

Able autistic adults' constructions of social disability

Thesis submitted in partial fulfillment of the
Doctorate in Clinical Psychology
for the University of Leicester.

by

Craig MacDonald, B.A. (Joint Hons.)
Department of Clinical Psychology.

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ABSTRACT

Since Wing's (1981) seminal paper, *Asperger's syndrome: a clinical account*, research into more able or 'high-functioning' individuals with autistic spectrum disorders has tended to focus on children. For adults, limited research has suggested a general trend toward recovery from earlier autistic 'symptoms'. However, continued social isolation and poor levels of social integration have been reported to remain common.

This study explored how six able autistic adults (five male; age range 22 to 37 years) understood their experiences of social disability. All participants had prior psychiatric diagnoses of an autistic spectrum disorder (one 'Infantile Autism', five 'Asperger's syndrome'). Candidates requiring residential care and those with a dual-diagnosis of learning disability (mental handicap / mental retardation) or psychiatric illness were excluded. A directed sampling procedure was used and qualitative data were gathered in individual interviews. Grounded theory methodology was used for data selection and transcript analysis.

A core construct termed 'Social fit' was identified in the analysis. This represented participants' constructions of disability as a relationship between self and 'others'. Within this construct, an explanatory process model was developed comprising three main categories of experience. These represented, respectively, participants' gradual awareness of personal difference, their revaluation of personal identity and their subsequent understanding of social inclusion.

The analysis was discussed in relation to literature on autism and disability theory.

1.0 INTRODUCTION

1.1 Overview

The objective of this study was to develop an understanding of how six intellectually-able adults with autism meaningfully construed their experiences of social disability. The study was exploratory because little is known of the life experiences of this population. This chapter provides general background material on autism and disability, the two main concepts in the research question.

The chapter introduces autism as a developmental disorder, now widely defined as a triad of impairments in social functioning. A limited literature on the progress of more able individuals with autism is then outlined. This includes particular difficulties arising in adolescence and two general trends in adulthood: the amelioration of earlier 'symptoms' and continuing social disability marked by isolation and poor social integration.

Generic definitions of disability are then described. These include the 'individual model', which explains disability as an expression of impairment, and the 'social model', which highlights external barriers and the lived experience of disability. Psychological approaches to disability are then described. These include accounts of adjustment to loss and the contribution of social labelling.

The chapter ends with the suggestion that, while relevant areas of research may be derived 'top down' from the general literature, issues specific to the experiences of able autistic adults could be overlooked. It is concluded that a practical first step in understanding social disability in this population is to investigate the experiences of autistic adults themselves.

1.2 Background: The development of 'autism'

The term 'autism' denotes a behavioural syndrome with the course of a pervasive developmental disorder (World Health Organization, 1992; Gillberg, 1990). However, since it was first described in the 1940s the concept of autism has itself continued to develop. The literature on autism is therefore not always consistent and can be confusing, not least because of different, sometimes changing terms. This introductory section provides background information on what autism 'is' and how the concept has developed.

Leo Kanner first described the characteristic features of a syndrome that he termed 'early infantile autism' in 1943. For Kanner, particular markers of autism in infancy included: the absence or significant delay of speech development, repetitive or echolalic speech that was not used communicatively, highly accurate rote memory, limited spontaneous activity or imaginative play, an anxious desire for 'sameness' in the environment or personal routine, and an oversensitivity to external stimuli (Kanner, 1943, summarised in Happé, 1994)

Most of Kanner's 11 original subjects were considered to have severe learning disabilities, although he believed that their occasional isolated areas of ability hinted at "good cognitive potentialities" that distinguished them from infants with general 'mental retardation' (Happé, 1994, p.10).

Overall however, Kanner was particularly struck by the poor reciprocal communication and social detachment or 'aloneness' of his infant subjects and he regarded autism as, primarily, a disorder of 'affective contact' (Happé, 1994; Kanner, 1943).

Research into Kanner's syndrome developed rapidly during the 1960s, particularly in North America (Wing, 1998; Tantam, 1988b). Kanner's (1943) descriptions of children that did not talk, 'parroted' others' speech, lined up toys in long rows and seemed oblivious to other people established a popular view of autism as a severe communicative disorder of early childhood development (Frith, 1991; see also Schopler, 1998).

In 1978, Rutter published the first set of formal diagnostic criteria for 'infantile autism'. These were:

- Onset before the age of 30 months,
- Impaired social development with a number of special characteristics and which is out of keeping with the child's IQ,
- Delayed and deviant language development that has certain defined features and is out of keeping with the child's IQ, and
- Insistence on sameness as shown by stereotyped play patterns, abnormal preoccupations, or resistance to change

(Rutter, 1978; cited in Tantam, 1988a, p.31).

However, little interest was directed toward children with less severe autistic 'symptoms' until the work of the psychiatrist Hans Asperger (Asperger, 1979, 1944) became more widely recognised in the late 1970s (Gillberg & Ehlers, 1998; Howlin, 1997; Frith, 1991)¹.

¹ Asperger and Kanner both trained in Vienna. However, they never met and were unaware of each other's work or use of the term 'autism' at that time. Kanner's work was published in English following his emigration to the U.S.A. in 1924; Asperger's own description was published in German during the 1940s and it did not appear in English translation until 1991 (see Frith, 1991).

Asperger (1944) worked independently from Kanner and he also identified a group of children characterised by marked social detachment and an apparent lack of emotional empathy. Asperger's subjects were older and more able than Kanner's infant sample. His original (1944) paper described four children aged four to 11 years² and he adopted a similar term, 'autistic psychopathy'³, to capture their characteristic "loss of [social] contact, withdrawal into self and ...disregard of the outside world" (Asperger, 1979, p.46), which he regarded as a disorder of personality (Wing, 1998, 1981).

Asperger's description of an autistic syndrome overlapped with Kanner's in its central features. For example, Kanner and Asperger both emphasised poverty of social interaction, failures in communication, stereotypic behaviour or isolated interests, resistance to changes in routine and occasional areas of special ability, such as memory, mathematical or artistic skills (Frith, 1991).

Kanner and Asperger also proposed that autism could affect individuals of all intellectual abilities and that the characteristic detachment of severely impaired autistic children masked an underlying intellectual ability. Kanner, for example, believed that his subjects' apparently severe learning disabilities represented an unwillingness to interact with others (Happé, 1994), while Asperger suggested that autistic children did not like to be distracted from their own thoughts and that they therefore failed to attend to academic tasks or tests of intellectual ability (Asperger, 1944; translated in Frith, 1991).

² The four cases reported by Asperger (1944) were considered representative of some 200 children seen in his paediatric work (Happé, 1994).

³ The term 'autism' (from the Greek 'autos', meaning self) was first used by Bleuler (1908) to describe social withdrawal in adults with schizophrenia. Kanner and Asperger adopted this term independently, because each considered the social detachment of their subjects to be a central and "innate" or "constitutional" feature of their respective syndromes (Happé, 1994, p.11).

Asperger's (1944) description of autism did differ in several areas from that of Kanner (1943). One area concerned motor skills. Kanner emphasised that autistic children showed a particular interest in inanimate objects and that they tended to develop exceptional fine motor co-ordination as a result. Asperger, however, emphasised both gross and fine motor difficulties in autistic children; for example their 'clumsiness' in sports activities, awkward gait and poor writing ability (Happé, 1994).

A more fundamental difference concerned speech development, because Asperger did not observe the striking abnormalities of speech and language comprehension of Kanner's 'early infantile autism'. Kanner (1943) reported that three of his original subjects had never spoken and that the remainder had never used language communicatively (Happé, 1994). By contrast, Asperger (1944) described normal vocabulary and grammar development. Asperger's subjects used speech communicatively although they showed idiosyncrasies in its use, for example using neologisms or speaking in a pedantic or overly formal manner. Asperger also reported that, while his subjects did not use speech to convey emotion, they did remain highly sensitive to others' criticism (Frith, 1991; Tantam, 1988b).

A third, related difference concerned learning ability. While Kanner suggested that autistic infants lacked imagination and learned better by rote, Asperger highlighted his subjects' capacity for spontaneous, novel ideas and abstract thinking, which he considered to be a partial compensation for their social and emotional 'distance'. In contrast to Kanner, Asperger felt that intellectually able autistic children could demonstrate "highly original genius" (Asperger, 1944; translated in Frith, 1991, p.74) and he remained optimistic of their achievements in later life.

Generally, the differences between Kanner's (1943) and Asperger's (1944) accounts of autism can be understood in terms of age, language development and 'symptom' severity. Frith (1991) for example, suggested that Kanner's prototype of autism was "younger - with delayed and markedly deviant language acquisition - ...in short, a child with a more blatant and severe communication disorder"; Asperger's description, however, has become more associated with "children and adults who are socially inept but often socially interested, ...articulate yet strangely ineloquent, ...gauche and impractical..." (Frith, 1991, pp.11-12).

Increased awareness of Asperger's (1979, 1944) work prompted changes in the concept of autism. His subjects had shown features of the 'aloneness' described by Kanner, most obviously in their tendency to develop solitary, restrictive interests such as collecting objects or 'facts' (Wing, 1998; 1981). However, their high social awareness and communicative language-use also suggested particular difficulties in social inter-action (Tantam, 1988a).

The British psychiatrist Lorna Wing led specific changes in the concept of autism. Wing (1981) published a seminal paper, *Asperger's syndrome: A clinical account*, by which she intended to raise professionals' awareness of autism as a lifelong condition with a wide range of expressions⁴. Wing introduced the term 'Asperger's syndrome' to emphasise that the aloof or detached interactive style traditionally associated with autism in infancy did not always apply to children with good language skills and less pronounced autistic features. Nevertheless, Wing stressed that children whose 'mild' symptoms developed beyond Kanner's description were likely to encounter particular difficulties because of their impaired abilities in social understanding.

⁴ Note that Asperger's (1944) paper had still not appeared in English translation.

Wing's own research with more able autistic children revised Asperger's original understanding of autism (Burgoine & Wing, 1983), emphasising it as a disorder of social interaction rather than personality. The popular view of autism was then broadened to include, for example, poor understanding of others' perspectives; one-sided social interactions, such as engaging in monologues or failing to take turns in conversation; pedantic, monotone or repetitive speech; literal interpretation of social rules; 'special' interests which could dominate conversations or behaviour; and poor non-verbal communication.

A second important development was Wing's (1988) proposal that three separate dimensions of social impairment could unite the varied expressions of autism at a conceptual level. Wing referred to this as an autistic 'spectrum'.

The first of these dimensions refers to impairments in 'social interaction'. At a severe level, these manifest in an aloof or indifferent stance toward others, such as that described by Kanner (1943). Less severe forms include a passive acceptance of social contact; 'odd', inappropriate attempts to initiate social contact, but with little attention given to others' responses; or a 'stilted', formal manner of speech with others (including family or friends), such as that described by Asperger (1944).

The second dimension refers to impairments in 'social communication'. Generally, these represent difficulties appreciating the social use of language, pleasure in conversation or the role of language as a means for conveying information. Severe impairments may include echolalic speech or 'mutism' and difficulties understanding the emotions or thoughts of others. This dimension also includes difficulties in 'reading' nonverbal social cues, such as facial expression, vocal intonation or body posture. More able individuals with good verbal ability may become fascinated with words and yet fail to use their vocabulary as tools of reciprocal communication or else talk 'at' others.

The third dimension categorises impairments of 'imagination'. In childhood, these may be expressed in a lack of imaginative play. Examples may include repeatedly spinning objects or rocking, or else paying attention to minor details of objects or people whilst failing to comprehend the meaning of the 'whole'. Less severe expressions include copying other children's play in a stereotyped manner inflexible to social pressure, engaging in complex but restricted pastimes (e.g. memorising facts), or insisting on highly rule-bound routines. In more able individuals, deficits in imagination may manifest in a limited understanding of complex verbal associations, such as fictional writing or metaphor. These latter deficits can interfere with all autistic individuals' abilities to draw from their own or others' experience, and predict the consequences of their actions (National Autistic Society, 1999; Wing, 1988).

Wing's (1988) 'triad of impairments' has gained widespread acceptance among clinicians and researchers (Tantam, 2000; Attwood, 1998) and it was adopted as the framework for the category of Pervasive Developmental Disorders in the diagnostic systems of the American Psychiatric Association (DSM-III-R; A.P.A., 1987; DSM-IV; A.P.A., 1994) and the World Health Organization (ICD-10; W.H.O., 1989) (Baron-Cohen, Tager-Flusberg & Cohen, 2000).

The most recent revisions of these systems introduced distinct criteria for 'Asperger's syndrome' in children. These criteria exclude language delay, the more severe symptoms of childhood ('Kanner') autism and general delays in cognitive functioning.⁵ Some commentators (e.g. Happé, 1994) have argued that these separate criteria confuse the conceptual model of an autistic spectrum. In any event, they remain tentative (Tantam, 2000) and are expected to change with further empirical research (Mayes & Calhoun, 2001; Holland, Clare, Baron-Cohen & Woodbury-Smith, 2001; Bailey, 1999; Fitzgerald, 1999).

Autism, then, remains a developing concept. For example, no consensus has been reached on a putative single impairment that may offer a further level of explanation for Wing's (1988) 'triad' and its range of behavioural symptoms (Tantam, 2000).

An active debate also continues over the relationship between Kanner's and Asperger's descriptions, and the nosological validity and clinical value of separating out further sub-groups within an autistic spectrum (Happé, 1994). For example, 'high-functioning autism' (H.F.A.), a term commonly used in the U.S.A., may denote a different form of autism to that usually termed 'Asperger's syndrome' in the U.K. (Holland, et al., 2001; Tantam, 2000; Volkmar & Klin, 2000; for examples, see Schopler, Mesibov & Kuncze, 1998; Lord & Rutter, 1994).

In the U.K., less severe variants of autism have been acknowledged increasingly by health and education services because of the particular social difficulties associated with them, and clinical diagnosis of able autistic children has also increased in recent years (Tantam, 2000; Bailey, 1999).

⁵ DSM-IV and ICD-10 criteria for 'Asperger's Disorder' and 'Asperger's syndrome', respectively, are included for information as Appendix 6.1.

For all ages, an inclusive or “loose approach” (Happé, 1994, p.85) to the clinical diagnosis of more able autistic individuals has remained common practice. This has allowed for those that do not meet diagnostic criteria for childhood autism (derived from Kanner’s description) to be recognised as a valid ‘type’ by services (Tanguay, Robertson & Derrick, 1998; Rutter & Schopler, 1992; Tantam, 1991). It has also recognised that labels which emphasise the absence of general cognitive delay or learning disability (e.g. ‘Asperger syndrome’, ‘H.F.A.’ and ‘atypical autism’) remain in flux, that they have been used interchangeably in diagnosis and the research literature (Holland, et al., 2001; Baron-Cohen, et al., 2000; Volkmar & Klin, 2000), and that the current D.S.M. and I.C.D. entries remain focused on childhood, so may not capture ongoing developmental changes (Piven, Harper, Palmer & Arndt, 1996; Happé, 1994).

1.3 Note on terminology

The term ‘able autistic’ was adopted for this study to refer, generally, to those people whose deficits in social interaction are consistent with Wing’s (1988) triad of social impairments, but who do not, as adults, present the more severe communication difficulties associated with Kanner’s (1944) syndrome (i.e. those captured by Rutter’s 1978 criteria).

‘Able autistic’ (borrowed from Howlin, 1997, Newson, Dawson & Everard, 1982, and others) acknowledges the current confusion in terminology in the literature on autism. It was also used to acknowledge the dominant spectrum model of autism (Wing, 1988; Wing & Gould, 1979), which suggests heterogeneity, few ‘pure’ cases of autistic subgroups (National Autistic Society, 1999) and the possibility of ongoing diagnostic change (e.g. Baron-Cohen, et al., 2000).

Throughout this study the term 'able autistic' has been used interchangeably with the terms 'Asperger syndrome' and 'high-functioning autism' unless qualified otherwise in the text. The operational definition of 'able autistic' used in the study is described in Chapter 2 (Section 2.4).

1.4 Able-autistic individuals beyond childhood

Following Wing's (1981) paper, research interest in more able autistic individuals has focused primarily on child samples (Tantam, 2000, 1991; Attwood, 1998; Howlin, 1997). In part, this has reflected the natural development of autism as a psychiatric construct, beginning with Kanner's (1943) work with infants before expanding in scope to older and more able children (Wing, 1998; 1991; see also Bebbington, 1997). A related factor is that deficits in social functioning are more noticeable during the developmental milestones of early childhood (Tantam, 1991).

The need for research into the long-term course and wider social 'outcomes' of autism in adulthood has been recognised in recent years. Some authors (e.g. Nordin & Gillberg, 1998; Piven et al., 1996; Morgan, 1996; Happé, 1994) have drawn on Wing's (1981) point, that autism is a disorder of social development that should be expected to manifest in various difficulties over the life span. Others (e.g. Holland, et al., 2001; Howlin, 1997) have observed that, for autistic youngsters currently recognised as 'high-functioning' or 'more able', there is little substantive research to inform them or their carers of their long-term prognoses or expectations for quality of life.

Holland, et al. (2001), in a draft report commissioned by the Department of Health, noted the absence of reliable prevalence data on 'Asperger syndrome' among adults. However, they did cite child studies (Cumine, et al., 1998; Ehlers & Gillberg, 1993) that suggested prevalence to be as high as one child in 300. 'Asperger syndrome', like all forms of autism, is more likely to affect males than females and an average ratio of around 9:1 has been reported in the literature (Holland, et al., 2001).

Despite the paucity of research specific to able autistic adults, some general trends have been suggested from the wider literature on autism (Tantam, 1991; 1988b). These include an apparent increase in social, behavioural and psychological difficulties during adolescence, but with 'recovery' from autistic detachment over time. However, for even the most able, wider measures of social integration, such as employment, independent living or relationships have also indicated a continuing social disability in adult life. These trends are outlined below.

Difficulties emerging in adolescence

A general feature of adolescent development is an increased emphasis on forming relationships and this period can prove particularly difficult for more able autistic adolescents (Attwood, 1998; Tantam, 1991; Wing, 1981). One reason is that conventions of social interaction tend to be learned more implicitly as children develop, and adolescence can therefore be a time when existing autistic deficits in 'reading the rules' of social exchange are brought into relief (Taylor, 1990; Wing, 1981). To illustrate, adolescents with 'Asperger syndrome' may often fail to recognise differences in others' age or social status, they may lack interest in fashionable clothes and fail to understand jokes or other nuances of language, such as sarcasm or irony (Tantam, 1988b; Wing, 1981).

Wing (1981) suggested that some older children with 'Asperger's syndrome' could be tolerated by their peers, perhaps as "eccentric professors" (1981, p.3)⁶ and especially if the formers' special interests or skills enable them to excel in popular activities. However, the narrow interests and resistance to change that remain common in older able autistic children and adolescents are also likely to invite bullying (Gross, 1994; Wing, 1981). Tantam (2000), for example, reported that 64% of adolescents and adults whom he diagnosed with 'Asperger's syndrome' had experienced verbal teasing or physical bullying at school, usually between the ages of 11 and 15 years.

A contributory factor to difficulties emerging in adolescence can be the increased active social interest of some able autistic individuals. As noted, youngsters with autistic spectrum disorders are generally described as socially detached or avoidant of social contact. However, those with 'milder' impairments often begin to make efforts to interact with others as they approach adolescence (Tantam, 2000, 1988; Howlin, 1997; Wing, 1987). These children may persist in their efforts, whilst remaining 'blind' to their own social deficits. Others, however, may be aware and increasingly distressed that they lack their peers' social dexterity (Tantam, 2000; Hare & Paine, 1997).

The interaction of an impaired ability to understand the social world with social and individual changes in adolescence may render more able autistic individuals particularly vulnerable to secondary mental health difficulties (Tantam, 2000). While there are, as yet, no large-scale epidemiological studies of psychiatric illness in the able autistic population (Holland, et al., 2001; Tantam, 2000), a general increase in psychological and behavioural disturbance has been noted in autistic adolescents and young adults (e.g. Nordin & Gillberg, 1998; Wolff, 1995; Lainhart & Folstein, 1994).

⁶ Asperger also used the term 'absent-minded professor' (1944; translated in Frith, 1991, p.74).

In particular, a high incidence of anxiety, mood swings and depression have been reported (e.g. Ghaziuddin, et al., 1998, cited in Holland et al, 2001; Tantam, 1991) and recent reviews by Tantam (2000) and Howlin and Goode (1998) have suggested affective disorders to be over-represented in the clinical presentation of able autistic adolescents and adults. Indeed, Tantam (2000) reported that a majority of his adolescent and adult clinical contacts with 'Asperger syndrome' presented with chronic social anxiety.

Other problems reported during adolescence and early adulthood (usually in single-case reports) have included increases in anger or aggression, 'bizarre' thoughts and behaviour and suicidal behaviour (e.g. Shah, 1999; Gillberg & Ehlers, 1998; Wing, 1998). However, Howlin and Goode (1998) have suggested that these problems tend to relate to autistic individuals' idiosyncratic interests and their resistance to change. As an example, they cited Tantam's (1991) description of a young man with a special interest in clocks who leapt into a river because the government refused to abolish British Summer Time.

Tantam (2000; 1991) has hypothesised that general increases in psychological disturbance in this population may be temporary and associated with the 'storm and flood' of adolescent development. However, he has also noted (Tantam, 1991) that the onset of acute mental health difficulties during adolescence would be expected to continue into adult life for a significant minority of able autistic adolescents, just as for the non-autistic population.

Progress in adulthood

There is little substantive research on the diagnostic 'outcome' of autism in more able adults and no large-scale, prospective studies have been completed that track changes in the course of autism through the early lives of high-functioning adults (Holland, et al., 2001; Tantam, 2000; Howlin & Goode, 1998).

Some general trends have been drawn from the general literature (often including those with 'milder' forms of autism) and from retrospective studies of able autistic adults, although there are several methodological weaknesses in this type of research. Particular problems include small sample sizes, differences in diagnostic criteria (Ghaziuddin et al., 1992, reported six different sets of diagnostic criteria for 'Asperger syndrome' alone) and difficulties obtaining reliable early developmental histories (Howlin & Goode, 1998).

The clinical presentation of able autistic individuals in adulthood is also marked by wide heterogeneity (Baron-Cohen, et al., 2000; Tantam, 2000; Howlin & Goode, 1998). However, a general positive trend toward 'recovery' or the amelioration of earlier symptoms of autism can be identified in adults with good cognitive and language abilities and this progress may continue beyond 30 years of age (Tantam, 2000, 1991).

Several researchers in the field (e.g. Howlin, 1997; Happé, 1994; Wing, 1991; Tantam, 1988a) have emphasised the complexity of measuring change in more able autistic individuals over time. For example, Tantam noted that there is "no clear line between classical early childhood autism and ... [later] autistic-like conditions" and that children and adults with 'Asperger syndrome', "may or may not have a typical history of early childhood autism" (Tantam, 1988b, p32).

In addition, Happé (1994) and Wing (1991) have highlighted the continued lack of consensus over factors that distinguish more and less able forms of autism. For example, Happé (1994) noted that the diagnostic criteria for Asperger's syndrome in I.C.D.-10 (W.H.O., 1993; see Appendix 6.1) do not make clear whether less severe social 'handicaps' (sic.) or the lack of clinically significant general delays in language or cognitive development mark the distinction from 'childhood autism'.

In practice, general intellectual ability (IQ) in the 'normal' range and the absence of "serious language difficulties" are often used to nominally differentiate the "more able" autistic population (Tantam, 1988b, p.30). Attwood (1998) has qualified this though, by stressing that IQ scores for more able autistic individuals often show significant differences between verbal and performance scores in either direction.

Given this, significant improvements in the diagnostic picture have been reported. For example, Rumsey, Rapoport and Sceery (1985) followed up 14 men, aged between 18 and 39 years, all of whom had met DSM-III criteria for childhood autism. As adults, nine were described as 'high-functioning' as defined by verbal IQ scores in the normal range, although Rumsey, et al. noted that a majority continued to present idiosyncrasies in their behaviour or language-use.

More recently, Piven, et al. (1996) identified five individuals from a sample of 38 adolescents and adults with 'high [nonverbal] IQ', whose development at five years had met current DSM-IV (A.P.A., 1994) criteria for childhood autism.

In their own review of the literature, Howlin and Goode (1998) claimed that innate factors, such as early communicative language development and minimal childhood deficits in nonverbal functioning, appeared strongly related to more successful outcomes in adult life. For example, they cited a follow-up study by Kanner (1973) that found significant improvements in the social functioning of around 12% of adults he had previously diagnosed with infantile autism in the absence of any specialist support.

Long-term improvements in autistic symptoms may also be influenced by social and psychological factors. Tantam (1991), for example, hypothesised that the emotional effects of family upbringing were crucial in individuals' ability to cope with their social impairments. Others (e.g. Attwood, 1998; Gillberg & Ehlers, 1998) have suggested that ongoing family support is common for many intellectually able autistic adults, and that the latter may have to accept that their 'mild' social impairments will preclude social or career ambitions appropriate to their skills.

This last point was relevant to the present study because improvements in symptom severity, combined with normal (general) intellectual functioning, do not appear to guarantee successful social integration for able autistic adults (Howlin & Goode, 1998). Several studies using wider measures of 'social outcome' have indicated that a majority of apparently 'high functioning' adults remain socially isolated and continue to encounter significant difficulties establishing and maintaining relationships, finding employment or living independently.

In an early study commissioned by the then Department of Health and Social Security, Newson, et al. (1982) surveyed a heterogeneous sample of 93 'able autistic' adults (mean age 23 years) registered with the National Autistic Society. Newson, et al.'s (1982) sample was considered to be of normal or borderline intellect. However, their study reported low rates of social integration. As examples, a majority (71%) continued to live with parents, 16% lived in residential care and only 7% lived independently. A minority (22%) were employed, 11% had attended further or higher education and 15% reported having had an opposite sex relationship (i.e. 'dating') for more than one month; and only one participant had married.

A later study by Tantam (1986; cited in Tantam, 1991) of 46 adults with 'Asperger syndrome' (mean age 24 years) reported more pessimistic findings. For example, a majority (53%) lived in residential care, with most of the remainder (41%) residing with parents, except two participants who lived independently. Four (9%) adults in Tantam's (1986) sample were employed and two (4%) had attended formal education after school; again, Tantam reported only one participant that had married.

Compared to the autistic 'aloneness' or detachment associated with Kanner's infant syndrome, the objective isolation of more able adults in these studies also appeared to indicate personal distress. For example, only 40% of Newson, et al.'s (1982) sample and 8% of Tantam's (1986) had felt able to reciprocate the support they received within their limited social networks and over 75% of participants in both studies hoped for an intimate relationship.

More recent studies have reported a similar asymmetry between individual potential and social outcome. In their U.K. study of 19 autistic men with normal nonverbal IQ, Rutter, et al. (1992) reported that none had married, only three reported having close friends, half claimed to have never had any friends and 15 had never had a close relationship. Only three of these men lived independently, one of whom lived in sheltered accommodation. A similar number (three) were employed, one in a specialist placement.

Many small-scale studies of social outcome have reflected high variability, consistent with the heterogeneity of presentation in the able autistic adult population. However, the relatively high levels of employment and independent living reported in some studies are likely to reflect cultural differences in community support and policy changes over time, which can affect the availability of specialist resources (Howlin & Goode, 1998).

In terms of relationships, Howlin and Goode (1998) noted some relatively high levels of friendships (e.g. 15% and 25%; Goode, et al., 1994; Mawhood, 1995 respectively) and close relationships with the opposite sex (over 40% in a Canadian study by Szatmari, et al., 1989). However, Tantam (2000) has cautioned that fears of social stigma and the naive definitions of 'friendship' used by some autistic individuals may render self-report data unreliable. A more useful measure may be that of marriage or long-term relationships, which Tantam (2000) and Howlin and Goode (1998) recognised as rare.

For those adults in whom the 'symptoms' of autism improve and who do not experience significant mental health difficulties, continuing social isolation and a failure to achieve similar social goals to their peers may be the main difficulties encountered in adult life. As Howlin (1997) stated,

Although many make good progress as they grow older, the impact of [their impairments] remains profound. ...They may be unable to find jobs, make friends or form close relationships. All too often they are well aware that they are 'different' and fully recognise their own limitations but they can do little to alter the fundamental deficits (Howlin, 1997, p.3).

Given this distinction, between 'recovery' from social detachment and ongoing isolation, the experiences of able autistic adults may be better understood as a severe social disability, rather than a form of personal illness or impairment per se (Holland, et al., 2001; Gillberg, 1998; Tantam, 1991, 1988). Tantam (1988) suggested that social disability in any population may be defined by objective social isolation, but may also comprise emotional isolation (loneliness) due to a perceived lack of close relationships. While infants with autistic disorders or adults with more severe symptoms show little attachment to others, this may not apply to able autistic adults because,

People with autism do not lack emotional responsiveness. ...Aloofness, or indifference to social contact, is not a universal feature of autism and most more able people with autism want, sometimes desperately, to have friends. (Tantam, 1988b, p.20).

It was able autistic adults' reported experience of relative difference to the wider population that the present study focused upon.

1.4 Definitions of disability

In the absence of a specific literature, generic definitions of disability offered one guide for approaching social disability in able autistic adults. 'Disability' is a comparative term and it is generally used to denote the loss or failure of an individual's ability relative to a wider, social norm. Hence, a person may be considered disabled if they cannot meet the overt or implicit standards of functioning within society (Harris, 1995).

Traditionally, disability has been located 'with' the individual (Abberley, 1997). Explanations have tended to focus on internal factors (i.e. 'within' individuals), for example, in the use of concepts of impairment or illness. However, alternative definitions that appeal to social factors have been proposed in last two decades (Borsay, 1997; Barnes & Mercer, 1996).

The remainder of this section outlines the two main 'models' of disability. These, together, provided a comprehensive framework for approaching disability in the present study.

The individual model

In the U.K., generic concepts of disability first emerged during the late 1940s alongside national provision of health and social welfare services (Barnes, 1997a). In large-scale health care settings, clinical labels associated with disability were, and are, used as indicators of prognosis; while in employment and social welfare settings 'disabled' status has served a parallel administrative function providing access to social, legal and financial resources (Stone, 1984, cited in Barnes, 1997; Blaxter, 1980).

The dominant medical model in health services (Oliver, 1996a; Gleidman & Roth, 1980, cited in Ferguson, et al., 1992) has influenced definitions of disability. The resulting "individualistic-medical approach" (Barnes, 1997, p.5) has tended toward a causal-reductive explanatory model, in which relative failures of ability are understood as expressions of impairments in behavioural or psychological functioning. These, in turn, are assumed to result from more fundamental physical pathology (Borsay, 1997; Oliver, 1996a).

This so-called 'individual model' of disability (e.g. Barnes & Mercer, 1997) was captured in a set of influential definitions published by the World Health Organization (W.H.O.) in 1980:

- Impairment: 'any loss or abnormality of psychological, physiological, or anatomical structure or function';
- Disability: 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'; and

- Handicap: 'a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual'. (Wood, 1980, pp. 27-29).

These ('W.H.O.') definitions continue to influence national policy in the U.K. For example, the Disability Rights Commission Act (Department of Education and Employment, 1999, p.2) defined disability as the result of "physical or mental impairment" that has "a substantial and long-term adverse effect on [an individual's] ability to carry out day to day activities".

The Social Model

National groups representing disabled people in the U.K. opposed the W.H.O. definitions of disability at their outset (Barnes & Mercer, 1996). Prominent critics in the disability rights movement (e.g. Oliver, 1983; Finkelstein, 1980, both cited in Barnes, 1997a) specifically challenged the status of impairment as a sufficient, causal explanation of disability and social disadvantage (Barnes, 1997; Barnes & Mercer, 1996).

In general, criticisms of the individual model have concerned its partiality and failure to represent the lived experience of disability. Borsay (1997), for example, has argued that, strictly understood, the individual model confines definitions of disability to underlying biology, biochemistry, genetics and psychology, and that this narrow understanding has negative consequences for disabled individuals.

One possible consequence is that social policy decisions affecting disabled people can remain unduly focused on internal mechanisms. This can result in attention being diverted from wider social or economic factors (Bury, 1996). Barnes (1997) has also argued that a culture of putatively 'expert' academic research may be fostered in which disability is objectified and removed from the experiences of its disabled 'subjects'.

A second consequence of the individual model follows from its assumption of normal human functioning. Critics have argued that this encourages a value system in which disability is viewed as deviation from a 'normal' majority (Borsay, 1997), and in which disabled people are deemed to be victims of "necessarily tragic loss" (Borsay, 1997, p.117) or "personal medical tragedy" (Shakespeare & Watson, 1997, p.264). As a result, models of health and social care may define success in terms of the restoration of normal functioning, while ignoring the responsibility of society to accommodate individuals' impairments (Oliver, 1996b; Harris, 1995; Phillips, 1992).

As a contrast to the individual model, proponents of alternative 'social' models have argued that disability is properly defined as a purely social phenomenon, causally distinct from 'internal' impairment or pathology (Oliver, 1996a). From this social constructionist perspective all forms of disability are understood to result from the imposition of external societal barriers which limit the opportunities of people with impairments, excluding them from mainstream society (Oliver, 1996a).

Social barriers may include negative, stereotyped or prejudicial attitudes. At institutional or political levels these barriers impact widely on resources available to people with physical or mental impairments. Supporting this, Borsay (1997) argued that people with different impairments often experience common needs resulting primarily from their “shared economic, social and political dependencies” (Borsay, 1997, pp.116-117), and Shakespeare and Watson (1997) have claimed that external barriers are often the main factor encountered by disabled people in daily life.

A comprehensive definition

Individual and social perspectives, then, offer separate explanations of disability. The first provides an understanding based on internal factors that cause individuals' performance to fall outside of societal norms. The second considers disability to result from restrictions imposed by a disabling society, and disabled people to represent a minority group within society.

The relationship between these perspectives is still debated. Bury (1996) suggested that differences may exist between disabled groups or individuals if some identify more readily with an individual or medical explanation. Bury (1997) and Johnston (1997) have also argued that individual and social models are unnecessarily polarised and that both are compatible. Others (Shakespeare & Watson, 1997; Finkelstein, 1996) have warned that a unified model could weaken the association between disability and society and inadvertently relocate disability ‘within’ individuals.

Acknowledging this debate, Oliver (1996a) proposed a definition of disability encompassing the distinct perspectives of the individual and social models and which acknowledged disabled individuals' experiences. Oliver accepted that all disabled people have particular impairments, but argued that a comprehensive understanding of any disability must recognise it as a social phenomenon emerging when people with impairments operate in social settings. Oliver (1996a) formulated this model as three separate, necessary conditions: the (contingent) presence of impairment; the existence of external barriers; and an individual's "self-identity" as disabled (Oliver, 1996a).

This definition, which captures physical, social and psychological aspects of disability, provided an inclusive conceptual frame for disability in this study.

1.5 Psychological approaches to disability

Psychological theories have provided general accounts of how people respond to the individual and social factors that contribute to disability. For the present study, these theories offered further points of reference from which social disability in able autistic adults could be approached.

Psychological research has traditionally approached disability as a negative state that impacts on the individual's self-concept or identity (Thomas & Siller, 1999; Harris, 1995). One approach has focused on 'internal', or intrapsychic, adjustment processes in response to loss of personal functioning. A second approach has focused on challenges to identity that result from the imposition of negative social stereotypes or labels. More recently, social constructionist perspectives of identity have suggested a more active role for psychological processes in disability. These claim that disabled individuals' responses to impairment or social barriers will depend on how their experiences are meaningfully construed.

Adjustment models

Adjustment models of disability have derived, primarily, from studies of loss due to physical injury or illness (Thomas & Siller, 1999). As mentioned, rehabilitation approaches based on the 'individual model' have tended to frame successful outcomes as the attainment of normal functioning (Phillips, 1992). However, this model suggests that when permanent loss occurs a disabled individual will be forced to modify his or her existing 'self-view' or identity through psychological processes of adaptation, acceptance or adjustment (Thomas & Siller, 1999; Borsay, 1997).

Adjustment models of disability assume loss of functioning to be experienced as a form of trauma, and the resulting psychological response to mirror a process of bereavement (Borsay, 1997). The latter is usually portrayed as an 'unfolding sequence' or relatively unvarying process comprising discrete phases of shock, expectation of recovery, mourning, defence and eventual adjustment (Thomas & Siller, 1999).

Livneh (1984) reviewed over 40 psychological adjustment models of physical disability and from these, developed a general, five-stage model. The first of these stages represented the initial psychological impact of a disabling event, marked by shock or anxiety. The second, termed 'defence mobilisation', stood for strategies of 'bargaining' and denial. The third stage represented an 'initial realisation' of loss, characterised by mourning, depression and internalised anger; and the fourth phase, 'retaliation' or 'rebellion', represented aggression or the expression of angry feelings. In the final stage, Livneh proposed a period of 'reintegration', marked by cognitive reconciliation, emotional acceptance and behavioural adjustment.

A weakness of adjustment models is that they can be too generalised. For example, Yuker (1994, p.9) claimed “many disabled people, particularly those with slight disabilities, do not view themselves as disabled”. Borsay (1997) too, argued that the assumption of a general bereavement process fails to differentiate the responses of groups with different impairments.

Adjustment models have also been criticised for their partiality. Bury (1996), for example, has argued that psychological explanations focusing exclusively on intrapsychic change maintain a value system that assumes disability to be a personal tragedy, and which still expect disabled people to adjust to ‘normal’ society. From this social stance, adjustment models describe responses to impairment, rather than disability (Barnes & Mercer, 1997).

Social labelling

A second psychological approach to disability then, has focused on ‘external’ social labelling and its contribution as a barrier to the experience of disability.

Goffman (1968), in his book *Stigma*, claimed that the process of attributing general descriptive clinical labels could lead to the creation of devalued group identities. Goffman suggested that the application of these negative stereotypes threatened self-esteem and encouraged stigmatised individuals to deny their disabilities and to ‘pass’ themselves as normal (Szivos, 1992).

One explanation for this process is that diagnostic labels suggest ‘hard boundaries’ between ability and dis-ability (Harris, 1995). This can discourage an understanding of disability based on graded differences or individual need (Clegg, 1993). As a result, descriptive labels for conditions that deviate from a social norm may become over-generalised, attaching to individuals as value-laden identities (Yuker, 1994; Szivos, 1992).

A second explanation, derived from 'labelling theory', suggests that disabled people are more likely to be regarded as a devalued group because of particular cultural values. 'Labelling theory' is a loose term representing a sociological view that social norms, and so labels which identify 'deviant' social groups, may be quite arbitrary and function to maintain the status quo or interests of powerful groups in society (Szivos, 1992).

Finkelstein (1996; 1980) has argued that disability has emerged as a social construct in modern industrialised societies because the value of individuals within society has become linked to their productive capacity. From this perspective, clinical and administrative labels associated with disability can suggest an *inability* to contribute to society and so contribute to a negatively valued social identity.

Research on attitudes toward people with disabilities, however, has suggested that not all disabled people will be devalued similarly, and that several factors account for differences (Yuker, 1994).

Generally, information that an individual has a disability tends to elicit negative or at least neutral attitudes in others. This is because information about particular forms of impairment does not convey details about what the person is 'like' and, in the absence of the latter, it may emphasise difference or weakness (Wright, 1988; cited in Yuker, 1994). Yuker has also reported that particular diagnostic labels can evoke "stereotypical perceptions based on myths" (Yuker, 1994, p.10), although disability labels may ameliorate existing negative attitudes if they are perceived to offer an explanation for unusual behaviour (Szivos, 1992).

Positive attitudes are more likely to result from personal contact with disabled people where disability is not the basis of the relationship. Generally, more effective relationships are those described as reciprocal, longstanding and of equal social status, and where the disabled person is socially skilled, communicative and open about his or her difficulties (Yuker, 1994; Clegg & Standen, 1991). First impressions of normal physical appearance are also more likely to elicit positive attitudes in nondisabled people, although perceptions of intelligence and good social skills do become more important for the establishment of longer-term friendships (Clegg & Standen, 1991).

For people with disabilities, the continued experience of unfavourable social comparison can force changes in their sense of identity and self-worth (Harris, 1995; Lea, 1988). Lea (1988) for example, reported qualitative research with adults with learning disabilities in which participants described their relative inabilities as an 'illness' or 'sickness' and their social status as 'deviant'. Lea also reported that participants' beliefs were associated with attributions of personal responsibility and feelings of guilt.

Social Identity Theory (S.I.T.; e.g. Tajfel, 1981) has provided one theoretical account of how individuals with disabilities respond to the emotional impact of negative stereotyping by managing the way they are categorised by others. Briefly, S.I.T. states that a positive social identity can be maintained by associating oneself with a relatively valued social group, or by distancing oneself from associations with devalued groups or labels. S.I.T. builds on the premise that group characteristics tend to be attributed to all individual members. Hence, group affiliation may form the 'raw material' for identity and self-esteem (Harris, 1995).

To illustrate, Harris (1995) cited studies of learning disabled adults in which participants attempted to dissociate themselves from learning disabled peers (Oliver, 1986) or else identified themselves as 'essentially the same' as non-disabled adults, despite the contrary views of their families and clinicians (Jahoda, et al., 1988).

Similar strategies have been reported in adults' responses to diagnoses of psychiatric illness. For example Whitbourne and Sherry (1991) found that young adults were more likely to accept diagnoses of chronic mental illness when they could associate it with a relatively positive 'patient' identity. However, adults first diagnosed when over thirty years old tended to resist or deny similar labels. S.I.T. can account for this if older adults are understood to have developed a positive self-view (or a negative view of psychiatric illness), so that they are more reluctant to accept a relatively stigmatised label.

Psychological accounts of social labelling are compatible with, and may complement, adjustment models of disability because they recognise the impact of some external barriers on personal identity. Additionally, acknowledgement of different attitudes toward disabled groups and individuals, and that the impact of social stereotypes may be managed to some degree, provides a less generalised account of disability experiences to that of adjustment models.

However, accounts of social labelling have attracted similar criticisms to those directed at adjustment models. Bury (1997) for example, has argued that while psychological accounts of social labelling provide some recognition of external factors in disability, they continue to emphasise disabled individuals' responses as an adjustment *to*, or else management of, inappropriate social stereotypes.

This is not a trivial criticism of approaches that assume an individual psychological subject, because social constructionist perspectives within psychology have also challenged the assumption of the passive subject in explanations of how people respond to personal loss and social barriers.

Social constructionist critiques of identity

Constructionist perspectives in psychology have offered a more fundamental critique of how individuals respond to the experience of disability. This is because constructionist approaches to identity (e.g. Gergen, 1991) have stressed that the ways in which any individual understands his or her 'self' are necessarily related to and defined by, particular social settings. Hence, identity cannot be understood independently.

This perspective suggests identity to be relatively plastic (i.e. changeable) and socially located, representing the relationships *between* each individual and the social world in which he or she exists. The constructionist account of identity differs from the assumptions of adjustment models of disability and with Social Identity Theory because both have assumed identity to be a relatively stable, internally located entity (Antaki, Condor & Levine, 1996).

As an illustration of the constructionist view, Luborsky (1995) reported qualitative research demonstrating that the reported 'self-views' of adults with physical disabilities changed during a standardised research interview. Transcript analyses of interviews showed that participants frequently contested and re-framed the meaning of questions before responding, and that their reported identities as disabled people reflected their ongoing appraisals of the interview's demands, rather than descriptions of stable personal characteristics.

In an earlier study Phillips (1992) also showed that expressions of 'disabled identity' were actively constructed and used according to social context. Phillips found that individuals with physical disabilities held apparently conflicting disabled identities, such as those of an excluded 'acquiescent cripple' and that of a member of a social minority group.

Phillips' reported that participants selected the way in which identities were deployed according to perceived situational demands. For example, one man claimed to have used a 'cripple' role to attain a particular social goal. In other circumstances adults with chronic disabilities rejected social expectations based on norms of physical functioning. In the latter case disabled participants adopted a 'social minority' identity by challenging unrealistic standards of 'normal' functioning, inverting popular stereotypes of disability or highlighting the need for adaptations to their physical environment.

An important implication of the constructionist critique of identity is that psychological responses to apparently disabling events should not be assumed explicable as merely a traumatic personal loss of, or a threat to, an established 'self-view'. Rather, the possibility of identities being actively constructed entails that the way people respond to the internal and external events associated with disability and, from Oliver's (1996a) inclusive definition (Section 1.4), identify themselves as disabled, will be mediated by the particular social worlds in which they live.

1.6 Approaching disability in able autistic adults

The objective of the present study was to develop an understanding of the social disability experienced by able autistic adults. As stated earlier, little is known of the life experiences of this population. This chapter has provided general background information on autism and disability because these were the two main concepts in the research question.

To recap, 'autism' denotes a category of pervasive developmental disorders. Three dimensions of qualitative social impairment currently define these disorders and the dominant model of autism proposes a wide spectrum of clinical presentations.

Young children with autistic disorders are characterised by their social detachment, avoidance of social contact or 'aloof' interactive style. However, some go on to develop communicative language, greater social interest and general intellectual ability in the normal range, despite their profound social deficits. As a result, more able autistic individuals may be more likely to encounter particular social difficulties, particularly in late childhood and adolescence.

A majority of able autistic adults appear to lead relatively isolated lives, characterised by few close relationships, low rates of employment and an ongoing dependence on family or other social support. Their relative social isolation has therefore been described as a severe social disability.

Generic models have defined disability as the expression of impairments in individuals' functioning, or the result of societal barriers that restrict opportunities for people who happen to have impairments. Advocates for the disability rights movement have emphasised that a comprehensive understanding of any form of disability must also appreciate how people with impairments experience their day-to-day lives and so define an identity as disabled.

The psychological literature has provided general theoretical accounts of the relationship between potentially disabling events and the individual's self-view or identity. Psychological responses to disability have been framed as adjustments to the loss of an established self-view, or as attempts to manage or defend a valued social identity in the face of negative social stereotyping.

More recently, social constructionist views in psychology have suggested that 'identity' should not be regarded as a fixed internal state, vulnerable to physical loss or social threat. Rather, identities reflect ongoing, active appraisals of the 'self' in interaction with particular social circumstances.

This latter view of identity, as less concrete and necessarily socially located, suggests that the ways in which people with impairments regard their 'selves' - and so define their disability - depends on how they construe their experiences as active participants in a social world.

Approaching disability in this study

In the absence of a specific literature, the general background information described in this chapter has provided an inclusive conceptual framework for the present study. In particular, the dominant model of an autistic spectrum (Wing, 1988; Section 1.2) provided a domain for all forms of autism and which allowed for developmental changes over time. Secondly, Oliver's (1996a) model (Section 1.4) provided an inclusive definition for all forms of disability, which allowed for factors associated with impairment, societal barriers and the personal experiences of disabled people.

Given this framework, one approach to developing a better understanding of social disability in able autistic adults was to derive potential research questions from the existing general literature. Several of these areas of research are suggested below.

Possible 'internal' factors

A focus on factors associated with impairment or underlying physical pathology could be particularly relevant for high-functioning adults with autism, given that all disabilities represent social phenomena (Harris, 1995) and that the particular impairments that define autism are just those of social interaction. A focus on internal factors could support a hypothesis that the apparent failure of able autistic adults to establish relationships, find work or live more independent lives is merely a direct consequence of individually-located deficits in social functioning.

A second possibility suggested in the autism literature, would be to focus on able autistic individuals' apparent vulnerability to mental health difficulties, particularly anxiety and depression. This is because the latter can be associated with social withdrawal. Tantam (2000), for example, has suggested that avoidance of social contact and restrictive behavioural routines in autistic adults may be reactive strategies for reducing anxiety and not 'core symptoms' of autism as such.

A third possibility would be to explore longer-term changes in the "innate" (Howlin & Goode, 1998) course of autism (i.e. as expressions of a putatively physical or organic pathology affecting social development). For example, the general trend in older able autistic children toward social interest could be hypothesised as temporary, in parallel with the rise in psychological and behavioural disturbance during adolescence, with social withdrawal in adulthood representing a return to 'true' autistic functioning.

Possible 'external' factors

A focus on external factors that contribute to social disability would direct an investigation toward societal barriers that limit the opportunities for able autistic adults to form relationships or achieve greater independence.

One barrier suggested in the literature is the lack of social support available to able autistic individuals as they enter adulthood (e.g. Howlin, 1997). In the U.K. many will continue to depend on their families for social support (e.g. Gillberg & Ehlers, 1998; Morgan, 1996). Specialist support, which addresses the social or employment needs of more able autistic adults, has only begun to emerge recently (e.g. MacLeod, 2002; 1999; Howlin & Mawhood, 1999; Howlin & Yates, 1999).

A second potential barrier is the limited understanding of some professionals. Wing (1981) claimed that professionals in adult mental health services had little understanding of the difficulties associated with 'milder' autistic disorders, and that they tended to view autism as a disorder specific to early childhood. Unfortunately, a general failure to detect problems associated with developmental disorders in adults may remain widespread, in part because adult mental health services do not routinely assess clients' early developmental histories (Tantam, 2000).

A third possible barrier is that low professional awareness will have had a specific impact on those able autistic people who reached adulthood before Asperger's (1944; 1979) work became widely known. Many of this cohort are likely to remain undiagnosed (Tantam, 2000) and they may not, therefore, have access to financial and social support that relies on a formal diagnosis. Others are likely to have received inaccurate diagnostic labels earlier in their lives (commonly 'non-specific learning disability', 'paranoid disorder' or 'atypical schizophrenia') and, in some cases, inappropriate restrictive treatment for many years (Tantam, 2000; Howlin & Goode, 1998; Attwood, 1998).

Possible psychological responses

Generic psychological theories of disability may also suggest ways in which able autistic adults respond to the internal and external aspects of social disability.

Adjustment models of disability for example, have included social withdrawal as a response to significant personal loss, and adults with autistic spectrum disorders may be more prone to significant loss events. Particular difficulties affecting this group are adjustment to the loss of significant carers (e.g. Morgan, 1996) and the abandonment of career plans because of their social deficits (e.g. Gillberg & Ehlers, 1996).

Second, the general literature on social labelling would suggest that adults diagnosed with autistic disorders are likely to encounter inaccurate or devalued social stereotypes. One possibility is that others' expectations will be too pessimistic. For example, Attwood (1998) reported that autistic children labelled 'high-functioning' frequently elicit inaccurate expectations of behavioural difficulties from teaching staff. Schopler (1998) too, has suggested that understandings founded in more severe forms of autism and communication disorder form the dominant stereotype among the adult population.

Alternatively, some able autistic individuals may encounter unreasonably high expectations of their abilities. Schopler (1998) noted that labels such as 'autism' and 'Asperger syndrome' are often associated with so-called savant skills in the popular mind. In fact, exceptional talents occur in only a small minority of the autistic population (e.g. National Autistic Society, 1999) and this suggests that positive stereotypes of autism may be counterproductive. Yunker (1994) for example, has claimed that when people cannot readily understand an individual's disability from clinical labels, they are more likely to feel uncomfortable and to develop negative attitudes toward disabled individuals.

Finally, social constructionist research on the deployment of different disabled identities as a means for accomplishing social goals could suggest that able autistic adults are less able to challenge social barriers in comparison to disabled groups with similar general intellectual ability. This is because less severe autistic impairments manifest in difficulties understanding social conventions, nonverbal communication and subtle features of social exchange (Happé, 1994). It could therefore be hypothesised that able autistic adults have particular difficulties recognising prejudicial behaviour and are therefore less able to deploy effective responses.

Difficulties with a deductive approach

There are several reasons, however, why a deductive or 'top down' approach to social disability in able autistic adults was not considered the most appropriate for the present study.

A potential difficulty was that the available research on autism has rarely been based on able autistic adult samples. Hence, any inquiry derived directly from the general research on autism would have had to assume that the impairments and social experiences of child samples, or those of children and adults with more severe social deficits, were applicable to high-functioning adults.

A spectrum model of social impairments unites autistic disorders. However, the model allows for developmental changes in adult life that may not follow those of childhood or adolescence. Furthermore, disability remains a social phenomenon that may not be related directly to impairment. Hence, adulthood could present more able autistic individuals with social barriers distinct from those of childhood.

A second issue concerned selection of the most relevant and potentially fruitful area of inquiry for a study of disability for which little directly relevant literature was available. An inclusive model of disability (Oliver, 1996a; Section 1.4) suggested internal impairment, external social barriers and disabled individuals' 'self-views' to be equally necessary for a comprehensive understanding of disability. However, it was not apparent from the research which of these factors, if any, would prove most relevant for able autistic adults.

A third issue was the risk of 'missing the point' by allowing the inquiry to be guided by existing themes in the literature. This acknowledged Barnes' (1997) criticism, that postgraduate health research often objectifies disability by imposing abstract models while ignoring the issues deemed most important by disabled people themselves.

Each of these issues supported the need to take an exploratory approach to an investigation of disability in able autistic adults, albeit bounded by the inclusive theoretical framework of an autistic spectrum and a comprehensive model of disability described above.

1.7 Aims of the study

The objective of this study was to develop an understanding of the social disability experienced by able autistic adults. The inclusive model of disability adopted for the study acknowledged the potential contribution of internal factors associated with impaired functioning, and external factors associated with societal barriers. However, the precise contribution of these factors for able autistic adults was not apparent from the existing literature. An important aim of the study, therefore, was that it explored the experiences of this population. A related aim was that it remained sensitive to novel information, perhaps unique to able autistic adults.

General literature on autism and disability was used to inform the study. However, the definitions of these two main constructs were intentionally inclusive, and existing themes in the literature were not assumed to be relevant. This was intended to prevent the study being unnecessarily restrictive in its scope.

It was expected that an explanation constructed from participants' own accounts would identify meaningful themes in their experience of disability, whilst offering an empirical base for further research.

The following chapter describes the design and methodology that were used for the investigation.

2.0 DESIGN

2.1 Overview

The objective of this study was to develop a better understanding of how able autistic adults meaningfully construe their experiences of social disability. In the previous chapter a rationale was provided for taking an exploratory approach to this issue. This chapter describes the design and qualitative methodology used to investigate the research question.

The chapter begins with an introduction to qualitative research. The grounded theory methodology used in the study and the rationale for its use are then described in more detail. In the following three sections, procedures used for selecting participants, gathering data and analysing data are outlined. The chapter ends by outlining the quality measures that were used in the study.

2.2 Qualitative research

The general aim of qualitative research is to understand the experiences and actions of people as they encounter, engage in and live through social situations (Elliott, Fischer & Rennie, 1999). Qualitative research is particularly concerned with the perspectives of its participants and with representing the meanings that phenomena hold for them (Turpin, Barley, Beail et al., 1997).

Use of qualitative methods has increased dramatically in social science and healthcare research in recent years (McLeod, 2001; Elliott et al, 1999) and its importance in clinical psychology research is now recognised increasingly (Turpin et al., 1997).

In healthcare settings, qualitative research can make an important contribution to the efficiency of services, for example in explicating how general research findings are successfully applied in individual cases. It can also promote effectiveness in clinical practice by, for example, capturing human factors in therapeutic or systemic exchanges (Dingwall, Murphy, Watson et al., 1998).

The relationship between qualitative and quantitative methodologies has been the focus of a longstanding debate in the social sciences (e.g. Bryman, 1988)⁷ in which the two approaches have often been portrayed as exclusive or opposed (Henwood & Pidgeon, 1992).

One reason for this polarisation has been the apparent difference in focus of the two approaches. Quantitative methods operate by coding and analysing 'raw' data in numerical form as a means of reducing complexity and with the aim of producing generalised and replicable findings. Qualitative research has often been negatively and narrowly defined from this position (i.e. as research that is not quantitative) because of its focus on non-numeric data sources such as archive materials, interview transcripts and observational field notes (Pidgeon & Henwood, 1997).

⁷ For examples of this debate in the psychological literature, see special issues of *The Psychologist*, 1995, 8 (3); 1997, 10 (4); 1998, 11 (10).

A second, more substantive reason is that qualitative and quantitative methods have tended to be associated with distinct epistemological assumptions, or theories of knowledge. Quantitative methods developed primarily within the traditional positivist paradigm⁸ of the natural sciences. This paradigm assumes a realist ontology and with it, the notion that theory-driven, experimental enquiry yields knowledge of an external world of objectively-defined 'facts', including cause and effect relations. The positivist paradigm remains dominant in scientific study of human activity (including psychology) and the use of quantification can be seen to have set a standard for scientific method in the social sciences (Henwood & Pidgeon, 1992).

Qualitative methods, by comparison, derive primarily from an alternative paradigm in the social sciences, usually termed 'interpretivist', 'naturalistic' or 'contextualist' (Henwood & Pidgeon, 1992; Bryman, 1988). The interpretivist paradigm developed with a need to understand subjective phenomena, including meaningful interpretations attached to experience, because these areas of enquiry were distinct from the positivist project of explaining regularities in physical events. Early proponents of an interpretivist approach in the social sciences (e.g. Dilthey, 1894, cited by Henwood & Pidgeon, 1992) argued that uncritical adherence to the methods of natural science resulted in an unwarranted reduction of attention to human consciousness and, therefore, the loss of fundamental aspects of human existence.

⁸ Scientific paradigms can be understood as sets of shared values that govern the methods, standards and generalisations of any group or community of scientists. A paradigm will define legitimate areas of inquiry, acceptable solutions and, importantly, the meaning of scientific terms (Kuhn, 1970).

The interpretivist paradigm can be characterised in several ways that differentiate it from the traditional positivist approach. These include emphases on describing phenomena rather than seeking reductive explanations; representing the 'insider views' (Turpin et al, 1997) or perspectives of research participants; and, importantly, efforts to capture the meaning of participants' experience and behaviour within its defining context.

Interpretivist research is also marked by efforts to derive theoretical concepts *from* data (rather than assuming them a priori) and an understanding of scientific theorising as the generation of hypotheses, rather than an attempt to establish immutable 'facts' or truths about the world. The assumption that research participants and researchers are each active interpreters of the world also manifests in a commitment to regard knowledge as constructed, rather than independently-defined (Henwood & Pidgeon, 1992).

Qualitative research methods are privileged within the interpretivist paradigm because they are considered to avoid (or minimise) difficulties inherent in methods based on quantification (Henwood & Pidgeon, 1992). These difficulties include the risks of reducing or neglecting unique aspects of individuals' experience, 'fixing' meaning inappropriately (e.g. in situations where meaning is negotiable or dependent on a changing social context) and imposing existing systems of meaning to structure others' subjective experiences (Miles & Huberman, 1994).

For this reason, qualitative research has been associated with the alternative interpretivist paradigm that has emphasised the irreducible and contextual nature of knowledge in the social sciences and has challenged the dominant (positivist) notion of a unitary science capable of producing a cumulative, objective body of knowledge. Historically, the interpretivist paradigm has sat uncomfortably alongside mainstream (social) scientific research and as a result, qualitative research has tended to be relegated (Glaser & Strauss, 1967), doubted (Morgan, 1996b) or misunderstood (Craig, 1996) within the social sciences⁹.

The polarisation that characterised the quantity-quality debate from the late 1960s has shifted over the last decade and the relationship between both approaches has become less clear (McLeod, 2001; Henwood & Pidgeon, 1992).

An important indicator of this change has been a wider recognition in the literature that quantitative and qualitative methods are not fixed to particular epistemological positions (e.g. Holloway, 1997). Parker (1994), for example, pointed out that research findings derived from quantitative methods can be compatible with a constructionist understanding of knowledge and Henwood and Pidgeon (1992) noted that some quantitative methods (e.g. structured questionnaires, Q-sort methodology and factor analysis) have been employed by discourse analysts and feminist psychologists. Additionally, several commentators in the psychology literature (e.g. Rennie et al., 2000; Pidgeon & Henwood, 1997; Charmaz, 1995) have highlighted that qualitative methodologies -notably that of grounded theory (see 2.3 below)- were originally developed within a positivist paradigm.

⁹ For accounts of the changing relationship between positivist and naturalistic paradigms in the social sciences, see Parker (1994), Bryman (1988) and Lincoln and Guba (1985).

One way of understanding a revised relationship between quantitative and qualitative methods has been to regard them as equivalent. This 'technical' view (Bryman, 1988) is derived from the premise that *all* research methods operate by re-representing the data to which they are applied in some form (Miles & Huberman, 1994). From this position, qualitative and quantitative methods may be selected as research tools purely on the basis of the research question and the form of available data.

Unsurprisingly, the technical view has been criticised as insufficient because of its disregard for substantive, competing claims over what knowledge 'is' (Bryman, 1988). For example, Pidgeon and Henwood (1992) have pointed out that the failure to acknowledge the epistemological underpinnings of research methods would ultimately risk 'regression' to a unitary (positivist) paradigm, in which inappropriate demands (e.g. for objectivity, replicability and generalisability) would be made on all qualitative research, thereby losing the distinct perspective of an interpretivist approach.

A solution, which avoids the polarity of quantitative and qualitative methods (or more accurately, the different theories of knowledge), has been a position of compatibility between paradigms and research carried out within them (see for example, Silverman, 1994). This position acknowledges that, whilst different scientific paradigms and their associated theories do represent distinct "ways of seeing the world" (Hacking, 1983, p.3), the forms of understanding developed within them are nevertheless assumed to be commensurable (Henwood & Pidgeon, 1992) or comparable in meaning.

This latter position has allowed social science research to be strengthened by the “principled mixture of methods” (Henwood & Pidgeon, 1992, p.100), whilst also allowing for the findings of quantitative and qualitative methods to ‘stand alone’ (within one or other defined paradigm). Given this, Turpin and his colleagues (1997) have suggested several ways in which qualitative methods may be used in clinical psychology research. One is as an initial approach with the aim of formulating a research question or hypothesis prior to further quantitative enquiry. A second is to use qualitative methods in parallel with a quantitative approach in order to provide additional validation or meaning to general findings. The third way is to use a qualitative approach ‘singularly’, for example to provide an empirical basis for novel theory.

The last of these relationships was particularly pertinent to the present study, which was concerned with exploring a research area where little specific literature exists and with the aim of developing an initial theoretical understanding of participants’ experiences. The particular qualitative methodology used was grounded theory and this is described in more detail below.

2.3 Grounded theory methodology

This section describes grounded theory methodology, including the aims of grounded theory research and its definitive processes, revisions to the original account and the rationale for using it in this study.

2.3.1 The development of grounded theory

Grounded theory research methodology¹⁰ was developed in the 1960s by the American sociologists Barney Glaser and Anselm Strauss. In their original account, *The Discovery of Grounded Theory* (Glaser & Strauss, 1967), they claimed that sociological research was dominated by the continued application of a few 'grand theories' that often failed to map onto the social worlds of research participants. Glaser and Strauss (1967) argued that this top-down research tradition had resulted in an impoverished theoretical base for sociology. Their objective in developing grounded theory research was to 'close the gap' between established ways of conceptualising social phenomena and the social worlds encountered in empirical research; grounded theory methodology offered a way to develop novel, representative theories.

A definitive feature of grounded theory research is its emphasis on induction in the development of theory (Glaser, 1992). Broadly, inductive inquiry requires the researcher to adopt an 'open-minded', atheoretical approach to phenomena under investigation. This aims to ensure that any conceptual understanding is shaped by its data, rather than the researcher's preconceived assumptions (McLeod, 2001). The primacy of induction in grounded theory research contrasts with other qualitative methods that tend to impose 'tighter' structure onto their data (Miles & Huberman, 1994).

¹⁰ A 'grounded theory' should be differentiated from the methodology by which it is developed (Backman & Kyngäs, 1999). Hence, studies that develop grounded theories can be said to use a 'grounded theory approach' (Strauss & Corbin, 1990), 'grounded theory research' (Glaser, 1978) or 'grounded theory method' (Chenitz & Swanson, 1986).

For Glaser and Strauss (1967) a 'bottom-up' inductive methodology allowed for the meaning of participants' experiences to be preserved during analyses, thereby providing theories 'grounded' in real social worlds. Grounded theory research was emphasised as a rigorous process in which the researcher becomes sensitised to the meaning of data, working to 'uncover' meaningful themes and categories and using these to develop an abstract yet representative theoretical account (McLeod, 2001).

Glaser and Strauss (1967) regarded the strength of grounded theory research to be its focus on the interpretation of meaning. They expected it to be used across social science disciplines and with a range of phenomena, and a growing body of research literature indicates this to be the case (McLeod, 2001).

The discovery-oriented approach of grounded theory is particularly appropriate for research areas where little existing understanding exists (Henwood & Pidgeon, 1992) or where a fresh perspective is sought about an established area of knowledge (Backman & Kyngäs 1999; Strauss & Corbin, 1990). Grounded theory methods are used increasingly in studies of psychological phenomena (McLeod, 2001; Pidgeon & Henwood, 1997; Charmaz, 1995; Rennie, Phillips & Quartaro, 1988) and they have proved particularly useful for opening up meaning and processes of change in studies of complex emotional experience and issues of identity (Charmaz, 1995).

2.3.2 Process in grounded theory research

Glaser and Strauss's (1967) original account presented grounded theory methodology as a set of general principles with some suggestions for its application (McLeod, 2001). Since then, many descriptive accounts have been published, some of which have provided formalised accounts of the process of 'doing' grounded theory research (e.g. Strauss & Corbin, 1990). Some of these accounts represent critiques of Glaser and Strauss's (1967) formulation (McLeod, 2001; see 2.3.3 below). However, all grounded theory studies share some definitive components, several of which are summarised below.

- *Research focus.* Strauss and Corbin (1990) emphasised the need for research questions to be broad, open-ended and action-oriented in grounded theory studies. Phenomena under investigation are expected to focus on action and change. This is because people are assumed as purposeful agents whose behaviour is underpinned by basic social and psychological processes. Grounded theory research therefore aims to provide a comprehensive conceptual account of these processes.
- *Delayed literature search.* Glaser and Strauss (1967) stressed that data analysis should be approached with an open mind to enable themes and categories to 'emerge' freely, unencumbered by existing theory. To that end, they downgraded the researcher's need to be familiar with (putatively) relevant literature. Whilst their (realist) epistemological assumptions have been challenged (see 2.3.3 below), the risk of unwittingly imposing theoretical preconceptions during grounded theory analysis, and the need to monitor for this has remained important (McLeod, 2001; Charmaz, 1995).

- *Synchronisation of data collection and analysis.* A third defining characteristic of grounded theory methodology is the explicit overlap between the processes of data gathering and analysis. In contrast to other qualitative methodologies, grounded theory analysis begins when data is first gathered. The purpose of this is to allow initial, albeit tentative, themes to 'sensitise' the researcher to significant and perhaps unforeseen areas of interest. These may then be used to shape the collection of additional data.
- *Theoretical sampling.* This refers to the strategy of selecting data according to its theoretical interest. Selection of participants, prompts used to generate data and the selection of relevant material from participants' accounts may be shaped by initial data analysis in grounded theory studies and sampling decisions are used to expand a developing theoretical framework. In this, theoretical sampling represents a broadly inductive strategy that helps to build a comprehensive, 'rich' account of the phenomena under investigation. It may include the selection of 'deviant' cases (i.e. participants or aspects of data that do not appear to fit with initial themes) as a method of testing and refining a developing category or theory (McLeod, 2001).
- *Constant comparative method.* This term refers to a general analytical approach, in which the researcher continually shifts focus between levels of interpretation in an iterative (i.e. constantly repeating) manner (Pidgeon & Henwood, 1997). In this way, novel data may add to the number of meaningful categories, but it is also used to revise and further define existing concepts throughout the process of data analysis.

- *Saturation*. This term refers to the point at which the collection and analysis of new data fails to give rise to new ideas or refinements in the development of a grounded theory (Glaser, 1978). The saturation of all categories ideally determines the end-point of data collection (McLeod, 2001).

2.3.3 Revisions of grounded theory methodology

Grounded theory has become widely accepted as a qualitative methodology in recent years and it can be regarded as the 'market leader' of qualitative methods within applied healthcare and social science research (McLeod, 2001). However, Glaser and Strauss's (1967) original account has been the subject of some criticism and revision (McLeod, 2001; Charmaz, 1995).

One debate in the literature has concerned the status of claims for grounded theory as a purely inductive methodology. This debate grew out of differences between the original authors' interpretations of the methodology in their later works (McLeod, 2001).¹¹

Briefly, Glaser (e.g. Glaser, 1992) continued to portray induction as the central characteristic of grounded theory research. He emphasised the process of theory-building as an open-minded and creative enterprise, dependent on the researcher's sensitivity to the data, innovative insight and, crucially, flexibility of approach. In contrast, Strauss and his associates (e.g. Strauss & Corbin, 1990) made efforts to formalise the process of 'doing' grounded theory by identifying specific analytical procedures to guide researchers. For Glaser, this move represented a retreat from the position of open-minded discovery toward a 'top-down' pre-structuring of data (McLeod, 2001).¹²

¹¹ For details of this debate see Melia (1996) and Stern (1994), both cited in McLeod (2001).

¹² McLeod (2001) has cited a variety of formal guides for conducting grounded theory studies (e.g. Kools, McCarthy, Durham & Robrecht, 1996; Rennie, et al., 1988; Turner, 1981; see also Charmaz, 1995) as a further 'fragmentation' of Glaser and Strauss's (1967) account.

The 'induction-deduction' debate remains active in the grounded theory literature, although several commentators have regarded it as a false dichotomy. Rennie et al., (1988) for example, noted that elements of deductive testing are inherent in the strategies of constant comparative method and theoretical sampling described by Glaser and Strauss (1967). Others (e.g. Pidgeon & Henwood, 1997; Miles & Huberman, 1994) have made the general observation that there are no 'pure' positions of induction or deduction in theory development because the practical tasks of delineating a research study and interpreting any form of research data require some interplay of both approaches. These responses have therefore stressed the relatively 'loose' approach to pre-structuring data in grounded theory research.

Given this, the above debate may also be interpreted as a question of which -if any- account of grounded theory methodology should be regarded as 'correct'.¹³ This interpretation is linked to a more fundamental area of debate concerned with the form of knowledge which grounded theories can represent, and so the epistemological assumptions of Glaser and Strauss (Charmaz, 1995).

¹³ Denzin and Lincoln (1994) have associated this with a wider 'crisis of representation' in the development of qualitative research methods in social science.

The accounts of grounded theory methodology proposed by both Glaser and Strauss (e.g. Strauss & Corbin, 1990; Strauss, 1987; Glaser & Strauss, 1967) were portrayed as compatible with the traditional positivist paradigm of scientific enquiry (Charmaz, 1995). The latter entails a 'realist' view of knowledge (see for example Dancy, 1992). That is, it assumes the notion of an external reality, distinct from the scientific observer and from which 'facts' may be discovered and read using appropriate method (Charmaz, 1995). From these assumptions Glaser and Strauss held that grounded theory research, properly conducted, could produce conceptual accounts that represent the social worlds of those under investigation as objective facts; this was reflected in their claims for the 'emergence' of meaningful concepts and the 'discovery' of theory.

Criticism of Glaser and Strauss's original position has focused on their assumption of a passive relationship between researcher and data. This is because, whilst they acknowledged practical difficulties in approaching data as a "tabula rasa" (Glaser & Strauss, 1967, p.3), they regarded the researcher as a neutral agent engaged in the discovery of external truths. As Pidgeon and Henwood (1997) have stated, Glaser and Strauss's assumptions were of,

"a set of social or psychological relations [that] exist objectively in the world...reflected in qualitative data, and ...therefore there to be 'captured' by any researcher who chances to pass by..." (1997, p.254).

By contrast, interpretivist critiques of grounded theory have claimed that the original authors did not address the active role of the researcher adequately. This is because constructionist views of knowledge assert that meaningful relationships 'in' data do not exist independently, but are introduced in the act of interpretation. Critiques of Glaser and Strauss's work have therefore claimed that grounded theories develop from an interaction between researcher and data (Charmaz, 1995) and therefore stand as a form of knowledge constructed in the active interpretation of data.

One revision following from constructionist epistemology is that the form of understanding portrayed by a grounded theory does not represent objective truth, but rather reflects the particular conditions under which it is developed. This is because, logically, it is not possible to meaningfully interpret unstructured data unless the researcher is first able to take some orienting position to it (Pidgeon & Henwood, 1997). The constructionist position, then, emphasises that the level and content of data deemed significant during qualitative analysis will be determined necessarily by the resources brought to it because the latter allow the researcher to become sensitised to the (meaning of) material under investigation (McLeod, 2001).

The resources brought to data analysis by a researcher will include overt parameters of a study, but will also include the researcher's philosophical assumptions, professional perspective, previous experiences, expectations, interests and biases (Pidgeon & Henwood, 1997; Charmaz, 1995). It follows from this that distinct qualitative accounts may be developed from the same data (Sherrard, 1998).

A related implication of the constructionist view of knowledge is that the project of grounded theory research is not to 'uncover' objective theoretical structures, but rather to *generate* novel theories, or forms of discourse, from social phenomena so that fresh understandings of existing social worlds may be obtained (Charmaz, 1995; Henwood & Pidgeon, 1992).

This revision of Glaser and Strauss's original position does not differ significantly from their original objective of 'bridging the gap' between existing forms of understanding and empirical data by the development of novel theories. It does, however, weaken the position of there being a 'correct' interpretation of grounded theory methodology.

From a constructionist position, grounded theory methods serve as useful strategies that aid the researcher's work in synthesising and understanding complex data within a defined area of study (Charmaz, 1995), but do they not represent a rigid 'recipe' for uncovering objective facts¹⁴. Recognition of the researcher as an active interpreter of data acknowledges the contextual nature of grounded theories and, with this, the ability of the researcher to understand and use research methods appropriately. The present study assumed an interpretivist approach to qualitative research and with this, a constructionist view of knowledge.

2.3.4 Rationale for using grounded theory

The objective of this study was to develop an understanding of how able autistic adults meaningfully construe their experiences of social disability. Grounded theory methodology was selected as an appropriate means of investigation for the following reasons.

¹⁴ Denzin and Lincoln (1994) adopted the concept researcher as *bricoleur* in this regard; that is, as a skilled craftsman (*sic*), using methodological strategies to achieve a particular end.

First, grounded theory methods were designed to explore research areas where no strong theoretical knowledge exists and where there is a need to generate new theory from relatively unstructured empirical data (Charmaz, 1995; Henwood & Pidgeon, 1995). As stated in Chapter 1, this study was exploratory because of the paucity of literature on disability in able autistic adults. A grounded theory approach was therefore deemed suitable because it did not require a pre-conceived structure for organising data (Miles & Huberman, 1996; Charmaz, 1995) and was “open-minded” to potentially novel information in comparison with other qualitative methods (Miles & Huberman, 1994, p.58).

Second, grounded theory was designed to uncover complexity and processes of change in investigations of ‘first-hand’ experiential data (Pidgeon, 1996; Charmaz, 1995; Rennie, et al., 1988). The inclusive definition of disability (Oliver, 1996a) adopted in this study suggested that data would be complex, because it allowed for several general factors and many specific issues to impact, potentially, on participants’ understanding of disability. Furthermore, the assumption of a spectrum model of autism (Wing, 1988), which includes the potential for developmental change, required a methodology that would be sensitive to changes in participants’ experiences over time.

A third reason for using grounded theory methodology was the aim of developing a generalised account of participants’ understandings that could contribute to the literature on autism and disability. Grounded theory analysis goes ‘beyond’ its data to generate abstract, conceptual accounts of phenomena under investigation (McLeod, 2001; Glaser & Strauss, 1967). It therefore promised a higher-order, more explanatory account of able autistic adults’ experiences, instead of (merely) re-ordering complex material at a ‘shallow’ descriptive level.

Last, grounded theory methodology was selected for pragmatic reasons. Primary among these was that it offered an overt, systematic approach to data gathering and analysis (Charmaz, 1995; Strauss & Corbin, 1990). One advantage of this was that the grounded theory literature provided a useful guide to the researcher (a relative novice in qualitative research). This was particularly useful given the time constraints in completing research in clinical psychology training. A second advantage was that the open and scientifically rigorous approach of grounded theory methods (McLeod, 2001; Dingwall, et al., 1998) offered a high degree of external validity for the study.

2.4 Procedure for selecting participants

This section describes the conceptual framework that determined the selection of participants. It describes the inclusion and exclusion criteria that were imposed. These criteria included the operational definitions of 'able autistic' and 'social disability' adopted for this study.

2.4.1 Sample frame

The first stage in the selection of participants was the development of a 'sample frame'. This provided a conceptual domain from which participants were selected. The sample frame allowed the scope of the project to be refined by specific inclusion and exclusion criteria.

Sampling decisions in scientific research are theory-driven (Miles and Huberman, 1994). In this study the sample frame was shaped by the two main constructs of the research question, specifically 'able autistic' and 'social disability'. The operational criteria used for the sample frame are described below.

2.4.2 Selection criteria for 'able autism'

Inclusion criteria

A spectrum model of autistic disorders (Wing, 1988) was assumed for two reasons.

First, selection on the (alternative) basis of discrete autistic subcategories was considered unduly restrictive and impractical. As noted in Section 1.2, a wide consensus has not been reached for the nosological status of sub-groups of 'milder' autistic disorders. Furthermore, diagnostic labels associated with more able autistic presentations are often used interchangeably, especially in adult populations (Volkmar & Klin, 2000).

Second, individuals in the current adult population who met criteria for autism in childhood were more likely to have been labelled with diagnoses of 'infantile autism' (i.e. Kanner's syndrome) than contemporary able autistic children. In part, this is because diagnostic labels for higher-functioning forms of autism (e.g. Asperger syndrome) were introduced in the UK only after Wing's (1981) paper. It is also because some adults may have presented severe autistic impairments in infancy, but 'recovered' significantly by adolescence or adulthood (e.g. Tantam, 2000; Howlin, 1997; Piven, et al., 1996).

The spectrum model of autism provided an inclusive conceptual frame for selecting participants whose early development had met criteria for an autistic disorder, while allowing for differences or inconsistencies in diagnostic labels and the possible amelioration of earlier symptoms by adulthood. The inclusion criterion for autism in this study was therefore a prior diagnosis of autistic spectrum disorder by a qualified psychiatrist or clinical psychologist.

Exclusion criteria

The working definition of 'able autistic' was then refined by the exclusion of adults with a dual-diagnosis of learning disability (otherwise 'mental retardation' or 'mental handicap'). This decision was taken for two reasons:

First, the construct of learning disability and that of the 'triad' of social impairments were acknowledged to be conceptually compatible (Volkmar & Klin, 2000) and so likely to overlap in clinical practice (Wing, 1991). This is because learning disability is defined in terms of intellectual and social development, and autism is (strictly) defined in behavioural terms (World Health Organization, 1992; Gillberg, 1990). It was therefore possible for some adults diagnosed with an autistic spectrum disorder to have a more generalised intellectual impairment.

The adopted definition of 'able autistic' was conservative because it did allow for adults with a misdiagnosis of learning disability to be excluded. Tantam (2000) has noted that a substantial number of intellectually able individuals diagnosed with 'Asperger's syndrome' in adolescence or adulthood have previously been (incorrectly) classified as having non-specific learning disability.

The second reason for defining 'able autistic' by elimination was practical. By focusing on current diagnostic status, potential participants were not required to undergo formal psychometric (IQ) testing as part of the selection procedure. Testing was also rejected as unnecessarily time-consuming, given the relatively brief, one-hour research interviews used and the overall time-constraints of the study.

2.4.3 Definition of 'social disability'

The research question implied that participants had experienced social disability associated with the qualitative social impairments of autism. This raised the need to decide which pre-existing ideas of disability were imposed prior to an exploration of participants' own views.

The comprehensive definition of disability suggested by Oliver (1996a) was adopted for the sample frame. This defined all forms of disability by three necessary conditions: the contingent presence of physical or mental impairment, the experience of external social and/or physical barriers, and an identification or 'self-view' associated with disability or being disabled.

Oliver's (1996a) definition was sufficiently wide in scope to include individuals with potentially varied experiences of social disability; it also required substantive evidence of internal impairment, which fitted the participants in this study. In addition, Oliver's (1996a) conceptual separation of impairment from the social phenomenon of disability did not exclude those able autistic adults who continued to report social disability despite some amelioration in underlying autistic 'symptoms'.

The sample frame therefore included only those able autistic adults who reported social disability and for whom this was associated with a diagnosis of autism. The decision to exclude individuals that did not report an experience of disability was an accepted limit in the scope of the study.

2.4.4 Healthy volunteers

An additional sampling criterion was the exclusion of individuals with a dual-diagnosis of psychiatric illness and/ or those who were receiving treatment for significant psychological problems. The decision to include only healthy volunteers was taken to minimise the risk of causing unnecessary distress to participants and to minimise the need to access participants' medical records.

2.4.5 Selection procedure

Participants were selected from the sample frame using a non-random, directed procedure. Selection was based on the need to gather rich, varied data from which to build a comprehensive grounded theory (Henwood & Pidgeon, 1992).

Purposive selection procedures are a common feature of qualitative studies that use relatively small samples (Kuzel, 1992). Miles and Huberman (1994) have defended this as conceptually sound because the social worlds studied in qualitative research are often closely defined. Directed selection therefore allows data gathering to be theory-driven by concepts in the research question; that is, selection is made on the basis of theoretical interest (McLeod, 2001). A random selection procedure was considered inappropriate for the study, because of the increased risk of bias in selecting a relatively small number of participants.

Initial selection decisions were deliberately inclusive and tentative with later participants being selected using the 'theoretical sampling' procedure described above (Section 2.3). This approach to selection was intended to balance the methodological advantages of directed selection with an inductive approach to the data that avoided imposition of potentially irrelevant theoretical assumptions.

In the event, four participants were selected by a directed strategy that aimed to capture a varied experience of social disability. Tentative selection criteria from the sample pool included 'face' differences of age and gender. Additionally, available information on candidates' educational or employment history and age at diagnosis were taken into account. These factors were considered to be related, respectively, to Oliver's (1996) disability criteria of experience of social barriers and identification with disability.

As the analysis progressed two further participants were selected using theoretical sampling. These were selected to enable the issue of geographical and cultural change in the experience of social disability to be explored further. As examples, one of these participants ('William Anderson') was selected because he had moved from a rural village to study in a large city, whilst a second ('Jacob McCluskey') was selected because he identified himself as a member of a minority black community in a predominantly white local population. (Details of participants are included as Appendix 6.2).

2.5 Data collection procedure

The data collection procedure is represented diagrammatically as Figure 1, overleaf, and described in detail below.

2.5.1 Recruitment

All participants were recruited from a confidential list of adults registered with the West Midlands Autistic Society Limited (WMAS). The WMAS is the largest regional autistic society in the UK. It is affiliated to the National Autistic Society (NAS) and its catchment area includes the metropolitan districts of Birmingham, Coventry, Solihull and Wolverhampton and the counties of Hereford and Worcester, Staffordshire, Shropshire and Warwickshire.

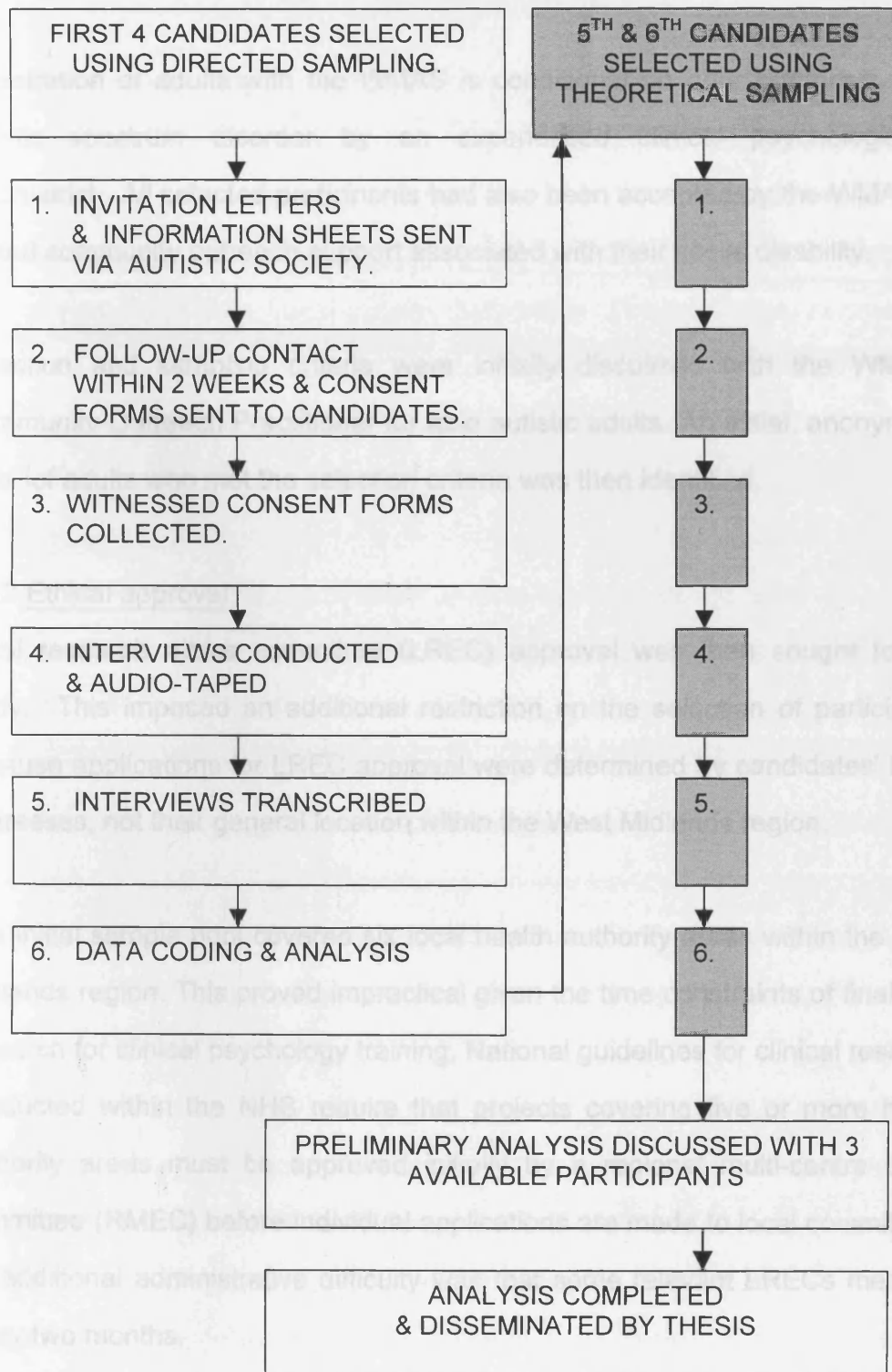


Figure 1: Diagram of research procedure

Registration of adults with the WMAS is conditional on prior diagnosis of an autistic spectrum disorder by an experienced clinical psychologist or psychiatrist. All selected participants had also been accepted by the WMAS for limited community outreach support associated with their social disability.

Selection and sampling criteria were initially discussed with the WMAS's Community Outreach Practitioner for able autistic adults. An initial, anonymised 'pool' of adults who met the selection criteria was then identified.

2.5.2 Ethical approval

Local research ethics committee (LREC) approval was then sought for the study. This imposed an additional restriction on the selection of participants because applications for LREC approval were determined by candidates' home addresses, not their general location within the West Midlands region.

The initial sample pool covered six local health authority areas within the West Midlands region. This proved impractical given the time constraints of final-year research for clinical psychology training. National guidelines for clinical research conducted within the NHS require that projects covering five or more health authority areas must be approved initially by a regional multi-centre ethics committee (RMEC) before individual applications are made to local committees. An additional administrative difficulty was that some relevant LRECs met only every two months.

Given these constraints, selection was initially restricted to the Local Health Authority area that held the largest number of candidates. A second Local Health Authority area was later included; this was determined primarily by the selection requirements of theoretical sampling noted above. LREC approval was gained from both Local Health Authorities. Formal letters of invitation (Appendix 6.3) and information sheets (Appendix 6.4) were then sent to candidates by the Community Outreach Practitioner at the WMAS.

2.5.3 Consent

Consent forms (Appendix 6.5) were sent to participants by post. Completed forms were returned to, or collected by, the Community Outreach Practitioner at the WMAS. To minimise the risk of candidate acquiescence consent forms were not administered or collected directly by the researcher. This decision acknowledged the pragmatic difficulties experienced by some able autistic individuals in 'reading' the conventions of novel situations (e.g. Attwood, 1998; Tantam, 1988b). As a further safeguard, consent forms were required to be countersigned by a person known to the participant, but not directly involved in the project.

Finally, participants' general practitioners (GPs) were notified of their patients' intention to take part in the study (Appendix 6.6); details of the study were also included. Concerns raised by consent witnesses or GPs formed a necessary exclusion criterion. In the event, no concerns were raised for any prospective participants.

2.5.4 Interview procedure

Each participant was invited to suggest a convenient location and time for the research interview and several possible dates convenient to the researcher were offered. The option to meet at the WMAS offices (familiar to all candidates) was made available (see Information Sheet, Appendix 6.4). In the event, all participants chose to be interviewed at their own homes.

Immediately prior to interview, each participant was reminded of the research question by reference to the Information Sheet. The Consent Form was then reviewed and participants were reminded of their continued right to withdraw from the study at any point. This preamble also provided an opportunity for participants to ask questions.

A four-item interview schedule (Appendix 6.7) was used to structure the interviews, for two reasons. First it provided a (purposely) minimal pre-conceived 'frame' for exploring the research question, so that interviews remained sensitive to novel information. Following Dey (1993) the interview schedule was developed from existing literature, specifically the concepts of autism and adulthood. (Briefly, all participants were prompted about their recollections of receiving a diagnosis of autism, their experiences of social disability in adulthood relative to childhood and adolescence, and their expectations of future change).

A second reason for adopting (some) imposed structure was to allow for the pragmatic difficulties of social interaction, such as turn-taking, demonstrated by some able autistic individuals (e.g. Attwood, 1998). Adults diagnosed with 'Asperger syndrome' have been noted to benefit from increased structure in clinical settings, such as cognitive-behaviour therapy (Hare & Paine, 1997). The interview schedule allowed the researcher to impose cues for social interaction during the interview, if required. This acknowledged that participants' impairments in social interaction could have been a feature of the 'social reality' of the interview as well as its content.

Each participant was interviewed on one occasion only due to the practical constraints of the project. Issues emerging in initial interviews were carried forward for exploration with later participants. (This was an example of the 'theoretical sampling' of data used in grounded theory research).

Interviews lasted between 40 and 60 minutes. Audio-recordings were made using a cassette recorder (Sony TCM-465V) with remote battery microphone. On one occasion (interview with 'William Anderson') the cassette recorder was replaced during the interview due to malfunction; this is indicated in the transcript (Appendix 6.8¹⁵).

2.6 Data analysis procedure

A descriptive account of the data analysis procedure is given below. For clarity the procedure is represented as distinct stages. In practice however, data gathering and analysis were combined (Strauss & Corbin, 1990; Glaser & Strauss, 1967).

¹⁵ Appendix 6.8 is bound as a separate volume.

2.6.1 Transcription

Audio-recordings of research interviews were transcribed verbatim. The researcher completed all transcription to facilitate 'theoretical sensitivity' with the data (e.g. McLeod, 2001) and the resulting transcript (Appendix 6.8) formed the permanent textual record for the analysis.

Transcription was recognised as a selective procedure, imposed upon the data, and which provided a transformed representation of the 'social realities' of the original research interviews (Flick, 1998). Peräkylä (1997) has pointed out that the convention of audio-recording interviews in qualitative research unavoidably excludes some (nonverbal and longer-term temporal) information. The additional decision to use interview transcripts as the primary source of analysis was justified in this study because of the increased access it offered to the original data, relative to the (sole) reliance on audio-recordings (Pidgeon & Henwood, 1997). However, audiotapes were used during the analysis to help the researcher to remain close to the original research interviews.

The procedures used for transcription of audiotapes were determined by the demands of the research question. Flick (1998; following Bruce, 1992) has pointed out that the reasonable aim of transcription is to produce a text that is manageable, readable, learnable and readily interpretable by the researcher, but that time-consuming, "exaggerated standards of exactness" are rarely justified for psychological research questions that focus on the content of linguistic exchange rather than its organisation (Flick, 1998, pp. 174-175).

Given these dual requirements, for balancing the integrity of 'message and meaning' with the production of a useable textual record, the following procedural features were adopted:

- The transcription process was inclusive: all speech recorded in interviews was transcribed verbatim by the researcher;
- Names of individuals and places that could have allowed individual participants to be identified were changed to ensure anonymity;
- Transcription conventions, taken from examples by Silverman (1997) and Drew (1995), were incorporated to indicate turn-taking, breaks or overlaps in conversation, silences, stress or emphasis and increased volume in speech. An explanatory key to these conventions is provided in Appendix 6.8 (p.5);
- Individual lines of text in the transcript were numbered to facilitate referencing¹⁶ during the process of analysis. (The convention used for referencing quotations from transcripts is given in Chapter 3, Section 3.1).

2.6.2 Initial coding

The initial 'open' coding of interview transcripts formed the first level of transcript analysis. Open coding is a tentative process in grounded theory methodology, in which all concepts in the data judged potentially relevant to the research question are identified and labelled by the researcher (Pidgeon & Henwood, 1997). As an interpretative procedure, it was recognised to impose an additional degree of selection on the original interview data.

Initial coding served two related purposes. First it dissected, or deconstructed, the transcript to a least-abstract level of meaning. (In practice coding represented 'chunks' of meaningful data that ranged from short phrases to paragraphs in the text). This process therefore led to the formation of the basic conceptual 'building blocks' (Charmaz, 1995) of the analysis.

¹⁶ Note that each interview transcript began at line 1.

Second, initial coding helped to ensure that the final theoretical account remained representative of, and so grounded in, participants' experiences (Pidgeon & Henwood, 1997; Glaser, 1978). The interpretation of any form of research data risks an imposition of personal motives, issues or 'flights of fancy' (Charmaz, 1995) and, as the first level of transcript analysis, particular emphasis is placed on the representativeness of initial codes in grounded theory research (Glaser & Strauss, 1967). Given this, the process of initial coding in this study was conducted at a conservative line-by-line level during analysis of the first four interview transcripts and an example of this open coding was included for the reader as Appendix 6.9.

In practice, basic concepts were indicated in pencil on a working copy of the transcript with tentative labels written in the margins. Concepts labelled during initial coding were chosen to capture 'active' psychological processes in participants' accounts. This was because the identification of actions or processes is more likely to facilitate interpretation between participants' accounts (Charmaz, 1995), so helps the analysis move to a more general level. By contrast, highly particular terms selected from the text during initial coding can tie the analysis to particular participants' accounts (Pidgeon & Henwood, 1997).

Written memos were also used from this early stage. Memos allowed for the many 'hunches' and queries that arose during the (six months of the) analysis; to be recorded. They therefore provided crucial aide-memoirs for revising and categorising initial codes as the analysis developed.

2.6.3 Focused coding

Focused coding formed a second level of transcript analysis. During this, properties of concepts that were judged particularly relevant to the research question were progressively refined and delineated by constant comparison within and between participants' accounts, and by the theoretical sampling of new data.

This 'core' level of analysis (Henwood & Pidgeon, 1997) led to the formation of categories (comprising initial codes). These, in turn, enabled new data and earlier codes to be organised more quickly. By the end of the fourth interview 52 tentative categories had been developed. Data from the fifth and sixth interviews were then coded almost exclusively by the application of categories developed in earlier interviews (an example of these focused codes is included as Appendix 6.10).

At this level of analysis, descriptive information of categories was also recorded on computer, following a format for card indexing suggested by Pidgeon & Henwood (1997). Entries for individual categories included a label (title) and references to specific exemplars in the transcript. Potential links and conceptual 'overlaps' with other categories, as well as previous (revised) category labels were also included.

This information served three purposes. First, it contributed to a working index that allowed an increasing body of analytical material to be stored, refined and retrieved. Second, it allowed for meaningful relationships between categories to be recorded and revised as the analysis progressed. Finally, it formed part of the analytical 'paper trail' (also including transcripts, open and focused coding labels and written memos) by which the process of data analysis could be rendered more transparent to external validation (Miles & Huberman, 1994).

2.6.4 Abstraction

Abstraction refers to a third level of analysis in grounded theory research, in which data categories are developed and related to create a higher-order, conceptual form of knowledge (Pidgeon & Henwood, 1997). This process adds another level of interpretation to the original data, because concepts represented by more abstract categories are further removed from participants' accounts and the researcher is required to formulate relationships between and within these extended categories.

The culmination of the abstraction process is, ideally, the development of a 'core category'. The core category represents a dominant explanatory theme in the data and integrates as many data categories around it as possible. Hence, a meaningful grounded theory comprises a representative concept, but also its constituent categories and the connections between them (Glaser, 1978).

During this study, many initial categories were 'promoted' to higher levels of abstraction during their development when they subsumed the concepts represented by lower-level descriptive codes and categories.

In the account of the analysis presented in Chapter 3, three levels of abstraction were used to represent (categories of) participants' experiences of social disability¹⁷. These contributed to a hierarchical framework, in which the relationships between higher-level categories were formulated as an abstract psychological process. A single core category was selected by the researcher.

¹⁷ These were termed 'main', 'intermediate' and 'low' level categories. Subcategories represented component concepts within some categories.

2.7 Quality measures

This section describes the various 'good practice' measures for qualitative research that were used in this study.

It was noted earlier in this chapter (Sections 2.2 and 2.3) that the interpretivist paradigm has highlighted an active role for the researcher and challenged the traditional (positivist) notion of objectivity in social science research.

One consequence of this has been a rejection of traditional standards demanded of scientific research by many of those using qualitative methods. This is because social constructionist understandings of knowledge that characterise interpretivist research do not assume that valid scientific findings require the assumption of objectivity (Sherrard, 1998). Additionally, the aim of qualitative research is often to 'open up' (rather than reduce) the meaning of human experience (Henwood & Pidgeon, 1992); hence, qualitative researchers often do not share traditional assumptions of what may constitute 'analysis' or 'explanation' (Madill, et al, 2000).

Unsurprisingly, the growth of qualitative research in the social sciences has been paralleled by concerns that studies may be poorly conducted, yielding unreliable findings (Silverman, 2000; Elliott et al., 1999). Criticisms from researchers working in 'mainstream' research have generally concerned the space afforded to researcher interpretation (Elliott, et al., 1999) and these have been particularly pertinent in psychology, which has traditionally based the credibility of its claims on a positivist epistemology and 'objective' and reliable methods of investigation (Madill, et al., 2000; see for example, Morse, 1997).

Advocates of qualitative methods have increasingly acknowledged the need for some standards that allow the scientific credibility of their findings to be substantiated, without having to rely solely on the authority of the researcher (Madill, et al., 2000; see also Turpin et al., 1997).

The quality measures used in the design of this study were drawn primarily from the 'evolving guidelines' for qualitative research developed by Elliott et al., (1999), although the work of other authors was referred to (e.g. Silverman, 2000; Peräkylä, 1997; Turpin, et al., 1997; Henwood & Pidgeon, 1992; Dey, 1993).

Elliott et al. (1999) suggest that quality measures for studies using qualitative methods serve four purposes. First and foremost they reassure those in mainstream research of the methodological rigor of qualitative inquiry. Second, they encourage appropriate reviews of qualitative research by offering valid standards for good practice. Third, they offer some basic 'quality control' standards that avoid charges of solipsism (i.e. the unchecked dominance of the researcher's perspective) or 'no method' relativism (e.g. Silverman, 2000; Kvale, 1996)¹⁸. Last, Elliott et al (1999) claim that a set of (evolving) standards can provide common 'reference points' for qualitative researchers to describe their own tailored variations and theoretical advancements to the methods they use.

¹⁸ Feyerabend (1977) has argued for 'methodological anarchy' as a legitimate epistemological position in the philosophy of science.

Elliott et al's (1999) guidelines, described below, were based on a review of some 40 different quality standards in the literature. The guidelines were intended to characterise appropriate considerations involved in the publishability of all forms of qualitative research with the expectation that they would be tailored to particular investigations (Elliott et al., 1999). Hence, the descriptions below also state how each measure was interpreted in this study.

2.7.1 Ownership of researcher's perspective

An important assumption of interpretivist qualitative research is that it is both impossible and undesirable for the researcher to (attempt to) set aside her or his personal perspective in order to maximise 'objectivity'. Instead, qualitative researchers adopt a position of critical reflexivity, in which they aim to make assumptions as scientists whilst remaining aware of personal or other extraneous factors that could otherwise be imposed unconsciously during the interpretation of data (Dey, 1993).

A reflexive stance encourages the researcher to locate him or herself in relation to the area under investigation, whilst remaining mindful of influences that may be involved in the development of an analysis (Cooper & Stevenson, 1998). This reflects the notion that research is not an isolated or value-free activity and that contextual factors that influence qualitative analysis may be recognised (and at best 'bracketed'), but not eliminated as putative 'bias'.

Reflexivity is a crucial factor in the *communication* of qualitative findings. A researcher's explicit ownership of contextual factors that affect the development of qualitative findings can enable the reader to interpret the researcher's understanding and to consider possible alternatives (Elliott et al., 1999).

This is particularly pertinent to disability research, which is usually conducted by non-disabled researchers engaged in post-graduate academic study or training, and commissioned within particular social or political contexts (Barnes & Mercer, 1997). In these cases it is crucial for researchers to consider issues such as how research questions have been formulated, how the findings could be used and how recommendations should be disseminated (see for example Barnes, 1997; Oliver, 1997; Priestley, 1997) and to convey the context in which research took place.

In this study, one important measure for encouraging researcher reflexivity was the use of a personal 'reflexive diary' (e.g. Lincoln & Guba, 1985). This was used to record the researcher's subjective impressions of research interviews and other important aspects of the research process (e.g. research supervision meetings in which preliminary findings were discussed) and it provided a concrete focus for the researcher to reflect on factors that may have influenced data gathering and analysis at the time.

One personal factor was that the researcher did not consider himself to be disabled (using Oliver's 1996a criteria) and did not have personal experience of being disabled. This was recognised as an important factor in the researcher's interpretative position in the early stages of the study. One reason for this was that it risked the assumption that participants would inevitably consider themselves *disabled* in relation to the researcher. An important consequence of this awareness was close scrutiny of an early category, initially labelled 'defence', which represented participants' reluctance to abandon an identity of normality or sameness -and the later understanding that participants' constructions of disability did not exclude personal normality or expertise.

In regard to *communicating* reflexivity, Elliott et al., (1999) and others (e.g. Dey, 1993) suggest that a clear explication of the researcher's perspective to the area under investigation can help to convey the context in which qualitative research is conducted. The statement below offers a brief description of the researcher's interest in understanding the experiences of able autistic adults. It is intended to convey part of the wider context in which the study took shape.

My interest in the needs of adults with autistic spectrum disorders (ASDs) developed through work as a residential support worker for adults presenting severe behavioural difficulties. In 1995 I acted as residential key worker to a 21-year-old man diagnosed with 'Asperger's syndrome'. I was struck by the mutual lack of understanding between that man and the service - including myself - that he was considered to challenge.

In 1996, working as an Assistant Psychologist in a learning disabilities service, I worked intensively in a forensic rehabilitation setting with a second young man diagnosed with 'Asperger's syndrome'. That work focused on eliciting his understanding of his offending behaviour, because the latter had proved difficult for prison and health services to gauge in previous risk assessments. That experience again impressed upon me the need to gain a better understanding of the world-views of adults with autistic spectrum disorders.

As a result, I became involved in facilitating an innovative discussion group for adults with ASDs organised by the West Midlands Autistic Society¹⁹ and, in parallel, became a befriender for a 35-year-old man diagnosed with 'Asperger's syndrome', a relationship that lasted for six years. These points of contact provided insights into the day-to-day experiences of adults with ASDs, including the particular social difficulties that they all described.

Having met over twenty intellectually able adults with diagnoses of ASD, but varied backgrounds, personal characteristics and interests, I developed an interest in understanding the common aspects of able autistic adults' social experiences in more depth. This opportunity arose during my postgraduate clinical psychology training and this study forms a necessary aspect of that qualification. My own experience of conducting this research has continued to inform my clinical work in an adult learning disabilities service.

2.7.2 Situating the sample

This refers to a related need for qualitative researchers to provide sufficient information about participants in an investigation. This information contributes to a definition of the contexts in which research findings were developed and it therefore enables the reader to judge the range of other people or situations to which those findings may be relevant (Elliott, et al., 1999).

In this study basic descriptive data on the six participants is included as Appendix 6.2.²⁰ This includes details of participants' age, gender and diagnosis, together with other relevant background information used in the directed selection decisions outlined in Section 2.5, above.

¹⁹ See MacLeod (2002)

²⁰ Names have been changed to protect the anonymity of participants.

2.7.3 Grounding of examples.

A third element of good practice is the need for researchers to provide clear examples of 'raw' data in the presentation of their analytic findings. This practice helps to illustrate the analytic procedures used in a study and the understanding of the material developed as a result (Elliott, et al., 1999). The grounding of categories using representative material is an important method of improving the reliability of qualitative research, because it increases the transparency for any analytic claims (Peräkylä, 1997). It is of particular relevance in studies using grounded theory methodology, because the latter emphasises good 'fit' between raw data, coding and the abstract categories that contribute to a theoretical account (e.g. Rennie, 2000; Strauss, 1978).

Three forms of grounding material were included in the present study. First, a complete copy of the interview transcripts has been included as Appendix 6.8 (separate addendum); these transcripts represent the 'raw data' of the study. Second, examples of the initial open coding and (later) focused coding procedures used during the analysis have been included (Appendices 6.9 and 6.10 respectively); these represent the initial level of transcript analysis from which categories were developed. Last, the account of the analysis presented in Chapter 4 includes many referenced examples from the transcripts to illustrate the bases of all data categories.

2.7.4 Credibility checks

This refers to procedures used in qualitative studies that enable the researcher to check the credibility of analytical categories, themes and accounts (Elliott, et al., 1999). These procedures contribute to the validity of data interpretation and they therefore vary according to qualitative methods used and the epistemological assumptions of the researcher.

Elliott et al. (1999) provide several examples of credibility checks. These include: 'respondent validation' procedures, in which the researcher checks his or her interpretation with the original participants (or else individuals from a similar population); the use of multiple analysts or an additional analytical auditor, or the incorporation of an internal 'verification step' in which the same researcher may review data for discrepancies, errors or overstatements; the comparison of findings with alternative qualitative perspectives; and 'triangulation' procedures, in which the researcher's understanding is checked against additional measures, such as quantitative data.

With one exception the present study did not adopt 'external' credibility checks for two main reasons. First, the rationale for the study acknowledged the lack of a specific literature on the disability experiences of able autistic adults and the risks of assuming themes in the general literature on disability and autism as relevant. The study was therefore an exploratory 'first step', which aimed to generate a conceptual account of participants' experiences as a *basis* for further research. Given this, 'external' comparison with other qualitative analyses was not possible, neither was a structure for more formal measures of participants' experiences of disability.

The views of three available participants were sought in the latter stages of the analysis. This was intended as (one form of) a check of how 'well grounded' the researcher's interpretation was in relation to participants' worldviews and, in the event, it did not result in any changes to the preliminary analysis.

This external check provided some confirmation of the researcher's understanding and, importantly, demonstrated that the analysis was comprehensible to (at least three) able autistic adults who contributed to the study. However, respondent validation was not regarded as a sufficient measure of 'fit' between analysis and data. This was because the power relationship between researcher and participants may have affected their feedback (Henwood & Pidgeon, 1992; see also Silverman, 2000).²¹

A second reason for not adopting external credibility checks was that the study adopted a social constructionist approach to research findings, and the analysis was understood to represent the *researcher's* interpretation of participants' accounts. This position assumed that alternative -and equally valid - interpretations of the data by other analysts would be possible (Cooper & Stevenson, 1998) and it did not aim to develop an understanding based on either (putative) objectivity or the inter-subjective consensus of other researchers. For this reason, external checks using additional analysts were not considered relevant.

This study did incorporate several internal credibility checks, all of which were characteristic of grounded theory methodology. Flick (1998) has noted that these constitute 'built in' reliability procedures that contribute to the validity of findings.

²¹ Participants' perceptions of people who did not have autistic disorders and especially those regarded as somehow 'expert' were identified as the basis of a power relationship between participants and 'others' in the analysis.

An important general standard was the comprehensive treatment of the data. One aspect of this was an effort to include all data that was relevant to the research question into the analysis. Silverman (2000) has stated that this form of inclusiveness goes beyond that of many quantitative methods in mainstream research. Examples of procedures used in this study were inclusive transcription procedures, the close coding of transcripts and efforts to incorporate 'deviant case' material into the conceptual framework of the analysis.

A second aspect of comprehensive data treatment was the constant comparison of data (see 2.3.2 above) during the analysis. This required that codes, categories and themes identified in later stages of the analysis were 'checked' against earlier forms of understanding. The use of memos and an index of (cross-referenced) category information also provided a means for relating the evolving conceptual framework. The constant comparative method therefore provided a robust means for ensuring that the analysis remained close to (i.e. grounded in) participants' accounts (Rennie, 2000).

2.7.5 Coherence

Coherence refers to (the extent to which) the researcher's analysis of participants' experiences provides an integrated account of the data whilst preserving its meaningful nuances. Coherent qualitative accounts are those in which the researcher's understanding is presented as a data-based narrative, and/ or those that offer a 'map', framework or underlying structure of the phenomena under investigation (Elliott, et al., 1999).

Grounded theory methods are particularly suited to the development of coherent conceptual accounts. This is because the objective of data analysis is to develop categories at several levels of abstraction, integrated around a core category (Strauss, 1987).

In this study, the account of the analysis (Chapter 4) was structured to provide a high level of coherence for the reader. Overall, this was achieved in the hierarchical structure of data categories, in which high-level (i.e. more abstract) categories subsumed those 'beneath' them and were represented in a single core category. Further, the relationship between high-level categories was formulated as a psychological process model; this was directed by participants' experiences and it provided a 'direction' for the account.

In terms of presentation, the conceptual framework of the analysis is represented diagrammatically (Figures 2 to 5)²² to provide a visual overview to the reader, in addition to a structured textual description.

2.7.6 Accomplishing general versus specific tasks

This measure refers to the extent to which the claims of a qualitative study are justified. For example, where the goal of an investigation is to develop an understanding of a *specific* case or instance (e.g. in a single case design), the researcher should demonstrate that the subject matter has been studied and described systematically and comprehensively. At the other extreme, where a *general* understanding of a phenomenon is intended, the researcher should be able to demonstrate an appropriate range of data (i.e. sample size, number of interviews, varied situations, etc.). In all circumstances, it is important for qualitative studies to include the limits of any findings (Elliott, et al., 1999).

²² See p.4 for the list of figures

The stated objective of this study (p.7) was to develop an understanding of how able autistic adults meaningfully construe their experiences of social disability. This broad objective was shaped - and so constrained - by several factors. Primary among these factors was the decision to adopt an exploratory approach, due to a paucity of specific literature. The aims of the study therefore acknowledged that research findings would represent a 'first step' in understanding the complex phenomenon of disability in the able autistic adult population. These aims (p.46) included the need for the study to focus on participants' experiences, remaining sensitive to the possibility of novel material, and to identify conceptual themes in participants' accounts, providing a basis for further research.

Additional limits on the study's scope - and so its findings - have been outlined in this chapter. These included necessary methodological demands, such as sampling decisions (which excluded some able autistic adults), and practical demands, such as limits on selection (e.g. geographical bounds of local research ethics committees) and limits on time for research conducted within postgraduate clinical psychology training.

An important consequence of these demands was that the grounded theory analysis presented in the Chapter 3 was restricted to data gathered from six participants. This provided a further measure of the 'generalisability' of the analysis, that is, the possible domains or contexts in which the analysis could be applied (e.g. Flick, 1998), in addition to efforts to convey the context in which the analysis was developed.

The particular limits of the analysis are discussed in more detail as part of the critical evaluation of this study in Chapter 4 (Section 4.4).

2.7.7 Resonance with readers

A final quality measure, suggested by several authors, concerns the extent to which the researcher's account is judged by its readers to accurately represent the phenomena under investigation and to provide an answer to (or a new form of understanding of) the original research question (Elliott, et al., 1999).

Sherrard (1998) has suggested that qualitative analyses can be regarded as more or less 'convincing' to the reader, a complex quality associated with internal characteristics such as completeness and consistency, but primarily the extent to which an analysis is considered to relate to its subject matter in comparison to competing bodies of knowledge. In a similar vein, Silverman (2000) has referred to the overall 'persuasiveness' of qualitative accounts, whilst Elliott et al. (1999) have associated this broad standard with an analysis' ability to 'stimulate resonance' in others.

In essence, this measure emphasises that the reader is the ultimate arbiter of quality in any research study. Hence, in addition to the need for methodological rigor and transparency of interpretative analysis, qualitative studies must also (be judged to) structure and convey their participants' experiences in a way that participants may otherwise find difficult to express and which also offers a useful form of understanding for others' practice (Elliott, et al., 1999).

The analysis presented in this study (Chapter 3) represented the researcher's understanding of how six able autistic adults had construed their experiences of social disability. As noted, efforts were taken to ground this account in the data and to present the analysis in a transparent, accessible format for the reader. The objective of the study was to develop an initial form of understanding of an area in which little specific literature exists. The grounded theory analysis went 'beyond the data' (Glaser & Strauss, 1967) to provide a structured, conceptual account of its participants' experiences. It was therefore expected to offer a limited, empirical basis for further research.

2.8 Summary

This chapter described the design and methodological procedures used in the study. An introduction to qualitative research was provided. Grounded theory methodology was then described. This included an account of social constructionist revisions to Glaser and Strauss's (1967) original account and the rationale for using grounded theory methods in this study. The procedures used for the selection of participants, collection of interview data and analysis of transcripts were then described. Last, quality measures used in the design of the study were described.

The following chapter provides a detailed account of the analysis.

3.0 ANALYSIS

3.1 Overview

This chapter presents an account of the analysis. In Section 3.2 the core category is described. This represents the six participants' constructions of their experiences of social disability. In Section 3.3 the process model is then outlined. The process model is a formulation of participants' developing understanding of disability, grounded directly in their accounts. The remainder of the chapter (Sections 3.4 to 3.6) provides a detailed description of the three main categories of experience that formed the process model.

The hierarchical category structure of the analysis is represented diagrammatically in the chapter to provide a quick reference for the reader (see List of figures, p.5). The core category and process model are shown diagrammatically as Figure 2, overleaf. Separate diagrams showing the structure of the main categories are included as Figures 3, 4 and 5.

The three main categories were derived from the experiences of all six participants. Intermediate-level categories also represented the experiences of all participants, unless qualified in the text (in all cases intermediate-level categories represented the majority of participants). Lower-level categories represented at least three participants.

Quotations from interview transcripts are also included throughout the chapter. These provide examples of the 'raw' interview data from which more abstract categories were constructed during the analysis. All quotations are inset, in *italic*. The following convention was used for referencing quotations: participant's initials (see Appendix 6.2), page number from Appendix 6.8 (separate volume), then transcript line numbers (e.g. AH, p.6, L20-22).

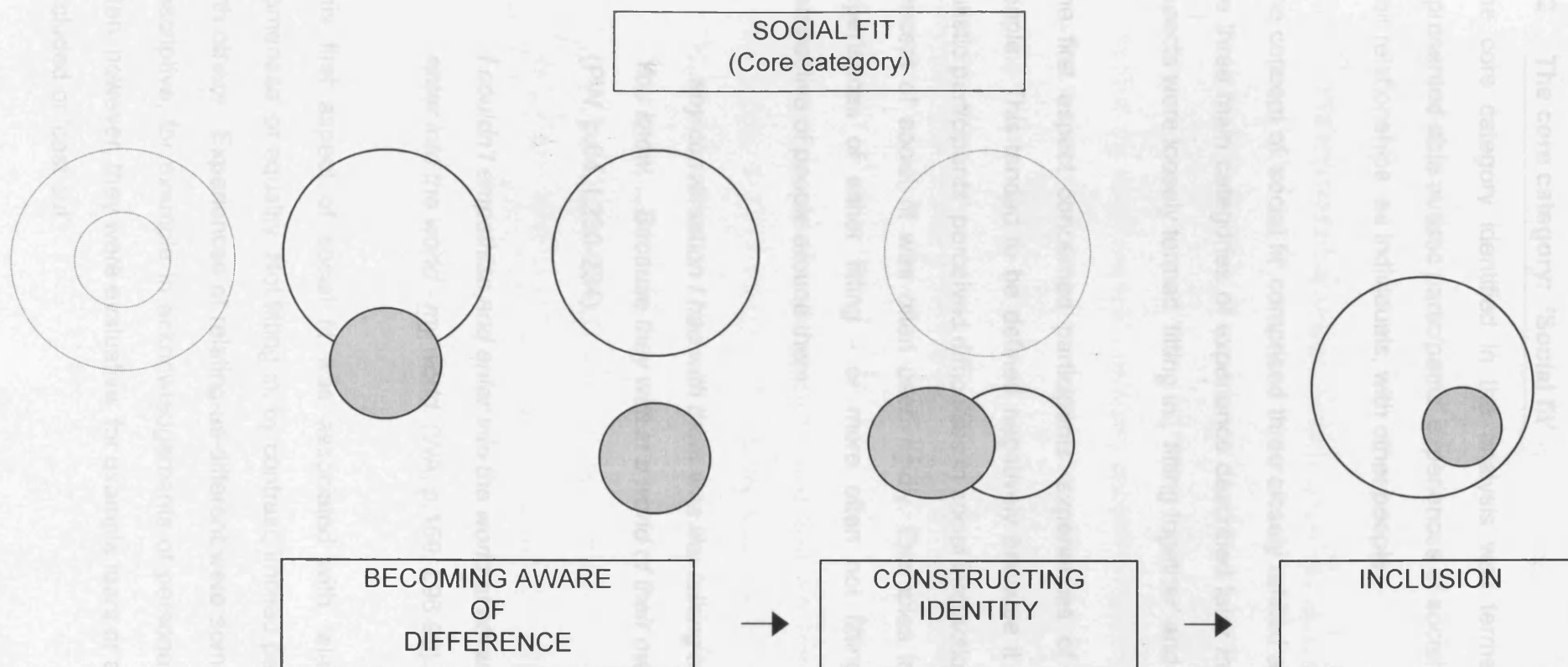


Figure 2: Diagram of the core category and the process model

3.2 The core category: 'Social fit'

The core category identified in the analysis was termed 'social fit'. This represented able autistic participants' experiences of social disability in terms of their relationships, as individuals, with other people.

The concept of 'social fit' comprised three closely related aspects that reflected the three main categories of experience described later in this chapter. These aspects were loosely termed 'fitting in', 'fitting together' and 'fitting with'.

The first aspect concerned participants' experiences of fitting in with other people. This tended to be defined negatively because it emerged from able-autistic participants' perceived difficulties in social interaction. In this sense, the concept of social fit was often used rigidly. Examples included participants' experiences of either fitting - or more often not fitting - with the social perspective of people around them.

...any conversation I had with them was like talking to a brick wall.

You know. ...Because they was in a world of their own.

(PW, p.64, L230-234).

I couldn't empathise and enter into the world of others, others had to enter into the world - my world. (WA, p.159, L96-98).

This first aspect of social fit was associated with relationships based on 'sameness' or equality. Not fitting in, by contrast, implied participants' difference with others. Experiences of relating-as-different were sometimes presented as descriptive, for example in acknowledgements of personal idiosyncrasy. More often, however, they were evaluative, for example fears or associations of being excluded or 'cast out'.

Three generations of my family have been to this school. And I failed because, again, I failed to fit in. (DH, p.97, L75-76).

...they won't have the patience or time. They're doing a very practical job or - or I might be annoying them, or I don't fit the normal line. (JM, p.130, L108-110).

The second aspect of the main category concerned participants' attempts to 'fit together' two apparently distinct components of their identity, specifically those of being fundamentally different to others and of being equal, the same or 'normal'. Here, the concept of identity was relative and it emerged from participants' appeal to social comparisons.

'Fitting together' was developed during the analysis from an initial category termed 'fitting, but not fitting'. The latter identified a theme of apparently contradictory identities in participants' accounts.

You say, "I'm disabled" and they go, "Well you're walking ok, you look ok". Right. Well can't I be disabled without then? (AH, p.14, L251-253).

I would like to believe that what I've got is not a disability. (AH, p.33, L787).

However the later formulation of this aspect of the core category, 'fitting together', encompassed these differences and tensions and, in this sense, social fit corresponded with the action of integrating or reconciling.

So I've got to try and control it [Asperger's syndrome] and make it work for me, while fitting in to the system. That's the dilemma I have.

(DH, p.125, L884-886, brackets added).

I see myself as an able person with A.S. That's - That's how I see myself ... They're both parts of the same thing, aren't they? (NN, p.52, L441-445).

The third aspect of the core category concerned participants' experiences of attaining a 'fit with' other people. This aspect was differentiated from 'fitting in', because it was not defined by assumptions of social 'sameness'. Rather, participants' recognition of (some) differences between themselves and others was maintained. This final aspect social fit was, therefore, understood to denote a sense of connection with other people.

I want to be with people. But they're like a- a different species to me.

I want to be on my own, but with somebody else. I want your company.

(PW, p.80, L718-720).

Given this, 'fitting with' represented a more flexible understanding of participants' relationships with others to that of 'fitting in'. This was because fitting with allowed the possibility of different forms of social inclusion, rather than the rigid distinction between social worlds noted above. Examples included later in this chapter included participants' accounts of variations in others' understanding, differences between social contexts and personal change 'within' participants themselves over time.

3.3 The process model

As already noted, three main categories of experience representing participants' accounts of social disability were identified in the analysis. These were termed 'Becoming aware of difference', 'Constructing identity' and 'Inclusion' (Figures 3, 4 and 5 respectively).

Using participants' accounts, the relationships between these categories were formulated as a linear process model (see Figure 2). This model was tentative and it represented participants' constructions of social disability as a gradual process of understanding of the relationship between themselves and others.

The first main category represented participants' developing awareness of significant personal 'differentness' in relation to other people. (In Figure 2 dotted concentric circles denote participants' initial assumptions of 'normality', or sameness with others). The second main category, 'Constructing identity', represented a phase of (attempted) integration of the two apparently disparate aspects of 'self': those of 'differentness' and normality. The third category, 'Inclusion', stood for participants' experiences or expectations of 'fitting with' others given a re-evaluated view of self

The process model proposed movement between these main categories as unidirectional. However, it did not presume a rigid 'stage' process in practice. Participants' understanding of social disability was suggested from the analysis to change with ongoing social experiences. The model therefore allowed for the three psychological components of the model to be active concurrently.

3.4 **First main category: 'Becoming aware of difference'**

The first main category of experience identified in the analysis represented a process of change, in which participants' unquestioned assumptions of normality or equal social status were increasingly challenged by their interactions with other people. A defining theme of this category was participants' inability to understand their difficulties 'fitting in', despite their developing, sometimes painful, recognition that something was 'wrong'.

I thought, you know, "I'll keep myself to myself". I don't socialise with many people. And I didn't. I carried on doing that. And I couldn't understand why I was doing this. And I blamed it on myself constantly, all the time. (PW, p.58, L58-61).

...this put a great deal of strain on me 'cause I knew I couldn't do it but I didn't know why and I thought I was pretty inferior....
(WA, p.171, L460-463).

'Becoming aware of difference' represented a conceptual shift in the way that participants viewed themselves in relation to the people around them. For all participants, difficulties experienced in social interaction were increasingly 'located' with themselves. Further, participants' gradual acknowledgement that others shared a similar view of their 'differentness' encouraged participants to question their own assumptions of 'normality'.

The overall structure of the first main category is shown diagrammatically as Figure 3, overleaf. The three intermediate-level categories (shaded in dark grey in the diagram) and their components are then described in more detail.

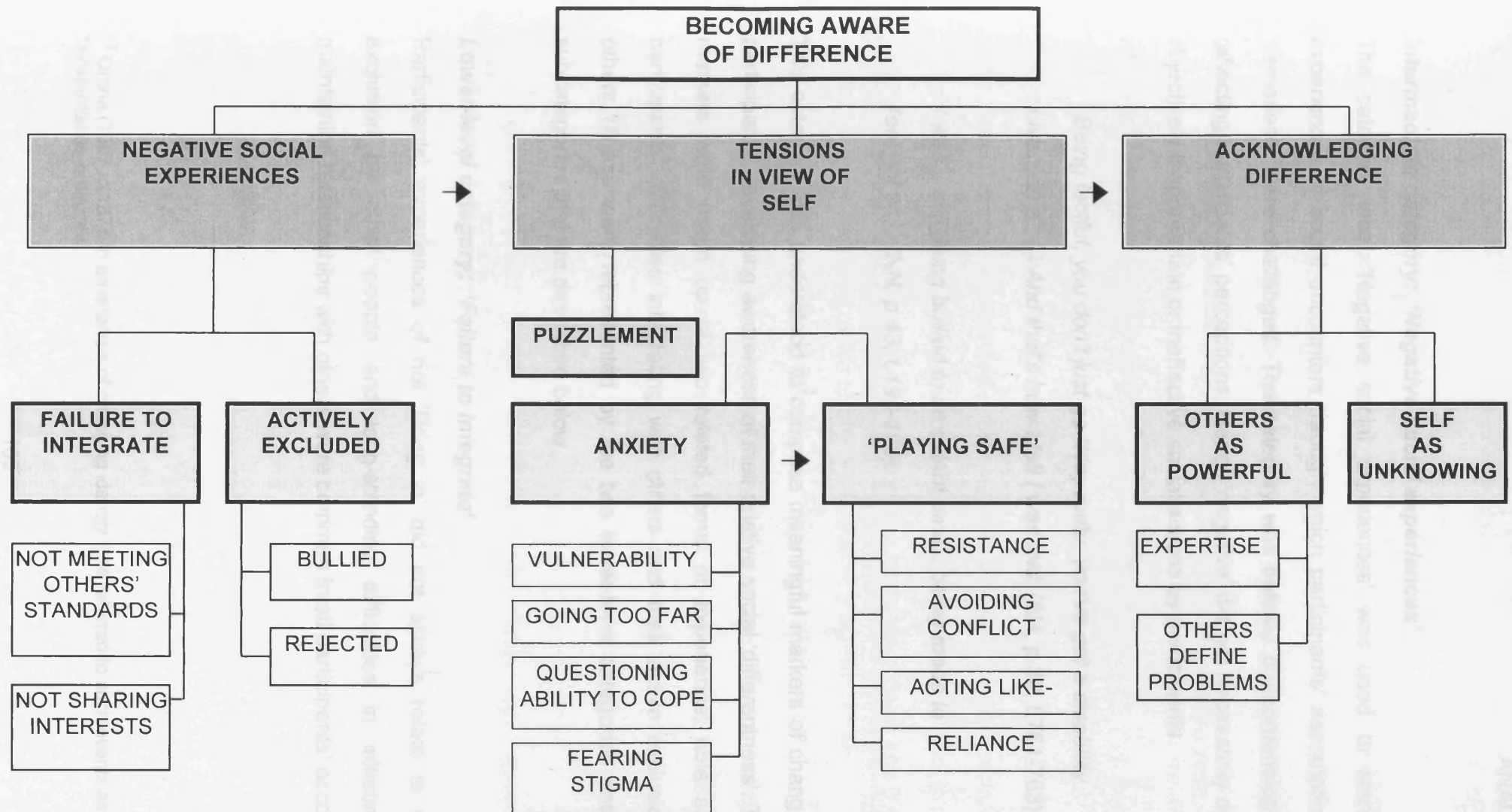


Figure 3: Diagram of first main category 'Becoming aware of difference'

Intermediate category: 'Negative social experiences'

The category label 'Negative social experiences' was used to stand for experiences of social encounters through which participants' assumptions of 'sameness' were challenged. The category was defined phenomenologically, reflecting participants' perceptions. Hence 'negative' did not necessarily denote objectively inappropriate or ineffective social actions by participants.

Being tactful, you don't just go "Hey mate, you've got a disability. Live with it". (.) And that's how I felt I was told. (AH, p.32, L761-763).

I was... still being bullied to an extent, and... being made to feel got at.... (NN, p.43, L196-198).

This category was understood to comprise meaningful markers of change²³ in participants' developing awareness of their relative social 'differentness'. These markers were made up of two related forms of experience: able autistic participants' difficulties integrating *with* others and their active exclusion *by* others. These were represented by the two lower-level categories and four subcategories that are described below.

Lower-level category: 'Failure to integrate'

Participants' experiences of not 'fitting in' did not always relate to active exclusion by other people and long-standing difficulties in initiating or maintaining relationships with others were common to all participants' accounts.

²³ Orona (1997, p.187), in an analysis of changing identity, has referred to such events as "existential co-ordinates".

I went to a school in a very rural area and the general personality of most of the kids was a fairly gentle one... even so I didn't get on terribly well... (WA, p.157, L27-32).

'Failure to integrate' was defined by two related forms of social experience, which were represented by the following two subcategories.

Subcategory: 'Not sharing interests'

This subcategory represented the difficulties that some participants experienced in sharing interests with their peers. Two facets of this category were the failure to elicit others' appreciation of a personal interest and the lack of interest or appreciation of the common interests of a majority group.

I was the only one who knew anything about the wildlife. ...And they thought that was very strange too. I was never very good at things that you should have been good at there...I never really fitted in.
(DH, p.101, L194-200).

I didn't get on terribly well - have that much in common with maybe the majority of the kids... . (WA, p.157, L32-33).

For 'Damian' and 'William' these differences remained during their adolescence and early adulthood. For example, 'William', "somehow wasn't wholly able to relate or mix" with his peers at university and he found that "[t]hings that interested [him] were of no interest to anyone else" (WA, p.173, L492-496; brackets added).

As an adult in his late thirties, 'Peter' was also aware that he lacked interest in others' interests:

I would understand, but I just wouldn't want to know...I wouldn't be interested... . (PW, p.84, L808-811).

Subcategory: 'Not meeting others' standards'

This second subcategory stood for experiences associated with a failure to meet externally imposed standards or expectations. Generally, instances of not meeting others' standards were experienced, at the time, as difficulties rather than mere differences. Unsurprisingly, they were offered as one explanation for personal isolation or exclusion.

My conversations wasn't interesting enough. ...With guys you could get away with it, but they'd always get themselves a girl so I was left isolated. (JM, p.143, 469-472).

I tried to prove it to her by doing Julie's portrait, which I did. ...And she said, "Well, that's not good enough". (PW, p.69, L386-389).

Three generations of my family have been to this school. And I failed because, again, I failed to fit in. I wasn't neat and smart, I didn't fit in all the pigeon-hole categories. (DH, p.97, L75-77)

Lower-level category: 'Actively excluded'

All participants drew on significant experiences, in which they considered that they had been 'singled out' and rejected by other people. Generally, instances of being actively excluded were paired with an awareness of being identified as 'different' by others. However, this connection developed only gradually. Two related aspects of active exclusion were identified in the analysis and represented by the following two subcategories.

Subcategory: 'Bullied'

Bullying was reported by five participants and it formed the dominant factor in their experiences of being excluded as 'different'.

I was bullied because I could not - I could not - Well basically because I was not the same as them. (AH, p.18, L 253-254).

I just felt like the moment I walked in those school gates, ...I was being teased and looked at all day, and just generally seen as something, ...something different. (NN, p.38, L33-36).

From participants' accounts, bullying ranged from persistent teasing or verbal abuse to serious physical assault. As examples, 'Jacob' talked about teasing progressing to being kicked when he reached secondary school, whilst 'Anthony' reported sustaining a broken leg in sport at school, which he considered to have been a deliberate assault.

Bullying was reported as a common experience in participants' primary, and especially secondary, education. Significantly though, two participants reported continued, albeit less severe, bullying as adults at college or university.

Subcategory: 'Rejection'

This subcategory represented a range of negative social experiences, united by the concept of being actively rejected by other people.

An important facet of 'Rejection' was expulsion. Instances of this included the actual or threatened exclusions from schools reported by 'Damian' and 'Anthony' respectively, and 'Peter's' "horrifying" (PW, p.59, L 90) experience as an adult, of being required to leave a shared community home:

Somebody had to go. ...There's a bloke that had learning difficulties... Who looked and could act as if he could live on his own. ...But no, they'd rather get rid of me because I- 'cause I look and act too independent. (PW, p.71, L447-456).

This facet of rejection tended to be associated with being excluded and devalued. Interestingly, for 'Peter', being identified as *more* able than his peers was also experienced as exclusion, whilst 'Anthony' had feared that his disability would result in the loss of a grammar school place which he associated with social rejection and stigma.

Once I'd left the, erm, group home they just dropped me. And I fell into a really bad patch. (PW, p.71, L440-441).

I looked at Wishbrook ((special school)) and thought, "Poor sods". ...Being shoved into a school because you're different. ...Well it said that society - it made them look like outcasts in a way. (AH, p.13, L202-207).

Also included in this category were participants' experiences of being rejected by family members. 'Damian', for example, felt that he had become emotionally "*detached*" (DH, p.105, L314) from his family, because his parents had sent him to boarding school:

I'd be feral because of my upbringing, the fact that I was forced away from my parents at an early age... . (DH, p.106, L324-325).

'Peter', too, felt that he had been excluded from appropriate mainstream education, when his adoptive mother sought a diagnosis of learning disability and later sent him to a residential college in Yorkshire; by contrast, 'Peter's' adoptive sister had attended a private college.

A related facet of 'Rejection' was that of being dismissed or not taken seriously by other people. This was identified in four participants' accounts. Being dismissed overlapped with the perception of being expelled, because it was experienced as a rejection of normal status or worth.

...the school's attitude toward [bullying] was, "Well, we can't watch her twenty-four hours a day and it's all in her imagination".

(NN, p.43, L170-172; for contrast with being a 'person', see p.44, L211).

I had a sense of humour, but I was discouraged at home because my brother thought I was being stupid... . (JM, p.146, L 564-566).

Intermediate category: 'Tensions in view of self'

This second intermediate category represented experiences of psychological conflict or dis-equilibrium, prompted by participants' negative social experiences. The term 'tensions' was selected to denote a dynamic relationship, in which participants' assumptions of personal normality were brought into focus and challenged in the absence of an alternative form of understanding.

I didn't care what I was doing before the age of sixteen. I... just thought, "Well, I'm normal". (AH, p.8, L55-56).

...until that point I guess - I guess I just thought that nothing... or anything was wrong with me, I suppose. (NN, p.37, L17-20).

Feelings of conflict, stress or frustration during interaction with others were a common theme to this category. For example, 'William' described becoming "very annoyed" when other people did not follow his "schedule" (WA, p.159, L101-102).

These feelings were hypothesised to represent a conceptual tension, in which participants' repeated problems fitting in forced them to question where such difficulties were located.

I always felt that there was a sort of conspiracy against me, and that I was somehow - I was just er, born inferior. (WA, p.161, L156-157).

...I thought, "Wait a minute, if these people are - if all the people around me are telling me the truth, then maybe if I start concentrating...then I'll be able to find out". (AH, p.7, L28-32).

Structurally, this category comprised the three lower-level categories described below. In Figure 3 two of these are presented as components of a dynamic, in which participants' tensions manifested in the categories 'Anxiety' and 'Playing safe'. A related but separate category, 'Puzzlement', preceded this dynamic.

Lower-level category: Puzzlement

This category represented an initial psychological response to negative social encounters. 'Puzzlement' was defined as participants' recognition of not fitting in with others, but with little understanding of why. An alternative term was 'bafflement'. This category was identified in all participants' accounts.

...I suppose, you know, I wondered why I was teased as a kid, which I was constantly.... (NN, p.37, L18-21).

...I just took it as erm, you know, as a norm. You know, 'Why are they doing this? I don't know'. I kept on questioning it. (PW, p.63, L218-219).

'Puzzlement' was not restricted to childhood naiveté and several participants referred to it as a response to novel situations in adulthood.

...in ninety-six...I was thinking, "How come people don't want to talk to me?", and "Why do people want to cut me up? ". (JM,p.142, L446-449).

[At University] I had difficulty in processing things, and sorting out things like money and practical arrangements...this put a great deal of strain on me 'cause I knew I couldn't do it but I didn't know why. (WA, p.171, L459-462; brackets added).

Within the process model, 'Puzzlement' preceded 'Tensions in view of self' only conceptually; it was not considered to be exclusive to those more fundamental tensions in participants' self-concept, described below

Lower-level category: Anxiety

'Anxiety' captured another important aspect of the tension prompted by participants' negative social experiences. It was constructed from four related subcategories. These represented aspects of fear or apprehension and they were hypothesised to follow from the erosion of participants' previously unquestioned views of self.

The concept of anxiety was closely associated with participants' attempts to maintain a social identity as 'normal' and the relationship, between 'Anxiety' and 'Playing safe', is indicated in Figure 3.

Subcategory: 'Vulnerability'

Awareness of social vulnerability was one manifestation of participants' anxieties in not fitting in. This subcategory represented apprehension related to the potential loss of social inclusion. For example, two participants' referred to their experiences of being exploited. 'Anthony' recalled that he had been disadvantaged when school bullies were informed of his disability and 'Peter' recalled his feelings of vulnerability after being "dropped" by his former carers.

It [diagnostic label] made it get worse for a while, because they now knew that there was something there which they could exploit.
(AH, p.22, L460-461; brackets added).

I had to learn it all the - the hard way. Which was being used for money left, right and centre, you know. (PW, p.73, L491-492).

These examples suggested participants' experiences of vulnerability to have been variable phenomena. This was important because, for 'Jacob', social disability had compounded the risk of appearing "unacceptable" to others.

Well I think it's double-jeopardy... just because you're black and you have - You're bound to be picked on much easier than if you're white with a disability, I think. (JM, p.149, L649-654).

Subcategory: 'Questioning ability to cope'

This subcategory represented the anxieties that some participants associated with imposed demands or change. Generally, participants' questioned their own coping abilities following a period of sustained effort, in which their assumptions were eventually confronted by experience.

...then I was forced to do a GCSE again... and I was not managing. I could not cope. (JM, p.135, L242-246).

I can't cope with the change with the routine which, might just come if someone has a different idea. (WA, p.159, L106-108).

In the latter case 'William' associated his difficulties coping with change with an increasing conflict, between his need to plan activities rigidly while living in an increasingly social and uncontrollable world. In 'Natalie's' case, early efforts to deny her 'differentness' in the face of bullying were "overloaded" with the separate imposition of a diagnosis of Asperger syndrome:

"Oh my gosh how am I going to cope with this?"... "How am I going to live with this?" and I actually knew nothing. (NN, p.37-38, L24-26).

Subcategory: 'Going too far'

'Going too far' represented anxieties of unwittingly overstepping social boundaries of acceptable conduct.

I can appear rude and not realise that I'm being rude.

(NN, p.47, L286-288).

I talk too much. (.) Just nod. ...Well everybody else tells me...I can't tell. (AH, p.28, L645-648).

An underlying theme to this subcategory was participants' growing awareness that they did not always understand, or have access to, the social norms understood by those around them. Hence, it captured a tension between participants' difficulties gauging their 'social performance' and their wariness of inviting negative attention from others by going 'too far'.

Generally, this category represented the apprehension of standing out as 'different'. For example, 'Peter' and 'Jacob' were conscious that apparent idiosyncrasies in their dress or appearance could invite criticism. For 'Anthony', however, 'going too far' drew on a more fundamental anxiety based on his experiences of trying to follow explicit social rules:

[Teachers] were giving me the traits of my disability and telling me how to behave about 'em. ...if somebody hits you don't be afraid to hit them back. So I wasn't, so I did, and look what happened. Three threatened expulsions. (AH, p.25, L565-568; brackets added).

Subcategory: 'Fearing stigma'

'Fearing stigma' represented participants' apprehensions of further social exclusion, which followed from being categorised negatively by others.

All six participants made some association between others' recognition of their differences in social interaction and the possible consequence of being treated as 'different'. These associations were a core feature of the category 'Negative social experiences' described above, although similar connections between social labelling and treatment did emerge in relation to more 'expert' opinions.

[Teachers] were telling the students how to treat me, how to behave towards me. (AH, p.22, L485-486; brackets added).

[M]y doctor said, "...your daughter is now on the edge of a nervous breakdown...you've got one of two options. Either you can give her drugs or she can go to psychotherapy". (NN, p.40-41, L 109-113).

Importantly, this subcategory did not always reflect fears of psychiatric diagnosis. Rather, it represented participants' apprehensions of gaining a negative social identity; that is, of being 'classified' or categorised by others, and treated according to perceived differentness.

'Cause as soon as you tell a school that, "Oh my son's got a disability", they tend to step back a bit... and think, "Autism. Problem child ". (AH, p.14, L237-241).

I was afraid of getting hold of a diagnosis in case I was treated wrongly by psychiatrists who didn't really know the condition. (WA, p.172, L472-474).

Lower-level category: 'Playing safe'

'Playing safe' represented participants' attempts to reduce anxieties associated with the loss of a 'normal' social identity and their assumed fit with others. The term 'playing' captured an underlying theme of inauthenticity in participants' experiences of safety - seeking; that is, of not being able to be oneself among others. This category represented another manifestation of the tension between participants' growing awareness of 'not fitting' in social situations and their lack of an alternative understanding. 'Playing safe' comprised the following four subcategories.

Subcategory: Resistance

'Resistance' stood for participants' reluctance to accept explanations of poor social fit, which they associated with the possibility of social exclusion. The category was derived from all participants' accounts.

Generally, 'Resistance' referred to a state of denial or disbelief. For half of the sample this included the aftermath of being diagnosed with an autistic spectrum disorder.

*I was in denial for a long time. ...I couldn't
actually believe that I had got the diagnosis of AS [Asperger syndrome].
(NN, p.37, L17-18; brackets added).*

*I was diagnosed with autism and I believe it...I didn't believe it up to the
age of sixteen to eighteen though...I hid like quite a few other people
that I know.... (AH, p.6, L14-17).*

In most cases continued resistance was associated with the negative consequences of accepting personal vulnerability. However, it was also defined by participants' insufficient understanding of others' views, or because others' views did not fit with participants' own experience.

Subcategory: 'Avoiding conflict'

'Avoiding conflict' represented an aspect of safety - seeking in which participants described distancing themselves from social interaction. The category was identified in five participants' accounts. 'Avoiding conflict' was defined by avoidance of situations associated with a risk of conflict or exploitation.

I didn't hang around with a lot of people. ...At that point in time I didn't know [if I wanted to], so I'd just keep away. (JM, p.131, L120-122; brackets added).

That's my attitude toward children. I will not go anywhere near them unless they have relatives, and even then I do it reluctantly. ... I know how cruel children can be. (DH, p.100, L156-159).

'Avoiding conflict' excluded participants' positive decisions to be alone. This distinction, between a preference not to engage in some social situations and the avoidance of other situations, was important. The former tended to assume a stronger sense of authenticity and identity, while the latter was associated with participants' anxieties over social exclusion.

'Peter', for example, said that he often felt isolated in his flat, although he felt that he would "have to" (PW, p.85, L862) leave a situation in which he disapproved of others' behaviour in case he caused offence. By contrast, he was categorical that he did not want anyone to visit him while he worked on a painting:

my concentration (to do that work must be absolute)... I don't want to know anything. I don't want to talk to anybody. (PW, p.79, L679-683).

'Avoiding conflict' was therefore understood as a 'reluctant retreat' from social interaction.

Subcategory: 'Acting like-'

'Acting like-' represented some participants' efforts to overcome the fear of being recognised as different, by seeking to copy or follow others' example. Strategies of pretending or acting like others were mentioned explicitly by three participants, although two others made associations between their appearance and others' acceptance of them.

The category label 'acting like-' was used to capture participants' growing acknowledgement that they were in some way different to those they sought to copy.

So I started acting like one of my friends does. (.) You know I started acting just like they did.(AH, p.7, L32-33).

I was trying to copy how the other kids were behaving at music college ...trying to copy what they did and the sort of things they said. (WA, p.172, L485-489).

Subcategory: 'Reliance'

'Reliance' represented participants' emphasis on external sources of information as a method for minimising anxiety. An underlying theme of this subcategory was participants' recognition that they did not share the common social understanding of others. The category was therefore closely related to anxieties of 'going too far'. In some cases 'reliance' emerged in references to the concept of social rules:

*...there's rules to the social game unfortunately. They don't tell you that.
Yeah, I'm going to get a book. (JM, p.145, L535-536).*

Equally, emphasis was placed on the need for 'proof' or evidence to substantiate personal claims.

So I tried to prove it to her by doing Julie's portrait, which I did...I'll show you the picture of a- a girlfriend... (PW, p.69, L386-388).

So I knew I was capable of winning competitions and being top student, and I proved to everyone else what I could do. (DH, p.111, L463-465).

Two facets of 'reliance' were identified. The first was gaining information from reliable sources. References ranged from using a mechanical metronome to information of social norms gained from media messages. Generally though, information was gained directly from other individuals.

*Well, I can only work on the comments of others at the end of the day.
I myself cannot really tell. I have to rely totally on feedback.
(AH, p.7, L50-51).*

I couldn't tell you all of it now, but I've asked. Over the years I've spoken to certain people about what they want from a guy. (JM, p.139, L358-359).

A second facet was a cautious, experimental approach, particularly when explicit rules were unavailable.

I started thinking..."I am very introvert, so let's start stepping that up. Let's not go too completely bananas...Let's just go to mildly extrovert... (AH, p.15, L271-275).

This strategy of tentative exploration reflected the tension between participants' growing awareness of social difference and their reluctance to risk further social exclusion.

Intermediate category: 'Acknowledging difference'

The third intermediate category stood for participants' acknowledgement of the difference in social functioning between themselves, as individuals, and 'others' as a unified social group. The term 'acknowledging' was used in the analysis to capture participants' experiences of reluctantly accepting, or conceding, that they did not share the social perspective common to those around them. Hence, participants' knowledge or awareness of social difference did not reflect a parallel degree of understanding for their experiences.

Several participants referred to particular events or significant turning points in their lives. For example, 'Anthony' recalled his conclusion at 17 years that he, and not his peers, would have to adapt.

...I just thought, "Something is wrong. Maybe I should start acting like society wants me to, because there's evidence that they're not going to adapt to me". (AH, p.15, L267-269).

However, 'acknowledging difference' was hypothesised as a conceptual shift, in which participants' early assumptions of 'sameness' were gradually changed by social experience. For most participants, these were experiences of adolescence and adulthood.

And of course then it [self-diagnosis] didn't make a great deal of sense, because I didn't know enough.After you've lived pseudo-normally for so long, mean it took a very long time to accommodate... .
(WA, p.172, L476-481).

Differences between self and others were defined by the two lower-level categories described below. A reciprocal relationship was hypothesised between participants' constructions of themselves as 'unknowing' and of others as 'powerful'.

Lower-level category: 'Others as powerful'

'Others as powerful' defined participants' experience of others from a perspective of acknowledged difference.

Society. Society means everybody else. (AH, p.32, L757).

An important theme was the often implicit conception that other people were united by a common perspective or form of understanding, to which participants did not have direct access. This perspective, or the social knowledge that others were presumed to share, defined participants' initial sense of personal 'differentness'.

I don't necessarily understand people in the same way that others understand each other, and I find other people difficult to interpret.

(NN, p.48, L334-336).

I can't read...the normal telepathic responses people have.

(DH, p.108, L390-391).

The term 'powerful' was adopted later in the analysis and it replaced an earlier label, 'others as knowledgeable'. This change captured participants' experiences of others as authoritative or influential because of their shared perspective.

Two subcategories shaped the meaning of this category. The first focused on the possession of knowledge and the second on its use. Both subcategories were derived from all participants' accounts.

Subcategory: 'Expertise'

The perception that some other individuals possessed expertise relating to participants' social difficulties was an important factor that defined 'powerful'. The concept of 'expertise' referred to knowledge or skill that was not immediately available to participants. Importantly, however, it did not imply that others understood participants' experiences of disability or differentness. (This distinction is more sharply defined later in the chapter). Typically, the concept of expertise is referred to individuals in recognised positions of authority, including health professionals, teachers, carers and parents.

my mother knew there was something wrong at the time, and it wasn't until the age of eleven to twelve that I was diagnosed.
(AH, p.9, L83-84).

I would have liked actually trained staff who knew what they were talking about...perhaps the counsellor, or perhaps some other professional... . (NN, p.40, L97-102).

The concept of expertise also provided a contrast to participants' own lack of understanding. For example, 'Natalie's' description of psychotherapy contrasted her psychiatrist's expertise with her incomprehension.

he'd talk about the little Natalie, and the baby Natalie... feelings getting through hedges and stuff ...And I was like, "What?".
(NN, p.41, L133-138).

Subcategory: 'Others define problems'

The experience of other people acting to define participants' social 'differentness' was identified as a second aspect of the concept 'powerful'. This category was broader in scope than 'expertise' because participants did not assume others to be aware of their specific difficulties. Rather, the subcategory 'others define problems' referred to others' ability to deploy a shared understanding of acceptable or normal social behaviour.

The term 'problems' replaced 'disability' in the analysis, because participants generally perceived others' judgements to be dis-empowering or negative.

I couldn't get out of the situation, because my Foster - mother ...got a doctor and said, "Oh I think- definitely he's got a learning disabilities".
(PW, p.64, L241-245).

wearing a record bag on a strap tells me I'm not acceptable. I get a lot of funny looks from local taxi men, and certain people used to say, "Batty boy", in other words, "You're gay". (JM, p.149, L658-660).

One exception to this was 'William's' "great relief" when a self-diagnosis of his social difficulties was eventually "endorsed" as Asperger syndrome by a consultant psychiatrist (WA, p.173, L506 and 516).

This category provided a further point of comparison, which defined participants' construction of themselves as 'unknowing'.

Lower-level category: 'Self as unknowing'

This category stood as a comparison with participants' experiences of others as powerful described above. This last component of the first main category 'becoming aware of difference' represented all participants' recognition of their 'differentness' as a lack of social knowledge or understanding.

This 'acknowledging of not knowing' was not paradoxical. Rather, it represented the limited, but meaningful, explanation for participants' repeated negative social experiences in the absence of a more substantive understanding of their differences in social functioning.

Its like hypothermia. You yourself can't tell that you've got it. You can be an expert in it ...[but] you can't tell when you've got it. You have to rely on what other people are telling you. (AH, p.28-29, L654-660; brackets added).

I don't understand at times society and how things run, or what are the expectations, you know. (JM, p.138, L337-338).

Summary of the first main category

The first main category, described above, represented a process by which able autistic participants had become aware of (some) personally - located differences to those around them. The process of becoming aware of 'differentness' was nevertheless characterised by a lack of understanding of continued difficulties fitting in with a majority previously assumed to be 'the same'. As a result, tensions in participants' established views of self emerged, marked by experiences of puzzlement, anxiety and safety - seeking. In the absence of a positive explanation, participants were able only to acknowledge their lack of a shared social understanding: knowing that they did not know.

3.5 Second main category: 'Constructing identity'

The second main category, termed 'Constructing identity', represented participants' attempts to reconcile (i.e. 'fit together') the two apparently conflicting aspects of their social experiences: being somehow different to others, whilst considering themselves the same. Two intermediate-level categories and their component subcategories represented these two forms of experience. The overall structure of the second main category is presented diagrammatically as Figure 4, overleaf.

Importantly, the two intermediate-level categories, termed 'defining 'difference' and 'defending normality', were not mutually exclusive constructions. The first represented a concept of difference that was compatible with social inclusion, while the second captured participants' attempts to preserve their social status as essentially 'normal'.

In the context of the process model, the main category 'constructing identity' was understood as an attempt to resolve internal tension and it was restricted to participants' understandings of their own identity or self-view.

Participants' experiences of being accommodated as 'different' by other people are described later in this chapter. It is noteworthy, however, that this second main category developed later in the analysis from two initial, tentative categories. The latter represented participants' comparisons between themselves (as individuals) and 'disabled' and 'non-disabled' (*sic*) others. Social comparison therefore describes the mode by which participants re-evaluated their identities.

I see myself as an able individual with A.S.... They're both parts of the same thing, aren't they? (NN, p.52, L441-445).

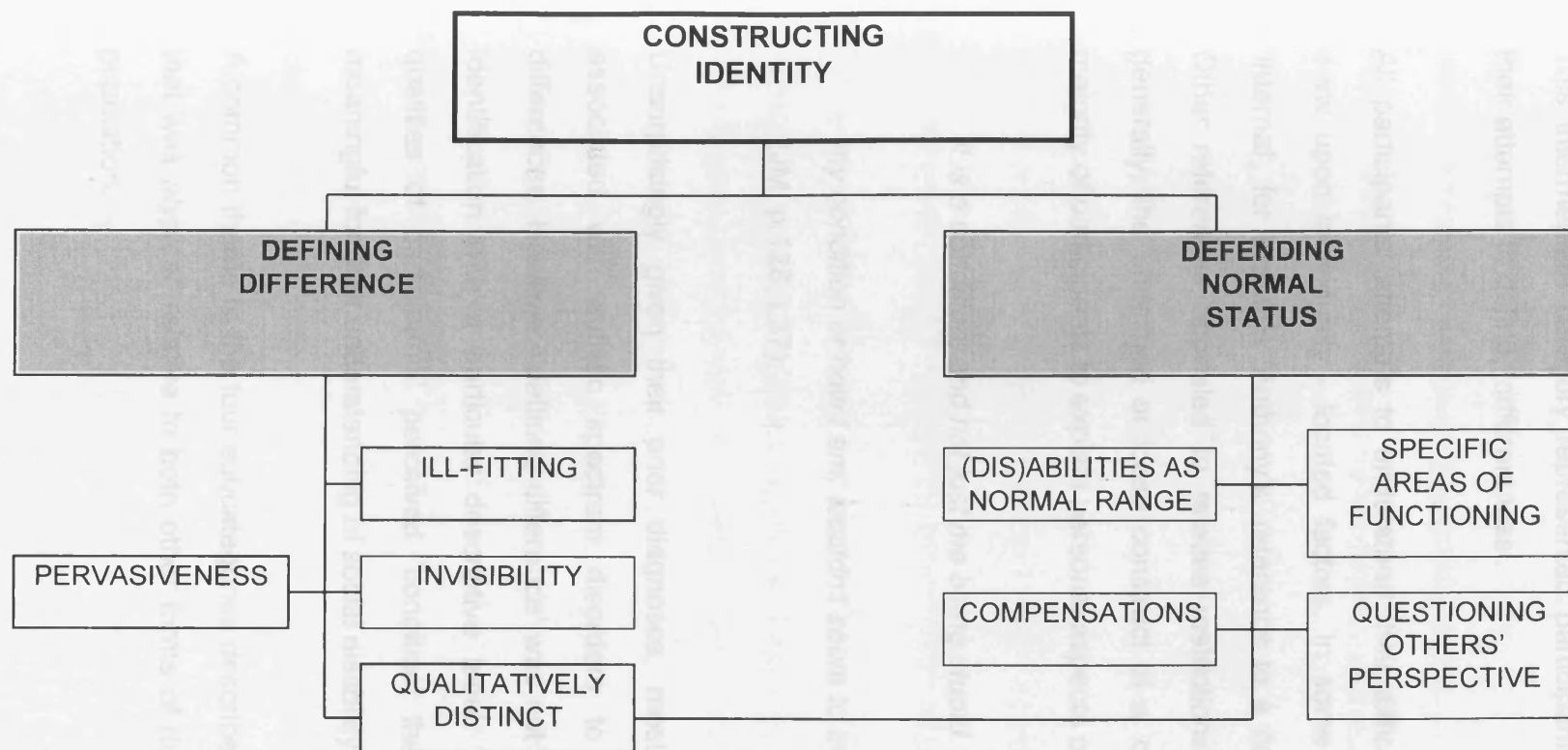


Figure 4: Diagram of second main category, 'Constructing identity'

Intermediate category: Defining ‘difference’

This intermediate category represented participants’ identifications with, and their attempts to define, ‘differentness’.

All participants’ attempts to understand their difficulties fitting in with others drew upon individually - located factors. In some cases these were clearly ‘internal’, for example ‘Anthony’s’ reference to a conditioned “mental barrier”. Other references appealed to relative restrictions in personal ability. More generally, the undefined or loose construct of a ‘condition’ was used by the majority of participants to explain personal aspects of ‘differentness’.

it is a condition, and not just me being stupid. (PW, p.58, L55-56).

my condition or how I am, wouldn’t seem to be the norm.

(JM, p.128, L37).

Unsurprisingly given their prior diagnoses, most participants used labels associated with autistic spectrum disorders to refer to their individual differences. However, ‘defining difference’ was not a reflection of participants’ identification with a particular descriptive label. Rather, it captured those qualities of participants’ perceived ‘condition’ that emerged as personally meaningful for their understanding of social disability.

A common theme to the four subcategories described below was of a condition that was *atypical*, relative to both other forms of disability and to the ‘normal’ population.

Subcategory: Ill-fitting

This subcategory, identified in all participants' accounts, represented a notion of 'differentness' that was not easily accommodated by popular conceptions of either 'normal' or 'disabled'. One aspect of the concept of 'ill-fitting' emerged from references to social norms as an explanation for participants' difficulties in social interaction.

I might be annoying them, or I don't fit the normal line.

(JM, p.130, L109-110).

I encountered bullying because I wasn't aggressive...I was too individual. (DH, p.96, L51-53).

However, 'ill-fitting' did not equate with being outside a norm and it did not reflect participants' identification with exclusion. In part, this was because the subcategory was shaped by several participants' use of contrast, which highlighted the incongruent aspects of their identity.

'Peter' for example, described having learned "too fast" during adolescence, in comparison to learning disabled peers. However, following re-diagnosis in adulthood, he felt that his "articulate" but "monotone" speech had not fitted with a popular understanding of autism. Similar contrasts, by and between participants, were deployed to explain ill-fitting differences in childhood.

I was not put into a special school [but]... They isolated me a normal school. (AH, p.36, L877-879; brackets added).

although it was a special school, it didn't cater for autism or Asperger at all. (DH, p.98, L84-85).

Subcategory: Invisibility

A related factor was some participants' recognition that, unlike some physical disabilities, autistic conditions were not always apparent to other people. Interestingly, this 'invisibility' was regarded as a negative factor in most cases, because it was associated either with others' disbelief, or their miscalculations of participants' abilities. 'Invisibility' therefore stood in some contrast to attempts to 'play safe' described in the first main category.

You say, "I'm disabled" and they go, "Well, you're walking ok, you look ok". (AH, p.14, L251-253).

I look like a... normal person. But it's one of those conditions that's a very hidden disability. (NN, p.46, L266-270).

Subcategory: Pervasiveness

A third way in which participants defined their 'differentness' was the perceived pervasiveness of their social difficulties. Pervasiveness captured a theme of fundamental or 'deep' individual difference, which affected many aspects of participants' social lives. For some, it included the notion of permanence.

this is almost entirely due to my lack of communication skills and the presentation skills that you need, which is how Asperger severely affects me. I'm always going to look odd... . (DH, p.109, L409-412).

it is a big deal to me... Because it has a very real and significant impact on - on the rest of my whole life... . (NN, p.48, L328-331)

This subcategory emphasised the manifestations of autism in participants' social interactions, rather than impaired (individual) functioning as such. 'Jacob', for example, located 'differentness' in the term 'character', but he added that this was "because character builds on every single thing you *do*" (JM, p.148, L631-632; emphasis added).

Subcategory: Qualitatively distinct

A related aspect of 'difference' was identified in the understanding of autism as a qualitatively distinct state to that of other people. Compared to the construct of 'pervasiveness', 'qualitatively distinct' focused directly on internal factors, such as underlying genetic, biological or cognitive differences.

I've always believed that they haven't got the same, not mentality, they don't have the same mental structure than a person with Asperger's.
(PW, p.78, L655-657).

I'm on a completely different wavelength, just a totally different working system... Literally, I think different. (DH, p.109, L416-420).

The concept of qualitative difference was also interpreted by the researcher as a device that emphasised the positive aspects of autism. In this way, participants' perceived uniqueness functioned as a 'defence' from devalued social status. To illustrate, 'Damian', in the quote above, employed a computer analogy to distinguish his own functioning (as an 'AppleMac' computer) from that of "most people" (as 'IBM' computers). He used this to then claim advantages to his qualitative differences:

for certain applications AppleMacs are vastly superior to I.B.M.s... I.B.M.s are the average thing. They represent ninety-nine percent of the population... . (DH, p.109-110, L429-433).

This subcategory therefore formed a conceptual link (see Figure 4) to the second intermediate category, 'defending normal status'.

Intermediate category: Defending normal status

Participants' efforts to defend their status as normal or socially included, formed the second aspect of their constructions of identity. Typically, the category included references of social comparison and contrast, in which participants' differences were distanced from less able and less valued 'others'; the category label was selected to capture this normative theme.

it just seemed ridiculous, me being disabled and I'm caring for the normal. (AH, p.24, L542-3).

it's not like I've got a physical disability ... if it weren't for [difficulties making friends] I'd just be the same as any other average person. (NN, p.53, L463-4; 469-470; brackets added).

In addition to the subcategory 'qualitatively distinct' above, 'defending normal status' was constructed from four further subcategories. The first two of these, described below, comprised participants' efforts to locate their social abilities within the range of normal functioning. The remaining two subcategories represented defences of participants' social status in attempts to broaden the scope of perceived social norms.

Subcategory: (Dis)abilities in normal range

One way in which participants attempted to minimise their 'differentness' was to locate their social functioning within a normal range of ability. Two strategies were identified in the analysis. The first of these operated by reducing the significance of imposed disability labels.

I think, hhh, that I'm just slightly off normal... . (AH, p.15, L255).

just erm, slight aut- erm Asperger's. Just slightly, you know, just on the narrow... gauge erm, of the spectrum. (PW, p.56, L8-9).

The second strategy involved framing (sometimes extreme) differences in ability, as 'normal'. Examples included 'Damian's' description of the late development of his speech and abilities that he regarded as exceptional following an early "poor prognosis" of infantile autism, and 'Anthony's' use of analogy, in which his experience of disability was likened to having further to 'travel' in order to achieve the same social goals as others:

I didn't learn to speak until (.) about four... Then they realised it may not be as bad as they had thought. And I was learning normally.
(DH, p.95, L17-19).

I've got to bridge a two-foot gap where you've only got to do two centimetres. Feels like that kind of difference... [But] It's on exactly the same scale... . (AH, p.17-18, L339-345; brackets added).

Subcategory: Specific areas of functioning

A second form of defending normal status was identified in emphases of the internal factors of disability as specific areas of functioning, rather than a global aspect of identity.

Superficially this category included descriptive references to the 'symptoms' of autism.

I always had very strong obsessional interests...and repetitive hobbies which were all-consuming and ...I couldn't empathise.

(WA, p.159, 92-96).

However, the identification of specific areas of functioning also acted to circumscribe, and so minimise, participants' differences with others. In some cases these finite differences were also presented as areas needing improvement.

certain areas are going to have to be looked at more, because they've been neglected... (JM, p.154, L794-795).

Subcategory: Compensations

This subcategory represented factors perceived as positive or beneficial that some participants associated with their 'condition', 'Compensations' typically denoted particular abilities. However, these were generally presented as 'secondary gains' which, although sometimes exceptional, did not offset the negative experiences of isolation or social exclusion.

I did stand out in being very good at certain things and pretty hopeless at other things. Same old situation. My social life was limited... .
(DH, p.120, L741-742).

The concept of compensation was therefore one of social comparison, in which social status was 'defended' by an emphasis on participants' talents or special skills.

I can sit down on a computer, walk away, and come back the following year and remember exactly what I did. (AH, p.10, L117-118).

I can concentrate as much as possible on it. ...I would have spent two days straight on a piece of work. (PW, p.79, L667-674).

Subcategory: Questioning others' perspective

'Questioning others' perspective' represented a fourth and assertive form of defence of normal status, in which participants challenged negative value judgements imposed by others.

Several participants were aware that the 'invisibility' of impairments associated with autism (see above) meant that their particular social difficulties were not recognised by other people. A counter to this, however, was that others' recognition, but unsophisticated understanding, of participants' 'differentness' could result in the loss of a normal identity.

If people wouldn't recognise this disability then I'd be the average, So - called normal person.(AH, p.29, L664-665).

A dominant theme of this last subcategory of 'constructing identity' included participants' experiences of being devalued when their abilities were misjudged as abnormal. 'Peter', 'Damian' and 'Jacob', for example, referred to negative judgements of their abilities, such as being considered "slow", "stupid" and "not right in the head", which they rejected as inaccurate.

Summary of second main category

The second main category, described above, represented the psychological process by which able autistic participants attempted to fit together or reconcile their developing awareness of personal 'differentness' with their positively-valued assumptions of social 'sameness' and normal identity.

Social comparisons between participants and other individuals and groups formed the dominant mode by which their identities were re-evaluated.

Within this process, two main strategies were identified whereby participants' had either 'downplayed' acknowledged differences or emphasised their claims to 'normal' status.

These strategies were complementary and, in the case of some participants' claims to qualitative differences with other people, they overlapped. In the context of the process model (Figure 2), this second main category represented a phase in which participants meaningfully construed their negative and excluding social experiences, and it preceded their understanding of attaining greater inclusion with other people.

3.6 Third main category: Inclusion

The third main category, termed 'inclusion', represented participants' understandings and expectations of positive social fit with others. The overall structure of this category is presented diagrammatically as Figure 5, overleaf.

From the process model (Figure 2) 'inclusion' followed, conceptually, participants' re-evaluation of their identities. The construct of 'inclusion' therefore assumed a greater authenticity in participants' relationships with others; that is, it represented 'fitting in' as *oneself* - or 'fitting with' others. This stood in contrast to the experiences of 'playing safe' described in Section 3.4.

it's a great strain to live under a veil of pretence...to pretend that you can understand things, and be at one with the world when really you can't. ...the greatest benefit of knowing what is the matter is that you can accept yourself as you are, and we all have to do that.

(WA, p.174, L528-532).

The concept of inclusion was defined in two ways. Minimally, it stood for the absence of subjective 'aloneness'. Here, participants' experiences of forming, or maintaining, even minor social relationships were contrasted with an alternative of feeling isolated.

it just means for me that I feel really socially isolated from the...world. Because I know that I want these friends, but yet I've got nobody.

(NN, p.50, L380-383).

I can spend all day in the pub without...talking to a single person. ...And yet, I'm not really wasting my time at all. If I didn't get that contact I- I'd be worse off. I'd be in here, suffering. (PW, p.86, L878-883).

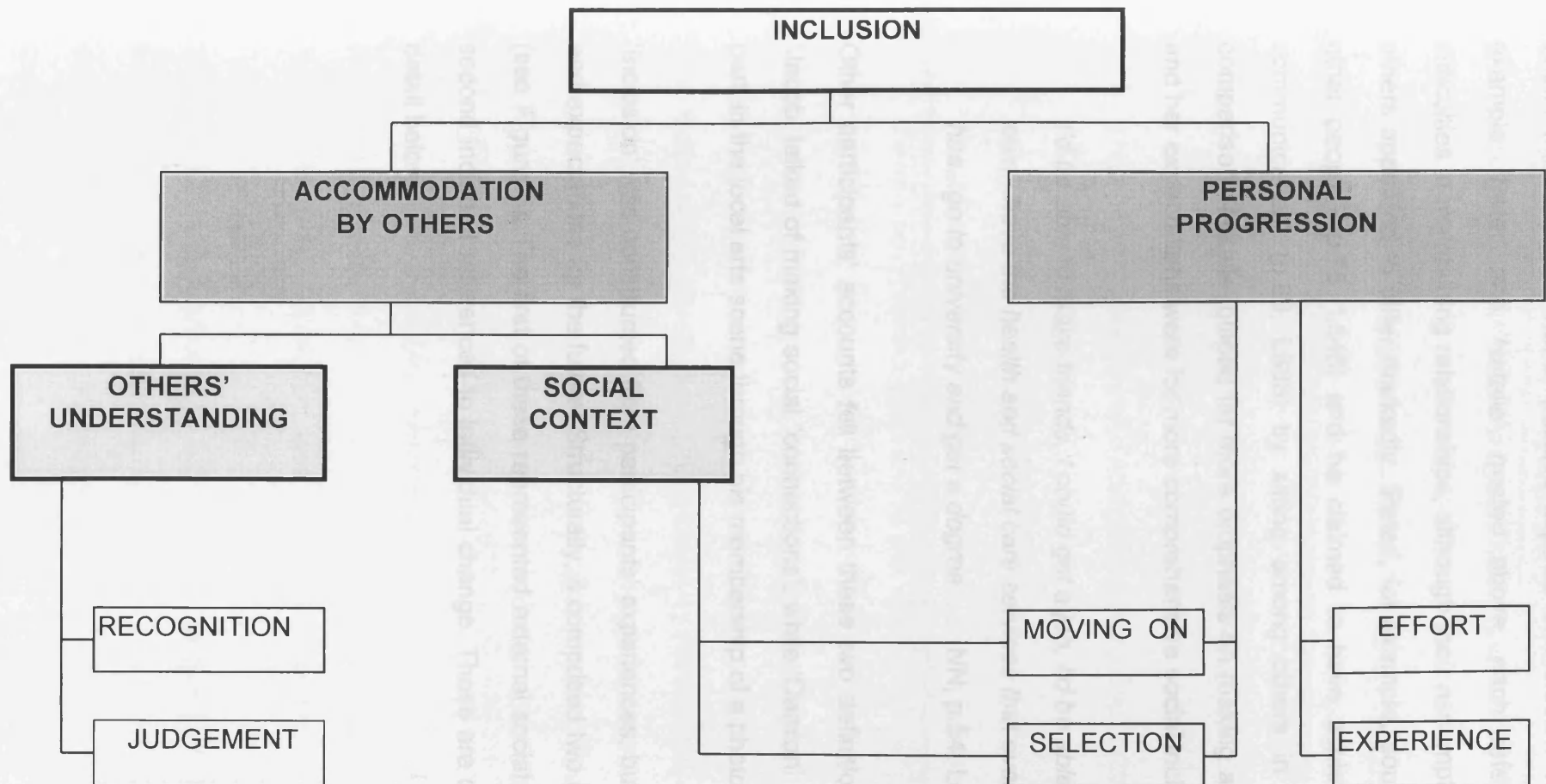


Figure 5: Diagram of third main category, 'Inclusion'

Within this common frame, positive aspects of inclusion varied widely. For example, 'Peter' and 'Natalie', quoted above, each referred to personal difficulties in maintaining relationships, although their assumptions of fitting with others appeared to differ markedly. 'Peter', for example, sought "contact with other people" (p.75, L548) and he claimed to have achieved a "feeling of communication" (p.86, L888) by sitting among others in a local pub. By comparison, 'Natalie' placed far more emphasis on making a "circle of friends" and her expectations were for more comprehensive social inclusion:

I'd be able to make friends, I could get a job, I'd be able to live on my own...have the health and social care services that everybody else has...go to university and get a degree... . (NN, p.54, L498-502).

Other participants' accounts fell between these two definitions. For example, 'Jacob' talked of making social "connections", while 'Damian' referred to 'taking part' in the local arts scene through his membership of a photography society.

'Inclusion' was constructed from participants' experiences, but also their hopes and expectations for the future. Structurally, it comprised two related categories (see Figure 5). The first of these represented external social factors, while the second included references to individual change. These are described in more detail below.

Intermediate category: Accommodation by others

During the analysis, the term 'accommodation' was adopted to denote others' openness to participants' social 'differentness'. The extent to which participants were accommodated by those around them was the dominant factor in their experiences or expectations of better social fit. Defining factors to the construct of 'accommodation' ranged from participants' perceptions of others' tolerance, through to others' positive acceptance or offers of support.

I had a great time abroad, I found I was accepted in Ghana... .

(DH, p.121, L770)

I really can't see any cons if you have a good supportive home and a friendly environment, such as I've got. (WA, p.174, L526-527).

In the context of the process model, this category formed a qualification to participants' experiences of being excluded by (powerful) others (Section 3.4). Two factors were identified that contributed to participants' understanding of being accommodated by others. The first was the degree to which other people were perceived to have understood participants' social difficulties. The second represented the contexts in which those interactions took place.

Lower-level category: Understanding

All participants viewed others' understanding of their difficulties as an important factor in being either accommodated or actively supported.

The concept of 'understanding' was defined as part of a continuum. Generally, this was identified in negative examples, in which others' inability to comprehend participants' 'differentness' was associated with others' lack of understanding.

if they weren't as ignorant about me and my disability, then they wouldn't be like that towards me. ...they'd probably have more awareness and more knowledge and more understanding... .
(NN, p.47, L294-297).

Because nobody can understand why that person is behaving the way they are. ...They just see you as odd. (PW, p.78, L645-648).

An important qualification, however, was that a shallow, 'factual' understanding of autism was not guaranteed to lead to greater accommodation. 'Jacob' emphasised this distinction forcefully:

I understand the facts about Saddam Hussein, but I don't like him.
(JM, p.151, L699-700).

For 'Jacob' and others the meaning of 'understanding' was influenced more by experiences of being tolerated together with the acknowledgement, by some, that their behaviour did not always 'fit in'. 'Understanding' was therefore sometimes defined pragmatically, referring to other people 'being understanding' of participants' idiosyncrasies.

but they were there for me, you know. Despite how obnoxious or whatever I was towards them... . (AH, p.26, L590-591).

Others' understanding included the two subcategories of experience that are described below.

Subcategory: Recognition

One factor defining 'understanding' was the ability to recognise participants' 'condition'. Importantly, the latter referred to participants' own constructions (of identity). Hence, experiences of 'being recognised' were generally positive, because they reflected recognition of participants' differentness within a context of 'normal' status.

Experiences of being valued, and so 'included', were a dominant theme of this subcategory. For example, 'Natalie' attributed improvements in social support with being "taken seriously" by her teachers at college:

[It] was completely different. It wasn't, you know, "Oh it's in her imagination...", it was more like, you know, "There's a person here that's being bullied". (NN, p.44, L208-211; brackets added).

For 'William', a diagnosis of Asperger syndrome was received with "relief". This "official" recognition, for him, represented an endorsement of his existing identity, because he had feared that his "condition" would be misunderstood by a psychiatrist (p172, L472-474):

I felt legitimate, ...that I was who I was, and had been properly endorsed as such. (WA, p.173, L515-516).

For some participants, particularly those diagnosed in adulthood, 'expert' recognition was also associated with positive changes in others' understanding. In particular, diagnostic labels were acknowledged to serve an explanatory function in convincing (PW, p.76, L600; JM, p.130, L95) other people and so as one means for gaining social support.

It's just as if they've pushed me aside. 'Til the diagnosis.

... it made a big difference. I thought, well "I might get the help now".

(PW, p.75, L550; 569-570).

Some participants' views of diagnosis were more ambivalent. 'Anthony' for example, felt that his early diagnosis of 'Asperger syndrome' had been "crucial" in informing teachers of his difficulties and that that had included the decision for him to remain in a "normal" grammar school; however, he also viewed the disability 'label' as a source of stigma:

I'd rather not have a bloody label, but hhh, I mean I'm glad that I have got it. It has got its advantages. But it's got severe disadvantages when you're trying to grow up... . (AH, p.29, L671-673).

Subcategory: Judgement

This second subcategory of 'understanding' referred to others' use of their knowledge. Participants' assumed that the way in which their 'differentness' was interpreted by other people determined the 'treatment' participants subsequently received from a relatively powerful group.

The concept of 'judgement' assumed a distinction between others' identification of participants as different (described in the first main category), and their ability to fully appreciate participants' perspective.

It all depends on them. 'Cause just like my family, they know about it, doesn't mean they understand it. (JM, p.151, L692-693).

I like people to know what the disability is. ...if they don't understand it then tough. (WA, p.177, L623-624)

Generally, this subcategory drew from negative social experiences that were attributed to the unwillingness of others to understand participants' difficulties or, more commonly, mistakes or misunderstandings in others' judgement.

[Before leaving home] my family used to give me a hard time, because they think I'm not using my common sense, my coping skills.

(JM, p.128, 47-48; brackets added).

The diagnosis is necessary, but how they handle it could be a hell of a lot better. (AH, p.32, L754-755).

For 'Jacob', his family had failed to use knowledge of his diagnosis to modify their expectations of him, while the poor implementation of a decision by 'Anthony's' teachers, in which they had told his peers that he was 'disabled', had (he felt) resulted in him being "completely isolated" (p.36, L893). Perhaps significantly, these participants generalised their view of others' misjudging their disability to "society" as a whole (AH, p.32, L757; JM, p.128, L50).

Lower-level category: Social context

A second factor in participants' understanding of their accommodation by others was that of 'social context'. This category label referred to differences in accommodation, which participants attributed to the general characteristics of particular social groups. Comparisons between contexts were a common theme of this category.

The only bigotry I've ever had in my life was at English schools. ...the further south and the further east you go in England the worse it gets. Birmingham's better than London, Manchester's better than Birmingham... . (DH, p.122, L785-788).

You maybe get a ...brush-off from the person erm from the Midlands, and a softer, wry smile from the person in rural Wiltshire, because the languages of living of the two areas, they're different. (WA, p.166, L300-304).

In addition to geographical locations, comparisons were made between local groups (e.g. family and friends), time periods and institutions. As the last quote indicates, this category tended to stand for the shared understandings or values of defined populations; it was understood by the researcher to refer to the 'cultural backdrop' of a particular social setting.

Given this, 'social context' was a broader concept than that of (others') 'understanding'. For example, it did not include references differences to individuals' understanding of disability, but it did include participants' generalised assumptions of large populations.

much nicer people. ...And that's for the whole of Scotland I found. As a general rule Scottish people are warmer, far more human. (DH, p.121, L754-756).

the character and personality contours of people from Birmingham and the Midlands are harder and tougher than those from ...Wiltshire... . (WA, p.163, L214-217).

As a rule, contexts judged to be most accommodating of participants' 'differentness' were those considered the least restrictive. This dimension emerged from participants' comparisons, some of which are outlined below.

'William' highlighted the marked differences between rural and urban contexts. Looking back, he felt that his "slow" communication and behavioural idiosyncrasies had been readily accommodated in the "more gentle" lifestyle of the village where he grew up. 'William' contrasted this, from his experiences as an undergraduate in Birmingham, with a city lifestyle characterised as generally 'fast', 'ruthless' and 'intolerant'.

'Damian' drew similar comparisons. He contrasted the restrictive regimes of boarding schools and "narrow-mindedness" of contemporary "normal, white society" with his life at two British universities and in field research in Ghana and South America. 'Damian' described these latter contexts as 'diverse environments' in which characteristics of differentness, oddness or eccentricity were commonplace and therefore accommodated or even accepted.

Lastly, 'Jacob' referred to cultural differences between his friends and the "black community" with which his family identified. For 'Jacob', the relatively conservative values of this community were expressed in others' expectations that he become a "self-dependent" (p.152, L723) individual, for example by not asking questions and not making excuses. 'Jacob' construed this in terms of different contextual 'rules', such as the recognition that a comment considered humorous in one setting could be dismissed in another.

*the way I might talk to you or the discussion group is not the way I
speak to the rest of my family, because they have standards.*
(JM, p.146, L573-575).

An awareness of different social contexts also contributed to (all) participants' understandings of individual change. This relationship is indicated in Figure 5 and it is described as two subcategories of 'personal progression', below.

Intermediate category: Personal progression

This intermediate category represented those aspects of individual change that participants associated with improved social inclusion. The broad concept of 'progress' was adopted during the analysis to capture all participants' understandings of previous, gradual change; it also indicated some participants' hopes for improved social fit in their future.

'Personal progression' was defined by the four subcategories described below. As noted, the first two of these were related to the category 'social context' (see Figure 5).

Subcategory: Moving on

This subcategory represented individual progression associated with moves from one social context to another. Whilst related to the category 'social context', 'moving on' captured personal experiences of change, as distinct from participants' understanding of others. This subcategory was identified in all participants' accounts.

A dominant theme was that of moving on from some educational settings, usually secondary school. For example, several participants recalled particularly positive moves to further or higher education settings. Of these moves, two general factors were identified.

The first was that of 'leaving behind' environments that were associated with restriction or negative social interactions such as bullying.

This is where I was leaving all my troubles behind. Literally as soon as I left school. (DH, p.104, L274-275).

The school was too strict to let you do the things you normally wanted to do. (JM, p.134, L208-209).

The second, related factor comprised experiences of being able to operate more freely, as individuals, when external restrictions were removed. 'Damian', for example, went on to say that he "thrived" in the 'diverse', "less restrictive" settings of universities (p.104, L276-278) and 'William', similarly, recalled that moving to his school's sixth form had provided the freedom to "structure" his own study and social life:

I was able to self-regulate, and I wasn't forced to spend a great deal of time trying to socialise. ...That's the way I liked it.
(WA, p.170, L429-430; 435).

Subcategory: Selection

'Selection' represented the active choices made by some participants, based on their previous social experiences. In these cases an understanding of their personal abilities and limitations was used to improve their social fit.

For some, 'selection' applied to their choice of work.

Asperger's syndrome has given me a head start. ...That's a legacy of my success with a camera...that gives me hope that there are ways that I can work this. That's what I'm trying to do, if I can work this Asperger like a turbocharger...I can win races. (DH, p.125, L874-882).

'Damian', for example, associated his ability to concentrate on detail as an advantage of autism and he had attempted to capitalise on this ability in his academic career and his work as a photographer. For 'William', an understanding of 'Asperger's syndrome' had allowed him to select clients in his career as a music tutor:

It's probably largely due to the condition that I find it very difficult to empathise with children, teaching children, teaching beginners. ... class teaching would be a disaster...because I don't have the speed of mind. ...Erm, so it's a question of finding the right aspects of work... . (WA, p.176, L574-580).

In other instances people and places were selected to minimise the risk of exclusion. For example, 'Anthony' had chosen friends by "common-sense" at university, according to his need for protection from bullies, whilst 'Jacob' had used nightclubs because he could dance without having to make "interesting" conversation with other people.

Subcategory: Effort

All participants' referred to persistent or ongoing effort as one aspect of personal progression. The category label, 'effort', was used to denote a dynamic process in which participants' efforts to improve their social functioning were defined against a background of resistance.

One facet of this was the expectation of inevitable regression, instead of limited attainment, if personal effort were to cease or fail to succeed.

If I stop concentrating I end up back as I was at the age of eleven... .

(AH, p.34, L820-821)

I think I'm drifting further and further away [from my family].

(JM, p.154-155, L804-805; brackets added).

A second facet was the potential resistance of others. For example, 'Jacob' expected that any improvement in his relationship with his immediate family would need to rely on reciprocity.

That's the two-way thing, where I'll have to make the effort and they'll

have to be more understanding... . (JM, p.155, L807-809).

For others, however, efforts to fit in with those who proved less understanding were described in terms of struggle or conflict.

Subcategory: Experience

The final category of 'inclusion' (and the analysis) related to experience. Participants' perceived abilities to fit with others were attributed to progress derived from previous social experiences. Typically, this subcategory included references to familiarity or practice in particular settings.

I'm much better with people I know. With strangers I always make a bad start". (DH, p.109, L393-394).

things were a lot different by then [university] because I'd already had a lot of practice... . (AH, p.23, L497-499; brackets added).

In most cases, experience was associated with improved abilities to negotiate social situations or else to cope when difficulties arose. As examples, 'Anthony', quoted above, referred to his improved ability to respond to bullying by the time he reached university while, for 'Jacob', experiences earlier in his adult life had resulted, he felt, in the skill to identify sincere people whom he could rely upon:

You know who are your friends and who are your foes..(JM, p.133, L170-171).

Summary of the third main category

The third main category represented participants' understandings of attaining greater social inclusion or fit (i.e. fitting with others as themselves). Minimally, the construct of inclusion was negatively defined as the absence of exclusion or isolation. However, a dimension of inclusion was identified within that domain and participants' accounts ranged from 'good enough' experiences of minimal contact to expectations of comprehensive inclusion.

Generally, the six able autistic participants in this study associated the possibility of inclusion with two related external factors: the understanding of other people and the relative tolerance of specific social contexts, local value systems or cultures. However, they also recognised that some internal changes had enabled them to fit with others more easily as adults.

From the process model, 'inclusion' represented the final phase in participants' understanding of their relationship to other people. However, their social experiences were ongoing, so the third main category did not represent a psychological 'end point' to participants' meaningful constructions of social disability.

3.7 Summary of the analysis

This chapter presented an account of the analysis. The core category, 'social fit' was described and this represented the six participants' meaningful constructions of their experiences of social disability as a complex relationship between themselves, as individuals, and others as a social majority.

The process model presented a formulation of participants' developing understanding of their social experiences. It comprised three psychological phases developed from the three main categories of experience identified in the analysis. The latter were described in detail with examples quoted from the transcript text.

A linear relationship was proposed between the three main categories in which participants' gradually developed an awareness of their 'differentness' to others, then re-evaluated their relationship with others in a process of constructing identity, before constructing an understanding of attaining greater social inclusion. These main categories of the process model were reflected in the three facets of the core category (not fitting in with others, fitting together social attributes of normality and difference and fitting with others as oneself).

Able autistic participants' experiences of disability were assumed as active social phenomena that were ongoing in their adult lives. It was therefore assumed that the psychological phases of the process model functioned concurrently.

4.0 DISCUSSION

4.1 Overview

The previous chapter provided a detailed account of the analysis. This chapter includes a discussion of the main findings of the study and its design. First, the main findings are interpreted with reference to relevant literature on autism and disability. Implications for theory and clinical practice are then suggested. The following section includes a critical evaluation of the design and analysis, and the chapter ends by identifying several areas for further research.

4.2 Interpretation of the analysis

4.2.1 Aims of the study

To recap, the objective of this study was to develop an understanding of the social disability reported in able autistic adults. An inclusive definition of disability was assumed because this acknowledged the potential contribution of internal factors associated with impaired functioning and external factors associated with social barriers. The role and nature of these factors in the lives of able autistic adults was not clear in the literature and the study was therefore exploratory.

The design of the study took a 'bottom-up' approach to the question of how six able autistic adults had meaningfully construed or 'made sense of' their experiences of social disability. The main aims of this approach were to remain sensitive to information that may have been unique to an able autistic adult population and to develop a conceptual account of participants' experiences, grounded in their accounts.

The analysis identified key themes and categories in participants' constructions of social disability. These were expected to offer bases for understanding able autistic adults' experiences and for guiding further research.

The remainder of this section follows the structure of the previous chapter. Part 4.2.2 includes a discussion of the core category; Part 4.2.3 the process model; and Parts 4.2.4 to 4.2.5 the three main categories identified in the analysis.

4.2.2 The Core Category

The core category, 'Social fit', represented able autistic participants' constructions of disability as a relationship between themselves, as individuals, and other people. As the label suggests, the six participants' experiences of disability were construed first and foremost as a *social* phenomenon.

Participants did not report a priori awareness of impairment; rather their initial assumptions of social 'sameness' had been gradually challenged during interactions with other people. From participants' points of view, awareness of any personal differences - and their subsequent efforts to make sense of these- had arisen only through their participation in a social world.

The core category supported Oliver's (1996a) emphasis on a sharp conceptual distinction between *disability*, as a purely social phenomenon, and *impairment*, as an internal but contingently-related factor in disability. This distinction was particularly poignant for the able autistic adults in this study because their developing awareness of poor social fit preceded their apprehension of any personal differences. Hence, they had experienced social disability prior to, and initially distinct from, their acknowledgement of any personally-located (i.e. 'internal') factors.

DISCUSSION

The construction of social disability as social fit offered some contrast to the dominant literature on autism, which has traditionally approached the 'aloneness' characteristic of people with autistic spectrum disorders as a symptom or direct consequence of internal social (sic) impairments. As described in Chapter 1, Kanner (1943) regarded social detachment as definitive of the autistic syndrome and Asperger (1979) considered that his more able subjects had 'withdrawn into themselves', effectively disregarding the social world. Later developments in the concept of autism, such as Wing's (1988) 'triad of impairments', have arguably maintained an individual model of social disability in regard to autistic individuals.

The able autistic adults in this study acknowledged their relative social isolation. However, they associated it with failure to achieve good fit with their social environments and, additionally, as a consequence of avoiding negative stereotyping and the perceived risk of social exclusion.

Against this social backdrop, participants' constructions of social disability were also characterised by a conceptual separation between themselves and those around them. That is, they understood social disability to be located *between* self and others. This complex relationship was represented in the core concept of 'fit'.

'Fit' was used by the researcher to denote a *relationship* between relatively stable entities (i.e. those of 'self' and 'others') because participants understood disability as a function of their fit with the social world. This emphasis on disability as relational meant that participants' assumptions of themselves and other people were not the sole focus of change; what did change were participants' understandings of the relationship between themselves and those who they initially assumed to be the same as themselves.

Emphasis on the relationship between self and others was reflected in three facets of the core category. First, difficulties 'fitting in' with others were characterised primarily by puzzlement and anxiety around negative social exchanges, rather than a priori assumptions of 'internal' impairment. Second, participants' attempts to resolve their perceived lack of fit were characterised by attempts to 'fit together' their assumed normality with notions of personal difference, rather than an abandonment of normal identity or denial of their experiences. Third, participants' understandings of social inclusion were characterised by notions of 'fitting with' others *as themselves*, rather than seeking to become 'well' or more like other people.

By maintaining their assumptions of fundamental 'sameness' with others, the six participants in this study did not construct identities for themselves that placed them outside of a 'normal' social world. Understanding disability in terms of social fit may, then, have had its advantages. People with disabilities who regard themselves as a minority *within* society have been reported to be more likely to develop a positive group identity and to resist unrealistic expectations of recovery, regardless of how they are valued by wider society (Phillips, 1996).

That said, it should be noted that the participants in this study remained apprehensive of being categorised as fundamentally 'different' and of not finding a better fit with those around them. For the six able autistic adults who took part in this study, better social fit remained a goal, a matter of degree and an ongoing process.

4.2.3 The Process Model

The psychological model described in Chapter 3 represented the six participants' constructions of social disability as a dynamic process of understanding. The three main categories of the model were grounded in participants' experiences and the relationships between those categories were formulated as a linear process. Participants in this study re-evaluated their identities (as normal, yet different) having become more aware of some personally-located 'differentness'; in turn, their sense of identity informed their understandings of social inclusion.

Importantly, the linear structure of the model did not reflect a rigid stage or developmental process in practice because participants' understandings of disability were driven by their ongoing social experiences. The latter meant that participants' awareness of how they were fitting in with those around them, their senses of identity and their understandings of achieving greater social inclusion were continually revised. Hence, the model proposed an iterative process of change characterised by three overlapping or concurrent psychological phases.

DISCUSSION

The accommodation of ongoing experience was considered to be a relative strength of the process model, for two reasons. First, it provided for the possibility of ongoing change in autistic adults' social understanding. All participants reported changes in understanding of their fit with the social world as adults. Their subjective accounts, and the process model developed from them, therefore concurred with literature based on clinical observation (e.g. Tantam, 1988, 2000; Kanner, 1973) that has proposed that some autistic individuals considered 'high functioning' in early adulthood continue to make social-developmental progress into at least their 20s and 30s.

Second, the process model proposed a flexible account of change in comparison to psychological models of disability that assume a staged, internal adjustment to loss (e.g. Livneh, 1984). Generic adjustment models have tended to portray an 'unfolding sequence' or relatively unvarying process of staged intrapsychic change (Thomas & Siller, 1999). However, these types of formulation rarely map onto empirical data directly when tested (Rape, Bush & Slavin, 1992) and they are vulnerable to criticism of being too abstract or conceptually simplistic.

The model developed in this study proposed a progression in able autistic adults' understanding through three discrete phases but, by accommodating continuing experience, it did not impose restrictive assumptions of exclusive developmental stages. Further, its recognition that participants' experiences of disability occurred within active social environments weakened the assumption of an end-point of psychological adjustment. Hence, this study presented participants' experiences of disability as a relative, changeable phenomenon and not simply an internal adaptation to loss or 'personal tragedy' (e.g. Barnes and Mercer, 1997; Bury, 1996).

A strong but trivial explanation for the difference between the linear formulation of generic adjustment models and that proposed in this study is that the latter was developed 'bottom up' from participants' experiences. It was therefore expected to represent first-hand empirical data more directly than generic models.

A second possibility is that generic adjustment models of disability are too generalised (Borsay, 1997; Yunker, 1994) and perhaps over-representative of those who have suffered physical trauma or else acquired overt impairments in functioning. Borsay (1997) has proposed that the assumption of a general bereavement process in generic adjustment models may not be sensitive to groups with different forms of impairment. A dominant theme of the process model in this study was that able autistic adults developed an understanding of their 'differentness' only gradually. It is therefore possible that the process model represented a different process to existing models of adjustment in the literature, not least because it allowed for a potentially continuous process of change.

As a process, the conceptual model developed in this study included aspects of psychological approaches to disability in the literature. These, together with relevant literature on autism, will be discussed in more detail below.

4.2.4 First main category: 'Becoming aware of difference'

The six participants' developing awareness of social disability was represented as a gradual shift, from initial assumptions of 'sameness' through tensions in personal identity to an acknowledgement of some personally-located, but undefined 'differentness'. This phase formed the largest component of the process model and it was characterised by three related themes.

First theme: Learning via others.

The first theme was that participants' awareness of a difference between themselves and others was derived *from* their interactions with other people; that is, the able autistic adults in this study had no a priori apprehension of qualities 'in' themselves that marked them out as different.

Participants' move away from assumptions of 'sameness' developed with their continued difficulties engaging with other people. Examples included low-level, but persistent difficulties sharing others' interests or the perspectives and standards of friends and family. Additionally, the majority of participants cited incidents in which they had felt actively rejected (as 'different') by other people and all six participants reported being verbally or physically bullied.

DISCUSSION

Generally, these negative social experiences were compatible with literature on the social development of more able autistic children; for example reports of decreasing tolerance exhibited toward able autistic children by their peers in later childhood (e.g. Attwood, 1998; Tantam, 1988; Wing, 1981) and, with this, an increased likelihood of verbal or physical bullying (e.g. Tantam, 2000; Gross, 1994).

Given this compatibility, three aspects of the awareness that participants derived from their experiences were noteworthy.

The first was that participants' experiences of failing to integrate and of being rejected or bullied had extended *beyond* childhood peer relationships. For example, two of those interviewed had continued to encounter verbal teasing or bullying from peers at college or university, while another did not encounter significant social disability, from his perspective, until he left home to go up to a busy city university.²⁴ Further, the actions of authoritative adults, such as parents, school teachers, doctors and residential care staff, had contributed to participants' experiences of not fitting in as children and adults. Examples included being placed in residential schools away from the family home, being singled out as 'disabled' in class by a teacher at secondary school and being refused a place in a college because of undiagnosed special educational needs.

²⁴ By contrast, a further participant ('Damian') regarded university settings as far less restricting than his childhood experiences in private boarding schools.

DISCUSSION

Clearly, it is difficult to derive 'objective' explanations for these experiences. However, participants' accounts were compatible at least with reports in the literature of low levels of awareness and understanding of 'milder' autistic disorders among professionals in mainstream education and adult mental health services (e.g. Tantam, 2000; Attwood, 1998; Wing, 1981).

A second aspect of this theme was that participants construed their difficulties 'fitting in' using a broad concept of *difference*. Initially, this concept was defined negatively because it developed from autistic participants' awareness of being identified as somehow 'not the same' as other people, rather than an a priori awareness of some individual quality. This concept therefore included *any* form of social label or category that participants felt had been used to differentiate them from other people and that had contributed to their effective social exclusion.

Two aspects of this were illustrative and somewhat counter-intuitive. One was occasions on which participants had felt excluded as a consequence of being labelled *more* able than their peers. (For example, this was the case for 'Peter', who reported being moved from a group home to a one-bedroom flat after being judged 'too independent').²⁵ A second aspect was the negative impact of clinical labels. This was the case for the three participants who received accurate diagnoses of autism in childhood, each of whom had regarded labels of autism or disability as either irrelevant in understanding their experiences of disability or as *additional* forms of social stigma at the time.

²⁵ Peter was misdiagnosed with learning disability until the age of 35 years (Appendix 6.2). A significant minority of the current population of able autistic adults are likely to have received inaccurate diagnoses earlier in their lives (Tantam, 2000; Howlin & Goode, 1998; Attwood, 1998).

DISCUSSION

Descriptive clinical terms can take on negative value associations if they are interpreted in terms of deviancy from a social norm (Yuker, 1994; Szivos, 1992; Goffman, 1968) and this was relevant to the points of view of participants in this study. A clear reason was that category terms applied by other people were associated first and foremost with negative *consequences*: this was the case for both aspects cited above. When diagnostic labels were construed negatively, it appeared to be because they had not been understood as descriptive terms by autistic participants and therefore *only* represented devalued group labels. This contrasted with the positive value associated with diagnoses of Asperger syndrome by those diagnosed as adults.

A third aspect of the first theme was that participants in this study had initially assumed their difficulties 'fitting in' to be an external or else interpersonal issue. All assumed their social interest to be no different to those around them and, while some stated that they did not tend to share the interests or world-views of others, none construed their social disability as adults in terms of the aloofness or social detachment characteristic of most young autistic children.

Whilst not representative, this aspect of participants' accounts did concur with a reported trend toward greater social interest in high-functioning autistic individuals in late childhood and adolescence (e.g. Tantam, 2000; Howlin, 1997; Wing, 1987) and observations that many such individuals remain 'blind' to their own social deficits (Tantam, 2000). In terms of social disability, it suggested that participants' autistic 'aloneness' was construed, by them, as a consequence of some external barrier and not an 'internal' impairment.

Second theme: Lack of understanding

A second theme in participants' gradual awareness of 'differentness' was their lack of a ready explanation for their negative social experiences. That is, whilst they grew more aware *that* they were encountering difficulties 'fitting in' with other people, they were not able to understand *why*.

The first main category represented a shift toward participants' acknowledgement of some personal factors that contributed to their social disability. Ongoing social difficulties brought participants' assumptions of social 'sameness' into question and, in the absence of an alternative form of understanding, prompted tensions between personal identity as normal and social experience as different. These tensions manifested initially in forms of 'puzzlement', then in anxiety and coping strategies based on safety-seeking.

One way of interpreting this shift is as a process of psychological adaptation, accommodation or adjustment. The experience of becoming disabled -a social phenomenon- redefines the relationship between self and others, and prolonged experiences of disablement are therefore likely to force psychological change (Harris, 1995). Adjustment models tend to assume a process of change analogous to recovery from other forms of personal loss. However, it is important to note that the object of that loss is a *psychological* entity, namely the individual's previous self-view or identity (Thomas & Siller, 1999) and not necessarily physical injury. For the autistic adults in this study then, becoming aware of personal 'differentness' in the absence of an explanation for their experiences bore some parallels to the experiences of other disabled groups.

A clear parallel with adjustment models was the categories of 'puzzlement' and 'anxiety' that were identified in this study. These included participants' experiences of shock, denial and disbelief in response to their continued difficulties 'fitting in' and resulting tensions in their assumptions of personal normality. In those respects autistic adults' initial psychological responses were similar to the first stage of Livneh's (1984) generic model of disability, which proposed 'sub-stages' of shock and anxiety following a physically disabling event.

The experiences of able autistic adults did not, however, map clearly onto existing stage models of adjustment. For example, 'puzzlement' also comprised less intense, but long-standing experiences of bafflement or questioning (i.e. over *why* participants continued to encounter particular social difficulties) and these co-existed with experiences of anxiety.

One hypothesis for comparative differences in autistic adults' initial responses to disabling events was that, for them, it was not altogether clear how their social difficulties were personally-located. Their acknowledgement of personal 'differentness' was deduced from continued negative social experiences, but not 'first hand' awareness of impaired functioning (such as that apparent to individuals suffering physical disability). It is therefore possible that autistic individuals were less likely to look to internal factors as reasons for their poor social fit. A related hypothesis was that autistic individuals' recognition of being socially disabled developed only gradually and was often ongoing. This may have resulted in a less intense and / or more prolonged process of adjustment in comparison to individuals who experience sudden traumatic loss.

Lack of understanding also influenced the various forms of anxiety that participants experienced in response to their difficulties fitting in. The category of 'anxiety' represented participants' increasing apprehensions of 'standing out' as different in social situations and their associated fears of further stigma and exclusion. These feelings were maintained by their growing awareness that they did not understand the 'rules' by which other people gauged acceptable conduct.

Generally, the category of anxiety identified in the analysis concurred with literature reporting relatively high levels of anxiety in older children, adolescents and young adults with 'milder' forms of autism (e.g. Tantam, 2000, 1991; Howlin & Goode, 1998; Ghaziuddin et al., 1998). In particular, it provided support to Tantam's (2000) observation that a majority of adults with Asperger's syndrome in clinical settings present with *social* anxiety difficulties.

Interestingly, autistic adults' views, that they did not comprehend the rules by which their behaviour was judged, provided some explanation for Asperger's (1944) observation that able autistic children are often highly sensitive to criticism, despite lacking insight into their gauche social manner. Those interviewed in this study were able to express the tension involved in needing 'feedback' from those that may have labelled them 'different'.

DISCUSSION

This dilemma of whether to 'come out' as disabled in order to gain support has been reported as common for people with less visible forms of disability (Szivos, 1992). For the autistic participants in this study this was made more difficult by their lack of understanding of how they were 'different' to those around them. In the event, they initially responded to negative social experiences by 'playing safe', attempting to maintain a normal identity.

The category of 'playing safe' was characterised by participants' intentions to avoid or minimise risks of social exclusion and so represented means for reducing anxiety. This category included strategies of (psychological) resistance, avoidance of social situations, reliance on the advice of other people and attempts to act 'normal'.

This aspect of the analysis again bore a parallel to the notion of psychological adjustment. This is because the second 'stage' of Livneh's (1984) generic model, termed 'defence mobilisation', represented attempts to deny or 'bargain' over the growing realisation of personal disability. In this study, participants' attempts to 'play safe' were perceived, by them, as essentially inauthentic; that is, they were aware of that their efforts to avoid exclusion were associated with externally-imposed standards of normality.

Goffman (1968) has described this form of response as the attempt to 'pass as' normal by those seeking to avoid imposition of a devalued social identity. This was pertinent to the participants in this study because, as noted above, their initial understanding of clinical labels was that they denoted ill-defined difference from normality, rather than a positive form of understanding for their social difficulties.

For participants in this study, attempts to 'play safe' were generally acknowledged to have been counter-productive because they maintained participants' sense of poor social fit. In terms of behaviour, avoidance strategies resulted in restricted social contact (i.e. with 'trusted' friends) and loneliness for some. Psychologically, conscious attempts to 'act like' other people reflected participants' reluctance to 'be themselves'.²⁶

From this, one point worth considering is that participants' attempts to 'fit in' with external norms may have actually contributed to others' impression of them as 'aloof' or disinterested in social contact. From their accounts, objective 'aloneness' served a practical function but it did not reflect a 'core symptom' (Tantam, 2000) of autistic detachment often assumed of those with more severe (i.e. 'Kanner') autism.

Kanner (1973), in a follow-up study of individuals whom he had identified as autistic in infancy, suggested that those who achieved the best social outcomes in adulthood had had to make significant compromises in their expectations and behaviour in order to attain inclusion. It is possible, though, that this reflected a partial 'individual' view of disability: the autistic adults in this study had, arguably, become *more* 'alone' in their attempts to fit with external norms that they did not fully understand.

²⁶ Ironically, Tantam (2000, pp.382-3) has claimed that adults with autistic spectrum disorders generally prove to be poor "imitators" because they cannot "make themselves temporarily into another person" ; rather, they may be regarded as effective 'mimics' of others' behaviour.

Third theme: Power asymmetry

A third theme in participants' gradual awareness of difference was the power asymmetry that characterised the relationship between 'self' and 'others'. In the first phase of the process model, autistic participants did not just come to acknowledge themselves as somehow different because of their failures to fit in, but they also recognised that they, as individuals, were different to a majority group that shared a common knowledge or social understanding.

An important consequence of this was that autistic participants initially constructed their experiences of disability in terms of a powerful external norm. From participants' accounts, this relationship was grounded in experiences of, for example, other people identifying or defining 'problems' in their behaviour - of which participants themselves were not immediately aware - and (therefore) other people regarding themselves or being seen as 'expert' in participants' disability. This, in turn, defined participants' construction of 'differentness' as an absence of others' common understanding; that is, autistic participants came to 'know that they did not know'.

In this, participants' initial constructions of differentness were compatible with a social model of disability because, from their perspectives, 'their' difficulties emerged only in social contexts and were often defined or imposed by other people. Finkelstein (e.g. 1996; 1980) has argued that 'disability' should be regarded as power-based social construct in situations where people encounter disablement because society does not allow for their impairments. A pervasive aspect of this in the present study was that others' knowledge or expertise did not necessarily represent an *understanding* of participants' experiences. Indeed, when perceived as mere labelling, it contributed to their disability.

4.2.5. Second main category: 'Constructing identity'

'Constructing identity' formed the second phase of the process model. It represented autistic participants' attempts to resolve psychological tensions prompted by their difficulties 'fitting in' and comprised two related aspects of participants' self-views or identities: their assumptions of 'sameness' or normality and their acknowledgement, through experience, of personal 'differentness'. While these two aspects were initially considered to be in opposition by participants, 'constructing identity' represented positive efforts at fitting them together. One component of this category included attempts to 'define' or qualify difference in various ways; the second comprised efforts to 'defend' normal social status.

From the literature on disability, one way of interpreting this category was as a further phase of 'internal' psychological adjustment. For example, Livneh's (1984) generic model of psychological adjustment proposed a final stage - 'reintegration' - marked, in part, by cognitive reconciliation of an existing identity with the reality of having become disabled.

'Constructing identity' did suggest that participants' self-views changed to accommodate their acknowledgement of internal or individually-located differences. However, important to recognise that they were not immediately aware of what those differences were.

Given this, two aspects of the category can be interpreted as a cautious process of identity change. First, participants' clearly sought to maintain claims to 'normal status'. For example, they emphasised the extent to which their personal functioning or abilities were unaffected by labels of autistic disorder or disability and, therefore, that they remained within wider norms. Second, notions of personal differentness were generally framed in terms that stressed compatibility with a normal identity, so did not require acceptance of a separate (devalued) identity. As examples, the notion of autism as an 'ill-fitting' concept maintained implicitly the possibility of better social fit; 'invisibility' of their condition stressed at least normal appearance; and the notion that autism implied a 'qualitatively distinct' world-view avoided the negative normative associations with *dysfunction* or *disability*.

The main difficulty with interpreting 'constructing identity' as a phase of internal adjustment was that the category identified in this study did not reflect a fully integrated or unified self-view, but participants' *attempts* to 'fit together' discordant aspects of experience that had begun in their early lives.

One hypothesis for this was that the participants in this study remained wary of abandoning a 'normal' identity, perhaps because they did not have a priori awareness of impaired functioning or because they did not have positive alternatives. This would fit with Harris's (1995) claim that disabled people who come to define themselves as excluded are less likely to establish a positive group identity and more likely to accept a self-view as devalued.

A related hypothesis was that autistic adults' were unlikely to reach an 'end-point' of adjustment, because the process model in this study allowed for continuing psychological change driven by participants' ongoing social experiences (see 4.2.3, above).

A second way of interpreting this main category was derived from Social Identity Theory (S.I.T.; e.g. Tajfel, 1981). This suggested 'constructing identity' to be a process in which participants managed their social identities so as to minimise the risk of external stereotyping. One reason for considering this was that the main category developed from autistic participants' comparisons of themselves with various disabled and non-disabled groups.

S.I.T. would suggest that participants' constructions of an identity, which emphasised their normal status and defined their 'difference' in terms compatible with a social norm, effectively distanced them from groups whom they construed to be socially devalued.²⁷ The latter included, variously, groups categorised by their visible physical disabilities, learning disabilities or more severe forms of autism.

From this theoretical perspective, 'constructing identity' could still be regarded as a progression from participants' developing awareness of personal difference. Their attempts to associate themselves with a majority norm, whilst accepting minimal, positive aspects of 'differentness', represented more sophisticated strategies for countering external social barriers compared to their earlier efforts at 'playing safe'.

²⁷ A good example of this was Anthony's view that it had been preferable, for him, to endure bullying in a 'normal' grammar school, than to have been placed in a 'special school' because of his social disability.

DISCUSSION

One aspect of this was that all six participants, as adults, appeared to accept diagnoses of autistic spectrum disorder. However, the subcategories that comprised the second main category served to qualify the meaning of their condition to others (i.e. presenting themselves as 'different, yet normal').

Additionally, SIT provided an explanation for why the three participants who were diagnosed with Asperger syndrome as adults²⁸ had regarded the label positively. This was because they had been unable to 'make sense' of their social disability in a positive way previously and, for them, diagnosis in adulthood offered a legitimate explanation -and a relatively positive group identity- that enabled them to reject earlier associations (e.g. with learning disability or special needs).

The suggestion that diagnostic labels of autistic spectrum disorder provided a way for participants to explain their social difficulties to others, also raised the question of whether participants actively used different forms of identity to minimise the risk of negative social labelling. Phillips (1992), for example, proposed that people with any form of disability may hold and deploy different forms of identity to counter prejudicial social barriers. This perspective, based in social constructionist views of identity, offered a further explanation for why the second main category did not represent a unitary form of identity.

However, it is important to note that the analysis in this study did not identify a 'fluid' use of disabled identity in able autistic adults: whilst participants did become aware that their social fit could vary according to social contexts, their attempts to fit with others as themselves did not.

²⁸ These were 'Peter', 'Jacob' and 'William' (see Appendix 6.2).

4.2.6 Third main category: 'Inclusion'

'Inclusion' represented participants' understandings of improved social fit. As the final phase of the process model it followed on conceptually from their attempts to integrate personal 'differentness' with assumptions of normal status. Hence, 'inclusion' represented a different, more authentic relationship between participants and 'others' than that portrayed in the first main category. For the able autistic adults in this study, inclusion denoted 'fitting with' other people as individuals with particular differences, rather than attempts to 'fit in' as if the 'same'.

Overall, the concept of 'inclusion', which was developed from all participants' accounts, was defined negatively (i.e. as the opposite of 'not fitting in' with other people). However, participants' understandings of what better social fit could involve were varied and ranged from minimal 'contact' with other people to expectations of being part of a 'circle of friends'.

The most obvious interpretation for this apparent range of understandings was that it reflected individual differences within a small sample of participants (for example, 'Peter' drew a distinction between occasions when he felt lonely and times when he chose to be alone). However, two alternatives were suggested by the literature on autism.

The first was that participants' views represented 'real' qualitative differences in their understanding of relationships, relative to a non-autistic norm. Howlin (1997), for example, has observed that many able autistic individuals demonstrate poor awareness of the complexities of social relationships, and that they rarely show evidence of shared experiences or mutual understanding when describing relationships. Hence, the different terms used by participants in this study (e.g. contact, connection, friends, etc.) may have referred to a common 'autistic' understanding of social fit.

A related interpretation was that participants' views referred primarily to their understanding of what 'normal' social functioning would be like. One reason for this is that, arguably, participants in this study had little experience of positive social relationships upon which to base views of better 'fit'. Given this, their understandings of what it would be like to *not* experience social disability may have been relatively shallow. Tantam (2000), for example, has reported that individuals with Asperger syndrome often refer to relatively superficial social contacts as 'friends'.

Participants' understandings of improved social fit were based on their recognition of two sets of factors: social factors, which related to others' accommodation of participants' 'differentness', and personally-located factors, which related to individual progress toward inclusion.

DISCUSSION

Ironically, an important social factor identified by autistic participants was the failure of many people to recognise or know about their 'condition'. Knowledge was regarded by most participants as a prerequisite for others understanding and accommodating their social difficulties; it was also recognised as an important basis for the judgements ('powerful') others made that affected participants' social disability.²⁹

As noted in the discussion of the first main category, low levels of awareness of 'milder' autistic disorders among professionals in mainstream education and adult mental health services have been recognised in the literature (e.g. Tantam, 2000; Attwood, 1998; Wing, 1981) and, whilst this situation may be improving (e.g. Schopler, 1998), the risks of misdiagnosis -and inappropriate treatment- remain (Tantam, 2000; Attwood, 1998). Further, the gap between others' knowledge and their understanding, which was highlighted by autistic adults in this study, supported Yunker's (1994) suggestion that health professionals may be less sensitive to information about *individuals'* difficulties, because their training can emphasise general knowledge about particular disabling *conditions*.

A second important social factor was that of context. A majority of autistic participants recognised that others' tolerance of social 'differentness' could vary between large populations or cultural groups. Social context represented a distinct social factor to that of others' understanding of autism or disability; hence some participants reported that they had been able to 'fit with' others, even when (or perhaps because) their social differences were not recognised.

²⁹ An example of this was William's initial reluctance to seek a diagnosis of Asperger syndrome, because he was unsure if a psychiatrist would know about the condition.

DISCUSSION

This aspect of participants' understanding of their experiences again supported Oliver's (1996a) emphasis of disability as a social phenomenon, distinct from 'internal' impairment. From participants' perspectives then, others' lack of awareness of their disability, their failure to understand participants' particular social difficulties and / or their level of intolerance of 'differentness' each represented significant external barriers to inclusion.

A final consideration of the third main category was that autistic participants' did consider that personal changes contributed to improvements in their disability. Personal factors included participants' recognition of previous, positive changes (for example their gradual awareness of 'rules' in particular social situations and improvements associated with 'moving on' from restrictive settings), and more active choices that, potentially, improved their fit with the social world (for example the possibilities of selecting less restrictive environments or making conscious efforts to improve social functioning).

These personally-located elements of 'inclusion' were still primarily concerned with overcoming social barriers, and so remained more consistent with a social model of disability. With regard to 'internal' factors associated with disability, participants' views of 'personal progression' did not include expectations of 'recovery' and this suggested that their understandings of their condition (i.e. autism) were of a relatively fixed 'differentness'. Hence, the able autistic adults in this study did not expect to regain their original assumptions of social 'sameness'. Rather, they sought to fit in as best they could.

4.3 Implications

This section includes several implications for theory and clinical practice, derived from the main findings of this study.

4.3.1 Implications for theory

- *Psychological adjustment.*

As noted, generic models of psychological adjustment to disability have been criticised for being too simplistic or generalised. One reason for this is that existing models tend to be based in experiences of physical trauma. The analysis developed in this study showed some close parallels with the notion of adjustment, although the experiences of able autistic adults suggested some implications for theory.

The most obvious was that the process of psychological change need not be linear: the process model developed in this study assumed ongoing, iterative change, in which different phases could operate concurrently. This was because autistic adults' experiences of disability were ongoing, and not assumed to derive from a single traumatic loss. This distinction may apply to other forms of impairment, particularly those who become aware of disability gradually (e.g. those with lifelong sensory impairments or progressive illness).

Further, the notion of *gradual* awareness suggested the possibility of less severe, less intense and longer psychological phases and the prospect that, for some forms of disability, 'adjustment' may not imply an end-point. Given this, a dimensional approach to adjustment would allow generic psychological models to represent a broader range of disability.

- *Autism*

Current understandings of the life experiences of able autistic adults have tended to rely on research with child and adolescent samples or studies using more severely impaired adults. However, as Wing (1981) argued, autistic disorders in older, more able individuals may have qualitatively different features.

The current study suggested that some characteristics popularly associated with the autistic syndrome –especially social aloofness or ‘aloneness’, resistance to change and solitary or circumscribed activities- were not just ‘symptoms’ of underlying pathology for more able autistic adults. Participants in this study assumed normal social interest and described feelings of loneliness when they were unable to ‘fit in’ with those around them. Additionally, they made sense of their social difficulties primarily in terms of *external* social barriers (e.g. active rejection or poor accommodation of their impairments by others). Whilst this study did not challenge the notion of participants’ underlying and pervasive cognitive impairments, their accounts did suggest social-psychological reasons for the high levels of anxiety and social withdrawal often regarded as ‘core symptoms’ of autism itself.

4.3.2 Implications for clinical practice

- *Awareness, knowledge and understanding.*

The analysis developed in this study highlighted distinctions between awareness, knowledge and understanding of able autistic adults’ disability and these distinctions suggested several implications for clinicians.

One important finding was that autistic adults appeared to lack first-hand awareness of their impairments, and their own knowledge and (developing) understanding of their disability experiences were effectively shaped by interactions with other people. Participants in this study were all too aware of their reliance on others' ability to recognise and understand their difficulties, and this was particularly important in their interactions with those perceived to be powerful and 'expert'. The failure of others to recognise or understand their difficulties had, too often, contributed to their disability.

One clear implication was the need for clinicians to not only be aware that (after Wing, 1981) autistic disorders can affect intellectually-able adults, but also to recognise that 'expert' knowledge of particular impairments may not be sufficient to understand a client's *disability*. Indeed, participants' apprehensions of others misunderstanding their difficulties provided one reason for avoiding social 'feedback'. An important issue for some of those interviewed was their experience of diagnosis because, where this was not combined with a meaningful explanation or social support, participants' were aware only of being categorised as 'different'.

- *Tolerance.*

A related implication for clinical services was the importance of tolerance of autistic adults' 'differentness'. The values or assumptions of large social groups or local cultures were powerful factors that influenced participants' experiences of social disability. It is important to note that some participants claimed not to have been disabled in situations where they perceived their acknowledged differences to have been tolerated, though not necessarily recognised or understood.

4.4 Critical evaluation

This section includes a critical evaluation of the study. It outlines the main limitations of the analysis as a 'grounded theory' and describes several factors that limited the 'generalisability' of its findings.

4.4.1 Saturation of categories

In Chapter 2, it was noted that the end-point of a grounded theory study should, ideally, be determined by the theoretical 'saturation' of data categories; that is, the point at which new data fails to give rise to new ideas or refinements in the development of the analysis (McLeod, 2001; Strauss, 1987).

In this study, no new low-level categories were identified after the end of the fourth interview (i.e. the point at which 'focused coding' was introduced). However, full saturation (i.e. definition) of data categories was not achieved because of time constraints. (One example of this was the main category of 'inclusion', which was generally negatively-defined).

Rennie et al. (1988) have stated that saturation of categories generally occurs between five and ten protocols in grounded theory studies, which was compatible with this study. Further, Charmaz (1995) has noted that, in practice, many examples of grounded theory research do not develop total theories. Rather they represent rich conceptual analyses of participants' experiences.

Given this, the conceptual analysis in this study was considered to have met the aim of developing an initial conceptual framework of able autistic participants' experiences, that was sufficiently "rich and dense" (Henwood & Pidgeon, 1992, p.108) to be relevant to other researchers.

4.4.2 Generalisability of findings

In qualitative research, 'generalisability' usually refers to the possible domains to which findings may be applicable (Flick, 1998). However, the issue of the *general* significance of findings that assume the contextuality of knowledge and which are not based on statistical sampling remains the subject of debate in the literature (e.g. Morse, 1997; Silverman, 1997). Given this, one suggestion is that qualitative findings should be considered in terms of 'transferability', rather than generalisability (Lincoln & Guba, 1985).

Transferability refers to applying the findings of a study in contexts that are considered similar. This is a judgement made by those applying qualitative findings. However, transferability places an onus on those reporting qualitative findings to convey the contextual features of their studies (Henwood & Pidgeon, 1992). Several efforts to 'situate' this study for the reader were described in Chapter 2; they included details of the participants, the researcher's perspective and the settings in which the study took place.

In addition, it is important to note that the six participants in this study were not assumed to be a representative sample of the able autistic adult population.

Directed sampling procedures were used with the aim of gathering a conceptually rich data set for the development of an initial grounded theory.

Selection was therefore guided initially by the research question and shaped by categories of experience identified in earlier interviews.

DISCUSSION

In the event, the profile of participants in this study was not dissimilar to large samples reported in the literature, such as those of Tantam (1991) and Newson et al (1982); for example, none were in a relationship, all but one were in paid employment, three had attended further education. However, several sampling issues were recognised that limited the general significance of the analysis. These are described below.

First, participants in this study were all relatively young (the oldest being 37 years) and, whilst an iterative process of psychological change was proposed in the process model, it was possible that the analysis did not identify categories of experience specific to later life. This possibility was difficult to gauge, because there is currently no literature on the life experiences of older adults with 'mild' forms of autism.

A second issue was that of gender. Asperger syndrome is much more likely to affect males than females (Holland et al., 2001, suggest a ratio of around 9:1) and, from this perspective the selection of five men in this study was justified. However, the fact that only one woman took part made it likely that any gender differences in the experience of social disability were not adequately explored.

Third, it is important to note that this study focused intentionally on a cohort in whom 'high functioning' autism could not have been diagnosed in infancy. It is therefore possible that the experiences of able autistic individuals who receive accurate, early diagnosis and appropriate support from an early age may differ from the participants in this study. One hypothesis would be that the process of awareness represented in the first main category would be shorter, providing a meaningful explanation were offered to them by other people.

Fourth and related, participants in this study had all received accurate diagnoses of autistic spectrum disorder prior to interview and had all sought support for a social disability that they acknowledged. It is likely that many adults with 'mild' forms of autism remain undiagnosed despite similar or more severe disability (Tantam, 2000) and that their experiences would be similar to those represented in this study. However, other able autistic adults may not have experienced such negative social interactions in their lives and may not consider themselves disabled. Schopler (1998) has argued that clinical diagnoses of 'Asperger syndrome' can be over-used, pathologising individuals whose autistic impairments do not impede their lives. Hence, model proposed in this study would only be expected to 'transfer' to those able autistic adults who experience social disability.

4.5 Future research

One aim of this study was to develop a conceptual understanding of able autistic adults' experiences of disability, to provide an empirical grounding for further research. The analysis presented in this thesis was considered to offer an initial framework from which a more comprehensive theory can be developed. Given this, two related areas of research are suggested as a 'second step':

- *Exploring analogous populations.*

Following on from the sampling limitations listed above, an important progression would be to compare the findings of this study with those of similar populations. In this way, the theoretical claims of the process model may be tested and developed further.

Analogous groups would be likely to include older adults with autistic disorders, able autistic individuals whose difficulties were accurately diagnosed at an early stage, and those who may not consider themselves to be disabled. The possibility of gender differences in the construction of social disability was not explored and may prove to be a fruitful area of study.

- *Social understanding.*

A second issue raised by this study was the question of how able autistic adults understand positive 'social fit' if or when it is achieved. The concept of inclusion was broadly defined in the analysis, arguably as the absence of exclusion. A useful area of inquiry then, would be to explore able autistic adults' understandings of *adequate* friendships and relationships -their experiences of fitting in.

4.6 Summary

This last chapter included a discussion of the main findings of the grounded theory analysis developed in this study, relating it to relevant literature on disability and autism. Several implications for theory and clinical practice were then suggested. The limitations of the study were then outlined; these issues helped to define the extent to which findings could be applied in other contexts. Finally, two areas for future research were suggested.

5.0 REFERENCES

- Abberley, P. (1997). The concept of oppression and the development of a social theory of disability. *Disability, Handicap and Society*, **2**, 5-21.
- Antaki, C., Condor, S. and Levine, M. (1996). Social identities in talk: Speakers' own orientations. *British Journal of Social Psychology*, **35**, 473-492.
- American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders*, 3rd edition. Washington D.C.: American Psychiatric Association.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders*, 4th edition. Washington D.C.: American Psychiatric Association.
- Asperger, H. (1944). Die 'Autistischen Psychopathen' im Kindesalter. *Archiv für Psychiatrie und Nervenkrankheiten*, **117**, 76-136.
- Asperger, H. (1979). Problems of infantile autism. *Communication*, **13**, 45-52.
- Attwood, T. (1998). *Asperger's syndrome: A guide for parents and professionals*. London: Jessica Kingsley.
- Backman, K. & Kyngäs, H.A. (1999). Challenges of the grounded theory approach to a novice reader. *Nursing and Health Sciences*, **1**, 147-153.

REFERENCES

- Bailey, A. (1999). Diagnosis. Conference proceedings of the National Conference on Asperger's syndrome: Diagnostic and management issues looking beyond childhood. Regent's College, London, 7 October 1999.
- Baron-Cohen, S., Tager-Flusberg, H. & Cohen, D.J. (2000). A note on nosology. In S. Baron-Cohen, et al. (Eds.), *Understanding other minds*, 2nd edition. Oxford: Oxford University Press.
- Barnes, C. (1997a). A legacy of oppression: A history of disability in Western culture. In L. Barton & M. Oliver (Eds.), *Disability studies: Past, present and future*. Leeds: The Disability Press.
- Barnes, C. (1997b). Disability and the myth of the independent researcher. In C. Barnes & M. Oliver (Eds.), *Disability studies: Past, present and future*. Leeds: The Disability Press.
- Barnes, C. & Mercer, G. (1996). Breaking the mould?: An introduction to doing disability research. In C. Barnes & G. Mercer (Eds.), *Doing disability research*. Leeds: The Disability Press.
- Bebbington, P. (1997). What's in a syndrome? *The Journal of Forensic Psychiatry*, **8**, 258-261.
- Blaxter, M. (1980). *The meaning of disability: A sociological study of impairment*. London: Heinemann.

REFERENCES

- Borsay, A. (1997). Personal trouble or public issue?: Towards a model of policy for people with physical and mental disabilities. In L. Barton & M. Oliver (Eds.), *Disability studies: Past, present and future*. Leeds: The Disability Press.
- Bryman, A. (1988). *Quantity and quality in social research*. London: Routledge.
- Burgoine, E. & Wing, L. (1983). Identical triplets with Asperger's syndrome. *British Journal of Psychiatry*, **152**, 377-382.
- Bury, M. (1996). Defining and researching disability: Challenges and responses. In C. Barnes & G. Mercer (Eds.), *Exploring the divide: Illness and disability*. Leeds: The Disability Press.
- Bury, M. (1997). Disability and the myth of the independent researcher: A reply. In L. Barton & M. Oliver (Eds.), *Disability studies: Past, present and future*. Leeds: The Disability Press.
- Charmaz, K. (1995). Grounded theory. In J.A. Smith, R. Harré & L. van Langenhove (Eds.), *Rethinking methods in psychology*. London: Sage.
- Chenitz, W.C. & Swanson, J.M. (1986). From practice to grounded theory. *Qualitative research in nursing*. Massachusetts, U.S.A.: Addison-Wesley.
- Clegg, J.A. (1993). Putting people first: A social constructionist approach to learning disability. *British Journal of Clinical Psychology*, **32**, 389-406.

REFERENCES

- Clegg, J.A. & Standen, P.J. (1991). Friendship among adults who have developmental disabilities. *American Journal on Mental Retardation*, **95**, 663-671.
- Cooper, N. & Stevenson, C. (1998). 'New science' and psychology. *The Psychologist*, **11**, 484-485.
- Craig, G. (1996). Qualitative research in NHS settings: Uses and dilemmas. *Changes*, **14**, 180-186.
- Dancy, J. (1992). *Introduction to contemporary epistemology*. Oxford: Blackwell.
- Denzin, N.K. & Lincoln, Y.S. (Eds.) (1994). *Handbook of qualitative research*. Thousand Oaks, California, U.S.A.: Sage.
- Department for Education and Employment (1999). *Explanatory notes to Disability Rights Commission Act 1999*. London: H.M.S.O.
- Dey, I. (1993). *Qualitative data analysis*. London: Routledge.
- Dingwall, R., Murphy, E. Watson, P., Greatbatch, D. & Parker, S. (1998). Catching goldfish: Quality in qualitative research. *Journal of Health Service Research Policy*, **3**, 167-172.
- Drew, P. (1995). Conversation analysis. In J.A. Smith, R. Harré & L.V. Langenhove (Eds.), *Rethinking methods in psychology*. London: Sage.

REFERENCES

- Ehlers, S. & Gillberg, C. (1993). The epidemiology of Asperger syndrome: A total population study. *Journal of Child Psychology and Psychiatry*, **34**, 1327-1350.
- Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, **38**, 215-229.
- Ferguson, P.M., Ferguson, D.L. & Taylor, S.J. (1992). *Interpreting disability: A qualitative reader*. New York, U.S.A.: Teachers College Press.
- Feyerabend, P. (1977). *Against method*. London: New Left Books.
- Finkelstein, V. (1980). *Attitudes and disabled people: Issues for discussion*. New York, U.S.A.: World Rehabilitation Fund.
- Finkelstein, V. (1996). Outside, "Inside out". *Coalition*, (April), 30-36.
- Fitzgerald, M. (1999). Criteria for Asperger's disorder. *Journal of the American Academy of Child and Adolescent Psychiatry*, **38**, 1071.
- Flick, U. (1998). *An introduction to qualitative research*. London: Sage.
- Frith, U. (1991). Asperger and his syndrome. In U.Frith (Ed.), *Autism and Asperger syndrome*. Cambridge: Cambridge University Press.
- Gergen, K. J. (1991). *The saturated self: Dilemmas of identity in contemporary life*. New York, U.S.A.: Basicbooks.

REFERENCES

- Gillberg, C. (1998). Asperger syndrome and high-functioning autism. *British Journal of Psychiatry*, **172**, 200-209.
- Gillberg, C. (1990). What is autism? *International Review of Psychiatry*, **2**, 61-66.
- Gillberg, C. (1991). Outcome in autism and autism-like conditions. *Journal of Academic Child and Adolescent Psychiatry*, **30**, 375-382.
- Gillberg, C. (1992). The Emanuel Miller Memorial Lecture 1991: Autism and autistic-like conditions: Subclasses among disorders of empathy. *Journal of Child Psychology and Psychiatry*, **33**, 813-842.
- Gillberg, C. & Ehlers, S. (1998). High-functioning people with autism and Asperger syndrome: A literature review. In E. Schopler, G. B. Mesibov & L. J. Kuncz (Eds.), *Asperger syndrome or High Functioning Autism?*. London: Plenum.
- Ghaziuddin, M. & Tsai, L. (1991). Depression in autistic disorder. *British Journal of Psychiatry*, **159**, 721-723.
- Ghaziuddin, M., Tsai, L.Y., & Ghaziuddin, L. (1992). Brief report: A comparison of the diagnostic criteria for Asperger's syndrome. *Journal of Autism and Developmental Disorders*, **21**, 349-54.
- Ghaziuddin, M., Weidmer-Mikhail, E. & Ghaziuddin, N. (1998). Comorbidity of Asperger syndrome: A preliminary report. *Journal of Intellectual Disability Research*, **42**, 279-283.

REFERENCES

- Glaser, B.G. (1978). *Theoretical sensitivity*. Mill Valley, California: Sociology Press.
- Glaser, B.G. (1992). *Emergence vs. forcing: Basics of grounded theory analysis*. Mill Valley, California, U.S.A.: Sociology Press.
- Glaser, B. G. & Strauss, A. L. (1967). *The discovery of Grounded Theory: Strategies for qualitative research*. New York: Aldine de Gruyter.
- Goffman, E. (1968). *Stigma*. London: Penguin.
- Goode, S., Rutter, M. & Howlin, P. (1994). A twenty-year follow-up of children with autism. Paper presented at the 13th Biennial Meeting of the International Society for the Study of Behavioural Development. Amsterdam, The Netherlands.
- Gross, J. (1994). Asperger syndrome: A label worth having? *Educational Psychology in Practice*, **10**, 104-110.
- Guba, E. & Lincoln, Y. (1982). Epistemological and methodological bases of naturalistic inquiry. *Education, Communication and Technology Journal*, **30**, 233-252.
- Hacking, I. (1983). Introduction. In I. Hacking (Ed.), *Scientific revolutions*, (Second edition). Oxford: Oxford University Press.
- Happé, F. (1994). *Autism: An introduction to psychological theory*. London: U.C.L. Press.

REFERENCES

- Hare, D. J. & Paine, C. (1997). Developing cognitive behavioural treatments for people with Asperger syndrome. *Clinical Psychology Forum*, **110**, 5-8.
- Harris, P. (1995). Who am I?: Concepts of disability and their implications for people with learning disabilities. *Disability and Society*, **10**, 341-351.
- Hayes, N. (1997). *Doing qualitative analysis in psychology*. Hove, U.K.: Psychology Press.
- Henwood, K. & Pidgeon, N. (1992). Qualitative research and psychological theorizing. *British Journal of Psychology*, **83**, 97-111.
- Holland, T., Clare, I., Baron-Cohen, S. & Woodbury-Smith, M. (2001). Current issues surrounding the diagnosis, management and treatment of children and adults with Asperger's syndrome. Draft report prepared for the Department of Health. University of Cambridge: Department of Psychiatry.
- Howlin, P. (1997). *Autism: Preparing for adulthood*. London: Routledge.
- Howlin, P. & Goode, S. (1998). Outcome in adult life for people with autism and Asperger's syndrome. In F. R. Volkmar (Ed.), *Autism and pervasive developmental disorders*. Cambridge: Cambridge University Press.
- Howlin, P. & Mawhood, L. (1999). The outcome of a supported employment scheme for high-functioning adults with autism or Asperger syndrome. Conference proceedings of the National Conference on Asperger's syndrome: Diagnostic and management issues looking beyond childhood. Regent's College, London, 7 October 1999.

REFERENCES

- Howlin, P. & Yates, P. (1999). The potential effectiveness of social skills groups for adults with autism. *Autism*, **3**, 299-307.
- Johnston, M. (1997). Integrating models of disability: A reply to Shakespeare & Watson. In L. Barton & M. Oliver (Eds.), *Disability studies: Past, present and future*. Leeds: The Disability Press.
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, **2**, 217-250.
- Kuhn, T. (1962). *The structure of scientific revolutions*. Chicago, U.S.A.: University of Chicago Press.
- Kuzel, A. J. (1992). Sampling in qualitative inquiry. In B.F. Crabtree & W.L. Miller (Eds.), *Doing qualitative research*. Newbury Park, California: Sage.
- Kvale, S. (1996). *InterViews: An introduction to qualitative research interviewing*. Thousand Oaks, California: Sage.
- Lainhart, J. & Folstein, S. (1994). Autism and affective disorders: A review of the literature. *Journal of Autism and Developmental Disorders*, **24**, 587-602.
- Lea, S. J. (1988). Mental retardation: Social construction or clinical reality? *Disability, Handicap and Society*, **3**, 63-69.

REFERENCES

- Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, U.S.A.: Sage
- Livneh, H. (1984). A unified approach to existing models of adaption to disability: Part 1A, model adaption. *Journal of Applied Rehabilitation Counseling*, **17**, 5-17, 56.
- Lord, C. & Rutter, M. (1994). Autism and pervasive developmental disorders. In M. Rutter, E. Taylor, & L. Hersov (Eds.), *Child and adolescent psychiatry: Modern approaches*, 3rd edition. Oxford: Blackwell.
- Luborsky, M. R. (1995). The process of self-report of impairment in clinical research. *Social Science and Medicine*, **40**, 1447-1459.
- MacLeod, A. (1999). The Birmingham community support scheme for adults with Asperger syndrome. *Autism*, **3**, 177-192.
- MacLeod, A. (2002). The development of a social skills group for adults with Asperger syndrome within Birmingham, U.K. (In press)
- Madill, A., Jordan, A. & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, **91**, 1-20.
- Mawhood, L. (1995). Autism and developmental language disorder: Implications from a follow-up in early adult life. Unpublished PhD. thesis, University of London.

REFERENCES

- Mayes, S.D. & Calhoun, S.L. (2001). Non-significance of early speech delay in children with autism and normal intelligence and implications for DSM-IV Asperger's syndrome. *Autism*, **5**, 81-94.
- McLeod, J. (2000). *Qualitative research in counselling and psychotherapy*. London: Sage.
- Melia, K.M. (1996). Rediscovering Glaser. *Qualitative Health Research*, **6**, 368-377.
- Michael, M. (1996). *Constructing identities*. London: Sage.
- Miles, M.B. & Huberman, A.M. (1994). *Qualitative data analysis*. London: Sage.
- Morgan, H. (1996a). *Adults with autism: A guide to theory and practice*. Cambridge: Cambridge University Press.
- Morgan, M. (1996b). Qualitative research: A practical deal? *The Psychologist*, **9**, 31-32.
- Morse, J.M. (1997). Recognising the power of qualitative research. In J.M. Morse (Ed.), *Completing a qualitative project*. London: Sage.
- National Autistic Society (1999). *Diagnosis: A brief guide for health professionals*. London: National Autistic Society

REFERENCES

- Newson, E., Dawson, M. & Everard, P. (1982). The natural history of able autistic people: Summary of the report to the D.H.S.S..
Communication, **22**, 64-69.
- Nordin, V. & Gillberg, C. (1998). The long-term course of autistic disorders: Update on follow-up studies. *Acta Psychiatrica Scandinavica*, **97**, 99-108.
- Oliver, M. (1992). Changing the social relations of research production?
Disability, Handicap and Society, **7**, 101-114.
- Oliver, M. (1996a). Defining impairment and disability: Issues at stake.
In C.Barnes & G. Mercer (Eds.), *Exploring the divide: Illness and disability*. Leeds: The Disability Press.
- Oliver, M. (1996b). *Understanding disability: From theory to practice*.
London: Macmillan.
- Oliver, M. (1997). Emancipatory research: Realistic goal or impossible dream? In C. Barnes & G. Mercer (Eds.), *Doing disability research*.
Leeds: The Disability Press.
- Orona, C.J. (1997). Temporality and identity loss due to Alzheimer's disease.
In A. Strauss & J. Corbin (Eds.), *Grounded theory in practice*. London: Sage.
- Parker, I. (1994). Qualitative research. In P.Banister, E.Burman, I.Parker, M.Taylor & C. Tindall (Eds.), *Qualitative methods in psychology: A research guide*. Buckingham: Open University Press.

REFERENCES

- Parker, I. (1999). Critical reflexive humanism and constructivist psychology.
In D.J. Nightingale & J. Cromby (Eds.), *Social constructionist psychology*.
Buckingham: Open University Press.
- Peräkylä, A. (1997). Reliability and validity in research based on transcripts.
In D. Silverman (Ed.), *Qualitative research: Theory, method and practice*.
London: Sage.
- Phillips, M. J. (1992). "Try harder": The experience of disability and the
dilemma of normalisation. In P. M. Ferguson, D. L. Ferguson &
S. J. Taylor (Eds.), *Interpreting disability: A qualitative reader*.
London: Teachers College Press.
- Pidgeon, N. & Henwood, K. (1997). Using grounded theory in psychological
research. In N. Hayes (Ed.), *Doing qualitative analysis in psychology*.
Hove, U.K.: Psychology Press.
- Piven, J., Harper, J., Palmer, P. & Arndt, S. (1996). Course and behavioral
change in autism: A retrospective study of high-I.Q. adolescents and
adults. *Journal of the American Academy of Child and Adolescent
Psychiatry*, **35**, 523-529.
- Priestley, M. (1997). Who's research?: A personal audit. In C. Barnes &
G. Mercer (Eds.), *Doing disability research*. Leeds: The Disability Press.
- Rape, R.N., Bush, J.P. & Slavin, L.A. (1992). Toward a conceptualization of
the family's adaptation to a member's head injury: A critique of
developmental stage models. *Rehabilitation Psychology*, **37**, 3-22.

REFERENCES

- Rennie, D.L. (2000). Grounded theory methodology as methodical hermeneutics: Reconciling realism and relativism. *Theory and Psychology*, **10**, 481-502.
- Rennie, D., Phillips, J.R. & Quartaro, G.K. (1988). Grounded theory: A promising approach to conceptualization in psychology? *Canadian Psychology*, **29**, 139-150.
- Rumsey, J.M., Rapoport, J.L. & Sceery, W.R. (1985). Autistic children as adults: Psychiatric, social and behavioural outcomes. *Journal of the American Academy of Child and Adolescent Psychiatry*, **24**, 465-473.
- Rutter, M. (1978). Diagnosis and definition of childhood autism. *Journal of Autism and Childhood Schizophrenia*, **8**, 139-161.
- Rutter, M. & Schopler, E. (1992). Classification of pervasive developmental disorders: Some concepts and practical considerations. *Journal of Autism and Developmental Disorders*, **22**, 459-482.
- Schopler, E. (1998). Premature popularisation of Asperger syndrome. In E. Schopler, G. B., Mesibov & L. J. Kuncie (Eds.), *Asperger syndrome or High Functioning Autism?* London: Plenum Press.
- Schopler, E. & Mesibov, G.B. (1983; Eds.), Autism in adolescents and adults. In *Current issues in autism*. New York: Plenum Press.
- Schopler, E. & Mesibov, G.B. (1992; Eds.), Neurobiological issues in autism. In *Current issues in autism*. New York: Plenum Press.

REFERENCES

- Schopler, E., Mesibov, G.B. & Kunc, L.J. (1998; Eds.), *Asperger syndrome or High Functioning Autism?* London: Plenum Press.
- Shah, A. (1999). Asperger's syndrome: Behaviour issues. Conference proceedings of the National Conference on Asperger's syndrome: Diagnostic and management issues looking beyond childhood. Regent's College, London, 7 October 1999.
- Shakespeare, T. & Watson, N. (1997). Defending the social model. In L. Barton & M. Oliver (Eds.), *Disability studies: Past, present and future*. Leeds: The Disability Press.
- Sherrard, C. (1998). Social dimensions of research. *The Psychologist*, **11**, 486-487.
- Silverman, D. (1997). *Qualitative research: Theory, method and practice*. London: Sage.
- Silverman, D. (2000). *Doing qualitative research: A practical handbook*. London: Sage.
- Stevenson, C. & Cooper, N. (1997). Qualitative and quantitative research. *The Psychologist*, **10**, 159-160.
- Strauss, A. (1987). *Qualitative analysis for social scientists*. Cambridge: Cambridge University Press.
- Strauss, A. L. & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. London: Sage.

REFERENCES

- Szatmari, P., Bartolucci, G., Bremner, R.S., Bond, S. & Rich, S. (1985).
A follow-up study of high functioning autistic children. *Journal of Autism
and Developmental Disorders*, **19**, 213-226.
- Szatmari, P., Bartolucci, G. & Bremner, R. (1989). Asperger's syndrome
and autism: Comparisons on early history and outcome. *Developmental
Medicine and Child Neurology*, **31**, 709-720.
- Szivos, S. (1992). Labelling: A path to stigmatization or to increased
understanding and awareness? *Clinical Psychology Forum*, **39**, 2-6.
- Tajfel, H. (1981). Social stereotypes and social groups. In J. C. Turner &
H. Giles (Eds.), *Intergroup behaviour*. Oxford: Blackwell.
- Tanguay, P.E., Robertson, J. & Derrick, A. (1998). A dimensional
classification of autistic spectrum disorder by social communication
domains. *Journal of the American Academy of Child and Adolescent
Psychiatry*, **37**, 271-277.
- Tantam, D. (1986). Eccentricity and autism. Unpublished PhD. thesis,
University of London.
- Tantam, D. (1988a). Lifelong eccentricity and social isolation I: Psychiatric,
social and forensic aspects. *British Journal of Psychiatry*, **153**, 777-782.
- Tantam, D. (1988b). *A mind of one's own: A guide to the specific
difficulties and needs of the more able person with autism or Asperger
syndrome*. London: National Autistic Society.

REFERENCES

- Tantam, D. (1991). Asperger syndrome in adulthood. In U. Frith (Ed.), *Autism and Asperger syndrome*. Cambridge: Cambridge University Press.
- Tantam, D. (2000). Adolescence and adulthood of individuals with Asperger syndrome. In A. Klin, F.R. Volkmar and S.S. Sparrow (Eds.), *Asperger syndrome*. London: Guildford Press.
- Taylor, G. (1990). Adolescence and early childhood: The needs of the more able young adult. In K. Ellis (Ed.), *Autism: Professional perspectives and practice*. London: Chapman Hall.
- Thomas, K.R. & Siller, J. (1999). Object loss, mourning and adjustment to disability. *Psychoanalytic Psychology*, **16**, 179-197.
- Turner, B. (1981). Some practical aspects of qualitative data analysis: One way of organizing process associated with the generation of grounded theory. *Quality and Quantity*, **15**, 225-247.
- Turpin, G., Barley, V., Beail, N., Scaife, J., Slade, P., Smith, J. A., & Walsh, S. (1997). Standards for research projects and theses involving qualitative methods: Suggested guidelines for trainees and courses. *Clinical Psychology Forum*, **108**, 3-7.
- Volkmar, F.R. & Klin, A.K. (2000). Diagnostic issues in Asperger syndrome. In A. Klin, F.R. Volkmar & S.S. Sparrow (Eds.), *Asperger syndrome*. London: Guildford Press.

REFERENCES

- Whitbourne, S. K. & Sherry, M. (1991). Identity processes and perceptions of the life span in chronic mental patients. *International Journal of Aging and Human Development*, **33**, 65-73.
- Wing, L. (1981). Asperger's syndrome: A clinical account. *Psychological Medicine*, **11**, 115-129.
- Wing, L. (1988). The continuum of autistic characteristics. In E. Schopler & G. B. Mesibov (Eds.), *Diagnosis and assessment in autism*. London: Plenum.
- Wing, L. (1991). The relationship between Asperger's syndrome and Kanner's autism. In U. Frith (Ed.), *Autism and Asperger syndrome*. Cambridge: Cambridge University Press.
- Wing, L. (1997). Asperger's syndrome: Management requires diagnosis. *Journal of Forensic Psychiatry*, **8**, 253-257.
- Wing, L. (1998). The history of Asperger syndrome. In E. Schopler, G. B. Mesibov & L. J. Kuncie (Eds.), *Asperger syndrome or high functioning autism?* London: Plenum Press.
- Wing, L & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders*, **9**, 11-29.
- Wolff, S. (1995). *Loners: The life path of unusual children*. London: Routledge.

REFERENCES

Wood, P. (1980). *International classification of impairments, disabilities and handicaps*. Geneva: World Health Organization.

World Health Organization (1989). *ICD-10: International statistical classification of diseases and related health problems*, 10th review. Geneva: World Health Organization.

World Health Organization (1992). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

World Health Organization (1993). *The ICD-10 classification of mental and behavioural disorders: Diagnostic criteria for research*. Geneva: World Health Organization.

Yuker, H. E. (1994). Variables that influence attitudes toward people with disabilities: Conclusions from the data. In D.S. Dunn (Ed.), *Psychosocial perspectives on disability*. Corte Madera, California: Select Press.

6.0 APPENDICES

6.1 Diagnostic criteria for Asperger's syndrome

Current diagnostic criteria for Asperger's syndrome, from the Diagnostic and Statistical Manual, Fourth Edition of the American Psychiatric Association (DSM-IV; A.P.A., 1994) and the International Classification of Diseases, Tenth Edition of the World Health Organization (ICD-10; 1992) are presented below.

These criteria are provided for illustration. Alternative criteria for Asperger's syndrome have appeared in the research literature, notably those of Gillberg and Gillberg (1989) and Szatmari et al. (1989).

6.1.1 Diagnostic criteria for 'Asperger's Disorder', DSM-IV (A.P.A., 1994)³⁰

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

³⁰ Taken from Attwood (1998, pp.198-199).

- B. (1) Restricted repetitive and stereotyped patterns of behaviour, interests and activities that is abnormal either in intensity or focus;
(2) Apparently inflexible adherence to specific, non-functional routines or rituals;
(3) Stereotyped and repetitive motor mannerisms (e.g. hand or finger-flapping or twisting, or complex whole-body movements);
(4) Persistent preoccupation with parts or objects.
- C. The disturbance causes clinically significant impairment in social, occupational or other important areas of functioning.
- D. No clinically significant general delay in language.
- E. No clinically significant delay in cognitive development or in the development of age appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another pervasive developmental disorder or schizophrenia.

6.1.2 Diagnostic criteria for 'Asperger's syndrome', ICD-10 (W.H.O., 1993)³¹

- A. No clinically significant general delay in spoken or receptive language or cognitive development. Diagnosis requires that single words should have been developed by 2 years of age or earlier and that communicative phrases be used by 3 years of age or earlier. Self-help skills, adaptive behaviour, and curiosity about the environment during the first 3 years should be at a level consistent with normal intellectual development. However, motor milestones may be somewhat delayed and motor clumsiness is usual (although not necessary for diagnosis). Isolated special skills, often related to abnormal preoccupations are common, but are not required for diagnosis.
- B. Qualitative abnormalities in social interaction are manifest in at least two of the following areas:
- (1) Failure adequately to use eye-to-eye gaze, facial expression, body posture, and gesture to regulate social interaction;
 - (2) Failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions;
 - (3) Lack of socio-emotional reciprocity as shown by an impairment or deviant response to other people's emotions; or lack of modulation of behaviour according to social context; or a weak integration of social, emotional and communicative behaviours;
 - (4) Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. a lack of showing, bringing, or pointing out to other people objects of interest to the individual).

³¹ Taken from Attwood (1998, pp. 200-201).

- C. The individual exhibits an unusually intense, circumscribed interest or restricted, repetitive and stereotyped patterns of behaviour, interests and activities manifest in at least one of the following areas:
- (1) An encompassing preoccupation with stereotyped and restricted patterns of interest that are abnormal in content or focus; one or more interests that are abnormal in their intensity and circumscribed nature though not in the content or focus;
 - (2) Apparently compulsive adherence to specific, non-functional routines or rituals;
 - (3) Stereotyped and repetitive motor mannerisms that involve either hand / finger flapping or twisting, or complex whole body movements;
 - (4) Preoccupations with part-objects or non-functional elements of play materials (such as their colour, the feel of their surface, or the noise / vibration that they generate); However it would be less usual for these to include either motor mannerisms or preoccupations with part-objects or non-functional elements of play materials.
- D. The disorder is not attributable to other varieties of pervasive developmental disorder, simple schizophrenia, schizo-typal disorder, obsessive-compulsive disorder, reactive and disinhibited attachment disorders of childhood.
-

6.2 Details of participants

This appendix presents brief biographical details of the six research participants. Information was gained from participants' self-reports in the first instance and, where possible, verified from reports provided to the West Midlands Autistic Society Limited. The latter included details of all participants' psychiatric diagnoses. This information is intended to assist the reader in gauging the transferability of the results to other settings. Names of individuals and places have been changed to protect participants' identities.

6.2.1 'Anthony Hill'

Andrew was aged 22 years at interview. As a child he attended mainstream school, including a local grammar school. At 14 years Anthony was assessed by an educational psychologist following difficulties in completing academic work on time. As a result, he was referred on to a Consultant Psychiatrist who diagnosed 'Asperger syndrome'. Anthony maintained his place at school and went on to a further education college. From this point he also received part-time social support, funded by social services. Anthony subsequently went up to a local university to read computer science; however, he left after one year after failing exams. He then took up voluntary work placements with two private companies, working as a computer programmer. At interview, Anthony continued to live with his parents. His main interest remained computers, and a room in the family home was dedicated to his hobby. When asked, Anthony reported two reciprocal friendships; these were a female friend of his parents, whom he regarded as a "girlfriend", and his previous male support worker.

6.2.2 'Natalie Newman'

Natalie was aged 24 years at interview. During childhood she attended mainstream schools, although she received individual support in the special educational needs (S.E.N.) unit at her secondary school. At 13 years Natalie was referred for individual (psychodynamic) psychotherapy prompted by increasing social withdrawal, which she associated with bullying at school. At 16, she was diagnosed with 'Asperger syndrome' by her therapist, a consultant psychiatrist. After school, Natalie attended further education college, gaining an advanced level vocational qualification (GNVQ). At interview she continued to live with her parents. She worked part-time as a volunteer in a local charity shop. Natalie was single, and reported having no close friends. However, she did report one "boyfriend" during her early years at secondary school.

6.2.3 'Peter Welford'

Peter was 37 years at interview. He was adopted in infancy and grew up with his step-parents and two step-sisters. Peter attended special needs schools. He was diagnosed with non-specific learning disability by a psychiatrist shortly after leaving school, and he then attended a residential college for adults with learning difficulties in Yorkshire. At 19, he returned to the Midlands to live in a supported home for learning disabled adults. Peter remained there until he was 35 when he was encouraged to move to a flat of his own, without support. Shortly after that, he approached the West Midlands Autistic Society as a volunteer, but was himself referred to a consultant psychiatrist. In 1998 Peter was given a revised diagnosis of 'Asperger syndrome', and learning disability was specifically excluded. At interview Peter had lived independently for two years. He worked as a part-time volunteer at a residential home, spent much of his time painting, and had started an G.C.E. A-level course in art studies. He was single, and reported no close friends or previous intimate relationships.

6.2.4 'Damian Heap'

Damian was 34 years old at interview. He had been diagnosed with 'infantile autism' at 3½ years by a consultant psychiatrist. At that time he had significant delay in his speech development and was noted to have presented "a typical pattern of autism". However, he went on to develop normal, communicative speech and attended mainstream schools. Damian's parents lived abroad during his childhood, and he attended several private boarding schools, including sixth form. At 18 years he went up to university, gaining a science degree. Damian went on to complete a PhD. that included two years of field research in South America and Africa. He subsequently worked as a university lecturer, but left the post when his university accommodation expired. At interview, he lived independently in a rented flat. He worked as a self-employed photographer and was involved in a local photographic society in his spare time. Damian was single. He reported having no close friends and no previous or current intimate relationships.

6.2.5 'Jacob McCluskey'

Jacob was 27 years of age at interview. He had attended special needs schools until 16 years of age, although he was not diagnosed with a learning disability. After school, he attended further education college, completing a GCSE in mathematics. He later gained a Higher National Diploma in an arts subject. At 26 years, Jacob was diagnosed with 'Asperger syndrome' by a consultant psychiatrist. At interview, Jacob lived independently in a rented flat. He was single and reported having no close friends. Jacob was not employed, and he reported never having been in paid employment. He identified himself as a member of the black community and he felt that this contributed to his experience of social isolation because he lived in a predominantly 'white' area.

6.2.6 'William Anderson'

William was 22 years of age at interview. As an infant he was diagnosed with diplegia, a form of cerebral palsy that affected his gait. He grew up in a small village and attended local mainstream schools, including sixth form. At 18 years, he went up to a university in the Midlands. William reported difficulties identifying with other students in the halls of residence. His parents then moved from their home in Wiltshire to provide social support. William subsequently gained a first class degree in music. In November 1999, he was diagnosed with 'Asperger syndrome' by a consultant psychiatrist, although William claimed to have realised he 'had' autism two years before after reading a magazine article. At interview, he continued to live with his parents. He was single, and reported never having been in an intimate relationship. He did report having "one or two friends" whom he met at university. William taught music on a part-time basis, and he hoped to use his degree to follow a career in music.

6.3 Letter of invitation to participants

[DATE]

Dear [CANDIDATE],

My name is Craig MacDonald and I am carrying out a research study as part of my post-graduate training to become a Clinical Psychologist. I am writing to ask you if you would consider taking part in my study.

Andrea MacLeod, Coordinator for adults with Asperger syndrome at the West Midlands Autistic Society, suggested that you may be interested in taking part in this research, and I have asked her to forward this letter to you.

Could you please read the enclosed Information Sheet, which explains more about the project and what taking part would involve.

I will contact you via Andrea within two weeks to find out if you have any further questions. If you prefer, you can contact me by post at the address above, or leave a message by telephoning 0116-252-2162 and I will return your call.

Thank you for your time. I hope to speak to you soon.

Yours sincerely,

Craig MacDonald

6.4 Information Sheet

Participant Information Sheet

Title of study: Able autistic adults' constructions of their social disability.
Principal Researcher: Craig MacDonald (Tel: 0116 252 2162).

What is the study about?

The aim of the study is to understand how adults who have been given a diagnosis on the 'autistic spectrum' (for example, 'Asperger syndrome' or 'High-functioning autism'), have made sense of their social disability. In particular, the study focuses on more able autistic adults' own points of view, rather than what other people -including psychologists- may sometimes understand the issues to be.

This information would be useful because psychologists need a shared understanding of their clients' view of the world. The results of the study will contribute to psychologists being better informed about the needs of able autistic adults that they may work with in the future.

Who else is taking part?

All of the people invited to take part in this study are adults who have been given a diagnosis on the autistic spectrum by a psychiatrist or a psychologist, and who have sought some outreach support associated with autism.

Everyone invited to take part will be relatively independent. This is because the study is concerned with the experiences of adults who are distinguished from other adults only in terms of autism. A maximum number of ten people will be taking part.

What will the study involve ?

Taking part in the study will mean meeting once with me, Craig MacDonald, to talk about your views. The meeting would take about one hour and would be arranged at a time convenient to you. If you agree to take part, we would meet at the West Midlands Autistic Society offices in Harbourne, Birmingham, or at your home if that were more convenient to you.

I would also like to audio-tape the conversation, to make sure that I do not miss anything that we talk about. You would be entitled to a copy of any tapes made.

Continued overleaf...

What happens to the information?

Anything that you say to me as part of this study will be kept strictly confidential. No names, addresses or any other information that may identify you will be kept on computer or will appear in any reports of the project. At the end of the project, any tapes made of our conversation will be permanently erased (that is, by 31st January, 2001 at the latest).

What if I don't want to take part?

You do not have to take part in this study if you do not want to. If you do choose to take part, you will be free to change your decision and withdraw from the study at any point.

Whether you decide to take part or not, your decision will not affect any help that you may be receive now or in the future from the West Midlands Autistic Society or the National Health Service.

What happens now if I decide to take part?

I will contact you within the next two weeks via Andrea MacLeod, Coordinator for adults with Asperger syndrome at the West Midlands Autistic Society, in order to answer any remaining questions you may have. If you would like any further information before then, you can contact me by post at the address at the top of the Information Sheet, or else leave a message for me by telephone and I will call you back.

If you do decide to take part, I will send you a Consent Form to confirm that you understand what is involved. Andrea MacLeod has agreed to witness and collect the Consent Forms for the study. She has no other involvement with the study, and her role will be to continue to act as an independent source of support for you.

If you do agree to take part, then I will write to your G.P. or consultant, to let him or her know, and to make sure that they have no concerns.

I will then contact you to arrange a convenient time and place to meet. Of course, if you do consent to take part, you will still be able to change your mind at any time.

Contact address and telephone number

My full postal contact address at the Centre for Applied Psychology is given on the letterhead of this Information Sheet. You can leave telephone messages for me there during office hours and I will return your call. The telephone number is: 0116-252-2162.

Thank you for your time.

Craig MacDonald

Version 3: March 2000

6.5 Consent form (Version 1: South Birmingham)

PARTICIPANT CONSENT FORM

Title of study: Able autistic adults' constructions of their social disability.

Principal Researcher: Craig MacDonald, Centre for Applied Psychology -Clinical
Section, University of Leicester, LE1 7RH. (Tel: 0116 252 2466)

This form should be read in conjunction with the Participant Information Sheet

- I agree to take part in the above study as described in the Information Sheet.
- I understand that I may withdraw from the study at any time without justifying my decision and without affecting any provision available to me under the National Health Service, or any support offered to me by the West Midlands Autistic Society.
- I understand that any information that I give will be treated as confidential by the Researcher, Craig MacDonald. I understand that no names, addresses or other information which may identify me will be held on computer or included in any transcript or report of this research project.
- The need for the research interview to be audio-taped has been explained to me. I understand that the audio-tape of my interview will be stored securely. I understand that the information contained on the audio tapes will remain confidential and will be used only for this research project.
- I understand that I am entitled to a copy of the audio-tape of my interview. The Researcher, Craig MacDonald, will permanently erase all remaining audio-tapes of my interview at the end of the project (that is, by January 31st, 2001 at the latest).
- If I choose to withdraw from the project, then the Researcher will permanently erase the recordings of my interview as soon as possible.
- I understand that clinical research of this type is covered for mishaps in the same way as for patients undergoing treatment in the N.H.S.; that is, compensation is only available if negligence occurs.
- I have read the Participant Information Sheet on the above study and have had the opportunity to discuss the details with the Researcher, Craig MacDonald, and to ask any questions. The nature and the purpose of the interview to be conducted have been explained to me. I understand what will be required if I take part in the study.

Signature of Participant Date.....

(Name in BLOCK CAPITALS).....

I confirm that I have explained the nature of the study, as detailed in the Participant Information Sheet, in terms that, in my judgement, are suited to the understanding of the participant.

Signature of the Researcher..... Date.....
(Name in BLOCK CAPITALS).....

6.5 Consent form (Version 2: Worcestershire)

PARTICIPANT CONSENT FORM

Title of study: Able autistic adults' constructions of their social disability.
Principal Researcher: Craig MacDonald (Tel: 0116 252 2162)

This form should be read in conjunction with the Participant Information Sheet

- I agree to take part in the above study as described in the Participant Information Sheet.
- I understand that you will write to my GP or consultant to advise that I have signed this consent form and that they have no concerns about my participation.
- I understand that I may withdraw from the study at any time without justifying my decision and without affecting any care available to me under the National Health Service, or any support offered to me by the West Midlands Autistic Society Ltd..
- I understand that any information that I give during this study will be treated as confidential by the Researcher, Craig MacDonald. I understand that no names, addresses or other information which may identify me will be held on computer or included in any transcript or report of this study.
- The need for the research interview to be audio-taped has been explained to me. I understand that the audio-tape of my interview will be stored securely. I understand that the information contained on the audio tape will remain confidential and will be used only for this research study.
- I understand that I am entitled to a copy of the audio-tape of my interview. The Researcher, Craig MacDonald, will permanently erase any remaining audio recordings of my interview at the end of the project (that is, by January 31st, 2001 at the latest).
- If I choose to withdraw from the project, then the Researcher will permanently erase the recordings of my interview as soon as possible.
- I understand that clinical research of this type is covered for mishaps in the same way as for patients undergoing treatment in the N.H.S.; that is, compensation is only available if negligence occurs.

continued overleaf...

- I have read the Participant Information Sheet for the above study and have had the opportunity to discuss the details with the Researcher, Craig MacDonald, and to ask questions. The nature and the purpose of the interview to be conducted have been explained to me. I understand what will be required if I take part in the study.

Independent Advice

If you would like independent advice about taking part in the study, you can contact the Community Health Council at:

Burgage Lodge, 184 Franche Road, Kidderminster, Worcs. DY11 5DA -
Telephone: 01562 69243; or

Red House, Church Green West, Redditch, B97 4BG -Telephone: 01527
61375; or

Severn House, 10 The Moors, Worcester, WR1 3EE -Telephone: 01905
22715.

If you do wish to take part in the study, please sign one copy of this consent form in the space below.

Signature of Participant.....
Date.....

(Name in BLOCK
CAPITALS).....

Witnessed by.....
Date.....

(Name in BLOCK
CAPITALS).....

6.6 Letter to participant's G.P. / Consultant

Dear [Dr./ Mr/Mrs/Ms]

re: [Name, D.O.B., Address]

I am currently undertaking a research project as part of the Doctorate in Clinical Psychology training course at Leicester University. I am interested in how able adults with diagnoses on the autistic spectrum (e.g. Asperger syndrome or High Functioning Autism) understand their social disability. This information would be useful for psychologists in highlighting any unidentified needs of this group, and by providing better understanding of how those needs are communicated in practice.

To obtain this information I intend to conduct semi-structured interviews with a small number of adults currently in contact with the West Midlands Autistic Society's Community Outreach Project.

Individuals consenting to participate in the study will be interviewed on one occasion for approximately one hour. These interviews will be audio-taped with the participants' consent. Relevant N.H.S. ethics approval has been obtained. I have enclosed a copy of the Participant Information Sheet and Protocol for your information.

The above named person was suggested as a potential participant for the study, and [he/she] has indicated [his/her] consent to take part and for me to inform you. However, before I proceed further, I would like to know if you have any objections to [his/her] participation in the study.

If you do have any concerns or queries, could you please contact me within the next two weeks?

Yours sincerely,

Craig MacDonald
Psychologist in Clinical Training

6.7 Interview schedule

A four-item interview schedule was used to structure research interviews. This provided a minimal pre-conceived 'frame' for exploring the research question and allowed the researcher to impose cues for social interaction during the interview, if required. Following Dey (1993) the interview schedule was developed from existing literature, specifically the concepts of autism and adulthood. Participants were prompted about:

- 1) Their experiences of receiving a diagnosis of autism.
- 2) Their early or initial experiences of social disability
- 3) Their understanding of how, if at all, their disability had changed as adults;
and
- 4) Their expectations of future change.

6.8 Interview transcripts

(Bound as separate addendum)

6.9 Sample of open coding procedure

The following four pages provide an example of the initial open coding procedure described in Chapter 2 (Part 2.6.2) and which took place during the early stages of the analysis.

Note that page numbers on the following four pages are those in the transcript (Appendix 6.8, separate volume).

PAGE
CONTAINS
PEN/PENCIL
MARKS

INTERVIEW WITH 'NATALIE NEWSON', 24th MARCH 2000

'C:' indicates Craig MacDonald

'N:' indicates Natalie Newson

1 C: I suppose a good place to start is when you got a diagnosis and what
2 it was of. Can you remember?

3 N: I don't remember getting a formal diagnosis as such, I just
4 remember as a kid of about twelve or thirteen years old erm, going to
5 see the- the doctor at school and erm- and then- and then it sort of
6 going from there and then I was referred to a- a psychotherapist, so I
7 think I actually got my diagnosis through the school doctor as I
8 remember it, My mom and dad would probably know more about this
9 than- than I would.

10 C: Yes. I'm just interested in your- your experience. You know, what
11 you remember of it, 'cause erm =

12 N: = Oh at the time it was just so hard for me to take in because, I mean-
13 like I say I was at school and I was- I was only young, I only must
14 have been about twelve or thirteen something like that so to take it all in
15 at such a young age was just- just- you know such a big shock and
16 I remember that you know I was- I was sort of- Now I look back
17 on it I was in denial for a long time. You know I couldn't actually
18 believe that I had got the diagnosis of AS because up until that
19 point I guess- I guess I just thought that nothing- that nothing or
20 anything was wrong with me I suppose. I suppose, you know, I
21 wondered why I was teased as a kid, which I was constantly and- and
22 er, well I mean, you know, that was about it really apart from that.
23 You know, I was in- in complete denial. It was really hard for me to
24 take it all in I was thinking, 'Oh my gosh how am I going to cope with

?
Not aware initially (of diag/label)

Diagnosis or recognition as a point of change
Diag./Recognition as a trigger for treatment (recognition consequences)

Others as experts or knowledgeable (x self as not knowing?)

Initial disbelief / shock + denial as explanation

? consequences of misdiagnosis?

Diagnosis/recognition marks a point of change
Something wasn't - ASD
Change from nothing was (x of identity)

Puzzled / hindered over - re treatment / bullying

? Diagnosis even 'surprise'

no challenge to existing self-view xref / identity

Initial denial &c.

Doubting / questions are asked to cope

APPENDICES

25 this?' and 'How am I going to live with this?' and I just actually
26 knew nothing.

27 C: What happened before you went to see the doctor at the school? Can
28 you remember how you kind of made sense of things then?

29 N: When you say 'made sense of things' how do you mean? =

30 C: = When you said that you were teased at school?

31 N: Well, I was- I was teased at school a lot and all I remember was, 'Why
32 are people being like this to me?', you know, 'Why are they being so

33 nasty?' // It was- you know- I just felt like the moment I walked in

34 those school gates, you know, I was being teased and looked at all day,

35 and just generally being seen as something, you know, something

36 different. So I suppose I always had a bit of an inkling that I was-

37 that I was different from them, and that's about it. I mean I wondered

38 why- why, you know people were the way they were and, you know,

39 // I couldn't understand, you know, why I was being teased or why

40 people behaved toward me in a certain way/or- or whatever and that

41 was- that was about it // I was wondering, I suppose- I suppose I was

42 worried I was in a unit, and obviously it wasn't until I got a diagnosis

43 that it began to make more- make a bit more sense to me, really.

44 C: Where did you go to school then?

45 N: I went to Long Heath Comprehensive School.

46 C: And you were in a unit?

47 N: Yeah, I was in a unit for children with special- special needs, you know,

48 with learning difficulties and special needs and all the rest of it // As

49 opposed to being in a mainstream school //

50 C: = Right.

51 N: I was- you know, I was in about my second or third year I think it was.

52 Or perhaps it was fourth. Erm, it was a bit more integrated into the

53 mainstream life if you like, because at that point I had an assistant

Not hearing

Bullying/being teased

Pegged/wounded over others - we looked

Appearing different to others (Recognised as different)

Others have point of view? Others judgement of different - we looked

Pegged initially xref Not knowing

Worried/Anxiety as being seen as different/teased

Diagnosis - obvious explanation

Recognised/Teased as different (LD)

But within mainstream too (xref location) - integrated

? Degree of integration here

Understanding of what it was / not quite distinct

Memo
"Process of understanding"

? Wasn't trying to make sense

54 and she used to go along and help me with my school work, and with
 55 my classes and all the rest of it, and stood- and took notes for me and
 56 all the rest of it, and anything else that erm, you know, I might need
 57 help with. And so I was taking part in mainstream classes, but to a
 58 certain extent I was- I was in a unit as well, so-

59 C: So- What? That was about the point that you went to see the doctor and

60 then =

61 N: = No. The point that I went to see the doctor was before I actually went
 62 into the mainstream.

63 C: = Right.

64 N: part of the school if you like because, as I say, I think I was only about
 65 twelve or thirteen at the time that I went to-

66 C: So, at that point did it seem like, you know, 'This is it. I'm about to go
 67 back and join the mainstream, so I'm not different any more'? Or
 68 did you still feel that you were different?

69 N: I suppose I suppose I was still very much in denial that, you know, I
 70 mean, that I couldn't even take in what was- you know, what was
 71 happening to me. Do you know what I mean, because I was- I was just
 72 I was so shocked. And also I suppose what made it harder was, not
 73 only to have to cope with this diagnosis of A.S.D. ((i.e. Autistic
 74 Spectrum Disorder)), but it couldn't have come at a worse time because
 75 you know, I was being bullied as well. And so being bullied on
 76 top of having to cope with the diagnosis was almost like having two-
 77 And I thought, 'I just can't handle this'. So I mean, I suppose it was
 78 almost like I was it was almost like I had some sort of defence
 79 mechanism, which was erm- which I guess was like denying it all
 80 and it not really sinking in, and all the rest of it because I just felt
 81 so overloaded with all this stuff I had to cope with and I just
 82 couldn't- couldn't cope with it. And I didn't have much support. I

Supported /
Help from
via +ve
support from
others

Tensions in myself
self
Identity
Defence

Diagnosis /
recognition
→ +ve change /
treatment

Initial denial
as a defence
(xref acceptance)

Doubting own
ability to cope /
or accommodate
(being treated as
different)

Initial shock

Having to
cope

Bullied -
(opposite to diagnosis
/ disability acc.)

Doubts own
ability to cope

Initial denial
(as a)
Defence
+ ref coping

Initial denial
defence

Doubting own
ability to cope

Having to cope

Coping
Help /
Support

83 mean my family- my family were er, you know, my family were
 84 obviously very worried about me at the time, being bullied and
 85 having this diagnosis of A.S.D.//so they had that to cope with as well//
 86 So I guess maybe they couldn't be as perhaps/as supportive as I would
 87 have liked them to have been//or needed them to be, or- wanted them
 88 to be, so I- I- it felt very much that I had to cope with all this on my
 89 own, because (I had no support) but there wasn't
 90 very much support.

91 C: What would you have liked?

92 N: I would have liked more support at school//I would have somebody
 93 who, you know, who- I suppose I would have liked- I suppose I would
 94 have liked an Andrea ((community outreach practitioner for adults with
 95 Asperger syndrome)). Do you know- Do you remember Andrea?

96 C: I know Andrea, yes.

97 N: I would have liked- I would have liked actually trained staff who knew
 98 what they were talking about, and who would be able to help me
 99 through all the difficulties I was going through at school, not just with
 100 the being bullied bit, but the actual perhaps coming with me to the
 101 diagnosis//Or, I don't know, perhaps the counsellor, or perhaps some
 102 other professional that knew what they were talking about//Although
 103 having said that, when I er- when I went to see my psychotherapist,
 104 which would have been about age twelve or thirteen- I mean my
 105 //parents were really worried about me//and my doctor said, you
 106 know, my doctor said that I was becoming really withdrawn and
 107 erm, you know, I wouldn't have wanted to go out- I would really not
 108 have wanted to go out to break times and lunch times at school and
 109 all the rest of it and so, my doctor said, 'Look, you know, your daughter
 110 is now on the edge of a nervous breakdown'//That's how serious it
 111 actually got. 'And, you know, you've got one of two options. Either you

6.10 Sample of focused coding procedure

The following three pages provide an example of the focused coding procedure described in Chapter 2 (Part 2.6.3). This represented a second level of transcript analysis in which initial categories were used to organise data.

Note that page numbers on the following three pages are those in the transcript (Appendix 6.8, separate volume).

INTERVIEW WITH 'JACOB McCLUSKEY', 18th JUNE 2000

'C:' indicates Craig MacDonald

'J:' indicates Jacob McCluskey

1 C: The first question is, erm, when did you get a diagnosis? Can you
2 remember?

3 J: Early last year. Early nine- Early ninety-nine, April time.

4 C: Right. And who was that by?

5 J: Consultant psychiatrist. Doctor Bhandal.

6 C: Oh right. Yes I know him.

7 J: Well that's news to me. ((Jacob laughs)).

8 C: And what- What was the diagnosis of?

9 J: Of Asperger's.

10 C: It was Asperger's? Because some people have a diagnosis of just
11 autism or =.

12 J: = Mm hm.

13 C: And erm- (.) what led to you going for a diagnosis?

14 J: I was trying to push forward / I was given certain information, I wrote
15 about myself, self-awareness, and I was pushing. I was having too
16 many problems and being told misled ((sic)) things, which I might
17 suffer from. Including- Including dyslexia, but I'm not dyslexic. //

18 C: Right. And was that- Was that at school as well?

19 J: No. This is- This is in the past three years.

20 C: Right. Ok.

21 J: No-one's ever questioned about whether I had a problem / or what,
22 except back in ninety-one when someone thought I had a short-term
23 memory ((sic)) But even then I tried to cover it, Nothing's wrong with
24 me". (.)

? Improvement
(as going forward)

Questioning others'
viewpoint / subject's
? contra Others as
misunderstandable
excess

? Diag / end as
something wrong
with
(Identity)

25 C: You tried to cover?

26 J: Tried to ignore it and say, "There's nothing wrong with me"/ I didn't
 27 want to show any negatives//

Dis/AS as
something
was
/...

28 C: Right.

29 J: Because I thought that it would be worse (). Especially when I was at
 30 college.

(Beliefs)
Recognition
→ -ve
feedback/
consequence

31 C: So how come you ended up going to see a psychiatrist to get a
 32 diagnosis?

Fears
exclusion/
-ve
feedback

33 J: Through my GP. Well, through the youth enquiries service 'Signal' in
 34 Worcester, I was encouraged to go to get some assessments/ That was

? Others as
expert

35 the main reason why (I went) towards assessment/ However I didn't
 36 get my assessment because they thought- because my continu- because

? Recognition
consequences

37 my condition or how I am, wouldn't seem to be the norm/ what sort of
 38 problem I had/

Not fitting

39 C: Yeah.

AS = ind. condition
personal, own
(xref identity)

AS/Idem
as not normal

40 J: I wasn't getting it. But then they asked for the diagnosis, because that

41 was the pressure I was- I was pressurised and saying, "Well I need

42 something because I can't carry on the same way"/ And them saying

Point of change

43 this and saying that and then saying, "You can't have an assessment"

? Diagnosis as
extension/
answer

44 and, "What's going to be done?"

45 C: So where did the pressure come from?

46 J: From self-awareness/ (.) from the press and everybody/ "Why aren't I at
 47 work?" / My family used to give me a hard time because they think I'm
 48 not using my common sense/ my cooping skills/

? Awareness
(press)
Pressure to
change from
flow

? NOT COOPING

49 C: Anyone else?

Others
judgment

50 J: (.) Society: Full stop. (.)

Contingent

51 C: And how did it go when you went? Was it just one meeting with

52 Doctor Bhandal?

53 J: There was two. There was- There was the one before the diagnosis,

54 that's the first time I seen him. And before that I met the community

55 nurse twice =

56 C: = Mm hm.

57 J: from the same department.

58 C: And how did it go?

59 J: Well, hhh, I just- It was- I thought- I thought it weren't going
60 nowhere ~~and I had a diagnosis, which is cool~~ but unfortunately they
61 didn't have any information to tell me about it // So the only way I found
62 out about Asperger's wasn't through them, it was through the World
63 Wide Web.

64 C: So did they tell you what the diagnosis was, at the time?

65 J: // They did tell me what the diagnosis was, but they didn't have any
66 information to tell me what it was about //

67 C: So it didn't mean anything to you?

68 J: // Well, I didn't talk about it - I didn't think about it 'til I found out what it
69 was /because it could have been another (.) catchword that might not
70 relate to me // and then I'd read about it =

71 C: = Yeah?

72 J: and it would start to make some sense // I mean, the main- the National
73 Autistic Society's the main website.

74 C: So you went to the- you went straight to the Web?

75 J: Straight to the Web, but there was other websites to look through and
76 the first one was one from Australia, believe it or not.

77 C: Yes. It that Oasis? Or am I thinking of another one?

78 J: Erm, I'm not sure if it's that one. Victoria, Victorian something.

79 C: Yeah. And when you saw information on the Web about Asperger's,
80 what did you think?

81 J: That- That- At that time it wasn't enough // They wasn't giving full
82 information, and they were focusing on autistic children on that one. So

nb. doesn't
say in
code
Others as
expert
(but not nec
identifying)
Need to
know / o/s
(Self as
uncaring)

Self as
not caring
re: Questioning
differs
viewpoint/
judgment/
humility

re: Need to
know/
identifying
(Self as
uncaring)
differs
(Self as
uncaring)