one mechanism through which environmental factors contribute towards variation in individual's problematic sensory-perceptual experience. Noisy, sensorially 'busy' situations or environments containing highly distracting or idiosyncratically salient features contribute towards greater confusion and greater difficulty in achieving or maintaining selective attending to specific events which in turn leads to a range of practical difficulties and problems.

Over-narrow beam

In the narrow or over-focused state the attentional beam is conceptualised as narrowly and intensely focused on one activity or event with little or no monitoring of the peripheral sensory environment outside of the particular event being focused on. This is a state of intense absorption resulting in no or inefficient awareness of events outside of the immediate attentional focus. This can include internal as well as external sensation. Consequently responsiveness to and distractibility by the wider environment is greatly diminished.

Sensory phenomena described by participants which are conceptualised as reflecting this over-narrow attentional focus include intense absorption in an activity, dynamic pattern, or thought; failure to hear, or delay in registering sound and lack of startle response to sound. This over-narrow focus is also seen as contributing to hypo-reactivity to pain, temperature and smell.

Participant accounts suggest that this overly-narrow focus arises involuntarily in childhood as a result of active engagement in an event, activity or thought. However,

particular types of sensory event may also 'entrap' attentional awareness leading to this narrowed focus: repetitive, predictable sounds; dynamic visual pattern or repetitive multi-sensory experiences.

Participants describe an altered state of awareness or consciousness akin to intense daydreaming which is described as hypnotic, relaxing or pleasant. In this state, sensory events or other intrusions which get through into attentional awareness from outside of this narrowed beam may for some participants be perceived as sudden and jarring such as the experience of certain sounds (e.g. sudden or unexpected loud sounds) as 'too loud' or an aversive experience of being interrupted or disturbed. For others it may be experienced as a shift or change in state of awareness or 'consciousness'. Difficulty or delay in widening of this narrow focus to become fully aware of 'outside' sensory information and events is conceptualised as underlying participant descriptions of 'waking up', coming back to the 'real world' and delay in 'registering' sensory information.

Effortful 'Interpretative 'Attending

Narrowing or widening of the attentional beam for the purposes of efficient processing, meaning making and response to sensory events is conceptualised as effortful and problematic. A number of participants explicitly and repeatedly refer to the need for active listening or deliberate and effortful concentration in order to make sense of and efficiently respond to the sensory environment referring to the 'strain' or 'effort' involved in seeing or listening to events around them.

This concept is considered implicit in participant accounts of the effortfulness of selectively attending to a particular event within the wider cacophony of sensory events in order to interpret or make sense of it. This includes efforts to screen out background sound or manage their susceptibility to distraction by events within the wider sensory environment. A number of participants particularly highlight difficulties in following others' speech.

This concept of effortful interpretative attending is also felt to be reflected in the description by a number of participants of deliberate efforts to disengage from particular stimuli, in the effortfulness of processing stimuli at a sensory and semantic level simultaneously and in combining the different elements of a task required for it's successful completion.

This process of interpretative attending is considered a skill which becomes less problematic and more automatic and efficient with age and learning. Nevertheless, the ability to selectively attend remains vulnerable to inefficiency and distraction. A number of factors are identified by participants as contributing to this inefficiency including the intensity and/or 'busyness' of the sensory environment, sustaining attention or

concentration over time, the cognitive demands of the task and distraction by stimuli which have particular appeal or salience to the individual.

In addition emotional state is also considered to impact on the efficiency of the automatic working of the attentional lens. While this factor was explicitly highlighted by only one participant, emotional state is conceptualised as potentially contributing to variability in the efficiency of selective attending for other participants also. In a relaxed state automatic narrowing and widening of the attentional beam is more efficient and less effortful. Emotions such as anxiety and fear lead to a less reliable system with increased difficulty in efficient selective attending. This is understood analytically as underpinning descriptions of increased sensory blurring and distortion, sensory overload, increased difficulty in screening out background events and an increased susceptibility to distraction when anxious or worried.

As a result under certain conditions it may be necessary or desirable to deliberately move towards a state of over-narrow focus thus 'switching off' distracting background sensory events. This is described by participants as a strategy to minimise distraction from the sensory environment, to enhance selective attending to one event or activity, or as a way of coping with aversive sensory experiences or unwanted intrusions. This is achieved through a variety of strategies including deliberately focusing on one sound or activity (e.g. repetitive humming, spinning a top), physically blocking out sound (e.g. fingers in ears) or cognitive strategies to 'switch off' background sensory events. A number of participants suggest a degree of current volitional control over the attention beam which allows them to very effectively and deliberately screen out particular sensations such as pain from attentional awareness.

Perseverative bias

This category draws together a broad range of experiences and behaviours which have in common an intrinsic predisposition to repetition and sameness. The concept refers to a bias within the attentional system towards the maintenance of attention to whatever is currently within the attentional focus (perseverative bias), and an attentional orientation to and preference for repetition and sameness (orientation to sameness). This is conceptualised as leading to lack of flexibility, difficulty or delay in switching attention from one attentional focus to another. This bias is manifested at a number of levels: at a sensory or physical stimulus level, at a cognitive level in relation to thoughts and at a behavioural level.

At a sensory level a perseverative bias is reflected in participants' descriptions of internally echoing or reverberating sounds and visual stimuli where (real or imagined) stimuli are experienced as repeating before gradually dying away. This reverberation is portrayed as contributing towards the unpleasant impact of certain types of aversive auditory and visual events through their being experienced as 'multiple exposures'. In

addition these 'mental repercussions' are considered to disrupt efficient sensory-perceptual processing by interfering with attentional awareness to the ongoing flow of 'new' events within the auditory and visual environments, described for example as 'drowning out' other sounds.

In addition an attentional orientation to predictability and sameness is conceptualised as underlying attentional preferences within the sensory environment. This is reflected in participant descriptions of heightened perceptual attunement to repetitive, predictable pattern and symmetry within the visual field and a preference for or fascination with repetitive auditory, visual or multi-sensory events. This orientation is associated with a sense of congruence or pleasure in stimuli with these characteristics and a sense of dissonance, irritation or in extreme cases fear where these characteristics are broken. Alongside this heightened attunement or attentional preference, participants describe an increased difficulty in disengaging from events characterised by these qualities.

At a cognitive level this bias is felt to underpin participant descriptions of 'thoughts sticking' or a difficulty in 'letting go' of thoughts. This is conceptualized as exacerbating the impact of distracting events, thoughts or minor irritations, which are then not easily dismissed, and of amplifying the impact of aversive or unpleasant thoughts or events because of the tendency for these thoughts to 'stick' and a difficulty in switching attention to a non-aversive focus.

This orientation is expressed behaviourally through stereotypic behaviour and repetitive play behaviour. Participants' descriptions suggest an in-built proclivity to, and 'automaticity' in, stereotypic behaviour which may occur without conscious awareness. Participant descriptions again suggest a degree of emotional congruence in this behaviour which is variously described as 'needing to do it', calming or as pleasurable at some level. Correspondingly participants describe a sense of difficulty or dissonance in its suppression. With growing social awareness, effortful inhibition of these behaviours may be required in order to 'fit in' although over time suppression of these behaviours may become more automatic.

Emotional state may exacerbate the impact of this perseverative bias at a number of levels. An increase in anxious rumination accentuated by the tendency to perseverate is described explicitly by one participant as interfering with efficient listening and conversational interchange. Emotional states of excitement or anxiety are described as leading to increased levels of stereotypic behaviours. In turn these behaviours may lead reciprocally to a gradual calming or lessening of these emotional states. The effect of anxiety or excitement in increasing repetitive behaviour may largely occur involuntarily but again with insight into the calming or pleasurable effect of these repetitive behaviours may, as described by one participant, be deliberately used as an active coping strategy to calm emotional state.

This attentional characteristic exists within the context of a more general orientation to sameness, a preference for the familiar and a dislike of change which pervades may aspects of participants' lives including activity patterns, living arrangements and environment. This broader orientation impacts in more general ways across the sensory modalities with participants describing a strong preference for the familiar, and a reluctance to explore, or anxiety around, change in areas such as taste and diet, clothing preferences and so on. Indeed difficulty in tolerating and adapting to change is described in a number of instances as underlying behaviours which may on the surface appear as examples of sensory or tactile defensiveness (e.g. reluctance to have nails cut because fingertips feel 'different' afterwards).

There is evidence from participants' accounts of a decreased propensity to sameness and an increasing tolerance of change and the unfamiliar as they get older. With age and insight into the impact of this orientation to sameness on his life, one participant describes efforts to counteract this predilection by an active strategy of seeking out 'variety' in his life which includes some level of monitoring and deliberate disengagement from repetitive, predictable sensory events. A number of participants also indicate greater ability to ignore or dismiss unpleasant sensory events from attentional awareness (thus ameliorating their impact) indicating more volitional control over the attentional system.

Sensory-based world

This category refers to a sensory-based attentional orientation which predisposes towards a non-reflective, fragmented 'in the moment' experience and a concrete, physical worldview. This is an experience and view of the world in which awareness is rooted in the physical and sensory with little reference to a peopled, social world of shared meaning and reflection. This a-social orientation is explicitly highlighted by a number of participants in recalling a childhood awareness which primarily centered on aspects of the sensory-perceptual environment. Participant descriptions of intense interest, curiosity and excitement in the details of the physical environment, which dominated their awareness, and a co-existing lack of interest in or awareness of people reflect this orientation. Fascinations with and pleasure in sensory events such as repetitive sounds, tactile sensations, patterns within the visual field or the sensory feedback arising from repetitive or stereotypic behaviour are examples of phenomena also considered to reflect this immersion in a sensory world.

Sensory events such as these are afforded affective salience, and the sensory world is described as a significant source of emotional experience. Strong emotional responses such as a sense of loss or anger are described in response to interruptions of or intrusions into these pleasant sensory experiences and further reflect this strong sensory orientation.

This attentional orientation to the physical world is associated with 'in the moment' awareness, a consciousness which resides in the sensory present and in which there is an absence of a search for meaning, perspective, explanation and connection other than at a basic associational level. 'In the moment' awareness is explicitly described by one participant but is considered implicit in the accounts of others'. This grounding of awareness in the present is conceptualised as amplifying both positive and negative experiences of sensory events, since at that moment the present is all there is 'the only thing in existence'. It is also felt to contribute to a naive sense of wonder about the world and to largely associational understandings (and misunderstandings) of connections between events.

These associational connections may in turn impact on the emotional resonance of particular sensory events or situations: sensory events such as sounds or smell associated with positive emotional experiences themselves become perceived as pleasant, and those associated with unpleasant events come to be experienced as unpleasant or aversive. Similarly, the occurrence of a pleasant or unpleasant sensory event may lead to a corresponding evaluation of its associated context. Objects or activities associated with past positive affective experiences such as safety or comfort may be sought out as a way of recreating this experience in anxiety provoking situations.

'In the moment' awareness is characterised by an absence of reflection on experience and the absence of a shared social context in which to attribute meaning or embedded experience. This is reflected in participant accounts which describe reactions based on a separation of the physical or sensory aspects of an event or activity from their wider social and emotional context, and a disconnection between the processing of events at a sensory and semantic level. This is in turn is considered to give rise to an over-physical, literal framework for interpretation of experience which might be described as a 'physical world view'. Behaviours which are considered to reflect this framework include interpretation of and response to thoughts as 'real' sounds, the literal interpretation of distant visual objects as 'small' and participant descriptions of a reliance on physical, concrete as opposed to social strategies for dealing with unwanted events or demands.

Running alongside this orientation to the physical sensory world is a lack of attunement to and trust in the social world. A number of phenomena described by participants are conceptualised as clearly reflecting the underlying social impairment in autism: a problem in understanding people and particularly the social affective world of emotion. Participant descriptions of problems with affectionate physical contact and other aspects of social touch highlight some of the challenges experienced by participants in negotiating this social world, perhaps most vividly expressed in one participant's recollection of a childhood lack of awareness of the 'personhood' of others'.

Participants' lack of intuitive understanding and comfort with the affective social world is conceptualised as underpinning difficulties described in relation to affectionate touch. Difficulties in understanding others' emotions and participants' own emotional reactions are described as leading to feelings of loss of control or being overwhelmed and thus to an aversive experience of affectionate physical contact such as being held, hugged or stroked. In addition as a result of a lack of understanding, ease with or pleasure in the affective meaning of these interactions, physical or sensory aspects of the experience may have greater salience for the individual and these in themselves may be experienced as unpleasant e.g. heightened salience of body odour or perfume. Lack of attunement to and reading of others' emotional signals may also lead to events being experienced as aversive, such as sudden or unexpected such as raised or sharp voice.

A number of participants suggest an orientation to the physical world because it is less problematic than the social world. For example difficulties with eye contact are described as leading to visual gaze being directed at the physical environment and one participant describes a preference for interacting with objects because 'getting it right' with people is difficult. Although not explicitly linked in participant accounts it is possible that because social routes to feelings of comfort, security or being held are reduced, participants may seek out these experiences through non-social sensory means, for example seeking out alternative sources of deep pressure touch and giving rise to an 'over-reliance' on these sources of stimulation.

As they get older a developing realisation that this lack of sociability is different from others' orientation to the world is described by a number of participants and this realisation is in itself considered to reflect a move away from the immediacy of a sensory based world to a more reflective, meaning based experience with greater awareness of the self in relation to others. This developmental change away from a purely sensory to a more cognitive and social understanding of the world is also understood as contributing to better ability to make sense of and predict events which in turn is described as playing a significant role in ameliorating problematic reactions, especially to sound, because these sensory events are recognised to a much greater extent and much less unexpected. This has in addition a corresponding impact on pleasure in and fascination with sensory events which attenuates with age.

Greater social awareness and increased motivation to 'fit in' is described as underpinning efforts to experience, manage and respond to sensory events in more positive and socially acceptable ways. Social identification with valued peer models and efforts to avoid social embarrassment are described as leading to willingness to try out and tolerate a greater range of food taste and textures. Inhibition of behaviour associated with sensory fascinations and suppression of manneristic or stereotypic behaviour is linked with increasing awareness of the social rules governing behaviour. In turn participants report increased automatisation in the inhibition and suppression of

socially inappropriate behaviour and responses to sensory events. However, while managing his reactions in more socially acceptable ways, one participant report highlights a danger in assuming that an absence of obvious behavioural reaction is indicative of a problem-free sensory-perceptual experience. For this participant, the emotional salience of sensory events and treasured objects also continues and is described as triggering on occasion major outbursts which may come as a shock to those around him. In addition continuing deficits in social attunement may lead participants to fail to recognise certain experiences as 'common' experiences.

With age, social behaviours are also described as becoming less problematic and more automatic with one participant indicating that 'shaking hands' has become 'more natural'. Increased social empathy and the needs of others (family members) for affectionate contact is described by one participant alongside some developing tolerance of people touch.

Hypersensitivity

The concept of 'hypersensitivity' refers to 'exceptional' or 'hyper-acute' sensory perception in one or more modalities which may be general within that modality or which may be limited to hyperacuity for particular sensory events. Hyper-acuity is reflected in participant accounts in two ways: what might be understood as an 'amplified volume' experience and secondly the experience of perceiving events outside of the normal perceptual range. Amplified volume is thought to underlie descriptions of hearing at greater distance or at lower volume than others, of a general intolerance of loud sound because it seems 'too loud', 'subliminal' hearing, and the over-intense experience of brightness in the visual environment. The second is reported by one participant who describes a capacity to hear sound outside of the normal frequency range as contributing to an aversive experience of shrill, high-pitched sound. This hypersensitivity can exist alongside under-reactivity to the sensory environment which was described earlier as a consequence of an overly narrow attentional focus. A narrower hyperacuity is reflected in participant descriptions of acute hearing for very specific sensory events such as idiosyncratically salient sounds, specific tactile sensations and the experience of specific types of smell as too strong or overpowering. Hypersensitivity to these events can occur alongside hypo-reactivity to other events within that particular modality.

Decreasing hypersensitivity with age is reflected in participant descriptions of a degree of reduction in 'exceptional' sensory -perceptual abilities such as acute hearing as they get older. This in turn is contributes to a lessening of unpleasant and aversive experiences which result from these hypersensitivities.

The extent to which this hypersensitivity reflects 'organic' sensory -perceptual capacity which is outside of the normal or typical range or reflects a well honed skill in

the detection of a greater range (intensity, volume) of sensory events in an attentional system that is embedded in the physical remains unclear. Participant accounts of an 'amplified volume' experience might be considered suggestive of an 'organic' hypersensitivity. However, hyperacuity for idiosyncratically salient events such as sounds, but under-reactivity to others, and decreasing hypersensitivity with age as immersion in or orientation to a sensory world lessens offers some tentative evidence for the latter hypothesis.

Disordered Attention: Individual Variability, Impact, Change

An attentional system which is characterised by the four key elements set out above is proposed as a model for understanding the sensory-perceptual experiences described by participants including the recurring theme of an 'unreliable' sensory-perceptual system. Each of the four key elements put forward to account for the central phenomena described by participants is conceptualised as existing along a dimensional continuum. Variation in sensory-perceptual experience between participants is understood in terms of unique dimensional combinations of each of these elements and in particular the interaction of these elements.

In addition, participant accounts suggest that specific perceptual aptitudes, deficits and/or modality preferences unique to the individual contribute towards variability in sensory-perceptual experience. These include particular aptitude or deficits in visualisation skills, visuo-spatial skills such as embedded figures, auditory memory and recognition, depth or size perception, face recognition and visuo-motor co-ordination. Two participants, for example, described themselves as having excellent visuo-spatial skills while another participant identified himself as having deficits in this area, including problems with depth perception and face recognition. Participants' accounts also reflected variability in the extent to which aspects of sensory-perceptual experience were viewed as different from the experiences of others and as contributing towards an overall sense of 'difference' from others.

A number of participant accounts reflect a perceived lack of reliable control and mastery over basic perceptual processes. This sense of a sensory-perceptual system over which they do not have full control may be evaluated by participants as problematic, neutral or, in specific situations (e.g. exceptional hearing), to be a source of 'positive' skills or experiences. However, a gradual attenuation over the course of development in both sensory fascinations and problematic experiences is a strong theme running throughout participant accounts and the attentional system is perceived as increasingly reliable and automatic although difficulties may remain in some areas. As well as the developmental factors previously highlighted, a number of other processes are described as contributing to this outcome.

The role of memory is identified as impacting on sensory-perceptual experience. An ability to remember the order and sequence of events (reported to have developed late

in middle childhood) is identified by one participant as contributing to greater reflection and meaning-making thus lessening immersion in a purely sensory world. Gradual improvement in the ability to remember previous experiences of internal body states associated with minor illnesses is identified by another participant as reducing anxiety about these bodily symptoms.

A process of familiarisation and repeated exposure to problematic sounds, tastes and textures is also described as contributing to a lessening of problematic reactions to specific sensory stimuli.

A number of participants suggest that learning better compensatory coping strategies has contributed to better management of sensory-perceptual difficulties. This is reflected, for example, in establishing routines around eating and drinking to compensate for lack of reliable awareness of or recognition of these internal sensations or, in the case of chronic muscle tension, becoming aware of and learning techniques to reduce this.

This conceptual model for understanding the sensory-perceptual experiences of participants in this study is represented in Figure 5 below. Figures1-4 that precede this, show how the categories described earlier in Section 1 relate to the four key higher-order categories (Disordered Attention Beam; Perseverative Bias; Sensory-Based World; Hypersensitivity) that underly the core concept of 'Disordered Attention System'.

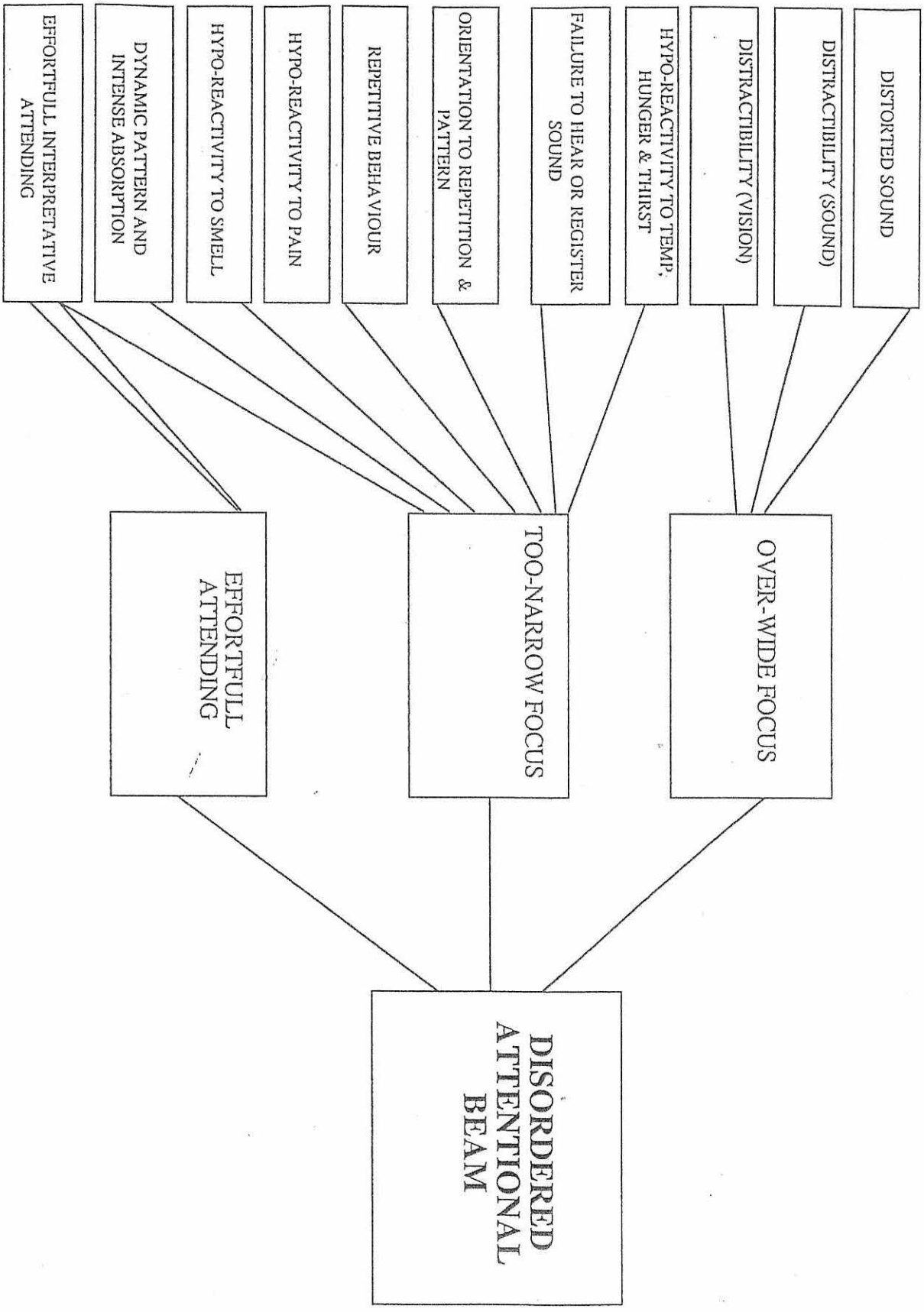

Figure 1 Summary of Category Development: Disordered Attention Beam

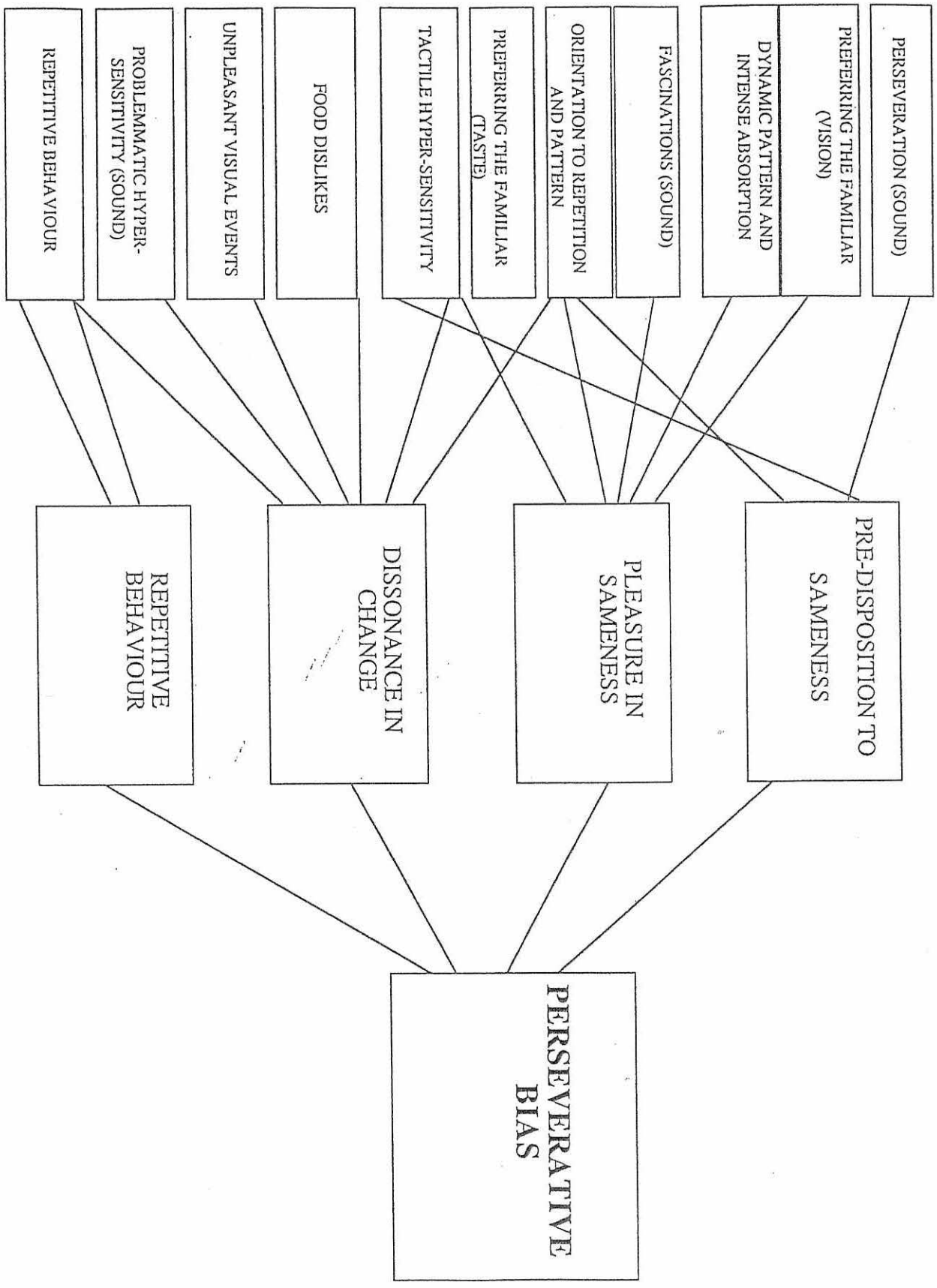

Figure 2 Summary of Category Development: Perseverative Bias

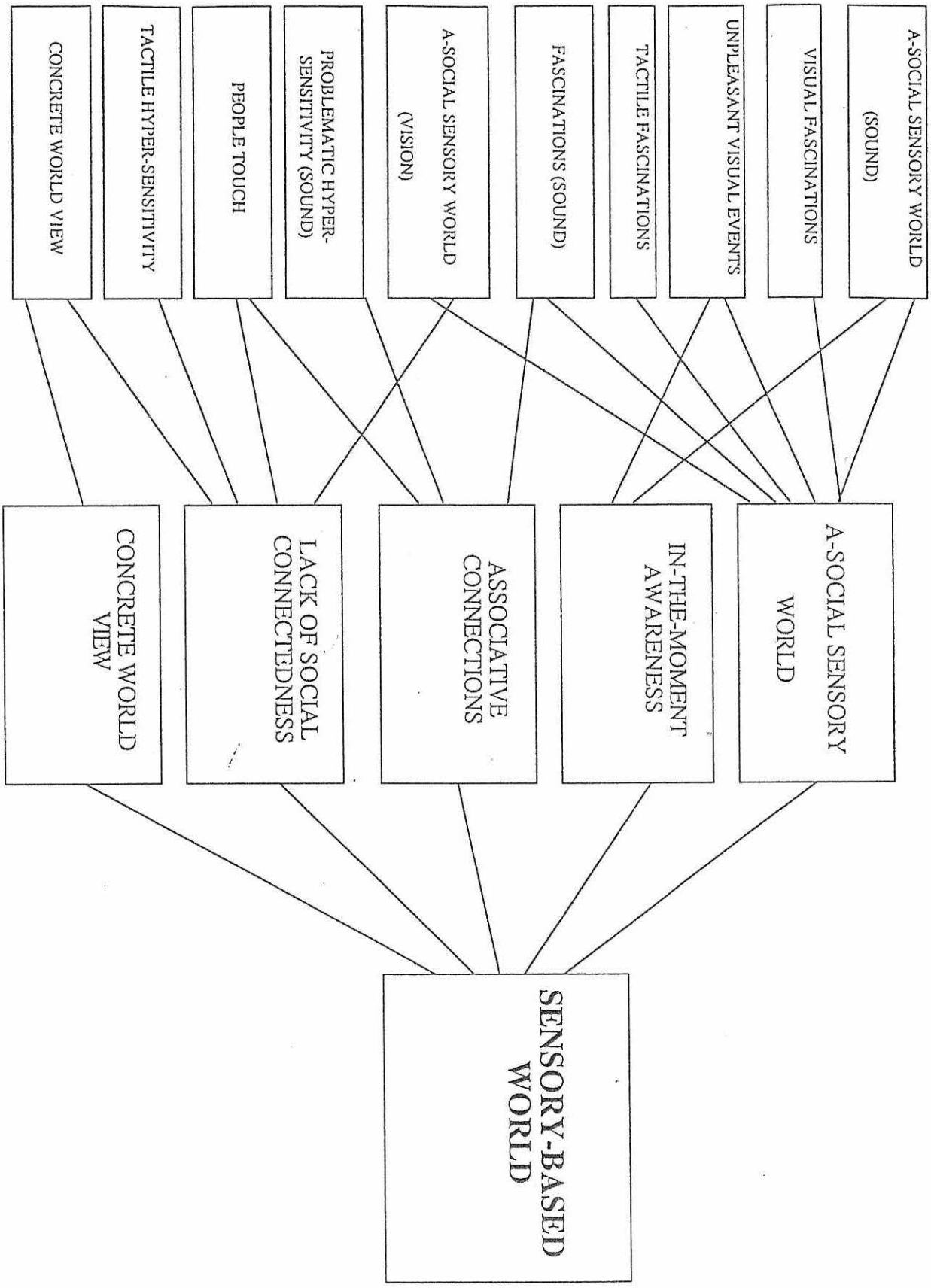

Figure 3 Summary of Category Development: Sensory-Based World

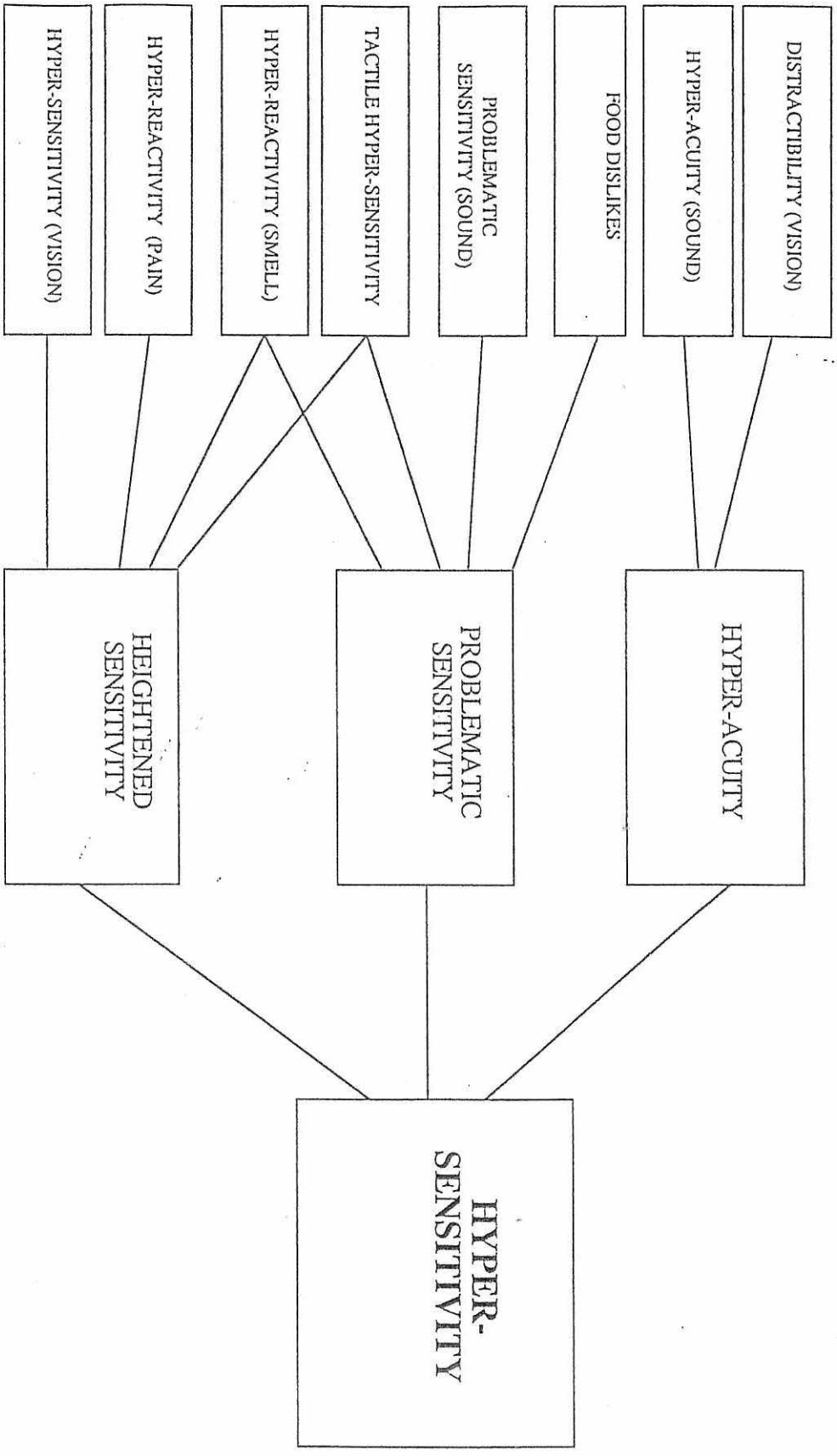

Figure 4 Summary of Category Development: Hypersensitivity

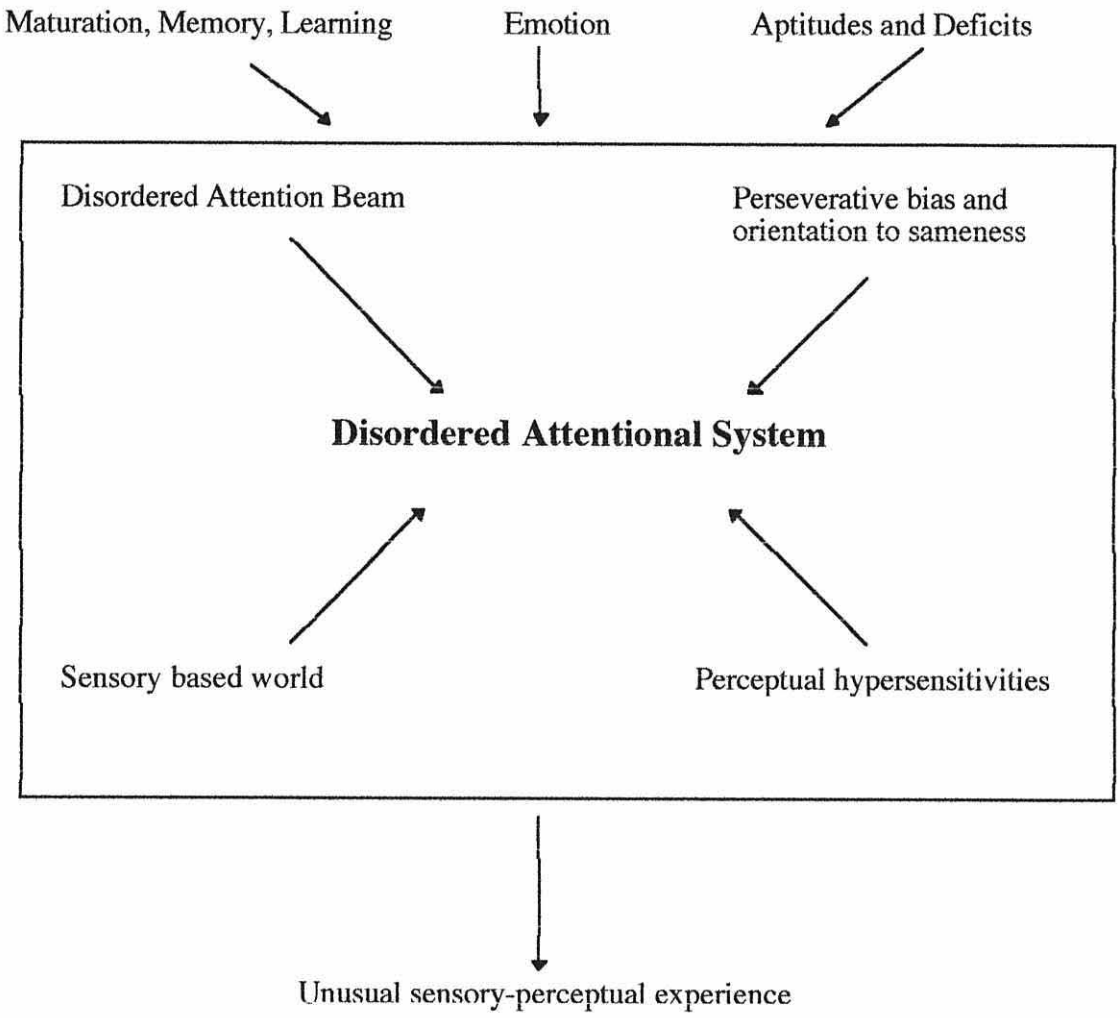

Figure 5: Conceptual Model of Unusual Sensory-Perceptual Experience

Discussion

The outcome of this study shows that interviewing people with High-Functioning Autism and Asperger's Syndrome is a useful and productive way of investigating sensory-perceptual phenomena in this population. Using a semi-structured interview format, participants drawn from a clinical sample were able to recall and describe past and current sensory -perceptual experience. While the study did find considerable variation between the individuals interviewed, most of those interviewed were able to articulate their experiences in sufficient detail to allow an in-depth analysis of sensory-perceptual experience. One participant was limited to reporting only in very general terms (such as liking/disliking sensory events) without a degree of detailed elaboration. Participants were able to reflect on and articulate the relationship between sensory-perceptual experiences and other factors such as context, age, behaviour and psychological states. Contrary to the findings of Hurlburt, Happé and Frith (1994) some participants were able to reflect on their affective states. Quite apart from the theoretical importance of their accounts, this finding that individuals with High-Functioning Autism can provide detailed and insightful accounts of their childhood and current experiences is in itself a significant finding within the clinical research literature.

One of the researcher's concerns prior to carrying out the study had been the dilemma of 'leading questions' and possible interviewee acquiescence. However, there was considerable evidence in the interview transcripts of participants' ability to respond in the negative to specific questions about their sensory-perceptual experience that offered reassurance on this issue.

Moving to the accounts themselves, the study provides convincing evidence that sensory-perceptual experiences of the sort described in published autobiographical and other first hand accounts are also experienced by less 'exceptional' individuals drawn from a clinical sample. All participants describe some form of 'unusual' sensory-perceptual experience.

Sensory problems are reported across all modalities. Aversive or problematic experiences ranged from problems in one or two modalities to problems across all modalities including proprioception and recognition of body states such as hunger and thirst. These experiences are described by participants in this study as impacting on behaviour, psychological state and social functioning. Behavioural responses to aversive events included distressed reactions such as putting hands over ears (to aversive sound), crying, escaping from the situation, and engaging in self-stimulatory behaviour. Both immediate and secondary psychological consequences were described. In some cases the consequences were confined to the immediate context and these included fear, irritation, anger and distress. In other cases, secondary consequences included anticipatory anxiety and avoidance of the feared situation. Both direct and indirect

negative social consequences were also described. Behavioural responses might be judged by others as 'weird' or avoidance of the aversive experience may lead to reduced social opportunities for interaction with peers.

Sensory-perceptual experiences were also reported as a source of fascination and pleasure. These 'pleasant' experiences were described in all modalities. Sensory events were described as sources of intense curiosity, interest, enjoyment and comfort. These could be helpful in dealing with a world that can appear difficult and confusing. However these fascinations could also have negative consequences. They could be a source of distraction, or alternatively, interruption or intrusion can provoke irritation or anger.

The study therefore, provides strong support for the view that abnormal or unusual sensory reactions are significant aspects of the experience of individuals with autism and important influences on behaviour and psychological state. In addition, the study indicates that the 'efficiency' of sensory-perceptual functioning is variable and dynamic, subject to the influence of a range of factors such as emotional state, activity and task demands and the 'busyness' of the sensory environment. This has implications for laboratory based experimental investigations of these phenomena. The study also suggests that developmental processes are important in understanding sensory-perceptual experiences: age, learning and memory impact on sensory - perceptual experience so that the nature of these experiences change over time. Thus, control for developmental age will be critical in future investigation of these phenomena.

The findings of the study also suggest that individuals with autism actively and effortfully manage their sensory-perceptual difficulties, employing a number of coping and compensatory strategies. The study suggests that they are not 'passive' victims of sensory-perceptual dysfunction. Some of the strategies employed include behaviours which others may perceive as challenging such as escape behaviour or repetitive motor movements. Without an understanding of the possible nature and impact of sensory-perceptual experiences in individuals with autism it is likely that the functional significance of these behaviours may be overlooked. As they become older and more socially aware, individuals may make efforts to suppress earlier but socially inappropriate coping behaviour, and this may include effortfully tolerating difficult and stressful sensory situations of which others may be unaware. This highlights the need for a respectful and discerning stance in interpreting the behaviour of individuals with autism.

The study also identifies individual variability in the type and range of phenomena experienced: one individual for example reported problematic reactions across all modalities while another reported problems in one modality only. The analysis also highlights variability in the degree to which individuals considered their sensory-perceptual experiences unusual and in the significance attributed to these

experiences in their lives. These findings provide evidence then to indicate that individual variability of experience is one characteristic of sensory-perceptual functioning in individuals with autism and this mirrors the general overview of published first-hand accounts presented in Study 1. This cautions against simplistic over-generalisations about 'autistic' sensory-perceptual experience or premature interpretations of individual autobiographical accounts as somehow 'representative' of others unable to articulate their experience. In particular, the commonly held assumption in clinical intervention services that visual information processing is necessarily a cognitive strength is challenged by the account of one participant who identified the auditory modality as his 'preferred' information channel. This participant identified strengths in auditory skills such as auditory memory, recall and recognition and a corresponding lack of interest in information processing through the visual modality.

Limitations

A number of limitations in the study must be acknowledged. The analysis is based on the accounts of a small sample of six individuals with autism. All those interviewed were male which reflects the predominance of males over females to be found in a clinical population at this more able end of the autistic spectrum. However this necessarily begs the question of possible gender differences and of what might be missing from this analysis due to the absence of females in the sample. The analysis is based on one-off (albeit comprehensive) interview so that there was no opportunity during data analysis to return to participants to follow up specific aspects of interest or to elicit feedback on the developing analytic representation and understanding of the accounts which they had provided.

Review of analysis

The central construct around which an understanding of participants' sensory-perceptual experiences is based is that of a disordered attentional system. This is characterised by four core elements:

(1) an impaired attention beam which without effortful management oscillates between a state of over-narrow and a state of over-wide focus;

(2) a perseverative bias that predisposes towards the maintenance of attention to whatever is within current focus resulting in a lack of flexibility in switching attention. This bias also privileges specific stimulus characteristics;

(3) an a-social attentional orientation to the physical and sensory world. This is a physical-sensory-based experience associated with a non-reflective, 'in the moment' experience and a concrete, physical world view;

(4) perceptual hypersensitivity which leads to exceptional capacity to detect or excessive reactivity to particular types of sensory events in one or more modalities.

The extent or degree of impairment in the working of the attentional system and in each of its constituent aspects is conceptualised as falling along a continuum of disorder with each individual participant affected to differing degrees. Specific perceptual skill aptitudes and deficits also contribute towards variability in individual experience. The working of the system is subject to a number of influences. Emotional state is identified as a key factor impacting on the working of the system. Developmental factors such as age, memory and learning are also highlighted: with increasing age, maturation and learning the system becomes more reliable. Because of the disordered nature of the attentional system participants may perceive to differing degrees a lack of control and mastery over basic perceptual processes.

Conclusion

The account of sensory-perceptual experience outlined here is proposed as a useful framework for understanding the sensory-perceptual experiences of the participants in this study. However, given the limitations of this study, the wider validity of these constructs remains unclear and for this reason will not be discussed further until this issue has been investigated. The extent to which these constructs hold up against other data sources (theoretical sampling) and are relevant to the experiences of a wider audience of people with autism will be addressed in the next three chapters. Study 3, reported in the next chapter (Chapter 5), will investigate unusual sensory-perceptual responding from the perspective of the parents of the participants who took part in this study (Study 2).

Study 3

Introduction

The parent perspective

The aim of this study was to investigate the nature and phenomenology of sensory-perceptual responding among individuals with High-Functioning Autism and Asperger's Syndrome by drawing on the perspective of the parents of these individuals. The decision to interview parents was made because of their unique position to observe the details of, and reflect on, their sons' sensory-perceptual responses and reactions over the course of development from infancy into adolescence and adulthood. The investigation of a parent perspective offered the opportunity to triangulate data sources thus providing a more comprehensive investigation of the phenomenon. In addition the study offered an opportunity for theoretical sampling of the core conceptualisations of the phenomenon developed in Study 2.

The use of parent report has a particularly strong salience in both clinical practice and clinically based research in autism. Because autism is a behaviourally defined disorder not generally diagnosed until the age of two to two and a half years, parent report through the taking of a detailed developmental history of the child's development from birth is an essential element of the diagnostic process. An abundance of clinical research has documented the key role of parents in initiating and pursuing developmental investigation leading to diagnosis as a result of their concerns about their child's development, even in the face of professional reassurance that there is no cause for concern (Midence & O'Neill, 1999). Parent report has been widely used in studies investigating the earliest markers of autism (e.g. Stone & Hogan, 1993; Wimpory, Hobson, Williams & Nash, 2000). In particular, parent report has been utilised in studies that have been instrumental in identifying the significance of anomalous sensory responses and perceptual-motor behaviour in the early discrimination of autism from other developmental conditions (Dahlgren & Gillberg, 1989; Gillberg, 1990). Investigation of parents' knowledge and views were therefore viewed as an important perspective in investigating sensory-perceptual phenomena.

The interview process

Although the same clinical-research requirements to allow for a degree of structure in the interview process did not pertain to parent interviewees as in Study 2, it was nevertheless considered useful to use a similar semi-structured approach in this study also. The reasons for this decision included the following: a major clinical reason for interviewing parents before participants was to enable parents to highlight particular areas of sensitivity or difficulty which they considered might arise for their son in exploring childhood and current sensory-perceptual experience. Consistency in the

areas explored was therefore useful in familiarising parents with the content to be covered. In addition covering similar content would allow for comparison of the parent and autistic participant perspectives with regard to the same behaviours and issues.

The approach to interviewing was designed therefore, with some additions and amendments, to follow the format that was used in Study 2. The semi-structured interview schedule used in interviewing participants with autism was modified for use in the present study. It covered the same sensory areas and was structured modality by modality. Exploration of the various aspects of sensory-perceptual responding was re-phrased in the third person and clearly inappropriate questions were deleted, such as those pertaining to the subjective emotional experience of various phenomena. A small number of additional questions were added to provide contextual background with regard to their son's development (see Appendix 10). In addition the extent to which parents had raised or discussed aspects of their son's sensory-perceptual responding with them was included as an issue for exploration. This issue was included so as to sensitise the researcher to situations in which participants might 'echo' previously heard stories of sensory-perceptual responding in childhood.

Method

Data collection phase

Participants

Ethical approval for this interview study was sought and obtained in conjunction with ethical approval for Study 2. Recruitment followed a similar procedure to that in Study 2: initial contact from their son's psychologist, followed by written contact and information from the researcher. All parents who were approached agreed to participate in the study and provided written consent. The parents of two of the participants were single parents. In three of the remaining five sets of parents, both parents participated for part or all of the interview.

Parents A:	Both parents of participant A participated in the research interview, although because of domestic commitments only the mother was present for the whole interview.
Parent B:	Mother of Participant B.
Parent C:	Mother of Participant C.
Parent D:	Mother of Participant D.
Parents E:	Both parents participated in the research interview.
Parent F:	Mother of Participant F
Parents G:	Both parents participated in the research interview.

Interview Process

The parent interviewees chose the location of the interview, and in each case the interview was conducted in the home. The interviews lasted between one and a half and two and a half hours and all were audio-taped for later transcription. A semi-structured interview format derived from the schedule developed for Study 2 was used to guide the interview. This protocol was used flexibly to support free-flowing description by parents of their sons' sensory-perceptual responding and to allow the researcher to pursue particular issues of interest as they arose. Parent interviews were conducted prior to interviews with participants with autism for the reasons previously outlined. In addition parents were asked to comment on the nature of their sons' understanding of their disability and their current emotional attitude towards it, so that this issue could be handled sensitively in the subsequent interviews. In a number of cases it was the parents' view that their sons had a somewhat confused and ambiguous understanding of their disability and a variable emotional relationship to it. On the one hand their son was described as being aware of his diagnosis and aware at an intellectual level of the long-term nature of the disability. Yet, on the other hand, their son considered the diagnosis to pertain primarily to his childhood and regarded himself as having 'outgrown' most of his difficulties. A number of parents identified emotional turbulence as a significant feature in their son's lives and in particular variability in the emotional acceptance of their diagnosis. Nevertheless all of the parents were happy with the interview with their son to go ahead subject to sensitive handling of the diagnostic issue.

After each interview the researcher completed an impressionistic summary of the major issues to have arisen and took note of issues relevant to the subsequent interview with the individual with autism. In all but one case interviews with the autistic son took place on the same day as the interview with the parents.

Data transcription and analysis.

The interviews with all seven parents were transcribed in full. Interview tapes were repeatedly listened to following transcription to ensure that the researcher was fully conversant with the meanings of the transcribed material. Each interview was anonymously labelled and imported as a separate document into the QSR NUD*IST software package.

Transcripts were analysed according to the grounded theory method set out in Chapter 3. Each transcript was read thoroughly and subject initially to line by line analysis and open coding. This was followed by clustering codes into more conceptual categories. This process was influenced, but not driven, by the concepts developed in Study 2. Where concepts and categories developed in Study 2 appeared to fit with the data, these were investigated for evidence of variation and difference. Additional categories were developed as necessary to comprehensively represent the data present in

parent accounts. A detailed presentation of the results of this investigation: 'Analysis of Parent Accounts, is contained in Appendix 11, with illustrative verbatim data. A summary of this analysis 'The Analytic Account', is presented in the 'Results' section overleaf.

Results

The Analytic Account

The core analytic concept of a disordered attention system that was generated in the previous study, was supported by parent interview accounts. Parents very clearly located their observations of many odd or unusual sensory reactions within an attentional framework rather than at the level of physical or structural abnormalities in sensory systems. Their descriptions provided evidence to support the major categories of a disordered attention beam, of a strong sensory based attentional orientation, and of a perseverative bias. Parental accounts emphasised the emotional or affective salience of sensory phenomena in their sons' childhood experience. Analysis of their accounts located hyper-sensitivity within a wider category of 'Faulty Modulation' which also includes hypo-reactivity to sensory events and problems in regulating internal body states. The analysis also identified the effect of emotional state and developmental changes on the working of the attention system.

Disordered Attention Beam

As conceptualised in the previous study, the attention beam is regarded as a dynamic 'spotlight' that automatically narrows and widens. The intensity and breadth of this beam determines what sensations and sensory events enter one's attentional focus or awareness. Parental report of their sons' sensory responses are seen as reflecting an impairment in the dynamic adjustment of this attention beam. Their descriptions suggest both an over-wide focus and an over-narrow focus at different times and a degree of effortfulness in processing information and making sense of the world. This impaired mechanism is particularly reflected in parent accounts of unusual reactions to the auditory and visual environment.

Over-wide focus

A number of observations reported by parents in relation to their sons' sensory responses are interpreted as evidence of an over-wide attention beam. Parents' accounts include descriptions of distress in or avoidance of sensorially busy environments and difficulty in distinguishing and identifying individual sensory events from the wider cacophony of incoming stimulation. This includes an account from one parent of her son's own explanation to her some years earlier of his lack of response to sudden loud

sound in which the auditory environment is described as 'all one sound to him'. Another parent reports the effectiveness of prosthetic supports in early childhood in highlighting individual visual events in order to assist her son in focusing on them. Other problems such as distractibility and difficulty following conversation in particular situations are also reported.

> *R.; C was unable to see things that other people could see?
> Parent C: Oh definitely, I mean, I don't know if it's he couldn't see them, 'cos really he could see things properly, but I think it's just his focusing on them.

> Parent F: ... I mean he umm, F is very rarely in noisy, crowded situations because he will go to great lengths to avoid them but he umm, he just doesn't, you know he says he can't make out sounds. I'm thinking of the swimming pool actually, we always laugh because he has to take his glasses off, and of course it is noisy, not where we go where it's open air, but in an indoor one where we don't go very often. Ummm he says he can't hear anything and he can't see anything 'cos he hasn't got his glasses on. And I think he means he can't distinguish the noise rather than he can't actually hear anything.

Overly narrow focus

An overly narrow attention focus is reflected in parent accounts of intense absorption in activity, and failure to or a delay in responding to even quite dramatic occurrences within the sensory environment. Indeed the primary quality reflected in several parental accounts is of narrow, intensely focused attending which strongly characterised their sons' responses to the world. This over narrow focus is described as particularly marked in childhood and was recalled by some parents as characterising their child's response to the world right from birth. It is reflected in states of intense absorption, often for long periods of time, and a general failure to respond to other events, opportunities and distractions outside of the particular event being focused on. This failure to respond to sound led in some cases to audiological investigation of the possibility of deafness in the early years.

> Parent B: Yea. Umm, he couldn't hear, like when we were on the beach, and there was this kind of jet screaming overhead. Everybody looked up except B. He didn't, and they were so loud, you know it was the sort of thing where you put your hand over your ears and shut your eyes because there were several of them doing manoeuvres across this beach on the south coast and he just didn't look up at all, he was too busy playing in the sand.

This over-narrowing of the attention beam is described as arising involuntarily in as a result of active engagement with an event or activity. However, particular stimuli such as repetitive, predictable events or activities are described as particularly associated with this state. One parent suggests that intense focus on repetitive stimuli may have assisted her son in dealing with sensorially busy environments thus preventing panic and distress as a result of overload. Attempts at intrusion into this state of intense absorption are described by number of parents as eliciting strong negative emotional reactions. Despite this quality of intense absorption and lack of responsiveness in early childhood, parents report apparently paradoxical heightened responsivity to certain specific sensory events. It is this dramatic oscillation between the two that parents cite as evidence for their early conviction that a general lack of responsiveness to sound in the early years was not due to a hearing impairment. 'Highly salient' sounds are described as triggering responsivity:

> Parent B: Well, I do remember that umm although if you talked to him or tried to get his attention, he didn't look up, umm but he could hear very small sounds like rustling of sweet papers and things, he could hear those all right. He'd be there expecting something, so it was obviously not a hearing problem at all.

This erratic response to the sensory environment is described by parents as most pronounced in childhood.

Effortful Attending

A number of parents describe some difficulties continuing into adult life highlighting a characteristic of 'effortfulness' in the way in which their sons process and make sense of the flow of events around. Factors such as anxiety state may continue to impact negatively on the system contributing towards variability in sensory-perceptual processing.

> Parent F: Umm, the [distressed reaction to] noises close to his head I think is pretty consistent. When he was a young baby and young child, the act that he could cut them out is consistent. Otherwise it varies, you know, sometimes he will umm, it's a question of whether or not he's engaged I think. Sometimes he's engaged and sometimes he isn't engaged. He really, ... you really can see now him going back into the Asperger's and he's like two different people. When he's not in the Asperger's, he is coming out more and more. He is one person. When he is stressed, he goes into Asperger's and he is quite different,

the away he reacts to stimuli, everything is quite, quite different. So you can't say there is one thing that's true of him, necessarily all the time.

In addition, parents suggest that other factors may contribute to a lack of normal responsivity to sensory events. Parents suggest that at times there seems to be a separation of hearing and the outward behavioural manifestation of having heard. A perceived lack of personal relevance or salience of the sound is one factor which is identified as potentially contributing to this. However, lack of awareness of the 'social etiquette' around listening behaviours may be another.

Sensory based world

This category refers to parent descriptions of a primary attentional orientation to sensory, physical and non-social events within the environment. The analysis indicates that awareness, interest and exploration are centred on a sensory and physical environment that has significant emotional resonance for the individual. It suggests that attunement to the sensory world is especially marked in childhood. This orientation is described within the context of impaired social relating and the absence of the 'normal' orientation to people.

All parents recalled a strong childhood orientation to the physical, sensory and non-social environment which dominated their son's interest and awareness. Parents describe childhood exploration as centred on the sensory and physical world and a failure of attunement to, and interest in, other aspects of the situation including people and shared social activity. A number of the accounts highlight a single-mindedness in the way in which sensory events were attended to which they considered unusual. Terms such as 'fascination' are used to describe the intensity of this orientation. This intensity is described by a number of parents in terms of a different consciousness or reality which served to separate them from their child. This intense focus on sensory events is described as excluding social interest and awareness, despite even quite intrusive attempts to gain or draw attention to people, that could give rise to a feeling that their approaches were intrusive or disruptive to the child.

In addition, the non-social environment is recalled as having strong emotional salience in the early years. Sensory events were regarded as being a significant source of emotional experience, and as a source of comfort and contentment which was difficult to deliver through social means. As a result parents describe the continued use of 'non-social' strategies to comfort and calm their children considerably past the stage when this would have been considered normally appropriate.

Parent A: You know, another child in the room where there happened to be something catching the light would perhaps be more interested in the people in

the room but to him that [light] was much more interesting the fact that grandma and other people were in the room, it seemed to be the most interesting..

Parent F: Umm, I, when he was a VERY young baby, very, very young, sort of days even rather than, days and early weeks, ummm he would look fixedly at lights, particularly patterns of lights, umm and the only other thing, well there are a couple of things I remember when he was slightly older. We had a little Ferris Wheel that you wound up and it went round and 'dah dah dah dah dee dee di' and he used to love that and it was the only way we could calm him down. And the number of times we have lain in the middle of the night, my husband with this thing on his chest, and me with F on my chest, winding this damn thing up, going round and round and round.

Throughout childhood certain aspects of the non-social world are described as a source of particularly intense emotional experience. Water and the sea are identified as a particularly strong source of joy by a number of parents, and a range of other events are also identified. One set of parents describe how certain physical events could dramatically 'lift' their sons' mood. However, the analysis indicates that the emotional impact of the non-social environment was not always positive. Aspects of the physical and sensory environment were also described by a number of parents as a source of fear and distress at times.

Parent E: Mum: And the happy, excited version [Mum demonstrates flapping, jumping] would be watching something on television later on, you know once we got television, umm, watching a spinning top or a penny spinning or something like that. Particular visual things that he liked the look of, sometimes just something like flames in the fire or something of that sort, ummm, it did it at a rainbow once, he flapped and jumped, oh, umm, waves, the sea, being at the sea. I can remember taking a group of [autistic] children ... and that was really funny because suddenly everybody was flapping and jumping! Including the adults, ha ha ha! Annie [another autistic child] used to flap at bubbles - that would have been the sort of thing that E would have flapped at too. Something like that, flames, bubbles, maybe even clouds, umm, snow falling and he would be flapping and jumping, and those were very happy things.

A number of parents describe their sons as showing accentuated emotional intensity in both positive and negative reactions to events around them. This may be conceptualised as a consequence of a non-reflective, in the moment experience. This conceptualisation and, in particular, poor self-reflection on feelings is given explicit

support in two accounts. The analysis suggests that impairment in the ability to reflect on experience gives rise to overly physical or concrete understandings of the world, sometimes leading to irritating physical or sensory events being seen as the primary source or 'cause' of distress or anxiety. Even when a greater capacity to self-reflect is present, the analysis suggests that there may be continued reliance on concrete metaphor and physical imagery to think about and articulate experience and/or continued use of physical, blocking strategies to deal with unwanted social demands or intrusions.

> Parent B: .... but there was something that he said, when he was 12 he occasionally said he was depressed because he hadn't, because he'd got no future. And he said " it felt like this because things bent the wrong way" and he got the urge " to bend them the other way". And he equated this feeling of hopelessness with this sort of bend, things bending the wrong way, needing to be bent the opposite way.
> *R.: Right, what do you think that was about?
> Mum: I think that is about this kind of ummm perception of how things feel umm, you know, bending, that's what seemed the strange thing. That if he could bend it the other way then that feeling would be released and it would be all right. ... Yea, that things had got too far one way and that he wanted to push them the other way again. ... He was just equating a feeling he had with an object. That was why I wrote that down, I thought that was rather strange. ... He translated a feeling into a concrete object, that was bent the wrong way.

The analysis suggests that preoccupation with the sensory world is most marked in infancy and early childhood and in two accounts was noted by parents within days or weeks of birth. A number of parents describe their feeling at the time that this orientation to aspects of the non-social environment was in some way different or unusual. The exclusivity of this orientation to the sensory and physical world and in particular the lack of interest in people was also a source of deep concern to a number of parents. The analysis suggests however that this strong attentional orientation to the physical, sensory and non-social world has attenuated with age and in some cases may be no longer be a feature of their sons' relating to the world. In other cases parent accounts suggest some continuing orientation to physical and sensory aspects of the environment albeit to a much lesser degree. Particular sensory experiences or objects may exert a continuing emotional significance in their sons' lives particularly at times of unhappiness or anxiety.

> Parents G: MUM: Only that he does seem to alternate these moods we were talking about earlier, there are times when he seems quite together and he can

control things, and there are other times where, almost I suppose he regresses a bit and doesn't feel so good, and needs the comfort of things that will make him feel more secure.

Lack of attunement to people

A sensory-based attentional orientation is clearly described in parent accounts within a context of an underlying social impairment or lack attunement to people and the social environment. A number of parents either directly or indirectly suggest that anomalous relating to the physical sensory world arises from this social impairment . This lack of attunement to people can result in a lack of recognition of people as people or a 'special' kinds of objects.

Parent E: but there's a different kind of memory that he talks about which is for instance not knowing that a particular little girl was not a doll. And he talks, it was a little girl with long hair, and he liked to play with her long hair, and he would now say 'I gave her a really hard time'. This was in nursery. Umm, but I remember him saying to me 'I gave her a really hard time but I didn't know she wasn't a doll' and ummm later on errr he, we had a very strange conversation once about ummm what he thought about his younger sisters - one of them's three years younger and the other is six years younger than him - and we had a very strange conversation about whether he knew they were alive or not. And he actually said he hadn't known that Linda was alive when she was a baby. Now he treated her quite badly, she's the one who's three years younger, and he treated her quite badly in that he went through a stage of pushing and throwing around that time and he was just getting past the stage of throwing, that was at the age of three, umm but then as the baby grew up he would push her over and that was generalised to other children but it started with her. Umm, and that was quite a difficult period. Umm, and he said that he didn't really realise that she was alive when he pushed her over and I remember saying I had the feeling at the time that you were pushing her over to see what would happen and that it was quite impersonal, it was like pushing over a doll, and he said 'yes, that's right, I didn't know I was hurting anybody'.

Anomalous social relating is also highlighted in parent accounts of their sons' reaction to 'people touch'. All but one parent describe problematic reactions to affectionate touch. The extent and developmental course of the difficulty varied from individual to individual. The difficulties with physical contact described by parents ranged from active avoidance of physical contact to a lack of responsiveness to contact. These differences were also reflected in parent accounts of the relative ineffectiveness of

social strategies in calming and comforting their children. For a number of parents problems with physical contact were obvious very early in life and in one case was noted by parents and others right from birth. However, in another case parents did not become aware of difficulty with affectionate touch until school-age. In another 'awkwardness' with affectionate contact became more pronounced with age. Similarly in some cases tolerance of affectionate touch has improved whereas in others the difficulties remain. The analysis indicates that parents adopted a range of strategies in order to achieve some level of physical closeness with their sons. These included: continuing to initiate hugs despite their son's reaction, encouraging physical contact with siblings, and using highly motivating activities to achieve physical closeness.

> Parent B: Well, that's quite easy really. Umm, he didn't want anyone touching him and he didn't touch anybody else. So you could get a quick hug off him now and again if, but it was obviously unpleasant for him and it wasn't something that he, he repelled it so, you know, you tried not to upset him too much (uhum). But he was a lovely little boy and everyone wanted to give him a hug so he didn't really, he spent a lot of time backing off, people would come up and say " Hello B" and he'd back off several paces in case they were about to give him a hug I think! He didn't really like being touched at all.

Despite difficulties with being held or cuddled, parents report enjoyment of play-based physical contact in rough and tumble play and tolerance of other aspects of functional touch. Familiarity and closeness of relationship are identified by parents as important factors influencing their son's tolerance of physical contact. Difficulties with childhood touch are described as particularly pronounced with people outside of the immediate family and even accidental or functional touch by 'outsiders' is described by some parents as continuing to pose problems into early adulthood. For example, problems around having haircuts and/or visits to the dentist are described by one set of parents as resulting from their son's difficulty in tolerating people he doesn't know touching him. This problem with touch is identified by these parents as being bound up with other problems in social interaction which includes speaking to people he doesn't know. A number of parents indicate that interest in sexual/romantic partners also impacts on tolerance of physical and affectionate contact.

Perseverative Bias

This category refers to an attentional bias or pre-disposition to repetition, predictability and sameness. A recurring theme running throughout parental accounts is that repetition, predictability and sameness strongly characterised their sons' attentional preferences, motor behaviour, object play, and interests throughout childhood. This predisposition is described as continuing in attenuated form into adulthood except in the case of one parent who considers that her son's great determination and effort have allowed him to successfully overcome this tendency.

This perseverative bias is described as characterising their children's relating to the world from earliest childhood. Even in infancy a number of parents recall their baby's attention being drawn to repetitive sensory events and patterns to an unusual degree. These included Christmas lights coming on and off, the shadows cast by rotating mobiles or discs or the dynamic pattern of reflected sunlight. Active repetitive play with objects, insistence on repetition and enjoyment of listening to music, story or poetry heard repetitively, characterises parental accounts of their child's behaviour and preferences in the early childhood years. There is also support from one parent for perseverative experience at a stimulus level with one parent recalling her son's description, years previously, of mental 'echoing' of loud speech.

> Parent A: I can remember as a very young baby when I had him in the sling listening to music, if a disc was on and there was a reflection going round the room, umm that would catch his attention, more than you would expect somehow. He was fascinated by the fact of those kind of reflections on glass ummm he used to spend hours watching the washing machine .. things spinning round. Hours and hours and hours, and he used to giggle and laugh. Umm...
>
> Parent B: ... this isn't now, this is a few years ago, about ten years ago, my friend did some research and I asked B a lot of questions and he said he could hear quiet speaking all right when he was young but loud speaking he said 'I heard what was said lots of times in my mind'

A tendency towards repetition and sameness in play and interests is a strong theme in parental accounts of their sons' play throughout childhood and into adulthood. Predictability is identified by a number of parents as central to the appeal of these activities and interests. A preference for or insistence on sameness and a corresponding difficulty in dealing with change, the unfamiliar or the unpredictable are described as general characteristics which pervaded all aspects of life. This predisposition to repetition and sameness is also considered to underlie stereotypic behaviour. Although there is variation in the extent to which they are reported as a central feature of childhood

behaviour, all parents describe some form of stereotypic motor movements with or without the use of objects, behaviours such as rocking, self-spinning, hand-flapping, finger flicking or running to and fro. Parent accounts suggest a number of functions of these behaviours. These include a "shutting out" role reflecting an emotional need to withdraw, to become inaccessible to others through stereotypic behaviour. Repetitive behaviours are also identified as a way of calming or relaxing. In two accounts stereotypies in the absence of directed activity are described as an integral feature of their son's childhood behaviour and as occurring unconsciously without apparent awareness. These parental accounts suggest a recognition of, and respect for, the emotional function and impact of repetitive motor movements, and the wider manifestations of a bias to repetition and predictability in their sons' lives. Variations in the presentation of repetitive behaviour are identified by a number of parents as reflecting different emotional states, and a number of parents highlighted the impact of anxiety on these behaviours. Parent accounts suggest that with increasing social awareness, and effort, these stereotypic movements have been brought under control. However, in some individuals, parental accounts suggest that a tendency to stereotypy remains. This is exacerbated by anxiety and occurs in private.

> Parent A: Mum: Yes, more hand-flappy, [when upset] ummm [pause] I can't remember any particular rituals. But I mean always, ever since he's been little, when he's been anxious he's looked more autistic, you know, finger-flapping, all that kind of thing, most of which now has disappeared and we only notice it now when he has a bout of anxiety, sleeplessness.

Faulty modulation

This category refers to parent descriptions of faulty modulation in the perception of both the internal and external sensory environment. It includes parent descriptions of over-reactivity (hyper-sensitivity) and under-reactivity (hypo-sensitivity) to external sensory events and accounts of anomalous awareness of internal body states and disrupted self-regulation. The analysis of parent descriptions of hypo-sensitivity suggests that this phenomenon is not adequately represented as merely a consequence of over-focused attending. The analysis suggests that hyper- and hypo-sensitivity are best represented as opposite polarities within a wider concept of modulation of sensory intake. Faulty modulation is described at two levels: a general level where perception in one or more modalities is described as either hyper- or hypo-acute and a more specific level where (usually) problematic hypersensitivity is described for specific sensory events within one or more modalities.

Hypersensitivity

Support for both the concept of 'general' hyper-acuity, and, for more specific problematic sensitivity to particular sensory events was strongly evidenced in parent accounts. General hyperacuity can be considered as a heightened or exceptional capacity to detect sensory stimuli: what might be termed an 'amplified' intensity experience within a particular modality. Problematic over-sensitivity refers to a heightened unpleasant/distress reaction to specific sensory events that may be idiosyncratic to the individual.

General hyperacuity was described in a number of parent accounts in relation to sound and, in one account, in relation to smell. With regard to sound, hyperacuity is reflected in accounts of the ability to hear sounds at lower volume or at greater distance than others and in accounts that suggest an experience of a given sound as 'louder' than others perceive it such as dislike or avoidance of loud music. A heightened sensitivity to smell compared to other family members is described in one account.

> Parent A: Yes, I know he hears things way before I do. He'll always hear the 'phone or hear a car coming up the drive, rather like a dog you know. Ummm and he always has been like that. Yes, I've always known his hearing is much more acute than mine. It's just difficult to think of lots of examples for you really but things like the 'phone going in the distance...

Hypersensitivity is also described for specific sensory events. This problematic over-sensitivity refers to a heightened unpleasant/distress reaction to specific sensory events which may be idiosyncratic to the individual. All parents described some form of problematic reactivity to specific sounds. Over-reactivity in relation to specific aspects of touch, and smell was also described by a number of parents.

A considerable range of sounds were described by parents as problematic. These include high-pitched or piercing sounds, distressed reaction to human voice, mechanical, electrical and loud or sudden noises. The analysis suggests that hyper-acuity may also have played a role for some individuals in the problematic experience of sound, for example a distressed reaction to barely audible sound of which others would be unaware.

Hypersensitivity was described in relation to specific types of tactile sensation, (e.g. certain types of fabrics or clothes) and in relation to specific body parts. A range of preferences and difficulties in relation to dressing and body care routines (e.g. hair washing/cutting) that may also reflect a degree of tactile hypersensitivity were also described. Parent accounts highlighted the complexity of these reactions since social interaction difficulties or motivation issues may also contribute to some of the difficulties.

A degree of problematic hypersensitivity to specific smells was suggested by a number of parents. These were described as circumscribed distress reactions to specific smells in childhood which they felt constituted a relatively minor problem.

> Parent C: He didn't like things like Hoovers, drills, vacuum cleaners, mixers, anything. ... Lawn mowers, that 'aaaaagh' sort of sound. ... He'd cry, and scream, and run away and .... Or he'd talk gibberish to himself. I'm sure it was him who talked gibberish. He'd sit there in his room talking absolute nonsense, just to sort of shut the sound out. ... I don't think that he did [cover ears]. He just used to do a lot of this talking and I'm sure he would have flapped around a bit!! ... Yes, very agitated. ... because he'd always run, he'd always go to his room.

The analysis of parental accounts suggests suggest wide variation between participants in the extent to which these hyper-sensitivities impacted on their lives and social functioning. For some distress and anxiety was, in their parents' view, limited to situations in which the aversive events/activities were present. For others, the problem contributed towards curtailment of social opportunities and interaction or other negative social consequences. The impact on one individual and his family was particularly severe because the initial fear of one woman's singing voice on TV generalised into a much wider phobia of all sound through speakers. This curtailed his life and that of his family for much of his childhood.

> Parent A: But then it did spread to all music or voices that came out of speakers, and again it was the quality of the voices that came out of speakers that was different, and that was a huge, terrible, terrifying phobia because we couldn't go to any public place without him immediately scanning the room for hidden speakers, you know, behind umm the ceiling, in shops, in railway stations, theatres, swimming pools. One of the worst times, we went swimming and there wasn't normally piped music there, but we were in the pool and suddenly they switched on this pop, piped music, and it filled the whole swimming pool ... We couldn't get him into a swimming pool for years after that. And it just dominated his life really, for a long time, ummm.

Parent accounts reflect their sensitivity to, and empathy for, the distress caused by these sensory events. Parents recognised their inability to allay this distress through normal comforting in the feared situation, and used a range of strategies which recognised their sons' need to avoid or escape from unpleasant events. Parent A, for example, identified lack of control over exposure to the feared sound as a significant

element in A's generalised phobic response. Involvement in activity was identified by another parent as one factor which mediated her son's reaction to at least some sounds.

The analysis also suggests individual variability in the developmental course of these hypersensitivities. For some individuals, problematic hypersensitivity was confined to circumscribed triggers in early or middle childhood. For other individuals, although attenuated, hypersensitivity continues.

Hypo-sensitivity

All parents note some form of behaviour indicating a degree of unreliability with regard to awareness of or accurate identification of internal body sensation and states. The most common phenomenon described is that of general under-reactivity to pain (not however reported by Parent D) but under-reactivity to temperature, thirst, hunger, satiation, and 'illness symptoms' are also described. This unreliability can pose serious problems for health and well-being. Hypo-sensitivity in relation to 'external' sensation in taste and smell is also described by one parent.

> Parent F: That is, he has an INCREDIBLY high pain threshold. Umm, that's possibly the most striking thing about his sort of sensory perception actually. He umm, when he started getting ear infections, which was when he was a little baby, several times his eardrums burst and in the end they realised, or I realised and the doctor - we had very good doctors where we were living - that he wasn't complaining until the thing was literally on the point of bursting so we had to have this arrangement whereby if he said his ears hurt I just rang up and they put antibiotics out and I would go and get them.

> Parent G: DAD: He doesn't seem to perceive ambient temperature (MUM: No) at all coherently in terms of going out in the cold with inappropriate clothing on but then obviously you can see, right down to him going blue, whatever, but he doesn't seem to perceive that or have felt that as an inconvenience and then the opposite also being on a sunny day having all your woolly jumpers on (MUM: coat and kagoul!) and going all red in the face and again he doesn't seem to feel uncomfortable or recognise what he feels as discomfort caused by that

> Parent A: Mum; ... and ummm he'll just go on eating, you know, old ladies are always delighted in having him to tea and you know our neighbour, famously the first time we went round, he ate ten mince pies. You know he'll not sort of, nothing will sort of teach him you know that I'm feeling full up and sick and he won't stop eating 'cos he feels sick. So we've had to teach him the really hard

> way to stop, it's always been very difficult and I've always felt it's because he doesn't seem to know when he feels ill.

However this under-reactivity may exist alongside apparently 'normal' responses or indeed hyper-reactivity in other situations. For example, with regard to pain, within a general context of under-reactivity a number of parents also provide examples of 'normal' reactivity or hyper-reactivity at other times to certain types of pain or illness. A number of potential contributory factors to this variability can be identified from parent accounts. These include self-absorption suggestive of an over-narrow attentional focus, poor memory or recall for previous experiences, difficulty in identifying or labelling sensation, impaired social communication, and with regard to satiation, compulsiveness around eating and drinking. In addition, specific incidents which were distressing or frightening may contribute to some aspects of hypersensitivity.

These difficulties with internal body states are described as being present very early in childhood but there is considerable variation in the extent to which they have now been reliably overcome. In some cases difficulties have been overcome or are gradually improving but in others problems with regard to the perception of pain, temperature, hunger or thirst continue. Only one parent identified 'general' hypo-sensitivity in relation to sense modalities. Parent C suggests that her son is generally under-reactive to smell and taste:

> Parent C: And he doesn't smell things. ... You'll say 'Can you smell that?' and he'll say 'No' you know ... I mean he puts aftershave on and he puts gallons of it on, and we all go 'Uhuh, uhuh' and he doesn't seem to notice ... Yes, and it's on, it's on his face, it's right near his nose and he doesn't seem to notice the smell at all.

Discussion

Interviewing parents about their adolescent and adult sons' sensory-perceptual reactions proved an extremely valuable and useful source of information in adding to our understanding of sensory-perceptual phenomena. Parent accounts provided detailed and insightful observations of their son's childhood and current functioning, and of the developmental and other factors which impinge on this aspect of experience. In a number of cases it was clear that parents had discussed aspects of anomalous responding with their son over the years or had gained insight into the role of sensory issues as a result of exploring aspects of their son's behaviour. Their accounts widened our understanding of the impact of these phenomena on parents and the family.

Review of findings

The analysis of parent accounts confirmed the usefulness of the concept of a 'disordered attention system' in representing sensory-perceptual phenomena. There was general consistency between parent and participant accounts in the four major analytic categories. Their descriptions provided evidence to support the concepts of a disordered attention beam, of a sensory based world, of a perseverative bias and of hypersensitivity as central elements of sensory-perceptual experience in autism. In addition, parent accounts identified hypo-reactivity to sensory events and problems in regulating internal body states. In the analysis of parent accounts therefore, hypersensitivity, hypo-reactivity to sensory events and problems in regulating internal body states are subsumed within a wider concept of 'Faulty Modulation'. Parental accounts emphasised the emotional or affective salience of the physical-sensory world in their sons' childhood experience. The analysis also identified the effect of emotional state, developmental change and other factors such as memory and motivation on the working of this impaired attention system.

Disordered Attention Beam

The attention beam is regarded as a dynamic 'spotlight' the intensity and breadth of which will determine what sensations and sensory events enter one's attentional focus or awareness. Parental report of their son's sensory responses are seen as supporting the analogy of an impairment in the automatic, dynamic narrowing and widening of this attention beam. Their descriptions suggest both an over-wide focus and an over-narrow focus and a degree of effortfulness in processing information and making sense of the world which is in keeping with the analysis of participant accounts in Study 2. In addition, the analysis of parent accounts suggest that the operation of this beam is strongly related to developmental stage, with over-narrowly focused attending strongly characterising infancy and early childhood. This is reflected in parent descriptions of intense absorption in an activity, often for long periods of time, and a general failure to respond to other sensory and social events, as being most marked in the early years.

The analysis supports the view that this over-narrowing arises involuntarily as a result of active engagement with an event or activity and that particular stimuli such as repetitive sensory events are particularly associated with this state. In addition to the concept of an over-narrow beam, parent accounts also identify an additional factor which may be relevant to understanding lack of responsiveness to sound or social approaches: a separation of hearing and the outward 'behavioural display' of having heard. This lack of behavioural display may be related to a lack of perceived relevance of the event to the self, or, the lack of social awareness of appropriate listening behaviour.

Sensory based world

Analysis of parent accounts provides support for the concept of a primary childhood attentional orientation to the sensory and physical environment and a failure in the normal attunement to people. Parent accounts highlight particularly the emotional significance of the child's relationship to the sensory and physical world. Associated with this orientation to the sensory world, the analysis identifies a heightened intensity of emotional reactions suggestive of 'non-reflective' experience, and concrete ways of managing events. Difficulty with, or lack of responsivity to, physical affection is identified as a significant aspect of the wider social impairment.

Attenuation of this orientation to the physical and sensory world and increased awareness of, and responsivity to, the social world is identified over the course of childhood. Nevertheless, parent accounts identify continuing difficulties around social interaction, most evident with those outside of the family, and a degree of continuing affective salience of aspects of the sensory-physical world.

In addition, analysis of parent accounts illuminates the impact of the child's orientation to the physical-sensory world on the parents and family. The analysis suggests that the intensity of their child's focus on the sensory world and the corresponding lack of responsiveness to people is experienced by parents in terms of an 'own world' consciousness which served to separate them from their child. This orientation was recognised early in the child's life as different or unusual by a number of parents. In dealing with their child's lack of comfort with physical affection, the analysis indicates that parents use a range of strategies to facilitate a degree of physical closeness with their child: rough and tumble play in particular is highlighted as a form of enjoyable physical interaction.

Perseverative bias

The concept of an attentional bias to repetition, predictability and sameness was also supported in the analysis of parent accounts. This pre-disposition is described as characterising their sons' attentional preferences, object play and interests from earliest childhood and as continuing in attenuated form into adulthood except where successful effort has been made to overcome this tendency. A childhood preference for, sameness, and a corresponding difficulty in dealing with change, are described as general characteristics which pervaded many aspects of life. The analysis indicates that this bias was also expressed behaviourally in stereotypic behaviour, often occurring without awareness. With age and increasing social awareness, 'inappropriate' repetitive behaviour becomes less of a problem. However the parent analysis suggests that while repetitive and stereotypic motor may not occur in the presence of others, for some individuals it continues to be a feature of their behaviour in private. Parental accounts

suggest recognition, respect and tolerance of the emotional function and impact of repetition and predictability in their sons' lives.

Faulty modulation

Analysis of parent accounts suggests impaired or faulty modulation in the perception of both the internal and external sensory environment. This concept of faulty modulation is wider than the concept of hypersensitivity which was developed to account for the experiences reported by participants in Study 2. Parent accounts suggest that hypersensitivity is part of a wider phenomenon that also includes hypo-sensitivity to external sensory events and internal bodily sensation. Faulty modulation is described at two levels: at a general level where perception in one or more modalities is described as either hyper- or hypo-acute and a more specific level where (usually) problematic hypersensitivity or problematic hypo-sensitivity is described for specific sensory events in one or more modalities or with regard to bodily sensation.

The analysis indicates that hyperacute hearing or an 'amplified volume' experience of sound is reported by a number of parents as characterising their sons' reactions to sound. General hypersensitivity to smell is reported in the case of one individual. This hyperacuity may be interpreted as a special or positive attribute ('exceptional hearing') but may also lead to negative consequences such as the curtailment or avoidance of social situations where sound is experienced as 'too loud'. Parent accounts indicate problematic hypersensitivity to specific sensory events in the auditory, tactile and olfactory modalities. The analysis indicates considerable variability in the impact of these unpleasant and distressing sensitivities. These range from distress in the immediate context of the unpleasant event to, in extreme situations, generalised phobic responses which significantly curtail social and other opportunities for the individual and his family. Analysis suggests that many of these hypersensitivities significantly attenuate or disappear over the course of childhood while others remain problematic.

Parent accounts identify hypo-sensitivity in relation to internal body states and, in the case of one individual, hypo-sensitivity in relation to taste and smell. The most common phenomenon described is that of general under-reactivity to pain but under-reactivity to temperature, thirst, hunger, satiation, and 'illness symptoms' are also described. This unreliability can pose problems in relation to the detection of illness or injury. The analysis identifies a number of factors which may contribute to hypo-sensitivity in specific situations. These include self-absorption suggestive of an over-narrow attentional focus, poor memory or recall, impaired social communication, and with regard to satiation, compulsiveness around eating and drinking. However, it is unclear if these factors alone can account for the sometimes dramatic examples of

under-reactivity described. Parent accounts indicate considerable individuality in the extent to which these hypo-sensitivities have attenuated with age.

Multi-dimensional experience

Analysis of parent accounts highlights the interactive and interlinked nature of these concepts in contributing to particular aspects of sensory-perceptual responding. For example parent descriptions of their child as being 'in his own world' and therefore unresponsive to events around him suggest that it is the combination of intense absorption (over-narrow focus) on a particular event or activity (sensory world) for a long period of time (perseverative bias) that characterises the essential quality of this experience. The analysis supports the notion of a continuum of impairment in relation to each of these elements as reflected in individual variability in parent accounts of their child's responses. Parent accounts also highlight the complex nature of these phenomena by articulating a range of additional factors such as lack of understanding of social etiquette that may contribute to abnormal responding.

Dynamic experience

The analysis identifies the dynamic and changing nature of sensory-perceptual responding. In addition to changes over the course of development, parent accounts also indicate the effect of emotional state and motivation on the working of the attention system.

Impact on parents and family

The analysis of parent accounts suggest that parents were aware of unusual sensory responding early in their son's development and for a number of parents this was a cause of unease and anxiety. The analysis identifies parental sensitivity to and respect for the affective salience of both distressing and pleasant sensory phenomena in their sons' lives. In this regard, the analysis suggests that behaviour such as sensory preoccupations and stereotypies may be viewed less negatively by parents, than in the professional literature. The analysis also indicates that phenomena such as problematic hypersensitivity impact not only on the child, but also on the wider family through curtailment of situations and opportunities associated with these unpleasant events.

Conclusions

The findings of this study support the view that anomalous sensory-perceptual responses are complex, multi-component phenomena. Disrupted sensory responding is viewed as the outcome of a number of impaired attentional processes. This analysis has confirmed the four core elements identified in Study 2 as contributing to this situation. In addition, however, analysis of parent accounts suggests that hypersensitivity is part of a wider category of impaired function, that includes hypo-reactivity to sensory events and problems in regulating internal body states. In this analysis these have been labelled 'Faulty Modulation'. Analysis of parent accounts also suggests that one extreme of the impaired attention beam, that of over-narrow focus is strongly characteristic of early childhood. This study also details the wider impact of anomalous sensory responding on parents and family. Finally, interviews with indicate that parents offer insightful and detailed observations about the complex and dynamic nature of their son's sensory-perceptual responding.

Study 4

Introduction

Process Issues

It was clear from the findings of the pilot study (Study 1) that sensory-perceptual phenomena were a sufficiently salient and common experience in people with autism to warrant doctoral research. Indeed, the decision to embark on the series of interviews with people with autism and their parents was based in large part on the findings from Study 1, and I was aware at the outset that the published literature contained accounts of sensory-perceptual experiences.

In returning to the first-hand account literature in the present study, therefore, I was very conscious that I didn't want simply to replicate Study 1 with a different sample of published accounts. Rather, I had a very specific aim in mind. I had already developed a theoretical integration of the themes that emerged from the interviews with the people with autism (Study 2). In the last study (Study 3) I interrogated the parental accounts to see if these would confirm or deny essential elements of this account. I now wanted to return to the published first-hand accounts and check the theoretical integration against this literature using a more formal qualitative methodology than that undertaken in the pilot study.

I had decided against modifying the theoretical account from Study 2 on the basis of feedback from the parental accounts. Instead, I would first interrogate the theoretical account separately against each of the other data sources available. I had already seen how some elements of the theoretical account might need to be modified on the basis of the findings from the parental interviews but I decided against modifying the account until I had separate feedback from parents, the published literature and from the individuals who responded over the internet (see next chapter). Thus, at this stage, the same theoretical account that was interrogated in the previous study was used in the present study. I decided that I would wait until the feedback was compiled from all these sources before modifying the account. This would be attempted for the first time in Chapter 8.

Therefore, in the present study, the original theoretical account was interrogated using published first-hand accounts from the published literature. This was a very different task than had been attempted in the pilot study.

Introduction

The use of documentary data sources in grounded theory research has long been recognised as a useful and valid source of evidence in investigating specific processes and phenomena (Banks, Louie & Einerson, 2000). A number of grounded theorists

have specifically advocated the use of multiple data sources. These include the use of 'non-technical literature' which includes biographies, letters, diaries and a variety of other materials, both as primary data, and, in extending and developing theoretical understandings derived from other data sources such as interviews and observations (Strauss & Corbin, 1990). Auto-biographical accounts have been used in grounded theory research either as the sole source of textual data on which the analysis is based, or, as a joint source of textual data (Cohen, 1995).

There are an increasing number of published hard-copy autobiographies by people with autism (Williams, 1992; 1994; Shore, 2001; Holliday-Willey, 1999) and also autobiographical accounts available through other media (internet personal web pages, radio broadcasts, television documentaries). These provide a rich source of information about the lives and experiences of these individual authors in growing up and living with the disability of autism. By extension, they provide valuable insights into the nature of this life-long condition. First-hand account material is also available in published conference proceedings, and in the newsletters of autism societies. Extracts can be found in articles by clinicians and researchers published in professional journals or as part of theses. In addition, extracts of first-hand account material from individuals with autism can be found in books written by parents or other family members or in web based discussion groups used by people with autism and their families.

These public first-hand accounts were considered a useful additional data source in developing an understanding of the phenomenology of sensory-perceptual experience in autism. However, a number of issues and concerns dictated that sampling of this body of material should be done according to a number of criteria:

- The accounts should be clearly autobiographical (i.e. written primarily with a focus on the life experiences of the individual and offering a degree of developmental perspective on their experiences). This excluded, for example, a number of 'scientific' or 'professional' accounts of autism by individuals with the disability, where the subjective experiences of the individual are included only as secondary, or incidental, to a wider aim of presenting a treatise on the nature or treatment of the disability (Williams, 1998; Grandin, 1992c). Also excluded on these grounds were a number of accounts by individuals that have to do with specific issues (e.g. employment) and do not contain a developmental or 'life-context' for the information presented (e.g. Meyer, 2000). In addition, articles or books by clinicians, researchers or family members in which extracts of first-hand material is presented as secondary to the author's theoretical viewpoint were also excluded.

- The accounts should include reference to the author's sensory-perceptual responding and experiences. This is in keeping with the objectives of the study and the methodological requirement of purposeful sampling:

  '...a researcher chooses the sites, persons, and documents that will maximise opportunities for verifying the story line, relationships between categories, and for filling in poorly developed categories. This may mean returning to old sites, documents and persons, or going to new ones where one knows the necessary data can be gathered'(Strauss & Corbin, 1990, p187).

  This criterion excluded a small number of autobiographical accounts in which the authors do not make reference to sensory-perceptual phenomena (Miedzianik, 1986; Carpenter, 1992).
- The accounts should be 'permanent' and 'traceable' thus excluding internet based public accounts which may be impermanent and/or difficult to trace.
- The accounts should be the words and efforts of the individuals themselves and not those generated through forms of assisted communication. This excluded a substantial number of published and other public accounts which have been generated through Facilitated Communication (e.g. Sellin, 1995). A substantial body of empirical evidence casts doubt on the validity of this approach with individuals with autism, suggesting facilitator influence on the text generated (Green, 1994; Mostert, 2001).

Method

Selection of Published Accounts

Using the selection criteria outlined in the introduction, a total of eight accounts, representing the experiences of seven individuals with autism, were selected for inclusion in this study. The experiences of one individual, (Williams, 1992; 1994), span two accounts: the first covering her childhood, adolescence and early adulthood and the second covering the years post-diagnosis as an adult. These eight accounts represent the experiences of an international sample of individuals with autism drawn from Australia, Britain, the United States and Sweden. Four were by women and three were by men. While this gender ratio does not reflect the gender breakdown in the incidence of autism, it does seem to confirm the researcher's anecdotal experience that a majority of autobiographical accounts are by women. Six of the accounts were published autobiographical books, one was an article published in the journal of a national autism society, and one was an autobiographical account broadcast on a national radio programme which focused on the life experiences of individuals with autism.

Bibliographic details of these accounts are presented in Table 2:

Table 2: Bibliographic details of Selected First-Hand Accounts

Barron, J., & Barron, S. (1993). *There's a Boy in Here*. London: Chapmans.

Gerland, G. (1997). *A Real Person: Life on the Outside*. London: Souvenir Press.

Grandin, T., & Scariano, M. (1986). *Emergence: Labelled Autistic*. Novato, CA: Arena.

Jolliffe, T., Landsdown, R. & Robinson, R. (1992). Autism: a personal account. *Communication*, Vol. 26(3), p.12.

Mc Kean, T. (1994). *Soon Will Come The Light*. Arlington, Texas: Future Horizons.

Weekes, L. (1995). *Autism: A Bridge of Voices*. Radio Documentary, British Broadcasting Corporation. Precise date of broadcast unavailable. This broadcast was audiotaped and transcribed in full. The contribution of Leslie Weekes was highlighted. The text generated by other contributors to this broadcast was not used as it did not satisfy the selection criteria.

Williams, D. (1992). *Nobody Nowhere*. Australia: Doubleday.

Williams, D. (1994). *Somebody Somewhere*. Great Britain: Doubleday.

Selection of text within accounts

Each of the written accounts was read in full with a view to identifying text relevant to sensory-perceptual phenomena. Relevant text was highlighted and included the following:

- Text that referred directly to specific sensory systems such as sound, vision, touch, taste, smell, movement , body states and body awareness.
- Text that contained references to an interest in, or enjoyment of, an object or activity which primarily related to its sensory or perceptual content or consequences. For example, text which contained a description of interest in the colours or shapes in a picture and not in what the picture represents.
- Text that contained reference to an unpleasant or aversive reaction to an object or activity which primarily related to its sensory content or consequences - for example dislike of the *bang* of a toy gun.
- Text that contained references to engaging in an activity, or interest in an object, (presented without explanation as to the source of its appeal) that in the researcher's view related primarily to sensory consequences (e.g. repetitive behaviour).
- Text that contained reference to a contextual concept which appeared relevant to an understanding of the sensory-perceptual phenomena described.

The units of text selected in this way were of variable length. The location of each unit of text within the wider account was noted by marking it with the page number from which it was drawn.

Data Storage and Analysis

The highlighted text for each account was word processed into a single document. The eight documents were then each imported in to the NUD*IST software package for storage and to facilitate the coding process. As coding and analysis proceeded the researcher frequently referred back to the relevant page in the original textual account in order to check out conceptual issues as they arose within the coding process. Any additional text identified as relevant in this way was then included with other textual data located at the appropriate code or category in the emerging analysis.

Data analysis followed the principles and procedures of Grounded Theory set out in Chapter 3. Each document was read thoroughly and all text analysed fully. Coding of this data involved both theoretical sampling of conceptual categories derived from study 2, and the coding of new ideas and processes within the data. The outcome to this analysis is presented in the 'Results' section below. A more detailed exposition of this analysis with verbatim data is presented in Appendix 12.

Results

The analysis confirmed the usefulness of the concept of a Disordered Attention System, generated in Study 2, in representing the sensory-perceptual experiences described in published first-hand accounts. There was support for the categories of Perseverative Bias, Sensory-Based World, and Disordered Attention Beam. The analysis suggests that hypersensitivity is one extreme in a wider category of Faulty Modulation that includes hypo-sensitivity to internal sensory events and a number of other anomalous phenomena identified in this study. The analysis provided evidence of the influence of emotional and developmental factors on the working of the attention system.

Perseverative bias

The analysis of first-hand accounts provided support for the concept of a perseverative bias in the attention system. The analysis identified a range of experiences and behaviours which have in common an orientation or predisposition to repetition and sameness. This is represented in the accounts in a number of ways: in descriptions of the intrinsic appeal of repetition and sameness in activity and sensory events; in descriptions of perseverative thought, and, in one account, the experience of sensory echoing. It is also represented in descriptions of repetitive behaviour, and in descriptions of a preference for the familiar and a corresponding dislike of the unfamiliar.

Analysis of the accounts also indicates individual variability between authors in the extent and pervasiveness of this bias. This supports the conceptualisation of this construct as existing along a continuum of severity with individuals falling at different points along it. The analysis suggests that this orientation to repetition and sameness is strongest in childhood. With age and increased social awareness, a number of authors develop insight into the limiting and negative impact of this orientation, and make active efforts to overcome it. For example, Gerland (1997) speaking the about repetitive touching that was a significant feature of much of her childhood, suggests that this behaviour continues to have appeal for her. As an adult, however, she describes a greater degree of control over this aspect of her behaviour :

> I still have a bent - I like that word - for curved things but it is no longer a fixation. It comes out mostly in things like finding I want to make a detour in order to take a road that bends instead of a straight one, or feeling a desire to touch something that is beautifully curved. It is good that I can choose to allow myself a detour, to enjoy that curve, but that I can choose not to if I think I haven't the time. And I know when it's all right to touch whatever arouses my

> desire to touch and when not, and I don't find it difficult not to (Gerland, 1997, p. 249).

Published accounts offer considerable reflection on the nature of this bias to repetition and sameness. Repetitive sensory events and activity are described as intrinsically pleasurable or appealing, as providing a sense of coherency, control or comfort in the context of a world which is perceived as constantly changing and unpredictable, as calming, and as facilitating a process of narrowing attention that is helpful in shutting out confusing or painful stimuli. An example of the appeal of repetitive activity is provided by Williams (1992):

> The constant change of most things never seemed to give me any chance to prepare myself for them. Because of this I found pleasure and comfort in doing the same things over and over again. (Williams, 1992, p. 39).

The analysis suggests a degree of continuity between this expression of the perseverative bias and other forms of expression such as repetitive thought or idea fixations, repetitive sounds and motor movements and the strong preference for the familiar. These are described as having similar impact.

The analysis also provides evidence that some aspects of repetitive behaviour may occur 'automatically' without awareness. Two authors suggest that for them, 'automatic' repetitive behaviour regulated level of arousal in the nervous system. The analysis identified additional aspects to repetitive behaviour: compulsion was identified as a dimension underlying repetitive behaviour in some individuals, another individual described repetitive questioning as offering a predictable structure for social interaction that he could control. Barron and Barron (1992) describe an early memory of compulsion in repetitive 'picking' behaviour:

> I remember lying on the floor picking at the carpet with my fingers. It's one of the first things I do remember. The feel of something that was not perfectly smooth was wrong to me— I picked at anything that did not have a solid surface. One rug in our house had many small ridges; by scratching them I could tell that all of the rug was the same, even if it looked different. I had to keep picking at it to be sure that the whole rug was the same, all of it. It must not change! (Barron & Barron, 1992, p. 15).

Faulty Modulation

This category relates to descriptions of faulty 'modulation' in the perception of both the external and internal sensory environment. Analysis of public accounts provides evidence for this category as a significant aspect of sensory-perceptual experience. It includes the concept of hypersensitivity developed in Study 2 and locates this phenomenon within a wider category of disrupted modulation which includes hyposensitivity. The evidence in relation to hyposensitivity contained in these accounts indicated that this phenomenon could not adequately be represented only as a consequence of an over-narrow attention beam. Rather, hyposensitivity is conceptualised as one extreme within a wider construct of 'Faulty Modulation' with hypersensitivity as another extreme. The analysis indicates individual variability in the range and extent of the experiences contained within this category which supports the notion of 'Faulty Modulation' as representing a continuum of disorder.

Hyper-sensitivity

Analysis of the author's accounts supported the concept of hypersensitivity. The term is used to include hyperacute or amplified /intensified experience of sensory events and a more specific problematic sensitivity to particular sensory events. Hypersensitivity is reported in sound, vision, touch and smell. Hypersensitivity in sound and touch are the most common hypersensitivities described. With regard to sound, all but one author report some form of hypersensitivity to one or more of a wide range of sounds. In the case of one author, hyperacuity for sound is reported to have been confirmed by audiological investigation. Two authors describe visual hypersensitivity to colour and/or brightness of light. All but one author described some form of hypersensitivity to tactile sensation. This included sensitivity to the texture of food, to materials or fabrics, to certain types of tactile body sensation, or hypersensitivity in particular areas of the body such as mouth, feet, hair, hands, neck and back. Hypersensitivity to smell is described by two authors. In one case this represented a generalised over-reactivity to smell throughout childhood; in the other a restricted sensitivity to a particular smell which developed for a short period only in middle childhood.

The analysis indicates that there is fluctuation and variability in the experience of hypersensitivity. Tension and anxiety are identified by one author as triggering or exacerbating some forms of hypersensitivity. The degree of predictability or preparedness for events may also contribute to hypersensitivity in certain situations. These hyper-sensitivities are described as resulting in a range of negative behavioural, psychological, and social consequences and as leading to a range of odd or unusual behaviours. In addition authors vulnerability to hypersensitivity may be used by others to punish or bully them. Grandin and Scariano (1986) describe how distress at sudden loud noises was exploited in this way:

> Now, years later, I know Miss Cray sensed my distress of loud noises. Such sounds not only startle autistic children but cause them intense discomfort. Like birthday parties. They were torture for me. The confusion created by noisemakers suddenly going off startled me. I would invariably react by hitting another child or by picking up an ashtray or anything else that was handy and flinging it across the room. ... Miss Cray, our governess, took advantage of my distress at noise. She used sound as a means of punishment. If I daydreamed, my spoon in mid-air, while eating lunch, Miss Cray would say, "Temple, eat. If you don't finish your soup right now, I'll pop a paper bag at you." She kept a supply of paper sacks on top of the refrigerator so that she could burst them in my face if I misbehaved or drifted away from the world of people (Grandin & Scariano, 1986, p. 24-25).

Authors used a variety of coping and compensatory strategies to manage their experiences. These included attempts to block out problematic auditory and visual events; escape from or avoidance of unpleasant events and situations, refusal to participate in activities associated with these events and active participation in therapy aimed at reducing sensory sensitivity. The analysis also suggests that the developmental course of these hypersensitivities is not straightforward. Although most accounts suggest that hypersensitivities were present throughout childhood, one author does described hypersensitivity on her scalp and hair, and hypersensitivity to smell, as developing in middle childhood. Some hypersensitivities were also described as continuing into adult life.

Hypo-sensitivity

Hyposensitivity refers to a diminished awareness or 'reduced intensity' experience of sensory events. Analysis of the accounts provided evidence of hyposensitivity to internal body states such as pain, temperature, hunger, bowel and bladder signals. Poor proprioceptive awareness was also described by some individuals as leading to poor sense of the physical self and poor sense of body boundaries. The analysis indicates that hyposensitivity is not an 'absolute' experience: there was some variability in the degree of awareness of these bodily signals and very intense sensation could be perceived. For example, Williams (1994) suggests that her hypo-sensitivity to pain did involve some awareness of sensation, although this was not perceived as 'painful'

> An eleven-year-old had greeted me by sinking his teeth deeply into my arm. There was a funny sensation to which I didn't know how to respond. The boy jumped away from me like something possessed. To his shock and horror, I hadn't reacted. The other two workers were surprised at his reaction. 'Take a

> look at that,' said the worker who'd hired me. 'He can't make sense of your reaction. Didn't it hurt you?' 'I think so,' I responded, not quite sure, but sure from their responses that it should have. You should have said "ouch", I reminded myself silently. People say "ouch" if they get bitten.' I told myself I'd remember to say it next time (Williams, 1994, pp. 26-27).

The analysis identified a number of strategies which were adopted by authors to deal with these difficulties. Examples include the use of occupational therapy techniques to improve body awareness or 'scheduling' of visits to the toilet to compensate for poor awareness of these internal sensations.

Sensory-based world

The study provides strong support for the concept of a primary attentional orientation to the physical and sensory world rather than the social world of people. The analysis identifies an early experience of the world in which awareness, interest, curiosity and exploration are embedded in detail of the physical and sensory world. This sensory-based world is described as a self-contained world, distinct from the social world. The experience is characterised by a sense of timelessness and absorption in detail. There is a strong sense of lack of intuitive connectedness with people and a preference for the non-social world. In a number of accounts people are first described in terms of their intrusion or impact into this sensory world. In these accounts the authors describe only gradually becoming aware that people are different from other objects. Jolliffe, Landsdown and Robinson (1992) recall the self-contained nature of this sensory world in early childhood:

> I spent a great deal of my time alone in my bedroom and was happiest when the door was closed and I was by myself. I cannot remember ever thinking about where my mother, father, brother and sister were. They did not seem to concern me. I think this was because I did not for a time realise that they were people and that people are supposed to be more important than objects.
> (Jolliffe, Landsdown & Robinson, 1992, p. 12)

The analysis indicates that the sensory world has affective salience and is the source of a range of positive emotional experiences. Authors describe a sense of congruence, control and security arising from immersion in the sensory world and intense pleasure in particular objects or activities. In contrast, the analysis suggests that interactions with people are difficult. The analysis provides evidence from a number of accounts of difficulty in tolerating eye-contact and, with the exception of one author, in dealing with close physical contact and affection. A number of authors describe a sense

of bewilderment or anger that people did not understand or respect their attachment to the sensory and physical world.

The analysis suggests that the lack of intuitive connection with, and understanding of, people leads to the absence of a shared social framework in which to embed experience, and the absence of shared meaning and interpretation. This in turn is viewed as contributing to an over-physical or idiosyncratic framework of interpretation of meaning and connection between events, often based on association. A number of consequences arose from the absence of shared meaning, including examples of false beliefs about the world. Gerland (1997) described an example of an over-physical framework of interpretation:

> ... I connected whatever happened with what I could see. To me, everything boiled down to what I saw, and sight was the most reliable of my senses. It was as if my sight was tangible. I desperately wanted to understand, and this led to theories: if everything looked in a certain way in the living room-the sun shining in through the curtains, the ashtray on the table with a newspaper beside it-and if Kerstin then came back from school . . . I thought that everything had to look exactly the same the next day, for her to come back from school. It quite simply had to be like that. And in fact, it often was (Gerland, 1997, p. 26).

The analysis indicated a gradual move into a more reflective and social world over the course of childhood. Nevertheless, the sensory and object world continued to have some continuing attentional and emotional salience. A number of authors described a feeling of dilemma and emotional conflict in straddling both the sensory and social worlds. A number of accounts suggested that in order to live more fully in the social world, it was necessary to give up some of the pleasure and appeal of the sensory world and the (false) beliefs that supported it. A number of authors perceived a need for continuing vigilance in order to avoid 'regressing' into the tempting pleasure and security of the sensory world of childhood.

Disordered Attention Beam

This study provides evidence supportive of the concept of impaired or disordered automatic functioning of the attention beam. The analysis provided confirmatory evidence of a tendency to function with an over-narrowed or an over-widely focused beam and of the need for 'effortful' attending in order to respond efficiently to the sensory environment.

Over-narrowed beam

The analysis provides evidence of over-narrowly focused attending and evidence that this strongly characterised sensory responding in the early childhood years. The accounts suggested an early childhood experience in which the authors had little awareness of the world outside of themselves and their immediate activity. This was described in a number of accounts in terms of a different consciousness, a 'my world' existence which was separate from 'the world'. An over-narrow attentional beam is considered to be a critical component of this 'my world' existence, together with an attentional orientation to the sensory-physical world and lack of attunement to people.

This intense absorption is associated with descriptions of a lack of response to other (internal and external) sensory events, and to others' attempts to engage their attention. As an example, Williams (1992) described a lack of response to even sudden loud sound due to the intensity of her absorption in 'my world';

> I also had hearing tests because, although I mimicked everything, it appeared that I was deaf. My parents would stand behind me and make sudden loud noises without so much as a blink in response. 'The world' was not getting in. (Williams, 1992, pp. 4-5).

The emotional experience of this state is described in terms of congruence, security and safety. The analysis suggests that, over the course of childhood, authors gradually become more aware of a wider world through the intrusion of people and their demands. Several authors describe early on a sense of jarring, irritation or anger at this intrusion into this narrow world.

The process of becoming more aware of 'the world' is conceptualised as an increasing tendency towards a widening of the attentional beam thus moving from a singular focus on an activity or event to include an awareness of people and a wider environment. The analysis suggests that this widening of the attention beam and awakening to the world of people brings with it a range of difficulties. Efficient attending to, and making sense of, this wider world is described as problematic. All but one of the authors described vulnerability to sensory overload, hypersensitivity, and other sensory difficulties.

As a way of dealing with overstimulation or 'painful' sensation, a narrowing of the attention beam or retreat into 'my world' for periods, was achieved in a variety of ways: focus on repetitive patterns, sounds or movement; focus on sensory detail, or engagement in a particular activity. The analysis suggests that with age, greater social awareness, and motivation to overcome their difficulties, a number of authors tried to avoid the temptation to retreat or succumb to the lure of their 'own world'.

Two-wide beam

The study also confirmed a number of phenomena which are conceptualised as reflecting an over-wide attentional beam. The analysis indicated experiences of 'openness' to overwhelming sensory stimulation in which control and meaning evaporate. Terms such as 'overload' and 'fragmentation' were used to describe an experience of the world in which incoming information was experienced as a confusing and overwhelming mass of stimulation. A number of authors described an experience in which people and objects were perceived as sensory events only. They could be experienced as a disjointed mass of shape, colour or angles without coherence or wholeness. Other examples suggest an openness to the world in rich detail that floods awareness.

Analysis also indicates heightened distractibility that interferes with concentration to thought or activity and difficulty 'foregrounding' one event from the 'background' cacophony. Vulnerability to distraction or overload was increased in unfamiliar, sensorially busy environments, and in high cognitive or multi-task demand situations. Social situations and the demands of people and social interaction were described in a number of accounts as particularly likely to overwhelm. Other factors such as stress and hypersensitivity could also trigger or exacerbate these experiences.

The accounts indicated that the emotional experience of overload is predominantly one of confusion, fear and panic. It may add to a sense of isolation and difference. Jolliffe, Landsdown and Robinson (1992), for example, suggest that the confusion of events and situations caused a high level of fear:

> Trying to keep everything the same reduces some of the terrible fear. Fear has dominated my life. Even when things are not directly frightening I tend to fear that something horrible might happen, because I cannot make sense of what I see. Life is bewildering, a confusing, interacting mass of people, events, places and things with no boundaries (Jolliffe, Landsdown & Robinson, 1992, p. 16).

The analysis suggests that a range of coping or adaptive strategies are used to deal with the experience of overload. These include 'escaping' to or seeking out a less stimulating environment, self-injury, self-stimulation, retreat into 'own world', and dissociation. In at least some individuals , the experience of very severe overload precipitates a dramatic and involuntary 'shutdown' reaction. This was described variously as a state of catatonia, sensory immobilisation, temporary functional deafness, blindness and dumbness, or inability to 'register' sensory information.

Effortful Interpretative Attending

The analysis also provides evidence that selective attending to sensory events is effortful and energy sapping. Accounts indicated a range of experiences that are conceptualised as resulting from a lack of automatic adjustment of the attention beam. These include the need for effortful screening out of other background cacophony in order to attend to one event, difficulty in making sense of complex and dynamic stimuli, and delay in orienting to, and responding, to sound. Because efficient attending is effortful, accounts suggest that a range of factors impact on the ability to attend for meaning: stress and anxiety, energy levels, multiple or complex task demands, sensorially busy environments, familiarity or unfamiliarity of the situation, and also participants' interest and motivation. A number of accounts suggest that this variability in efficient attending can be misunderstood by others as evidence of laziness or defiance. Gerland (1997), writing about the strain of listening in a noisy environment, explains how the nature of her difficulties were misunderstood:

> I kept trying to hold up a wall in my head between listening and everything around me so that the two shouldn't get mixed. Every sudden sound meant risking losing hold of the wall. With one 'hand' I held the wall up between the sounds, and with the other I tried to clean out my ear so that no new rubbishy sounds got in the way of what I was trying to listen to. With my third 'hand', the one I almost didn't have, I tried at the same time to sort out the information, the content of what I was listening to. This required total concentration, but no one could see what an effort it was. The fact that on certain occasions I was actually able to listen seemed to emphasise the adults' theory that it was only laziness and disinclination on my part that made me often hear nothing at all. (Gerland, 1997, p. 95).

Authors found a number of different strategies helpful in facilitating the process of attending; doodling was described by one author as helpful in certain situations, and listening to music as calming and helpful by another. Cutting down on the amount of extraneous sensory information was also identified as helpful. With age and increased social awareness individuals were more likely to 'work at' attending and less likely to use less helpful strategies such as retreating into the narrow 'own world' to deal with their difficulties.

Specific Aptitudes and Deficits

The analysis provided evidence of additional perceptual anomalies. These included a problem in depth perception leading to the experience of two- dimensional vision, face blindness (prosoprognosia), and 'seeing in pieces rather than whole'. One author

described her vision as two-dimensional. This was described as leading to difficulties in understanding basic aspects of the physical world (e.g. that houses in the street have depth and are therefore lived in), but also as contributing to exceptional drawing ability. Difficulty in recognising faces was described by two authors: one describes seeing faces as empty outlines or contours, the other as seeing faces as either empty outlines, or, as parts only but not as integrated wholes. This author also described this tendency to see in parts as also pertaining to other objects such as pictures.

The analysis identified a number of other anomalous sensory experiences. These experiences include descriptions of generalised sensory pain, intense unpleasant sensation in a specific area of the body, and a craving or need for deep-pressure touch. The pursuit of strategies and experiences to alleviate these problems are described as having had, or as continuing to have, a very significant impact on their lives.

> There is a constant, low-intensity pain going through me at all times. Sometimes it is not so low-intensity. And there are many things that I want to do, many things that I know that I should be doing, and sometimes I cannot do these things because I have to put that energy into dealing with this pain. This I find to be very frustrating (McKean, 1994, p. 63-64).

One author also described synaesthetic-type experiences. These were described in the perception of some specific objects and in the perception of emotion:

> If I was made to touch jewellery, I felt a sharp whistling metallic noise in my ears, and my stomach turned over. Like a note falsely electrified, that sound would creep from the base of my spine upwards until it rang in my ears, tumbled down into my throat and settled like nausea in my stomach. These physical sensations produced by jewellery frightened me, and I transferred that terror on to the jewellery itself, so that the very sight of it terrified me (Gerland, 1997, p. 54).

> Everything became a colour inside me - people, words, feelings, atmospheres. Not understanding was faintly orange, a pale orange with sunlight coming through it. Tiredness, what I hadn't the energy to try to understand, came and laid a dark green on top of the orange light and put it out. The dining-room world, the kitchen world and the hall world - none of these had anything to do with each other until a colour made me connect. If my mother said something in a violet-coloured way in the kitchen and two months later used that violet tone of voice in the bathroom, I suddenly realised that the kitchen and the bathroom had

> something to do with each other, so I could begin to find other similarities such as that there was water in both rooms. But the first connection was always via colours (Gerland, 1997, p. 21).

Discussion

Analysis of published and other 'public' first-hand accounts by people with autism provided a rich and informative source of material. Although there was some variability in the degree to which individual authors reflected on their experiences, and in the degree of detail provided, all accounts contained useful recollections and descriptions of their sensory-perceptual experiences. The analysis of these accounts indicates that, as adults, these individuals are able to reflect on their experiences and feeling states in a way which provides useful insights into the nature of their sensory-perceptual functioning, and the factors which influence this. The more rigorous and detailed analysis to which accounts were subjected in this study compared to Study 1, confirms the subjectively perceived significance of sensory-perceptual phenomena in the lives of these authors. Indeed in a number of these accounts, sensory-perceptual difficulties are described as central to the experience of autism.

The analysis of these accounts supports the usefulness of the unifying concept of 'Disordered Attention' proposed in Study 2, in representing sensory-perceptual experience in autism. The accounts of these authors provided evidence for, and expanded understanding of, the major analytic categories developed in Study 2: the concepts of disordered attention beam, of a sensory based world, of a perseverative bias and of sensory-perceptual hyper-sensitivity. However, the analysis suggests that the concept of hypersensitivity is most usefully viewed as part of a wider category of sensory difficulties which include hyposensitivity and problems in detecting internal body states. It suggests that hypersensitivity and hyposensitivity can usefully be viewed as opposite polarities on a dimension of 'Faulty Modulation'.

The analysis also highlights individual variability in the extent to which the major categories are evidenced in individual sensory-perceptual functioning, thus supporting the notion, developed in Study 2, of a continuum of impairment in each of these constructs.

A number of additional sensory-perceptual difficulties not described by participants in study 2 are also identified within the analysis of published accounts. The additional sensory difficulties identified include chronic body pain, unpleasant sensation in particular areas of the body, craving for deep-pressure touch, and synaesthetic-type experience. These phenomena are identified as having significant emotional, behavioural and social impact. However, understanding of these phenomena and how they relate to the constructs generated in this analysis are poorly understood.

The analysis also highlights change in sensory-perceptual experience over the course of development. The tendency to over-narrowly focused attending and orientation to the sensory world are most pronounced in childhood. Although detail of developmental course and progression of all key aspects of sensory-perceptual experience is not always clear in these public accounts, there is evidence to suggest that as insight and social awareness improve with age, there is greater control over the perseverative bias. The pattern of developmental change is less straightforward however, than suggested in Study 2. In Study 2 a gradual attenuation in difficulties with age was suggested. In author accounts there is evidence that specific aspects of hyper-sensitivity may develop for the first time in middle childhood and that other sensory difficulties may come and go over the life span.

This study provides support for the finding in Study 2 that aberrant sensory-perceptual responding in autism is the outcome of interaction of multiple processes. These processes are represented in this analysis by the four major constructs of disordered attention beam, sensory-based world, perseverative bias and faulty modulation. A category of sensory-perceptual 'aptitudes and deficits' is also identified. In addition factors such as emotional state and developmental processes impact on these processes leading to dynamic and changing sensory-perceptual experience.

Conclusions

The findings of this study provide further evidence that anomalous sensory-perceptual reactions in individuals with autism are complex, multi-component phenomena. The study suggests that 'difference' or impairment in a number of key aspects of the attentional system are central to understanding sensory-perceptual functioning in autism. The study confirms the core elements identified in study 2: disordered attention beam, sensory-based world, perseverative bias and hyper-sensitivity. However in this study analysis of accounts suggests that hyper-sensitivity is only one aspect of a wider category of disrupted functioning in the modulation of sensory intake, termed 'Faulty Modulation'. The study suggests that in childhood sensory reactions are strongly characterised by an over-narrowly focused attention beam and that orientation to the sensory world is at it's strongest in the early years. Understandings from this study which are considered 'additional' to those developed in Study 2 can be summarised as follows:

- Hyper-sensitivity is one polarity of a wider construct of 'Faulty modulation' with hypo-sensitivity as the other polarity
- Over-narrowed attention beam strongly characterises sensory-perceptual experience in early childhood
- Within the category 'Aptitudes and Deficits' a number of additional perceptual difficulties are described. These include face blindness, seeing in two-

dimensions and seeing in parts. Other unusual sensory experiences include whole body pain, unpleasant sensation in specific areas of the body and synaesthetic-type experiences.

- The developmental course of aberrant sensory-perceptual experience is variable and does not necessarily follow a 'linear' progression of gradual attenuation over time,

The next chapter (Chapter 7) will report on a further investigation of the validity of the model developed in Study 2, through a process of Respondent/Cohort Validation. In the final chapter (Chapter 8) the findings from all of the studies will be integrated and discussed.

Study 5

Introduction

Process issues

An important element in the design of this investigation is the incorporation of respondent validation of the emerging findings. However, as the investigation progressed it became apparent that the original intention to revisit the participants in Study 2 for the purposes this 'face to face' validation was no longer feasible. Due to interruption of the research schedule there was a considerable time delay between the initial research interviews and completion of the analytic account. During this period I became aware of clinical issues to do with some of the participants that would made further interviewing an unwarranted intrusion in their lives. For this reason, I made the decision to use a less intrusive approach that offered participants the opportunity to provide feedback on a written summary of my findings via telephone, e-mail or letter. In addition I decided to seek feedback from a wider group of people with autism via the Internet.

In presenting respondents' feedback I made the decision not to edit the accounts for spelling mistakes or other errors. Respondents' feedback is presented, with the exception of font style and size, in the written format in which it was received. This has been done in order to preserve the immediacy and feel of each respondents's feedback. In some cases in particular, the style and manner in which the feedback is written seemed to me important in highlighting the particular contribution and personality of the respondent.

Respondent and Cohort validation

Feeding back findings to participants in the research process with a view to seeking their feedback and comment (respondent validation or 'member checking') has a long tradition within the qualitative research literature. This process has been viewed as a source of phenomenological validity (Bronfenbrenner, 1976) and as a way of ensuring confirmability of findings (Guba, 1981). Others have argued that going back to participants with tentative findings and refining them in the light of participants' feedback is one hallmark of good qualitative research practice (Reason & Rowan, 1981). Feedback may be given during the data collection and analysis phase or at the end when a final account is presented (Melnick & Beaudry, 1990). However, giving feedback at the end when findings are clearer has been advocated as preferable (Miles & Huberman, 1994). Other researchers have argued that respectful/ethical research practice dictates that feedback should be given to participants as a way of informing them of what the researcher has found (Stake, 1976). Reservations have, however, been expressed about a reliance on respondent validation as the only strategy to ensure interpretative validity of

findings (Mason, 1996) and a number of researchers have advocated the use of multiple strategies to verify findings (Silverman, 2000).

A decision to use respondent validation and to use it towards the end of the investigation was made early in the research process for two main reasons. The first was its usefulness as one of a number of strategies (including triangulation, constant comparison and negative case analysis) to assist in ensuring the validity of research findings. The second was for quasi-ethical reasons, in order to respect the contribution of each participant in the research process and their right to know the outcome of the research in which they took part. The decision also reflected the researcher's commitment to ensuring as far as possible genuine equality and collaboration with participants in the pursuit of better understanding of this aspect of their experience. It was intended that findings would be reviewed critically in the light of respondents' feedback. However, as the investigation progressed it became clear that going back to the original participants in Study 2 for the purposes of face to face respondent validation was problematic.

Cohort validation has been used as an augmentative strategy, or as an alternative strategy where going back to original participants is not feasible. This process involves bringing findings back to another group or sample from the same target population to seek their views and observations (Adams, 1996). In the present study therefore a combination of both respondent and cohort validation was considered the most useful way of achieving the research aims.

In order to achieve meaningful respondent or cohort validation a number of difficulties must be overcome. Most critically, the account must be presented in a way that the reader can understand and relate to their experience and observations. Mason (1996) cites the experience of Skeggs (1994) where this was not achieved: the most common response from her research participants to reading an account of her findings was 'Can't understand a bloody word it says' (1994, p. 86). For this reason, throughout data analysis and write-up of the analytic accounts, a conscious decision was taken to eschew as far as possible the use of jargon or technical terms, and references to the psychological or qualitative research literature with which respondents might be unfamiliar.

A further difficulty relates to finding appropriate access both to respondents and to a wider cohort of individuals with autism. With regard to the original interview participants (Study 2) and their parents (Study 3) it was decided to seek a non-intrusive approach to respondent validation. This involved sending a written summary of the findings of Study 2 to those interviewed, via parents. Participants could then respond if they wished via telephone, e-mail or landmail. In terms of cohort validation it was decided that use of the Internet offered a useful and convenient opportunity to seek the views of a wider group of individuals with autism. The use of the Internet for research

purposes has grown rapidly in recent years (Michalak & Szabo, 1998). This is particularly the case within the field of autism, and a number of studies have now been carried which have used public information posted by individuals with autism as a data source (Jones, Zahl & Huws, 2001; Jones & Meldal, 2001).

Recruitment of participants with autism via the Internet is facilitated by the existence of a growing number of discussion groups and chat rooms dedicated to individuals with autism and/or their families. A number of sites contain sections specifically for notification of research projects, recruitment of participants or active research purposes (e.g. http://www.users.dircon.co.uk./~cns/index.html). Guidelines with regard to Internet based research have also been developed to promote ethical research practice (Childress & Asamen, 1998).

The aim of this study was to gain feedback on the analytic account of sensory-perceptual experience in autism developed in Study 2, from the participants in the study, from their parents, and via the Internet from a wider group of individuals with autism. This feedback would then offer an opportunity to critically review the usefulness of the account in representing sensory-perceptual experience in higher-functioning individuals with Autism and Asperger's Syndrome.

Method

Procedure

In order to achieve meaningful feedback from the individuals with autism and their parents who participated in Studies 2 and 3, and to make the account of findings more accessible to a wider audience of people with autism, the account developed in Study 2 was summarised in a condensed format and written in 'plain English', avoiding the use of jargon or technical terms (see Appendix 13).

Respondent Validation

All parents and participants who had participated in Studies 2 and 3 were sent the summary of the analysis. They were invited to provide feedback via telephone, e-mail or letter (Appendix 14). Seven individuals with autism and their parents were invited to provide feedback in this part of the validation study.

Cohort Validation

In this part of the validation study, feedback on the summary of the analysis was sought from a wider audience of people with autism. This involved three different channels of approach:

1)Posting a message inviting participation in the study on two Internet forums: a major e-mail discussion group used by people with autism (AUTINET@listserve.iol.ie), and on an Information and Support website which had a 'Call for Volunteers' section specifically for researchers wishing to recruit participants for autism related research projects (http://www.users.dircon.co.uk./~cns/index.html). The message posted (and subsequent e-mail contact with potential participants) made clear that respondents in the study should have received a definite diagnosis of Autism or Asperger's Syndrome (see Appendix 15).

In total seven enquiries from individuals representing themselves as having Autism or Asperger's Syndrome were received through this approach, all of whom were sent consent forms (Appendix 19) and copies of the analysis. Completed consent forms and feedback was received from four of the seven individuals. Family members who indicated their interest were not included in the study.

2) Visiting personal websites of people with autism who share information about aspects of their life and identifying those who invited e-mail contact and provided e-mail addresses. A number of these individuals were then e-mailed with a standard message outlining the nature of the research and invited to respond if they were interested in participating in the research (see Appendix 17). In total five people were contacted in this way. Two individuals responded to affirm an interest and subsequently provided feedback.

3) E-mail contact attaching a summary of results were sent to two internationally known individuals with autism whom the researcher had met some months previously at an international conference on autism (Appendix 18). These individuals had expressed interest in providing feedback on my research. Feedback was received from both of these individuals. (Note: The autobiography of one of these individuals was also used in Study 4).

Participants

Feedback was therefore received from a total of ten respondents. Of these, six were 'Internet' responders, two were published autobiographers, one respondent was a participant in Study 2 and one was a parent interviewed in Study 3. Of the nine individuals with autism who responded, six were female and three were male.

Data Analysis

Respondents' feedback was analysed as follows:

(i) Each respondent's feedback was read individually a number of times, noting down points of affirmation, disagreement, and additional or augmentative observations with regard to each of the core categories of my analysis.

(ii) More general comments on my analysis were also extracted from each feedback, again noting areas of agreement, disagreement, additional or augmentative observations, cautions and other comments relevant to my analysis.

(iii) where reported, a note was taken of the range and type of sensory-perceptual phenomena experienced by each participant. These included phenomena not previously identified in earlier studies.

(iv) the comments from individual respondents were then summarised together under the following category headings:

General Comments
Impaired Attentional Beam
Sensory-based World
Perseverative Bias
Hyper-sensitivity

A summary of this analysis is presented in the 'Results' section below. A more detailed analysis with extensive verbatim data from respondents' feedback is contained in Appendix 19.

Results

Feedback

The nature of the feedback I received varied from individual to individual. Five provided detailed reports of their own sensory experiences together with more general comment on my analysis. One respondent provided a very detailed accounts of his own sensory-perceptual experience but little overall general comment on my analysis. Another respondent provided only an overall general comment on my report. The respondent who had taken part in the interview study responded with specific comments on aspects of my analysis but understandably did not provide details of his own sensory-perceptual experience since these were already known to the author. Another respondent (published autobiographer) confined her comments to specific aspects of my analysis and contrasted these with her own theoretical position on the nature of the autistic condition. The parent respondent provided comment on both the range of experiences reported and on the analysis. For the purposes of this analysis the comments of the parent respondent will be separately identified from those of the other respondents.

Analysis

General comments

This section deals with general comments about the research, and observations on the analysis as a whole. With some cautions and reservations that will be described later, those who expressed overall evaluative observations on my analysis were positive in their comments. In addition to positive observations about content, the feedback also contained comments welcoming the focus of the research and expressing appreciation of the opportunity to provide feedback. This included comment on the positive value of self-reflection that was offered by involvement in the study.

> R1: Wow! Interesting. Fabulous! You should write a book on the sensory-perceptual experiences of autism. This is something of major importance for people to know about. Fascinating! Let me begin my comments by saying that I am an autistic gentleman of 57 years of age. I find your analysis of the sensory-perceptual activities to be absolutely astounding. I may indeed be an ideal case in regards to your analysis. I have experienced about 95 percent of all the things that you have described in your report. ... I agree with most of your analysis.

Two respondents took issue with the what they saw as negatively value laden terminology which they felt devalued autistic experience in comparison to neurologically typical (NT) norms. In particular terms such as 'disordered', 'naive wonder' and 'literal' drew strong censure. These respondents provided strong argument for a more respectful language of difference (as opposed to that of dysfunction or deficit) that would serve to emphasise the positive strengths and contribution of their experience and view the world.

> R8: .. If folk only see our difference in the terms of disorder, dysfunction and so on, then they may fail to see the benefits of being singly minded, singly focused etc.

The feedback also highlighted a number of potential limitations of the research investigation and resulting analysis. One respondent highlighted the potential risks for her in honestly articulating the nature of her world experience to an 'NT' audience who she considered might use pejorative frameworks for interpreting 'difference'. This respondent also drew attention to the problem of finding a 'communication system,' common to respondent and researcher in which experiences could be adequately

communicated and understood. As a visual thinker she described the difficulty she and many other people with autism who also 'think in pictures' have in translating the richness and fullness of their experience into the 'foreign language' of words. An implication of her position is that the researcher may have the reverse difficulty, and as a result may make false or 'culturally unfair' assumptions about the nature of the other's experience. These concerns, if shared by others with autism, may be seen as limitations for the researcher in accessing full disclosure and understanding of sensory-perceptual experiences through approaches which utilise self-report.

> R6: I feel like I am trying to explain all of this in a foreign language.
> I am very very picture oriented.
> Using words to fit the pictures inside my head
> is like putting a square peg in a round hole.
> Just because I have a limited vocabulary in the world of words
> does not in any way mean my world inside of me
> is so limited.

In terms of overall analysis, one respondent suggests that my analysis, of which she was generally supportive, is insufficient to account for sensory-perceptual experience in autism. She posits, in addition, a problem with habituation and an orientation to detail rather than the whole.

> R9: I find your theory of attention interesting but not sufficient for explaining the problems with sensory processing. I would like to enter also a problem with habituation (delayed) (what you at the end mention as getting used to) and a perception which is orientated towards detail rather then wholeness into that theory.

There was comment also on the specificity or otherwise of unusual sensory-perceptual experiences to autism. While viewing these experiences as more highly typical of people with autism one respondent nevertheless quite correctly points out that people without a diagnosis of autism may also experience unusual sensory-perceptual phenomena.

Impaired Attentional Beam

The concept of an impaired attentional beam received very positive affirmation in respondents' feedback. All respondents identified difficulty in flexible and automatic attending to events around them in keeping with core elements of the analytic account. Respondents highlighted difficulties congruent with the idea of an attentional beam that can be 'too-wide' or 'too-narrow'. They identified delay or difficulty in switching attention flexibly from one attentional focus to another in order to fully make sense of events around them. The feedback also provided support for the notion of difficulty in maintaining efficient selective attending to events, especially in sensorially busy environments. This is described by a number of respondents as effortful and problematic.

> Parent: I liked your notion of a beam of attention which narrows and widens and your subsequent discussion of how participants' attempt to control their focusing of attention. Your analysis does ring true and makes an interesting and novel contribution to our understanding.

> R5: I find it hard to concentrate when I'm in busy, high visual and auditory stimulus environments such as my workplace, stores and other crowded areas. Trying to attend to everything that's happening also makes me experience "inner noise," which are thoughts jumping around in my head. At these times I'm disorganised and jump from task to task.

Respondent feedback also supported the idea that a range of factors such as interest, motivation, mood state, energy level and activity affect the efficient working of the attention beam. Doodling is identified as helpful in facilitating the ability to selectively attend in some situations e.g. the ability to listen in situations such as lectures. However, respondents' feedback indicated that the idea that the working of the attentional beam becomes more automatic and reliable with age is true for some individuals but not for others.

> R6: I am not a person whose senses have calmed with adulthood. I have no idea what the people who told you they are doing better with these things were talking about. For me my IQ has figured out more coping strategies. But nothing stops the wide beam as you would call it. I am always at risk for sensory overload.

The feedback offered some support for the 'deliberate' narrowing of the attention beam as an adaptive or coping strategy, described by one respondent, as 'tuning out the world that hurts me'.

Feedback also provided some tentative support for the notion of an involuntary shut down under sensory overload. One respondent reported that overload can lead to 'switch down' but this is not described in detail. However, the term does resonate with 'shutdown' as described in the published accounts. Respondents' feedback also suggested that sensory overload can lead directly to challenging behaviour.

The feedback from two respondents suggests that other conceptualisations of the phenomena are also possible. One respondent had previously considered Central Auditory Processing Disorder (CAPD) as a possible explanation for some of her difficulties with sound. Nevertheless this respondent considered the notion of a disordered beam as making sense of her experiences. However, the second respondent offered only qualified support to the concept of a disordered attention beam. While pointing out that we may be talking about the same thing using different language, she proposed an alternative conceptualisation of the experiences represented in 'disordered beam'. This respondent proposed the concept of 'monotropism' to describes her tendency to function, with what in the researcher's framework would be conceptualised an over-narrowed attentional beam. This respondent viewed sensory overload and/or shutdown as being the result of information being presented simultaneously through multiple channels, to an attentional system that can only deal with one channel at a time:

> R8: When you talk (write) about 'disordered attention' I experience this not as 'disordered' but 'ordered' attention. It is selective, not so much by choice as by my being monotropic and only able to focus in on one thing at one time. ... It's the same with my senses and emotions. I 'home in' (as it were), (so to speak), on only one element at a time. If more than one is presented to me then I only 'see', hear, taste, smell, feel etc. one and the other either moves into the background, gets missed or, if it is very intrusive, it may prevent me from giving my attention to anything! ...When lots of 'channels' (visual, auditory, tactile etc.) are challenged simultaneously, or when I am tired and not so able to cope, then I can experience 'over load' and may either switch down or explode!!

The experience of being 'only able to focus on one thing at one time' is echoed by another respondent, (R7) who writes of a 'need' to focus on one thing at a time. Within this researcher's conceptual framework this evidence would suggest that some individuals have a tendency towards operating with an over-narrowed attentional beam. Others, such as R6 above, are prone to operating with an over- wide attention beam.

Feedback from one respondent suggests that the lack of automaticity in the working of the attention beam should be seen as part of a wider difficulty with automatisation which affects all aspects of her functioning.

> R9: The problems with perceptual automatisation are very accurate described, and I personally believe you could use the automatisation thought on other parts of the disorder (social difficulties, for instance). I have for example also poor motor automatisation which means I have to concentrate on movements too. The problem is that we don't know exactly what 'automatisation' is and where in the brain it is located.

Sensory-based World

The concept of a sensory-based world resonated strongly within respondents' feedback, with all respondents offering comment supportive of the idea. There was support for an attentional orientation to, and comfort in, the physical and sensory world and for a corresponding difficulty with people and the social world. A number of elements are represented in respondent comments: the sensory world is described as less problematic than the social world (where interaction may be problematic or unpleasant); there is a lack of emotional connectedness to people and a heightened emotional salience of the physical -sensory world, and an absence of the usual distinction between the animate and inanimate world. Feedback also indicated particular difficulty with social or affectionate physical contact.

> R1: Attentional orientation to a sensory world. This describes me to a T, as well as from A to Z, exactly as you have described it. ... A problem in understanding people and emotion. And the physical world is less problematic than the social world. You got it, Meena. That's it, definitely. And I am constantly gazing at anything and everything but people.

Analysis of feedback identified a number of ways in which the sensory, physical world has emotional salience for respondents. It is described as a source of pleasure, a source of comfort and protection, and a source of companionship. One respondent suggested that because she finds no comfort in the social world, she has had to find it elsewhere.

Respondents offered differing views on the nature of the relationship between their social difficulties and their sensory-perceptual functioning. Feedback from one respondent suggested that her problems with people and her preference for objects stems from sensory-perceptual difficulties, and in particular, her low threshold for sensory overload. People are described as too complex and stimulating. Other feedback identified a primary problem in understanding and relating to people that leads to a focus on the sensory-and physical world. The interaction between the absence of social connectedness/a shared social framework for viewing the world, and attentional

difficulties is highlighted by another respondent. For this respondent both these elements combine to make social interaction difficult:

> R3: But even "every day" kinds of one-on-one interaction - e.g., with a co-worker or with a store clerk - are socially wearing on/for me. In social situations we must strive not only to focus that attentional beam but also, simultaneously, to sort through all the potential objects of focus and identify the ones deemed appropriate by "normal" people. And we must hold that focus while excluding from our "beam" all the other potential objects of interest. It ain't easy.
> ...There are some subjects and some ideas (even some terms) on which I have an incredibly hard time making myself focus, simply because I am unable to want to. It's as if the parts of my brain that are supposed to handle those subjects/ideas/terms are supposed to have a sticky surface (like Velcro) but instead are smooth and slippery. The ideas slide right off every time, along with my attention.

Other aspects of the concept to receive support included the notion of a grounding of awareness in the present and a literal and concrete way of interpreting experiences. One respondent however, took issue with the notion of non-reflective awareness. Instead, she identified a 'difference' in the way that she reflects on her experiences arising from her visual thinking style:

> R6: I finished your paper.
> The only thing I that stands out
> is the assumption that there is
> non-reflective sensory experience vs reflective social experience
> that I supposedly evolve into
> to fit into the NT world.
> Again just because
> I don't always have words from you language
> to describe
> my wonderful sensory experiences
> doesn't mean
> it is non-reflective.
> It may be non-reflective as far as the english language is involved
> but believe me
> I have hundreds of pictures going through my system,
> connecting to the picture in front of me.

> Yes, I am collecting all the data from the picture in front of me.
> Experiencing it totally in the moment.
> But I can't stop all the other pictures being there too.
> ...I was processing and reflecting in my own way
> I just couldn't give
> back the formulas I was developing
> in an NT way.

The parent respondent suggested that the concept of the physical-sensory world should include the insect and animal world. Relating to this world is contrasted with problematic relating to the 'human' world. This respondent suggested that the problem lies with the system of human communication that people with autism find difficult.

> Under a sensory world you stress that attention is rooted in the physical and sensory aspects of the world and stress that this contrasts with interest in or awareness of people. My reaction is that the physical world includes animals and insects which can also become preoccupations, perhaps because they do not use human gestural, facial and verbal intonational modes of communication which autistic people find difficult.

Peresverative Bias

Respondents' feedback also provided support for the concept of a deeply ingrained bias to repetition and sameness. There was support for the idea that events already within awareness tend to repeat or stick, for an orientation to repetitive and predictable events, and support for a general preference for sameness that pervades many aspects of life. In addition, there was evidence of repetitive behaviour. Feedback suggests that this bias results in difficulty switching attention from one focus to another.

> R2: I do like repetitive, blinking lights, "psychedelic" light shows, screensavers, stuff like that to watch over and over. Get a bit entranced by this kind of thing and have done so as far back as I can remember.

Analysis of respondents' feedback identified a number of factors which may contribute to comfort in repetition and sameness. These included the effort involved in shifting attention and, in the context of being easily overwhelmed by the unexpected, the feeling of control and of being prepared that is offered by repetition and sameness. Stress and unpleasant events are identified as exacerbating the tendency towards perseverative thought

R6: But also there is something going on
inside my brain in which pictures and sounds
get caught in a loop so to speak.

...These things happen more often when I am overloaded
from all the sounds that do not match me.
In particular when too many people
have talked to me.

Then their sounds get trapped inside my brain
and it takes a long long time to let go of them.
Even the sound of my own voice
can haunt me for hours.

Respondent 1 included repetitive and stereotyped behaviour and movement as another strong manifestation of this tendency. He reported that once started on an activity he keeps on going and can find it difficult to stop. However, another respondent felt that the tendency towards repetition and sameness is overstated within my analysis. Instead he suggested that any reluctance to engage with change is limited to what is perceived as 'adverse' change. He cited as evidence the fast pace of change in Information Technology, a field which attracts many people with autism:

R7: However, I think the idea that autistic people are averse to change is overstated. It would be more accurate to say that autistic people are adverse to change which seems to be for the worse. I think you'll find that a lot of Asperger's people do well in information technology, and not many fields change faster than that, but most of the change there is for the better.

Hyper-sensitivity

There was strong support in respondents' feedback for the category of hypersensitivity. However, taken as a whole their feedback suggested that this concept alone is inadequate to account for the full range of, and variation in, respondents' experiences. These experiences included hyposensitivity to internal or external sensory events and for some individuals fluctuation in the intensity with which events were experienced.

General hyperacuity or an 'amplified intensity' experience of sensation was indicated in respondents' feedback. In addition, there was support for problematic sensitivity to particular stimuli. A high degree of variability between individuals in relation to this aspect of their sensory experience was also confirmed. Only one respondent, R7, indicated that hypersensitivity was not a feature of his sensory-perceptual experience.

Feedback indicated that an amplified intensity experience could occur in a number of modalities or could be confined to one modality. This included hypersensitivity to pain and other forms of bodily discomfort. Problematic sensitivity to specific stimuli could occur even within the context of a general sensory impairment within the same modality. Tactile hypersensitivity is reported by two respondents as underlying problems with social touch.

> R6: My mother has always felt very rejected by me.
> Well, she did typical female types of affection with me.
> She tried to hold me and rock me and hurt my skin.
> Her higher pitched voice hurt my ears.

Frustration is identified by one respondent as triggering or exacerbating hypersensitivity and in turn hypersensitivity may precipitate outbursts of aggressive and challenging behaviour. Respondent feedback also indicated that hypersensitivity attenuated with age in some individuals. For others it continued or even exacerbated with age.

Hypo-sensitivity

Respondents' feedback also provided evidence for a category of hyposensitivity or under-reactivity which can be considered as a 'reduced' as opposed to an 'amplified' intensity experience of sensation. Feedback suggested that for some individuals this can lead to seeking out high intensity experiences. Feedback also suggested that hyper-sensitivity in one modality can exist alongside hypo-sensitivity in another and that hyper- sensitivity to particular events can occur even within an overall context of hypo-sensitivity within the same modality e.g. smell. Poor proprioceptive awareness and

hypo-sensitivity to internal body states was reported as a problem by a number of respondents.

R6: There is a connection missing between me and this body.
I don't understand I am hungry.
And when I start to eat
I don't understand I am full.
I don't think I run into furniture that has been in the same place
for years
because I am not paying attention.
I think I can't feel the space my body occupies
and so I miscalculate the space between me and the solid
body in which I run into.

Feedback suggested that for some individuals, modulation of sensation fluctuated between over-reactivity in one situation to under-reactivity in another. In addition hypersensitivity in one modality could trigger hypersensitivity across other modalities in specific situations.

Respondent feedback illuminated the complex nature of under and over reactivity. A number of factors were highlighted by respondents as impacting on their experiences. For example, one respondent suggested that his very high pain threshold was due to an ability to 'screen out' pain while another respondent indicated that an inability to switch attentional focus exacerbated the impact of her sensory difficulties. The issue of control was also identified as important in how sensory stimuli are perceived. Another respondent identified a problem in applying 'general world knowledge' to the self as an important issue in her failure to respond to internal body states:

R6: At first I don't know that I am hungry.
Then I realize I am hungry and I don't seem to understand
that food will help me.
I know food helps others, but why would it help me?

Discussion

The process of seeking feedback from a group of people with autism on the understanding of sensory-perceptual experience developed in Study 2 was pursued through a number of avenues. These included a form of member checking (original interviewees), and cohort validation (wider group) using opportunities offered via the Internet. The process was successful in achieving feedback from an international sample of individuals that was helpful in evaluating the utility and robustness of the developing account. The feedback received provided both additional detail on the range of sensory-perceptual phenomena experienced by individuals with High-Functioning Autism and Asperger's Syndrome and critical comment on the analysis developed in Study 2. This comment clearly indicates that these adult respondents have the ability to reflect on, and report their experiences.

At the most basic level, this study provides considerable support for the finding that sensory-perceptual phenomena are a significant feature of the experience of a number of individuals with autism, and that these phenomena contribute to a range of problematic social, psychological and behavioural consequences. The study confirms individual variability in sensory-perceptual responding. The study also suggests that abnormal sensory responses are complex and dynamic phenomena, subject to a number of environmental, psychological and developmental influences.

In understanding the nature of this complexity, respondents' feedback provides evidence to validate the usefulness of the core analytic construct of 'Disordered Attention System' in representing sensory-perceptual experience in individuals with autism. With some qualifications, feedback was generally positive and supported the categories of 'Disordered Attention Beam', 'Sensory-Based World'; 'Perseverative Bias' and 'Hypersensitivity'. However, this study does suggest a number of qualifications, amendments and additions to the understanding developed in Study 2. The study suggests that the concept of hypersensitivity alone is insufficient to account for a range of related phenomena. Respondents' feedback provides evidence for hypersensitivity as part of a wider problem in 'Faulty Modulation' where hypersensitivity is one extreme and hyposensitivity is another extreme in this wider category. Faulty modulation is reported in relation to both 'internal' and 'external' events.

In relation to 'Disordered Beam', feedback suggests that some individuals may be more prone to 'too-narrow' focus while others may be more prone to 'too-wide focus'.

With regard to 'Sensory-Based World', respondent feedback includes the view that this should also encompass all aspects of the 'non-human world'. Feedback also

suggests that problems with physical contact and affectionate touch may in some cases reflect tactile hypersensitivity rather than a failure in social and emotional connectedness.

The study also indicates that the developmental attenuation in the core constructs proposed in Study 2 requires qualification. Respondent feedback indicates that this is true only for some individuals and that for other individuals, there may be no attenuation or problems may get worse at different points in their lives. Coping strategies may however improve.

The feedback received in this study also highlights a number of other issues in relation to the understanding of sensory-perceptual experience developed in study 2. One issue relates to the terminology used in the account, aspects of which were experienced as pejorative. Instead a number of respondents proposed terminology couched in terms of difference rather than disorder.

Another issue raised is more fundamental and centres on how far it is possible for researcher and participant to find a common 'communication system' in which experiences may be adequately communicated and understood, given that at least some individuals with autism may think in pictures rather than words. Indeed, one respondent takes issue with the account of 'non-reflective' experience as an aspect of 'sensory-based world' for this reason arguing that her way of processing her experiences is difficult to articulate in words. This issue is a general one and pertinent to any investigation of these phenomena utilising self-report. This may be regarded as a limitation on the extent to which self-report is useful in investigating sensory-perceptual phenomena in individuals with autism.

Another issue highlighted was that of alternative or supplementary conceptualisations of sensory-perceptual phenomena by respondents who had reflected on sensory-perceptual experience in terms of scientific or psychological processes. One respondent suggested that additional dysfunction in habituation, and a tendency to perceive detail rather than gestalt is necessary to account for sensory difficulties. Another respondent proposed an alternative conceptualisation of monotropism instead of the researcher's concept of a disordered beam. Additionally respondent feedback raised the issue of how far the sorts of experiences described are specific to autism and/or the extent to which they are shared by neurologically typical individuals.

Limitations of the study

A number of cautions need to be acknowledged in relation to interpretation of the findings of this study. The number of respondents was relatively small (N=10) and so the results are limited by the small sample size. In addition, there is the possibility of a positive response bias in the feedback of those who responded. The feedback that was received, however, offers some reassurance on this point. As well as supportive comment, respondents also qualified or disagreed with elements of the analysis.

A further limitation is that, despite the steps take to minimise the risk, the diagnosis of those who responded as a result of the Internet posting or e-mail contact cannot be independently confirmed. Similarly, the potential presence of additional difficulties or disabilities that might have a bearing on sensory-perceptual experience can not be discounted. Again however, the nature of the feedback that was received, and it's broad resonance with the accounts in other data sources, suggests some degree of confidence in the bona fides of those who responded. The names of a number of those who responded are familiar to the researcher from acquaintance with autism related discussion groups. Two of the respondents are known to the researcher as speakers at autism conferences. There is a danger that this limitation in relation to confirmability of diagnostic status, common to much Internet based research, can be overstated.

Conclusions

The process of seeking feedback from a wider group of individuals with autism was successful in eliciting evaluative comment on the analysis of sensory-perceptual experience developed in Study 2. The findings of this study provided broad support for the validity of the core constructs of disordered beam, perseverative bias and sensory-based world in representing these experiences. In relation to the fourth construct, of hypersensitivity, this study suggests that this is one element of a wider problem in Faulty Modulation that also encompasses hyposensitivity to both internal and external events. In addition to the widening of this category, this study also suggests the following developments of the analysis presented in Study 2:

- Difference or dysfunction in the core elements identified does not necessarily attenuate with age. For some individuals there may be no improvement, aspects of their experience may become more problematic as they get older or they may be variable over the lifespan.
- Some individuals may be more liable to operate with an over-narrow focused attention beam while others may be more liable to operate with an over-wide beam
- Sensory based world may include an orientation to the animal and insect world i.e. all aspects of the 'non-human' world
- Problems with physical 'social' touch may reflect tactile hypersensitivity for some individuals and problems in social-emotional relating for other individuals

In addition this study highlighted potential limitations in the self-report methodology used to investigate sensory-perceptual experience and sounded cautions about the use of a terminology of dysfunction which may be perceived as negative and value-laden by individuals with autism. The question of similarity and difference in sensory-perceptual experience in individuals with autism and in neurologically typical

individuals was also identified as relevant to a full understanding of aberrant sensory-perceptual responding in autism.

In the next chapter the findings of this study will be integrated with the findings of the earlier studies, 2, 3, and 4 to produce an overall analytic account of sensory-perceptual experience based on this series of investigations. In addition the findings will be discussed in relation to existing theoretical accounts of autism. Implications for clinical practice and further research will be explored.

General Discussion

Chapter outline

Section One of this Chapter draws together the key findings from each of the studies and sets out a model for understanding sensory perceptual experiences in autism (in this sense the first section of this chapter resembles the 'Results' section of a more traditional thesis).

Section Two discusses the theoretical and clinical implications of this model and some issues for future research. The limitations of the series of studies on which the model is based are then explored. Finally overall conclusions are discussed. The chapter begins by setting out a number of significant issues with regard to the process of integrating the individual study findings into a coherent framework.

Process Issues

Disorder vs. Difference

In my analysis of interviews with participants with autism (Study 2), I used the terminology of 'disorder' to articulate my understanding of the processes at work. The Respondent/Cohort validation feedback, however, made me aware that this terminology can be offensive to people with autism. At least two respondents argued strongly for a terminology of 'difference' rather than one that pathologises their experience in terms of disorder. One respondent claims that the tendency by non-autistic people to pathologise autistic experience is a reason for caution in being open about her life experiences. This is a difficult issue to resolve. On the one hand, I am conscious of the need not to pathologise the experiences of people with autism in such a way as to create negative evaluation of them as 'less than' their neurotypical peers. On the other hand, the participants, respondents and published 'voices' in my study clearly articulate a range of difficulties and problems with which they have struggled. My understanding of these difficulties does suggest at least a degree of 'inefficiency' in the way incoming information is attended to and it is difficult to convey a sense of this without acknowledging some degree of dysfunction.

I wish to convey a sense in which the life experience of people with autism is different to the experience of the non-autistic majority, but where this difference and diversity is equally valued and respected. In trying to understand the reasons for, and in trying to respect this 'difference', however, there is a need to acknowledge the impairments or inefficiencies with which people with autism live. It is likely that as with the heterogeneity of many other aspects of autism, categorical boundaries between the sensory perceptual experiences of people with autism and those without this disorder are

not clear. Certainly my analysis suggests that the idea of a 'continuum of difference' is important in representing the range of experiences reported by people with autism. This issue is not fully resolved in this chapter.

In the interests of clarity in integrating the findings from the series of studies, I have decided to continue to use the term 'disordered' to reflect the nature of the difficulties represented in the different accounts. This is not intended to diminish the argument for a language of difference rather than disorder, but rather, resolution of this dilemma is identified as an issue for consideration in future conceptual development and investigation.

Integration of Studies

There were a number of issues to be resolved in integrating the findings from the different data sources in a way that did not compromise the validity of each perspective. From a 'positivist' perspective there could be a tension in trying to reconcile 'conflicts' in some of the evidence from different data sources that might be considered by some as 'proof' of the lack of reliability of self-report. For example, parents experienced their child's orientation to the sensory world (and not to the social world) as a more central aspect of their child's behaviour than was articulated by the person with autism. This might simply be because social connectedness is more valued by the parent. Another more specific example is that of one participant who reports no problems with sound sensitivity and yet his parents report a him as having shown a distressed reaction to certain sounds in early childhood that they felt was extreme and unusual. In the individual study analyses I do not challenge the validity of either of these perspectives, since each reflects a different experience of the phenomenon. My primary interest is in bringing together different perspectives in order to extend and enrich a developing understanding of sensory-perceptual phenomena. A necessary part of this is to articulate complexity and diversity as reflected in different perspectives. Thus in representing the participant study I have indicated that this participant does not report sound sensitivity. Similarly in the parent study, the parent report is accepted as evidence of hypersensitivity to sound in the parent analysis. It is, in general, not unusual that a parent would recall aspects of a young child's behaviour that the child might not recall. Each data source has therefore been valued for offering a different perspective on the phenomenon under investigation, but also as an opportunity for 'theoretical sampling' where concepts can be further explored and developed. I have also valued these different data sources as an opportunity to look for new or additional ideas that may be relevant to the phenomenon under investigation.

Having delineated a small number of central concepts in the participant study I wanted to check if these were relevant to understanding the new data provided by parents and by the first-hand accounts. I investigated whether or not the new accounts support

these concepts and looked for any 'contrary' evidence that might have contradicted these ideas. Where new concepts emerged in a data source, I then checked back with the other texts to see whether or not these ideas were compatible with them. Therefore, this series of studies is best viewed as an ongoing process of discovery which facilitates an evolving understanding of sensory-perceptual phenomena in the lives of sampled individuals with autism.

Section One: Review of Findings

The findings from each of the five studies will be very briefly summarised in turn before presenting a more detailed integration of overall findings arising from this investigation.

Study 1: The findings from Study 1, based on a systematic review of the published first-hand account literature provided evidence that unusual sensory-perceptual experiences are a significant aspect of the experience of the minority of people with autism who publish autobiographical accounts. This evidence, together with feedback from parents and professionals, supported the need for further research into the topic of unusual sensory-perceptual experiences in autism. Two questions in particular followed on from this study: Would people with autism from a clinical sample also report these phenomena? If so, what is the nature or phenomenology of these experiences?

Study 2: This study was designed to address the questions arising from Study 1. The findings of this study were based on in-depth interviews with six individuals with autism drawn from a clinical caseload. The study found that unusual sensory-perceptual phenomena were also a feature of the experience of these individuals, and that they had a significant impact on behaviour, psychological state, and social functioning. The study indicated variability in unusual sensory-perceptual experiences between individuals, and within individuals across situations and over time. A range of behavioural and managing strategies adopted by individuals in response to these experiences were identified. The study generated a model for understanding the phenomenology of these sensory-perceptual experiences that centred on the concept of an inefficient and disordered attention system. This model is based on four key constructs: Disordered Attention Beam; Perseverative Bias; A-social Sensory world, and Hypersensitivity. Variation in sensory-perceptual experience between participants is understood in terms of unique dimensional combinations of each of these elements.

In addition emotional state, specific skill aptitudes, and deficits and developmental factors such as maturation, memory and learning were identified as impacting on sensory perceptual experience. The study found that, because of the disordered nature of the attentional system, participants perceived (to differing degrees) a lack of control and mastery over basic perceptual processes. The working of the attention system was identified as becoming more efficient and reliable with age and learning. Major questions arising from this study included (i) the extent to which unusual sensory-perceptual experiences would be confirmed by other data sources and (ii) the extent to which the concept of a disordered attention system and its key constituent elements would adequately represent the phenomenology of unusual sensory -perceptual responding as detailed in other data sources.

Study 3: This study involved detailed interviews with the parents of the seven individuals with autism interviewed in Study 2. The findings confirmed anomalous sensory-perceptual responding as a behavioural feature of their sons' development and confirmed individual variability in these responses. The concept of a disordered attention mechanism proposed in Study 2, was found also to be useful in representing the nature of these phenomena as elaborated by parents. Analysis of parental accounts provided evidence supportive of the key constructs of Disordered Attention Beam, Perseverative Bias, and Sensory-based World. Evidence of 'Hypersensitivity' was also found. The study found that this concept of hypersensitivity was too narrow to represent the full range of unusual 'intensity' reactions described by parents. The study introduced a wider concept of 'Faulty Modulation' to represent both hyper-sensitivity and hypo-reactivity to sensory events, including problems in regulating internal body states that were described by parents as a significant feature of their son's presentation. In addition, the study indicated that an over-narrow attention beam is strongly characteristic of sensory-perceptual responding in early childhood, and added emphasis to the emotional salience of sensory and physical events. The study also detailed the wider impact of anomalous sensory responding on parents and family.

Study 4: This study reported the qualitative analysis of eight published first - hand accounts by individuals with autism as a further data source against which the findings of Study 2 could be evaluated. This study was supportive of, but also extended, the findings of Study 2. The

study confirmed that the core elements identified in Study 2 were also relevant to representing the accounts of sensory-perceptual experience of individuals with autism drawn from this data source (Disordered Attention Beam, Sensory-Based World, Perseverative Bias and Hypersensitivity). In keeping with the findings of Study 3, however, in this study the analysis of accounts suggested that hypersensitivity is only one aspect of a wider category of disrupted functioning 'Faulty Modulation' that includes also hypo-sensitivity to internal sensory events. The study indicated also that in childhood sensory reactions are strongly characterised by an over-narrowly focused attention beam and that an orientation to the sensory world is strongest in these early years. Within the category 'Faulty Modulation' a number of additional sensory-perceptual difficulties were identified: synaesthetic-type experiences, face blindness, low level sensory body pain and intense unpleasant sensation in an area of the body. Findings from this data source suggest that the pattern of developmental change is less straightforward than suggested in Study 2 where a gradual attenuation in difficulties with age was suggested. This study provides evidence that, for some individuals, specific aspects of hypersensitivity, and other sensory difficulties may come and go over the life span.

Study 5: This final study involved the analysis of feedback gathered from nine individuals with autism on the relevance of the findings and model generated in Study 2. In addition, feedback was received from one parent. The study provided evidence to validate the usefulness of the core construct of 'disordered attention system' developed in Study 2. With some qualifications, feedback was generally positive and supported the categories of 'disordered attention beam', 'sensory-based world'; 'perseverative bias' and 'hypersensitivity'. This study suggested a number of qualifications, amendments and additions to the understanding developed in Study 2. In keeping with the findings of Studies 3 and 4, Study 5 indicated that hypersensitivity is part of a wider problem in 'Faulty Modulation' where hypersensitivity is one polarity and hyposensitivity is an other polarity in this wider category. In relation to 'disordered beam', feedback suggests that some individuals may be more prone to 'too-narrow' focus while others may be more prone to 'too-wide focus'. The study also indicates that the developmental attenuation in aberrant sensory-perceptual experience proposed in Study 2 requires

qualification. Respondent feedback indicates that this is true only for some individuals and that for other individuals, there may be no attenuation or problems may increase at different points in their lives. This study also raised a number of other issues in relation to the account presented in Study 2. The first relates to the issue of terminology that has previously been discussed. The others relate to supplementary or alternative conceptualisations of sensory-perceptual experience in autism and possible limitations of self-report methodology.

Integration of findings

The integration of findings from the series of studies outlined above will be presented in two parts. The first part will summarise the overall findings with regard to unusual sensory-perceptual experience in autism. The second part will set out a model for understanding the phenomenology of sensory-perceptual experience in autism developed over this series of studies.

General findings

This series of studies provides confirmation from a number of data sources for anomalous sensory-perceptual experience in people with autism. There is clear and substantial convergence of evidence between accounts of people with autism themselves ('insider perspective') and the accounts of parents ('outsider perspective'). These experiences are reported in autobiographical accounts, by individuals with autism sampled via the internet, by individuals with autism drawn from a clinical population, and by parents of individuals drawn from a clinical sample. Unusual sensory-perceptual phenomena are reported in all modalities, but most markedly in sound, touch, vision and body state awareness. Furthermore, this research highlights the significance of these sensory-perceptual experiences in terms of their impact on behaviour, psychological states and social functioning.

From the point of view of the individuals with autism sampled in this study, sensory-perceptual phenomena are a salient aspect of the experience of living with autism, impacting on their behaviour and requiring active strategies in order to manage them and compensate for them. Parent accounts support this evidence and extend our understanding to include the impact on parents and the wider family. Anomalous sensory responding falls into two broad categories: problematic or unpleasant phenomena and pleasant sensory phenomena. Sensory problems and the person's efforts to manage them can lead to a range of 'inappropriate' behaviours and can have a negative emotional and social impact. On the other hand, sensitivity to aspects of the

physical and sensory world can be a source of positive emotional experience and comfort and can help the person with autism deal with the demands of the social world.

There is individual variability in unusual sensory-perceptual experience and also variability across situations and over time. Factors such as busyness of the sensory environment, predictability, familiarity, degree of task demand, energy levels, motivation and emotional state impact on sensory-perceptual experience as do developmental factors such as age, learning and memory.

Disordered Attention System: A conceptual model of the phenomenology of sensory-perceptual experience

Integrating findings from all of the studies, a model is proposed for understanding unusual sensory-perceptual experience in autism. This model centers on the concept of a 'Disordered Attention System'.

In keeping with the attempt to use simple and accessible language in the description of the model presented on the internet in Chapter 7, a deliberate attempt has been made to keep to the discipline of using the simplest language to describe the sometimes complex, and interrelated concepts involved. This summary will also form the basis for a final feedback of the results of this investigation to all participants, parents and internet respondents who took part in the study who have requested a summary of the final integration of the results.

The core idea around which an understanding of sensory-perceptual experience has been built is that of a "Disordered Attention System". The term 'attention' is used in a broad sense as a unifying concept to represent the integration of various aspects of detection and processing of information necessary to make sense of, and act on, the world. The researcher's analysis of the accounts of sensory-perceptual experience generated in this investigation suggests that these experiences arise from the interaction of a number of key anomalies in this attentional system: Disordered Attention Beam; Perseverative Bias; Sensory-Based World and Faulty Modulation. The working of this attention system is subject to the influence of factors such as emotional state and developmental processes such as age, memory and learning. In addition, specific perceptual skill aptitudes and deficits and modality preferences contribute towards individual variability in sensory-perceptual experience.

1) <u>Disordered Attentional Beam</u>:

Some of these reactions are due to a problem with the way people with autism focus their attention: automatic narrowing and widening of attention, that normally assists in helping us to make sense of the world around us, is inefficient. Extra effort is needed in order not to get stuck with attention being either too narrowly focused or too widely focused.

An overly wide focus can result in the person with autism being distractible, having difficulty distinguishing and making sense of individual sensory events, and suffering sensory overload. Having too-widely focused attention seems to be a particular problem where the person with autism is not actively engaged in an activity, and in sensorialy intense or busy environments. The experience of sensory overload is often unpleasant and may cause panic or fear. People with autism may try to deal with this by escaping from or avoiding the situation or deliberately focusing on one thing, sometimes through self-injury or self-stimulation. In extreme situations overload can lead to an involuntary reaction or 'shutdown' where the senses no longer seem to operate properly.

Once actively engaged in an activity, however, there seems to be a tendency for attention to become over-narrowly focused. In addition, certain types of sensory events (e.g. repetitive events) seem to lead to over-narrowing of focus. This over-narrow focus results in a failure to or delay in becoming aware of other internal and external sensory events. Events such as very loud or sudden sounds that do get through into awareness can be experienced as disturbing or jarring. This over-focused attending is a particular characteristic of early childhood. Sometimes in order to cope with sensorially difficult situations, or other demanding situations people with autism deliberately narrow their attention. They can also get angry if someone intrudes on their awareness when they are in this state. For some individuals certain sounds that are particularly salient may easily get through into awareness even when the attention beam is narrowly focused.

Because of inefficiency in automatic adjustment, and the tendency for the attention beam to be too-wide or too-narrowly focused, effort and concentration are needed to make sense of the ongoing flow of events. This is especially so in busy and distracting environments, or with more demanding tasks where concentration has to be sustained over time.

A number of individuals say that activities such as doodling may help in some situations to keep their attention focused. For many people with autism this problem with inefficiency in the way they focus their attention seems to get better with age. For others the problems seem to persist throughout life. Anxiety and stress may add to the problem. Sometimes others may misinterpret these difficulties in attending as being due to laziness or defiance. Some individuals may be more prone to operating with an over-narrow focus and others with an over-wide focus.

2) Perseverative bias:

There seems to be a bias in the attention system towards repetition and sameness that plays a role in people's sensory experiences. This involves a tendency for whatever is in awareness to stay there, making it more difficult to switch attention to new things, and also a preference for events that are repetitive and familiar. Some people with autism report a problem with sensory events and reports thoughts echoing or sticking in their mind. This makes it difficult for them to follow the flow of changing events. It is also more difficult to dismiss unpleasant sensory events and thoughts from their awareness and therefore the negative impact of these things is exaggerated.

People with autism also seem to be drawn to repetitive and predictable sensory events in their environments. These seem to capture their attention and can distract them for other things that are happening such as following a conversation. Once attention is caught by these events, people with autism may become entranced by them - their attention narrows and interferes with their ability to follow what is going on around them. They may then find it difficult to disengage their attention from these things. People with autism say that these sorts of repetitive and predictable sensory events are pleasing to them and/or provide a sense of control and coherence. Sometimes they may seek these out in order to feel calmer or just for the pleasure involved. If these characteristics are broken in some way then this can be disquieting for them or alternatively they can lose interest in them.

This bias to repetition and sameness is also expressed in the person's play and behaviour. Stereotypic behaviour seems to happen naturally, often without awareness and is frequently associated with feeling content or as having a calming impact. A general preference for sameness and a dislike of change and the unexpected seems to influence choice of food, clothing and other aspects of the lives of people with autism. This can cause a range of problems. One example described was of not wanting to get fingers or toenails cut because these feel 'different' afterwards. This bias seems strongest in childhood but stress may also make it worse. Individuals also vary in the extent to which they are affected by this bias. As they get older people with autism may actively try to resist this perseverative bias by suppressing stereotyped behaviour and/or deliberately seeking out variety.

3) Sensory-based world:

One of the most significant findings from this study involves the emotional salience of the physical and sensory world in the lives of people with autism. What is often thought of as an absence or 'deficit' in social responding may be

re-interpreted as having a flip side: an emotionally rich relationship with sensory and physical phenomena.

Attention and awareness are immersed in the physical and sensory world rather than the social world. This world may include the 'non-human' animal or insect world. This means that people with autism are more aware of, and interested in, these aspects of their surroundings than they are of people. This non-social world can be an important source of emotional experience, of pleasure, joy or comfort but can also be a source of anger, upset or fear. This immersion in a sensory world is associated with a very immediate 'in the moment' awareness. There is little reflection on experience (i.e. reflecting about what one is feeling and thinking) and events are frequently connected at an associational level. This can lead to events and emotions being experienced very intensely. Events that are associated with either pleasant or unpleasant emotions can themselves take on positive or negative affective meaning. Events may be experienced at a sensory level without an awareness of their meaning. For example, the person may be aware of the sounds of speech but not recognise what the sound means. This immersion in the sensory world is primarily a childhood phenomenon and tends to diminish with age, although attachment to physical objects and sensory events may continue to have some emotional significance in their lives.

Alongside this sensory orientation, people with autism describe a lack of attunement to the social world. There seems to be a lack of intuitive connectedness with people and difficulty understanding and sharing social-emotional experience. For some individuals this means that as children they may only gradually become aware that people are 'special' and different from other objects. This can lead to problems with affectionate social touch because this can feel confusing or overwhelming and the physical experience in itself can seem unpleasant (e.g. feeling squashed, being aware of body odours etc.). This also means that events may seem unpredictable and unexpected because the person has not read the signals from other people that led up to them. Because understanding the people world is difficult the physical and object world may seem safer. This lack of emotional attunement to people may be one reason why people with autism seek out comfort and other forms of stimulation through non-social means.

As they grow older people with autism become more socially aware and may try to better 'fit in' with the social world. This means that they may have to learn to behave in more socially acceptable ways in dealing with their sensory problems or indulging their sensory fascinations. This may also involve 'giving up' some of the comfort and safety of the sensory world. Because the meaning of and

connection between events becomes clearer, sensory events may seem less unpredictable and less unpleasant as a result. Gradually social behaviour and shared social understanding may become easier, although significant difficulties remain especially with unfamiliar people.

4) Faulty modulation:

People with autism describe problems in the intensity with which they perceive internal or external sensory events. This involves two extremes: 'hyper-sensitivity' and 'hypo-sensitivity' to sensory events. Hyper-sensitivity includes a heightened experience of sensory events, hyperacuity in detecting events that would not normally be perceived, and a painful or problematic experience of very specific events such particular sounds or colours. Hyposensitivity includes failure (or greatly reduced capacity) to detect sensory events. Hypersensitivity in one modality can co-exist with hyposensitivity in another modality. Hypersensitivity to specific stimuli can exist alongside hyposensitivity to other events within the same modality and indeed some people may experience hypersensitivity to sensation in one situation and hyposensitivity in another. Problems with hypersensitivity can lead to a range of negative psychological and behavioural consequences, including distress, panic, fear and anxiety, avoidance or escape from situations associated with the aversive event, and aggression. Hypersensitivity may contribute directly or indirectly to curtailment of social interaction. In extreme cases (such as in extreme sound sensitivity) it can lead to very generalised phobic avoidance of any situation where the feared stimulus might occur, thus restricting the lifestyle of the individual and their family. Control over, and gradual familiarisation with, the aversive stimulus are identified as helpful in overcoming hypersensitivity for some individuals. In other situations hyper-acute perception may be experienced as a 'special' aptitude or skill (e.g. the ability to hear conversations at greater distance than others). Hyposensitivity can have both negative and positive consequences. For example, failure to feel pain normally can lead to risks to health in some situations but can also contribute towards the achievement of considerable feats of endurance.

This over-reactivity and under-reactivity are also influenced by other difficulties. For example when a person with autism eventually becomes aware of sensation of cold or hunger he/she may not realise that they can do something about it or may not understand or be motivated to communicate this experience. Alternatively the person may be aware of sensation but may not remember from previous experience how it should be identified. Stress can also aggravate the tendency to hypersensitivity. Although in general people tend to manage their

reactions to these situations in a more socially appropriate way as they get older, this does not always reflect a reduction in the underlying sensitivity. Many participants reported a reduction in hypersensitivity as they got older but others reported no attenuation and/or an increase at some points in their life.

These four elements are closely linked and it is their interaction that seems to contribute to problematic and pleasurable sensory-perceptual experiences. Not everyone is affected to the same extent in each of these areas and this contributes to individual variability in the degree of unusual sensory-perceptual experience. Strengths or weaknesses in particular perceptual skills, and preferences for one modality over another, also contribute to this variability. For example, some individuals may be more tuned in to the visual modality and have better skills in this area while others may be tuned into the auditory modality and may be more likely to notice sounds in the environment. Anxiety and stress seem to accentuate problems. Factors such as getting older, becoming more familiar with events and situations, better memory and learning more about the world and how to deal with sensory difficulties may help to lessen sensory-perceptual difficulties although this may not be true for everyone.

Section 2: Interpretation of Findings

This investigation has attempted to explore the phenomenology of aberrant sensory-perceptual responding in autism using a qualitative research methodology drawing primarily on the accounts of individuals with autism themselves. This has involved face to face interviews, analysis of public and published first-hand accounts and validation of findings through feedback from individuals with autism via the Internet. In addition, the approach has drawn on the interview accounts of parents of individuals with autism. In this section the significance, implications and limitations of this investigation will be discussed. Findings will be discussed under the following headings: General Implications; Theoretical Links; Clinical Implications; Limitations; Further Research; and Summary and Conclusions.

General implications

This investigation has found that the use of a qualitative (Grounded Theory) methodology to investigate the experience and understanding of people with autism in relation to unusual sensory-perceptual phenomena has generated a useful and detailed account of these phenomena that has contributed to our understanding of this area. This outcome suggests that the use of qualitative methods to investigate the experiences of individuals with autism offers a potentially fruitful, and to date largely untapped, source of evidence not only in relation to sensory-perceptual phenomena but also to our wider

understanding of other aspects of experience in autism and thus by extension, the nature of autism itself.

This process is consistent with a wider movement within disability research towards an active role for disabled individuals in generating knowledge and in articulating the issues and concerns that are of primary importance to them, thus facilitating a greater voice in driving the research agenda (Wholmsley, 2001). Furthermore, this research has shown that aberrant sensory-perceptual experiences are a significant aspect of the experience of living with autism. It is argued therefore that there is a strong argument for greater research focus in this area. Additionally, the findings support the small number of previous studies using qualitative methodologies that have identified disrupted sensory-perceptual experience as a central aspect of living with the condition (Cesaroni & Garber, 1991; Olney 2000).

The series of studies reported here (hereafter referred to as 'the study') supports the evidence from early clinical accounts (Bergman & Escalona, 1949) and clinical research studies (Ornitz, Guthrie & Farley, 1978) that abnormal sensory-perceptual responding is a significant feature in the presentation of individuals with autism. The study confirms that reactions reflecting both hyper- and hypo-sensitivity to sensory events can occur in the same individual (Orntiz, 1989). The findings also extend the range of anomalous sensory reactions that have been documented in previous research to include awareness of body states (e.g. hunger, thirst) and chronic unpleasant body sensation or pain. In particular the study highlights pleasure in sensory events, and the affective salience of sensory fascinations and preoccupations as important aspects of unusual sensory-perceptual responding in autism.

This study emphasised aberrant responding to sound, touch, vision and pain while smell and taste were less prominently problematic: a finding consistent with the results of previous work (Ornitz, Guthrie & Farley, 1978; Whelan, 1996). The study highlights a number of factors (mood state, motivation, task demands, energy levels, nature of the sensory environment, degree of control over sensory event) relevant to understanding the within-subject variability in sensory-perceptual responding that has previously been identified by other researchers (Rincover, Newsom, Lovaas & Koegel, 1977).

The study concurs with findings from the limited psychological literature on the topic (e.g. Bettison, 1996) and with findings in the occupational therapy literature (Kientz & Dunn, 1996) of a high level of within-group variability in sensory-perceptual responding. The study adds to our understanding of this variability by identifying a number of factors from the accounts of individuals with autism and their families that contribute to this variability. These include age and maturation, memory, learning processes such as increased ability to recognise and predict sensory events, and learning better coping and compensatory strategies.

The study adds to our understanding of the behavioural and psychological sequelae of sensory-perceptual phenomena for the individuals concerned that again reflects considerable individual difference. For example, problematic reactions range from mild and circumscribed distress in the presence of aversive events for some individuals to severely restricting phobic responses in others. Similarly, the investigation illuminates the developmental course of these phenomena: for many individuals there is a gradual attenuation over the course of development whereas for others problems remain or may come and go through adult life.

The study also highlights the complexity and multi-component nature of abnormal sensory-perceptual reactions in autism. The accounts of these phenomena generated in this research suggest that it is a changing and dynamic interaction of a number of key processes that underlie the nature and impact of abnormal sensory-perceptual experience. This complexity poses a significant challenge to research in this area and to clinical interventions that seek to treat aberrant sensory responding (see under clinical implications).

This study suggests that a range of within- and between-person, and contextual/environmental factors impact on abnormal sensory-perceptual processing in a manner that challenges the ecological validity of much laboratory-based research. Similarly, attempts to delineate the construct at a behavioural level are challenged by the fact that the same behaviour (e.g. dislike of having hair cut) may be the outcome of very different processes in different individuals (e.g. difficulty in social interaction in one individual, difficulty with tactile hypersensitivity in another).

The processes or elements outlined in the model of sensory-perceptual experience presented above include the pervasive impact of two of the three-core 'triad' impairments in autism: the social impairment and the restricted and repetitive patterns of interests and behaviour. The social impairment is identified as contributing both directly and indirectly to abnormal sensory responding. For example, a difficulty with emotional content is identified in a number of accounts as underlying the aversive impact of physical affectionate gestures such as hugs. Similarly, a difficulty in reading social communication cues may lead to a raised voice being experienced as sudden or unexpected adding to it's aversive impact. Similarly, a desire for sameness is identified in relation to a range of difficulties with food and clothing, and repetitive behaviour is strongly represented as both an aspect of pleasure in sensory experience and as a managing strategy in dealing with aversive sensory experiences.

The relationship between these core triad impairments and unusual sensory-perceptual experience will be explored further below in considering theoretical linkages between the model presented here and existing theoretical accounts of autism. The essential point here is that an understanding of the pervasive impact of core triad impairments on sensory-perceptual functioning will be necessary for a full elaboration

of the nature of unusual sensory-perceptual responding in autism. An argument supporting the converse will however also be tentatively presented below: in order to fully understand the nature of the core impairments in autism, an understanding of the nature of sensory perceptual experience in autism may also be necessary. Elaborating these complex relationships will require both the juxtaposition and interweaving of research on normal and abnormal development.

Theoretical linkages

Because of the relative neglect of this area, and the limited nature of existing research on aberrant sensory-perceptual functioning in autism, current theoretical accounts of the nature of autism do not attempt to deal explicitly with this aspect of autistic experience. There is, therefore, no clear theoretical framework in which to embed the findings of this research investigation. Indeed until basic 'first-wave' (Briere, 1992) descriptive and comparative research on the nature of sensory-perceptual experience in autism and other clinical groups is further advanced, attempts at theoretical integration may be premature. Furthermore, the model developed in this study indicates the complex nature of these phenomena. The constructs suggested in this model as contributing to unusual sensory-perceptual responding in autism, represent quite disparate influences within the attention system that makes any overall theoretical integration difficult. Nevertheless, an attempt will be made here, taking each of the core constructs in turn, to explore linkages with existing theoretical accounts, and to identify more general implications for future research.

Sensory-Based World: This construct represents a primary attentional orientation (especially in childhood) to the non-social sensory and physical environment and a failure in the normal attunement to people. This orientation is characterised by a strong affective quality in the nature of the relationship with the non-social world. This concept clearly relates to affective theories of autism (Hobson, 1983, 1993; Mundy, 1995; Mundy & Neal 2001) that have at their core a failure in the innate predisposition towards people that characterises normal human development. This theory was first articulated by Kanner (1943) as an 'inability to form the usual, biologically given affective contact with people' (page 250). In particular three facets of these primarily affective accounts are considered especially pertinent to the construct of 'sensory-based world' delineated in this investigation. The first two are articulated by Hobson (1993).

Hobson's account rests on a failure in affective intersubjectivity. He argues that as a result of deficits in constitutional components necessary for reciprocal personal relations, there is a relative failure to recognise other people as affectively special, and a failure to recognise people as people, with their own feelings, thoughts, wishes, intentions etc. Hobson (1993) also argues that a lack of participation in intersubjective

social experience leads to a severe impairment in the capacity to abstract and to think symbolically.

In the present study, a failure in attentional and affective attunement to people is a central characteristic of the construct of 'sensory-based world' derived from participants' accounts. An early failure to recognise people as different from objects is explicitly supported in a number of the accounts. The concept of 'in-the-moment awareness' leading to largely associational understandings of the relationship between events (also represented here within the construct of 'Sensory-based world') is viewed as conceptually similar to Hobson's proposition of impairment in the capacity to abstract and to think symbolically.

The third element that is considered especially relevant to the present construct arises from the account by Mundy and colleagues (Mundy, 1995; Mundy & Neale, 2001). Mundy and Neale (2001) argue that autism arises from a basic failure in the normal preparedness to spontaneously orient to and process social information. This failure starts the child on a developmental trajectory in which experiences of, and opportunities for, social information processing are reduced. Mundy and Neale (2001) argue that as a consequence non-social information processing is over-emphasised perhaps through compensatory mechanisms. A heightened salience of the non-social, physical and sensory world is clearly articulated within the present analysis.

Within the framework articulated by these authors, immersion in a sensory world would reflect the developmental outcome of a primary failure in social orienting. The construct of sensory-based world represented in this study may be viewed as evidence of the interlinking of compensatory mechanisms at both cognitive and affective levels. A heightened emotional relationship with the sensory and physical world is an essential element of the immersion in the non-social world proposed in this study. This finding highlights the inseparability of affective and cognitive factors in (especially early) development.

In addition, the finding illuminates the manner in which comprehensive investigation of unusual sensory-perceptual phenomena can contribute to our understanding of the social impairment in autism. The construct of sensory based world highlights the reciprocal links between relations to people and relations with the physical, sensory and object world. This finding is in keeping with much sociocultural theory and research that points to the critical role of caregivers in developing the child's sense of meaning or 'preferred affordances' (Loveland, 1991) of the non-social as well as the social world. The findings of this investigation can be taken to support the view that as a result of failure in social relating, this normal process of meaning -making is disrupted in autism and leads to unusual relating to the non-social world. In turn idiosyncratic relating to objects and the non-social world is likely to further disrupt social relating given the key role of objects in critical aspects of social-emotional

development (Williams, Costal & Reddy, 1999). The finding supports the argument of these authors that there is a need to widen the currently dominant research focus on *interpersonal* aspects of the social impairment in autism (e.g. joint attention, social referencing) to include greater attention to other aspects of development such as relating to objects and the physical/sensory world.

The findings from the present study also support those emerging from recent work by Mottron and Burack (2001) arising from studies initially aimed at exploring the central coherence hypothesis. These authors have proposed that autism is characterised by enhanced abilities in, and dependence on lower-level perceptual processing that interfere with higher-level mechanisms, thus supporting the notion of heightened salience of the sensory world.

Perseverative Bias: This construct represents a bias in the attention system towards the maintenance of attention to whatever is within current focus resulting in a lack of easy flexibility in switching attention. This bias also privileges specific stimulus characteristics. This bias is manifested at a number of levels: at a sensory or physical stimulus level, at a cognitive level and at a behavioural level. This construct offers support to findings from the Executive Dysfunction literature in autism. Executive function is conceived of as the mechanism that enables an individual to shift attention flexibly, to inhibit prepotent responses, generate goal directed behaviour and solve problems in a strategic way. The concept of 'perseverative bias' fits particularly with the idea of a failure to inhibit ongoing thought and action at will that is suggested by robust findings of response perseveration and problems in attentional set shifting i.e. lack of cognitive flexibility (Hughes et al. 1994; Turner, 1997). Indeed Turner (1997) draws attention to the spontaneous comments made by some of her subjects while engaged in perseverative responding on sequence generation tasks that are strikingly similar to some of the accounts in this study, e.g. 'It's hard to stop doing pink, blue, green, yellow-it's stuck in my head'.

In the present study the proposition that the bias to repetition and sameness is manifested at a number of levels (sensory events, thoughts and behaviour) supports Turner's (1997) finding of a close association between defined classes of repetitive behaviour and both response perseveration and attentional set-shifting.

An important characteristic of the construct of 'perseverative bias' presented here is an attentional 'preference' for repetitive, predictable events and this has not been investigated or described in the executive literature. However such a preference might be considered likely in an attentional system characterised by difficulty in disengaging from one event or idea and re-orienting to another.

Disordered Attention Beam: This analytic construct refers to an impaired and poorly refined attention beam that without effortful management oscillates between a state of over-narrow and a state of over-wide focus. This construct is difficult to locate

within the major theoretical accounts of autism reviewed in Chapter 1 although it does fit with a number of key findings drawn from the attention literature. Indeed the concept itself arose from accounts that seemed to reflect the phenomenon of "stimulus overselectivity" that was an early finding in relation to selective attending in autism.

Lovaas, Schreibman, Koegel and Rehm (1971) found that children with autism responded to a restricted range of environmental stimuli, suggesting that their attention was 'over-selective'. This finding was supported by clinical observation and confirmed in other studies (e.g. Lovaas, Koegel & Schreibman, 1979). Rincover and Ducharme (1987) interpreted these findings in terms of excessively narrowed attending.

However, 'under-selective' attending has also been demonstrated. In the visual modality Burack (1994) found evidence of an abnormally broad focus of attention evidenced by difficulty in focusing attention optimally in the presence of distracters among learning disabled individuals with autism compared to learning disabled and normal controls. Townsend and Courchesne (1994) have proposed that the presence or absence of parietal abnormality may underlie these apparently contradictory findings. These authors identified a large subgroup of individuals with autism (43% of their sample) who showed evidence of abnormality in the parietal cortex. Compared to normal controls and autistic individuals without parietal abnormality, this subgroup demonstrated evidence of a narrowed distribution of spatial attention, reflected in unusual event related potentials (ERPS) to visual stimuli, characterised by enhanced sensory stimulation at the attended location and diminished sensory processing outside of the attended location. Autistic individuals without parietal damage also showed evidence of an abnormal pattern of attentional distribution, in this case broad and ungraded relative to normal controls. Thus the findings of Townsend and Courchesne (1994) offer support to the understanding developed in the present study that some individuals may be prone to operating with over-narrowly focused attention beam while others may be more likely to operate with an over-wide focused beam.

The intense absorption characteristic of over-narrowly focused attending in the present account may reflect a further aspect of this finding highlighted by Townsend and Courchesne (1994) and subsequently supported in a number of studies (Westerfield, Townsewnd, Edwards, Makeig, Jung & Corchesne, 2000; Townsend, Westerfield, Leaver, Makeig, Jung, Pierce & Courchense, 2000). This finding is that while attention is narrowly focused, attention within this central focus appears to be 'supernormal' as evidenced by ERPS findings and significantly faster reaction times (RTs).

The present study suggests that individuals with autism may show both an over-narrow and an over-wide attention beam at different times and it unclear at this point how this could be accounted for in terms of parietal abnormality. In the present study, active engagement is identified as a key factor in this variability. A number of studies

have demonstrated impaired ability to shift the focus of mental attention rapidly and accurately between different sources of information, for example between visual and auditory modalities (Courchesne, 1987) when already engaged in an activity (Pascualvaca, Fantie, Papegeorgiou & Mirsky, 1998).

The need for effortful concentration was also identified as another key factor in this variability thus raising the possibility that motivational factors may be influential in determining the level of effort applied in a given situation. Some support exists for this notion. Garretson, Fein and Waterhouse (1990) found that motivational factors are important in the performance of individuals with autism in sustaining attention to task. They found that performance was poorer in situations of social reinforcement than in situations of tangible reward.

Taken together these findings from the attention literature concur with the understanding developed in this study of lack of efficient and automatic widening and narrowing of the attention beam that interferes with optimal intake of relevant sensory-perceptual information from the environment. Furthermore, this study highlights the need to investigate the effects of a range of factors such as the busyness of the background sensory environment, the nature of the stimuli requiring attention, age, anxiety levels, and motivational factors, in future investigations of attention in autism.

Faulty Modulation: This category relates to abnormality in the intensity with which people with autism perceive internal or external sensory events. This involves two extremes: 'hyper-sensitivity' and 'hypo-sensitivity' to sensory events. Again this construct is difficult to locate within what are currently considered the major theories of autism outlined in Chapter 1.

Earlier arousal theories (Ornitz & Ritvo, 1968; Dawson & Lewy, 1989) developed to account for abnormal sensory responses could account for some, but not all, of the features of the construct presented here. Variability in the intensity with which events are experienced by the individual, and the role of stress and anxiety in triggering or exacerbating hypersensitivity, would appear to fit with the position advocated by these theorists that fluctuations between states of over-and under-arousal result in a failure to modulate sensory intake adequately and an unstable perceptual experience. The finding that hypersensitivity, although most commonly reported in sound and touch, occurs across modalities also supports this position. Clearly the account presented here indicates that a range of stimuli that do not normally elicit an aversive response do elicit this type of response in individuals with autism. This finding is also in keeping with Dawson and Lewy's (1989) proposition of a narrower band of optimal stimulation: novelty and unpredictability in particular are identified in a number of accounts as among the characteristics of events likely to be perceived as unpleasant. There is also support for the notion that one function of repetitive behaviour and activity may be to regulate the level of stimulus intake and arousal (Hutt et al., 1965).

It is less clear how arousal theories would account for a number of other features identified in this category. For example, it is unclear how fluctuating arousal levels alone could account for the very specific nature of some of the stimuli identified in some accounts as leading to aversive responses (the sound of a specific voice or specific types of equipment). It is also unclear how fluctuating arousal levels alone could account for the particular and chronic difficulties identified in body awareness, or, for some individuals, the hyper-detection only of very specific stimuli that have salience for the individual. These findings suggest an interplay of factors including 'lower -level' sensory dysfunction and 'higher-order' processes including motivation and attention. As previously indicated further investigation of the nature of this construct may be necessary in order to advance theoretical understanding of the processes underlying it.

There is some evidence of sensory dysfunction in the auditory modality that is relevant to this issue. Hyperacusis has been found to be considerably more common in autism based on audiometry, auditory brainstem response and parent report measures (Rosenhall, Nordin, Sandstrom, Ahlsen & Gillberg, 1999; Rimland & Edelson, 1995). In addition, Berard (1993) presents evidence, based on audiometric findings in individuals with autism, of hearing dysfunctions centred on abnormal sensitivity or insensitivity to certain frequencies independent of overall hearing ability. While Berard (1993) also reports these problems in other clinical conditions, the evidence nevertheless suggests that hearing dysfunction may play a role in abnormal response to sound in at least some individuals with autism.

Summary of theoretical linkages

The nature of the relationships between these constructs and their wider theoretical significance remains unclear. For example, a failure in social relating and the normal orientation to people could be the cause or the result of the dysfunctions represented in other constructs. Early infant-caregiver interactions may be jeopardised by an inability to flexibly and rapidly disengage/ engage attention as encapsulated in the construct of perseverative bias. Alternatively, failure in opportunity to learn and practice rapid and flexible engagement/disengagement of attention through normal infant-caregiver interactions as a result of a basic failure in social orienting could also be considered to give rise to these same difficulties.

At a more general level, the findings of this investigation suggest that theoretical accounts of autism need to reflect and account for both cognitive and affective differences in autism. A key outcome of this investigation has been to highlight the interconnectedness of these factors in the aberrant sensory-perceptual experiences of individuals with autism, suggesting that traditional boundaries between affect and cognition in the investigation of abnormal development will need to be overcome. This is particularly important in informing clinical practice where an appreciation of the interaction between cognitive and affective processes is vital to effective intervention.

Clinical Implications

There are a number of general and more specific implications for clinical practice arising from this investigation. At a general level, the investigation suggests that greater awareness of and sensitivity to anomalous sensory -perceptual responding in autism is warranted than has traditionally been the case. The investigation highlights the need for awareness of the difficulties faced by individuals with autism in this aspect of functioning and in particular the effortfulness involved in living with and managing these difficulties. Whereas for ourselves the processes involved in the intake of information from the environment are automatic and trouble free, this is not the case for individuals with autism. The additional 'costs' involved for them in managing a disordered attention system are likely to deplete the attentional and energy resources available to them for other aspects of information processing, learning and interaction.

One finding to arise from the investigation is that parents may not 'pathologise' common autistic behaviours (e.g. sensory fascinations, stereotypies) to the same degree as is reflected in the clinical literature. A number of parents articulated a sensitivity to and respect for the positive function that these behaviours fulfil for their child. For example, a number of parents described their 'reading' of stereotypic behaviour as reflecting different emotional states and functions at different times. This included a positive emotional or adaptive role for the child on some occasions that they respected, recognising the child's 'need' to do it and waiting for this behaviour to 'pass' rather than intruding on it or stopping it. This suggests a need for sensitive and mutually respectful dialogue between clinicians and parents in relation to interventions with these behaviours. In general there may be a need for greater sensitivity on the part of service providers and interventionists to the emotional salience of these behaviours and greater respect for 'difference' in the emotional relationship between the individual with autism and the physical and object world.

The study findings widen the range of hypotheses that need to be explored in understanding the behaviour of individuals with autism. Both problematic and pleasurable sensory perceptual phenomena may contribute to behaviour that others find challenging. Aversive and problematic sensory-perceptual experiences may lead to behaviours such as escape, avoidance, reactive aggression or an increase in repetitive and stereotypic behaviour. Similarly, intrusion into, or interruption of, emotionally salient sensory activities or the loss of treasured objects may similarly provoke anger, distress or even aggression. Severe distress reactions to sensory events may give rise to wider phobic avoidance of, or panic reactions to, particular situations or activities. Lack of awareness of the personhood of others, and in particular perhaps of other children, may also contribute to inappropriate behaviour towards others by young children with autism. The finding that stereotypic and repetitive behaviours may occur 'involuntarily' and without awareness suggests that strategies that seek explicitly to develop awareness

of and control over these behaviours may be helpful for some individuals. In this investigation an example of such a strategy used by parents included encouraging their son to 'practice' stereotypic movements, and learning to stop and start at will, thus achieving more conscious control over these behaviours.

The study also cautions against over-generalisation in relation to sensory-perceptual functioning in autism. Individual variability in experience was an important finding. Individuals with autism may have quite different profiles of skill aptitudes and deficits. The findings of this study suggest that the common assumption that individual with autism respond better to visually presented rather than verbally presented information may not hold up for all high-functioning individuals. One individual in this study clearly indicated an attunement to the auditory environment, and a lack of interest in the visual modality.

The findings of this study suggest that the nature and impact of aberrant sensory-perceptual responding is the outcome of multiple processes. Therefore, our interventions must not be based on simplistic concepts and must address the issue on a number of fronts and in a wholistic manner. Providing a range of prosthetic supports such as earplugs, dark glasses or a Walkman for dealing with sensorially difficult environments may be helpful in addressing difficulties such as hypersensitivity. These sorts of intervention are more likely to be successful if delivered in a context that supports the individual with autism at a number of levels. Interventions should aim to ameliorate anxiety and stress, assist the individual to predict and make sense of the world and take account of the impact of the range of other factors that have been identified as influential in this study. This study suggests that extreme caution around current 'single-focus' treatments such as Auditory Integration Training is warranted, especially as these are sometimes marketed as treatments for autism.

The findings may have particular relevance to early intervention with young children with autism. The study suggests that the elements of disorder in the attention system are most marked in the early years. In intervening intensively with this age group a difficult balance is required in intruding on the self-contained world of the young child in order to foster greater awareness and understanding of the social and wider world, while at the same time avoiding overwhelming the child's precarious capacity to deal with outside demands. Recognising and avoiding 'overload' will be necessary for successful intervention.

Use of the emotional and motivating significance of the physical and sensory world offers one important channel for connection. In a number of the accounts of early childhood, social connection was established with those who entered into and skilfully used the child's fascination with aspects of the sensory world. This is in keeping with the suggestion by Williams, Costall and Reddy (1999) that it may be necessary to enter into the 'idiosyncratic meanings' afforded to particularly salient aspects of the physical,

sensory and object world by the child with autism if interactions with objects are to play the role they serve in normal development: that of a bridge or vehicle for the development of social interaction skills and language development.

Limitations of the study

This investigation is limited in a number of important respects. These are the small sample size used, concerns over diagnostic status, representativeness of the sample, the gender bias of the participants, and the limitations of the interviewing process.

Sample size/representativeness

Firstly, the sample size on which this model for understanding sensory-perceptual experience is based is small. This was in part due to a deliberate decision, to try to achieve in-depth and comprehensive exploration of sensory-perceptual phenomena across the modalities rather than exploration of a more restricted range of modalities. In practical terms, therefore, this placed limits on the number of interviews that could be conducted, transcribed and analysed. Similar constraints applied in terms of the number of first-hand accounts that could be used. In addition, one participant interview was lost because of equipment failure. In generating the analysis, interviews were therefore available from six people with autism (Study 2) and seven parents (Study 3). Eight public accounts, representing the experiences of a further seven individuals were analysed (Study 4). This account of sensory-perceptual experience in autism is therefore based on the accounts of 20 people, plus the views of ten additional respondents who gave feedback in the validation study (Study 5), making a total of 30 people. Thus there is a need for caution about the generalisability of the analysis presented. A necessary next step will be to pursue this issue with a wider sample of people with autism.

Secondly, this research is based on the accounts of people with High-Functioning Autism or Asperger's Syndrome whose experiences may or may not be representative of the majority of people with autism who also have a learning disability. Nevertheless, there may be theoretical utility in the model in exploring similarities and differences between different groups of people with autism and between people with autism and normally developing individuals, and with other clinical groups who also report anomalous sensory-perceptual experiences.

Validity of Autism/Asperger Diagnosis

A third limitation concerning the sample used relates to the validity of the Autism/Asperger diagnosis of some of the individuals who participated in the mixed Respondent/Cohort Validation study via the Internet. In the case of the six respondents concerned a number of steps were taken to ensure that the people who responded were indeed people with a diagnosis of autism (see Chapter 6). However, there was no way

of independently verifying respondent claims of their diagnosis, and therefore some of the participants in Study 5 are most accurately described as people who claimed to have a diagnosis of Autism or Asperger's Syndrome. This question mark over diagnosis also pertains to a lesser degree to the published accounts used in Study 4. In this case, however, the accounts used were by individuals who have a 'public' standing as people with autism, several being well -known figures on the conference circuit and all would have received a diagnosis of autism at some point in their lives.

Gender

All participants in Study 2 were male. This reflects the very marked predominance of males over females (estimated at around 10:1) in clinical samples. In contrast females are over-represented in the published autobiographical literature and this is reflected in the predominance of females over males (4:3) in the accounts analysed. Similarly, females were over-represented (relative to clinical ratios) in the Respondent/Cohort Validation study. The effect of these gender biases is difficult to evaluate. While the triangulation design of this study supports the robustness of the model across data sources, clearly however the inclusion of female participants in Study 2 would have offered opportunities to explore possible gender-based similarities and differences.

Limitations in the interviewing process

Prior to this study people with autism had not been interviewed about their sensory-perceptual experiences in such detail as part of a research process. Although the finding that such interviews were possible was a major contribution of the present study, the interviewing process itself poses limitations when compared to those typically used in a grounded theory analysis. The process of recalling and articulating past experience may be difficult for some people with autism and in some cases quite specific questions were needed to elicit information. Even though the researcher was constantly aware of the possibility of 'leading' participants and tried to minimise this occurrence (see Chapter 3), it must be acknowledged that this remains a possibility. Furthermore, for clinical considerations, follow-up interviews were not possible with the participants in Study 2. The opportunity to go back to participants to follow up issues and to garner further details in relation to emerging categories, would have allowed greater flexibility in the 'flip-flop' between data gathering and data analysis, and as a result might have generated a fuller and more detailed analytic account of participants' experiences. Without an ongoing relationship between researcher and participant, perhaps through longer-term clinical involvement, however, this is a difficult issue to overcome given the turbulence of emotional well-being frequently evidenced in young adults with autism.

Further Research

The multi-construct model of sensory-perceptual experience generated in this study does not generate a single overarching prediction. Rather there are a number of aspects that relate to current dominant theoretical accounts that are open to further testing.

Transactional Social -Orienting Model

A failure in the normal attunement to people that is central to the affective theories of autism (Hobson, 1993; Mundy & Neal, 2001) is a central feature of the construct of sensory-based world. This construct predicts a spontaneous attentional 'preference' for non-social sensory and physical events over social events in young children with autism. This construct further predicts that this preference should diminish with age. Previous research has demonstrated a deficit in social orienting (such as spontaneous gaze shifts between objects and people) in young children with autism (Swettenham et al., 1998; Dawson et al., 1998) but has not addressed the issue of 'preference' in spontaneous orienting between social and non-social stimuli. This prediction might be tested by comparing the duration and frequency of visually directed gaze to concurrent social and non-social sensory events in naturalistic settings by children with autism and matched normally developing and developmentally delayed control groups.

Executive Dysfunction model

The construct of perseverative bias resonates strongly with the findings from the executive dysfunction model that have demonstrated impairment in the ability to flexibly shift attentional set and findings of response perseveration in children and adults with autism. A feature of this construct is an attentional orientation to repetitive and predictable stimuli. A heightened propensity to these stimulus characteristics is considered more likely where there is difficulty in disengaging from one event or idea and re-orienting to another. In order to test the validity of this feature, and to investigate a possible relationship with executive dysfunction, the following study could be carried out. The performance of children with autism and developmental age matched normally developing and developmentally delayed control groups could be compared on (i) measures of visual orienting to repetitive pattern and symmetry of stimuli in naturalistic settings (ii) measures of executive function such as those used by Mc Evoy et al. (1993).

Feeding into these wider theoretical investigations a number of additional questions need to be addressed in investigating the validity of the model developed in this study. The first concerns the extent to which the model and constructs developed are relevant to the experiences of a wider sample of able individuals with autism, including

females with autism and across more systematically stratified age ranges. This could be investigated using a combination of survey and interview methodologies.

A survey methodology would require the development of a 'sensory-perceptual experiences' inventory that allowed respondents (I) to indicate the type and range of their problematic and pleasant experiences and (2) to reflect on the nature, basis and impact of these experiences e.g. what it is about physical affection that they find unpleasant. This inventory could be used in postal or internet based survey research to investigate the extent to which a larger sample of people with autism report the types of unusual sensory-perceptual experiences found in this study.

A series of face to face interviews with a wider group of able individuals with autism (perhaps within the context of an ongoing clinical or research relationship) would allow for a more detailed test and exploration of the model developed in this study. The utility of the constructs generated in this study could be directly explored with participants in a more focused manner than was possible in the present study. The extent to which self-report is a useful strategy with less able but nonetheless verbal individuals with autism could be explored using strategies such as the provision of concrete examples of sensory stimuli (e.g. presentation of a range of different types of sound or tactile sensations) and the utilisation of visual approaches to representing experiences, to complement verbal report.

A further question arising from this study concerns the specificity to autism of the types of unusual sensory-perceptual phenomena reported in this study and of the model generated to represent these experiences. This question could be addressed by conducting parallel investigations of the phenomenology of sensory-perceptual experience with typically developing individuals and with individuals drawn from other clinical groups where abnormal sensory responding has been cited. This would facilitate the delineation of unique versus shared aspects of these phenomena and allow for further refinement of the concepts and model developed here.

Summary and Conclusions

This study represents the first qualitative investigation of the phenomenology of unusual sensory-perceptual experience in autism drawn from a body of exclusively first-hand accounts of individuals with autism. A primary aim was that of discovery: an attempt to explore and articulate the nature and impact of unusual sensory-perceptual experience in individuals with autism as represented in the main by individuals with autism themselves. The investigation provides evidence that sensory-perceptual phenomena are significant in the life-experience of living with autism and that an understanding of these phenomena is important in achieving a full understanding of the behaviour, psychological states and social functioning of individuals with this condition.

Furthermore, this investigation provides an account of the phenomenology of sensory-perceptual experience that forms a rich descriptive foundation for further research. This account provides evidence of the variability of these phenomena, of how they are responded to and managed, of their developmental course, and of a number of factors that impinge on them. The individual variability in the extent and impact of unusual sensory-perceptual phenomena found in this study cautions against inappropriate generalisation with regard to these phenomena. Thus an important contribution of the study is in highlighting the complexity of the phenomena under discussion. One of the challenges facing further research will be to unravel this complexity.

The account suggests that sensory-perceptual problems and fascinations are complex and dynamic multi-component phenomena. The conceptual understanding generated in this study centres on a disordered attention system. This disordered system reflects the interaction of abnormal function in a number of key areas (represented by the constructs of sensory-based world; disordered attention beam; perseverative bias and faulty modulation). Individual variability in the experience of unusual sensory-perceptual phenomena is seen as reflecting differing degrees of dysfunction in these areas. Emotional state, and developmental processes such as maturation, memory and learning are identified as factors impacting on the working of the attentional system. In addition, the individuals' specific perceptual aptitudes, deficits and preferences are further sources of variability.

This investigation represents only the very first steps in achieving a detailed understanding of the phenomenology of unusual sensory-perceptual experience in autism. A necessary next step will be to investigate the extent to which the model and constructs developed in this series of studies is relevant to the experiences of a larger sample of able individuals with autism. In addition, comparative investigation of the phenomenology of sensory-perceptual experiences in normally developing individuals and individuals from other clinical groups, especially those groups where unusual sensory responding has been cited (schizophrenia, Williams syndrome, general learning disability) is necessary. Such research would facilitate the delineation of unique versus shared aspects of these phenomena thus allowing for further refinement of the concepts and model developed here.

At a more general level the investigation has demonstrated the utility of a qualitative research methodology that draws on an 'insider perspective', and provides an example of how individuals with autism can usefully contribute to and share in the construction of knowledge about the nature and complexity of the disorder with which they live.

References

Adams, T. (1996). A descriptive study of the work of communtiy psychiatric nurses with elderly demented people. *Journal of advanced Nursing*, **23**: 1177-1184.

Allen, G., and Courchesne, E. (2001). Attention function and dysfunction in autism. *Frontiers in Bioscience*, **6**, 105-119.

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

Attwood, A. (1988). The Understanding and Use of Interpersonal Gestures by Autistic and Down's Syndrome Children. *Journal of Autism and Developmental Disorders*, **18**: 241-57.

Attwood, T. (1998). *Asperger's Syndrome: A Guide for parents and Professionals*. Jessica Kingsley Publishers. London.

Ayres, A. J. (1979). *Sensory integration and the child*. Los Angeles: Western Psychological Services.

Ayres, A. J., and Tickle, L. S. (1980). Hyperresponsivity to touch and vestibular stimuli as a predictor of positive response to sensory integration procedures by autistic children. *American Journal of Occupational Therapy*, **31**: 444-453.

Bailey, A., Le Couteur, A., Gottesman, I., and Bolton, P. (1995). Autism as a strongly genetic disorder: evidence from a British twin study. *Psychological Medicine*, **25**: 63-77.

Bailey, A., Phillips, W., and Rutter, M. (1996). Autism: towards an integration of clinical, genetic, neuropsychological, and neurobiological perspectives. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **37**: 89-126.

Banks, S. P., Louie, E., and Einerson, M. (2000). Constructing personal identities in holiday letters. *Journal of Social and Personal Relationships*, **17**, 299-327.

Baranek, G. T. (1999). Autism during infancy: a retrospective video analysis of sensory-motor and social behaviors at 9-12 months of age. *Journal of Autism and Developmental Disorders*, **29**: 213-24.

Baranek, G. T., and Berkson, G. (1994). Tactile defensiveness in children with developmental disabilities: responsiveness and habituation. *Journal of Autism and Developmental Disorders*, **24**: 457-71.

Barker, C.; Pistrang, N.; Elliot, R. (1994). *Research methods in clinical and counselling psychology. Wiley series in clinical psychology*. New York, NY, John Wiley and Sons.

Baron-Cohen, S. (1989b). Do autistic children have obsessions and compulsions? *British Journal of Clinical Psychology*, **28**: 193-200.

Baron-Cohen, S. (1989c). Perceptual role taking and protodeclarative pointing in autism. *British Journal of Developmental Psychology*, **7**:113-27.

Baron-Cohen, S. (1989a). The autistic child's theory of mind: A case of specific developmental delay. *Journal of Child Psychology and Psychiatry*, **30**, 285-298.

Baron-Cohen, S. (1995). The eye direction detector (EDD)., and the shared attention mechanism (SAM): Two cases for evolutionary psychology. In: C Moore, P Dunham (Eds), *Joint attention: Its origins and role in development*. (Pp. 41-60). Hillsdale, NJ: Lawrence Erlbaum Associates.

Baron-Cohen, S. (1997). The child with autism: First lessons in mind-reading. *Psychology Review*, **3**: 30-33.

Baron-Cohen, S. (2001). Theory of mind and autism: A review. In: Glidden, L. M. (Ed). International review of research in mental retardation: *Autism*, **23**: 169-184 San Diego, CA, US: Academic Press.

Baron-Cohen, S. Cox, A., and Charman, T. (1996). Psychological markers in the detection of autism in infancy in a large population. *The British Journal of Psychiatry*, **168**: 158.

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

Baron-Cohen, S., Allen, J., and Gillberg, C. (1993). Can autism be detected at 18 months? The needle, the haystack, and the CHAT. *Annual Progress in Child Psychiatry and Child Development*: 95-103.

Baron-Cohen, S., and Hammer, J. (1997). Parents of children with Asperger syndrome: What is the cognitive phenotype? *Journal of Cognitive Neuroscience*, **9**: 548-554.

Baron-Cohen, S., and Ring, H. (1994). A model of the mindreading system: Neuropsychological and neurobiological perspectives. In: Lewis, C., and Mitchell, P. (Eds). *Children's early understanding of mind: Origins and development* (pp. 183-207). Hillsdale, NJ, US: Lawrence Erlbaum Associates, Inc.

Baron-Cohen, S., and Swettenham, J. (1997). The theory of mind in autism: Its relationship to executive function and central coherence. In: Cohen, D., and Volkmar, F. (Eds). 2nd Edition. *Handbook of Autism and Developmental Disorders*, (pp. 880-893). New York: Wiley.

Baron-Cohen, S., Jolliffe, J., Mortimore, C., and Robertson, M. (1997). Another Advanced Test of Theory of Mind: Evidence from Very High Functioning Adults with Autism or Asperger's Syndrome. *Journal Child Psychology and Psychiatry*, **39**, 813-822.

Barron, J., and Barron, S. (1993). *There's a Boy in Here*. London: Chapmans.

Bemporad, J. (1979). Adult recollections of a formerly autistic child. *Journal of Autism and Developmental Disorder*, **9**:179-197.

Berard, G. (1993). *Hearing Equals Behavior*. (Translated from French). Keats Publishing.

Bergman, P., and Escalona, S. K. (1949). Unusual sensitivities in very young children. *Psychoanalytic Study of the Child*, **3**, 333-353.

Bettison, S. (1996). Long-term effects of auditory training on children with autism. *Journal of Autism and Developmental Disorders*, **26**: 361-367.

Biersdorff, K. K. (1994). Incidence of significantly altered pain experience among individuals with developmental disabilities. *American Journal of Mental Retardation*, **98**: 619-31.

Birger, S. (1995). *I Don't Want To Be Inside Me Anymore: Messages From an Autistic Mind*. New York: Basic Books.

Bishop, D. V. (1993). Autism, executive functions and theory of mind: A neuropsychological perspective. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **34**: 279-293.

Bleuler, E. (1916). *Lehrbuch der Psychiatrie (Translation)*. In: Brill, A. A. (1951), Textbook of Psychiatry. New York: Dover.

Bliss, J. (1980). Sensory experiences of Gilles de la Tourette syndrome. *Archives of General Psychiatry*, **37**, 1343-1347.

Bolton, P,, Macdonald, H., Pickles, A., and Rios, P. (1994). A case-control family history study of autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **35**: 877-900.

Boucher, J. (1981). Memory for Recent Events in Autistic Children. *Journal of Autism and Developmental Disorders*, **11**: 293-301.

Boucher, J., and Lewis, V. (1989). Memory impairments and communication in relatively able autistic children. *Journal of Child Psychology and Psychiatry*, **30**: 99-122.

Bowler, D. M, Gardiner, J. M, and Grice, S. (2000). Episodic memory and remembering in high-functioning adults with autism. *Journal of Autism and Developmental Disorders*, **30**: 295-304.

Bowler, D. M., Matthews, N. J., and Gardner, J. M. (1997). Asperger's Syndrome and Memory: Similarity to Autism but Not Amnesia. *Neuropsychologia*, **35**: 65-70.

Briere, J. N. (1992). Child Abuse Trauma-Theory And Treatment Of The Lasting Effects Interpersonal violence: The practice series, No. 2. Thousand Oaks, CA, Sage Publications.

Bronfenbrenner, U. (1976). The Experimental Ecology of Education. *Educational Researcher*, **5**: 51-115.

Brown, R., Hobson, R. P., and Lee, A. (1997). Are there 'autistic-like' features in congenitally blind children? *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **38**: 693-703.

Burack, J. A. (1994). Selective Attention Deficits in Persons with Autism: Preliminary Evidence of an Inefficient Attentional Lens. *Journal of Abnormal Psychology*, **103**: 535-543.

Carpenter, A. (1992). Autistic Adulthood: A Challenging Journey. In: Schopler, E., and Mesibov, G. B. (Eds). *High-Functioning Individuals with Autism*. (pp. 289-293). New York: Plenum Press.

Carruthers, P. (1996). Simulation and self-knowledge: a defence of theory-theory. In: Carruthers, P., and Smith, P. (Eds). *Theories of Theories of Mind*. (pp. 22-38). Cambridge University Press.

Cesaroni, L. (1990). *Exploring the experience of Autism through first-hand accounts from high-functioning individuals with autism*. Master's Thesis, University of Toronto.

Cesaroni, L., and Garber, M. (1991). Exploring the experience of autism through first-hand accounts. *Journal of Autism and Developmental Disorders*, **21**: 303-13.

Chakrabarti, S., and Fombonne, E. (2001). Pervasive developmental disorders in preschool children. *Journal of the American Medical Association. Special Issue*: **285**: 3093-3099.

Charmaz, K. (1990). Discovering chronic illness: Using grounded theory. *Social Science and Medicine*, **30**: 1161-1172.

Charmaz, K. (1995). Grounded Theory. In: Smith, J. A., Harre, R., and Langenhove, L. V. (Ed.), *Rethinking Methods in Psychology* (pp. 27-49). London: Sage Publications.

Chelune, G. J., Ferguson, W., Koon, R., and Dickey, T. O. (1986). Frontal lobe disinhibition in Attention Deficit Disorder. *Child Psychiatry and Human Development*, **16**: 221-234.

Chess, S., Korn, S.J. & Fernandez, P.B. (1971). *Psychiatric disorders of children with congenital rubella*. New York: Bruner/Mazel.

Chess, S. (1977). Follow-Up Report on Autism in Congenital Rubella. *Journal of Autism and Childhood Schizophrenia*, **7**: 69-81.

Childress, C. A., and Asamen, J. K. (1998). The emerging relationship of psychology and the Internet: Proposed guidelines for conducting Internet intervention research. *Ethics and Behaviour*, **8**: 19-35.

Clark, P., and Rutter, M. (1979). Task difficulty and task performance in autistic children. *Journal of Child Psychology and Psychiatry*, **20**: 271-285. London, Pergamon Press.

Clegg, J. A., Sheard, C., Cahill, J., and Osbeck, L. (2001). Severe intellectual disability and transition to adulthood. *British Journal of Medical Psychology,* **74,** 151-166.

Clegg, J. A., Standen, P. J., and Jones, G. (1996). Striking the balance: A grounded theory analysis of staff perspectives. *British Journal of Clinical Psychology,* **35,** 249-264.

Cohen, P. (1995). *Empirical Methods for Artificial Intelligence.* MIT Press, Cambridge, MA.

Condon, W. (1975). Multiple response to sound in dysfunction children. *Journal of Autism and Childhood Schizophrenia,* **5**: 537-56.

Cook, E. H. (2001). Genetics of autism. *Child and Adolescent Psychiatric Clinics of North America. Special Issue,* **10**, 333-350.

Courchesne, E. (1987). A Neurophysiological view of autism. In: Schopler, E., and Mesibov, G. B. (Eds). *Neurobiological Issues in Autism,* Plenum Press: New York.

Courchesne, E., Akshoomoff, N. A., and Townsend, J. (1990). Recent advances in autism. *Current Opinion in Paediatrics,* **2**, 685-93.

Cox, A., Klein, K., Charman, T., Baird, G., Baron-Cohen, S., Swettenham, J., Wheelwright, S., and Drew, A. (1998). *The early diagnosis of autistic spectrum disorders: Use of the Autism Diagnostic Interview-Revisited at 20 months and 42 months of age.* Unpublished manuscript, University of London, UK.

Currie, D. (1988). Rethinking what we do and how we do it: A study of reproductive decisions. *Canadian Review of Sociology and Anthropology,* **25**, 231-253.

Dahlgren, S. O., and Gillberg, C. (1989). Symptoms in the first two years of life. A preliminary population study of infantile autism. *European Archives of Psychiatry and Neurological Science,* **238**, 169-174.

Damasio, A. R., and Maurer, R. G. (1978). A neurological model for childhood autism. *Archives of Neurology,* **35**, 777-786.

Dawson, G., and Lewy, A. (1989). Reciprocal Subcortical-Cortical Influences in Autism. In: Dawson, G. (Ed.). *Autism: Nature, Diagnosis, and Treatment,* pp. 144-173. New York: Guilford.

Dawson, G., Meltzoff, A. N., Osterling, J., Rinaldi, J., and Brown, E. (1998). Children with autism fail to orient to naturally occurring social stimuli. *Journal of Autism and Developmental Disorders,* **28**: 479-85.

Dawson, M. (1983). *Able autistic people of normal or near-normal intelligence: their management and functioning in social context.* Doctoral Thesis, University of Nottingham.

Dawson, M. (1983). *Personal accounts, able autistic people's memories and perceptions of their life experiences.* Preliminary Report to DHSS.

Delacato, C. (1974). *The Ultimate Stranger: the autistic child.* Noveto, CA: Academic Therapy Publications.

Denzin, N. (1970). *The Research Act in Sociology.* London: Butterworth.

DeVilliers, J. G., and DeVilliers, P. A. (2000). Linguistic determinism and the understanding of false beliefs In: Mitchell, P., and Riggs, K. J. (Eds). *Children's reasoning and the mind.* Hove, England: Psychology Press/Taylor and Francis (UK).

DiLavore, P., and Lord, C. (1995). *Do you see what I see? Requesting and joint attention in young autistic children.* Poster presentation at the Society of Research in Child Development, Indianapolis, IN.

Dingwall, R. (1992). 'Don't mind him - he's from Barcelona': Qualitative Methods in Health Studies. In: Daly, J., Mc Donald, I., and Willis, E. (Eds.), *Researching health care: designs, dilemmas, disciplines.* London: Tavistock.

Fielding, N.G. and Fielding, J.L. (1986). *Linking Data.* London: Sage.

Fletcher, P. C., Happé, F., Frith, U., Baker, S..C., Dolan, R. J., Frackowiak, R. S., and Frith, C.D. (1995). Other minds in the brain: a functional imaging study of "theory of mind" in story comprehension. *Cognition*, **57**: 109-28.

Folstein, S., and Rutter, M. (1977). Infantile autism: A genetic study of 21 twin pairs. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **18**: 297-321.

Fombonne, E. (1999). The epidemiology of autism: A review. *Psychological Medicine*, **29**: 769-786.

Frankel, F., Freeman, B., Ritvo, E., Chickamin, B., and Carr, E. (1976). Effects of frequency of photic stimulation upon autistic and retarded children. *American Journal of Mental Deficiency*, **81**, 32-40

Freeman, B.J., Frankel, F., and Ritvo, E.R. (1977). The effects of response contingent vestibular stimulation on the behavior of autistic and retarded children. *Journal of Autism and Childhood Schizophrenia*, **6**, 353-358.

Frith, U. (1989). *Autism: Explaining the Enigma.* Oxford: Blackwell Publishers.

Frith, U. (1991). *Autism and Asperger syndrome.* Cambridge, UK: Cambridge University Press.

Frith, U., and Baron-Cohen, S. (1987). Perception in autistic children. In: Cohen, D. J., Donnellan, A. M., and Paul, R. (Eds). *Handbook of autism and pervasive developmental disorders.* (pp. 85-102). New York: Wiley and Sons.

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

Frith, U., and Happé, F. (1995). Autism: Beyond "theory of mind." In: Mehler, J., and Franck, S. (Eds). Cognition on cognition. Cognition special series (pp. 13-30). Cambridge, MA, US: The MIT Press.

Frith, U., Happé, F., & Siddons, F. (1994). Autism and theory of mind in everyday life. *Social Development*, **3**, 108-124.

Frith, U., Morton, J., & Leslie, A.M. (1991). The cognitive basis of a biological disorder: autism. *Trends in Neuroscience*, **14**, 433-438.

Frith, U., and Snowling, M. (1983). Reading for meaning and reading for sound in autistic and dyslexic children. *British Journal of Developmental Psychology*, **1**: 329-342.

Garretson, J. B., Fein, D., and Waterhouse, L. (1990). Sustained attenition in children with autism. *Journal of Autism and Developmental Disorders*, **20**: 101-114.

Gepner, B., Mestre, D., Masson, G., and deSchonen, S. (1995). Postural effects of motion vision in young autistic children. *Neuroreport: An International Journal for the Rapid Communication of Research in Neuroscience*, **6**: 1211-1214.

Gerland, G. (1997). *A Real Person: Life on the Outside*. London: Souvenir Press.

Ghaziuddin, M., Butler, E., Tsai, I., and Ghaziuddin, N. (1994). Is Clumsiness a marker for Asperger's Syndrome? *Journal of Intellectual Disability Research* **38**: 519-527.

Gillberg, C. (1989). Asperger Syndrome in 23 Swedish Children. *Developmental and Medicine and Child Neurology*, **31**: 520-31.

Gillberg, C. (1990). Autism and pervasive developmental disorders. *Journal of Child Psychology and Psychiatry*, **31**, 99-119.

Gillberg, C., and Wahlstrom, J. (1985). Chromosome Abnormalities in Infantile Autism and Other Childhood Psychoses: A Population Study of 66 Cases. *Developmental Medicine and Child Neurology*, **27**: 293-304.

Gillingham, G. (1991). Autism: Disability or superability? Designing a therapy based on experiences and feelings as described by individuals with autism. *Therapeutic Approaches to Autism: Research and Practice*. (Proceedings of the Autism Research Institute Conference, University of Durham).

Glaser, B. G., and Strauss, A. C. (1967). *The discovery of Grounded Theory: Strategies for qualitative research*. Chicago: Aldine

Goldfarb, W. (1961). *Childhood Schizophrenia*. Harvard University Press: Cambridge, Mass.

Goodman, R. (1990). Technical note: are perinatal complications causes or consequences of autism? *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **31**: 809-12.

Gottschaldt, K. (1926). The influence of experience upon the perception of figures/Ueber den Einfluss der Erfahrung auf die Wahrnehmung von Figuren. *Psychologische Forschung*, **8**: 261-317.

Grandin,. T. (1984). My experiences as an Autistic Child and Review of Selected Literature. *Journal of Orthomolecular Psychiatry*, **13**: 144-174.

Grandin, T. (1989). An Autistic Person's View of Holding Therapy. *Communication*, **23**: 75-78.

Grandin, T. (1990). Recognizing Faces is Difficult. *The Advocate*, **22**:Summer/Fall, p. 6.

Grandin, T. (1990). Sensory problems in autism. In: *Proceedings of Annual Conference of the Autism Society of America*, Buena Park, California.

Grandin, T. (1992). An inside view of autism. In: E.Schopler and G. Mesibov (Eds). *High-functioning autism*. (Pp. 105-124). New York: Plenum.

Grandin, T. (1992c). Calming Effects of Deep Touch Pressure in Patients with Autistic Disorder, College Students and Animals. *Journal of Child Adolescent Psychopharmacology*, **2**: 63-72.

Grandin, T. (1992b, May). Paper presented at IAAE Congress, The Hague, Netherlands.

Grandin, T., and Scariano, M.(1986). *Emergence: Labelled autistic*. Novato, CA: Arena.

Green, G. (1994). The quality of evidence. In: Shane, H. C. (Ed). *Facilitated Communication: A Clinical and Social Phenomenon*.(pp 157-226). San Diego, CA: Singular Publishing Group.

Griffith, E. M., Pennington, B. F., Wehner, E. A., and Rogers, S. J. (1999). Executive functions in young children with autism. *Child Development*, **70**: 817-32.

Guba, E. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology Journal*, **29**: 75-91.

Hallberg, L., and Carlsson, S. (1993). A Qualitative Study of Situations Turning a Hearing Disability into a Handicap. *Disability, Handicap and Society*, **8**, 71- 86.

Hammersley, M. (1990). Reading Ethnographic Research: A Critical Guide. London: Longmans.

Happé, F. (1991a). *Theory of mind and communication in autism*. PhD thesis, University of London.

Happé, F. (1991b). The autobiographical writings of three Asperger's Syndrome adults: problems of interpretation and implications for theory. In: Frith, U. (Ed.) *Autism and Asperger syndrome*, (Pp. 207-242). Cambridge: Cambridge University Press.

Happé, F. (1994a). *Autism: An introduction to psychological theory*. London: UCL Press.

Happé, F. (1994b). Annotation: current psychological theories of autism: the "theory of mind" account and rival theories. *Journal of Child Psychology and Psychiatry*, **35**: 215-29. Review.

Happé, F. (1994c). An advanced test of theory of mind: understanding of story characters' thoughts and feelings by able autistic, mentally handicapped, and normal children and adults. *Journal of Autism Development and Disorders*, **24**: 129-54.

Happé, F. (1996). Studying weak central coherence at low levels: children with autism do not succumb to visual illusions: A research note. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **37**: 873-7.

Happé, F. (1997). Central coherence and theory of mind in autism: reading homographs in context. *British Journal of Developmental Psychology*, **15**: 1-12.

Happé, F. (1999a). Autism: Cognitive deficit or cognitive style? *Trends in Cognitive Sciences*. **3**, 82-86.

Happé, F. (1999b). Understanding assets and deficits in autism: Why success is more interesting than failure. *Psychologist*, **12**: 540-546.

Hare, D. J., and Paine, C. (1997). Developing Cognitive Behavioural Treatment for People with Asperger's Syndrome, *Clinical Psychology Forum*, **110**: 5-8.

Hare, D.J., and Flood, A. (2001) Approaching work with people with a diagnosis of Asperger's Syndrome: some notes for the perplexed. *Clinical Psychology Forum*, 247.

Harré, R., and Secord, P. F. (1973). The explanation of social behaviour. Totowa, NJ: Littlefield, Adams.

Harris, P. (1993). Pretending and Planning. In: Baron-Cohen S, Tager-Flusberg, H., and Cohen, D. J. (Eds). *Understanding Other Minds. Perspectives from Autism.* (Pp. 228-246). Oxford: Oxford Medical Publications, Oxford.

Heaton, P, Hermelin, B., and Pring, L. (1998). Autism and pitch processing: A precursor for savant musical ability. *Music Perception*, **15**: 291-305.

Henwood, K. L., and Pidgeon, N.F. (1995). Grounded theory and psychological research. *The Psychologist*, . *Special Issue: Qualitative Research Special Issue*, **3**, 115-118.

Hermelin, B., and O'Connor. (1970). *Psychological Experiments with Autistic Children.* New York: Pergamon.

Hobson, P. (1983). *Origins of the personal relation, and the strange case of autism.* Paper presented at the meeting of the Association of Child Psychology and Psychiatry, London.

Hobson, P. (1986a). The autistic child's appraisal of expressions of emotion. *Journal of Child Psychology and Psychiatry*, **27**, 321-342.

Hobson, P. (1986b). The autistic child's appraisal of expressions of emotion: A further study. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **27**: 671-680.

Hobson, P. (1989). *Beyond Cognition: A theory of Autism.* In: Dawson, G. (Ed). Autism: Nature, diagnosis and treatment (pp. 22-48). New York, Guildford.

Hobson, P. (1993). *Autism and the Development of Mind. Essays in developmental psychology.* Hove, Psychology Press.

Hobson, P., and Lee, A. (1999). Imitation and identification in Autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **40**: 649-59.

Hobson, P., Ouston, J., and Lee, A. (1988). What's in a face? The case of autism. *British Journal of Psychology*, **79**: 441-453.

Holliday, A. (2001). *Doing and Writing Qualitative Research.* Sage Publications

Holliday-Willey, L. (1999). *Pretending to be Normal.* London: Jessica Kingsley.

Hughes, C. (2001). Executive dysfunction in autism: Its nature and implications for the everyday problems experienced by individuals with autism. In: Burack, J. A., and Charman, T. (Eds): *The development of autism: Perspectives from theory and research* (pp. 255-275). Mahwah, NJ, US: Lawrence Erlbaum Associates, Inc., Publishers.

Hughes, C., and Russell, J. (1993). Autistic children's difficulty with mental disengagement from an object: Its implications for theories of autism. *Developmental Psychology*, **29**: 498-510.

Hughes, C., Leboyer, M., and Bouvard, M. (1997a). Executive function in parents of children with autism. *Psychological Medicine*, **27**, 209-220.

Hughes, C., Plumet, M. H., and Leboyer, M. (1999). Towards a cognitive phenotype for autism: increased prevalence of executive dysfunction and superior spatial span amongst siblings of children with autism. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **40**: 705-18.

Hughes, C., Russell, J., and Robbins, T. W. (1994). Evidence for executive dysfunction in autism. *Neuropsychologia*, **32**: 477-492.

Hunt, A., and Dennis, J. (1987). Psychiatric disorder among children with tuberous sclerosis. *Developmental Medicine in Child Neurology*, **29**: 190-8.

Hurlburt, R., Happé, F., Frith, U. (1994). Sampling the inner experiences of autism: a preliminary report. *Psychological Medicine*, **24**, 385-395.

Hutt, S. J., Hutt, C., Lee, D., and Ounsted, C. (1965). A behavioral and electroencephalographic study of autistic children. *Journal of Psychiatric Research*, **3**: 181-197.

Huws, Jones, R. S. P., and 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.

Incagnoli, T., and Kane, R. (1981). Neuropsychological functioning in Gilles de la Tourette's Syndrome. *Journal of Clinical Neuropsychology*, **3**: 165-169.

James, A. L., and Barry, R. J. (1980). A review of psychophysiology in early onset psychosis. *Schizophrenia Bulletin*, **6**: 506-525.

Jarrold, C. (1997). Pretend play in autism: Executive explanations In: Russell, J. (Ed). *Autism as an executive disorder* (pp. 101-140). New York, NY, US: Oxford University Press, New York, NY, US: Oxford University Press.

Jarrold, C., and Russell, J. (1997). Counting abilities in autism: Possible implications for central coherence theory. *Journal of Autism and Developmental Disorders*, **27**: 25-37.

Jollife, T., Landsdown, R., and Robinson, R. (1992). Autism; a personal account. *Communication*, **26,** pp. 12-19.

Jolliffe, T., and Baron-Cohen, S. (1997). Are people with autism and Asperger syndrome faster than normal on the embedded figures test? *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **38**: 527-34.

Jolliffe, T., and Baron-Cohen, S. (1999). A test of central coherence theory: linguistic processing in high-functioning adults with autism or Asperger syndrome: is local coherence impaired? *Cognition*, **71**: 149-185.

Jones, R. S. P., Zahl, A., & Huws, J (2001). A qualitative analysis of first-hand accounts of emotional experiences in Autism *Disability and Society*, **16**, 3, 393-401.

Jones, R. S. P., and Meldal, T. O. (2001). Social relationships and Asperger's syndrome: A qualitative analysis of first-hand accounts. *Journal of Learning Disabilities*, **5**: 35-42.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2: 217-250.

Kientz, M. A., and Dunn, W. (1996). A comparison of the performance of children with and without autism on the Sensory Profile. *The American Journal of Occupational Therapy*, **51**: 530-537.

Kirk, J. And Miller, M. (1986). Reliability and Validity in Qualitative Research. London: Sage.

Klin, A. (1991). Young autistic children's listening preferences in regard to speech: A possible characterisation of the symptom of social withdrawal. *Journal of Autism and Developmental Disorders*, **21**, 29-42.

Klin, A., Volkmar, F. R., Sparrow, S. S., Cicchetti, D. Y., and Rourke, P. P (1995). Validity and Neuropsychological Characterization of Asperger Syndrome: Convergence with Nonverbal Learning Disabilities Syndrome, *Journal of Child Psychology and Psychiatry*, **36**: 1127-40.

Kolvin, I., Ounstead, C., Richardson, L., and Garside, R. (1971). Studies in the childhood psycoses I to VI. *British Journal of Psychiatry*, **118**: 381-419.

Kolvin, I., Ounsted, C., Richardson, L. M., and Garside, R. F. (1971). The family and social background in childhood psychoses (III). *British Journal of Psychitary*, **118**, 396-402.

Koppelman, M., Wilson, B., and Baddeley, A. (1990). *The Autobiographical Memory Interview*. Thames Valley Test Company, Bury St Edmunds.

Kvale, S. (1992). Ten standard responses to qualitative research interviews. *Viewpoints*, 1-31.

Leekham, S.R, López, B., and Moore, C. (2000). Attention and Joint Attention in Preschool Children with Autism. *Developmental Psychology*, **36**, 261-273.

Leslie, A. (1994). Pretending and believing: issues in the theory of ToMM. *Cognition*, **50**:211-38.

Leslie, A. M. (1987). Pretence and representiaon: The origins of "theory of mind". *Psychological Review*, **94**, 412-426.

Leslie, A. M., and Frith, U. (1988). Autistic children's understanding of seeing, knowing and believing. *British Journal of Developmental Psychology*, **6**: 315-24.

Leslie, A. M., and Thaiss, L. (1992). Domain specificity in conceptual development: Neuropsychological evidence from autism. *Cognition*, **43**: 225-251.

Lincoln, A. J., Courchesne, E., Harms, L., and Allen, M. (1995). Sensory modulation of auditory stimuli in children with autism and receptive developmental language disorder. Event-related potential evidence. *Journal of Autism and Developmental Disorders*, **25**, 521-539.

Lockyer, L., and Rutter, M. (1970). A five to fifteen-year follow-up study of infantile psychosis: IV. Patterns of cognitive ability *British Journal of Social and Clinical Psychology*, **9**: 152-163.

Lord, C. (1995). Follow-Up of Two-Year-Olds Referred for Possible Autism. *Journal of Child Psychology and Psychiatry*, **36**: 1365-1382.

Lord, C., and Schopler,E. (1987). Neurobiological implications of sex differences in autism. In: Schopler E and Mesibov, GB (Eds). *Neurobiological issues in autism. Current issues in autism*: (pp. 191-211). New York, NY, US: Plenum Press.

Lotter, V. (1966). Epidemiology of autistic conditions in young children. *Social Psychiatry*, **1**: 124-137.

Lovaas, O. I., Koegel, R. L., and Schreibman, L. (1979). Stimulus overselectivity in autism: A review of research. *Psychological Bulletin*, **86**: 1236-1254.

Lovaas, O. I., Schreibman, L., Koegel, R. L., and Rehm, R. (1971). Selective responding by autistic children to multiple sensory input. *Journal of Abnormal Psychology*, **77**: 211-222.

Loveland, K. (1991). Social affordances and interaction: Autism and the affordances of the human environment. *Ecological Psychology*, **3**, 99-119.

Ludwig, S. (1998). Making a difference-Preventing and responding to abuse of people with developmental disabilities. *Book Review*, **7**: 194-195.

Lueger, R. J., Gill, K. J. (1990). Frontal-lobe cognitive dysfunction in conduct disorder adolescents. *Journal of Clinical Psychology*, **46**: 696-706.

Macdonald, H., Rutter, M., Howlin, P., and Rios, P. (1989). Recognition and expression of emotional cues by autistic and normal adults. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **30**: 865-877.

Macdonald, H., Rutter, M., Howlin, P., Rios, P., Le Couteur, A., Evered, C.., and Folstein, S. (1989). Recognition and expression of emotional cues by autistic and normal adults. *Journal of Child Psychology*, **30,** 865-677.

Manjiviona, J., and Prior, M. (1995). Comparison of Asperger Syndrome and High-Functioning Autistic Children on a Test of Motor Impairment, *Journal of Autism and Developmental Disorders*, **25**: 23-39.

Mason, J. (1966). *Qualitative researching*. Thousand Oaks, CA, US: Sage Publications.

McEvoy, R. E., Rogers, S. J., and Pennington, B. F. (1993). Executive function and social communication deficits in young autistic children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **34**: 563-78.

McKean, T. (1994). *Soon Will Come The Light*. Arlington, Texas: Future Horizons.

Melnick, C. R., and Beaudry, J. S. (1990). *A qualitative research perspective: Theory, practice, essence*, Paper presented at the Annual Meeting of the American Education Research Association, Boston.

Metz, J. R. (1967). Stimulation level preferences of autistic children. *Journal of Abnormal Psychology*, **72,** 529-535.

Meyer, R, N. (2000). *Asperger Syndrome Employment Workbook :An Employment Workbook for Adults with Asperger Syndrome*. London: Jessica Kingsley Ltd

Michalak, E. E., and Szabo, A. (1998). Guidelines for Internet Research: an update. *European Psychologist*, **3**: 70-75.

Midence, K., and O'Neill, M. (1999). The experience of parents in the diagnosis of autism. *Autism*, **3**: 273-283.

Miedzianik, D. (1986). *My autobiography*. Nottingham: University of Nottingham, C.D.R.U.

Miller, J.N., and Ozonoff, S. (2000). The external validity of Asperger disorder: Lack of evidence from the domain of neuropsychology. *Journal of Abnormal Psychology*, **19**, 227-238.

Miles, M. B., and Huberman, A. M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook*. 2nd edition. Thousand Oaks, California, Sage.

Millward, C., Powell, L., Messer, D., and Jordan, R. R (2000). Recall for self and other in Autism: Children's Memory for Events Experienced by Themselves and Their Peers. *Journal of Autism and Developmental Disorders*, **30**: 15-27.

Mostert, M.P. (2001). Facilitated communication since 1995: a review of published studies, *Journal of Autism and Developmental Disorders*, **31**, 317-328.

Mottron, L., and Burack, J. A. (2001). Enhanced Perceptual Functioning in the Development of Autism. In: Burack, J. A., Charman, T., Yirmiya, N., and Zelazo, P. (Eds.). *The development of autism: Perspectives from theory and research.* (131-148). Mahwah, NJ, US: Lawrence Erlbaum Associates.

Mottron, L., Belleville, S., and Menard, E. (1999). Local bias in autistic subjects as evidenced by graphic tasks: Perceptual hierarchization or working memory deficit? *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **40**: 743-755.

Muller, R. A., Behen, M. E., Rothermel RD, Chugani DC, Muzik O, Mangner TJ and Chugani HT (1999). Brain mapping language and auditory perception in high-functioning autistic adults: a PET study. *Journal of Autism and Developmental Disorders*, **29**: 19-31.

Mundy, P. (1995). Joint attention and social-emotional approach behavior in children with autism. *Development and Psychopathology*, **7**: 63-82.

Mundy, P., and Marcus, J. (1997). On the Nature of Communication and Language Impairment in Autism. *Mental Retardation and Developmental Disabilities Research Reviews*. **3**, 343-349.

Mundy, P., and Neal, R. (2001). Neural Plasticity, Joint Attention and a Transactional Social-Orienting Model of Autism. *International Review of Research in Mental Retardation*, **23**:139-167.

Mundy, P., and Sigman, M. (1989). The theoretical implications of joint-attention deficits in autism. *Development and Psychopathology*, **1**: 173-183.

Mundy, P., Sigman, M., and Kasari, C. (1993). The theory of mind and joint deficits in autism. In: Baron-Cohen, S., Tager-Flusberg, H., and Cohen, D. (Eds). *Understanding other minds: Perspectives from autism* (pp. 181-203). Oxford: Oxford University Press.

Mundy, P., Sigman, M., and Kasari, C. (1994). Joint attention, developmental level and symptom presentation in young children with autism. *Developmental and Psychopathology*, **6**, 389-401.

National Autistic Society. (1997). *Statistics Sheet 1*, National Autistic Society, London.

Newson, E. (1977). *Making sense of autism.* Child Development Research Center, University of Notingham.

Norman, D., and Shallice, T. (1980). *Attention to action: Willed and automatic control of behaviour.* Centre for Human Information Processing Technical Report, **99**. University of California, San Diego.

Norman, D., and Shallice, T. (1986). Attention to action: Willed and automatic control of behaviour. In: Davidson, R., Schwartz, G., and Shapiro, D., (eds.) *Consciousness and Self-Regulation: Advances in Research and Theory*, **4**, (pp. 1-18). Plenum, New York.

Olley, G., and Reeve, C. (1997). Issues of Curriculum and Classroom Structure. In: Cohen, D.J. and Volkmar, F.R., (eds.) *Handbook of autism and pervasive developmental disorder* (2nd ed). 484-508.

Olney, M. F. (2000). Working with autism and other social-communication disorders. *Journal of Rehabilitation*, **66**: 51-6.

O'Neill, M., and Jones, R. S. P. (1997). Sensory-perceptual abnormalities in autism: a case for more research. *Journal of Autism and Developmental Disabilities*, **27**: 283-93.

Ornitz, E. M. (1985). Neurophysiology of infantile autism. *Journal of the American Academy of Child Psychology*, **24,** 251-262.

Ornitz, E. M. (1989). Autism at the interface between sensory processing and information processing. In: Dawson G (Ed). *Autism: nature, diagnosis, and treatment* (pp174-207). New York: Guilford.

Ornitz, E. M., and Ritvo, E. R. (1968). Perceptual inconsistency in early infantile autism. *Archives of General Psychiatry*, **18**:76-98.

Ornitz, E. M., Guthrie, D., and Farley, A. J. (1978). The Early Symptoms of Childhood Autism. In: G. Serban (Ed.), *Cognitive Defects in the Development of Mental Illness* (pp. 24-42). New York: Brunner/Mazel.

Osterling, J., and Dawson, G. (1994). Early recognition of children with autism: a study of first birthday home videotapes. *Journal of Autism and Developmental Disorders*, **24**: 247-57.

Ozonoff, S. (1995). Executive functions in autism. In: Schopler, E., and Mesibov, G. B. (Eds). *Learning and cognition in autism. Current issues in autism* (pp. 199-219). New York, NY, US: Plenum Press.

Ozonoff, S., and Jensen, J. (1999). Brief Report: Specific Executive Function Profiles in Three Neurodevelopmental Disorders. *Journal of Autism and Developmental Disorders*, **29**: 171-77.

Ozonoff, S., and Strayer, D. L. (1997). Inhibitory function in nonretarded children with autism. *Journal of Autism and Developmental Disorders*, **27**: 59-77.

Ozonoff, S., Pennington, B. F., and Rogers, S. J. (1991). Executive function deficits in high-functioning autistic individuals: relationship to theory of mind. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **32**: 1081-1105.

Ozonoff, S., Rogers, S. J., Farnham, J. M., and Pennington, B. F. (1993). Can standard measures identify subclinical markers of autism? *Journal of Autism and Developmental Disorders*, **23**: 429-41.

Ozonoff, S., Strayer, D. L., McMahon W. M., and Filloux, F. (1994). Executive function abilities in autism and Tourette syndrome: An information processing approach. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **35**: 1015-1032.

Pascualvaca, D. M., Fantie, B. D., Papageorgiou, M., and Mirsky, A. F. (1998). Attentional capacities in children with autism: Is there a general deficit in shifting focus? *Journal of Autism and Developmental Disorders*, **28**, 479-485.

Pennington, B. F., and Ozonoff, S. (1996). Executive functions and developmental psychopathology. *Journal of Child Psychology and Psychiatry and Allied Disciplines. Special Issue: Annual research review*, **37**: 51-87.

Pennington, B. F., and Smith, S. D. (1997). Genetic analysis of dyslexia and other complex behavioral phenotypes. *Current Opinion in Pediatrics*, **9**: 636-41.

Pidgeon, N. (1996). Grounded theory: theoretical background. In: Richardson, J. (ed.) Handbook of Qualitative Research Methods. (pp 75-85).Leicester: BPS Books

Pidgeon, N. F; Turner, B. A., and Blockley, D. J. (1991). The use of Gounded Theory for conceptual analysis in knowledge elicitation. *International Journal of Man-Machine Studies*, **35**, 151-173.

Piven, J. (1996). Regional brain enlargement in autism: a magnetic resonance imaging study. *Journal of American Academic Child and Adolescent Psychiatry*, **35**: 530-6.

Piven, J., and Palmer, P. (1997). Cognitive deficits in parents from multiple-incidence autism families. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **38**: 1011-1021.

Piven, J., Arndt, S., Bailey, J., Havercamp, S., Andreason, N., and Palmer, P. (1995). An MRI study of brain size in autism. *The American Journal of Psychiatry*, **152**: 1145-1149.

Plaisted, K. (2001). Reduced generalization in autism: An alternative to weak central coherence. In: Burack, J. A., Charman, T., Yirmiya, N., and Zelazo, P. (Eds.). *The development of autism: Perspectives from theory and research*. (Pp. 148-169). Mahwah, NJ, US: Lawrence Erlbaum Associates.

Plaisted, K., O'Riordan, M., and Baron-Cohen, S.(1998). Enhanced visual search for a conjunctive target in autism: a research note. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **39**: 777-83.

Prior, M. R. (1979). Cognitive Abilities and Disabilities in Infantile Autism: A Review. *Journal of Abnormal Child Psychology*, **7**: 357-80.

Prior, M., and Hoffmann, W. (1990). Brief report: neuropsychological testing of autistic children through an exploration with frontal lobe tests. *Journal of Autism and Developmental Disorders*, **20**:581-90.

Prior, M., Dahlstrom, B., and Squires, T. L. (1990). Autistic Children's Knowledge of Thinking and Feeling States in Other People. *Journal of Child Psychology and Psychiatry*, **31**: 587-601.

Reason, P., and Rowan, J. (1981). (Eds). *Human Enquiry: A Sourcebook of New Paradigm Research*. Chichester: Wiley.

Ricks, D. M., and Wing, L. (1975). Language, communication, and the use of symbols in normal and autistic children *Journal of Autism and Childhood Schizophrenia*, **5**: 191-221.

Rimland, B. (1990). Sound sensitivity in autism. *Autism Research Review International*, **4**, 6-12.

Rimland, B., and Edelson, S. M. (1995). Pilot study of auditing integration training on autism. *Journal of Autism and Developmental Disorder*, **25**: 61-70.

Rincover, A, Newsom, C. D., Lovaas, O. I., and Koegel, R. L. (1977). Some motivational properties of sensory reinforcement with psychotic children. *Journal of Experimental Child Psychology*, **24**: 312-323.

Rincover, A., and Ducharme, J. M. (1987). Variables influencing stimulus overselectivity and "tunnel vision" in developmentally delayed children. *American Journal of Mental Deficiency*, **91**: 422-430.

Rogers, S. J., Bennetto, L., McEvoy, R., and Pennington, B. F. (1996). Imitation and pantomime in high-functioning adolescents with autism spectrum disorders. *Child Development*, **67**, 2060-2073.

Rosenhall, U., Nordin, V., Sandstrom, M., Ahlsen, G., and Gillberg, C. (1999). Autism and hearing loss. *Journal of Autism and Developmental Disorder*, **29**: 349-358.

Royeen, C. B. (1987). TIP-Touch Inventory for Preschoolers: A pilot study. *Physical and Occupational Therapy in Peadiatrics*, **7**, 29-40.

Royeen, C. B., and Fortune, J. C. (1990). TIE: Touch Inventory for school aged children. *American Journal of Occupational Therapy*, **44**, 165-170.

Rumsey, J. M. (1985). Conceptual problem-solving in highly verbal, nonretarded autistic men. *Journal of Autism and Developmental Disorders*, **15**: 23-36.

Rumsey, J. M. (1992). Neuropsychological studies of high-level autism. In Schopler, E., Mesibov, G. (Eds). *High-functioning individuals with autism. Current issues in autism.* (pp. 41-64). New York, NY, US: Plenum Press.

Rumsey, J. M., and Hamburger, S. D. (1988). Neuropsychological findings in high-functioning men with infantile autism, residual state. *Journal of Clinical and Experimental Neuropsychology*, **10**: 201-221.

Rumsey, J. M., and Hamburger, S. D. (1990). Neuropsychological divergence of high-level autism and severe dyslexia. *Journal of Autism and Developmental Disorders*, **20**: 155-168.

Russell, J., and Hill, E. L. (2001). Action-monitoring and intention reporting in children with autism. *Journal of Child Psychiological Psychiatry*, **42**, 317-328.

Russell, J., Mauthner, N., Sharpe, S., and Tidswell, T. (1991). The Windows Task as a measure of strategic deception in preschoolers and autistic children. *British Journal of Developmental Psychology*, **9**, 331-349.

Russell, J., Saltmarsh, R., and Hill, E. (1999). What do executive factors contribute to the failure on false belief tasks by children with autism? *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **40**: 859-68.

Rutter, M. (1970). Autistic Children: Infancy to Adulthood. *Seminars in Psychiatry*, **2**: 435-50.

Rutter, M. (1978). Diagnosis and definitions of childhood autism. *Journal of Autism and Childhood Schizophrenia*, **8**: 139-161.

Rutter, M. (2000). Genetic studies of autism: From the 1970s into the millennium. *Journal of Abnormal Child Psychology*, **28**, 3-14.

Rutter, M. (2000). The Nature of Intelligence (Introduction). *Novartis Foundation Symposia*, **233**, 1-5.

Rutter, M., and Schopler, E. (1987). Autism and pervasive developmental disorders: concepts and diagnostic issues. *Journal of Autism and Developmental Disorders*, **17** p.159-86.

Schopler, E. (1998). Premature Popularization of Asperger Syndrome. In:. Schopler, E., Mesibov, G. B., and Kunce, L. J. (Eds). *Asperger Syndrome or High-Functioning Autism?* (pp. 385-99). New York: Plenum.

Schopler, E., and Mesibov, G B. (1998). *Learning and cognition in autism.* New York: Plenum Press.

Seale, C. (1999). The Quality of Qualitative Research. London: Sage.

Sellin, B. (1995). *I don't want to be inside me anymore.* New York: Basic Books.

Shah, A., and Frith, U. (1983). An islet of ability in autistic children: A research note. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **24**: 613-620.

Shah, A., and Frith, U. (1993). Why do autistic individuals show superior performance on the block design task? *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **34**: 1351-1364.

Shah, A., Holmes, N., and Wing, L. (1982). Prevalence of autism and related conditions in adults in a mental handicap hospital. *Applied Research in Mental Retardation*, **3**: 303-317.

Shore, S, M. (2001) *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome.* Autism Asperger Publishing Co.

Siegel, B. (1996). *The World of the Autistic Child: Understanding and Treating Autistic Spectrum Disorder* Oxford University Press, New York.

Sigman, M. And Rushkin, M., (1999). Continuity and change in the social competence of children with autism, Down's syndrome and developmental delays. *Monographs of the Society for Research in Child Development*, **64**:1+.

Silverman, D. (2000). *Doing Qualitative Research: A Practical Handbook.* London Sage.

Sinason, V. (1992). *Mental handicap and the human condition: New approachs from the Tavistock.* Free Association Books: London.

Skeggs, B. (1994). Situating the Production of Feminist Ethnography. In: Maynard M. And Purvis, J. (Eds). *Researching Womens's Lives from a Feminist Perspective*. London: Taylor and Francis.

Smalley, S. L. (1988). Autism and tuberous sclerosis. *Journal of Autism and Developmental Disorders*, **28**: 407-14.

Smalley, S. L., Asarnow, R. F., and Spence, A. (1988). Autism and genetics. *Archives of General Psychiatry*, **45**: 953-961.

Sodian, B., and Frith, U. (1992). Deception and sabotage in autistic, retarded and normal children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **33**: 591-605.

Stake, R. E. (1976). *Evaluating the arts in education: A responsive approach.* Columbus, OH: Charles Merrill.

Stehli, A. (1990). *The sound of a miracle: A child's triumph over autism.* New York, Doubleday.

Stone, W. L., and La Greca, A. M. (1994). Social deficits in children with learning disabilities. In: A. J. Capute and P. J. Accardo and B. K. Shapiro (Eds.), *Learning disabilities spectrum: ADD, ADHD, and LD* (pp. 155-175). Baltimore: York Press Inc.

Strauss, A., and Corbin, J. (1990). *Basics of Qualitative Research.* London: Sage Publications.

Swettenham, J., Baron-Cohen, S., Charman, T., Cox, A., Baird, G., Drew, A., Rees, L., and Wheelwright, S. (1998). The frequency and distribution of spontaneous attention shifts between social and nonsocial stimuli in autistic, typically developing, and nonautistic developmentally delayed infants *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **39**: 747-753.

Szatmari, P., Tuff, L., Finlayson, M. A. J., and Bartolucci, G. (1990). Asperger's syndrome and autism: Neurocognitive aspects. *Journal of the American Academy of Child and Adolescent Psychiatry*, **29**: 130-136.

Tager-Flusberg, H (1993). What Language Reveals about the Understanding of Minds in Children with Autism. In: Baron-Cohen, S., Tager-Flusberg, H., and Cohen, D. J. (Eds). *Understanding Other Minds. Perspectives from Autism.* (Pp.138-157). Oxford: Oxford Medical Publications, Oxford.

Tager-Flusberg, H. (2001). A reexamination of the theory of mind hypothesis of autism. In: Burack, J. A., Charman, T., Yirmiya, N., and Zelazo, P. (Eds.). *The development of autism: Perspectives from theory and research.* (Pp. 173-193). Mahwah, NJ, US: Lawrence Erlbaum Associates.

Talay-Ongan, A., and Wood, K. (2000). Unusual Sensory Sensitivities in Autism: a possible crossroads. *International Journal of Disability, Development and Education*, **47**, 201-212.

Tipper, S. P. (1985). The negative priming effect: Inhibitory priming by ignored objects. *Quarterly Journal of Experimental Psychology: Human Experimental Psychology*, **37**: 571-590.

Townsend, J., and Courchesne, E.(1994). Parietal damage and narrow "spotlight" spatial attention. *Journal of Cognitive Neuroscience*, **6**: 220-232.

Townsend, J., Westerfield, M., Leaver, E., Makeig, S., Jung, T., Pierce, K., and Courchesne, E. (2000). Abnormalities of topography and composition of ERP response in autism during spatial attention, *Cognitive Brain Research*, **11**: 127-145.

Tribe, D. (1992). Making sense of sensory experience. In: *Autism: The puzzle. Are the pieces starting to fit*? National conference 1992 Proceedings (pp.141-147). Melbourne, Australia: VACAA.

Trottier, G., Srivastava, L., and Walker, C. (1999). Etiology of infantile autism: A review of recent advances in genetic and neurobiological research. *Journal of Psychiatry and Neuroscience*, **24**: 103-115.

Turner, M. (1997). Towards an executive dysfunction account of repetitive behaviour in autism. In: Russell, J. (Ed). *Autism as an executive disorder* (pp. 57-100). New York, NY, US: Oxford University Press, New York, NY, US: Oxford University Press.

Volkamr, F. R., Cohen, D. J., Paul, R. (1986). An evaluation of DSM-III criteria for infantile autism. *Journal of the American Acadamy of Child Psychitary*, **25**, 190-197.

Volkmar FR and Klin A (1998). Asperger Syndrome and Nonverbal Learning Disabilities. In: Schopler, E., Mesibov, G. B., and Kunce, L. J. (Eds). *Asperger's Syndrome or High-Functioning Autism*? (pp. 107-21). New York: Plenum.

Volkmar, F., and Cohen, D. (1985). The experience of infantile autism: A first-hand account by Tony W. *Journal of Autism and Developmental Disorders*, **15**: 47-54.

Waterhouse L, Morris, R., Allen, D., Dunn, M., Fein, D., Feinstein, C., Rapin, I., and Wing, L. (1996). Diagnosis and classification in autism. *Journal of Autism and Developmental Disorders*, **26**: 59-86.

Wechsler, D. (1981). Historical Review: The Psychometric Tradition. Developing the Wechsler Adult Intelligence Scale. *Contemporary Educational Psychology*, **6**: 82-85.

Weekes, L. (1995). *Autism: A Bridge of Voices*. Radio documentary British Broadcasting Corporation. (Precise date of broadcast unavailable).

Weeks, S. J., and Hobson, P. (1987). The salience of facial expression for autistic children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **28**: 137-52.

Wehner, E., and Rogers, S. J. (1994). *Attachment relationships of autistic and developmentally delayed children.* Paper presented at the bimonthly meeting of the Developmental Psychobiology Research Group, Denver, CO.

Welsh, M. C., and Pennington, B. F. (1988). Assessing frontal lobe functioning in children: Views from developmental psychology. *Developmental Neuropsychology*, **4**, 199-230.

Westerfield, M. J., Townsend, E., Edwards, E., Makeig, S., Jung, T.P., and Courchesne, E. (2000). Cerebellar lesions affect the late positive complex in visual spatial attention. *Journal of Cognitive Neuroscience*, 60D, [Suppl.S], 98.

Whelan, M. (1996). *You Don't Have Words to Describe What I Experience: The Sensory Experiences of Individuals with Autism Based on First Hand Accounts.* (booklet) Geneva Centre for Autism. Toronto Canada.

White, B. B., and White, M. S. (1987). Autism from the inside. *Medical Hypotheses*, **24**: 223-229.

Wholmsley, S. (2001). *Special Media Interest in a clinical learning disabilities population.* Unpublished D. Clin. Psych. Thesis. University of Leicester.

Williams, D. (1992). *Nobody Nowhere.* London: Doubleday.

Williams, D. (1994). *Somebody Somewhere.* London : Doubleday.

Williams, D. (1996). *Autism: An Inside-Out Approach.* Jessica Kingsley Publishers. London and Philadelphia.

Williams, D. (1998). *Autism and Sensing; The Unlost Instinct.* London: Jessica Kingsley Publishers.

Williams, E., Reddy, V., and Costall, A. (1999). Children with autism experience problems with both objects and people. *Journal of Autism and Developmental Disorders*, 29, 367-378.

Wimmer, H., and Perner, J. (1983). Beliefs about beliefs: Representation and constraining function of wrong beliefs in young children's understanding of deception. *Cognition*, **13**: 103-128.

Wimpory, D. C., Hobson, R. P., Williams, J. M. G., and Nash, S. (2000). Are Infants with Autism Socially Engaged? A Study of Recent Retrospective Parental Reports. *Journal of Autism and Developmental Disorders*, **30**, 525-536.

Wing, J.K. (1966). Diagnosis, epidemiology, aetiology. In: Wing, J.K. *Early Childhood Autism. Clinical, Educational and Social Aspects.* Pergamon Press: London.

Wing, L. (1969). The handicaps of autistic children: A comparative study. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **10**: 1-40.

Wing, L. (1981). Asperger's Syndrome - A Clinical Account. *Psychological Medicine*, **11**: 115-129.

Wing, L. (1988). The continuum of autistic characteristics In: Schopler, E., and Mesibov, G. B. (Eds). *Diagnosis and assessment in autism. Current issues in*

autism (pp. 91-110). New York, Plenum Press.

Wing, L. (1991). The Relationship between Asperger's Syndrome and Kanner's Autism, In: Frith, U. (Ed). *Autism and Asperger Syndrome*,(pp. 93-121). New York: Cambridge University Press.

Wing, L. (1996). *The autistic spectrum: A guide for parents and professionals.* London: Constable.

Wing, L. (1998). The history of Asperger syndrome. In:. Schopler, E., Mesibov, G. B., and Kunce, L. J. (Eds). *Asperger Syndrome or High-Functioning Autism?* (pp. 385-99). New York: Plenum.

Wing, L., and Gould, J. (1978). Systematic recording of behaviors and skills of retarded and psychotic children. *Journal of Autism and Childhood Schizophrenia*, **8**: 79-97.

Wing, L., and 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.

Wing, L., Attwood, A. (1987). *Syndromes of autism and atypical development.* Handbook of Autism and Pervasive Developmental Disorders. (pp. 3-19). John Wiley and Sons, Inc.

Wulff, S. B. (1985). The symbolic and object play of children with autism: A review. *Journal of Autism and Developmental Disorders*, **15**: 139-48.

Yirmiya, N., Sigman, M., Kasari, C., and Mundy, P. (1989). Facial expressions of affect in autistic, mentally retarded and normal children *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **30**: 725-35.

Zelazo, P. D., Burack, J. A., Benedetto, E., and Frye, D. (1996). Theory of mind and rule use in individuals with Down's syndrome: a test of the uniqueness and specificity claims. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, **37**: 479-84.

Zoller, D. (1989). *Wenn isch mit euch reden konnte*. Bern: Scherz Verlag. (Introduction translated by Annie Humphreys, Autism Research Unit, Sunderland Polytechnic, 1990).