

HOW CAN AUTISTIC INTELLIGENCE BE RECOGNISED AND ACCOMMODATED IN AN INCLUSIVE EDUCATION FRAMEWORK?

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Abstract

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How can autistic intelligence be recognised and accommodated within an inclusive education framework?

The aims of this study were twofold and integrated. The first was to explore whether Hans Asperger's expression 'autistic intelligence' was a valid and possibly helpful concept to educators. The second was to discover whether this theorised cognitive style could be accommodated within an inclusive education framework. Four students on the autism spectrum, in mainstream schools, their parents and their teachers were interviewed in a case-study approach, to analyse their beliefs and understandings about autism.

Data analysis showed that parents and students in particular believed autism to involve a recognisable cognitive style. It tended, they said, to have sensory elements which impacted upon engagement and learning, and appeared to give rise to some social difficulties. These in turn were thought to impact upon the emotional wellbeing of students on the autism spectrum. Significant bullying and exclusion of these students was reported. They recognised their 'difference' from their peers and attempted to negotiate that difference. However, teachers tended to reject the concept of 'labelling' these students.

These findings in part reflect developing current theoretical and cognitive neuroscience consensus supporting a theorised Local Processing Bias as perhaps being a key element in defining core characteristics of autism. Additionally the research showed that the inclusive framework was perceived to be failing these students in many ways. In particular, the difficulties in obtaining educational help and support were believed, by students and their parents, to be obstructive. Another area of concern was the use of teaching assistants as the main educational intervention offered.

The inclusive framework, according to these stakeholders, appears to have little recognition of or accommodation for what might be called autistic intelligence. Yet this might possibly be accomplished by making some environmental adaptations. The concept of autistic intelligence, with its theorised perceptual bias, might be useful in considering the nature of any adaptations.

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**How can autistic intelligence be
recognised and accommodated within
an inclusive education framework?**

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Chapter 1: Introduction

1.1. Aims of this study

The question, 'How can autistic intelligence be recognised and supported within an inclusive education framework?' has been prompted by current controversies regarding the education of children on the autism spectrum, in terms of placement, provision and facilitation. The purpose of this study is therefore to access the beliefs and attitudes of three groups of stakeholders: four children with Autism Spectrum Conditions (ASCs) their parents, and their teachers, to discover whether insights can be offered which might shed light on these controversies.

The underlying purpose will be to discover whether the term 'autistic intelligence' has any validity or usefulness. This is the first qualitative study of autism spectrum conditions within an educational setting to have employed these three groups of stakeholders. Few studies have used the expression autistic intelligence, the first being a paper which concerned IQ results (Dawson et al, 2007). It has not been used in that specific sense in this current study, but as a proxy to explain the cognitive differences thought to characterise autism, and as first employed by Hans Asperger (1944).

The term Autism Spectrum Conditions will be used throughout this study, except where quotation is necessary. This has been chosen to replace the

more commonly used Autism Spectrum Disorders, a clinical term. Autism Spectrum Conditions has been employed as the preferred term by the Autism Research Centre in Cambridge, UK, for over 10 years (Baron-Cohen et al, 1999) and has recently (2009) been adopted by the Department of Health in their documentation, websites, reports and advice on autism (Department of Health, 2009), and by all local authorities throughout the UK, in, for example http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/DH_079431.

This has been done so as to further clarify the nature of this research. It does not examine autism as a clinical disorder, except where it is necessary to refer to the history and current standing of research in this field. The focus of the study is educational in nature, seeking to define those qualities of cognitive engagement which might be presented by children and adults on the autism spectrum in an educational setting.

Currently autism, as a condition, is viewed as a problem or a difficulty to educators, as the only access to understanding how it presents, and therefore what might help in making supportive adaptations, is through the diagnostic criteria used to describe the behaviours associated with the clinical diagnosis. These can be confusing as there appears to be little connection between the three separate elements, or Triad of Impairments (Wing and Gould 1979), included in the criteria. These are impairments in communication, social facility, and in imagination, which is often described as cognitive, and therefore behavioural, inflexibility. What is necessary is to find, if possible, a unified and explanatory theoretic which could enable educators to understand exactly how these individuals may process information. This might empower

teachers to adapt the environment to suit this particular cognitive style where necessary. It is hypothesised that the term 'autistic intelligence', together with direction as to what this may be and why it may occur, may act as the key to unlocking understandings.

In order to attempt to define autistic intelligence, this study returns to essential primary sources, to the initial findings by Kanner (1943) and Asperger (1944), and to recent cognitive neuro-scientific studies. It is a research project which intentionally and systematically crosses many disciplinary boundaries in order to discover and enable new understandings.

1.1.1 Background to this study

In 2006, the Education and Skills Committee of the House of Commons reported on an Inquiry it had undertaken into Special Educational Needs, taking oral and written evidence from parents, educationalists, voluntary groups and MPs (HOC Education and Skills Committee, 2006). A repeated concern voiced throughout this report was the provision for autism spectrum children within an inclusive education framework. The government response, published in October of that year (HMSO, 2006:61) included the statement:

....[the Government] does not believe that, building on the experience of these children and their families, it is fair to characterise the provision made generally for these children as being in a state of crisis. Such comments fail to take account of the complexity of autism and the

inherent difficulties individual children with a developmental, social communication disorder can present to a school system

There is a Code of Practice for special educational needs (DfES, 2001) and there have been many publications on special educational needs (DfEE, 1997; DfES, 2004b). Yet currently, pressing policy concerns have become evident in a very recent series of national inquiries and reports, including two Ofsted Reports on Inclusion (OFSTED, 2004; OFSTED, 2006), and the commissioning of a further report, the Lamb Inquiry into special educational needs and parental confidence, (Lamb, 2009) in which autism spectrum conditions were a major subject. Recently the Autism Act, which makes provision for the support of adults and youth, became law (HMSO, 2009). There appears to be considerable inquiry and documentation as to what might now best be achieved for children and young people with special educational needs, in particular those who may be on the autism spectrum. The acknowledgement of the 'difficulties' these students 'present to a school system' does demonstrate some awareness of governmental concerns regarding those with autism.

There are other examples of documented evidence which appear to strengthen the concerns which are being raised by those on the autism spectrum and those who support them. Each year the National Autistic Society (NAS), the UK's leading non-governmental organization in the support of autistic children and their families, commissions a survey into some aspect of their lives, which then becomes the campaign for the year. In common with

all other years, in 2006, questionnaires were sent out to all relevant members, with 1,271 returned, a proportion of only 13.5% of their total membership, which attempted to discover their experiences with the educational system. The results were published in that year's campaign, 'Make Schools Make Sense' (Batten et al, 2006). 25 children were also interviewed for the campaign and the survey, and some teachers were interviewed. 47% of those who returned the survey said that their child was educated in a mainstream setting, and 37% in a special school setting.

In interpreting the findings, caution must be exercised, as this sample may consist of parents who feel so strongly about their child's condition that they have joined an advocacy group, and filled out and returned a questionnaire. A low overall response level such as this (13.5% of total membership) is perhaps more likely to reveal strong feelings or particularly poor experiences. However, the findings are useful, and are relevant to this study as they reveal experiences of some parents in accessing a suitable educational provision for their child (Batten et al, 2006). It was the biggest survey on autism education ever carried out in the UK.

Results revealed that over 50% of these particular children were not in the kind of school that their parent thought might best support them. 66% of parents of these children said that their choice of school was limited by a lack of appropriate placements for children with autism in their local area. 30% of parents of these children in some form of mainstream placement were satisfied with the understanding of autism within the school, while only 27%

reported that mainstream teachers were adjusting their approach and teaching materials to the child, with that figure dropping to 13% for secondary school aged children. Worryingly, 23% of parents felt that the Special Educational Needs Coordinator in their child's school had little understanding of autism. 45% of parents said that it took over a year for their child to receive any support. Only 53% of children aged between 14 and 19 had a transition plan in place, and that figure dropped to 38% for children in mainstream schools.

The NAS findings are also reflected in research undertaken by Philip Whitaker (2007) throughout the county of Northamptonshire into the views of parents whose children had been diagnosed with an autism spectrum condition. 49% of the 599 parents to whom the questionnaire was sent responded. Although mainstream schools fared poorly in the satisfaction ratings, and almost 40% of all parents, whatever the setting and provision, expressed dissatisfaction with the education of their child, it was the understandings of school staff of the child's difficulties, and the flexibility in response to the child which determined whether the child and parent were happy. The key statement 'Most staff understand my child's difficulties' was the most important in determining satisfaction with educational provision. There is some small consensus in these responses, although the methods employed were slightly different, with the Whitaker (2007) study being a postal questionnaire to all parents of children on the autism spectrum within a designated geographical area and responses given on a four point Likert scale. It must be said that the county of Northamptonshire has very highly-developed autism support within its

mainstream schools, and that 25% of all children on the autism spectrum in that county attend special schools (Whitaker, 2007).

The 40% figure for dissatisfaction quoted in this survey, and the 51% in the Batten et al (2006) study are contrasted with a perhaps more reliable national telephone survey of parents of all types of pupils in 2008 (Ivens, 2009) in which only 4% in total from (n=1999) parents expressed that they were either 'fairly dissatisfied' (2%) or 'very dissatisfied' (2%) with their child's education.

1.1.2 Evidence of Exclusionary Practices

What the two studies underline is the possible exclusionary practices which may be thought to exist within the wider educational framework. The NAS study has findings for both fixed-term and permanent exclusions from school for children on the autism spectrum. 20% of those children whose parents responded had been excluded from school, 67% of these more than once and 24% of the excluded children had been excluded permanently. Assuming a school-age population of a little under 10 million, and an average permanent exclusion rate of .12 in recent years, the permanent exclusion rate of the children on the autism spectrum whose parents responded to this survey was 50 times the national average. Children with ASCs, in this survey, had fixed term exclusions 20 times more than children not on the autism spectrum. The general exclusion rate is 1.2%. 27% of children with autism spectrum conditions had been excluded from school (Batten et al, 2006). Caution must

again be exercised, as those with difficulties in accessing suitable education for their child are more likely to join an advocacy group like the NAS and respond to a survey of this kind.

But official exclusion, even of this perceived magnitude, is not the only form of exclusion. 40% of the children in the NAS survey, according to their parents, had been bullied, revealing exclusion by their peer group, and this figure rose to 53% of those with Asperger's Syndrome, who may arguably be more likely to attend mainstream school. Only half of the children in the Whitaker survey had formed any friendship at school, and only one in five of the 'dissatisfied' parents felt that their children were accepted by their peers. One in ten parents, in that study, mentioned that their child was bullied, in the open-ended questions. We should retain an awareness, previously expressed, of the possible limitations of these reported figures.

Curricular and environmental exclusion was also evident in the NAS survey, with only 23% of the parents agreeing that teachers adapted the curriculum or environment for the needs of the child, and in the Whitaker survey 'a significant minority of parents mentioned concerns about a perceived tendency for some staff to respond to challenging behaviour by blaming the child...' An example of this is quoted in the study, and unsurprisingly perhaps, it involves the central problem of failure to recognise the sensory difficulties which these children face. According to the parent of one child (Whitaker, 2007: 175)

If a child has sensitive hearing and hides under a table, shouting at him to get out is actually only going to make him stay there

A parent in the NAS survey echoed this dissatisfaction with the lack of understanding of sensory issues (Batten et al, 2006:25):

Danny would not have been excluded if the school had understood the difference between 'normal' behaviour and Asperger syndrome. They inflamed situations because they didn't understand that my son finds physical contact, or being touched by teachers, really difficult.

This can be contrasted with an interview with a secondary school teacher, whose precise understanding of the needs of these children was a clear example of good practice (Batten et al, 2006:14)

We allow children with autism to use different coping strategies. So for example one lad has real problems concentrating and looking, he hides under his jacket while he is listening, and does so much better. It is just too much for him otherwise. Gradually teachers are allowing the kids to do things like that in class – they tend to react with 'I can't let him do that, they will all want to', but of course the rest of the kids don't want to hide under their blazers.

The opinion and practice outlined here is fundamental to what an accommodating teaching approach may be able to provide.

1.1.3 Inclusion

In order to find answers to the initial question posed by this study we must locate it within contemporary educational practice by investigating what exactly is meant by the term 'inclusion' with regard to children who may have special educational needs. It is important to determine what might be necessary to enable the educative process to include those children whose cognitive profile may offer challenges to conventional understandings about how children learn, and how that learning may be best facilitated (Rogers, 2007).

The conceptualisation of inclusion rests heavily on a social model of disability and education, as set against, and sometimes constructed in opposition to, a 'medical model' (Oliver, 1990). In the social model, the problems encountered are seen as being largely created by environmental factors, including other people, and that adjustments in manipulating the physical environment and in helping adjust attitudes may remediate the problems. We should not lose sight of the fact that this model was built on the premise of physical disability (UPIAS, 1976), and that it may be more problematic to adjust the model to accommodate cognitive or psychological or social differences. On the other hand, notions of medicalised disability, or the 'individual' model, could have been said to have characterised to some extent education policies in the early

part of the twentieth century, even beyond the Underwood Report (Ministry of Education, 1955) which appeared to regard 'maladjustment' as a collection of symptoms listed under various categories of a psychological nature (Cooper et al, 1994). At this time, and until the 1970s, education for those regarded as having a physical or psychological disorder was organised under the auspices of the Department of Health, rather than that of Education.

False oppositions are sometimes constructed between the legacies of the 'medical' or individual model which propose within-person difficulties, and the currently-adopted social model, which proposes environmentally-created difficulties. This is particularly expressed by those who reject to some extent the retention of special schools. Special schools could be said to be based on a medical model of disability, and may therefore be in some senses linked to an era in which children with various named disabilities were segregated from their peers and under the professional eye of the health profession rather than the teaching profession. They are seen to represent social segregation which runs counter to the social model of disability.

Skidmore (2004) argues for the existence of social/medical model oppositions, which could be said to characterise the existence of special schools alongside inclusive schools. He claims (Skidmore, 2004:57) that there are two forms of pedagogical discourse, that of 'deviance' (based on a medically-theorised model) and that of 'inclusion' (based on a socially-theorised model). His is a polarised version of conflict between what he views as mutually opposing pedagogies. One, 'deviance', he sees as characterised

by a reliance on IQ levels, a concern with deficits in ability, weaknesses in individual students, and the use of an alternative curriculum to be provided for the less able. The 'inclusion' pedagogy he presents is based on the understanding that every student has an open-ended potential for learning, that the presentation of curriculum is a determining factor in success and failure, that there should be support for learning, and a common curriculum. He presents little theoretical basis for his belief in this binary version of pedagogy and it appears to be poorly supported by evidence that the 'inclusion' model actually exists in practice. He offers no proof that the two models he proposes are mutually exclusive, or, in fact, that they present oppositionally.

Runswick-Cole (2008) in an exploration of parental attitudes to this assumed dichotomy, offers a challenge to some of these assumptions, as they play out in educational practice. She studied the views of (n=24) parents who had attended Special Educational Needs Tribunals. She discovered that far from the expected beliefs of those who seek mainstream education, and those who seek special education, those who sought a special school placement were not necessarily seeking this based on a medical model of disability. Those who sought mainstream education, initially, sometimes wanted to move to special education, later, having encountered problems for their children, particularly in secondary education. Ultimately, she concludes, parents are not guided by ideology, but by pragmatism. This is not a simple dichotomy and 'the process of inclusive education continues to be fragile'. The thinking of the parents remained exceptionally complex and fluid, moving between a

medically-defined model and a social model without noting a conflict between these two positions (Runswick-Cole (2008: 179).

At its best some awareness of a biological basis for certain difficulties can identify certain deep-rooted behaviours which constitute deviations from what might be expected and enable the consideration of the possible ways to address those behaviours (Weissman, 2002). A diagnostic label might also give to the child, thus labelled, a sense of belonging to a larger, if minority, group who are 'like me' in certain respects (Galinsky et al, 2003). Underlying the original arguments in favour of a social model of disability by the architects of the social model, is an acceptance of the notion of their personal 'impairment' (Hughes and Paterson, 1997), while arguing for the removal of environmental barriers to their social and physical acceptance (UPIAS, 1976). The social model is sometimes erroneously thought of as implying a total rejection of any diagnosed condition.

An awareness of a medically-defined basis for some difficulties, when applied to educational needs, can also acknowledge that there may be aspects of behaviour which may not easily comply with normative expectations, and can also acknowledge degrees of individuation, and that one curriculum may not fit all, despite Skidmore's (2004) assertion that an inclusive pedagogy may enable curricular uniformity . This is very much the position taken by Norwich and Lewis (2007) in referring to the 'signalling function of the label'. The social model, in educational terms, can sometimes be seen to operate from too

broad a base, in that it may assume that all children with a variety of special educational needs (SENs), may need the same environmental adjustments. Norwich and Lewis, however, in examining pedagogies in a variety of SENs, suggest that a refusal to consider the common elements, group differences, which might define a distinct group of learners, in order to inform pedagogy, may not be useful (Norwich and Lewis, 2007:143)

... two contributions argued for the significance of distinctive group pedagogy, ASD and AD/HD. It was argued that, though children with ASD have common pedagogic needs, their individual needs can only be identified through a framework of group needs. This is the most coherent case that was made in the project for a group-differences pedagogic position. It is notable that the two SEN areas that took this perspective are two areas based on medically-defined conditions which have come more recently to parent, public, and professional attention.

The argument here, is that in order to access differentiated pedagogy, the factors which are thought to define this particular group of learners must be part of teacher knowledge (Jordan, 2008).

However, the argument is, and should be, deeper than this. It is a question of how strongly psychological understandings and the findings of the fledgling discipline of cognitive neuroscience may facilitate the effective education of any group of learners. Where a perhaps poorly-understood social model may take political precedence, this may disallow or devalue input from other

disciplines which could perhaps, usefully inform educational practice. By resisting clinical research evidence which could be illuminating for educators, educationalists may well be placing themselves in the same position as those medical experts who, in the past, regarded special educational needs as their exclusive remit. Medical 'professionals' sought to place themselves as having an expertise which could alleviate the confusions of parents of children with special educational needs (Lindsay, 2003) until the late 1970s. This may have been unhelpful.

The social model of disability leads to the view that in order to ensure that children are not marginalised and stigmatised by being segregated into special forms of education, which accommodate certain specific needs, it is most fair to educate all children together. It would be counter-productive, for the good of all these children, if the issue of special educational needs leads to a further interdisciplinary battle between those professions which can offer knowledge and insights.

'Inclusion' as a concept is poorly defined, managed or understood. It is a slippery term. Inclusion has been based on a moral and ethical premise in which education is seen as every child's fundamental right, which is bound up with the duty of educational practice to stand as exemplar to society in order to combat discriminatory attitudes. This is underlined in the Salamanca Statement (UNESCO, 1994: ix).

regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system.

The 'rights' issue embodied in the Salamanca Statement could be seen as a moral imperative. However, little is said in the Statement about the practical means by which most schools can play a part in 'creating welcoming communities' and as Lindsay (2003) points out, what research is available appears to suggest that with effective support, an inclusive educational system can sometimes be successful for children with special educational needs. It is, he adds, the quality and nature of support which enables inclusion, not the ideology itself.

Booth and Ainscow (1998:3), in full support of a version of the social model, see the notion of inclusion as being inseparable from the notion of mainstreaming on a basic locational level, with little regard for special or specialised schooling: '....in England the concept of 'inclusive education', that is, increasing the participation of all students in the neighbourhood in their local school – cannot sensibly be separated from ideas of community "comprehensive" education.' This makes little pragmatic sense. Although mainstream schooling exists to accommodate all children, as a right, the strategies which have been shown to be successful with those disaffected and

disenfranchised and excluded from mainstream education in the past, have often been learnt and practised in alternative forms of therapeutic educational provision, outside a mainstream system (Bridgeland, 1971; Asperger, 1944/1991). There is little evidence that those essentially inclusive practices, for all children, have been incorporated or even recognised by those who claim that locational mainstreaming is best for all children. There is little in recent surveys into autism spectrum conditions in educational settings to demonstrate that mainstream education, in its present form, is a valid construct for those who may have difficulties in adjusting to its possibly rigid demands (see 1.1.2). This in itself is an irony. The proponents of one version of the social model ask us to recognise that it is the environment and attitudes which should adjust. If it appears to fail to do this, the inclusion policy would appear to be delivering mixed messages.

The mixed-message mixed-understanding issue is complex, and some seek to address it practically. Lindsay (2003) offers useful pointers to practical changes and stresses the need for more focussed research. Humphrey (2008) suggests that there is far more to be considered in inclusion than merely placing a child in a mainstream classroom. He argues that the child's presence in a classroom is only the first stage of inclusion, and must be followed by three more: participation, acceptance and achievement (Humphrey, 2008: 42). Armstrong (2005:149) presents a politically libertarian view arguing that there is a political agenda behind the notion of inclusion, seeing in the politics of inclusion a drive towards normalisation. 'The contribution of New Labour's inclusive educational policy has been to forward

a process of assimilation based upon an uncritical view of 'normality', itself structured by the values of performativity that legitimate state regulation and control'. Armstrong's Foucauldian view is shared by Copeland (1999).

The 'normalising' agenda could be said to be present in the medical model of disability, in the suggestion of deficit which must be remediated: 'ableism' as it is labelled (Wolbring, 2008). There is in the alternative, if we assume that this is an alternative, social model, a tendency to err in the assumption that a moral belief in equality settles questions of human and educational difference, and accommodation. Terzi (2005), echoes Norwich's (2002; 2008) elegant phrase 'dilemmas of difference' when examining the question of allowing for difference without labelling and dividing, and proposes a capability approach, based on the writings of Amartya Sen. Dowse (2001) argues cogently that disability politics, based on the social model, cannot be led by this model unless there is a recognition of social, psychological and cognitive difference as 'a pre-requisite to an inclusive theory'. Dowse emphasises that the social model of disability does not allow for the voices of those who may have learning difficulties, but prioritises the voice of those with physical difficulties. This is an important factor to consider in the educational context: that the social model of disability is based on disability politics which were led by those with identifiable physical disabilities (Oliver and Barnes, 2008). Where there are developmental difficulties, as in the case of autism, these may not easily be recognised by the social model of disability. Goodley and Roets (2008) argue for a re-examination of the cultural formations of 'impairment' as applied to those with developmental and psychological difficulties and place it in a

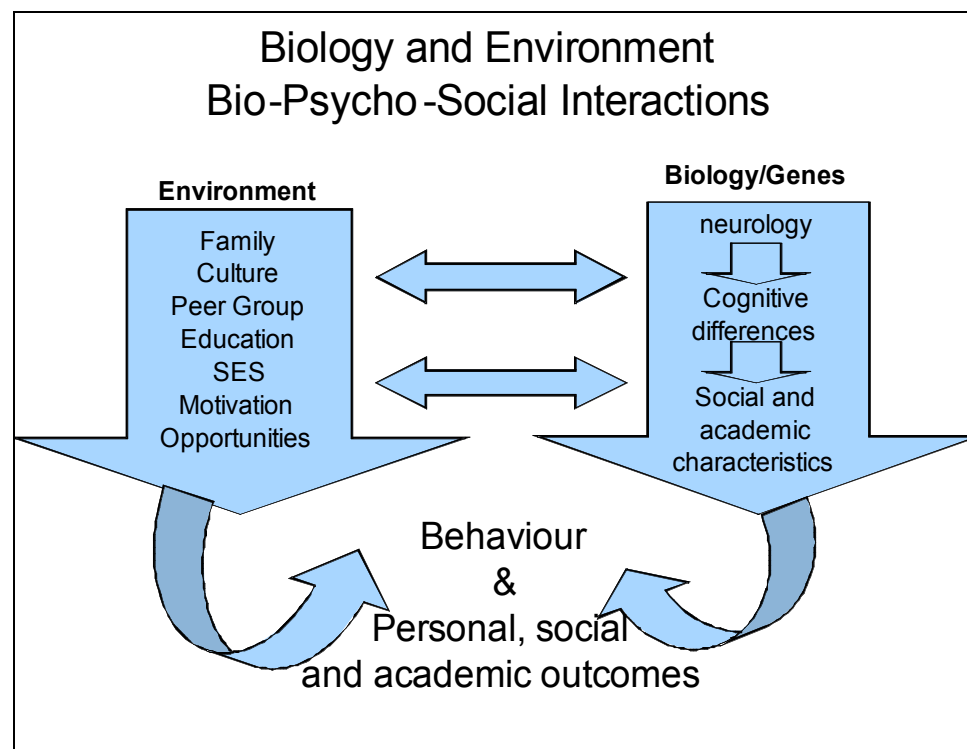
poststructuralist argument in which 'impairment' is re-conceptualised as a fluid and ever-moving set of processes, and suggest that current modernist notions of unchanging binary oppositions do not accommodate complexities of difference.

However, there is a further crucial element to the notion of inclusion. It is that inclusion as a political and social theory is not confined in its remit to the complexities of competing arguments in the disability agenda, nor to questions around education. It is a widely encompassing ideology which, at its political centre involves wider questions of community, and the voices of those who make up community, and their rights to contribute, equally, to their communities. Communities have a right to define and determine their meaning of the word community (Milner and Kelly, 2009). Ideologically, the notion of inclusion cannot divorce itself from issues around power-structures, hegemonies, and the devolution of decision-making (Davis and Daly, 2004; Pearce and Mawson, 2003). To some extent, there has been a little progress in recent governmental efforts to consult the stakeholders in England. The Every Child Matters agenda involved, to some extent, consultation procedures with young people (DfES, 2003; 2003a; 2004a; Aubrey and Dahl, 2006). The consultations outlined in 1.1.1 also could be said to illustrate it. The Extended Schools agenda (Cummings et al, 2007; Dyson and Raffo, 2007; Orchard, 2007) also underlines the imperative of the school at the hub of the community, and could be said to be, however inadequately at times, working towards an inclusion ideology.

1.1.4 The biopsychosocial model as theoretical framework for this study

Any competing and reductive theoretical bases of the variants of the medical model and the social model, do little to elucidate or enable academic research. Each can become a paradigm which distances itself from the complexities and interactions of the special needs discourse and may have become as weakened as, in most philosophical frameworks, Cartesian mind/body dualism. What is necessary is an understanding of their interdependence within this discourse, overlaid with an acknowledgement of the temporal interchanges which occur, continually. Developmental conditions like autism, require a model which can accommodate the fluidity and heterogeneity of their presentation within a pedagogical setting. It is only by analysing the components of what may be seen as a problem that we can make decisions about what should be and could be changed: the person or the environment, or both. Examining the part each plays in remediating the other, over time, and following adjustments made, is a crucial monitoring process. The prognosis of a pervasive developmental condition cannot be separated from the part played by ever-changing environmental factors.

Figure 1.1.4 A biopsychosocial model – (Source: Cooper and Jacobs, 2011)



A useful model to apply is the recently-theorised biopsychosocial model, originally conceptualised by Engel (1977) as explanatory of the part biomedical, social environmental, and psychological issues are central to physical health: and originally designed to examine the psychosomatic nature of illness. Cooper (1997; 2002; 2004; 2005, 2008) applies this model to pedagogy, arguing that combining biomedical and psycho-social insights within a systems' framework enables us to reframe disorders as difference, and to recognise 'within child' factors without stigmatising individuals. This model usefully enables educational engagement which flows from an holistic negotiating position (Cooper and Jacobs, 2011).

The model also reflects Klaus Wedell's 'compensatory interaction' theory

(1980), a systems' theory-based explanation of the relationship between the child's inherent characteristics and the environmental supports or barriers. Wedell (2005; 2008) later incorporated the dimension of time into his model, suggesting that both inherent characteristics and environmental factors interplay over time, and are subject to continual change, very much in line with Goodley and Roets' (2008) conceptualisation of ongoing processes rather than pre-determined linear progression.

The model also offers the enabling factor of the consideration of useful strengths which can be harnessed where, conventionally, weaknesses have dominated conventional educational discourse in the case of children with special educational needs. This enables a balanced view of the child's potential, a strength as well as weakness profile, which was the whole-child approach employed by Hans Asperger in his own study (Asperger 1944 *trans* Frith 1991). The biopsychosocial model is also a position embraced by Leo Kanner, who first identified autism. He directed researchers to a type of biopsychosocial approach to elucidate the nature of autism (1956/1973:100):

Early infantile autism is a total psychobiological disorder. What is needed is a comprehensive study of the dysfunction at every level of integration: biological, psychological and social.

The interactive biopsychosocial model is therefore a suitable model for this study, as it provides for the complex relationship between the nature of a developmental disorder, in this case autism, (Frith, 1992), and the mediating

or challenging role which environmental factors, including other people, may play at any time. The notion of developmental change is provided for in this model. Frith (1992) names experience, motivation, maturation and compensation as elements which mediate the biological features of autism in the social context to produce observed behaviour.

The model is suitable for use in the field of pedagogy as it empowers the educator to envisage the possibility of removing some environmental barriers to learning, thus facilitating the learning experience of all children, while recognising that there may be certain inherent behaviours in ASCs which can, with understanding, be accommodated. It is a model which allows for the existence of autistic intelligence. With its recognition of cognitive difference, it can perhaps be an enabling position for the child on the autism spectrum and the child's parents and teachers. It may suggest that physical and social environmental adjustment can play a crucial role in their inclusion in the educative process to achieve social justice. This, then, is the theoretical framework of this study. Social justice may be a personal and differentiated viewpoint. But at the same time it may be a closely-held construct, which may guide some in the views they hold, and the behaviours they adopt, as a result of this view.

1.1.5 Educational background: The Warnock Report

The UK had been adopting practices which could be said to be very broadly inclusionary, using the term 'integrated' in the Warnock Report (DES, 1978)

over twenty years before the signing of the Salamanca Agreement. That report rejected the categorisation of disability, in common with Denmark and Norway, and adopted the broader term 'Special Educational Needs'.

This is an expression originally employed in the UK but partially employed in the Salamanca Statement (UNESCO, 1994). Although its adoption was common in educational circles from the early 1960s, the expression appeared in Gulliford (1971) and entered into official circulation with the publication of the 1981 Education Act (HMSO, 1981) which included many of the recommendations of the Warnock Report (DES, 1978: 3.6):

We wish to see a more positive approach, and we have adopted the concept of SPECIAL EDUCATIONAL NEED, not seen in terms of a particular disability which a child may be judged to have, but in relation to everything about him, his abilities as well as his disabilities – indeed all the factors which have a bearing on his educational progress.

The Warnock Report, and the Act which followed it, marked a watershed in conventional educational provision as it sought to distance itself from the medical model which was reflected in the Health and Handicapped Pupils Regulations (1945). It proposed that barriers be removed for those children who had been segregated in special schools to allow, for them, a possibility of entering mainstream schooling, if they and their parents saw that as being in the child's best educational interests. The educational system was to be seen as integrated, offering a continuum of provision to a range of special

educational need which was also seen as a continuum. The provision was wide-ranging and comprehensive, and appeared flexible, as it emphasized social contact and possible movement between bases. Provision could be viewed as being locational, or social or functional. Children could be educated within a suitable locally-provided school, or in specialist provision which nevertheless enabled social contact with a mainstream school, or, where needs were greatest, in a school which enabled them to function comfortably, perhaps with medical assistance.

The Warnock Report was far-sighted in wishing to reconceptualise the notion of only categorised and recorded disability or diagnosed disorder as being worthy of additional educational help but broadening the concept of special educational need to include a further one in six children who may require extra resources to help them at some time through the school years. It was also far-sighted in creating the relatively neutral term 'learning difficulties', which in itself is a confusing term. Where we use as a term 'learning difficulties' we may not be accommodating those students who may have little obvious cognitive disability. The key recommendations included emphasising that parents play a major role in the education of their children, and that the assessment and monitoring of needs as an ongoing process should begin with inter-agency working between social services, the NHS and education, including child development assessments from birth by Health Visitors.

The Warnock Report (DES, 1978), while advocating a five-step process in determining the help a child may need at school, providing it through various

staged means, and abolishing the categories of handicap which had to be officially recorded, retained a recorded procedure (Form SE4) for the final and fifth stage in the process. This fifth stage, redesignated by the 1981 Act as the statement of educational needs, was to be delivered according to the 1981 Act when significant extra help was adjudged to be necessary, and was a Local Authority record of the child's complex needs and the steps necessary to accommodate those needs, which would be officially reviewed annually. The five step process, now reduced to four: Universal, School Action, School Action Plus, and Statement, is common across many international educational conceptualisations of staged support for children in school.

1.1.6 Barriers to implementation

Although the Warnock Report could be said to have marked a radical change in educational thinking, the 1981 Education Act, which did not incorporate all the recommendations, did not produce the desired changes for those children with special educational needs, including those with autism spectrum conditions. The first reason for this is that while many of the recommendations, were incorporated in the Act, it was passed without any funding to support the changes it proposed. Thus, as Merry (1986) discusses in his examination of the implementation by three Local Authorities: Leicestershire, Coventry and Barnsley, decisions on how to manage and fund the innovations was left to the discretion of Local Authorities, which managed the obligations demanded by the Act, in disparate and often inadequate ways. The requirements of funding for statements of special educational needs were

in themselves lengthy and costly. However, it must be remembered that the Warnock Report had attempted to include a further 18% of children into the category of special educational needs. The question of lack of funding for, for example, extra staff in mainstream school to support these identified children, therefore remains crucial to possible provision.

Another barrier to full and funded integration of these children into what were referred to as 'ordinary' (as opposed to 'special') schools, was the Educational Reform Act of 1988 (ERA) seven years later which required Local Authorities to devolve responsibility for budgeting to individual schools. The ideology of the Educational Reform Act was in many ways a challenge to the ideology of the Warnock Report, as it introduced a standards' agenda which could be said to conflict with notions of integration or inclusion, or, in fact, of social justice in general (Thrupp and Tomlinson, 2005). Special Educational Needs were neglected by ERA. By introducing a National Curriculum, and regular attainment testing of the children to offer whole school league tables of performance as a guiding factor to parental choice of school, it therefore demanded curricular conformity and academic attainment in those 20% of children identified as having problems in accessing the curriculum, and engaging with school. The ERA is based on an ideological construct in which competition is the dynamic force, taking the market forces theory into the arena of education (Bagley, 2006; Wilkinson, 2006). It is predicated on the assumption that disadvantaged students would be best served by those service providers who with their excellence in overall provision would attract the patronage of the most consumers, allowing those who had been

previously theorised as failures to be carried along by the best outcomes of market-driven forces. However, this agenda depends strongly on the construction and identification of quality measures which might not easily accommodate those who might have problems in contributing to those measures. Some solution to this problem was provided by the facility to disapply the curriculum, should this been seen as crucial to a child's success. However, Bradley and Taylor (2002: 295) in examining the data on exam success following the ERA conclude:

Using data obtained from the Schools' Census and the School Performance Tables, we find strong evidence that the quasi-market has led to a substantial improvement in efficiency (as measured by a school's exam performance and by the productivity of staff) during the 1990s. The same market forces have led to a greater social segregation of pupils between schools.

The ERA on this evidence appears not to have achieved a perhaps theorised hope that the quasi-market would carry along those whose needs were greatest.

But while the Warnock Report and the 1981 Education Act, followed by ERA in 1988, had strong and possibly competing impacts on the implementation of an integrated educational system for children with special educational needs, the word 'integrated', which speaks of a continuum of a variety of educational placement, was gradually eroded and conflated with the word 'inclusion',

which is a theoretical rather than a pragmatic conception. Integration was finally replaced by inclusion in the mid 1990s, in the years leading up to and following the Salamanca Statement (UNESCO, 1994). While 'integrated' remains principally a functional term as to the organisation of educational provision, 'inclusion' is generally regarded as an ideology, a rights issue, as expressed in the Salamanca Statement (UNESCO, 1994).

1.1.7 Autism Spectrum Conditions

Autism has been medically defined as a social-communication *disorder*, encapsulated in Wing and Gould's Triad of Impairments: impairments in language, social understanding, and imagination (1979) which form the framework of the diagnostic criteria in both current DSM and ICD manuals. The deficit model, a necessary feature of a manual defining 'disorders', emphasises the difficulties experienced by a child on the autism spectrum. These include problems in non-verbal and verbal communication, 'appropriate' peer relationships, emotional reciprocity, and a rigid and repetitive pattern of behaviour, which may present at times as distress over changes in small non-functional details of the environment. The diagnostic criteria were determined through a process outlined in **2.1.4**.

The question remains about whether diagnostic criteria can actually help educators to understand this condition and how it might impact upon specific educational needs. Diseases and medical conditions outlined in DSM-IV aid clinical diagnosis by classifying presentation of behaviours, and their inclusion

in the manuals could be said to suggest that there is a cause for these behaviours, and that there may be remediation or accommodation of some kind for them. The potential value of these criteria to teachers is to provide some framework for interpreting behaviour and for distinguishing between those behaviours which may be episodic and related to immediate circumstances and those which appear more deeply rooted, the Norwich and Lewis (2007) 'signalling function of the label'. Where behaviours are deeply rooted they tend to be resistant to the routine behaviourally-based management strategies employed by competent parents and teachers. This indicates the need for strategies aimed at accommodation of cognitive-behavioural characteristics (Moree and Davis, 2010; White et al, 2010; Wood et al, 2009). The biopsychosocial model takes account of these deeper-rooted behaviours, while neither catastrophising them, nor resorting to biological determinism. It is also a model which offers the teacher the opportunity to adapt the curriculum and the environment, in recognising that social accommodations to each child's needs can be made. A flexibility of approach, based on that model, could possibly enable the 'rights' and policy issue of inclusion to be implemented more effectively (Cooper, 2008)

1.1.8 The concept of Autistic Intelligence

The expression 'autistic intelligence' is a term coined and used by Hans Asperger in his post-graduate submission, 'Die autistischen Psycopathen im Kindesalter' (1944). Asperger was not, as some mistakenly think, a psychologist nor a psychiatrist. He trained in general medicine, but was

employed at the University of Vienna Paediatric Clinic, where he specialised in remedial pedagogy as the head of the hospital residential school. He was a teacher and educator of those who might now be termed children with special educational needs (Frith 1991).

His speciality was orthopaedagogy (www.amazon.de). The orthopaedagogical approach, which in Austria was strongly influenced by the Freudian psychodynamic model at the time when Asperger was working, is similar to that employed in many pioneering therapeutic communities in the UK in the early and mid twentieth century (Bridgeland, 1971). Very much in line with his training in remedial and therapeutic education determined on principles of 'Haelpädagogik' and orthopaedagogy, Asperger's paper is therefore not limited to clinical symptomology, but is characterised by a disciplined and detailed pedagogical approach to the four children he described, out of the 200 he had studied, and is informed by his observation of these children in an educational residential setting.

His examination and observations of the children involved his drawing up, for each child, a rich and detailed cognitive and behavioural profile, with the strengths of their original and striking capabilities balanced against an awareness of their atypicality. The title of the paper reflects his attitude to this cognitive profile: that it was an enduring and pervasive part of the child's entire being, a 'personality disorder' is the closest translation, rather than a psychosis, which was the preferred explanation of arguably the same disorder described by Leo Kanner, and named as 'Autistic Disturbances of Affective

Contact' (1944). What is now known as Asperger's Syndrome has been predicated, from the outset, on a pedagogic model.

I have chosen to foreground 'autistic intelligence' (Die "autistischen Intelligenz"), (Asperger/Frith *trans* 1991), in order to attempt to re-examine his findings within an educational and cognitive framework. Autistic intelligence could perhaps be a useful term for educators to reclaim, as 'autistic' then becomes detached from its connotations of medicalised deficit and detached from its adjectival use to denote extreme withdrawal into the self, and could be reframed as a possible mind-set, a cognitive difference. Part of the purpose of this study is to examine the validity of such a construct, and to discover whether autism is inherently understood by the groups of stakeholders whose beliefs and understandings are explored here, as a cognitive construct.

Asperger describes autistic intelligence in terms which could, even now, act as useful guidance for any educator (Asperger/Frith *trans* 1991:70):

The skills that a child acquires grow out of a tension between two opposite poles; one is spontaneous production, the other imitation of adult knowledge and skills. They have to balance each other if the achievement is to be of value. When original ideas are lacking achievement is an empty shell: what has been learnt is merely a superficial and mechanical copy. Autistic intelligence is characterized by precisely the opposite of this problem. Autistic children *are* able to

produce original ideas. Indeed, they can *only* be original, and mechanical learning is hard for them. They are simply not set to assimilate and learn an adult's knowledge. Just as, in general, somebody's good and bad sides are inextricably linked, so the special abilities and disabilities of autistic people are interwoven.

There appears to be some contradiction in this paragraph as Asperger, while claiming that mechanical learning is hard, therefore possible, for these children, also says that they are only capable of being original. However, it is to be assumed that there may have been some exaggeration here, and that the author may be suggesting that what is notable about these children is their more natural originality of thought than that seen in typical children.

Leo Kanner, who believed that autism was a 'disturbance of affective contact' also realised that the mind of a child with autism had an unusual original quality, reliant on associative connections which many would be unable to interpret or follow, but which were creatively and individually defined according to personal algorithms, (Kanner, 1973: 4)

He seemed unable to generalize, to transfer an expression to another similar object or situation. If he did so occasionally, it was a substitution, which then 'stood' definitely for the original meaning. Thus he 'christened' each of his water color bottles by the name of one of the Dionne quintuplets – Annette for blue, Cecile for red, etc. Then, going

through a series of color mixtures, he proceeded in this manner:
'Annette and Cecile make purple'.

The reasoning, as Kanner did not note, is the basic thought processing which leads to algorithms. The boy had water colour pots for the three primary colours, and black and white, making five. Five is a quintile. Five children are quintuplets. The association of the birth of the Dionne quintuplets¹ with the number of colours in his bottles was therefore not accidental, but a carefully and individually constructed order of thinking on a visual and associative level (Deacon, 1997)

Kanner's work informs research very significantly indeed. His case studies of his initial eleven children were not only referenced longitudinally in his original paper (1943) but were then followed up in a series of further studies (Kanner, 1971). It is important to note, as an introductory statement, that the research base for what are now known as autism spectrum disorders in the manuals, Kanner's ('classic') autism and Asperger's Syndrome, may have deviated from the original understandings which characterised and actually unified them. Contemporary research, diagnostic criteria, academic positions, public opinion, and pedagogical understandings, appear to have lost their crucial connection with the combined weight of the findings from detailed case notes and analyses provided by both Kanner, as clinician with a shared cultural tradition of *Haelpädagogik*, and Asperger, as paediatrician and pedagogue.

¹ These were five Canadian sisters, born in 1934, who were the first quintuplets to survive their infancy.

I wish to return to their significant evidential bases, as my starting point in this study of autistic intelligence. I intend, for the most part, to disregard the clouded issue of autism with associated intellectual impairment (Hoekstra et al, 2009, Noterdaeme and Enders, 2009, Goin-Kochel et al, 2008), which has been mistakenly conflated with what has been called 'classic autism' or 'Kanner's autism'. These expressions are unknown to diagnostic criteria which use merely the term 'autism', but are evidenced in much of the literature, as 'low-functioning' (with apparent intellectual impairment or delay) or 'high-functioning' (without intellectual impairment), again categories not present in diagnostic criteria. In the diagnostic criteria the diagnosis of 'autism' can be given only when there is language delay. This is not very apparent in Kanner's original papers as few of his subjects had severe language delay. Asperger's syndrome has been defined as autism without significant language delay. But both Kanner's and Asperger's original papers deny that essential rift. They speak of the same broad condition, as evidenced in what they write, which is currently defined by the phrase 'autism spectrum disorders' or 'conditions'.

1.1.9 Autistic Intelligence: Methodological factors in evaluations

Before referring to recent studies in autism research, there is a very important factor which should be taken fully into account. It should be noted that sample sizes in most studies on autism are considerably smaller than is conventional. Autism spectrum conditions are currently diagnosed in fewer than 1.6% of children (Baron-Cohen et al, 2009). This incidence means that in gathering data, consideration will have to be taken of the relatively low numbers of subjects available for testing in any study. When factors of chronological age

and mental age, have to be considered by the study, there may be very few children who meet the criteria for inclusion in a research project, even when working from a clinical sample. Those who may be eligible may not wish to be included. Sample sizes may therefore be smaller than those required to draw valid conclusions. Also confounding empirical research is the heterogeneous nature of autism spectrum conditions. What may be true of three or four children with autism spectrum conditions in one study, may not generalise to all autistic children, as the nature of the deficits/strengths of an alternative cognitive style with splinter skills and scatter deficits is not predictable. However certain core characteristics are shared.

Empirical research, therefore, is challenged by autism in ways not easily provided for by scientific enquiry and particularly in producing the essential component of all positivist research, the Randomised Controlled Trial. Although RCTs are more common in clinical testing of medical interventions, they are highly regarded in psychological research, especially when assessing the value of an intervention, but are very difficult to organise (Drew et al, 2002), can be costly in terms of time and money and the efficiency of the intervention may not be easily generalised although efficacy can sometimes be established. Schopler (2005:710) added other concerns to a discussion of the problems of conducting RCTs with an ASC population, most specifically in the USA:

It is very difficult to locate cases (*of ASC*) that do not involve dual or multiple diagnostic designation.... It is often difficult to control subject

variables as required by the RCT method. Identification of ethnicity may be blocked by civil rights policies, IQ measures are increasingly controversial, randomized group assignments to treatment or placebo control groups may be against social policy. Single treatment may be required by RCT method but in educational therapy it may run against... laws requiring Individual Educational Programs.

In the main study, to which Schopler's commentary serves as an introduction (Lord et al, 2005) further challenges in evaluating psychosocial interventions were highlighted. Outcome measures and the instrumentation available were discussed, as were ways of adapting diagnostic tests to serve as outcome instrumentation by widening the scoring range, but there was a note of pessimism or reality in one of the concluding statements (Lord et al, 2005: 707), 'developmental change over time in ASD may often exceed the effects of interventions'. This is a very important issue, which is often overlooked. It was balanced by a query 'whether (*educational research*) should endorse...one model, an array of models, or work to embed effective practice into existing programs?' The consensus in the UK appears to support the last of these options (Howlin, 1998; Jordan and Jones, 1999; Shields, 2001; Jones, 2006). However, some research appears to suggest that while routine child health surveillance can improve the early diagnosis of autism spectrum conditions (Tebruegge, 2004), there was until a few years ago, little monitoring or assessment of educational intervention procedures in the UK (Martin et al, 2003).

1.2 Current Consensus on the Local Processing Bias (LPB) Theory

In very recent years, the development of brain imaging technologies (Kennedy and Courchesne, 2008) has enabled many researchers and theorists to converge to an extent on an explanatory theory which could be said to be descriptive of the cognitive difference of autism spectrum conditions (ASCs) and which might be of great assistance to educationalists. There is ever-increasing consensus in recent studies: in different forms of functional and structural brain imaging, in genetic studies, and in experimental studies, which are producing, within and between their own research disciplines, some corroborating findings. While this consensus is as yet developing, it appears very promising.

It is that in what we know as autism, there could be excessive internal short-range neuronal connectivity in each sensory, perceptual modality (visual, tactile, olfactory, auditory, gustatory, vestibular and proprioceptive), and long-range *under*-connectivity with the motor cortex and with the theorised mirror neuron system which is considered by some researchers to play a crucial part in sensorimotor integration and empathy (Rizzolatti et al, 2009, Oberman, 2008; Gallese, 1998; 2000; 2002; 2005; 2006; Iacoboni et al, 2005). There may also be weak connections or underconnectivity to those parts of the brain believed to integrate the modalities and meaning-making (semantics) leading to what is often called higher-order thinking (Just et al, 2004). The pre-frontal cortex is theorised to play an important part in this. Under-connectivity with the putative mirror neuron system could result in difficulties in motor-control,

social relationships and in language, and under-connectivity to the pre-frontal cortex could, it is theorised (Brun et al, 2009; Sayhoun et al, 2010; Belmonte et al, 2004; Belmonte and Yurgelun-Todd, 2003) give difficulties in set-shifting, prioritising and editing, timing and sequencing, those issues which are often referred to as executive functions (Barkley, 2001).

In short, the current consensus based on brain-imaging studies is that those on the autism spectrum appear to have a local (sense impression) rather than a global (conceptual) bias in information processing. Perception rather than meaning-making (narrative accounting) is prioritised, and the input from one modality may be so excessively detailed as to overwhelm simultaneous input from another. It may also overwhelm what is regarded as necessary integration between the senses. Local processing produces a heightened response to the physical environment with a distinct and complex individually determined sense of pattern-formation. This is thought to derive from the fact that the child makes personal algorithms to explain the highly arousing environment and systemises it according to an unchanging formula, if possible (Baron-Cohen et al, 2009b).

1.2.1 LPB Theory as a guide for parents and teachers

The theorised local rather than global processing bias in children on the autism spectrum could also account for the problems generally cited by

parents of these children and the children themselves, which are so far absent from the diagnostic criteria: sensory difficulties (Baker et al, 2006; Baranek et al, 2006). This is despite the keen attention given to these issues by Hans Asperger (see **2.3.6**) and noted by Eisenberg and Kanner (1956) in their own summation of the core characteristics of autism which could inform diagnostic criteria. As a conclusion to their study which revealed extreme visual acuity in a small group (n=15) of people on the autism spectrum, Ashwin et al (2009) suggested that sensory hypo- and hyper-sensitivities be included in diagnostic criteria for autism spectrum disorders. 'Unusual sensory behaviors' (Gabriels et al, 2008) has been suggested as a further criterion in autism, in invited discussions on proposed changes in DSM-5. Anecdotal sensory integration difficulties (Ayres and Tickle, 1980), sensory defensiveness, and sensory stimulation-seeking, in children on the autism spectrum, are explored in Olga Bogdashina's (2003) book in which these sensory hyper and hypo sensitivities are illustrated by references to the autobiographical writings of some ASC adults, and in the interviews she conducted with others on the autism spectrum.

For educators, the explanatory evidence of the theorised nature of autistic intelligence as characterised by LPB provided by the current research consensus is invaluable. If clearly explained and understood, it may enable practical environmental strategies to be devised which may, in many cases, empower teachers and other school personnel to develop immediate solutions to the challenges posed by and for children on the autism spectrum.

1.2.2 Local Processing Bias Summary

For those attempting to understand the complexities and apparent contradictions offered by the conventional Triad of Impairment model of autism spectrum conditions, the local processing explanation is a helpful insight into the workings of the autistic mind, which does not imply deficit, merely difference. It also validates Hans Asperger's intuitive use of the expression, 'autistic intelligence'. What it prioritises is the answer to the questions: 'how might this child think?' and 'what are this child's responses to the environment?' which are questions that perhaps all teachers should ask about all children.

However, it must be recognised that if we are looking at the modalities and their individual processing abilities, this will raise questions about homogeneity. Not all people on the autism spectrum, who are believed to discover the world through their own individualised perceptual hyper- and hypo-sensitivities will interpret the world in the same way. A perceptual bias rather than a conceptual information processing bias could be said to enable a more heterogeneous pattern which may not be easily addressed by a single educational intervention. A more conventional processing bias, it could be argued, may lead to a greater conformity in the majority, and therefore a tendency to regard deviations from information processing expectations as in need of remediation.

1.3. LPB/Autistic Intelligence and Inclusion

1.3.1 Stakeholders

The conditional and theoretical nature of this area of educational research means that it is important to study this problem from the perspective of stakeholders. One of the purposes of this study is to examine and evaluate the impact of current professional practices on a group of individuals and to explore the potential application of the best understanding we have of what autistic intelligence may be.

In an educational system which favours inclusion, defining it in ideological terms, largely as a political and social rights issue, attempting to listen to the voices of those whose future may be shaped by it has become part of the political agenda. This was highlighted by the commissioning of the Lamb report, to identify parental dissatisfaction with Special Needs Education (Lamb, 2009), and by the consultation processes involved in the *Every Child Matters* (DfES 2004a) publication. This argument also lies at the political heart of the ideology of inclusion as laid down in the Salamanca Statement (UNESCO, 1994:ix) in its call on governments to:

encourage and facilitate the participation of parents, communities and organizations of persons with disabilities in the planning and decision-making processes concerning provision for special educational needs.

Therefore in the case of autism, we should look towards what the stakeholders, the children with autism and their parents and teachers believe about autism and how it can be accommodated, educationally. It is also important to discover whether what they believe reveals understandings of what might be called autistic intelligence. This is what this study sets out to do, using a phenomenological methodology to access the views of parents of children on the autism spectrum, the children themselves, and their teachers about what autism means to them. All the children in this study are educated in mainstream schools, in the framework of inclusion. It is the only study identified in the literature search, which has used the voices of this triad of stakeholders in an autism spectrum educational study in this way: to discover where agreements, disparities and conflicts occur.

1.3.2 Insights from autistic adults

Accessing the views of children on the autism spectrum has rarely been attempted in studies, although it must be acknowledged that there is a weight of anecdotal evidence found in weblogs and biographies by autistic adults on the lived experience of autism, which can offer insights into the workings of autistic intelligence (Billington, 2006). While such evidence is not necessarily reliable, these insights can be challenging to any preconceptions we may have about autistic cognitive processing (Grandin, 1995). However we must bear in mind that revelations by adults on the autism spectrum have been conditioned by the self-awareness acquired with age and a degree of social

understanding, accessed perhaps at a later age than most typically-developing others. The reliance on local processing may be more easily communicated in a conventionally accessible way by those who have the maturity to understand and interpret how their autistic intelligence, in childhood, impacted upon their learning ability, and created a difference of which they may not, at the time, have been aware. For example, this is what Marc Segar, who gained a biochemistry degree, worked as a children's entertainer, and died in a traffic accident in 1997 said. His autobiography is published on the internet (www.autismandcomputing.org.uk/marc2.en.html):

Perhaps my earliest thoughts were about phonetics. Without actually knowing what "phonetics" meant and probably not even knowing the alphabet, I was able to think to myself that "P" was a harder version of "b" as was "T" to "d", "K" to "g" and "S" to "z". This all worked reasonably well inside my own head but at the time I was only 4, an age at which apparently I wasn't even speaking yet except to express basic needs. However, I didn't know I wasn't speaking. I simply assumed I could.

Insights such as this into autistic intelligence, into its tendency to theorise on a local processing level, in this case on sound discrimination and association, help us to understand Hans Asperger's perhaps exaggerated observation (Asperger/Frith *trans* 1991:70) 'Indeed, they can *only* be original'.

1.3.3 Methodological challenges in accessing the views of children on the autism spectrum

This originality may create problems for those wishing to obtain the views of children on the autism spectrum, and there has had to be some methodological adjustment for this in interviewing the five children in my study, which will be explained in the Methodology chapter. However, it is important to note that in order to take accurate readings from these children about what they think and believe, due regard should, ideally, be given to close observation of each child, in addition to listening to the words they use, as they are likely to have a heightened relationship with their physical environment rather than with the social demands of an interview or the interviewer. They may also prefer to communicate in ways other than in words. Some researchers have failed to take that into account. A close observation of behaviour in naturalistic settings, especially in the case of these particular children, gives strong supporting or apparently contradictory evidence to their accounts.

1.4 This study

1.4.1 Summary

This present study may add to the research knowledge of how these children view their own autistic intelligence, although it must be borne in mind that there may be little consensus, due to the heterogeneous nature of their

condition. It can also shed light on what, if any, impact a knowledge of autistic intelligence could have upon inclusionary pedagogical practices. The Code of Practice (DfES, 2001) offers guidance to schools on the requirement to make certain accommodation to children with special needs and it is interesting to explore what accommodations are made, and why, for children with ASCs. Another issue is whether there is a drive towards normalisation inherent within the quasi-market education system (Armstrong, 2005; Copeland, 1999), and whether this in any way impacts on the inclusion agenda.

One of the mothers in this study, the parent of thirteen children, eight of whom have been diagnosed as being on the autism spectrum, echoed almost exactly the words of Hans Asperger (Asperger/Frith *trans* 1991:70), although she has never read the translation of his work, in saying, ‘ A lot of people go on about lateral thinking, and that is just what they have. That’s what they *have*, they just don’t have a normal way of thinking! I have a friend who says about one of my children that he always thinks outside the box – he never gets *in* the box!’ Perhaps this is what is meant by the Government Response (HMSO, 2006:61):

.....take account of the complexity of autism and the inherent difficulties individual children with a developmental, social communication disorder can present to a school system

The question posed by this research study could perhaps be reframed to enquire whether those with autistic intelligence perceive the education

process as a box, a rigid container, and whether those who parent and/or teach these children share that view, and whether that view is compatible with the ideology of inclusive education.

1.4.2 Structure

Following this Introductory Chapter (1), Chapter 2 consists of a Literature Review. This seeks to evaluate the strength of the evidential base for the theories and positions regarding the nature of autism and supportive interventions. The three original theoretical models of autism: Theory of Mind, Central Coherence, and Executive Dysfunction are examined, together with evidence since their creation, both in child development theory and in neurological research, which support or challenge or elucidate each of the three models. The possibly unifying nature of the LPB theory of autistic intelligence is added, and relevance to educational practice, and in particular to inclusionary practice, is noted. The leading educational interventions are examined, and while the individual weaknesses and strengths are noted, in line with current consensus, deviations from the original conceptualisation of autism by Kanner and Asperger are also noted.

Chapter 3 outlines the Methodology of this study, an examination of the lived experience of autism spectrum conditions consisting of five case studies, each of which takes evidence from three stakeholders: a child on the autism spectrum (m=3; f=2, 3 White British, 2 Mixed Race), his/her parent, and his/her teacher. One of these children is the subject of the pilot study. The methodology chosen is interpretative, and phenomenological, and is based on

the theoretical model provided by Alfred Schutz. There were several methodological innovations in this study. The rationale for each will be explained. The procedures for textual analysis are examined. The pilot study is presented and its results analysed and discussed, in regard to its fitness for purpose.

Chapter 4, Findings, is a full examination of results from the main study supported by qualitative analysis of the four research questions.

Chapter 5 Discussion, re-examines the theoretical position adopted, in the light of findings, and links the findings to the Literature Review, and to its strengths and weaknesses in methodology and execution.

Chapter 6 is a Conclusion chapter which begins with a summary of the main findings and theoretical conclusions, and ends with recommendations for further research.

Chapter 2: Literature Review

Introduction 2.1

In examining the question 'How can autistic intelligence be recognised and accommodated in an inclusive education setting?' it has been necessary to examine the literature very robustly in order to evaluate the theoretical evidential base which might enable an answer.

2.1.1 Literature searches and reference organisation

In preparing this Literature Review there was a considerable amount of research material available from previous informal research. Most of this material was a library of books although there was some journal material already saved to the computer. The initial stage in setting up the current Literature Review was to define search terms which may be useful, and to decide the most time-efficient way of conducting the search. It was decided to search electronic databases, as these would provide the reliable journal articles.

The main database chosen was Scopus. This is because of its very wide range of searchable data in the Social Sciences, as well as in other areas like medicine which could perhaps have some bearing on the subject of the Review. ERIC was also used, as being a database dedicated to Education. However, there are certain limitations to ERIC, as it draws mostly on North

American research data, and has fewer references to European educational research. While PsychInfo and PsychArticles were also accessed, it was discovered that the journals referenced in these databases were also available through Scopus. There was considerable cross-over between ERIC and Scopus, but inputting data from ERIC does not conform to the demands of the Harvard form demanded by the majority of academic institutions.

The bibliographic software chosen was RefWorks. One reason is that it allows direct export from the Scopus database. Data can be exported as 'Abstract plus References' so that the Abstract can be read easily through accessing the bibliography. Another advantage of using bibliographic software such as this is that it saves considerable time and enables far more extensive searches. Using RefWorks and Scopus together, enables 'hand-searching' through certain journals as provided these exist in electronic form, the journal itself can be searched electronically. Further, in contrast to the traditional method of preparing a list of likely titles, next accessing the Abstracts of some of them, and finally choosing a collection of Abstracts which require a Full Text version, the first two stages in a traditional search are bypassed. These electronic data were supported by Inter-library loans and books borrowed and bought.

The search terms employed were those familiar to the researcher, to establish a bibliography of the journal papers to complement the library of books already acquired. These consisted of theoretical terms such as 'Theory of Mind', 'Central Coherence' and 'Executive Function' in conjunction with the

term 'autism' as 'autism' tended to include references to the entire autism spectrum literature. The words 'autism' and 'Asperger's Syndrome' were also searched independently as this gave access to all current literature, which in the case of autism, is produced very rapidly, at the rate of approximately 1,000 papers per year. Selection of material relevant to this study was a lengthy process.

'Autism' was also combined with 'educational interventions' and 'schools', to facilitate the sections on empirical research into educational interventions, and again, terms familiar to the researcher: 'TEACCH', 'ABA', 'Lovaas', 'PECS' and other educational programmes were searched. 'Educational policy' and 'teacher attitudes' were also among the many terms which were searched, then placed in folders bearing their names in the RefWorks bibliography, as were terms such as 'child development', 'emotional literacy', 'evolutionary theory' and 'genetics'.

Other terms were necessary to complete a theoretical framework. These included such search terms as 'inclusion', 'exclusion', 'disability politics', 'social justice', 'biopsychosocial', 'autistic intelligence', 'local processing' and 'social constructivism', for example.

Where it was known that certain authors were known to be very important in the field of autism research, an author search on names such as 'Rutter', 'Howlin', 'Baron-Cohen' and 'Gillberg' was conducted, and folders were created and named for them. Methodological terms, for instance 'phenomenology', 'interviewing' and 'ethics' were also searched. Ultimately the initial searches resulted in over a hundred folders, some having been created

in response to bibliographies in the full papers read, some having been prompted by searches in Google, and Google Scholar, but always tracked back to Scopus or ERIC, and stored in RefWorks.

The writing started in the second month, as the researcher realised the importance of ongoing and iterative daily writing in creating a document of this length and academic rigour. As a first draft of each section was undertaken, material from each folder, expanded by further daily searches as the writing continued, was moved into other folders reflecting the section numbering of this draft, for ease of later reference and editing. An 'Introduction' folder was created at this stage for material which might be important as background.

As the editing moved into second, third and fourth drafts, the material ultimately selected was moved into an all-encompassing Final Bibliography folder. Material which was unused remained in its named original folder for possible inclusion at the stage of final edit. It was anticipated that some chapters and sections, particularly the Introduction, may require up to ten re-drafts in order to reflect the re-thinking imposed by the structures taking place, and the importance and weight of more current research papers. A period of three years in a rapidly-changing and multi-disciplinary research field such as autism can produce radical changes of direction and interesting developments in consensus positions. Almost 2,000 references were collected and read, in Abstract or complete form, within the first 30 months of this study. Complete papers were stored in a computer file.

2.1.2 The structure of the following sections

In order to examine the determinants in the original question, the Literature Review is divided into three separate sections:

1. How is autistic intelligence understood, and how has it been researched, through a historically-constructed model of autism as a cognitive disorder or condition? How has the understanding changed over time, and what factors may have influenced these changes?
2. What are the theoretical underpinnings of that understanding and what empirical validation from a variety of sources is provided for these theoretical models? Have these underpinnings diverged or converged? Is there any current consensus?
3. What educational interventions are available for autistic intelligence and how far do these interventions support what is known about autistic intelligence, based on the evidence provided by the previous two questions?

The research question 'How can autistic intelligence be recognised and accommodated within an inclusive education framework' requires a Literature

Review which addresses the notions of both recognition and accommodation. The three questions posed above have therefore been asked in order to separate the literature into sections which reflect that:

Recognition 1 – medical/historical model **(2.1)**

Recognition 2 - theoretical models **(2.2)**

Accommodation – Interventions **(2.3)**

2.2 History of Autism

2.2.1. Kanner.

Leo Kanner, in 1943, published case notes on eleven children who showed shared characteristics of a disorder which he named as ‘autistic disturbances of affective contact’ (1943). The word ‘autism’ was taken from a study of schizophrenia by Bleuler in 1911 (Kanner 1965/ 1973: 124) where it was used to denote schizophrenic withdrawal from the external world (Bleuler, 1913). Kanner had been born in Vienna, and was influenced by the psychodynamic tradition in noting that these children may have been subjected to poor mothering strategies. Many of the parents he saw appeared aloof, and along with his original case notes’ title which highlighted difficulties in emotional

response in the children, his later statement that 'emotional refrigeration has been the common lot of autistic children' (Eisenberg and Kanner, 1956) was to lead to a misconception that lack of parental bonding may have been a contributory cause to the disorder (Bettleheim 1964; Tustin 1981) and autism was named by some as a psychogenic issue, which might be remediated by psychoanalysis (Houzel, 2004), since a possible neurological substrate had not, at the time, been discovered.

Another misconception about autism arose from the fact that the children Kanner diagnosed were mostly from the upper strata of society, and from families in which some relatives had achieved considerable success in their fields. An assumption, based on this information, was later made that autism was perhaps a socio-cultural issue, an assumption which received support in studies in the UK (Lotter, 1967; Kolvin et al, 1971; Treffert, 1970) which examined the records of hospitalised children or otherwise diagnosed children with autism, over a period of many years. These showed them to have parents who were more highly educated and came from a higher social class than the parents of control subjects. In 1971, a study in California showed that autism was prevalent in all social classes (Ritvo et al, 1971) and suggested that previous test data may have been biased by methods of referral, differential diagnostic criteria and geographical area. It was hoped that more research should be done to establish whether research worldwide might replicate their findings. Further research appears to support this position (Wing, 1980)

Another complication of Kanner's publication was that he worked in the field of childhood psychosis, notably schizophrenia, which is why he had selected Bleuler's coinage (Bender, 1959). Despite criticisms of the concept of childhood schizophrenia, as a 'fashionable and much abused diagnosis' of possible personality and environmental disorders (Mosse, 1958), Kanner's work on autism therefore became conflated with his work on early childhood psychosis and childhood schizophrenia (Bender, 1952). He attempted to distance it and claim it, in some cases, as a separate condition (Kanner, 1965; 1971). Kanner's original notes made his position clear: 'a pure culture sample of inborn autistic disturbance of affective contact' (Kanner, 1943). However, despite his own categorical assertion that autism is 'inborn' he appears to agree with Bender that schizophrenia, too, is 'an inborn disposition' (1969, cited in Kanner, L. 1973:157) and makes no particular distinction between 'inborn disturbance' which is a description of state, and 'inborn disposition' which is a description of potentiality. Both DSM I (1952) and DSM II (1968) fail to include autism under the name which had been chosen by Kanner, *early infantile autism*. Instead, the condition was admitted into the criteria under 000-x28, *Schizophrenic reaction, childhood type*, in DSM I, and under 295.8 *Schizophrenia, childhood type*, in DSM II. Autism, then throughout three decades was assumed to be a childhood form of schizophrenia, or psychosis. The criteria for Infantile Autism did not appear until DSM III in 1980.

Eisenberg and Kanner (1956) chose to highlight five diagnostic markers for the disorder as seen in the children presenting to the clinic. Some of these

were behavioural: aloofness from others, mutism or non-communicative language characterised in many of the children by echolalia and personal pronoun confusion. Some were assumptions of internal states: a desire for the preservation of sameness, a fascination for the properties of objects. Some were cognitive: unusual cognitive skills. They also drew attention to other characteristics which many children had in common: impairment of body-language skills including eye-gaze and social reciprocity. They noted some gross motor agility contrasting with extreme fine motor clumsiness. There was also a tendency to perform stereotyped movements. Attention was drawn to hypo- and hyper-sensitivities, echolalia, eating difficulties and temper tantrums, negativity and destructiveness. Few of Kanner's subjects appeared to have severe intellectual impairment, another fact which is often overlooked in historic and current stereotypes. Two core characteristics were said by them to be constant in all cases: a profound lack of affective contact, and repetitive, ritualistic behaviour.

The confusions which could be said to characterise the early studies of autism therefore arose within the first 25 years following its identification. These were a tendency to associate the condition with schizophrenia and to diagnose it as such, a further tendency attribute its causation to maternal bonding problems which may be remediated by psychodynamic therapy, a possible personality disorder perhaps related to environmental factors, and a socio-cultural phenomenon. For these reasons, research into autism took a variety of different routes, and many of the influences of the unrefined and exploratory

nature and definitions of these early years remained, underpinned by a number of theoretical positions within psychological research.

2.2.2. Triad of impairments

In the late 1970's, Wing and Gould carried out an epidemiological study into the incidence of autism in one London Borough (Wing and Gould, 1979). The research methods they used were similar to those used by Lotter (1966) who had conducted a whole population study of the county of Middlesex to determine the prevalence of autism in children born between 1953 and 1955. Wing and Gould conducted a whole-population study of the children of Camberwell born between 1956 and 1970. The purpose was to discover whether those regarded as having and perhaps diagnosed with, intellectual impairment, may also merit a diagnosis of autism.

From all children in the borough, 35,000, they concentrated on 914 who were known to the education, health and welfare services as suffering from a learning disability. From the initial screening they selected 132 who appeared to have characteristics outlined by Eisenberg and Kanner (1956). These children were observed and tested over time. In all, 58 children were found to have some small measure of social capability, which would not classify them as falling completely under the criteria for autism and 74 were much impaired in social interaction. 70% of these children had IQs below 70.

Wing and Gould hypothesised that these 74 children, irrespective of their known intellectual impairment, shared additional problems, socially-withdrawn and communication-impaired features, together with the repetitive behaviours described by Kanner. They named these difficulties as an impairment in social interaction, an impairment in social communication, and an impairment in social cognition. This study confirmed Lotter's (1966) study as to the prevalence of autism in the general population: about 4.9 in 10,000 for 'typical' autism and 'atypical' autism. However a high number of children, 16.3 in 10,000 were found to have some deficits in social, linguistic and imaginative capabilities that were not as consistent. These cases were described as being 'other socially impaired'.

The Wing and Gould study provided autism research with what they called, rather than 'childhood psychosis', 'the triad of language and social impairments', a deficit in language, responsiveness, and imagination. The three key deficits or impairments employed in the study have become set into all diagnostic criteria. The study also detected that there were many children with autistic traits who nevertheless did not appear to be classically autistic. This led Wing to conceive of autism as a 'continuum', or a 'spectrum' (Wing, 1988)

2.2.3. Asperger

In 1943, as Kanner published his findings in the United States, Hans Asperger, in Vienna, completed a doctoral thesis on notes he had taken in

observing four children in his hospital school. He was not, as Kanner was, a pure clinician, but combined paedology with remedial pedagogy within a residential hospital school setting. His work, *Die 'Autistischen Psychopathen' im Kindersalter* was published in 1944 and translated as, 'Autistic Psychopathology in children' (Frith, 1991).

Unlike Kanner who described autism as psychosis, in the Bleuler tradition, Asperger whose pedagogical tradition was psychotherapeutic, used the word autism to describe personality disorder. Van Krevelen distinguishes between the two: 'Kanner described psychotic *processes*, characterised by a *course*. Asperger's autistic psychopathy represented *traits*, which were *static*' (Van Krevelen and Kuipers, 1962: Van Krevelen, 1971). Apart from the interest from Van Krevelen and some later (Wing, 1981) examination of Asperger's findings, little interest was aroused in clinical circles by Asperger's paper, which did not find universal acceptance until Uta Frith's published translation of his notes into English (Frith, 1991). Essentially Asperger's account of the autistic children he had encountered in his hospital school in his paper, differed very little from the case notes by Kanner.

The minor differentials have been well documented by Lorna Wing (in Frith, ed., 1991) as previously by Van Krevelen (1971) and consist mostly in a more advanced linguistic development of Asperger's subjects, and their greater willingness, than the Kanner subjects, to develop a form of pseudo-communicative and age-appropriate social skill, however rudimentary and however inappropriate. Their communication skills were dominated by their

own interests, concerns and initiatives, and their failures to respond to verbal or non-verbal cues in others. Hans Asperger says, 'autistic language is not directed to the addressee, but is often spoken as if into empty space' (Asperger, 1991: 70). Asperger also noted the aloof quality in parents which had been described as 'refrigeration' by Kanner, but drew different conclusions: 'parents suffer deeply from the unfeeling behaviour of their children' (Asperger, 1991: 77) and 'These states are undoubtedly polygenetic...We have been able to discern related incipient traits in parents or relatives, in every single case where it was possible for us to make a closer acquaintance.' (Asperger, 1991: 84).

The question of heritability was investigated by Gillberg and Gillberg (1989) in a study of six families in Gothenburg, all of whom had a child who could be classified according to the criteria for Asperger's Syndrome which they had delineated (Gillberg and Gillberg, 1989) in which familial traits were very apparent. The current consensus is that genetics play a pivotal role in the aetiology of autism and autism spectrum conditions (Volkmar et al, 1998; Folstein and Rosen-Sheidley, 2001; Auranen et al, 2002; Buxbaum et al, 2002; Barnby et al, 2003; Muhle et al, 2004; Spence, 2004; Veenstra-VanderWeele, 2004; Bartlett et al, 2005; Hu-Lince et al, 2005; Shastri, 2005; Grice and Buxbaum, 2006; Ronald et al, 2006;) although many genes are thought to be involved and none has as yet been clearly identified as contributing to the conditions

2.2.4. Diagnostic criteria

Internationally, most psychiatrists work to two manuals of guidance, one prepared by the American Psychiatric Association - the DSM, or Diagnostic and Statistical Manual of Mental Disorders, already referred to, and the other the International Classification of Diseases, which is a full outline of all diseases, illnesses and mental and neurological conditions, presented by the World Health Organisation. In the USA, although practitioner diagnosis is usually from DSM, national bodies take their guidance from ICD. The first two DSMs (1952 and 1968) were devised by a panel and defined mental disorders in a psychodynamic fashion, but from DSM III there was an effort to use empirical and consensus evidence from a variety of practitioners in the same format as that used by the World Health Organisation. The empirical and descriptive approach to diagnosis was first used by the WHO in ICD-8 in 1968.

It became clear that the definitions of autism in the two manuals were very different, and in 1980 the DSM adopted the same organisational principles as ICD-9. There were still clear differences. DSM criteria for autism were more stringent, and although these were eased with the interim publication of DSM III-R in 1987, these criteria were then criticised for producing too many autism false positives (Szatmari, 1992; Volkmar et al, 1992). It was not until 1993 and the publication of ICD-10, followed by DSM IV in 1994 that criteria in use internationally for the diagnosis of autism were aligned more effectively (Volkmar, 1998;). Criteria for Asperger's Syndrome were added to both manuals in those years of publication.

Generally, both manuals employed as their benchmark for autism the 'triad of impairments' identified strongly by Wing and Gould (Wing and Gould, 1979). However, there was and remains a major difference in the two manuals which has caused some confusion in diagnostic description of autism spectrum conditions. The 1980 DSM III usefully placed autism in the category of 'pervasive developmental disorders' (Volkmar et al, 1985; Cohen et al, 1986; Hoshino et al, 1986) clarifying what was known about the aetiology, and removing all doubts that the disorder might be psychogenic. But while ICD-9 included a category 'atypical autism', DSM-III criteria categorised this version of pervasive developmental disorder, in which fewer criteria may be met than that of autism, as PDD-NOS, pervasive developmental disorder not otherwise specified. Since the criteria for Asperger's Syndrome have been included in both DSM-IV and ICD-10, the confusion between it, and PDD-NOS, and atypical autism, continues (Mahoney et al, 1998; Buitelaar et al, 1999).

The diagnostic criteria of PDD/ autism are important in that they form the basis not only for the surveys into prevalence and incidence, but that wherever they are broadened to allow for advances in knowledge, they can also narrow investigations into these conditions, by disallowing in criteria what has been recorded by clinicians. Another factor is that as autism definitions have changed over time, research papers have been written using a variety of diagnostic criteria, and therefore a slightly different cohort. These issues are of crucial importance in the empirical base of research into autistic conditions, and in public awareness of what might constitute 'autism'. However, it should

be understood that diagnostic criteria for autism spectrum conditions are a work in progress. They involve efforts to delineate clearly, over time, and according to advances in research techniques, the essential factors of these conditions which were first noted very recently, in medical historical terms.

2.2.5 The autism spectrum

In their Camberwell study, Wing and Gould identified some children who did not have classic Kanner autism, but showed many of the characteristics of autistic tendency (1979). They hypothesised that there may be a broader and as yet unrecognised classification of autism, which they described as the 'autism spectrum' or 'autistic continuum' (Wing, 1988). Asperger's contribution (Asperger/Frith *trans* 1991) bore out their hypothesis. The term 'autism spectrum' in part overlaps with the concept of pervasive developmental disorders, as used in diagnostic criteria, but is a broader and more inclusive term used with caution by researchers, as it remains vague and its inclusions and exclusions are subjectively determined (Wing and Attwood, 1987)

Wolff researched childhood personality disorders from the early 1970s. She noted that some of the children she had studied shared with Kanner's descriptions a tendency to solitariness and poor social reciprocation combined with pedantry. These children had been diagnosed with schizoid or schizotypal personality disorder (Wolff, 1979; 1980; 1986) She hypothesised that there was a point on the autism spectrum at which those with certain 'loner' traits shaded into normality, and suggested that mild personality disorders of the schizoid type may represent this point. Some similar findings

from Nagy and Szatmari (1986) appeared to support her view. The authors argued that differential diagnoses than schizotypal personality disorder might better be employed for most of the twenty children in their study.

The question about the point on an envisioned spectrum where autistic traits were present but considered extremely mild began with Wolff's queries over schizoid/schizotypal personality disorder. Szatmari's criteria for Asperger's Syndrome (1989) emphasise solitariness, which perhaps explains his interest in Wolff's research. The concept of a continuum of symptoms, a spectrum, has now been widely accepted by most researchers, as has the notion of a 'broader Autism phenotype' which may not show autistic traits at the level of diagnosis, but will nevertheless present with them, particularly in immediate family members of those diagnosed with autism (Jobe and Williams White, 2007; Bölte and Poustka, 2006; Klin et al, 2002; Happé and Briskman, 2001, Bolton et al, 1994)

2.2.6 Incidence and Prevalence

Before moving on to the theoretical models, this literature review must finally establish the incidence and prevalence of the autism spectrum conditions, in order to clarify the importance of their consideration by the education services. Fombonne's studies, using fairly strict definitions, place the incidence at .6%, (2005) and he says that this figure, one in 166, has remained stable over time according to a follow-up whole population study in Stafford (Chakrabarti, 2005). A Danish study, comparing incidence over time, 1971-2001, noted an increase in the diagnoses of pervasive developmental

disorders in the years 1990-2000, which can be explained by the publication of diagnostic criteria, especially for Asperger's Syndrome, in those years (Lauritsen et al, 2004). In the USA, (Shattuck, 2006). researchers found that where the prevalence of autism appeared to increase in the administrative classification of special education needs in the years between 1984-2003, the prevalence of 'mental retardation' and 'learning disabilities' diminished correspondingly. The terms had merely been substituted in the recording of children's educational difficulties to more accurately reflect the child's current diagnosis.

Meanwhile, a UK whole population study which was conducted in the South Thames region, and included a sampling of those who were suspected of having a pervasive developmental disorder who were then screened, in addition to those already diagnosed, produced a figure of just under 1%, or one in 116 (Baird et al, 2006). A recent whole-population child study in Cambridgeshire estimated the prevalence at 1.57% (Baron-Cohen et al, 2009a), or 1 in 64. These more recent figures, which included a county-wide screening to enable undiagnosed children to be referred for diagnosis, are interesting. They suggest that many children with autism characteristics may not carry a diagnosis.

This is supported by a recent study (Russell et al, 2010) in which children whose behavioural traits corresponded to the traits of autism, in the Avon Longitudinal Study of Parents, were investigated for diagnosis. It discovered that 55% of children with autistic traits at the same level of those with a diagnosis had not been identified as needing extra support from education services or health services. As in the Baron-Cohen et al study, it may be that

teachers are not sufficiently skilled or confident enough to identify ACSs in order to enable extra help in the absence of a diagnosis, and that skills of health personnel are not being shared with their teacher colleagues. This study also offered the statistic that in the Avon area, 26% of those who did have special provision at school had an autism spectrum diagnosis. Similar results were obtained in Olmsted County Minnesota in a similar population-based retrospective study (Barbaresi et al, 2009) in which only 46.8% of research-identified cases of ASC received a clinical diagnosis. The figures are remarkably similar.

These figures suggest that even in a average mainstream UK primary school there is likely to be one child per year with a pervasive developmental disorder whether or not this is diagnosed, and in a secondary school, allowing for the fact that some of these students may be differently placed in special or specialist schools, there should be at least two in every Year-group. It is therefore highly unlikely that a school teacher will not have to consider the needs and abilities of a child with this complex learning style at some stage in their career.

2.2.7 Summary

The understanding of the complexity of autism spectrum conditions is partial in the general public (Harnum et al, 2006), and in health practitioners (Heidgerken et al, 2005), teachers (Helps, 1999; Morgan and Hastings, 1998; Kirby et al, 2005) and parents (Mansell and Morris, 2004). This is inevitable, given the relatively recent discovery of the condition, the delays in devising

diagnostic criteria, the conflicts and limitations of the criteria, and the confusion over the meaning of the word 'autistic', from its earliest coinage and connections with schizophrenia.

Although Wing and Gould's (1979) identification of the 'triad of impairments' has helped to define it as a condition in which language, social engagement and imaginative flexibility are limited, their initial survey among children with intellectual impairment in Camberwell, to determine whether these children should have an additional diagnosis of autism, has unfortunately led to an assumption that autism is very highly associated with intellectual impairment. On the other hand, the Autism Research Centre in Cambridge, led by Simon Baron-Cohen is able to study autism in academic scientists and mathematicians as they can provide a convenience sample (Baron-Cohen, 2001). There is, therefore, some polarity in views on the autism spectrum, with some believing that 'low-functioning' people with ASCs, those with intellectual impairment, have a more valid version of autism, than those with 'high-functioning' ASCs, like Asperger's Syndrome.

Additionally, that intelligence may be one factor in enabling the discovery of strategies to manage some of the core characteristics of autism is not denied. However, the core characteristics of autism, of which intelligence is not a diagnostic factor, may be equally shared throughout the spectrum, albeit more strategically managed. In a recent study (Leekham et al, 2007), 93% of children with autism (n=33) matched with IQ comparators, were found to have

sensory abnormalities in multiple sensory domains. An important finding of this study was the following discovery (Leekham et al, 2007: 903)

We found that when high functioning autistic children were compared with an IQ-matched comparison group the difference was greater than when low functioning children with autism were compared with developmentally disabled children. In the current study, the high functioning autism group had more sensory symptoms overall and were more affected by multiple sensory domains than the language impairment comparison group. In contrast the low functioning autism group did not differ from the developmental delayed group...

Surprisingly, high functioning children with autism also showed a high frequency of proximal abnormalities. Proximal abnormalities are associated with low developmental immaturity, yet over 35% of HFA children had abnormalities in virtually all of the proximal categories and did not differ from low functioning autism group in the frequency of these features.

It should be noted that 'proximal' as used in that study (Leekham et al, 2007) is descriptive of all sensory functions and motoric functions which are neither auditory nor visual. This finding, which the authors describe as 'striking' appears to suggest that when matched with 'matched others', even 'matched others' with specific learning difficulties, the sensory profiles of the apparently higher functioning children on the autism spectrum are similar to those of those thought of as low-functioning. A similar finding was that of Hilton et al

(2010) in which the responsiveness of the proximal senses in High Functioning Autism subjects (n=36) was the strongest predictor of greater social impairment. The authors conclude (Hilton et al, 2010:1) that their findings suggest 'the relationship between sensory responsiveness and other autistic traits is more important than previously recognised, and addressing sensory modulation issues in children with HFASD may be more critical than previously understood.' This conclusion reflected that of Lane et al (2010).

Reinterpreting the autism spectrum as a continuum, not only in diagnostic terms, but also in the individual development of each child is helpful, as is Baron-Cohen's question, 'Is Asperger's Syndrome/High functioning autism necessarily a disability?' (Baron-Cohen, 2000) in which he suggests that it may be best to think of autism as a 'difference' rather than an impairment, and as a cognitive style. Whether an alternative information processing variant is a viable Darwinian theoretical position has also been examined by Baron-Cohen (2006) in an interesting paper in which he looks at the prevalence and incidence of autism in certain global cities, attributing the apparent rise of autism in centres of technological advance to assortative mating in those whose cognitive skills are more geared towards systematising processing, than to social empathic processing (Baron-Cohen, 2006). It must be said that in centres of technological advance there is likely to be more access to diagnosis. This is an opinion piece rather than a research project, however. It is helpful, too, in readjusting perception, and enabling parents and educators to understand that if such a processing style proliferates and is primarily genetic in origin, despite autism's label as an impairment there may be an

evolutionary principle which does not deselect this trait or condition, as Baron-Cohen (2006) claims, and therefore it may be advantageous to the survival of humankind. Such an opinion, although radical, challenges the prevailing views and practice of education, mental health, and child development. This question of difference raises the first supplementary research question:

Do professionals and parents, and children on the autism spectrum regard autism as a deficit, or a difference, and is there any recognition of the skills and strengths and advantages of this condition?

2.3. Theoretical perspectives of autism

2.3.1 Introduction

Three theories have dominated the clinical research investigations into autism. These are seen as overlapping rather than as inter-challenging, and roughly correlate with the triad of impairments, although some explain more than one element. An hypothesised delay in Theory of Mind for children with pervasive developmental disorders has been posited by one research field, dominated by Baron-Cohen and colleagues, (Amsterlaw and Wellman, 2006; Dykens et al, 1991; Evans and Wellman, 2006; Hobson, 1990; Moore et al, 1996; Wellman et al, 2001; 2000; Baron-Cohen, 1989; 1991; 1992) This theory in part may be said to account for the social discrepancies noticeable in children with autism, and may account for some of the speech and language deficits.

The theory of weak central coherence has been developed and investigated by another body of research led by Frith and Happé (Berger et al, 2003; Burnette et al, 2005; Frith, 1996; Frith and Happé, 1994; Happé, 1996; Hoy et al, 2004; Jolliffe and Baron-Cohen, 1997; 2000; 2001; Lopez and Leekham, 2003; Lopez et al, 2004; Morgan et al, 2003; Pellicano et al, 2006; Plaisted et al, 2003; Rinehart, et al 2000; Ropar and Mitchell, 1999; Shah and Frith, 1993; van Lang et al, 2006) This theory, which focuses on the monotropism of autism (Murray et al, 2005), and the ability of those on the autism spectrum to prioritise perceptual detail rather than the 'gist' or 'big picture', could be said to account for the imaginative inflexibility of autism, the contextual problems associated with the cognitive patterns of those with this condition, and some of the linguistic problems which are evident.

The third theory has been investigated more fully by those involved in the exploration of the role played by the pre-frontal cortex, and its pathways to the limbic system, a neurological difference most strenuously investigated by researchers into AD/HD, which appears to share some of the executive function differences with autism. The Executive Dysfunction Theory, originally based on what is known about patients with frontal lobe lesions, but now elucidated by brain-imaging, explains the failure in many autistics to inhibit response, to set-shift, to prioritise, and to maintain attention. (Lopez, 2005; Moore et al, 1997; Ozonoff et al, 2004; 1991; 1994; Hill, 2004).

There are also three minor theories in the literature, all of which relate to those cited above. While most researchers originally followed Baron-Cohen's

modularity version of Theory of Mind, theory-theory and simulation theory were also used in an effort to explain the way that the child on the autism spectrum appears to lack what is known as 'the social brain'. Central Coherence theory also has a competing theory: Enhanced Perceptual Processing, which attempts to refute the deficit model of weak central coherence.

All six of these theories are summarised below at Figure **2.3.1**. Minor theories are italicised in the first and last columns as are those explanatory neurological underpinnings which were unknown at the time the theory was devised. It must be noted that in the time taken to construct and write this research study, research into autism has accelerated at such a pace that theories which appeared to be relevant and valid at the start of the project no longer occupy the consensus position they did in 2006, at the start of the research. It may well be that the current consensus changes, too, as autism is an exceptionally rapidly-developing research area, and the study of autism is, as yet, in its infancy. Many of the theoretical positions outlined in Figure **2.3.1** have now been modified by their theoreticians. It has therefore been necessary to reframe and readjust this examination of the theory, and this readjustment will be summarised at the end of this section.

Figure 2.3.1

Theories of autism

THEORY	Names	Explains	Diagnostic criteria	What is it?	Tests	Neurology
Theory of Mind (TOM)	Baron Cohen Leslie and Frith (1985)	Social deficits in autism	Impairments in social interaction	Problems in realising that other people have different minds from their own	False belief tests particularly the Sally Anne test	<i>[Mirror Neuron System]*</i> * not identified until 1996
<i>[Theory-Theory]</i>	Gopnik(1996)	How children think	N/A	Children are 'little scientists' who build theories about their environment	N/A	N/A
Simulation Theory	Gallese et al (1996)	Social and motor integration and failures in this	Impairments in social interaction and language skills	Typical children are able to simulate others' actions and feelings	N/A	Mirror Neuron System (MNS)
Central Coherence Theory	Happé and Frith (1994)	ASC children's preference for parts to wholes - fragmenting	Impairments in social interaction, language and imagination	ASC children tend to fragment information rather than process it for gist and meaning	Block Design, Embedded Figures, and homophones	<i>[Local Processing Bias]*</i> *current research consensus based on fMRI and ERPs
<i>[Enhanced Perceptual processing]</i>	Mottron and Belleville (1993)	As above, but viewing this as a skill not a deficit	N/A	An enhanced ability to use perception to process information	As above, but includes investigation of 'savant skills' and tests of fluid intelligence like Raven's Progressive Matrices	Local Processing Bias - LBS
Executive Function	Norman and Shallice (1982)	The inability to plan, inhibit, organise, attend and prioritise, within time frames	Impairments in imagination (flexibility)	Processing information by priority, inhibiting response, and giving due weight to what should be attended to, in organising and planning	Based on frontal lobe trauma studies: Go/ No Go, Tower of Hanoi, Wisconsin card-sorting and others	Frontal lobe connectivity problems

2.3.2 Theory of Mind

The term 'theory of mind' has long been used in a generalistic sense, deriving from the essential Cartesian mind/body duality. In 1978, Premack and Woodruff, in a research paper, asked an evolutionary biological question, 'Does the chimpanzee have a theory of mind?' (1978). The question arose from a study of the life of primates, the fact that they live in herds and families, and whether they developed an instinct to judge the wishes and intentionality of others in order to protect the group, and to survive. By interpreting gesture and facial expression as a predictor of action, primates may possibly have an evolutionary advantage.

The research answer, that an ability to infer the volition and or intentionality of others is a basic necessity where protected group sizes are large, and that chimpanzees may well have this ability to some extent, has been challenged, notably by Dennett (1978) on the conclusions made in the study about the capabilities of the chimpanzee in question and whether the test requirements were met. The evolutionary question about the adaptation provided by having a theory or facility to enable one to understand what others may want or intend has been accepted, and has been further explored by other evolutionary biologists, taking a human perspective on theory of mind, notably by Dunbar (1998; 2003).

Baron-Cohen, Leslie and Frith (1985) studied the theory of mind of autistic children, 'Does the autistic child have a "theory of mind"'. In this study, children over the age of four, or with the IQ levels of 4-years old and above, were subjected to what has become known as a 'false belief' test, the test of

whether we understand that others can have beliefs and understandings which may be different from our own.

In this test, now called the 'Sally Anne' test, children were asked to specify where Sally would look for her marble, if they, and the testers, knew that it had been removed secretly by Anne, to another place. The study looked at three groups of children: normal controls aged on average 4.5, Down's Syndrome children with an IQ equivalent to four years old, and children on the autism spectrum with an IQ in the normal range at 12. 80% of the autism spectrum children failed this test. 85% of the Down's Syndrome children (12 years, IQ equivalent to 4.5 years) passed it, as did the same proportion of typically-developing 4.5 year olds.

The research appeared to show that there was a deficit or maturational lag in autistic children in the understanding of others' mind states which was independent of intellectual capacity. Children with autism, at the age of 12, did not appear to know that others could have beliefs which differed from their own experienced knowledge. They did not have a 'theory of mind'. This cognitive capacity has also been labelled 'folk psychology', albeit contestedly (Ratcliffe, 2006), emotional intelligence (Mayer and Salovey, 1993), empathy (Gallese, 2003) albeit challenged by Rogers et al (2006), and metarepresentation – the ability to think about thinking (Leslie, 1987).

Baron-Cohen (1995) hypothesised on a child-development model that ToMM (the Theory of Mind Mechanism) is innate but modular, a position also take by Alan Leslie (1994). He proposed four mechanisms which are present from birth but mature within the first years of a child's life. These are ID (the

Intentionality Detector), EDD (the Eye-Direction Detector), SAM (The Shared Attention Mechanism), and finally, the ToMM.

The theory follows current child development theory. The length of eye gaze is a key to parent-child bonding in face-to-face situations (Bartrip et al, 2001; De Haan and Nelson, 1997; Lavelli and Fogel, 2005; 2002; Ranote et al, 2004, Trevarthen, 1985), dyadic relationships are thus established and from the earliest weeks of life children are capable of distinguishing between animate and inanimate objects. The child also appears to recognise intentionality from following eye-gaze from about the end of the first year of its life (Phillips et al, 2002). Declarative gesture, pointing, then develops with the child drawing others' attention to intention, emotion and objects of interest (Liszkowski et al, 2006; Carpenter et al, 1998). This established, shared, or joint attention eventually leads to pretend play which is a rudimentary level of Theory of Mind, as it allows an object to be, and to be something else in mind. In Baron-Cohen's (1995) hypothesis of an innate but staged modular development, one which he has now largely rejected, the child develops a 'theory', well-provided with axioms, of interpersonal relationships, through accessing, in turn, the modular structures provided from birth. At the point at which ToMM is reached, the child has accessed 'theory', and is now capable of mentalising.

Opposing Baron-Cohen and Leslie's modular views, and those of Gopnik (1996) who argued that children actively build scientific theories about their experiences: 'theory-theory', were the views of Gallese and Goldman. They proposed Simulation Theory as an explanation for the capacity to understand cognitive states. Simulation Theory is also nativist, claiming that the child is

from birth capable of instant role-play, placing itself in the position of another, and that this ability is honed throughout infancy (Gallese, 1998). It was claimed that this ability works far more quickly than theorising might, and that it must therefore be the first ability called upon.

However, although modular accounts and simulation theory accounts differ substantially from each other in hypothesising the nature of social development, there is a common core: the importance of eye gaze. In Baron-Cohen's account the EDD (Eye Direction Detector) is named as a precursor of ToM. In simulation theory, it is eye gaze which switches on the ability to replicate action and emotion and to detect intentionality.

Eye contact in children on the autism spectrum is noticeably aberrant, and is included in diagnostic criteria. Autistic children are less likely to point or show objects, but more likely to manipulate an adult hand as a tool (Stone et al, 1997). They are less likely to seek joint attention, less likely to use symbolic play, or to use social signalling (Wetherby et al, 1998). In face-processing they fragment, and do not always look to the eyes for information, choosing instead to look at mouths, or at objects (Klin et al, 2002). The reason for this difficulty in facial processing was thought to be 'disruption' or 'derailment' of normative development in the first few months of life (Trepagnier, 2002, Klin, 2003).

However, two studies suggested that some children with autism may have the ability to use others' eyes as direction cues, although more slowly than expected (Chawarska et al, 2003; Kylliäinen, and Hietanen 2004), and one found that the children in their study could accept the directional cue given by the symbol of an arrow as frequently as that of eyes, showing equal

preference (Senju et al, 2004). There is also evidence that autistic children are more likely to attend to an incongruent cue, following eye direction even if there is no object present in the visual field (Wallace et al, 2006).

Grice et al, (2005) found neural eye-gaze processing in a study of a group of children on the autism spectrum to be not only different from that of age-matched groups, but very significantly immature. While the 5-year-old controls performed at the same level as a group of non-autistic adults on a test involving High Density Event Related Potentials, those particular 5-year-old children on the autism spectrum performed at the level of data obtained from four-month-old infants.

Perhaps there may be some children who have not acquired the basic building blocks of social competence. What theory of mind research reveals to education is that children with autism may not have the capacity to build adequate pre-language skills, and even those with unimpaired intelligence may be working at a much lower pre- and pro-social ability than anyone has yet realised. That children of five years old may have the pre-verbal cognition of a four-month-old baby is a major research finding. That secondary school children of average intelligence at 12 may not have the social capacity of a four-year-old, must present challenges to those designing courses in Arts and Humanities in particular, and to the pastoral care of all pupils and students who may be neurologically or developmentally unable to articulate or fully understand their and others' intentions, fears and thoughts,

2.3.3 Central coherence

In the 1940s and 1950s Herman Witkin devised a theory of cognitive style, more properly called cognitive control, based on differences in perception (Witkin and Asche, 1948; Witkin, 1949). He determined that on a variety of tests of perception, including one involving tilting, and another involving being able to separate a detail from its surroundings, that there are two distinct cognitive operating styles. He devised the Embedded Figures test, to determine whether geometric shapes could be seen by subjects when the shapes were hidden in a picture (Witkin, 1950; 1965). From the results he deduced that thinking styles were either Field Dependent (FD), those who had difficulty disembedding the figures, or Field Independent (FI), those who could disembed with varying levels of speed. He concluded that those who could disembed tended to be analytical and autonomous, mathematical, reflective and innovative in their thinking. He contrasted this style with that of the FD type who was distracted by the picture and tended to be sociable, impulsive and arts-biased (Witkin, 1967; 1977). His cognitive control theory, extending to personality evaluation, is very robust, as a theory of learning, and consistently referenced in research papers (Sheriff and Williams, 1980; Leino and Puurula, 1983; Thompson et al, 1983; Drane et al, 1989)

Frith and Happé (1994) proposed that several of the diagnostic features of autism could be explained by another theory than Theory of Mind. Noting, as had Baron-Cohen, that children on the autism spectrum performed poorly on social tasks but surprisingly well on tasks involving the physical properties of

the world around them, they pointed to outstanding findings in their study. These were that the children performed at a much higher level than average controls on block design tasks and Witkin's Embedded Figures Test (Witkin, 1965). Their experiments were partially replicated, with the inclusion of a novel drawing test by Joliffe and Baron-Cohen (1997). Frith and Happé concluded that children on the autism spectrum showed a distinct preference for local rather than global processing, in demonstrating a capacity to process detail over gestalt and meaning. They theorised that autistic children showed 'weak central coherence'. This had already been partially explored by Frith (1989).

'A weak central cohesive force....would simulate field independence... It would entail thought detachment and social detachment, but this would not be the same as in an older normal child. In the normal child detachment is the sophisticated end-product of education, a sign of control over the high level central force towards cohesion. In the case of Autism I propose that such a control is lacking and that this results in an incoherent world of fragmented experience.' (1989: 98)

The theory was additionally based on Sperber and Wilson's Relevance Theory (Sperber et al, 1995), a communication theory originally researched by Happé for its links with autism and theory of mind (Happé, 1993). It postulates that communications are driven by the optimum use of processing resources, which implies that it is quicker and easier and less costly to those perceptual resources to seek to derive more meaning from utterances than that which

can be explained by a mere coding and decoding exchange. We also, the theory hypothesises, attempt to bypass lengthy or complex communication by making inferences, by understanding implicit as well as explicit messaging, which in turn suggests that in order to use communication effectively we have to determine intentionality from context very rapidly. We reject what is unnecessary in understanding, and prioritise what appears to make sense through context.

This theory may go some way to explaining the pragmatic difficulties experienced by children on the autism spectrum in their use of semiotics (Leinonen and Kerbel, 1999). If theory of mind is compromised, then communication ability, too, will be compromised (Caparulo and Cohen, 1977, Solomon, 2004) even in those more able children who appear to have a mastery of semantics. If they use, as seems possible, a simple coding and decoding methodology, they will use language in a manner which may be formally correct, even pedantic, but may not process metaphorical language, irony or sarcasm efficiently (McDonald, 1999; Martin and McDonald, 2004). They may not understand that context of communication is relevant to its content (Shriberg et al, 2001, Norbury and Bishop, 2002; Lopez and Leekham, 2003). They may fail to disambiguate, which is why they make errors with homophones (Hoy et al, 2004)

In some ways Relevance Theory and the drive towards central coherence appears to accord with Theory of Mind, but it adds an important consideration, that of context. It suggests that in order to preserve efficient processing, cognition generally moves towards a global, meaningful, inference from a

local, detail, perception. It is inclined towards generalisation from specifics, allowing processing to ignore non-meaningful input, leading to higher order causal links to be established from disparate local information. As this higher order process is constructed, local detail may become less and less meaningful and may be discarded. The question of the usefulness of what may be called fragmentation, local detail, is crucial to Frith's theorising a cognitive drive towards central coherence in those not on the autism spectrum. She hypothesises that this tendency is not domain specific, but is a general perceptual and processing difference.

This hypothesis has been tested by other researchers who studied visual-spatial processing in those on the autism spectrum (Plaisted et al, 1998; Happé, and Frith 1996; Rinehart, 2000, Davis et al, 2006) and auditory processing (Foxton et al, 2003; Plaisted et al, 2003; Paul, 2008; Groen et al, 2009) noting perceptual differences in autistic subjects which suggests that local rather than global processing is more common in those on the autism spectrum. That detail-driven focus may enable the splinter skills and savant abilities noted in some autistics is also explored by researchers (Pring and Hermelin, 1995; Pring et al, 2002). Autistic superiority on the Embedded Figures Test is one of the most robust findings in research (Motttron et al, 2003, Jolliffe and Baron-Cohen, 1997, Caron et al, 2006) with only one recent study unable to replicate this (Kaland et al, 2007). The Kaland (2007) authors suggest that with only n=13 participants in the experimental and the control groups, statistical power was necessarily low, and that the tasks in their study may have been too insensitive to measure an underlying difference. They also say (2007: 90):

Another finding in the present EFT study was that some of the participants in the clinical group, but fewer among the controls, had problems finding the hidden figure when the first pattern was exposed. This difficulty seemed to influence their performance on the following trials, as in 20 of the assessments the participants in the clinical group gave up finding the hidden figures. In such instances the participants became insecure and hesitant, and afraid of committing faults. This personality trait seems to characterize many individuals with AS or HFA (Soderstrom et al., 2002), and may partly explain why so many persons in the clinical group gave up finding the figure, thus extending their mean response times.

As noted in the Introduction, the heterogeneity of ASCs, particularly when studying such small samples, may confound results, and certain other traits of the ASC children, rather than the one tested may come into play.

The possible neural underpinnings of the local bias in autistic processing, a consensus arrived at by over fifty research studies (Happé and Frith, 2006) were more difficult to determine than the neural underpinnings of Theory of Mind. Belmonte and Yurgelun-Todd (2003) carried out an fMRI study in which autistic children and normally-developing children were given attentional tests. They recorded that while in normally developing children the frontal and pre-frontal cortices were activated, in autistic children the occipital (visual) cortex was activated. Their conclusion was that in autism local neural pathways may be over-connected creating hyper-arousal and reduced selectivity. The

findings parallel those of Iacoboni et al (2005) in a study in which the mid-brain failed to deactivate, disrupting attentional processes. Belmonte and Yurgelun-Todd (2003:651) say: 'these low-level attentional traits may be the developmental basis for higher order cognitive styles such as weak central coherence', linking the central coherence theory to the theory of executive dysfunction. Caron et al (2006) echoed Belmonte's conclusion in their experiment on the Embedded Figures Test which compared typically-developing subjects who had a high visual-spatial peak, (the ability to disembed at a high level) with autistics with a similar peak. The study discovered an enhanced activity in the posterior-central visual cortex (VI) in autistic subjects, an over-functioning of this region which could be explained by Belmonte's hypothesis. It could be explained also by reduced cross-talk between brain regions, or by diminished feedback of higher order mechanisms, or by enhanced lateral inhibition of neural connectivity. Caron et al (2006: 1801) conclude that, as research has already shown similar local processing enhancements in the auditory cortex, 'perception *per se* may be reorganised in autism'. This conclusion will be examined at the end of the Theoretical Perspectives section.

Murray et al, (2005) speculate that the central coherence theory could be said to explain monotropism, diagnostically described as restricted interests: the tendency for those on the autism spectrum to pay attention to a few highly-aroused interests. They conclude by hypothesising that it is the third element of the triad of impairments, an impairment in imagination (flexible thinking), which more accurately describes autism than the other two impairments, and

may even be responsible for the other deficits. Their argument is compelling, and their conclusions are valuable for educationalists, stressing as they do the need for others to scaffold those with autism spectrum conditions, giving them positive views about how society is helpful, but beginning by appealing to the child's own highly-focussed interests, and working from those. They suggest practices already successfully in use: 'reduce task demands in complexity, time pressure and irrelevant stimuli' and 'if tasks and ideas are conveyed in small portions, ensure that the overall relatedness of the parts is understood'. The summation of this research paper might be that in autism connectedness of all kinds is compromised, and the nature of useful intervention should be to teach the child whose experiences are 'fragmented', how to connect.

This section gives rise to a further supplementary research question:

'To what extent do teachers, parents and the children themselves identify the sensory and perceptual differences which are theorised to be essential features of autistic intelligence?'

2.3.4 Executive Function/Dysfunction

This executive dysfunction theory has the most robust neural findings (Schmitz et al, 2006; Silk et al, 2006), yet the least specific to this particular developmental disorder (Pennington and Ozonoff, 1996; Hill, 2004), and in some ways the least explanatory for the many complex deficits and

differences which are apparent in autism spectrum conditions. Although it may account in part for aspects of cognitive inflexibility (Kenworthy et al, 2005; Hill and Bird, 2006) and the impairment of imagination (Hughes et al, 1994; Ozonoff et al, 1994), research findings are inconsistent with executive dysfunction being a core deficit, as some aspects of executive function have been seen to be preserved in autistic children (Griffith et al, 1999; Russell et al, 1999; Luna et al, 2007). Unlike the other two theories, research into executive function did not arise from research into autism, but is generalised as a theory relating to child development and brain injury or deterioration.

Executive dysfunction is also widely used as a descriptor of the difficulties faced by children with AD/HD, and its origin as a theory is in studies of those known to have suffered frontal lobe damage (Shallice, 1982). Executive function, and aspects of the same, have also been variously named as Central Executive (Baddeley, 1986) and the Supervisory Attentional System (Norman and Shallice, 1980; Shallice, 1982)

It is hypothesised that Executive functions are performed in the pre-frontal cortex, in neural tandem with the limbic system: hippocampus, amygdala and olfactory bulb in the medial temporal lobes, and are said to consist of the abilities :

- to initiate action or to cease it or adapt it in the light of observed failure
(*cognitive flexibility*)

- to pay attention to salience and ignore extraneous interference (*attentionality*)
- to delay or reject automatic response or gratification while holding information in the working memory (*inhibition*)
- to move rapidly from one perceptual mode to another (*set-shifting*)
- in a progressive manner (*sequencing*).

These controlling mechanisms for automatic action enable children, gradually, to face novel experiences and consider them in the light both of past immediate and past longitudinal experience (*working memory, declarative memory and long term memory*) (Lopez et al, 2005; Happé et al, 2006; Pennington and Ozonoff, 1996, Baddeley, 1986), the present and ongoing process of decision-making (*monitoring*), (Robinson et al, 2009) and of an imagined future outcome (*goal-setting*) (Hill and Bird, 2006) which may be affective (*motivational*) or cognitive (*rule-formation*), and are probably both, (Hill, 2004).

Executive functions are therefore seen to be productive of and dependent on an awareness of time as a dimension (Barkley, 2001). They also function as the basis for the formation of complex learned automatic actions, like touch-

typing or reading. There is evidence that a range of these functions is operant a year before theory of mind false belief tasks can be passed, but no evidence that theory of mind can precede competence in executive capacity (Hughes et al, 1994). They are also largely involved with global processing.

If we examine the behavioural profile of and diagnostic criteria for children with autism spectrum conditions, and compare these to the demands posed by higher order conceptualising, Executive Functionality (EF), there appears to be a mesh. Children with these conditions display behavioural rigidity and a dislike of change (set-shifting difficulties), they can fall victim to what is known as 'autistic inertia' which at times approaches catatonia (initiating difficulties), they have perseverations (cessation difficulties), are distracted by environmental disturbance (attentionality), they are often inappropriate (inhibition difficulties), have little sense of time (working memory and sequencing problems), and their lack of cognitive flexibility is in all diagnostic criteria.

To discover whether these assumptions may be valid, we should return to the studies on autism spectrum executive functionality. Hughes et al's (1994) results, confined to set-shifting and Tower of London (planning) tasks, appeared to show that autistic children were differentiated from typically developing children in those stages of tasks which placed the heaviest burden on executive control, and in both tasks showed significant differences, delays, from the ability-matched controls. In Ozonoff et al's (1994) study in which both typically-developing children and children with a diagnosis of Tourette's

Syndrome were used as controls, processing paradigms were used. In contrast to Frith and Happe's conclusions and results (1994), this research study noted no global/local processing difficulties in the autistic group, nor on neutral response inhibition tasks, one which may have been considered to be a problem for those with Tourette's, but a difficulty with cognitive flexibility was significant for the autistic group.

The ability of autistic children to inhibit neutral response was also noted in a further study carried out by Ozonoff and Strayer (1997) on non-retarded children with autism. In Pennington and Ozonoff's (1996) study, a comparison of children with AD/HD, conduct disorder (CD), Tourette's and autistic children, yielded results that there were no difficulties in EF for children with Tourette's or CD, but the other two groups had marked EF deficits. AD/HD children had significant problems in motor inhibition where autistic children had none, and that tasks demanding a high level of verbal working memory were significantly difficult for autistic children, but not for those with AD/HD. A study of pre-school children with autism (Griffith et al, 1999), mean age 4.3, matched on age, verbal and non-verbal ability, found no differences in the groups on eight tasks which purport to measure executive function. The differences noted were merely those of social exchange, in which the autistic children were less able. It is interesting to note that this research study included only tests of inhibition (no deviance), and visual-spatial executive function tests (no deviance), which could be said to rely strongly on the Baron-Cohen hypothesis of no differentiation in autism and typically developing children in 'folk physics' (1997). Tested after a year's lapse, the

results remained stable, a very important finding at this crucial developmental stage at which typically-developing ToM may have the influence to vary results (Hughes et al,1994).

Russell et al (1999) appear to confirm the finding that autistic children are as able as non-autistic controls where the test parameters for EF take account of a differing social understanding, and a differing level of communications/linguistic skills. The 'tube' task which was set by this research study, a simple test of the understanding of physical systems and rule-inference derived from non-verbal reasoning, and no arbitrariness or novelties, showed that children on the autism spectrum were as capable as typically-developing children in higher-order thinking and EF, provided that the socially-constructed and linguistically-dependent variables were removed. The finding was consistent with the hypothesis that children with autism are challenged by executive tasks because they are perhaps unlikely to encode rules in verbal form. Kenworthy et al (2005) echoed the consensus that EF is compromised in autism, but in the domains of cognitive flexibility and disorganisation (planning, set-shifting and sequencing), not in motor inhibition.

Hill and Bird's study (2006) may hold the key to these contestant findings. While concluding that there may be executive function deviations in the test results of children with ASCs, the authors report that the greatest problem in a set of new tests devised to determine the executive functionality of children on the autism spectrum, well-matched across controls, was significant dysfunctionality in tests of response initiation and intentionality at the highest

level. Results show difficulties in engaging and disengaging in the service of goals, and that these dysfunctions correlated with severity of symptomology.

Consensus appears to be that there is little discernable inhibitory dysfunction in autism spectrum conditions, but that there may be disorganisation, inflexibility and a problem with set-shifting in cases where external task demands are high. That this dysfunction is less apparent in a physical modality is well-established. Testing issues may be a problem in that current tests may not be not fine-grained enough.

But another problem lies with the concept of Executive Function itself, and the fact that the term may be too wide, too vague, and too poorly differentiated into its components without an understanding of how some of those components are inter-related, and how much other cognitive factors and developmental factors may impact upon their progression and relatedness. Barkley (2001) who builds a model of executive function which is not dissimilar to but more humanistic than the computational models produced by Baddeley (1986) and Norman and Shallice (1980) describes these problems of definition, but concludes, 'The EFs are composed of the major classes of behaviour toward oneself used in self-regulation...Such actions may be covert but need not be so to be classified as 'executive' (Barkley, 2001:5)

As for neural underpinnings, research into Executive Functions in autism has tended to drift away from mainstream autism research, and positioned itself more strongly in research into AD/HD where frontal lobe and medial temporal

lobe functioning are believed to play a central role (Plessen et al, 2006; Barkley, 2001). However, as referenced earlier, it is the role of the prefrontal cortex to assist what may be called 'higher order thinking' in the processing of information (Kana et al, 2007), and links to the pre-frontal cortex may be differently disorganised in ASCs than in AD/HD. An early research finding in AD/HD was that there appears to be a disruption to the catecholamine reception and transmission system, involving dopamine, norepinephrine and serotonin, from the amygdala to the pre-frontal cortex in some sub-types of AD/HD (Ernst et al, 1998). There is no research to support a neurotransmission dysfunction of this kind in autism.

2.3.5 Local Processing Bias Theory: under- and over-connectivity and the Mirror Neuron System.

The local processing bias theory owes much to the developments in brain imaging in very recent years which have identified a mirror neuron system (MNS). The MNS is said to enable empathy and real-time mirroring of the actions and feelings of others whilst integrating the five modalities to the motor cortex (Rizzolatti, 2008; Cornelio-Nieto, 2009; Fabbri-Destro et al, 2009; Gallese et al, 2009; Buccino and Amore, 2008; Chen and Yuan, 2008; Gowen et al, 2008; Martineau et al, 2008; Oberman et al, 2008; Gallese et al, 2007; Iacoboni and Mazziotta, 2007; Rizzolatti and Destro, 2007; Triesch et al, 2007; Gallese et al, 2006; Rizzolatti et al, 2006; Gallese and Lakoff, 2005; Iacoboni et al, 2005; Gallese et al, 2004; Grezes et al, 2003; Gallese et al, 2002; Rizzolatti et al, 2001; Gallese, 2000; Gallese and Goldman, 1998; Gallese et al, 1996)

The Mirror Neuron System (MNS), and the role it is thought to play in integrating sensorimotor experiences could be seen as the preferred explanation for Theory of Mind, a Simulation Theory explanation, in fact, as proposed by Gallese and Goldman (1998) and Gordon (1986). This has been explored since the discovery of mirror neurons in the macaque monkey (di Pellegrino et al, 1992) and in humans (Fadiga et al, 1995). The original study showed that when the monkey observed another monkey performing a motor task, like reaching or grasping or placing, the part of the brain stimulated in the observer was exactly the same as if he had performed the task. Mirror neurons seemed to provide a capacity for matching and executing motor actions (Gallese et al, 1996). The visual cue enables primates and humans to map this information directly into its nervous system (Rizzolatti et al, 2001) even when the final part of the action is obscured (Umiltà et al, 2001). This describes a cognitive neuroscience understanding of the relationship between action and perception. (Gallese, 2000) and could be an essential key to pre-linguistic development and form a substrate for mentalising (Gallese et al, 2002).

In humans, in an fMRI study, a similar system underlying the visceromotor centres is theorised as being central in understanding and experiencing the emotions of others (Gallese et al, 2004). Moreover, other studies in facial-expression understanding, particularly of fear, anger and disgust show that deficits in face-reading these emotions are paired with deficits in producing the emotions (Goldman and Sripada, 2005). The facial recognition of disgust was found to be impaired in pre-clinical Huntington's disease (Sprengelmeyer et al, 2006) and in Parkinson's disease, in which there was also a failure to

recognise the facial expression of fear (Suzuki et al, 2006; Lachenal-Chevallet et al, 2006). The fear-identification problem has been recognised in AD/HD (Singh et al, 1998) and a failure to recognise the facial expression of fear has been identified in 8.8% of 371 'healthy' males (Corden et al, 2006).

Ekman and Friesen (1971) who claimed that six basic emotions are cross-culturally and universally identified from facial expression: happiness, surprise, fear, disgust, anger and sadness. This may not apply to those with an autism spectrum condition. Many educational interventions in emotional literacy have based their materials on the assumption that all children can recognise these six emotions from facial expression, yet research appears to support a theory that some children on the autism spectrum may suffer from alexithymia, the inability to recognise or name even simple emotions in self or others, and that this could be a cognitive rather than an affective problem (De la Rubia and Rojas, 2001; Hill et al, 2004; Berthoz and Hill, 2005; Hill and Berthoz, 2006). We should not forget, however, that there may be multiple pathways to the same outcome.

Mirror neurons have also been implicated in intentionality. In an fMRI study, (Iacoboni et al, 2005) scanning of subjects watching intentional action showed that it was the mirror neuron section of the brain which was activated. The authors concluded that

'the pre-motor mirror neuron areas, previously thought to be implicated only in action recognition are also involved in understanding the intentions of others. To ascribe an intention is to infer a forthcoming new goal, and this is an operation that the motor system does automatically.' (Iacoboni et al, 2005:0529)

Gallese et al (2006:15) finally suggested that deficits associated with autism may be related to dysfunctions in the mirror neuron studies, postulating that

‘a defective intentional attunement caused by a lack of embodied simulation might cause some of the social impairments of autistic individuals.’

The Local Processing Bias theory suggests that in autism the five sensory modalities are internally over-connected, producing hyper-sensory arousal, and hypo-sensory reactions (Kern, 2006; 2007) as the subject tries to shut down the interference to information processing, but weakly connected to the MNS and to the prefrontal cortex (Rippon et al, 2007). If further research supports this theory, then it serves to offer one possible neurological explanation for the triad of ‘impairments’, offering a neural underpinning of language and communication problems, which depend on the smooth integration of the motor cortex with the five modalities, although there may be other factors involved. It could be said to explain failures in ‘Theory of Mind’, as strong MNS connections are vital to ensure that the subject is able to experience, personally, the actions of others and to understand intent (Rizzolatti et al, 2009).

2.3.6 Local Processing Bias Theory and sensory difference

The evidence for preference of local over global processing also helps clarify, in part, the possession of what have been called ‘savant skills’ in some cases of autism (Pring, 2005; Heaton and Wallace, 2004, Etchepareborda et al, 2007). There may be a particular enhancement of ability and pattern recognition in a single modality: perfect pitch and musical ability, for instance

(Bonnell et al, 2003; Heaton et al, 2003; Mottron et al, 2000; Heaton et al, 1998; 1999; 2001; Young and Nettelbeck, 1995). There may be some forms of outstanding mathematical or calendar calculation ability (O'Connor et al, 2000), or drawing (Mottron and Bellville, 1993; 1995). In a recent study Ashwin et al (2009) examined visual abilities in 15 people with autism, comparing them to 15 controls in performance on the Freiburg Visual Acuity and Contrast test, and discovered that their visual abilities (20:7) so far exceeded that of the control group (20:13) that they lay 'within the region reported for birds of prey'.

This finding can serve to elucidate one of the noted behavioural characteristics in diagnostic manuals, the difficulty in maintaining eye contact in children on the autism spectrum. As Hans Asperger notes (Asperger 1991:69):

...autistic children do not look with a firmly fixed glance at anything, but rather seem to perceive with their peripheral field of vision. Thus it is occasionally revealed that they have perceived and processed a surprisingly large amount of the world around them.

The exceptional over-connectivity in the visual cortex of the 15 ASC participants in the Ashwin study (2009) would account for their ability to perceive and process visual information in such a rapid peripheral glance, and longer maintenance of eye-contact may be painful in someone with this intense visual acuity, and may cause physiological reaction as measured by

skin-conductance studies (Kylliainen and Heitanen, 2006). What has long been regarded as a deficit may, in fact, be a skill, and a compensatory adaptation. This was a point explored in a study of lateral vision in 15 autistic children aged between 33-73 months (Mottron et al, 2007) in which the team observed these children for evidence of atypical visual exploratory behaviours, lateral glances, towards inanimate objects. The finding of the study was that these lateral glances were far more evident in autistic children and 'may reflect early attempts to regulate and/or optimize both excessive amounts of local information and diminished perception of movement' (Mottron et al, 2007: 23).

There are other noted sensory differences in studies of people on the autism spectrum (Adamson, 2006; Ben Sasson et al, 2009). Jones et al (2009) in a study of the auditory discrimination of adolescents with autism spectrum conditions (n= 72) and 57 IQ and age-matched controls found that in the ASD group more sensory problems by poor performers in the auditory discrimination task were associated with loudness levels. The study concluded (Jones et al, 2009: 2858) that:

- (i) enhanced frequency discrimination is present in around 1 in 5 individuals with ASD and may represent a specific phenotype; and (ii)
- individual differences in auditory discrimination ability in ASD may influence the expression of auditory sensory behaviours by modulating the degree to which sounds are detected or missed in the environment.

Khalfa et al (2004) also noted an enhanced response to loudness in the (n=11) subjects on the autism spectrum tested against age-matched controls, indicating a tendency to hyperacusis in autism spectrum conditions, a finding reflected by Downs et al, (2005). Rosenhall et al (1999) in an audiological study of 199 children on the autism spectrum discovered 18% of these children had hyperacusis as compared with 0% of the matched controls, while 23.5% had otitis media with some resultant hearing loss (18%). Gomes et al (2008) report that in a meta-review of studies relating to auditory hypersensitivity, this is the most common of all the sensory perceptual abnormalities which are known to exist in 90% of all children with autism spectrum conditions, with a prevalence range in these individuals from 15% to 100%.

2.3.6 Local Processing Bias: range of brain-imaging studies

The most significant recent neuro-scientific studies of these phenomena of global and local processing were carried out, among others, by Belmonte and Yurgulen-Todd (2003), who examined the brain regions under fMRI of six subjects with autism, and six typical matched controls, performing an attentional task. In conclusion they suggested a model of autism in which 'a pervasive defect of neural and synaptic development produces over-connected neural systems prone to noise and cross-talk' Belmonte and Yurgulen-Todd (2003:651). Just et al (2004) in a further functional brain-imaging study examined the under-connectivity of these perceptual over-connected neural systems to circuits which enable integration of information

during sentence-comprehension, in 17 subjects with high-functioning autism spectrum conditions and 17 matched controls by fMRI examination. Their aim was to test the previously noted finding that those on the autism spectrum have a preserved or enhanced ability to read individual words, but a deficit in the broader-scope task of decoding grammatically complex instructions. After analysis of the fMRI images, the researchers concluded that there was a deficit in those areas relating to the integrative processing of language, and that specialisation centres are abnormal in that they are largely autonomous: 'The impairment in social interaction in autism may, for example, be an outcome of lack of integration of different types of information at a high level' (Just et al, 2004:1819). They offered the explanation that there was a local processing approach to cognitive challenges, a position supported by Bölte et al (2008). However, Thai et al (2009) caution that there may be some limitations in fMRI investigations, and that methodological issues are sometimes not fully addressed. The authors suggest that EEG/MEG techniques could be used alongside fMRI so as to confirm the reliability of findings.

But the evidence for this local and global processing explanation of autism does not reside merely in functional fMRI studies. It is borne out by studies using Event Related Potentials (ERPs), a means of tracking brain activity through the use of non-invasive scalp sensors.

In an analytical review of studies using this methodology, Jeste and Nelson (2009) analyse results from this type of research into the modalities spanning

over 40 years, auditory and visual in particular. These show a convergence of research opinion, with most studies completed in recent years, towards the understanding that there appears to be intact or enhanced local processing in autism, but that there are connectivity problems in synthesizing the information so processed. They conclude by suggesting that future research into this connectivity issue should be multimodal, using a variety of techniques in a single cohort to establish a full and integrated consensus, although to some extent these already exist in the literature, albeit in experimental studies, over many years.

In one of the most recent of these, Wang et al (2007) investigated 15 people on the autism spectrum, on a free-and forced-choice procedure, to determine hierarchical processing of Navon-type hierarchical numerals, with a similar comparison group. The autistic subjects presented with atypical local to global interference. The study concludes that the relative insensitivity of local bias to task constraints in these 15 people with ASCs indicates that local bias, with local to global interference, is a key and characteristic feature of autistic visual cognition and 'a strong candidate for the endophenotype of autism' (Wang et al 2007: 550). Other experimental studies of this type include those by Iarocci et al (2006), Walter et al (2009), Bölte and Poustka (2006) and Gross et al (2005). Recent meta-reviews by Minshew and Williams (2007) and by Takahata and Kato (2008) appear to support a multi-disciplinary consensus on this issue.

This method of information processing is also described as low-level processing, and as bottom up, rather than top down, processing. The over-connectivity within modalities might help to explain Leo Kanner's case-study observations on the concentration in autistic children for parts rather than gestalt, contributory detail rather than wholes (Kanner, 1951), and Hans Asperger's statement, 'Over-sensitivity and blatant under-sensitivity clash with each other' (Asperger 1991:80), following which he clearly notes and lists some of the hyper- and hypo-sensitivities in his subjects, suggesting that there may be sensory differences in children on the autism spectrum, who may process sensory information differently from the typical child :

In the sense of taste we find almost invariably very pronounced likes and dislikes. The frequency of this phenomenon provides yet more proof of the unity of the type. There is often a preference for very sour or strongly spiced food, such as gherkins or roast meat. Often there is an insurmountable dislike of vegetables or dairy produce. It is no different with the sense of touch. Many children have an abnormally strong dislike of particular tactile sensations, for example, velvet, silk, cotton wool or chalk. They cannot tolerate the roughness of new shirts, or of mended socks. Cutting fingernails is often the cause of tantrums. Washing water too can often be a source of unpleasant sensations and hence, of unpleasant scenes. In the hospital we have observed hypersensitivity of the throat which was so strong that the daily routine inspection with the spatula became an increasingly difficult procedure. There is hypersensitivity too against noise. Yet the same children who

are often distinctly hypersensitive to noise in particular situations may appear to be hyposensitive. They may appear to be switched off even to loud noises.

2.3.7 Local Processing Bias as a unifying theoretic

The explanatory theory of locally-enhanced and preferred processing, validating the initial research of Asperger and Kanner, has the advantage of combining the three basic theoretical models of Theory of Mind (see **2.3.2**), Central Coherence (see **2.3.3**) and Executive Dysfunction (see **2.3.4**), whilst also incorporating the Enhanced Perceptual Processing theory advanced by Mottron and Belleville (1993). O'Connor and Kirk (2008) have reviewed the 'social deficit' model of autism spectrum conditions and rejected it. Their paper theorises that social impairments may arise from a weakness in integrating information from multiple sensory modalities, an integrated processing method which plays a vital part in social communication. The paper is very recent, but cites no studies after 2006, which could account for the serious omission of the putative corroborating evidence of the weak connections to the MNS (Rizollati et al, 2009), which would appear to support their hypothesis.

It may be that the over-connectivity of modalities and an enhanced local processing bias accounts for the phenomenon of weak Central Coherence: a problem in editing for meaning, as referenced by the Sperber and Wilson Relevance Theory (Happé, 1993) and replacing that with a marked preference to find patterns based on sensory processing. This latter quality may also lead

to a necessity for the subjects to control for variables, constantly, in the patterns sought in the modalities, which could explain the element in the diagnostic criteria which reference a 'liking for sameness', and which has been characterised as inflexibility of imagination.

This type of information processing, collecting and classifying, would necessarily prioritise rote memory for quantitative data, a marked feature of autism (Toichi and Kamio 2002; Minshew, 2001; Williams, 2006), while overloading working memory and temporal awareness (Martin, Poirier and Bowler, 2009; Baddeley, 1986), which tend to be poor in those on the autism spectrum. Weakened longer connections to the prefrontal cortex could also explain the Executive Dysfunction (disorganisation) model preferred by researchers to categorise the nature of the Executive Dysfunction in autism. Perceptual processing, if internally over-connected, could interfere with cognitive organisation where certain higher order skills involving language (Järvinen-Pasley et al, 2008) and social understanding may carry too much informational material for sequencing and set-shifting priorities to be smoothly established.

Frith and Happé (2006) revised their 'weak central coherence' theory and acknowledging the work by Mottron and colleagues on the advantages, in certain circumstances, Enhanced Perceptual Processing (see Fig 2.3.1). They subsequently made three changes to their original theory (Frith and Happé, 2006). One is that the preservation of a detail-focussed bias does not necessarily imply a failure in global processing, and may be a secondary

factor. Another is that they now acknowledge that this processing may be described as a 'bias' or 'cognitive style'. The third is that the explanatory remit of their account has now been limited to this cognitive bias, rather than explaining deficits in social cognition.

In recent years, Baron-Cohen has also moved from his original modular account of a deficit in Theory of Mind to account for the social problems of those with autism spectrum conditions and has adopted, instead, a binary account of 'systemizing' as opposed to 'empathizing', where empathizing was what he had previously accounted for by his view of Theory of Mind (Baron-Cohen, 2008). He names this theory as the E-S theory and in a similar vein to that of Happé and Frith, has eschewed a deficit model (Baron-Cohen et al, 2009b) We may say that Gopnik's 'theory-theory' (see **fig 2.3.1**) can be accommodated within the E-S model, as it offers some explanation of how rules and algorithms may be made by a child who might have weak access to the short cut of the MNS, and relies instead on a local-processing bias in determining physical laws.

Figure 2.3.1 The systemising nature of autistic intelligence (Baron-Cohen, 2008)

Systemising	Severe	Mild
Sensory	Tapping surfaces or letting sand run through fingers	Insisting on the same food each day
Motoric	Spinning round and round, or rocking back and forth	Learning knitting patterns or a tennis technique
Collectible	Collecting leaves or football stickers	Making lists and catalogues
Numerical	Obsessions with calendars or train timetables	Solving Maths problems
Motion	Watching washing machines spin round and round	Analysing exactly when a specific event occurs in a repeating cycle
Spatial	Obsessions with routes	Developing drawing techniques
Environmental	Insisting on toy bricks being lined up in an invariant order	Insisting that nothing is moved from its usual position
Social	Saying the first half of a word or phrase and waiting for someone else to finish it	Insisting on playing the same game whenever a child comes to play
Natural	Asking over and over again what the weather will be today	Learning the Latin names of plants and their optimal growing conditions
Mechanical	Learning to operate the DVD	Fixing bicycles or taking apart gadgets and reassembling them
Vocal/auditory/verbal	Echoing sounds	Collecting words and word meanings
Action sequences	Watching the same DVD over and over again	Analysing dance techniques
Musical	Playing the same tune over and over again	Analysing the musical structure of a song

The figure above, **Fig 2.3.7** is an adaptation of a diagram by Baron-Cohen (2008). This has been selected because it is explanatory of what is meant by 'local' processing, in a number of different rule-making situations. His original diagram was labelled 'autism' and 'Asperger's Syndrome', but these have been replaced by the researcher's preferred use of 'Severe' and 'Mild'. It is

interesting to note that behaviours on the 'Severe' scale which might appear to lack purpose if performed by a young child could be purposive and developmentally precursive, perhaps, of behaviours which may, in an older child, 'Mild', show that lessons were being systematically learned and rules created, which might guide the child through his environment, while ensuring that his environment remained as law-bound and predictable as possible.

2.3.8 Summary of theoretical perspectives

What is interesting in current theoretical perspectives is that they are converging. The multiple models created in an effort to explain in one overarching theory the 'enigma' of autism appear to be giving way to consensus, largely driven by brain-imaging techniques. Moreover, this consensus is moving towards a model which could be said to honour the original case-note descriptions of Kanner and Asperger: that there may be an alternative cognitive process, framed as a biopsychosocial difference rather than conceived as a biologically-reductive deficit, and that this may be described as autistic intelligence.

That the authors of two of the most robust theories, 'weak' Central Coherence, and Theory of Mind, are, in their most recent papers (Frith and Happé, 2006; Baron-Cohen, 2009b) emphasising the possible strengths of this local processing bias, and delineating it, sometimes, as in the above diagram, in fine detail, can only enable others to arrive at an understanding of autistic intelligence.

This is one of the most important features of this convergence and consensus: while acknowledging that ASCs are complex, they can be described in terms which simplify the concept. This can be of great help to educators. The simplification of the theoretical framework could perhaps allow for those who may have been confused by the collections of apparently unlinked behaviours in the diagnostic criteria to find confidence in their own ability to recognise and accommodate these children within an inclusive classroom.

We can, therefore, précis the current theoretical perspectives, and the outcomes of the studies referred to in this section, **2.3.** in the following way, as a summary and conclusion of this part of the Literature Review. This section has been an attempt to evaluate the theoretical evidence base for the existence of what might be described as autistic intelligence :

- Some children with ASC appear to have a different information processing style
- This is theorised as being heavily dependent on their own five senses, rather than by the short-cut provided by mirroring others' actions, feelings and intentions

- It is suggested that the senses may become overloaded if too many demands are made on them to operate in conjunction with each other and with motor control and executive ordering
- This theorised type of processing is likely to be detail-focussed
- The five senses, it is thought, can make rules about the world in which they live, but each child will have to work out their own rules which may then become immutable
- To work out rules is a lengthy process, and depends on reducing the unpredictable, and controlling for variables, thereby possibly increasing repetitive behaviours.
- The rules so formed are thought to be based on pattern recognition, so teaching these children by encouraging patterning will be helpful.
- It is theorised that there may be a heavy demand on the long-term memory, and a less efficient working memory, which may make instructional learning difficult at times, especially if too much verbal instruction is given.
- Narratives of all kinds, if this theory is correct, will be difficult to construct as these depend on long causal chains rather than on what is experienced as contingent.

- Because these children may find social information overwhelming in its demands on the interaction of the senses and their integration with 'global' information processing, they may appear socially aloof or marginalised and may appear to lack social graces.
- The putative pattern-formation and attention to detail processing style is slow, but very reliable, and can be very perceptive and original in conception as it ignores the 'taken-for-granted'.
- Local processing is believed to be more likely to be positivist and quantitative, rather than interpretative and qualitative.

2.4. Interventions

Interventions for autism spectrum conditions could be characterised as medical or educational, or purely as multi-agency support for families and children. It is outside the scope of this study to consider medical interventions. Therefore it will confine itself to those interventions which are of an educational nature. As the majority of interventions tend to be 'eclectic' ie combinations of various educational practices believed to enable the child to function most successfully within a school setting (Eikeseth et al, 2002; Howard et al, 2005; Eldevik et al, 2006; Zachor et al, 2007; Eikeseth et al, 2007), those interventions which are program specific and most widely-used

will be examined. Most of these are behavioural interventions, designed to ease the relationship of the child with a spectrum condition, with his/her environment.

2.4.1 Initial considerations

The most vexatious question relating to autism spectrum conditions concerns what interventions might work to enable these children to enjoy and achieve, because fundamentally what educators might regard as desirable or acceptable or emotionally and cognitively successful, may not accord with the child's own needs, goals and individual cognitive style (Bumiller, 2005, Gray, 2001). While social inclusion in its broadest sense strives to embrace forms of difference, the underlying rationale seems to prioritise an understanding that we are socially-aware beings, and where that rationale may be challenged by the cognitive dissonance of autism, this can be seen as deviant (Harnum et al, 2006) and in need of intervention. Many of the interventions for autism spectrum conditions are said by critics to have a normalising compulsion (Trivedi, 2005).

One problem when investigating the literature of intervention strategies is pragmatic. It is that autism was, in diagnostic manuals until 1980, originally described and treated as psychosis. The earliest and some of the most detailed empirical intervention studies were carried out by clinicians, in conjunction with academic researchers (Howlin and Rutter 1987). The Howlin and Rutter controlled studies in the 1970s investigated a home-based intervention for autistic children over the course of six years, including follow-

up studies. Many of its findings have been replicated in further research, both by the authors and by others. But it, like other early studies, was based on knowledge about the autism spectrum which had not, at that time, been identified as a spectrum nor expanded into what we now know as a broader phenotype, with the addition of Asperger's Syndrome (ICD-10, 1993). It was strongly associated with intellectual impairment throughout the 1970s and 1980s (DeMyer, 1981) and educational initiatives were therefore constrained and confused by this association. Clinicians and researchers had, however, noted that those children diagnosed with autism had better educational outcomes if their cognitive abilities and language skills approached a typical score on what instrumentation was then available to measure those skills in this particular population (Freeman et al, 1985; DeMyer, 1981)

The nature of autism spectrum conditions, appearing initially in infancy, with onset typically noted by the age of 30 months and often diagnosed before the age of five, dictate that probably the first contact for parents of a child with a pervasive developmental disorder would be a medical diagnosis (Howlin, 1998, Rhoades et al, 2007). Therefore all interventions, even those which are educational, were likely to stem from clinical decisions, and may have followed, and may still follow, a clinical route. Children on the autism spectrum were, and are, initially overseen in outpatient departments and observed in clinical settings. This clinician-dependent and perhaps diagnosis-dependent trajectory is further emphasised by research which appears to suggest that very early educational interventions may assist the child to progress, socially and linguistically (Rogers, 1999; Tebruegge et al, 2004), and that early

diagnosis is therefore useful, although there are few early intervention programs which are backed by sound empirical evidence (Baker and Feinfield, 2003). It appears important, therefore, that children with ASCs, if they are to progress educationally in the pre-school years, are clinically assessed, competently, accurately, and early enough (Limon, 2007; Woodbury-Smith and Volkmar, 2009)

Further research points to the crucial role which parents play in facilitating this progress (Renty and Roeyers, 2006; Hodge and Runswick-Cole, 2008; O'Connor et al, 2005; Benson et al, 2008). Some research findings place parental involvement as the most important factor in supporting a child on the autism spectrum. Parental cooperation is essential in organising, developing and facilitating intervention, and many parents are instrumental in setting up their own strategies for the child (Francis, 2005). Some of these strategies can involve many hours of parental and therapeutic input, but may not be easily adhered to within the educational system (Jacobson, 2000). A child may be parentally encouraged along a certain interventional route in pre-school years, then have to adapt to a different system at school (Boyd and Corley, 2001). Change is not easy for a child on the autism spectrum. While the parent may consider the child to be in need of therapy, teachers may see their role as that of an educator (Grey et al, 2005).

Seamlessness is not easily achieved. Where the child is first classified clinically, the burden of care and intervention is then transferred to the parent (Whitaker, 2002; Baker, 2003; Ryan and Cole, 2009; Stuart and McGrew,

2009) before being entrusted to the education system (Ingersoll and Dvortcsac, 2006, Beveridge, 2004). Responsibility for the outcome rests on an ongoing, and much-encouraged cooperation between teachers, parents and clinicians (Krasny et al, 2003; Mansell and Morris, 2004, Callahan et al, 2008, O'Keefe and McDowell, 2004; Swiezy et al, 2008; McLennan et al, 2008). However, Valle (2009) notes that educational meetings often involve many professionals with perhaps only one parent present, and that parents can feel overwhelmed or sidelined by this procedure, rather than feeling an equal partner in a collaborative process. In addition, the child's complex needs may draw on other agencies. Speech and language therapy may be needed to help the child with semantic and pragmatic problems which are a core element in autism (Cummings, 2007; Diehl et al, 2008; Dockrell et al, 2006; Colle et al, 2008, Geurts and Embrechts, 2008; Kamio et al, 2007; McCann et al, 2007; Pijnacker et al, 2008). Where there is dyspraxia, a common feature of Asperger's Syndrome (Dzuik et al, 2007; Missiuna and Polatajko, 1995, Leary and Hill, 1996; Jansiewicz et al, 2006, Rinehart et al, 2006; Vanvuchelen et al, 2007) or severe sensory issues (Humphries, 1993; Asai and Sugiyam, 2007; Liss et al, 2006), occupational therapy may be necessary (Schaaf and Miller, 2005, Case-Smith and Arbesman, 2008). Voluntary agencies may also be called upon to offer help and support to parents (Nesbitt, 2000).

Where the burden of care for a child with multiple needs becomes excessive for parents, involving perhaps excessive stress and perhaps marital breakdown as noted by a number of research findings (Koegel et al, 1992;

Baker-Ericzén et al, 2005, Lee, 2009, Tissot and Evans, 2006; Altieri and Von Kluge, 2009; Epstein, 2008) with resultant financial and caring difficulties, social care may have to be offered to the family. Although the multiple needs of some children have been recognised by statutory bodies (Parton, 2006; Martindale, 2006), multi-agency involvement and cooperation, a necessity in most cases for children on the autism spectrum, is noted to be difficult to manage (Cameron, 1997; Brandon et al, 2006; Russell, 2003; White, 2006, Williams, 2004; Abbott et al, 2005; Featherstone, 2006; Percy-Smith, 2006; Carpenter, 2005; Preece and Mott, 2006). Some of the dissatisfactions felt by parents of these children have been examined in a recent government publication, the Lamb Inquiry into Special Educational Needs and parental confidence (2009)

There are three main categories of educational intervention: those which are primarily home-based, those which are primarily school-based, and those which can work in both settings. Many of the interventions have been devised in the USA for pre-school children and arise from a cultural and social imperative which differs from UK societal patterns. In the USA, in the absence of a national health service, a child diagnosed with autism can have recourse to a number of commercially-competing intervention strategies often paid for by health insurance if they are deemed 'medically necessary'. This could, theoretically, bias the findings of empirical research into the strategies, in an effort to 'prove' that one intervention is more successful than another.

While UK national voluntary support organisations for autism do not see the aim of the intervention as 'cure', other perceptions exist elsewhere. One of the leading voluntary organisations in the USA, backed by some eminent researchers, was named Cure Autism Now (now integrated into the umbrella organisation, and major research-funding body, *Autism Speaks*). There is a vocal group of parents in the USA who are anxious to find an environmental cause and a 'cure' for autism or at least a universal treatment (Bodfish, 2004) and a widespread lay belief that this is possible (Clarke and van Amerom, 2007). Gray (1993) discovered that a major barrier between staff at a state centre for autism and the parents of the children, was a parental belief in a cure while Nickel (1996), who reiterated the findings that parents are anxious to find a cure and are attracted to controversial treatments, suggests that this may be a natural stage in coming to terms with the diagnosis of developmental disorder. Tharpe (1999) ironically names Auditory Integration Therapy, an unproven and now discredited intervention for autism, as a 'magical mystery cure'. Some of the USA research findings therefore may make claims that 'recovery', (Lovaas, 1987) has been achieved by some of the research subjects. The UK lay and expert consensus appears to be in line with that of Howlin and Moore (1997) who have said that there is currently very little evidence for a 'cure' but that intervention strategies may play a significant role in enhancing future functioning in later life.

We should, therefore take into account a commercial bias there may be in the scientific findings of those who developed various intervention strategies, and note those cases where the team which developed the intervention is the

team investigating its efficacy. We should also take into account, in examining the empirical basis of many of the research studies, the practical limitations imposed on research in this field, the most obvious of which is that we have no yardstick by which to judge the unmediated progress of a pervasive developmental condition. Since autism research is relatively young (Kanner, 1943; Asperger, 1944) there are very few reports of the prognosis of autism in a child who has no social or educational or medical interventions. We have partial reports from follow-up studies by both Kanner and Asperger, we have anecdotal reportage, and we have first person accounts, and some research accounts (Townson et al, 2007; Davidson, 2010) from able adults diagnosed with autism which have added to the epistemology of autism. However, it is difficult, at this time, to gather clear research evidence on longitudinal outcomes for those children on the autism spectrum who have had no, or minimal, remediation interventions.

Finally, standardising the content and delivery of interventions is exceptionally complex. It is not therefore surprising that a Cochrane review (Diggle et al, 2003) on the effectiveness of parent-mediated interventions for children with autism spectrum conditions showed that only two RCTs had been performed in this field, which is considered to be the most promising for intervention success. The first of these favoured parent training for children with autism spectrum conditions, and showed that higher parental knowledge about autism was an important factor in developing communication skills. The other showed measurable improvements in child skills after intensive intervention by therapists, with parental help, but there was no observable improvement in

behaviour. These two studies could not be related usefully to each other, according to this review. The fact that sample sizes were small was also criticised. The review concluded 'Research in this area is hampered by barriers to randomisation, such as availability of equivalent services.' (2003:1) The equivalence factor is a major barrier given the patchiness of autism support services both locally and nationally.

In 2002, a team of UK autism researchers (Drew et al, 2002) set up and later abandoned a pilot RCT into parent-training intervention. Here again, sample sizes were small, with only 24 children involved at mean age 23 months, with a follow-up after 12 months. Methodological problems led to the failure of the study. Initially, the children were not matched for IQ, there was no systematic monitoring which meant that some parents may have worked less effectively than was anticipated, and the study relied too heavily on parental reports to measure language. In a family with a child on the autism spectrum, already burdened by the demands of the child, and with perhaps a genetic predisposition in the parents to autism spectrum traits, parental cooperation cannot be taken for granted by researchers.

In 2004, a pilot RCT was successfully set up to examine another parentally-mediated intervention in communication (Aldred et al, 2004). Again the sample size was small, involving only 28 children, but the failure of the previous study was addressed: the sample was matched for baseline severity of symptoms, IQ, and age. However, this team also discovered a problem, in that there are few standardised outcome measures. Permission was given

from the designer of the ADOS test, Autism Diagnostic Observation Schedule, for her test to be used as an outcome measure. The Vineland Adaptive Behaviour Scales were also used as outcome measures. The study involved a weekly visit from a trained communications therapist who worked with the parents in the active treatment group. The control group continued with existing care. Results showed that there were significant improvements in the treatment group in reciprocal social interaction, as measured on the ADOS test. The question of whether this is a suitable instrument for its purpose remains, and as the authors concluded, the RCT suggests that replication on a larger and independent sample may be necessary. This was an efficacy/explanatory trial. No large-scale effectiveness trials have been as yet used to measure interventions into autism spectrum conditions.

Before large scale effectiveness trials are undertaken, a consensus has to be reached to deal with the methodological problems in basic autism research, some of which have been discussed above. One of the most crucial may be the use of measurement instruments, and the development of instrumentation which is specifically tuned to deal with the cognitive differences of autism spectrum conditions. Edelson (2006) has drawn attention to the inadequacy of certain IQ results as a baseline measurement in empirical autism research. She claims that because IQ tests which demand a level of verbal efficiency have been used to assess children on the autism spectrum, many children have been under-assessed on intelligence levels. If baseline IQ tests are to be used, Edelson believes, then researchers should determine whether the test was one which favoured (visual-spatial), or did not favour (verbal/social),

autistic subjects. Wechsler Tests, WISC-R, give a spiky sub-test profile for these children, although the shorter version is more reliable (Mayes and Calhoun, 2003; Minshew et al, 2005), and may be inadequate in assessing the heterogeneity of the presentation of skills in the range of autism spectrum conditions. Mayes and Calhoun (2003), and many other researchers point to the skills of those diagnosed with autism on certain WISC sub-tests like Block Design, and their relative weakness on verbal comprehension, while many diagnosed with Asperger's Syndrome may show the opposite imbalance, with verbal skills outclassing performance skills. For typically-developing children on whose abilities these measures are averaged, there is a typically even profile.

Improvement on IQ in post-intervention testing must be related to previous performance to make meaningful results for research findings into intervention therapies, as a sudden acquisition of verbal skills following an intervention designed to increase verbal ability could be interpreted as an increase in general IQ on most scales, rather than as a skill-acquisition following intervention. Additionally, outcome measures need to be agreed or developed. It is not sufficiently rigorous to adapt a diagnostic tool to 'measure' an outcome, despite logical inference that it might work. Very specific psychocognitive tools are essential in the research work on autism spectrum conditions, and some agreed standardisation may be needed before research can be validated and results generalised (Wolery and Garfinkle, 2002; Lord et al, 2005). Although some valuable measures have been designed for use in the field of autism, like the diagnostic instruments ADOS-G and CARS

(Childhood Autism Rating Scale), and the Autism Behaviour Checklist, and although the Vineland Adaptive Behaviour Scales have been modified for use in autism and are thought to be reliable, there are few autism-specific or autism-adapted instruments which are capable of testing intervention outcomes and little general agreement on what might be the desirable outcome, and for whom.

Behavioural modifications to make the child more manageable could be the priority for teachers or parents but could impact badly on the child. Shared-attention and social reciprocity improvements may be the preferred outcome for researchers and parents, because these are the building blocks of communication, although these are not necessarily mutually exclusive preferences, and this gives rise to a further supplementary research question:

Is there consensus among teachers, parents, and students as to desirable outcomes in intervention strategies for autism spectrum conditions, and the means appropriate to achieve them? Where there is conflict, what is its nature?

2.4.2 Challenges provided by educational context

There is one more very important consideration to take into account before proceeding with an examination of the interventions which are routinely used, world-wide in pre-school and school settings. It is that the programmed and manual-based interventions examined in this study are US based and conceptualised for that educational context. This is a very important factor, because the US educational context differs somewhat from that in the UK. Some of the cultural factors have already been referenced: the adoption of the medical model of disability is often more evident the USA, as is a hope for a cure, which could be said to influence attitudes to autism spectrum conditions (Schechtman, 2007; Silverman, 2007; Green, 2007). There is also a commercial factor, as parents of very young children diagnosed with autism in the USA may, and do, seek a package of care to be paid by medical insurance or through federal funds or Medicaid (Bouder et al, 2009; Leslie and Martin, 2007; Ronder et al, 1999; Shimabukuro et al, 2008; Wegner and Macias, 2009). Certain interventions which are classified by their developers as educational programs, like Early Intensive Behavioural Intervention (EIBI), which is conventionally sought for pre-school children, can be demanded as 'medically necessary' in applications to the courts for funding (Mulik and Butter, 2002; Yell and Drasgow, 2000; Reinke, 2008). However, where provision of services is alternatively largely state-determined and nationally-provided, as in the UK, the onus is mostly on the state to provide those services, which could possibly alter the nature and range of the services

available, although even in the UK, litigation on the issue of securing pre-school and other educational interventions is not uncommon (Runswick-Cole, 2007)

Unlike in the UK, educational provision for children with special educational needs in the USA is often based on a diagnosis of a recognised clinical condition in order to obtain specialist provision in the 'least restrictive environment' (Yell et al, 2006). In order to benefit from the protection of federal laws passed to ensure that disabled people are entitled to non-discriminatory practices (Yell et al, 1998), the parents of a child with an autism spectrum condition need to prove that the child has a recognised diagnosis and that this diagnosis has an adverse educational effect. Autism is one of the diagnostic categories covered by the IDEIA legislation (Rep Castle, 2004), the latest version of the laws relating to education and disability (Yell et al, 2006). In the USA there is no exact equivalence to the very broad category of special educational needs, as set out in the Warnock Report and the 1981 Education Act (Baker, 2004). The area of educational need is still a category- and medically-based model, as it is in most countries worldwide. Only Denmark and Norway employ, as is the case in the UK, an apparently non-categorical system. Non-categorical systems have certain advantages for children with special educational needs. One is that there may be a reduced sense of a one-size-fits-all approach to the education of each child with that diagnostic label, and in the case of a condition as complex as autism spectrum, this can be useful in viewing each child as an individual, rather than as a collection of symptoms (Riddell et al, 2006).

An advantage of the US educational system, on the other hand, is that because funding for the implementation of interventions depends strongly on the evidence-based grading of that intervention, most of the interventions in use in schools and pre-school settings are subject to ongoing rigorous testing and evaluation. This involves considerable data-production and gathering, long-term research, and monitoring (<http://ies.ed.gov/ncee/wwc/>). US educational legislation and funding often tend to foreground the part played by systematised evaluations, such as functional behavioural analysis (Scott et al, 2004, Drasgow and Yell, 2001), and can usefully promote an empirical research agenda when considering what educational interventions might be of value to the student with ASC. This issue is, however, dependent on the quality and reliability of the research produced (Jones, 2006; Bodfish, 2004; Goin-Kochel et al, 2009)

2.4.3 Applied Behavioral Analysis / Lovaas

Applied Behavioural Analysis (Lovaas), also named as EIBI: Early Intensive Behavioural Intervention, is an intervention program devised by Ivar Lovaas at what is now the Young Autism Project (YAP) of UCLA. Taking as its theoretical framework behavioural and particularly operant conditioning practices, it was argued that a behavioural model, rather than an 'illness' model, or the psychodynamic methods used with little success in the 1950s and 1960s (Lovaas 1979), may be more effective in treating autism spectrum conditions. The form of operant conditioning Lovaas advocated is discrete trial

training, and takes the form of repeated trials of various tasks broken down into very small elements, like, in the first year pointing, or sitting, or making eye contact. Successful completion of sets of trials are rewarded with reinforcers which can take the form of verbal praise, or may be more tangible, such as stickers or foods or small toys. In Lovaas's original version of Applied Behavioural Analysis, there could also be physical aversives, which, in the 70s and 80s could be a shout, or a smack, or a mild electric shock (Lovaas, 1979) or may be deprivation of something the child values, perhaps even food (Lovaas et al, 1973). The most commonly used aversives in current ABA therapy are ignoring, or the use of 'time out', in which the child is removed from the problem which has preceded the behaviour, and encouraged to calm down. This, in the early research was referred to as isolation and involved the child being placed in another room (Lovaas et al, 1974)

Lovaas's hypothesis was that if the trials were intensive enough, were conducted for every waking hour, began as early as possible in the child's life from around the age of three, and were systemised into a program which built social and language skills lasting for a total of at least three years, together with opportunities to be with typically developing children, there would be a possibility of the autistic child relating more functionally to the environment, and entering into mainstream classrooms rather than special classrooms.

Early experiments conducted by him and his team appeared to confirm this hypothesis. In a treatment-research study begun in 1964, nineteen children, in all, were treated in an intensive program based on these principles (Lovaas et

al, 1973). Seven of them were in institutional care. The remainder were seen as out-patients. Full data are produced for 13 of these children, with some data available on all. What is notable about this presentation of a series of treatment-research experimental studies, over the six years of the project, is the depth and quality of the methodological sections. There are careful individual profiles presented of each child's progress in response to the intensive interventions, very detailed writing-up of the evaluations including charts and graphs, and detail of treatment procedures, with extensive follow-up data. It is a full, clear and lengthy paper, with three individual case studies, to illustrate the then noted heterogeneity of presentation of autism.

In 1987, Lovaas summarised the findings from his individual work in the 1970s which began in 1970 and finished in 1984 (Lovaas and Smith 1989). Lovaas (1987) was a controlled but not randomised study with one experimental group (n=19 children), who would be assigned 40 hours per week of intensive behavioural therapy, and two control groups, one (n=19) similarly matched children who would have ten hours of therapy, and one (n=21) children who had no contact with the research study, but had had pre-test and age 6 follow-up scores from another UCLA experimental study (Freeman et al, 1985). The intervention for each child ran for three years, and children were followed-up between the ages of 6 and 7, at first grade level of schooling.

Children below the age of 40 months were selected for these studies, although echolalic children up to 46 months could be admitted, and were

tested for IQ. Only children with a mental age of over 11 months/IQ 40 were included (Lovaas 1987). The children in the experimental group had a mean age of 34.6 months; of Control Group I, of 40.9. Of the experimental group, two children on pre-test scored within normal range, seven in the mildly-retarded range and 10 in the severely retarded range. The mean initial IQ was 53. Lovaas's hypothesis, by now refined through the previous research (Lovaas et al, 1973) was that if children younger than four were subjected to discrete trial training for all their waking hours by trained staff, usually 40 hours, great gains could perhaps be made by these autistic children and that these gains would not be limited as earlier behavioural interventions had appeared to suggest, to the context in which the material had been learned, but would generalise to other environments. The hypothesis was also informed by further inductive reasoning that if these children were enrolled in regular pre-school, with therapist support, they would acquire useful social skills from socialising with 'normal' peers, after their trials had enabled them to communicate and given them the basic capabilities of self-care. Thus, it was reasoned that if this were facilitated by the intervention, the children would perhaps be able to enter, and maintain a place in, mainstream education.

His results appeared to confirm his hypothesis. Nine children of the nineteen (47%) in the experimental group were deemed to be 'recovered' *<sic>*: with IQ within the normal range and attending mainstream school without additional interventions, 40% were found to be mildly retarded and placed in special schools or classrooms, and only 10% were classed as profoundly retarded. Of the control groups, only one child achieved 'normal functioning'. The

experimental group gained on average 30 IQ points over Control Group 1 subjects (Lovaas, 1987:7) The study showed an IQ range of between 94 and 120, a mean of 107, in the experimental group at the age of 6.5, after three years of treatment. It must be noted that IQ is not a diagnostic feature of ASCs.

A variety of different IQ tests was used on different children before treatment, and one of these was a developmental scale (the Bayley Scales) which have poor predictability for later IQ outcomes (Horner, 1980; Hack et al, 2005; Chandlee et al, 2002), and one was the Catell Infant Intelligence Scale, which at the higher age-group end has poor predictability (Atkinson, 1990). Outcome IQ tests were different. This is one of the implementation issues in assessing non-verbal or developmentally-delayed children, of a very young age, as the available instrumentation, largely developmental, is poorly adapted to this population (Matson, 2007). That outcome and pre-study measures were so various, and differed from each other is not good design practice, although perhaps inevitable (Magiati and Howlin, 2001). This study was the most impressive validation of early intensive applied behavioural therapy as an intervention for autism. Its findings have not been replicated to date, but have often been quoted in support of this intervention, particularly the 47% finding, the use of which may be thought to be inappropriate to a study with such a small (n=19) sample size. The paper (Lovaas, 1987) is not as rigorous in its presentation as was the Lovaas et al (1973) earlier study. Results both pre- and post-test are expressed as means, so that it is not possible to view data

from individual cases, and some of the methodology may be difficult to determine from the text.

The publication of Lovaas's study gave rise to immediate criticism, initially from Schopler, Short and Mesibov (1989). They criticised the Lovaas paper on methodological grounds. They questioned the choice of outcome measures querying whether IQ 'improvements' and mainstream school placement could be justified as outcome measures. They raised concerns about the criteria for subject selection and the intellectual levels of the subjects, which were not clearly defined or specified. They were also concerned about the method used for assigning subjects to control groups and challenged the validity of the design on the grounds that this was not a randomised control trial and that the control group was six months older than the experimental group. In 1996 two papers by Gresham and MacMillan again drew attention to the worrying faults in the study, pointedly citing the use of physical punishment in the Lovaas experiments. They suggested that EIBI in its Lovaas form should not be recommended for use in schools for these reasons and because of problems in implementation and fidelity for such a therapist-intensive intervention, which had been strongly directed and controlled by the YAP guidelines and assistance (Gresham and Macmillan 1996a; 1996b). In a 2004 paper, another researcher reiterated many of the methodological criticisms which have been levelled at the UCLA Young Autism Project study (Shea, 2004).

EIBI as described in the Lovaas paper has not yet been tested successfully and non-controversially, and the original findings matched (Smith and Lovaas, 1998; Eikeseth, 2001; Mudford et al, 2001; Howard et al, 2005; Butter et al, 2006; Cohen et al, 2006). An RCT (Smith, Groen and Wynn, 2000) was also carried out by colleagues of Lovaas in which some of the methodological issues deficient in Lovaas's study were fully addressed. This carefully-randomised and data-rich study compared EIBI in an experimental group with parentally-directed treatment in the control group. The study involved 28 children matched for age (24-43 months in all), IQ and diagnosis (PDD or autism) placed in an experimental group (n=15, 12m:3f) or a control group (n=13, 11m:2f), studied over the years 1989-1992. Without physical aversives, except initially for four children in the experimental group, successful outcomes of increase in IQ scores and mainstream placement, according to Lovaas outcome criteria, were achieved by only two of the 15 children, both with PDD diagnoses, in the experimental group, and one in the control group, again with a PDD diagnosis. Despite rigorous testing on a variety of measures including language development, adaptation and achievement, there were no other significant group differences. It has been noted in a recent review of evidence-based comprehensive treatments for early intervention in autism (Rogers and Vismara, 2008:21) which references the Smith et al (2000) study that attempts to replicate Lovaas's original research by which the original methodological problems were addressed, actually failed to produce similar results:

However, post-treatment, Smith, Groen, and Wynn's treated group still

functioned in the IQ range associated with mental retardation. Two of 15 children in the treated group and 1 in the comparison group achieved the “best outcome” status. Fourteen of 15 experimental children and 11 of 13 comparison children were verbal, and the difference in language performance between the groups was not significant (Smith, Groen, & Wynn, 2000). There were no post-treatment group differences in adaptive behavior or intensity of behavior problems. Thus, the experimental treatment resulted in much less improvement in the replication than in the original study.....Furthermore, and sobering, is the lack of evidence of positive treatment effects on the subgroup of children with the full syndrome of autism especially because, in the authors’ experience, this type of treatment is considered by many clinicians to be the treatment of choice for children with autism with greater levels of impairment.

In 2005 Sallows and Graupner reported from one of the many replication sites set up internationally, this one in Wisconsin, for three intake years: 1996 (n=13) 1997 (n=11) and 1998 (n=14). Reports on the final 1998 intake group have not yet been published. The groups were again randomly assigned, either to intensive EIBI therapy or to parent-directed therapy. Mean age was 33 to 34 months at assessment. The control group was to have 40 hours of intensive therapy, and the parent-directed group chose, themselves, how many hours they wished to devote to intervention. The average for this group was much higher than anticipated, with parents choosing, on average, to give 32 weeks to their own directed therapy in the first year, although controlling

for treatment fidelity was limited in this group with only 6 hours per month of therapist supervision, as opposed to 6 hours per week in the experimental group. 22 of all participants in both groups chose to use additional interventions, including speech therapy, private tuition, and biomedical remediation (Sallows and Graupner, 2005) The results from this study were so unexpected, although to some extent encouraging, that the authors chose to de-control the study at the Results stage. The unexpected finding was that control group results were superior to the experimental group results. 6 of the 10 control group children and 5 of the 13 children in the experimental group achieved average IQ scores. Rather than show no advantage for the intervention, the results were combined to produce a joint finding of 11 (48%) of all children in the study achieved IQ in the 'normal' range and were placed in mainstream school, and the study, which was an attempted replication, was turned instead into an examination of those 11 children who were named as 'rapid learners'.

In many respects the EIBI intervention would appear to mesh perfectly with the early needs of children on the autism spectrum of all intellectual levels (Harris and Delmolino, 2002), as it breaks down tasks into small realisable steps, creates structure and operates from a behavioural-modification base which is both familiar to and well-used in its broadest sense by teachers and parents. In therapist-led interventions it can take some burden from the overstretched parent (Hastings and Johnson, 2001) while providing comparative safety and stimulation for the child for most of its waking hours (Johnson and Hastings, 2002): 40 hours each week is recommended for this intervention.

However, doubts remain as to its efficacy in teaching the autism spectrum child to generalise behaviours to alternative naturalistic or educational contexts, one of the inherent difficulties in autism spectrum conditions (Delpratol, 2001) and part of its original success in the USA may have been the employment of highly-trained psychology students as behavioural therapists (Steege et al, 2007). It should also be noted that there is no evidence of longitudinal outcomes of this very intensive intervention. Determining whether the intervention is safe, in terms of psychological and ethical considerations, would be very helpful.

The defining features which have created the demand for ABA are perhaps the use by Lovaas of the word 'recovery', and the compelling statement that 47% of the autistic children in his study 'achieved normal intellectual functioning' and were admitted to mainstream school, where they remained in grade-appropriate classes, and '..school personnel describe these children as indistinguishable from their normal friends' ((Lovaas, 1987:7). In 1999, the New York Clinical Practice Guidelines Report of Recommendations for Pervasive Developmental Disorders validated the Lovaas ABA, and thereby agreed to place its funding recommendations behind any parent wishing to demand this intervention.

It is interesting to compare this study with that carried out by Howlin and Rutter (1987). Both studies were carried out in the early 1970s and were published in the 1987, both were behavioural in approach although less systematically so in the UK study, both were based on clinical samples with

an outlying control group and an additional control group and both were directed by researchers/clinicians. The Howlin and Rutter experimental studies were on a cohort of boys (n=46). 16 of these were assigned to a home-based and therapist-supervised treatment group without randomisation, 14 to a short-term (6 months) matched control group, and a further 16 to a matched long-term control group. The median age of the groups was 6.5 years, with no treatment commencing in either controls or experimental group on any child under the age of 40 months. The experimental group was initially assessed by a variety of instrumentation, with a full functional analysis undertaken in the case of each child to establish if any environmental adjustments needed to be made to enhance progress. Individual data were noted in each case, and there was painstaking recording of behaviour and language skills.

Operant conditioning was, in this case, the principle method used in the intervention, although parent training and social skills training were incorporated into the intervention as were environmental modifications, and parents were 'guided to make use of whatever other strategies seemed important' (Howlin and Rutter, 1987: 25). This was, then, neither a randomised nor well-controlled study. Time spent on the intervention was determined by the time each parent wished to spend, and there was considerable variability. The intentions of the study were very different from those of the Lovaas studies. They were to enable the families to manage on their own, and within their own community setting, with a child with an ASC. The input into familial interventions to facilitate greater and more flexible language use is a keynote

of their study since the researchers note, as had Lovaas, that 'unless useful language has been acquired by the age of about 6 or 7 years subsequent language skills were very limited' (Howlin and Rutter, 1987: 56).

Follow-up results were obtained at six months, and again after a further year of 'treatment'. Finally, long-term follow-ups of the children's progress were obtained, six years after the start of the research project. Only one child from the UK study was admitted to 'mainstream' school, a private school. Most importantly, 'there were no significant changes in IQ scores over time' (Howlin and Rutter, 1987:176) and 'The correlation between IQ scores before and after treatment was similar to that found in other studies of autistic and normal children' (Howlin and Rutter, 1987:176). It should be noted that although both the Lovaas (1987) studies and the Howlin and Rutter (1987) projects were carried out at the same point in time, in the early 1970s, they differ in almost every significant respect from each other: age group, purpose, intensity, and ideology.

The differences in ideology can be summarised, in simplistic terms, by the fact that the Howlin and Rutter (1987) purpose was twofold: to offer coping strategies to parents of autistic children by the use of a flexible and eclectic model, and secondly to conceptualise the child's environment as being the object of change and modification. Lovaas (1987), however took the broadly opposite view, that with a particular intensive intervention in the child's earliest years, the autistic child could adapt to the expectations of a normative educational procedure. Here, the child is conceptualised as the object of

change. The Howlin and Rutter (1987) model conforms most strongly to the principles and practices of TEACCH: Treatment and Education of Autistic and related Communication-handicapped Children

2.4.4 Treatment and Education of Autistic and related Communication-handicapped Children: TEACCH

Division TEACCH was developed in North Carolina as the Lovaas studies and programs were being developed at UCLA. It is the only autism intervention program which is state-wide in its application, and is a life-long program. While the Lovaas team deal only with the behaviour of autism, rejecting the diagnostic entity of 'autism' (Lovaas et al, 1989), the TEACCH team makes claims that it is respectful of the 'culture of autism' itself (Schopler, 1976), respectful of the role played by parents in management (Schopler, 1971), and respectful of the individual (Schopler, 1982) while rejecting the notion of normalisation as a viable outcome (Mesibov, 1990). TEACCH programs are individually designed, as ABA treatment schedules are, but while ABA determines each individual assessment by a functional behavioural analysis of the child's behaviour (Delpratol, 2001), TEACCH claims to take into account the variables of parental need, child presentation, and time available (Schopler, 1974), working on looser and arguably non-measurable whole-life outcomes which can to some extent be successfully incorporated into educational provision. The problematic issue, therefore is that from an evaluation point of view, the multiplicity of these desired outcomes would appear to confound any efforts to measure, precisely, what element might work and what might not. The advantage of purely behavioural approaches is

that they lend themselves to precise measurement and therefore to more useful evaluation.

With a commitment to the idea of parents as co-therapists, co-designers and advocates, which was based on Schopler's observations on the heterogeneity of autistic presentation, due to the perceptual processing individuality of the children (Mesibov et al, 2004) the TEACCH program was designed as a highly individualised intervention, determined on each child's preferred modality bias in presentation, while based largely on the broad diagnostic feature of a resistance to change in autism spectrum children (South et al, 2005, Baranek et al, 1997). The program seeks to adapt the child's environment, making it structured, predictable, and sequential very much in line with the E-S theoretical position now taken by Baron-Cohen, to allow for systemising and control of variables (Baron-Cohen, 2008). Rather than purely behavioural in conception, this program is influenced by developmental considerations (Ospina et al, 2008).

The child's day is organised in exactly the same way as the previous day, with activities occurring at the same time, for the same length of time, with materials laid out in the same way, and work and folders colour-coded in sequence, so that the child always knows the length, time and structure of each task. Timetables and transition instructions are visual, and as much effort as possible is put into presenting tasks not only in oral or written form, but also graphically. In school, the child is provided with a personal workstation so that s/he can work without distraction. The rationale behind this

highly-structured environment is that when the autistic child's anxiety is addressed, by offering tight structure, and a variety of perceptual routes into learning, the child will be able to learn more effectively. The principle of its core element, this Structured Learning, TEACCH claims, aids all aspects of development, including communication, social reciprocity, and play skills, Classrooms are adapted so that there are certain designated areas for different types of activity, including one-to-one teaching and group work, as well as the personal work-stations.

The validity of the program has rarely been rigorously tested. There is an early matched controlled study (Ozonoff and Cathcart, 1998) which showed improvements in the experimental group on development measures, but the methodology of this study was criticised as the influence of a parent-mediated intervention alone, and the intensity of treatment were not accounted for Mesibov has explained (1997) that lifelong organic interventions such as this do not lend themselves easily to instruments to measure clearly defined developmental milestones. There is a small-sample study in Italy (Panerai et al, 2002) which compared the TEACCH experimental group of 8 with a matched control group of 8 who were taught through an integration program for individuals with autism. Vineland adaptation measures showed positive gains for the experimental group after a year's intervention. This improvement was noted again by some of the same authors (Panerai et al, 2009), in which the TEACCH program was used in three different settings: residential centre, home and mainstream school, and mainstream school alone. There was a study again with a very small sample (n=3) tracking whether individual work

systems as used in TEACCH involved the participants in more on-task behaviour, which it appeared to (Hume and Odam, 2007).

TEACCH has been adopted in special schools in the country of Northamptonshire in the UK (Preece et al, 2000). There is some evidence in another small-scale residential care home setting in Greece (Siaperas and Beadle-Brown, 2006) with 12 residents, that TEACCH increased their independence, communication and social abilities. The evidence of the efficacy for the TEACCH program is cumulative through consensus and adoption, rather than through RCTs or rigorous trials. Another problem in the testing of outcomes for TEACCH is that the program has now developed many additional components: social skills components, language components, and play elements. TEACCH has become an eclectic program in its own right, and evaluation is now far more difficult as the questions of which component is being examined, are the components interdependent, and does the core intervention still hold true to its original purpose, are likely to arise in test design and confound researchers.

The Structured Learning program has inherent if mild dangers, mostly that autistic children are known to have a high dependence on structure, and may value the structure so much that they are at a loss when trying to learn in a setting where structures are looser and where learning is not explicit but implicit. Another problem is that the modifications of the learning environment into specific autism-friendly workstations may not be easily incorporated into

general classroom provision, and may appear to imply that autism spectrum children need to be taught together in a modified classroom, although this either/or logic is difficult to understand.

Mesibov and Shea (1996) have argued against the notion of full inclusion for autistic children, on the basis of their need for very specific environmental modifications, a contentious issue in its own right. Although a degree of personalised space allows the child with autism spectrum conditions to escape from the sometimes overwhelming sensory demands of a large and noisy school environment, it may have the disadvantage of reducing the possibility of typically-developing peer interaction, within the classroom environment (Boutot and Bryant, 2005; Garfinkle and Schwartz, 2002; Sawyer et al, 2005; Chamberlain et al, 2007; Wainscot et al, 2008). It may be more helpful for future educational research to investigate differentiations in the balance required by each student, temporally and specifically, between private and social space for learning, and how this balance may be continually and flexibly adjusted, according to a variety of environmental and developmental factors. Instrumentation would have to be devised to assess these ever-changing and situational-specific needs.

2.4.5 Picture Exchange Communications System: PECS

PECS is Picture Exchange Communications System devised by Bondy and Frost, and in use throughout the world as an augmentative program for enabling autistic children with limited or delayed speech to communicate with others (Bondy and Frost, 1998). It is a pictorial system, which begins by

teaching what Skinner calls 'mands', or demands, the stage in speech where a child expresses desires and needs. In Phase 1, pictures, photographs and cut-outs are collected of the items which a child may want to request, and can do so by placing the Velcro picture on a board. These are then 'exchanged' in a communicative manner with the child being encouraged to exchange the picture immediately for the re-enforcer he asks for. An understanding of this communicative process is said to be rapidly acquired, and the child is encouraged to progress through gradually establishing greater distance between the child and the object s/he needs. The principle of the exchange is that it should be spontaneous, arising from the child, and that it should be built on through stages in which the child is encouraged to choose between two items, then to choose and use the requisite pictorial verbs for 'want' and 'need' to build pictorial sentences. In the final two stages adjectives are introduced to further refine the need, and then sensory verbs are introduced, so that the child can make observations about the environment, 'I hear', 'I see' 'I feel'.

The derivation is Skinnerian. However the emphasis on spontaneity offers advantages as it replicates the natural progression of verbal language, and through prompting and cueing and communicative procedures based on developmental models, can offer an alternative means of communication, for those with oral dyspraxia, or can precede speech. A basic appreciation of the purpose of communication, which this system promotes, has been identified as a precursor to pro-social behaviour in autism spectrum children, and this has been evaluated in several small-scale studies. Charlop-Christy et al

(2002) conducted a multiple baseline study of three children using the PECS system, and all three showed improvements, not only in oral ability over a variety of settings, but in improved social skills and a lessening of problem behaviour. Similar results were produced in a more limited study into the use of PECS by a 6-year-old autistic girl (Kravits et al, 2002). Rather less positive results were obtained from Magiati and Howlin's (2003) pilot study of the training of teachers in PECS, and into outcomes for the (n=34) children from 8 specialist schools trained by the teachers. Although mastery of the system was at first rapid, it was found that PECS appeared not to generalise so convincingly as it had done in the previous studies to a variety of communicative environments. This pilot study was severely compromised by many methodological and organisational weaknesses. The evaluation was only requested after the arrangements for the teacher training programme had been made. The children were selected from a number of special schools settings, some of which had prior training in PECS and some had none. The levels of the children's knowledge of PECS, and the profile of the participants' verbal abilities, at pre-test, was very uneven. Some of the children were actually verbal at the start of the evaluation process, and there were problems with data-gathering both from schools and from parents (Magiati and Howlin, 2003). No definitive results can be usefully relied upon from this poorly-conducted pilot study.

Another small-scale study examined the number of verbalisations facilitated by the PECS method, and findings were positive (Ganz and Simpson, 2004), but studies on three children (Tincani et al, 2006) produced findings which

were are not particularly significant, and a randomised study (Yoder and Stone, 2006) which compared two communications interventions: PECS and Responsive Education and Prelinguistic Milieu Teaching on n=36 children revealed that REMT produced more joint attention and turn-taking communication, for children who had already started to initiate joint attention, and that PECS was more successful in generalising requests, even in children with little prior joint attention. The effect sizes were quite large. This was a very carefully designed study, with well-analysed data.

PECS would appear to be a very useful tool in an eclectic pattern of treatment, offering as it does some facilitation of communicative exchange in those who may be speech-delayed, and this may be why it is widely used in educational intervention programmes, as an assistive tool. But the time and effort demands which it places on family life, as it must be developed and used in familial settings, may perhaps be logistically difficult.

2.4.6 Social Stories / Peer intervention

Social Stories (Grey, 1991), are a narrative and child-directed form of discovering some of the unwritten rules of social behaviour and redirecting children on the autism spectrum to adaptive behaviours (Gray and Garand, 1993;). It is described as a socio-constructed intervention. The principle is simple, and the practice is not time-consuming which means that Social Stories can be a useful tool which can work in conjunction with other interventions, especially in an inclusive classroom (Chan and O'Reilly, 2008; Spencer, 2008). They are also easy and flexible enough to be taught to

teaching assistants as mentors (Quilty, 2007) and to parents (Dodd et al, 2008). They can be adapted for use as in teaching children with autism spectrum conditions about their sexuality (Tarnai and Wolfe, 2008) and can be constructed as 'Sensory Stories' to help with perceptual processing (Marr et al, 2007). Video, DVD and computer-generated versions of Social Stories have also been used (Sansosti and Powell Smith, 2008; O'Connor, 2009). In a recent survey of 105 Australian teachers (Renhout and Carter, 2009) it was discovered that many teachers were using Social Stories in ways which did not follow the recommended guidelines, but felt that their adaptations were more efficacious.

In Social Stories, the child and teacher/parent collaboratively construct a story about a social problem as a means to modifying behaviour. These stories combine a value-free *descriptive* statement which sets out the basis of the problem, with *perspective-taking* sentences which look at the behaviour from another person's point of view, and set out a way that this problem could be solved: *directive* sentences. For an able child on the autism spectrum, these stories can enable self-reflection, are under the child's cooperative control, establish perspectives, and set goals, while conforming to the autistic child's security in rules and structures. From a theoretical perspective, Social Stories work in the cognitive behaviourist tradition, and work on the establishment of Theory of Mind and a theory of self, as the stories are 'owned' by the child. Once the short story is constructed, collaboratively between the child and the mentor, the child reads it frequently, usually every day, to consign the story to

rote memory with the hoped-for outcome being that this can redirect behaviour.

This is an example of a social story (Scattone et al, 2002: 542) for a 7-year-old boy on the autism spectrum, who tipped his chair over frequently in lessons:

Kenny: Keeping in My Seat

When I sit in a chair all four legs of the chair should touch the floor. If only one or two legs touch the floor, my chair can tip over. Tipping my chair over can make me fall. If I fall, I can get hurt. (descriptive) Tipping my chair can make my teachers sad or mad. I do not like it when my teachers are sad or mad (perspective). I will try not to tip my chair. I will try to sit in my chair with all four legs touching the floor (directive). My teachers will be happy if I sit in my chair with all four legs touching the floor. (perspective). Then I will be safe. (control)

Social Stories have been evaluated as to efficacy, although there have been no large-scale studies, the largest being for a pretest, posttest study (Quirnbach et al, 2009) which in a participant group of (n=45) children with a diagnosis of ASD, aged 7-14 were randomised into standard story, directive story, or control group. Both tested story types were effective in eliciting, generalising and maintaining the targeted social skill. Many have been single case (Bledsoe et al, 2003; Agosta et al, 2004), or limited to two (Hutchins and Prelock, 2006; Chan and O'Reilly, 2008; Dodd et al, 2008) or three (Scattone

et al, 2002; Sansosti and Powell-Smith, 2006, Ozdemir, 2008; Okada et al, 2008; Crozier and Tincani, 2007; Delano and Snell, 2006). Questions have been asked about whether the results, which in the Scattone et al (2002) study were quite promising on the behaviour of all three of the experimental group, but patchy in the Sansosti and Powell Smith (2006) study with one participant's behaviour unmodified by the intervention with a similar outcome in the Crozier and Tincani study (2007), are generalisable to other contexts (Reynhout and Carter, 2006).

In some respects this could be said to miss the point, as Social Stories are so easy to construct and use that they can be written for and tested in a variety of specific settings. A potential strength of this intervention may be that repeated and contextual use of Social Stories could possibly lay the ground work for theoretical accumulation about the usefulness of perspective-taking as a mediating point between social questions and possible answers. Some of the children learning through Social Stories could be acquiring elements in a pattern or a system for eventually assessing their own and others' social behaviour. However, although most of the testing to date appears to concentrate on behaviour modification effects and Social Stories have been tested as behaviour modification without use of the perspective-taking element (Okada et al, 2008), behaviour modification may not be the only key element, but another may be the emphasis on perspective-taking as a system which can be slowly acquired, even when innately delayed. Howlin, Baron-Cohen and Hadwin (1999) are amongst those who believe that there are

strategies which can encourage the development of what they call 'mind-reading'.

Perspective-taking itself may be more complex than Piaget (1925), who used this term originally, envisaged, and may be more complex than that used in Social Stories. The understanding of perspective-taking has to be more fine-grained than we have assumed if we want to address the particular nature of the issue for those on the autism spectrum. Frith and de Vignemont (2005) examined the complexities involved in perspective-taking in children with Asperger's Syndrome. They argued that children with Asperger's Syndrome are noted to take a particularly egocentric stance when examining social phenomena. Moreover, this egocentric stance adopts the position that other people are understood only in relation to the self. On the other hand, there also exists in the Asperger cognitive profile, an ability to view the entire social structure as objective, and children with autism spectrum conditions may appear aloof, viewing others in a particularly detached way.

This is why the Scattone study (2002) is referenced above in the quotation from a Social Story constructed for 'Kenny'. An incidental finding which involved ego- and allo-centric perspective-taking may be of significance, as it may offer insights into delayed but effective implicit learning in social constructivism. A criticised weakness in the study was that two subjects, Kenny and Howard, were in the same class, and the authors recognise that this may not have been an uncontaminated test, for this reason. However, the

weakness revealed an unexpected side-effect. Kenny could read, where Howard had his story read to him. As the study continued, Kenny began to take an interest in Howard's story, too, and began to read it to him, daily, and to remind Howard of the story intermittently. Not only did Kenny realise the value of his own story, which helped modify his behaviour, but had generalised and begun to grasp the concept of allocentrism. He was able not only to accept that other people might be hurt or upset by his own behaviour, and that this was unhelpful ultimately for his emotional well-being, but that they might be hurt or upset by Howard's behaviour, and he wanted to help Howard with this understanding.

Some of the most robust findings in research into interventions for autism spectrum conditions have been in the field of peer-assisted social skills learning, as in the above example of Kenny's informal and unexpected assistance. This type of learning, which may take its initial direction from teacher instruction of non-autistic peers, who then intervene to help their classmates respond to social cues (Odom, and Strain, 1986), or increase their language ability or reading skills (Kamps et al, 1994), or play skills (Baker et al, 1998) in naturalistic settings (Brown et al, 2001), is often formalised as an intervention named Classwide Peer Tutoring. Its theoretical base is Vygotsky's social constructivist theory of scaffolding the child to explore and move beyond the assumed limits of cognition and skills into the Zone of Proximal Development (Vygotsky, 1978). Vygotsky did not limit the position of the MKO, More Knowledgeable Other, to formal educators, and social-

constructivist practices have been applied to scaffolding by parents (Prizant et al, 2003), and by peers.

Children with ASCs have a retained capacity for modelling, despite the limitations on their social development, and modelling on children of their own age appears in these studies to produce generalisation of learnt skills to other settings (Odom et al, 1999), at whatever educational stage or chronological age this intervention occurs (Haring and Breen, 1992; Kamps et al, 2002). However, those studies which had the most positive and lasting outcomes were those in which the MKOs had been taught in advance *how* the autistic child communicates, and were able to reciprocate in turn (Gernsbacher, et al, 2006, Ochs et al 2001, Sasso et al; 1985). The positive nature of these findings does appear in some respects to support the ideology of the inclusion of children on the autism spectrum in mainstream schools (Harrower and Dunlap, 2001; Garfinkle and Swartz, 2002; Sawyer et al, 2005), although caution was exercised (Odam et al, 2006) in a finding that children with disabilities were more acceptable to their peer group if they do not have disabilities which affect social problem-solving and emotion-regulation, and another concluding that children with these problems are more likely to be socially rejected (Swaim and Morgan, 2001). They appear to have different social groupings and social behaviours (Whitehouse et al, 2008; Wainscot et al, 2008)

An apposite and useful point of reference to this current study is the series of studies conducted by Bauminger et al into the nature of friendships made in

inclusive school settings by children on the autism spectrum (Bauminger and Kasari, 2000; Bauminger, 2002; Bauminger and Shulman, 2003; Bauminger, Shulman and Agam, 2004; Bauminger et al, 2007; Bauminger, 2007; Bauminger et al, 2008; Bauminger, Solomon and Rogers, 2009) and by other teams investigating the understandings shown by classroom teachers of children with ASCs in inclusive settings (Robertson, Chamberlain and Kasari, 2003) and the social networks of these children (Chamberlain, Kasari and Rotheram-Fuller, 2007). All of these studies show that these children have a marked degree of isolation from their peers, with the Chamberlain, Kasari and Rotheram-Fuller (2007) study claiming that the children did not report greater degrees of loneliness. This was disputed by the findings of Lasgaard et al (2010) in which 21% of the 39 adolescent boys studied described themselves as often or always feeling lonely. A recent study (Jones and Fredrickson, 2010) produced a finding which may be highly significant if it can be replicated. It was that autistic children in mainstream classrooms (n= 43) were less well-accepted by typically-developing peers (n=43) if they had more pro-social behaviour. The authors suggest that the more typical their behaviour appears, the fewer concessions will be made for them by their peers. The authors conclude, Jones and Fredrickson (2010:9)

The findings of this study cast doubt on whether 'not making them different' is the best approach in promoting the social inclusion of students with ASD. It might be predicted that treating students with ASD as different and deserving of special consideration would be important in preventing characteristic asocial behaviour being perceived in a negative

way.

This is a finding which, although tentative, appears to challenge much of the current thinking about how best to facilitate inclusion of autistic students, especially in mainstream education and is in line with Gernsbacher (2006) and Ochs et al (2001). It may not be in these children's best interests to assume that they will be accepted by their peers if we decide not to recognise and communicate their subtle 'difference'.

However, it is possible that not all social relationships will lead to possible degrees of relative isolation for the child on the spectrum. As referenced in the Batten et al (2006) and the Whitaker (2007) surveys there may be other peer problems for children on the autism spectrum. One may be that they are bullied by others with the percentage of children with Asperger's Syndrome whose parents report that they have been bullied standing at 53% in the Batten et al (2006) survey. This is reflective of the percentage of adolescents with autism spectrum conditions who were bullied in Dutch special schools, between 6% and 46% (van Roekel et al, 2009).

This gives rise to a further supplementary research question:

How might the relationships between students on the autism spectrum and typically-developing students, and others, be characterised?

2.4.7 Summary of programmed interventions

- Studies on programmed interventions for autism conditions are severely limited in their generalisation potential because of small sample sizes, and the heterogeneity of the conditions.
- The bulk of evidence on programmed interventions is on Applied Behavioural Analysis, most specifically early intensive behavioural intervention, pioneered by Ivar Lovaas. Behaviourist interventions appear promising, gather considerable data, but remain to date unproven in efficacy for autism because of methodological flaws in most of the studies. The outcome measures: increases in IQ scores and placement in mainstream school through first grade do not address the core diagnostic criteria for autism.
- No longitudinal studies into outcomes in adulthood following the Lovaas YAP have yet been published.
- The YAP programs are heavily dependent on considerable parental Investment of time, involving, on average, 30 hours per week.
- The acquisition of useful language is thought to be a major factor in enabling improvements in all social behaviours.

- For non-verbal children PECS a picture exchange system built on the behaviourist paradigm, may encourage pre-language skills. There are limited or poorly designed studies on PECS
- TEACCH is predicated on respect for autistic culture, and on parents as co-therapists. It is unusual in the USA in that it has been adopted state-wide in North Carolina. Unlike YAP it prefers to adapt the environment to the needs of the child. However, the reliance on its structured learning may not always be in the best interests of generalising adaptive behaviour, and the environmental modifications may mean that the child is educated in a specially adapted classroom, away from peer support. There are few studies on TEACCH.
- Social Stories is a flexible socio-constructed intervention used as a behaviour modification tool, which also allows the child to practice perspective taking. There are few large-scale studies into its efficacy.
- Peer assisted learning may enable the child on the autism spectrum to acquire social skills.

2.4.8 Non-programmed interventions: UK perspective

The conventional educational intervention employed for the students on the autism spectrum in the UK is to provide them with learning support, usually a teaching assistant. This, it is thought, may protect them from

underachievement. Children on the autism spectrum reportedly underachieve at school. Ashburner et al (2010; 2008) claim that this underachievement expressed as results compared with IQ level, is 54% in children with ASC compared to 8% of typically developing peers, despite receiving a range of support in mainstream classrooms. The deployment of a teaching assistant is the most frequent outcome of the statementing process. The report issued by the Lamb Inquiry (2009) into Special Educational Needs and parental confidence, does not give unequivocal support to the deployment of teaching assistants (Lamb, 2009:28):

2.32. All the evidence from work on leadership shows the importance of staff development in setting the ethos and in developing staff skills and expertise. The overwhelming message from parents is of the value they place on staff with the skills and expertise to enable their child to learn and progress: someone who understands my child's needs. Yet, for disabled children and children with SEN, there is evidence of significant amounts of teaching assistant time being used to substitute for teacher time.

There is a noted variation in the deployment of teaching assistants and in their roles, both within schools and nationally and internationally (Takala, 2007; Russell et al, 2005; Woolfson and Truswell, 2005; Werts et al, 2004; Moran and Abbott, 2002; Minondo, Meyer and Xin, 2001; Bowers 1997; McGarvey et al, 1996). The most recent study on the DISS Deployment and Impact of

Support Staff project (Blatchford et al, 2009) found variation in their use. In primary schools, generally, their presence was much appreciated by class teachers, and appeared to enable more on-task performance in the children, as observed by researchers. Teachers were more able to deliver the curriculum rather than having to spend time controlling behaviour, a task undertaken by support staff. In secondary schools where they were used more exclusively on support of one child, this was often a child with special educational needs. The researchers believed that the use of teaching assistants may be supporting the inclusion agenda. They noted that while adult/child interaction was enabled by the teaching assistants, this interaction was largely with the assistant, rather than the class teacher, and that teacher attention and interaction with the child was lessened by this deployment. MacBeath et al (2006) in a study on inclusion of children with special educational needs in mainstream schools found that there was little training for support staff who were 'indispensable to making inclusion work' (:39) but that 'they could not offer the high level of specialist expertise required to support complex learning needs' (:40)

Giangreco et al (1997:7) list eight major problems associated with an overuse of teaching assistants for children with disabilities:

- (a) interference with ownership and responsibility by general educators,
- (b) separation from classmates,
- (c) dependence on adults,
- (d) impact on peer interactions,

- (e) limitations on receiving competent instruction,
- (f) loss of personal control,
- (g) loss of gender identity,
- (h) interference with instruction of other students.

While there are clear benefits in a student on the autism spectrum being supported by an in-class assistant, the above studies would appear to demonstrate that there are also serious concerns in depending too heavily on staff who are largely untrained and unqualified, those referred to, quite fondly, in the MacBeath study by one headteacher as ‘mums’ (Macbeath et al, 2006: 40).

As to the specific experience of children with ASCs in secondary schools, Humphrey and Lewis (2008b) in a multiple case study of 19 students on the autism spectrum found that some students were unable to actively participate in the curriculum, ‘leading to a state of ‘integrated segregation’ that was often as a direct consequence of the practice of teachers and/or LSAs [*Learning Support Assistants*]’ (Humphrey and Lewis, 2008b : 135). In one classroom observed in this study, the child on the autism spectrum was seated at the back of the classroom, facing away from the rest of the class with a laptop computer on which differentiated work was provided. He worked on this with the assistance of the LSA throughout the lesson, and was never approached by the class teacher. Some of the students felt comfortable with this reassurance of adult support, while one of the students in interview pointed out to the researchers that teachers rarely spoke to him or looked at his work.

There are other strategies and interventions which can be of particular help to children on the autism spectrum. One of these is social skills training (Banda et al, *in press*; Leaf et al 2010; Cotugno, 2009; Herbrecht et al, 2009; Laugeson et al, 2009; Koenig et al, 2009; Barry et al, 2003, Mayton, 2005) and can specifically involve the use of Social Stories (Kokina and Kern, 2010; Graetz et al, 2009; Mancil et al, 2009; O'Connor, 2009; Quirnbach et al, 2009; Reichow and Sabornie, 2009; Reynhout and Carter, 2009; Chan and O'Reilly, 2008; Okada et al, 2008; Ozdemir, 2008; Spencer et al, 2008). Another referenced above is the use of peer-mentoring (Kalyava and Avramidis, 2005; Garfinkle and Schwartz, 2002; Harrower and Dunlap, 2001; Hall and Smith, 1996). Peer mentoring, well applied and carefully used, can have useful socialisation effects. Cognitive behavioural therapy interventions are also shown to have positive results on those on the sometimes overwhelming anxieties of those on the autism spectrum (Wood et al, 2009; Reavon, 2009), including evidence from a Type 1 RCT (Sofronoff, Attwood and Hinton, 2005).

2.5 Conclusions

In the introductory remarks to this section the researcher wrote:

However, it is difficult, at this time, to gather clear research evidence on longitudinal outcomes for those children on the autism spectrum who have had no, or minimal, remediation interventions.

Currently, and in the light of some consensus that early intervention to enable social skills and language to develop is the best way to approach autism spectrum conditions in children (Howlin et al, 1973; Howlin, 1998; 2000; 2003; Jordan and Jones, 1999; Hwang and Hughes, 2000; Smith et al, 2000; Goldstein, 2002; Kasari, 2002; Wolery and Garfinkle, 2002; Whitaker, 2002; Aldred et al, 2004; Thiemann and Goldstein, 2004). Very few children, after diagnosis, will not be offered additional support, including the useful but low-intensive NAS Early Bird scheme (Shields, 2001) which is largely a parental neuro-educational programme, supportive of the role that parents play in the early development of their children.

However, there is a useful comparator, albeit historical, which might shed some light on that question, and could be said to work as a baseline for intervention studies. In 1971 and 1972, Kanner, completed follow-ups of the children he had observed in his clinic in the 1930s and 1940s, which had been the basis of his diagnosis of 'autistic disturbances of affective contact' (1943).

Out of a total cohort of 96, he selected nine to discuss,. Another of the best outcome group, an outstanding university student of mathematical physics, had been killed in a street accident and therefore could not be included in the

case notes. But if we include him, and another very promising student who disappeared, there is a total of 13 'best outcome' cases from a cohort of 96.

Autism researchers have tended to neglect this very clear contestation between Kanner's original research based on case study, and the UCLA Young Minds Lovaas studies which offer some empirical evidence that early intensive intervention can alter this baseline for the better. Some research appears to suggest that these early intervention strategies do not seem to work in the majority of cases (Francis, 2005)

Follow-up studies for autism spectrum children diagnosed in childhood are numerous, but they offer insights from different points of the spectrum. Those dealing with classic autism are largely pessimistic, and usually quote their findings as percentages, showing that 50% of autistic adults require institutionalisation (Wolf and Goldberg, 1986), that 53% live in residential accommodation (Ballaban-Gil et al, 1996), that mortality rates are higher in those previously diagnosed with autism rather than Asperger's Syndrome (Schonauer et al, 2001), that 12% have a 'very good' outcome, 10% a 'good' outcome, and 19% a 'fair' outcome (Howlin, 2004), and, in a large scale population-based follow-up study after 22 years, that 74% have a 'very poor' outcome (Billstedt et al, 2005). Follow-up studies of 'higher-functioning' children are more hopeful. In a follow-up study of 16 such adults, 4 had 'very good' outcome (Szatmari et al, 1989). It should be noted that most of these data are drawn from children who were diagnosed with 'childhood schizophrenia'.

Most of the follow-up studies concur with Kanner's findings that the presence of speech by the age of 5 and higher intelligence levels in childhood, are good indicators of future social adaptation, but Kanner emphasises that some of the children with these initial hopeful signs, do not make expected gains. He says that in childhood there was little to distinguish those who might become socially adaptive except 'a chronicle of gradual change of self-concept and reactions to them along the road' (Kanner, 1973: 209). He notes that this change accelerated in some children during their teenage years, when 'they became uneasily aware of their peculiarities and began to make a conscious effort to do something about them' (Kanner 1973: 208) by using their special interests to make themselves useful to others and to 'open a door for contact' (Kanner, 1973: 210). Kanner's perception, here, could be a recognition of late development of metacognition in some children. He draws attention to 'self-assessment' and is aware that this is crucial to social reciprocity, and is the only autism longitudinal researcher to have highlighted the development of personal reflexivity ('uneasily aware'), rather than measurable IQ and adaptation scoring, as being the one critical component in 'good outcome'.

Kanner's summation deals with the cognitive and affective underpinnings of socialisation: the social anxiety which autism and spectrum conditions can engender, and warns of the repercussions of not understanding this. Allowing the autistic child to discover self and other, in his/her own time, may be a more sensible option:

They made the compromise of being, yet not appearing, alone and discovered means of interaction by joining groups in which they could make use of their preoccupations, previously inured in self-limited stereotypies, as shared 'hobbies' in the company of others. In the club to which they 'belonged', they received – and enjoyed – the recognition earned by detailed knowledge they had stored up in years of obsessive rumination of specific topics....Life among people thus lost its former menacing aspects. Nobody had shoved them forcibly through a gate which others had tried to unlock for them; it was they who, at first timidly and experimentally, then more resolutely, paved their way to it and walked through. (Kanner, 1973: 211)

Finally, on a prescient note, Kanner adds:

It must be kept in mind that our 'emergers' grew up in the days before the introduction of therapeutic techniques especially intended to remedy the autistic illness, be they based on circumscribed psychotherapeutic, psycho-pharmacological, or behaviorist orientation. Would any of these have in any way altered the outlook for our 96 children? Will any of those increase the ratio of 'emergers' in the future? What can we make of the fact, documented in this study, that almost 11 to 12 percent 'got there' without any of those techniques? (Kanner, 1973:212)

There are several possible conclusions to be drawn from the fact that Kanner's 11 to 12% is very similar to the percentage of 'emergers' from early intensive intervention studies. One is that consensus may be mistaken, and that early and intensive therapy with the most seriously affected children does not alter the course of autism. Another is that early intervention may have much longer-term cumulative outcomes than we imagine, although follow-up studies from Howlin et al (2004) appear to show stability over time. A further interpretation which could be applied to the data is Kanner's own conclusion – that until the children have a degree of self-awareness, something that might emerge perhaps in adolescence, they may not be able to access the support and short cuts to learning given to all by socio-cultural reciprocity.

There is however another perspective from which to view Kanner's findings about the nature of his 'emergers'. It is the perspective of peer acceptance, and peer values. Perhaps it is not merely the realisation in these children that they can contribute something to the constitution of groups during early and mid adolescence, but also that by this age peers themselves are beginning to form loosely-knit groups based on common interests: 'fan' groups, technology and computer groups, collectors' clubs, games' teams, in which obsessional interests are no longer regarded as freakish but as unifying, and those who can offer advice, knowledge and memory for incidental facts and unusual skills, may become adopted into mainstream or alternative groupings. For the first time, some children on the autism spectrum, may discover social reciprocity, that is, they may find themselves approached by others and invited to share their special interests.

Special interests, noted by Hans Asperger (Asperger, *trans* Frith 1991: 72) can be of great benefit to a child on the autism spectrum, if attention is paid to them by perceptive teachers who may be able to modify the curriculum to take account of those things which fascinate the child to a degree which many would describe as obsessional (Bianco et al, 2009). Winter-Messiers (2007) conducted an exploratory study into the special interests of 20 children with Asperger's Syndrome, discovering a high correlation between special interests and social, communication, emotional and sensory skills, creating from the data a strength-based model of Asperger's Syndrome and special interests, and concluded that there is a critical need for teachers to understand and value the special interests of these children. Klin et al (2007), in a partial rejection of this view, describe what they name as 'circumscribed interests' as a fascinating and understudied phenomenon in most individuals on the autism spectrum (75% of younger children and 88% of older children in the 96 participants in their exploratory survey) but drew the conclusion that the level of 'interference' of these interests in social functioning is 'predictive of lower social and communicative adaptive behaviour in later life'. However, this conclusion may be misleading as the data collected was from children in pre-school and elementary school. The authors write (Klin et al, 2007: 98)

....there is increased awareness of individuals whose success in life (e.g., in information technology or academics) resulted from highly circumscribed, but real knowledge and passionate pursuit of a given topic or area of study. Our hope would be that the same talents

subservient nonadaptive pursuits such as encyclopedic knowledge of sports statistics, political geography, or botanic nomenclature might be channeled to learning that is more readily translatable into skills promoting independent living, remunerable pursuits, and meaningful employment and relationships.

This would appear to be a rather narrow academic view of 'non-adaptive pursuits'. The authors give some credence to this alternative viewpoint by referencing one child in their study whose special interest in childhood was in creating imaginary electronics components and who is now a software designer (Klin et al, 2007:98). Their view, however, does reflect that of Frith in discussing the autistic child's superior performance on the Embedded Figures tests and deciding that this does not accord with Witkin's Field Independence category but 'simulates' it :

'A weak central cohesive force....would simulate field independence... It would entail thought detachment and social detachment, but this would not be the same as in an older normal child. In the normal child detachment is the sophisticated end-product of education, a sign of control over the high level central force towards cohesion. In the case of Autism I propose that such a control is lacking and that this results in an incoherent world of fragmented experience.' (1989: 98)

Frith and Happé have now readjusted their view in line with other researchers who advocate a local processing bias view, rather than the 'incoherent world

of fragmented experience' description used in 1989 (above). That paragraph, from a less-enlightened era in autism understanding, fails to note that what is seen as academic detachment is not necessarily an end-product of education, but can be an innate cognitive style.

Within an inclusive society, and an inclusive education system, we should be able to accept a view of diversity as recognised and valued, however difficult it may be for us to understand the nature of that divergence from what we class as 'normal'. One of the key elements in educational policy is 'accommodation' of those with differing educational needs: a legacy of the enlightened views expressed in the Warnock Report. Part of this accommodation may be in a range and variety of provision, which as the Report delineated, need not be necessarily be mainstream, but additionally the issues of locational, functional, or social mainstream school should be considered. Another key element, which has been to date very poorly addressed in the education of those with autistic intelligence, as provision has been viewed as the overriding issue, is curricular modification, as demonstrated by recent research reports. But perhaps the most important element, and the least addressed, is the social constructivist model of learning, at the heart of which is the recognised social drive, not towards normalisation, but towards reciprocity. Both Kanner and Asperger recognised that issue. Kanner said (Eisenberg and Kanner, 1956, *in* Kanner, 1973: 96):

If one factor is significantly useful, it is a tolerant reception by the school. Those of our children who have improved have been extended

extraordinary consideration by their teachers. They constitute a most trying group of pupils. School acceptance of behavior that elsewhere provokes rejection is undoubtedly a therapeutic experience.

Kanner worked closely with two such educators. One was Helena Devereux, the other Jeanne Simons, who ran the Linwood Children's Center, in Ellicott City, Maryland, both a day school and a residential school for those children who may have needed more intensive intervention from time to time. The Center worked on totally flexible principles, able to provide temporary residence alongside its day school provision which was arranged on an individualised basis. (Kanner, 1973)

Kanner's finding is echoed by Hans Asperger (1944/1991: 48)

These children often show a surprising sensitivity to the personality of the teacher. However difficult they are, even under optimal conditions, they can be guided and taught, but only by those who give them true understanding and genuine affection, people who show kindness to them and, yes, humour. The teacher's underlying emotional attitude influences, involuntarily and unconsciously, the mood and behaviour of the child.... Mere teaching efficiency is not enough.

These original researchers into the conditions we now know as autism, offer guidance to the accommodation of autistic intelligence in mainstream inclusive education. What they both say is that the educational system should,

and could with effort, understand, care for, remediate, and accept, the difference that is autistic intelligence. It has been the purpose of this Literature Review to examine the evidence provided by their initial discovery of autism, and to determine what, in the additional research literature, may further serve to answer the research question.

2.5.1 Research Questions

The main research question in this study is, *'How can autistic intelligence be recognised and accommodated in an inclusive education framework?'*

Four supplementary questions have arisen from an examination of the literature, as areas which may need further exploration in the context of this study into the recognition and accommodation of autistic intelligence in an inclusive educational setting. These will help to define more exactly the nature of autistic intelligence, and the challenges which might be posed by it to an inclusive view of the educational process, and the challenges which an inclusive educational process may set down for those on the autism spectrum. These supplementary questions are:

1. *Do professionals and parents, and children on the autism spectrum regard autism as a deficit, or a difference, and is there any recognition of the skills and strengths and advantages of this condition?'*

2. Do teachers, parents and the children themselves identify the sensory and perceptual differences which are theorised to be essential features of autistic intelligence?’

3. To what extent is there consensus among teachers, parents, autistics and researchers as to desirable outcomes in intervention strategies for autism spectrum conditions, and the means appropriate to achieve them? Where there is conflict, what is its nature?

4. How might the relationships between students on the autism spectrum and typically-developing students and others be characterised?

The main question, supported by the supplementary questions will now be incorporated into a research design which most aptly fits the nature of the questions, and the biopsychosocial theoretical framework which has been articulated in the Introduction and Literature Review.

Chapter 3: Methodology

3.1 Introduction

It is now necessary to look at which theoretical approaches, methods and methodology will provide fitness for purpose to seek answers to the questions provided at the end of Chapter 2, which arose from the Literature Review. Cohen, Manion and Morrison (2007: 78) say, 'The purposes of the research determine the methodology and design of the research'. This research is carried out through study for a PhD, which sets certain constraints, particularly those of time and wordage. However, within those constraints the essential rationale of the research should be honoured by a process which proceeds by weighing up the possibilities of what best allows insights to be generated. A suitable means of operationalising the research is discussed in this chapter.

This study has taken as its theoretical framework a biopsychosocial model. The model acknowledges the existence of the theoretics of bio-medicine in possibly and partially defining certain group differences in educational needs (Norwich and Lewis, 2007). However it also acknowledges the fluid interaction of psychological, social, and temporal factors in considering what may modify, to some extent, those needs. That is, educational provision may best be informed by a consideration of all these factors, holistically.

3.1.2 Paradigm exploration: positivism and post positivism

Many of the studies into autism spectrum conditions are based on the positivist paradigm of knowledge-seeking which seeks to produce statistical or quantified data, employing a model deriving from scientific method. The subject or site is studied through observation and recording of behaviours where a predetermined hypothesis can be evaluated through an established step-wise progression. The aim is often to investigate causation in experimental research. There is a linear progression towards a product. Determinism of this kind is one of the hallmarks of the paradigm.

Positivist approaches, then, aim for an objective 'truth' which is believed to exist, 'out there' as revealed statistically, through various measurements. Internal validity is determined by the scientific rigour employed by the researcher to control variables, within an appropriate study design, and appropriate use of instrumentation throughout this process. External validity is established through generalisability: evidence so produced can be generalised from the particular, and replicability. Its direction is to parsimony, a reduction of a mass of observed or recorded evidence into the most parsimonious and clearest form, the numerical form (Cohen, Manion and Morrison, 2000).

This approach has been, and is, used by researchers into the effects of educational interventions in autism, particularly those investigating through experiment the effects of early intensive educational interventions (Lovaas,

1987; Smith, Groen and Wynn, 2000). The purpose of these studies was to test, through the generation of data, whether the intervention was efficacious, exploring the possibility of a causal link between the intervention and a measurable outcome.

In the early days of this researcher's project, an experimental educational intervention was considered, not involving students, but parents and teachers. Had this concept been developed, then the research question would have been an hypothesis, and a positivist paradigm may have been used in the design. It could also have been set in a post-positivist paradigm, somewhat more tentative than logical positivism, holding as its guiding theoretic that the nature of 'reality' or 'truth' can only be held provisionally until possibly falsified (Popper, 1959:33):

If this decision is positive, that is if all the singular conclusions turn out to be acceptable, or *verified*, then the theory has, for the time being, passed its test: we have found no reason to discard it. But if the decision is negative, or in other words, if the conclusions have been *falsified*, then their falsification also falsifies the theory from which they were logically deduced.

In examining the current research questions, it may be thought possible to respond by employing surveys and questionnaires, within a positivist paradigm using quantitative methods. Numerical evidence could be gathered

about opinion or behaviours sought by the questions. With reported prevalence of ASCs ranging in various studies between 1:64 and 1:160, small sample sizes are inevitable in most ASC research but the survey could overcome this. Postal, telephone, or online surveys can reach scattered and small sample participants, and can access an existing database of parents, such as those members of the NAS in the Batten et al (2006) survey, or those resident in the county of Northamptonshire in the Whitaker et al (2007) survey. Longitudinal studies could also be conducted in this quantitative manner to investigate whether these opinions and behaviours change over the course of time, and by what proportion.

Although the survey material cited above is available and useful in seeking to access current opinion, one limitation to their applicability is that they may seek to confirm or deny what is already believed. They may use closed questions, based on hypotheses. Cohen, Manion and Morrison say (2007: 320), 'there is a simple rule of thumb: the larger the sample, the more structured, closed and numerical the questionnaire may have to be.' They may therefore be less useful at exploring what is unknown, or partially-understood. The Whitaker (2007) survey did contain some open questions, but it could be argued that a certain degree of literacy was required of those who did wish to offer additional comments.

Another problem with surveys is that they tend to contain some bias. Membership of a campaigning group can define a certain group of service users who may not be typical of the parents of children on the autism

spectrum who have not joined such a group. They may also have an embedded bias, in that those who are satisfied are less likely to return questionnaires than those who have problems with the services. Creswell (2005:368) comments:

Response bias occurs in survey research when the responses do not actually reflect the views of the sample and the population. For example, the individuals who return a questionnaire may be overly negative or positive.

Another limitation to the use of surveys with this population in the past is that surveys have rarely questioned children or young people on the spectrum. Traditionally they have been mailed to parents, and sought information from this source in particular. The Batten et al (2006) survey publication also included some interviews with teachers and students, but these were illustrative of the data rather than data-productive. A further issue is that surveys have no ability to interact with respondents to clarify and explain meanings.

This study does not test, as do many in the positivist paradigm, an hypothesis as its primary aim. There is an element of hypothesis-testing in the suggestion of the theorised term 'autistic intelligence' and whether this may be a valuable term to consider in an educational setting. That question is not asked directly, however, but instead has informed the supplementary research question

three. It can be held back in the fieldwork itself to serve as a personal shorthand means by which this researcher views autism non-medically and holistically and as an alternative pattern of cognition. Similarly, the word 'inclusive' which is equally complex and heterogeneous in its nature, can be held back in fieldwork. Therefore the main research question can be reframed as 'How can/does A ('autistic intelligence') operate in B ('an inclusive educational framework').

The current study is an exploratory in nature seeking to gain access to beliefs, understandings and how these may link to behaviour. A pointer to its exploratory nature is its small sample size, a pragmatic consideration in studies of this minority autistic spectrum cohort that cannot be overlooked in methodological design. The study looks at the beliefs and understandings about autism of 14 people in all. The methodological design should therefore be capable of accommodating small sample sizes.

3.1.3 Paradigm exploration: Interpretivism

The supplementary research questions suit a paradigm which is not predicated upon the positivist parsimony of data analysis in its reduction to numerical rankings and relations, but which can offer access to the richness and depth of experiences as expressed in words. It is through words that participants can explore their own beliefs and understandings and share their insights about the accommodation of children with ASCs within an inclusive educational framework. It aims to access a thickness and richness of description (Geertz, 1979).

Neumann (1987:159) asserted, perhaps too emphatically, that 'problems relating to the theory of educational science cannot be solved using quantitative methods'. His argument, which is supported by others in educational research and the social sciences (Hammersley, 2000; Metz, 2000; Riehl, 2001), is that knowledge itself is socially constructed. Therefore in research dealing with the nuances of human interaction, the most useful results are obtained by employment of an interpretive paradigm. In a meta-review of qualitative research articles published in the *Journal of Educational Review* between 1992 and 2001, Shank and Vilella (2004) noted increased use of qualitative methodology in educational research from one per year on average in the first seven years, to an average of one per issue in the last three years of this period. They selected as one of the advantages of the interpretive paradigm in educational research, the particularly appealing phrase 'illuminative fertility' (Shank and Vilella, 2004:46).

The ontological stance in this educational study is the examination of social realities. Alongside this runs the understanding that there may not be a single social reality, but rather a series or aggregation of alternative co-existing social constructions (Lincoln and Guba, 1990). This stance is particularly useful when studying children with autism spectrum conditions, in which social understanding and communication may take a form which is atypical or alternative. The criteria which govern this study are process-driven, rather than product-driven, as evidenced and supported by the adoption of the fluid biopsychosocial model (Cooper, 2008) as the theoretical framework. This

most aptly reflects the complex and unpredictably-mutable relationship of 'self', in autism, with environment.

The subjectivity of the researcher, also, is acknowledged fully in the interpretive paradigm, which recognises that the researcher brings his or her own beliefs and knowledge to the interactive site of the research, which is a socially-constructed process in itself and is realistically a part of rather than apart from the matter under exploration. Here, the researcher is the instrument, who inductively examines the issue, while remaining aware that s/he should seek out patterns rather than determining them. This acknowledgement and awareness lies at the core of the interpretive paradigm, as it encourages iterative self-examination and metacognitive strategies (Hammersley and Atkinson, 1983: 19). This paradigm, then, is perfectly positioned for enquiries into cognitive processes, which is the purpose of this research. It is a study of a group of students whose condition is often theorised as an alternative cognition.

The intention in this innovative study is to attempt to identify a variety of viewpoints from an ASC population which is essentially heterogeneous. The heterogeneity may derive from a highly individual strong profile of hypo- and hyper-sensitivity to environmental influences in each person on the autism spectrum, despite the sharing of core characteristics as defined by diagnostic criteria as a Triad of Impairments (Wing and Gould, 1979). One of the strengths of the interpretive approach is the opportunity it provides to explore

and expose heterogeneity, the inherent understanding that no two may be alike. Its inductive approach accords with this type of exploration, resulting in findings which foreground transferability of ideas, not static generalisation.

Autism's highly individual profile has posed some challenges for positivist studies. If identifying variables are ignored, or underplayed, or simply not fully understood, as may be the case in the six months' difference in age between the control group and the experimental group in the Lovaas (1987) study (see page 135), validity and generalisability of the findings may be challenged. However, within the interpretive paradigm, validity is not dependent on generalisability. Instead, this criterion is replaced by 'transferability' (Lincoln and Guba, 1985), where an individual assessment of the truth value of a study is theorised as dependant on the view of the reader as to its applicability: whether it is 'sufficiently like' (Lincoln and Guba, 1990).

It would appear, therefore, that the interpretive paradigm may be more suitable than a positivist or post positivist paradigm as a vehicle in which to drive this particular set of research questions. However, there is a note of caution in claiming a perfect fitness for purpose, in this case. Creswell (2005: 46; 79/80) claims that one of the differences in the quantitative study and the qualitative study, is that of the purpose of Literature Review. His view is that in positivist research the Literature Review is extensive, and that supplementary research questions develop within it and from it. In the interpretative paradigm, on the other hand, the Literature Review is less determinant of the research questions. He says of qualitative research (2007:79) :

..authors [of qualitative research papers] do not discuss the literature extensively at the beginning of a study. This allows the views of the participants to emerge without being constrained by the views of others from the literature.

This particular paradigm issue is crucial in planning the itinerary of this thesis, and creates something of a logistical problem in determining vehicles, drivers and passengers, and destinations and routes, for the proposed journey. While the trajectory of the study is educational in terms of destination and purpose, certain routes may be unfamiliar to those in educational research and practice. This is evidenced by the plethora of documentation on the poorly-understood 'challenges' provided by autism to the educational system (see **1.1.1**).

These basic issues needed to be examined and displayed before the research question, and its significance, could be fully mapped by researcher and followed by readers. The examination necessarily involved an in-depth Literature Review approach to the subject in order to gain access to the question itself. The supplementary research questions derived from that process. One might say, as Creswell does, in this statement, that the dominant Literature Review process as adopted here, is not fully suited to an interpretive approach. It becomes the driver. This researcher fully understands that viewpoint. However, there can be perhaps little direct bias

from theory unless it is demonstrated by the researcher in data collection and analysis.

An important issue arising from Creswell's statement is that rather than the theory explored in a Literature Review constraining the study, it can open up new possibilities. It helped, in this particular case, to go beyond preconceptions. Insights provided by the Literature were valuable in exploring and illuminating previously-held biases and allowed for a more open and fluid approach to the study.

Having decided to adopt an interpretive paradigm, a suitable theoretical approach was then sought.

3.2. Seeking a relevant theoretical approach

As a bio-medical entity autism could be said to present challenges to some social science approaches in that one of its features is considered to be an atypical profile which is resistant to many established social science theoretics. Autism is medically-defined as a social/communication disorder. Therefore any theory espoused should be capable of encompassing social 'otherness' in its approach.

This study looks towards individuals, rather than groups, albeit that the triads themselves may be said to constitute 'groups'. Its aim is to look at individuals' personal beliefs and understandings, to discover whether and where notions

of otherness may be located within verbatim accounts on the subject of autism. While its focus may be thought to rely strongly on the accounting by those on the autism spectrum, it is as important to study in equal depth the accounts of those who represent the environment in which the student with an ASC operates. This is home life as represented by parental accounts, and school life as represented by teacher accounts.

In considering a theoretical approach, the researcher now turns very briefly to considering some of the more prominent approaches which could appear suitable to guide the study.

3.2.1 Considering symbolic interactionism

The work of Blumer was considered in determining the aptness of symbolic interactionism to this study's aims. First, it appears to marry well with the biopsychosocial nature of this study's theoretical framework. It sees human existence in terms of a negotiation between self and objects, between self and environments as the site of meaning-making. One of the aims of this study is to try to gain insight into the relationships which are believed to exist between the selfhood of autistic intelligence and the environment of inclusive education. The foregrounding of these negotiations, the essence of social constructivism itself, is at the heart of the study. Blumer (1969: 35) contends,

The life of a human society, or of any segment of it, or of any organization within it, or of its participants consists of the action and

experience of people as they meet the situations that arise in their respective worlds.

Another feature of symbolic interactionism which meshes strongly with the aims of this study, is Blumer's view that there are many of these negotiations which may be hidden from sight. His assertion is that positivist social scientists, removed from personal genuine engagement with those things which they believe themselves to be investigating, are not engaged with a 'reality' at all. He also says (1969: 39) 'there are levels of happening that are hidden to all participants'. This, too, is central to the current study, as what it seeks to uncover is whether all participants in this study have similar beliefs about autism, and whether beliefs are explicit or tacit.

Where symbolic interactionism is less helpful is that it is based on a premise that all human beings have a similar innate communicative capacity. It assumes a normative position. By making assumptions about communication itself, the part played by social constructivism in autism cannot be fully embraced by its theoretic. Blumer's basic three premises are (1969:2): that human beings act towards things on the basis of the meaning they have for *them*; that meaning in things is derived from social interaction; and that these meanings are modified by personal interpretative processes. The first is certainly applicable to autism, the second two less so.

Strongly identified problems in autism are that there is some social difficulty, that the co-construction of self and other is not clear, and that self-reflection

itself is theorised as compromised or delayed, because of the other two issues. The chief difficulty arising from a use of this theoretical approach is that it assumes co-construction of meaning, and social interaction, are typical in the lives of all human beings. Where a striking failure to mesh with understandings of autistic intelligence is in Blumer's statement (1969: 10) 'Such mutual role-taking is the *sine qua non* of communication and effective symbolic interaction'. The key word here is 'mutual'.

There is always a danger in well-intentioned and strong theory if variables are not fully accounted for. It appears that the basis of symbolic interactionism is the assumed ability in all people to understand the minds and intentions of others. Therefore, symbolic interactionism is not a suitable vehicle for providing insights in a non-biased and useful study of autistic intelligence, as it privileges the typical researcher above the autistic participant.

3.2.2 Considering phenomenology

Phenomenology, as a guiding theoretic, would appear to mesh well with the structural intentions of this study which are first to acquire a framed knowledge of a phenomenon in order to pose informed questions, then to bracket this knowledge in an investigation of what is as yet unknown. The theoretical approach of the phenomenological social scientist Alfred Schutz would seem to support the second of these aims in certain useful respects.

Firstly Schutz's perspective differs from that of Blumer. While respecting, as Blumer does, the social construction of knowledge, his theoretic gives more

weight to the individuality so constructed, and emphasises unique ownership of self (Schutz 1970: 73), '...as such his unique possession, given to him, and him alone'. This perspective, a little broader than that of symbolic interactionism can accommodate difference such as autistic intelligence far more easily. It is detachedly observational while predicated upon 'the grounding of the social sciences in the Thou experience', a second person (Depraz, 2006) generous understanding of 'beloved others'.

Schutz was guided in his theoretics by looking for what he called the 'natural attitude' (Schutz 1970: 183), the taken-for-granted view that others assume in their daily lives and which influences their interpretation of experience. This again links to the purposes of this study. The 'natural attitude' of participants was sought: what are the views of this group of participants to both autism and its context in inclusive education, is central to the focus of the study. Also central is an effort not to bias findings, to remain 'bracketed' through the process, although this is difficult to achieve, particularly at the stage of analysis. Schutz names this bracketing as 'epoché' a suspension of preconceptions to be adopted on the part of the researcher, and a suspension of doubt in a life view noted as being a part of the 'natural attitude' (Schutz 1962: 229).

However, phenomenology as a guiding principle in approach, is not without its problems when conducting research. It aims to produce clear descriptive findings, rejecting taxonomies, drawing upon the data, but presenting analysis in descriptive form as generating 'ideal types'. It develops theories 'through

the dialogic relationships of researcher to researched' (Cohen, Manion and Morrison, 2007: 170).

While the underlying principles and attitude of the approach are very close to the philosophy underlying this study, and much closer than symbolic interactionism, the research design demanded by phenomenological approach was not adopted. This is because its full adoption would have demanded a much lengthier immersion in the field, and with a limited population from which to sample, would have taken many years to complete. This was clearly outside the scope of this PhD study.

3.2.3 Considering Grounded Theory

Grounded theory is both an approach and a method. It is strongly informed by interview data, as this study is. Interview data are gathered from the posing one or few very open questions, as it is in this study, and allowing interviews to develop to some extent conversationally (Rapley, 2004). From the answers to these questions, codings are developed which are then subjected to a 'constant comparison' applied to further data gathering and analysis (Glaser and Strauss, 1967). This process can lead further theoretical sampling based on the regularities appearing in codings.

In principle, a kind of grounded theory lies at the base of most qualitative design, as it is always necessary in data analysis to return to the data continually and iteratively as data-gathering continues, to search for patterns, and also to search for deviances from what were early assumptions.

In many cases the deviant data are the most illuminating as they compel the researcher to rethink, open up the codings, and encourage the reflexivity which is the hallmark of all rigorous qualitative research. The refining of codes and the self-questioning attitude to interpretation is central to interpretive social science enquiry.

In practice, however, few of the methods, rather than the principles, of grounded theory appear to gel with the needs of this particular study. First, a methodological imperative of Grounded Theory is to enter fieldwork with a totally open mind, uncontaminated by any prior literature search. This particular study, while taking an exploratory stance on what is unknown in current thinking on autism and education, informed its research questions through a thorough Literature Review. Dey (2004:90) says of this inductive open-mindedness:

One problem with this approach is that it requires research always to begin from scratch, instead of using whatever theoretical and conceptual resources that social inquiry already has to hand.

Another challenge which grounded theory sets for this study is its use of theoretical sampling to refine and further test any developing theory. Such a process is dependent on there being a wide range of possible participants, all of whom may give accounts which illuminate the process of theory-building from the developing codings. In the case of this particular study, no such opportunity exists. The relatively low incidence of autism in the population,

coupled with problems in accessing information about those with autism, would appear to rule out the possibility of refining theory-building through theoretical sampling.

3.2.4 Summary of theoretical approach considerations

While an examination of various alternative theoretical approaches has not identified one which has an exact fit with the aims of this study, the population of this study, or the limitations of sampling and time constraints, what it has done is to reveal where broad agreements in principle might lie. The examination has been useful in helping the researcher define and clarify certain elements in the study which can be informed by the above theoretical approaches:

- This study concerns itself with the relationship between the student participants in this study and their environment ('things') as represented by parents and teachers (*Symbolic Interactionism*)
- Some of the issues which need to be revealed by this study may be hidden from plain view (*Symbolic Interactionism*)
- This study attempts to respect the individual ownership of views and beliefs which have been socially constructed but represent a lived-life reality (*Phenomenological sociology*)

- Preconceptions on the part of the researcher must be held back from the site of the research (*Phenomenological sociology*)
- Data should be carefully and iteratively interrogated as an ongoing process through its collection (*Grounded Theory*)

3.3 Choice of method

Examining through a series of inquiries into what might be a suitable vehicle for this study, and determining which of the theoretical approaches might be apt, has enabled a greater insight into the nature of this particular study. It has been a process of defining what it is not, and where it fails to fit into certain theoretical approaches. That has enabled a clearer vision of what it *is*.

The main research question is about a tightly defined system. It asks how A can be accommodated within B. These two elements, autism and inclusion, form a strongly bounded system. Within that system, the study aims to examine the processes which may interplay, and about which there is little empirical evidence. Again, as has been said, surveys have been carried out on this topic, therefore there is some form of documentation. But an *in vivo* study, looking at beliefs about autism within a home and school context is not available.

In this study there are four main sources of possible interaction and thereby data production: people, places, events, and processes (Robson, 1993). The people are as identified above. The places are homes and schools, as it is possible that what is revealed in one, the base of home, may not be revealed in the other, the school classroom. The events are the noted behaviours as evidenced by themselves and perhaps others. Finally, the processes under scrutiny are the relationships of the participants with the environmental issues created by the other people, including the researcher, and by the settings, and by their understandings and beliefs, further contextualised by time.

It is not a system which one could enter without prior knowledge. A depth of understanding of both autism and the inclusive educational framework is essential. If the intention is to rely to a large extent on interviews, then the careful use of probes and prompts, for instance, must be guided by a degree of expertise. Many social science explorations and studies can be based on a understanding of the means by which people communicate and socially-construct meaning. Yet some theoretics may not take account of the issues involved in autism. The failings of symbolic interactionism to allow for social/communication atypicality is a case in point. Therefore this study must take as its vehicle a method which does not disavow or disdain prior knowledge. The study is based on prior knowledge, otherwise the research question could never have been asked in the first place. An in-depth survey and understanding of the Literature on autism is an a priori requirement.

For the reasons outlined above, which have been explored in the previous section and summarised here, the vehicle chosen for this study is case study. Some methodological commentators place case study as a method, or 'style', rather than a methodological approach, among them Cohen, Manion and Morrison (2007). Citing Hitchcock and Hughes (1995) they follow the reasoning that, 'case studies are distinguished less by the methodologies they employ than by the subjects/objects of their enquiry' (Cohen, Manion and Morrison, 2007: 253) On the other hand Creswell (1998:61) sets case study as one of his chosen five 'traditions' of inquiry, alongside phenomenology, biography, grounded theory, and ethnography. The inclusion/exclusion criteria for case study as method/approach appear to be a matter of opinion.

3.3.1 Examining case study for fitness of purpose

The reasons delineated above appear to make case study, as an over-arching method, a more positive fit than any others considered. The essential factor here is that the research question is a clearly bounded system involving the possible integration of A (autism) and B (inclusion). Stake (1995:2) summarises:

The case is an integrated system. The parts do not have to be working well, the purposes may be irrational, but it is a system. Thus, people and programs clearly are prospective cases.

This statement provides an exact match for the main research question.

Moreover, case study, unlike Grounded Theory, takes as one of its guiding principles the prior knowledge of the researcher in handling both data collection and analysis. According to Yin (2009: 161)

....you should use your own *prior, expert knowledge* in your case study. The strong preference here is to demonstrate awareness of current thinking and discourse about the case study topic. If you know your subject matter as a result of your own previous investigations and publications, so much the better.

This view is not one which is so strongly valued or articulated in other research methods or methodologies in applied social science. It is one that conflicts with some of the current views on qualitative methodologies, including that cited in Creswell (2007:79). It is, however, a fit for this researcher's background, as a published author in this field (Jacobs, 2003). It must be said that a priori knowledge and research questions deriving from these, if applied too stringently, can limit the data analysis by forcing it into too tight, and perhaps restrictive codings. This should be borne in mind.

The design of case study focuses on research questions, named 'issues' by Stake (1995) and 'propositions' by Yin (2009) derived from close reading, clear understanding and presentation of a detailed Literature Review. This study differs somewhat from this 'issues' and 'propositions' outlined by Stake and Yin respectively. Here the supplementary research questions derived from the Literature Review largely remain at an exploratory ('how?') level,

rather than the interrogative ('why?') level, yet the principle remains the same. It is that the questions to be explored are defined before the fieldwork commences. This does not necessarily imply that they cannot be adjusted or added to during fieldwork. In some definitions case study can be conducted partially quantitatively if necessary (Yin, 2009: 132).

3.3.2 Exploring the type of case study

Stake identifies two alternative types of case study (Stake, 1995: 3). One is the 'intrinsic' study, the other the 'instrumental' study. The intrinsic study is essentially one conducted in order to explore, from curiosity, what we 'need to learn from that particular case'. The other is instrumental, that is, a study designed to promote general understanding of something else. In many ways, this particular case study is intrinsic, in that it seeks to understand the mechanisms of a very specific case, that of autism in an inclusive educational framework. On the other hand, it may act as instrumental, in that we may be able to apply the findings to other frameworks, perhaps outside education. On balance, the researcher identifies this as an intrinsic study, as it concerns a specific issue, within a specific framework.

Another issue to be taken into account is whether this study should be regarded as a single case. As the sample proposed was that of four groups: one student on the autism spectrum, their parents and their teachers, a possibility is that the study could comprise of four linked case studies, a multiple framework, enabling cross-case comparisons. Yin (2009:61) says, 'the analytic benefits from having two (or more) cases may be substantial'. It

can lead to seeking corroboration, or contestation, between several different cases, thus enabling an analytic depth to the findings.

However, in the view of the researcher, who considered that possibility, this would have brought in data analysis which may have been extraneous to the main research question. At one point in the analysis, this was a possibility which was explored, not merely in planning, but in execution. The data were interrogated on the basis of familial linkage and the beliefs and experiences of each family were looked at separately. What was revealed by analysis at this level was that the family relationship itself was under analytic scrutiny, and retrospective experience was also foregrounded. The relationships internal to that particular family, and their hindsight evaluations of the educational experience became the focus of the study. This was not what the research question, and the supplementary questions were concerned with.

Essentially, what this consideration, and the attempt at practical level to view the data in this way produced, was a denial of the 'snapshot' quality which the researcher was attempting to explore. She wished to gain insight into this research question in a situated manner. It was situated specifically in time, the time was the present, and she wished to capture the beliefs and understandings about autism of *all* the participants, equally. Essentially, the study was holistic in its attempt to address the question.

Another possibility was to set parent/student/teacher 'groups' as separate but linked case study. This was a more helpful possibility, and would provide

useful analysis at every level. However, this also did not meet the exact requirements of the research question, which was to explore each participant's contribution to this question as crucial and informative, independently of their role. An analysis of roles inevitably involves questions of power, hegemony and control, which might well be pertinent, but may not necessarily be central to the issue of autism.

Ultimately, it was decided to retain a single holistic case study approach. However, within that, quasi 'embedded' cases may exist on an analytic level (Yin 2009:59). These would be evident in some aspects of analysis, but would be solely employed on the basis of aspects of the analysis. That is, the student/teacher/parent groups would retain their specificity during analysis, where conflicts and consensuality appeared to occur, and could be regarded as such on some analytic levels. The notion of familial groupings was rejected as not primarily applicable to the research question or the supplementary questions.

3.3.3. Considering data gathering

In case study research, six sources of evidence can be utilised. These are (Yin, 2009: 102) documentation, archival records, interviews, direct observation, participant observation, and physical artifacts. Physical artefacts are particularly useful in ethnomethodology, as they can often express cultural beliefs and understandings. However, in the framework of this particular study, they were thought to be, if not irrelevant, perhaps too demanding on participants. In the Pilot Study, for reasons which will be explained in 3.5 there

was some use of artefacts, in this case photographs taken by the participant. Some use of photographs taken by students was considered in the initial stages of planning the fieldwork. Where communication skills may be limited in autism, photographs taken by participants may give insight into their social and emotional preferences, although the researcher must be aware that in attaching meaning to them, she may be introducing a further layer of interpretation.

It was also an intention of this study, as far as was possible, to offer the same data-presenting options to all participants, rather than placing one group or another as a special case. Although parents were interviewed more often than other participants, in order to provide access to the descriptions available in Case Histories (see Appendix 1), the format of interviews remained identical for all the participants in the study. This was to provide an holistic framework for the case itself.

Documentation and archival records are often useful in establishing agreements or challenges to what discourse may present. They are, however, more useful in longitudinal research and research into organisations, as they can be an accurate reminder of time frames, and dates. Some emails were received by this researcher from parent participants which may have been relevant in checking the veracity of their accounts. One contained extracts from developmental diaries kept by Health Visitors and parents. For the most part, however, this kind of material was felt to be less important to this case than it may be to others. This is because of its 'snapshot' approach to data-gathering.

Participant observations were considered too intrusive in the lives of these children, as they were likely to draw attention to them as a subject of research. This may have highlighted the difficulties theorised as characterising the autism spectrum. Also, participant observations were thought to be too highly dependent on social interaction, another issue to be considered in researching autism.

Ultimately, the main forms of evidence considered were observations, and interviews.

3.3.4. Approaching interviews.

Interviews are said to be the 'essential' factor in case study. Yin writes (2009:106), 'The interview will be guided conversation rather than structured queries'. Kvale (2007:1) reflects that view:

Conversation is a basic mode of human interaction.....The research interview is an inter-view where knowledge is constructed in the interaction between the interviewer and the interviewee

What is necessary for interviews to be successful, as all researchers note, is a position of active listening taken by the researcher. Active listening involves total engagement with the interviewee, in what is being said, how it is being said, and why it is being said. It also involves a keen observational skill in

noting paralinguistics because pauses and hesitations, fidgeting and eyebrow-raising can be subtle invitations for probes and prompts. It demands a very high degree of empathy on the part of the interviewer. This is particularly important in interviewing those on the autism spectrum. The interviewer's understanding and prior knowledge and experience of autism are crucial in conducting interviews with those whose communication skills may not be typical (Preece and Jordan , 2010).

It may appear, therefore, that the case study tradition of extensive prior knowledge is also valuable in the conducting of interviews, one of Yin's (2009) 'sources of evidence'. This may make case study an even closer fit to the needs of this specific research project. Kvale, who asserts 'interviewing as a craft' also writes (2007:49):

Substantial familiarity with the theme and context of an inquiry is a precondition for the expert interviewing... Good interview research goes beyond knowledge of formal rules and encompasses more than just mastering the technical skills of a craft, to also include personal judgement about which technical rules to invoke or not to invoke.

This is a particularly relevant observation, because the researcher has had over thirty years' craft knowledge in conducting interviews. It is, as Kvale notes, both a learned and practiced craft. The researcher has not only, as an ethical journalist, conducted face-to-face and telephone interviews for print outlets, but has also extensive experience as a television and radio

interviewer. Having held television and radio counselling posts for many years and in conducting nightly radio 'problem phone-ins', the researcher has learned to know when to ask questions, and where to allow for and listen to pauses and silence. There are times when what may be regarded as 'leading questions' are asked as prompts. As Kvale claims (2007:88):

..leading questions need not reduce the reliability of interviews, but may enhance it; rather than being used too much, deliberately leading questions are today probably applied too little in qualitative research interviews.

Further, there are times when researchers conducting interviews must deviate from their path in order to accommodate the diversions demanded by interviewees. These include, in the case of autism, 'zoning out' (disengaging attention) during the interview, slipping from the question posed, and covering this by returning to a monologue on their special interest. There can also be intense and apparently irrelevant questioning of the researcher by those on the autism spectrum, a phenomenon which may be mistakenly resisted, as it might appear to contaminate the data because it intrudes into the bracketing position usually adopted in interpretive methodology. Rather than that, it contributes to the data. The position taken by the researcher is best conceptualised as facilitative, and as a conduit for authentic data generation.

Where interviewing is central to the study, it can create problems, and these should be addressed in the study design. One major problem with

interviewing is that it can create too many pages of transcript which could be overwhelming for the researcher to transcribe and store. But in addition to the practical problems, there is also the fact, rarely acknowledged, that if the load of information becomes too great some data may escape analysis for meaning, or may be too often reduced to paraphrase. In general, it must be the judgement of the researcher as to how much data to collect, based on the intent and purpose of the study. One purpose of this study was to allow readers to adopt a listening stance to those whose voices are rarely heard. Therefore, the inclusion of lengthy quotations, where apposite, was necessary.

This research study involves a small sample size. It is exploratory of a tightly-bound and clearly defined case. It is concerned with issues of some considerable complexity: autism, and the meaning of 'inclusive educational framework'. It is concerned with beliefs and understandings, rather than behaviours. It is a snapshot of those beliefs, rather than a longitudinal examination of how these may change over time. Therefore, in-depth interviewing is suitable as the central method of data-collection. This is likely to produce verbal material which can be closely interrogated by a variety of means, to reveal the complexities which may present in considering and responding to the research question. It can also give 'voice' to each participant, reflecting the heterogeneity and individuality anticipated. The question must be explored in depth rather than pursued at length. This is the researcher's judgement, informed by prior knowledge and extensive prior experience in this field.

3.4 Method

The methods employed in this study will now be discussed. Although methodological literature provides exceptional guidance as to what can or should be done within research studies, it rarely takes account of what it claims to draw attention to: the existence of deviance from the socially expected, and what we can learn from it. Autism tends to confound typical expectations. This researcher would not be so bold as to claim that this study is a 'critical case' in challenging normative methodological assumptions. However, there are elements of the study which lie somewhere outside the valuable guidance which is usually accorded to research students by conventional methodological literature. This is inevitable. Methodological guidance must deal with average scenarios, and illustrative vignettes. Beyond that point, decisions must be taken by researchers on a subjective and reflexive level, informed by practical considerations. This presented method, within a Case Study approach, is necessarily a personal response to field work considerations.

3.4.1 Sampling

Sample size is generally crucial to the reliability of a study, and certainly in quantitative analysis, 30 is generally held to be the smallest sample to generate reliable data (Cohen, Manion and Morrison, 2007:101). However the sample in this study, as was realised at proposal stage, was likely to be extremely small. In autism research in general, sample sizes are particularly small, even in those studies which have access to clinical populations. The

question of sample size has been discussed in some depth in this thesis. This section summarises some of those concerns.

One of the leading problems is the relatively low incidence in the population as a whole of those who may be on the autism spectrum, a figure thought to lie between 1:64 and 1:160. Another question to be considered is whether the participants in this study should have a clear diagnosis, which may be difficult to obtain. In the case of Asperger's Syndrome, a diagnosis may not be made before the child reaches secondary school, or even later (Batten et al, 2006). However, it was decided that the trustworthiness of this study would be seriously compromised without an insistence that every student in the study must have a formal diagnosis. This therefore limited the available population even further, generally to students above the age of 11, as in Asperger's Syndrome, in particular, diagnosis at primary school stage is rare.

A further limit was imposed by the fact that the study proposed to examine the beliefs and understandings of students only in an 'inclusive' educational framework. That exclusion criterion meant that those on the autism spectrum who were no longer in full-time education could not be used as primary informants. They would be likely to report only retrospectively, which might bias findings. It also meant that those who had been home-schooled probably fell outside the available sample.

Another consideration in regard to the possible population size for sampling, was that this was a study to be undertaken by a single researcher working

within the constraints of a PhD thesis. Moreover, the researcher was limited in terms of geographical area. She is epileptic, and therefore does not drive a car. The population size was therefore, through the researcher's disability, further restricted to an area reachable by public transport. As it was intended to make several visits for face-to-face interviews, it was considered to be difficult to designate an area from which to sample which would be outside the scope of daily travel.

Therefore, ultimately, the parameters of the sample available were restricted to those with a formal diagnosis of an autism spectrum condition, in full-time education. Restrictions applied therefore to:

- Autism spectrum
- Formal diagnosis
- Within a current educational framework
- Within a geographical area reachable by public transport in a single day

Cohen, Manion and Morrison (2007: 100) point to 'access' to the sample being an important consideration, but, as do other methodological authors, they rarely consider that this may be the most crucial consideration of all. Access involves not only selecting, but also selecting within the pragmatics imposed. In fact, in the case of this study, pragmatics dominated.

The process of recruitment, because of above inclusion/exclusion criteria, became paramount. It tended to overwhelm any proposal-level fieldwork plans

which had to be revised on several levels. This will be explored in the next section.

3.4.2 Recruitment

The initial decisions taken on the overall research design were modified several times in the course of this study as it progressed and as events and environments impacted upon what was originally envisaged. The strength of an interpretive paradigm is that it does offer this flexibility to adjust and re-determine some of the assumptions and beliefs held, and to accommodate unexpected set-backs, and reflexive working within the parameters of the chosen design.

The researcher approached, within the first month of the study, October 2006, three different official and voluntary bodies which may know of children on the autism spectrum within an inclusive system, which would not necessarily mean a mainstream school. The aim was to attract participants who would have a range of differences in experiences, backgrounds and gender, and possibly ethnicity. The participants, moreover, should be accessible by public transport.

The official body was the Outreach service of a Midlands city autism service in which the study was based. The second was a not-for-profit consultancy agency which had recently been set up in the same city, which specialised in interventions for children with autism. The third was the National Autistic

Society. All organisations were supplied with full details of the research envisaged.

Problems arose with the city Outreach service which determined that the Data Protection Act would not allow them to help in any way, and suggested the researcher approach individual schools. The National Autistic Society responded by email that requests for participants in research were overwhelming, and that the request may be placed on their website, but may not, and that no correspondence could be entered into with them. The researcher was to watch the website to check whether or not it appeared. It was not selected.

The researcher then approached two local support groups, and was invited to speak at one group meeting, in May 2007. Printed details about the proposed research were handed out. The other group invited the researcher to publish details in their next newsletter. Concurrently with this, towards the end of the first year of study, the consultancy found three parent participants with whom the researcher entered into lengthy negotiations as to who should be the focus of the pilot study.

All three families, after several months, withdrew from the study. In all cases the parent had become disillusioned by the school their child attended. Exclusions had been used, and parents were intending to proceed to litigation, and were concerned that the participation of their child in the study may be viewed as aggressive on their part. It is important to bear in mind

these outlying and accidentally-produced data, as they may be said to demonstrate to some extent the fragility of some of the home/school relationships of some of this population of children and their parents and schools. This finding is borne out by the Education and Skills Committee report (HOC Education and Skills, 2006), the NAS report (Batten et al, 2006), and the Northamptonshire report (Whitaker 2007). Shortly following, a parent who had seen the appeal for volunteers in the newsletter, contacted the researcher, in October 2007. This allowed the pilot study to proceed.

The researcher then contacted the Disability Service of the University in November 2007 to ask for assistance in providing participants for the study. The head of the service refused, with a strongly-held ethical stance that, 'These students have been put under the bell-jar all their lives and have enough just getting by from day to day, without being the focus of someone's research project.'

This unexpected response was valuable in making the researcher question the ethics or morality of the study. The point of view is entirely valid. It could be linked to an important point made by Robson (1993: 30) when discussing the morality or ethics of a scientist sewing up the eyelids of a kitten:

Views about the morality or otherwise of this work depend crucially, of course, on what constitute 'accepted' notions of right and wrong. One position would be that it is simply and absolutely wrong to do this to an animal. An opposing view would seek to balance the costs (to the

animal, and possibly to the researcher through adverse publicity) and the benefits (to science, with possible medical or other 'spin-offs')

It was not possible to argue cogently against the view of the head of the Disability service. Although the Robson argument is presented in deliberately stark and affective terms, it contains a consideration which had to be taken into account: that of the participant in a research project who is being overwhelmed by research demands, to, perhaps, the detriment of living a life.

Where the NAS felt itself 'overwhelmed' by requests for research volunteers, partially perhaps because of the small sample size available to researchers, this, the researcher realised, must additionally impact on the lives of those studied. This was of prime importance, whatever the need of research into this topic. This created an impetus in the researcher to reduce the interview demands on the participants. The original research plan was therefore considerably modified.

In proposal stage, it had been decided to interview each student three times, over the course of a year, and to observe the student in three settings: home, school, and a social event, three times during the course of that year. It also became clear that the original plan would have been too stressful for the student participants. Several of the parents who withdrew early in the process expressed some concern about the commitment that would have been necessary. A decision was made, in view of the recruitment and intrusion elements which had become evident, to limit the demands on participants.

Students would be interviewed once. It was hoped that this limitation would aid recruitment, without weakening, too greatly, the production of data.

As the questions to be asked in the interview had no temporal frame or longitudinal implications, a single interview for each student participant and teacher participant would, it was decided, produce sufficient data to explore the answers to these questions, provided that parent interviews were extended to at least two. This was to be trialled at Pilot Study stage

An assistant in the University Disability service then expressed an interest in the researcher's research topic, having worked extensively with students on the autism spectrum as an outreach worker for the county autism service. Further discussion on the aims and reduced demands of the project led her to telephone the parents of two possible participants. She also gave the researcher, with the parents' permission, their email address and telephone number. One of these mothers was the parent of 13 children, in her two marriages, eight of whom had been diagnosed with autism spectrum or related conditions.

Finally a fifth participant was located through a Google search of 'autism' and the city in which the research study took place. This search led to a message board on which a mother had posted for advice on obtaining a statement of special educational needs for her son who had been diagnosed with Asperger's Syndrome. The researcher contacted her, told her that she was unable to give advice but invited her to participate in the research. This, in all,

produced the five participating families, 14 individuals, listed below, one of which was to act as the pilot study.

These participants were an opportunity sample. Nevertheless they present with a range of age, educational provision, ethnicity and gender. They also show a range of socio-economic status (see Appendix 1 for Case History vignettes.)

There are two girls and two boys, and ages range from 11 up to 22. While it could be said to be a weakness of the study, the fact that two of the participants were siblings was informative. This is because there were a further eleven siblings in the family, eight of whom had been diagnosed with either an autism spectrum condition or a condition known to be strongly associated with autism: dyslexia and dyspraxia in particular.

Because two siblings from the same family took part in the study, the parents were represented by only three participants. Again, this could be seen as a limitation of the study, but the experience offered by this parent, Maggie, in rearing 13 children, nine of whom were diagnosed with an autism or autism-related condition was valuable as it may have given her different insights and beliefs from the other parents.

Fig 3.4.2a Student Participants

NAMES	Evie	Kieron	Harry	Lisa	Adam (pilot study)
Age	22	18	11	15	8
Siblings	1 younger brother (birth brother adopted into same family)	5 brothers, 7 sisters: brother to Lisa	2 younger sisters	6 brothers, 6 sisters: sister to Kieron	Ben, classic autism, 12
Diagnosis	Asperger's Syndrome	Asperger's Syndrome	Asperger's Syndrome	Autism spectrum	Autism
Age of Diagnosis	17	8	10	10	4
Parent	2 adoptive parents	Twice-divorced mother	Divorced mother, now remarried,	Twice-divorced mother	Mother and father living together
Additional Diagnosis/needs?	Previously diagnosed AD/HD	None	Previously diagnosed AD/HD inattentive	Gifted and Talented	Limited expressive language
School/college	City College of Further Education, studying BTech	City 6th form College, studying ICT AS Level	County High (10-14) school, previously City Secondary (11-16)	City Secondary, studying 11 GCSEs	County Primary school
Location	County location, large modern private estate	Inner city social housing	Outer city social housing now privately owned	Inner city social housing	County location, affluent suburbs
Ethnicity	White British	Mixed race: White British/Eurasian	White British	Mixed race: White British/Eurasian	White British

Fig 3.4.2b Parents

PARENT NAME	Frank and Gill	Irene	Maggie
Parent to	Evie	Harry	Kieron and Lisa
Age range	55+	35+	45+
Number of children	2 adopted	3	13 from 2 marriages
Marital status	Married	2nd marriage	Divorced twice, now single
Work	Frank - Retired Works Manager	Former nurse, now clerical worker	Parent

Fig 3.4.2c Teachers

TEACHER	ET	HT	KT	LT
Student	Evie	Harry	Kieron	Lisa
Age group	55+	30+	35+	35+
Status	Lecturer	Teacher	Teacher	Teaching Assistant
Subject speciality	Chemistry	Technical Design	ICT	Art
Education setting	College of Further Education	High School (10-14)	Sixth Form College	Secondary (11-16)
Qualified	BSc	BA (Ed)	BA (Ed)	
Teaching years	30+	2	11	10

As this study deals with vulnerable participants, ethical considerations are particularly important. A discussion of these follows.

3.4.3 Ethical considerations

An ethical approach is a crucial part of research procedures (Vallance, 2005). There are two inter-related ethical considerations. The first is the general codes of practice as recommended by, for example, the British Psychological Society. The other is the important issue of field relations, as these can impact very strongly on decision-making.

An example of this has been cited in the previous section. The researcher should at all times be mindful of the design of the study, and attempt to limit any possible negative effects the study might have on the participants. This may, as it did in this particular case, involve changing the design. Kvale (2007) claims that ethics should permeate all research. He writes (2007:24):

Ethical issues go through the entire process of an interview investigation and potential ethical concerns should be taken into consideration from the very start of an investigation and up to the final report.

The following categories of basic ethical consideration have been highlighted as being of prime importance in this study:

Informed consent. This issue can be divided into two separate categories, that of information, and that of consent which relies on this information. In this

study, all participants were informed of the nature and scope of the study in an initial written document.

The subject matter, time scale, demands on participants, together with the aims and purposes of the study were given freely, in advance, with no withholding of information. After this, the information was followed up by telephone calls, if the participants wished to reveal their telephone numbers, and/or emails, if the participants wished to ask for further clarification.

Following this, those who wished to give their consent were asked to sign a document agreeing to take part in the research, and a further document, to be sent to the headteacher of the child's school, asking if the school was willing to take part in the research.

Children on the autism spectrum are considered 'vulnerable' on the issue of informed consent (King, 2000; Kuther, 2004). Although none of the children whose parents agreed to take part in this study were diagnosed with intellectual impairment or a co-existing mental health problem (Olivier and Williams, 2005; Truman 2003), that fact was determined from the beginning. The issue of vulnerability for those on the autism spectrum without additional mental health difficulties involves a cognitive question of whether there will be full understanding of a complex set of procedures. This depends on the information processing abilities of the child.

Therefore, the design of the study took account of this, by keeping the informational demands on the child, as simple as possible: 'I want to talk to you about what you know about autism spectrum conditions, and I would like

to record that, if you give permission for me to do that.' This question was posed at the start of the arranged interviews, also.

Withdrawal All families were fully aware that they could withdraw at any time. Three families withdrew after initial consent but before the interview/observation had begun. This matter was discussed in the recruitment section of the research design details.

Confidentiality All participants were made aware that the information gathered was for research purposes only, and that nothing would be shared, without their permission. This ethical issue is also a legal matter, reflected in the Data Protection Act. Steps were taken to protect the participants by changing their names where they are referred to in this study (Walford, 2005). The names chosen have merely been selected alphabetically.

Interviews were usually conducted in the child's own home, where others were present, although usually out of earshot. Two of the participants were siblings who may have wished to share information with each other. Most of the child participants may have wished to share information with their parent, and in one case the parent was present during the interview as the child was particularly young (eight years old) and had marked communication difficulties.

Observations Observational research also requires consent, unless those observed are in environments where they would expect to be observed by strangers. As a summary of the entire study and its requirements were given to participants before they gave consent, and as parents cooperated and helped coordinate the observational visits to schools, there was little risk to the participants under observation ie the students.

However, in order to minimise any embarrassment to the students, schools were asked to treat the researcher as a general classroom observer, something quite familiar to most students, rather than someone watching a particular student. Additionally students were free to choose which session they wished the researcher to observe, so that they were able to select one in which they felt most comfortable. The researcher offered to have an enhanced criminal background check, but as at no time was she alone with a child in school, this was felt to be unnecessary by the school or college gatekeepers

Debriefing Each parent received a final telephone call from the researcher, to offer thanks, and to offer any help and advice they may wish to ask for in the future. Those who wanted to be advised of the findings of the research were assured that this would be done. Three parents (Carrie, Irene and Maggie), and two of the students (Lisa and Kieron) expressed a wish to review the thesis, and were sent a copy of the completed thesis.

Additionally, all parents were offered two free tickets to attend an International Conference on Autism organised by the researcher and featuring some of the world experts on Autism Spectrum Conditions. This was offered not only to

reward their participation in the research, but also to extend and disseminate the nature of research itself. Two parents (Irene and Maggie) and one student (Kieron) attended the conference on June 16th, 2010.

Frankfort-Nachmias and Nachmias (1992) cite 'cost/benefits ratio' as being an important consideration in social research. Cohen, Manion and Morrison (2007) say that it is insufficient to do no harm, what is important to consider is whether it is possible to do some good.

3.4.4 Field relations

But an important consideration of an ethical process is the one of relationships, and how these are created and maintained. The establishment of mutual trust is at the heart of ethics. This is often under the management of the researcher. In this particular study three different types of relationship were fostered: that with the parent, that with the student, and that with the teacher, each requiring a slightly different set of skills on the part of the researcher.

First, the researcher had to take into account that the participants were the 'experts'. They were regarded as informants as they were in possession of the information the researcher was trying to access (Cooper, 1993). It was important that to none of these three groups the researcher adopted an assumption of superiority nor was regarded as in any way superior by the stakeholders. There were certain strategies which the researcher adopted to try to achieve the required balance.

To the teachers, the researcher presented herself as an elderly former colleague, who was not challenging any of the beliefs they held. Instead she was trying to find out what knowledge they had acquired about the nature of autism spectrum conditions, and, most importantly, how they saw them impact on classroom behaviour and interactions. In this interaction it was necessary to appeal to their 'craft knowledge' (Cooper and McIntyre, 1996).

With the students it was necessary for the researcher to ask about their particular beliefs about autism. This requirement was in itself a request for expert knowledge. Apart from one exception the students were interviewed in their own homes. This negated the possibility that they may see the researcher as an authority figure aligned to a different culture or power base.

In the excepted case, the participant, a 22-year-old student, invited the researcher to interview her at the college she attended. She had, prior to this met the researcher in her own home, although she was not interviewed there. At college, where she chose to be interviewed, she used the researcher's presence and her own organisational skills in arranging that, and in obtaining the necessary permissions. It appeared to the researcher to be celebratory of her position as an object of special interest..

The children and the teachers were interviewed once only. In ethnographic research projects, the researchers' position, and their experience in managing and maintaining a relationship which is lengthy and constructed over time,

and in which the participants may feel that they are under scrutiny, field relations can be more challenging (Hammersley and Atkinson, 1995). The less intrusive encounters which were eventually built into this research design aimed to avoid the 'bell-jar' experience referred to in **3.4.2**). The teacher interviews were arranged in conjunction with the student observation, and were therefore conducted at the end of the school/college day, or before lunch-time.

The most carefully nurtured relationships within this study were those between researcher and parents, since much of the organisation of the study was worked through them, and their willingness to share their knowledge. There was a much heavier demand on the parents. They were interviewed at least twice each, once or twice to obtain a case history of their child, and once to tape-record their interview material. To each was given the opportunity to select the location for the first case-history meeting(s).

The decision to allow the parent to dictate the location was in order to reduce the possibility that they may feel intimidated or alienated, and was a signal that the researcher was under their own control. The parents were also contacted frequently by email and by telephone to offer information about arrangements made for visits. Their permissions and advice were sought on whether they wished the researcher to contact the schools or whether they themselves felt happy in doing this.

All interviews were successful on a relational basis because of the initial care which was taken to establish their ownership of their part in the project. Issues of field relations and ethical behaviour as outlined were central to the study and can be said to enhance trustworthiness (Rallis et al, 2007). Ownership, accommodation and recognition are important facets of the research question, and of the theoretical basis of the study. Therefore, these aspects were built into the research design, particularly of the data collection which is outlined in the next section.

3.4.5 Data Collection

All necessary outlines of the project, and permission forms were sent and returned. The first stage of the data collection was then begun. This was a 'history-taking' session with the parent or parents, in which they outlined their experiences in dealing with their child's autism. This was the first meeting with the parent and served as an important introductory session.

The choice of location for the interview was given to the parent. Two parents chose to be interviewed in their own homes. Two chose to be interviewed elsewhere. Maggie chose to be interviewed in a coffee shop as she felt one of her sons, who was at home, might intrude and dominate the discussion if she remained at home. Another, Irene, was a City councillor and chose to be interviewed in the privacy of her Council office. The Case Histories involved, in two cases, that of Maggie and Irene, two interviews, as the one-hour allotted time-frame was insufficient to record the information they offered in the first interview.

The case history-taking was conducted as informant interview rather than respondent interview (Powney and Watts, 1987) as 'guided conversation' (Yin, 1994:106). The single question asked was, 'Tell me about your child's experiences with autism'. At all stages of this research study control was largely guided rather than imposed. It was important that participants felt able to share their narratives, directed in their own way to a large extent although probes and prompts were used. This method was important for establishing rapport and gaining the trust of parents (Fontana and Frey, 2000) who, it was theorised, may have faced problems in the past in negotiating the challenges of their child's autism.

At this meeting, full field notes were taken, with observations. The field notes were then re-read, often on the train or bus journey back home, and added to while the interview was freshly remembered. Important passages were underlined. These notes were to form the 'Case Histories' (see Appendix 1)

The second stage of data collection was conducted with the parent(s), in the same location but several weeks later. The interview format, as trialled in the Pilot Study, was a tape-recorded interview. Parents had been asked in advance if they would agree to being tape recorded. It was also explained to them, before the interview, that whereas the first interview had been about their experiences, and those of their child, this one would be a more general interview about the nature of autism itself.

Again, this was an informant interview. Whereas the first had been totally open, this one sought answers to four interview questions in a semi-structured manner. These were:

1. What is autism?
2. How did you learn about it?
3. What problems might it create?
4. Is autism a disability?

The four questions were not always framed in this manner. Nor were they asked in this order, apart from the first question, which remained the first question. In all cases, however, the answers to these questions were sought. Sometimes they did not need to be asked, as they were naturally supplied. In early interviews there was also a final list supplied of words associated with autism, and participants were asked if they recognised them (See Appendix 3). This list was in later interviews abandoned as some interviewees appeared to regard it as a test, or a quiz, and somewhat intimidating

The interviews had no fixed time limit. Again, this was largely determined by the participants. The experienced interviewer/researcher had to use craft judgement to determine when the interview was felt to have finished. There was considerable variation in this. There was a lengthy pause before the researcher believed, and announced with thanks that the interview had finished. Only in one case, that of Frank and Gill, was important information

given after this paralinguistic expression of closure had been offered by the researcher.

This phenomenon, which the researcher, during her long radio interviewing experience, called 'The hand on the doorknob moment' should always be accounted for. Sometimes, when apparently leaving the room, or the radio space, the participant chooses to disclose something very significant. In the case of Frank and Gill, what was said at that point was crucial to generating data.

Notes were also taken during the tape-recorded interview, and immediately following if necessary, to reflect additional paralinguistic information and other observational detail. The use of a notebook, and note-taking itself is helpful when interviewing those on the autism spectrum, even while tape-recording, as it offers a researcher's shift in eye-gaze, and an opportunity for those on the autism spectrum to gather their thoughts without having to think about eye-contact. Fully worked-up examples of transcripts of the tape-recordings can be found in Appendix 4.

The next stage of data gathering was interviews with the student participants, again allowing for a gap of at least two weeks after the interview with the parent. This allowed the researcher time to examine in some detail, the data generated by the parent(s) in each of their interviews. It also allowed space for the researcher to examine her own interview practice and to consider ways

of adapting and improving it. The tape-recorded interviewing conformed to the pattern and procedures of the parent tape-recorded interviews.

Students were interviewed in their own homes with the exception of Evie (see **3.4.3**). The reasons for this were threefold. First, the researcher had built some rapport with the parent, therefore the student would be more likely to accept this intrusion into their lives and would be more likely to accept this change to their routines. Those on the autism spectrum are theorised to have difficulties with changes, transitions, innovations, and strangers. Maintaining one possible constant, that of the familiar home environment, was less likely to cause disruption.

Next, it was important, for the purposes of this study, for the researcher not to be identified as part of a separate 'system', that of school, with the possible hegemonies or power structures involved in that system. This imperative is central to this study. Never before has educational research into autism and its possible challenges to an educational system, been conducted outside school premises.

It was crucial for the researcher to observe, informally, the student within the home context. Educational research in general may be said to suffer from this occasional oversight in not viewing the student holistically, regarding him or her only in a context in which they may have problems, rather than also one in which their personhood is more comfortably established, recognised, and perhaps, even, accommodated. Observations in the home context appear,

where appropriate, in the vignettes provided in Appendix 1. The biopsychosocial theoretical framework of this study is important in establishing contextual limitations or liberations.

The final stage of data collection was one which combined two forms of data collection on a single occasion. This was a school-based observation of the student in a class taught by the teacher or teaching assistant that the student had themselves selected to be the teacher informant. Again, control was given to the research participants, so as to establish trust. The lesson was one which took place prior to lunch time or at the end of the day. This enabled the researcher to interview the teacher immediately after the lesson. Again, necessary permissions were sought from gatekeepers, and from the teachers themselves, who had also been in prior discussions with either the parent, the student, or the researcher, or all three, as to what the research entailed.

The observation of the students in this lesson also enabled authenticity of the teacher interview, as they had been aware that the researcher had watched the lesson itself, as well as the student. Observation was done in the least intrusive manner. The researcher sat in the back of the classroom, taking notes, but not obviously observing that particular student. The observations were informal, and were not dictated by pre-determined codings. It was anticipated that they would be written-up in narrative form, following the field notes taken at the time. Adam's observation is included in the write-up of the Pilot study, and those for Evie, Lisa, Harry and Kieron can be found in Appendix 2.

Following the observation the tape-recorded interviews with the teachers took place. These followed the exact format and ethical procedures of the tape-recorded interviews with parents and students to establish conformity and reliability.

The questions allowed for flexibility, with the researcher following the lead of the participant and asking any number of further questions, or giving prompts or probes, or following the direction taken by the interviewee. It was noted that some of the students, in particular Evie and Harry, were overwhelmed for a few minutes by the openness of the first question a fact which had not been anticipated, but should have been.

The four questions were asked of all participants, so as to establish common ground between the three groups. This provides cohesion and coherence as a baseline for the data analysis in a certain commonality of focus. This, it was anticipated, would nevertheless lead to variances of prioritising. Where heterogeneity of various kinds can provide apparent methodological challenges, it is important to incorporate and embrace those differences, and to see them not as challenges, but as usefully generated data. The openness of the questions also allowed the participants to lead the conversation into directions they felt were important.

The one participant who was not interviewed in the format above was Adam, the eight-year-old. He is the subject of the Pilot Study. Although verbal to a

large extent, it was felt that the questions would be too difficult for him to answer, and therefore an innovative method of interviewing him, and possibly others in the study who might find direct questioning and answering difficult, using forms of analogy, was employed. The alternative devised, and its strengths and weaknesses, is described in full in the Pilot Study section.

Tape recordings, on the day they were made, but after initial checks against the notes taken, were dispatched to a professional transcriber with a familial, and personal experience of ASCs, as soon as they were available. Her familiarity with autism and her diagnosis on the autism spectrum, were essential in ensuring accuracy of the transcripts. Tapes and completed transcripts were returned immediately to the researcher and deleted from the computer files of the transcriber to ensure confidentiality. This transcriber, a partner in a voluntary organisation founded by the researcher in 2005, also contributed to peer checking of the ensuing analysis. She has a post-graduate qualification in ASCs from the University of Birmingham.

No part of any interview was summarised. All transcription was verbatim. Most included, where relevant and in line with the brief given to the transcriber, pauses, changes in voice pitch or pace, although this was confirmed by the researcher listening to the tape recording several times again and adding relevant sounds and pauses if necessary.

3.4.6 Data Analysis

Tesch (1990) makes an important distinction in separating data organisation from data interpretation as two different, if synchronous activities. The process of organisation and analysis (interpretation) and the essential process of long, daily immersion in the data began before all transcripts were available, and themes could be seen to develop, and could be sought across future transcripts and recordings. It should be noted that the researcher is of the opinion that the Case History data provide important descriptive and additional evidence, although they are presented in Appendix form only as narratives.

The reason they occupy that space is that they may not appear to conform to the strict demands of this study, in which beliefs and understandings about autism itself were central to the thesis, and Case History vignettes may be disregarded in importance because of this. However, they contain, in some cases, particularly that of Irene and Maggie, further levels of understanding, in offering to the reader directions to an holistic and individually characterised account of autism in a familial context. They are crucial to any account of reliability of this study. Issues of wordage management have limited their resonance, also, as they have been edited to accommodate the word limitations of this thesis.

The researcher had considered the use of a data management tool like NVivo, but had rejected it as lengthy and time-consuming, and the effort to understand the unfamiliar software itself may have detracted from the analytic process. After extended exploration of the NVivo program, although its

advantages were clear, particularly in managing a variety of data in different media formats, and enabling multiple coding, it appeared less efficient in accommodating this researcher's inclination towards textual analysis by holistic presentation. There is sometimes a danger in cutting and storing the text in fragments under coding elements which remove the utterance from its context, thereby limiting meaningful interpretation. Further, the researcher wished to retain the individuality of each participant's contribution and aimed to allow the characterisation of these individuals through enabling their identifiable 'voice' to be heard through a careful reading of the selected displayed text.

Retaining the transcripts holistically was particularly advantageous in this case as there were supplementary salient and unexpected issues which the researcher wished to explore. These were not thematic alone, in answering the research questions, but were concerned with each individual's overall view of autism as deficit, difference or strength. Certain communicative strategies were noted, and mediating or moderating factors thought to be important were often articulated (see **Fig 4.3.1**). These strategies offered general insight into efforts to express the complexities of the subject matter. Coding this would have demanded a further coding programme, running alongside that which was searching for themes reflective of the research questions.

in general, this researcher's view accorded with that of Creswell (2007: 165), 'A computer program may, to some individuals, put a machine between the

researcher and the actual data. This causes an uncomfortable distance between the researcher and his or her own data.' This researcher preferred to remain immersed in the full data, throughout the analysis process, for the reasons stated above. The data were analysed manually.

Organisation and interpretation were conducted in the stages outlined below, but it should be noted that as analysis continued the stages became more synchronous as a familiarity with the themes of previous transcripts developed. The process is in line with that proposed by Miles and Huberman (1994:10-11) of data reduction, data display, and conclusion-drawing in an iterative fashion. Examples of these stages are provided in Appendix 4 (Transcripts) and 5 (Quotes and Notes)

It was decided that the data be organised using a loosely 'grounded' approach. This took as its starting point the four supplementary questions, seeking to identify themes emerging from the data in relation to these questions. The organisation should, however, take note of the possibility of multiple codings. The questions were:

1. Do professionals and parents, and children on the autism spectrum regard autism as a deficit, or a difference, and is there any recognition of the skills and strengths and advantages of this condition?'

2. Do teachers, parents and the children themselves identify the sensory and perceptual differences which are theorised to be essential features of autistic intelligence?’

3. To what extent is there consensus among teachers, parents, autistics and researchers as to desirable outcomes in intervention strategies for autism spectrum conditions, and the means appropriate to achieve them? Where there is conflict, what is its nature?

4. How might the relationships between students on the autism spectrum and typically-developing students, and others, be characterised?

The highlighting facility of Microsoft Word was used to colour-code sections of each transcript, with four different colours relating to the four questions. Using colour-coding in this way retained the gestalt of the transcript while enabling a coloured ‘map’ to emerge. Where a section of text was thought to apply to more than one question, that was noted, using the ‘Comments’ facility of the Reviewing tool. Also, the Comments facility acted as a memo to identify emergent themes. As themes emerged through these memos, previously worked transcripts were re-examined for evidence of identified themes. At times, these memos were used as a means of reflection on issues which needed to be commented on in the report (See Appendix 4)

The sections of transcript relating to each question were then copied into further files named ‘Quotes and Notes’ for each question. They were further

subdivided at this stage according to stakeholder group: Parent, Student, and Teacher, and these, in turn, subdivided as to participant name. The Comments were included in this copying process. The process allowed at this stage for those sections which were multiple in coding to be multiply recorded. (See Appendix 5)

The Comments sections were then further re-examined on the basis of emergent themes, patterned regularities, both generally and between and within stakeholder groups. At this stage some variance in themes was evident. Although some themes were held in common by two or all three groups, some appeared to be specifically held by one group rather than another. The themes were 'difference', bullying, handwriting, 'zoning out', and special interests which were a particular feature of student accounts, and often included in parental accounts. Teacher themes were labelling and 'no two are alike'. Parent themes, while including some of those already identified were, additionally, perceived failings in communications by official bodies, and exclusionary practices and behaviours.

This then was the analysis process. However, it is now important to look at the Pilot Study to determine whether it was likely from its outcomes that the data collection methods and the research design methods outlined in the previous sections required adaptation prior to conducting the Main Study.

3.5 Pilot Study

Yin (2009) asserts that a Pilot Study is not a pre-test. He makes a clear distinction, claiming that a pre-test remains faithful to the data collection plan determined by the Pilot, of which he says (Yin, 2009:92):

The pilot case is more formative, assisting you to develop relevant lines of questions – possibly even providing some conceptual clarification for the research design as well.

More importantly, for this study, he suggests that there can be a number of reasons why a particular case be used as a pilot: geographical location, a plethora of documentation, or particularly co-operative participants. However, he also highlights an issue which has considerable relevance, here (Yin, 2009:92)

One other possibility is that the pilot case represents a most complicated case, compared to the likely real cases, so that nearly all relevant data collection issues will be encountered in the pilot case.

This clearly captures the nature of this pilot case. It was potentially the most complex the researcher felt she might encounter. In fact, it was that very complexity that she wished to address in order to explore the data collection methods proposed. The key issue was that the student participant, Adam, in this study, was at the age of 7/8 during the investigation, very young. He was also quite seriously limited in expressive language.

The issue of interviewing children on the autism spectrum, in order to discover what they believe and understand, has never been addressed in the literature. There are, as yet, no research guidelines as to how this type of information which accesses self-knowledge, might be elicited from those with this particular social-communication problem. The majority of research into this condition uses parent-report rather than self-report. The researcher chose this case as the pilot, as it was seriously challenging to her proposed data collection method.

The proposed four interview questions about autism, the researcher decided, were unlikely to be fully understood or responded to by Adam. Although an intelligent boy of 7, with a diagnosis of autism, his language skills, both pragmatic (Loukusa et al, 2007) and syntactical (Eigsti et al, 2007) may not have been expressively capable of answering the questions, nor of constructing a coherent oral narrative (Miniscalco et al, 2007). Language skills are differentially developed in autism (Rutter, 1979, Groen et al, 2008). Visual material is often preferred to linguistic content (Grandin, 2009), and picture-naming may be enhanced (Walenski et al, 2008),

Denzin and Lincoln (2008:5) in describing the characteristics of a qualitative researcher, write, 'If the researcher needs to invent, or piece together, new tools or techniques, he or she will do so'. This researcher therefore pieced together, for this difficult pilot study, a method of data collection specifically designed to facilitate communication of social and emotional issues. It was felt that should other students in the study be similarly challenged, or even non-

verbal, this method of data collection could be employed, if successful. The method was as follows.

In the first phase of data collection, Adam was given a disposable camera, and asked to take photographs of things he that liked. It was understood that his mother would have to take some control of this process in order to limit the perseverations which are a diagnostic feature of autism. The photographs would then form an initial basis for 'discussion' with Adam, as it was thought that his attachment to the objects and people photographed, would give insight into emotions, and social understanding.

The second phase of the data collection was arranged to take place during a meeting to look at the photographs that had been taken. In the voluntary organisation for autism which she established in 2005, the researcher had worked on using mechanistic analogy (Baron-Cohen et al, 2009; Glicksohn, 2001; Miguez and Garcia, 2006; McGregor et al, 1998; Swettenham et al, 1996; Kamhi et al, 1990; Nippold and Sullivan 1987) to stimulate social and emotional learning in children on the autism spectrum. It has been noted that these children often have a strong attachment to objects rather than the human face and figure (Hobson, 1988), and may find it easier to express social relations by humanising physical objects or stylised cartoon characters, and therefore placing the complexity of social detail at a slight distance. A liking for such play objects as Thomas The Tank Engine (Desha et al, 2003) and for Japanese Manga and Anime (Kan, 1996) is often noted in the literature.

Having spoken to his mother, the researcher was aware that Adam liked all forms of transport, and that this was one of his 'special interests'. She therefore bought a poster with pictures of railway engines, and hoped that Adam may be able to analogise from any people he had photographed, to these engines. That would perhaps enable some understanding of his emotional and social world, and would encourage forms of communication which could perhaps address some of the research questions, especially question 4. This type of interviewing of children has been described (Cohen, Manion and Morrison, 2007:375) as a 'projection technique'.

Data collection from parent and teacher would continue as planned, in order to test the capability of the projected interview questions to generate data. Observation of Adam in a school setting would proceed as intended. Case histories of Adam, and briefly of his brother, Ben, taken from the mother proceeded as planned, and the field notes from the initial meeting with their mother are written up in the Case History section of Appendix 1.

It was recognised that the data collection method from Adam would differ in his case, and would therefore not be directly comparable, and would be an indirect view. Therefore, it was decided that Adam's interview would be recounted separately as a narrative presentation of alternative data collection, a study within a study, but that where the indirect evidence was apposite in consideration of the research question analysis, it would be included as a comparative. This presentation follows.

3.5.1 Adam – data collection presentation

The interview progressed in four clear stages, marked initially by a certain reluctance on Adam's part. However, this reluctance, characterised by responses of 'I don't know' and monosyllabic answers. Most of the photographs were clearly classified in groups of three or four: there were four photographs of foodstuffs (yogurt, oranges, Heinz tomato sauce and bananas), four of transport (Jaguar, Ford Focus, Toyota, and a distant plane), three of bushes and trees (laburnum, unknown bush, silver birch), three of friends (Georgie (f), David and Marcus), one of the school swimming pool, and one of the remote control of his play station.

In the first stage the photographs were duly shared with the researcher, quite shyly at first but with more confidence eventually, with constant referral to the master sheet. One very evident behaviour at this stage was a strong emotional attachment to the photograph of Georgie.

The second stage was introduced by the presentation of the poster after Adam had been distracted by a plane in the sky. This stage was characterised initially by Adam's liking for the researcher's imitation of the sounds of different railway engines, to which he responded with sounds of his own.

He was asked to link each of the photographs he had taken of his friends to one or other of the railway engines. The engines were described by the researcher in human terms as 'wearing glasses' or 'smiling' for instance.

Adam proceeded to identify all three of the friends he had photographed according to the analogy, determined which train he 'is' and which his mother is, and spontaneously and surprisingly named a friend, Jules, who was not photographed, as being represented by one of the engines because he had 'sabre teeth'. Adam showed in this stage that he had understood the algorithm on which this conversation was based. He had become engaged.

The third stage of the exchange began accidentally, in the second phase, by the researcher looking for one of the photographs, the photograph of David, and being unable to find it had an imaginary conversation with 'David' in which she asked him to come out from where he was hiding. The imaginary conversation had amused Adam. A little later, both she and Adam were looking at a photograph of a Toyota which Adam had photographed with its bonnet up.

Unusually, Adam initiated, spontaneously, a new game, a fourth stage. The researcher had said that the car was asleep, and asked Adam how to make the car better. Suddenly he shouted, 'It woke up!' and looked at the researcher for response. This showed both his understanding of the 'game' of animating inanimate objects, an urge to take it to a new level and a flexibility of imagination which is unusual in autism spectrum conditions. It also shows a narrative drive, which again is unusual.

One of the most salient things revealed by Adam's interview, and which will be mostly used in the discussion of Question 4, was his certainty about his

circle of friends, and his apparent ability to note relationships. It was then important to discover whether this interpreted social and emotional capability was reflected in classroom observation.

3.5.2 Classroom observation

The classroom observation, for almost an hour, three weeks after the interview, appeared to confirm many of the interpretations the researcher had made about Adam's understandings and beliefs. The narrative description of this observation appears below.

Lesson: The Tudors. Costume colouring and cutting out.

Teacher: Seated at the front of the class. Students approached her when they had completed the task. A teaching assistant had been provided with worksheets and had made a visual timetable for him.

Other students: 30

Seating: He had been well-placed with his back to the window, in a front left corner, with the (full time) teaching assistant sitting slightly behind him so as not to intrude into his relationships with peers.

Field Notes

Adam is struggling with his task, although he does try to use scissors at one time. Most of the work appears to be done for him by his teaching assistant, although he is well engaged with the rest of the class, with his work-partner, and with the other children around him. He appears

well-liked and others seemed to enjoy interacting with him, including him in their quiet working conversations. He is however, noticeably more distractible than other children in the class, distracted by a flapping Exit sign over the outer door into the field, and by a motor mower which is mowing the field, and by a money spider which appeared on his desk. He asks the teaching assistant to translate 'spider' into French, using the French dictionary provided.

He appears very tired. His assistant asks him several times if he is tired. He presses his forehead often, flapping and clicking his fingers together, and nose-picking, all described in the literature as self-stimulatory behaviours ('stimming'). His assistant informs the researcher at the end of the lesson that he had taken part, that morning, in a class presentation to the school assembly on the Tudors. Late in the morning he had had a 'meltdown', sometimes described as a tantrum, in which he had thrown himself on the floor and sobbed and made some very loud noises and had to be removed from the classroom.

3.5.3 Pilot study data analysis: Findings related to research questions

Interviews with Adam's mother, and his teacher, enabled the following analysis.

Question 1

Do professionals and parents, and children on the autism spectrum regard autism as a deficit, or a difference, and is there any recognition of the skills and strengths and advantages of this condition?

It was often difficult to unpick whether participants were referring to autism in general, or to Adam's own differences, deficits, or strengths. The teacher appeared to talk about Adam himself, as she said that this was the first child with autism that she had taught. Both used the language of deficit, with Carrie tending to use such expressions as 'don't quite understand', 'difficulties', 'misunderstanding', while the teacher was more forthright in using terms such as, 'big problem', 'can't', 'obsession', 'his disability', 'would not be acceptable'.

Some skills and strengths were mentioned by both, with the teacher saying, 'intellectually I think he perhaps picks up on quite a lot of what we do', and 'I know he is quite good at Maths', 'he loves reading', and 'He is interested in words as well'. Carrie's assessments were generally explanatory using third person pronouns, 'they cope well with things that are unchanging such as numbers or words', but becomes experiential often, 'he is very bright in certain areas and is really a sponge full of knowledge'. Carrie's concern, however, appeared to be about a certain detachment, in autism, from what she names as 'every day', even when there are evident skills:

they can do this and they can do that, yes they do have fantastic skills ... but then to go on and use that information in an every day situation in a job, you have still got to understand other people and communicate and understand body language and fit in.

Both teacher and parent appear to hold the belief that social factors may be a major difficulty for those with autistic intelligence, and this will be analysed further in Question 4.

Question 2

To what extent do teachers, parents and the children themselves identify the sensory and perceptual differences which are theorised to be essential features of autistic intelligence?

Adam's teacher did not refer to any sensory differences directly, although she did emphasise the problems that Adam has with gross and fine motor coordination. On the other hand, Carrie's interview was replete with references to sensory differences and noted the individual pattern they may take in different individuals:

There are so many different things, seems to be each individual has their own set of idiosyncrasies. Seems to be a sensitivity to sounds and light is another thing. I know the sounds of fans and fridges affect a lot of autistic people, sounds we don't tend to pick up on those....mean we all know the fridge hums in the kitchen but we don't take any notice of it

whereas maybe an autistic person, that would be the first thing they would hear.

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This understanding appeared to be particularly strong, as she also mentioned the problems that some might encounter in a classroom, and ways to alleviate the problems: 'Not to have any strip lighting' and 'the windows need to be obscured because anything going on outside particularly on a windy day is a distraction'. Her description here aligned with classroom observation of Adam (3.5.2) in which distractibility was clearly evident.

Question 3

To what extent is there consensus and/or conflict among teachers, parents, and students as to desirable outcomes in intervention strategies for autism spectrum conditions and the means appropriate to achieve them? Where there is conflict, what is its nature?

Several interventions were named both by the teacher and by Carrie as being essential to Adam's educational well-being within the inclusive framework. Both mentioned the fact that Adam had an early Statement of Special Educational Needs. The teacher believed that it was the provision of the statement which was the enabling factor in his being included in mainstream school:

Adam came to this school from nursery with a statement for autism and even with that and full time help, he gets help 25 hours a week and we couldn't really cope without that.

T

It is uncertain whether by 'we' she refers to herself, or to the school in general. However, her reliance on the teaching assistant was evident from the lesson observed by the researcher in which the children were using pre-prepared outlines of Tudor dress, colouring them, cutting them out and 'dressing' a paper figure in them. Most of Adam's work was actually done by the teaching assistant, although he was seen to use scissors, and colouring pencils, during the lesson. There was also some appreciation shown by the teacher of the work of the Autism Outreach team:

Well we did have someone come from the Autism Outreach, Adam was in the school but wasn't in my class and this was a proper session on autism with the whole staff. So we had two sessions like that.

T

Adam's chair was next to a cupboard on top of which were teaching materials for him, including a visual timetable and examples of Social Stories that had been used with him. There was also a French dictionary which was consulted by the teaching assistant when Adam was distracted by a money spider. The interventions for Adam also included adaptations to enable him to cope more easily with the school's procedures:

So now we have said he can have his lunch first and then he has a longer time to go out to play. So he chooses two different children each day to go with him so he can have his packed lunch early coz normally they don't.

T

Although Carrie has expressed a belief that the school might be more successful if they dealt with his interests as a means to 'unlock his enthusiasm' that does not appear to have happened according to her account.

Question 4

How might the relationships between students on the autism spectrum and typically-developing students/others be characterised?

This was the question which generated the greatest amount of data in the Pilot study. It is a complex question which operates in two ways. Relationships are both active and passive. Therefore it was interesting to explore the views of the participants as to approaches that may be made by those not on the autism spectrum, as well as the beliefs regarding how those on the spectrum relate to others, and what may be expected from them.

This question is also, in this case, more heavily data-generating as it can utilise in some tenuous ways the data which emerged from Adam's interview

effectively. While that interview was not exploratory of beliefs about autism, it did provide certain indications about Adam's view of others, and his understandings of relationships in general. It is important, however, to understand that this is not a direct view.

There was a strong perception that Adam's limited social skills may hold him back. Carrie's reason was that we live in a world where people are expected to network, and any inability to do that may stand in the way of full social participation:

the emphasis is so much on nowadays getting on with people and knowing how to network and be sociable and if you are seen as not being sociable, that is a definite disadvantage I think.

C

For the teacher there was a strongly expressed perception that Adam should try to work out ways to be 'acceptable':

Yes I think it is really, because I think he has got, obviously he has got to work out ways to try and control his disability so the social situation.... can be acceptable in social situations.

T

The words 'control his disability' appear to contradict the social model of disability.

Both teacher and parent expressed a belief that some of Adam's behaviours disrupted the other children. His teacher says,

...he is making a lot of noises all the time and when he starts clapping a lot it gets a little bit disruptive but then when he starts making noises it is even worse. Screaming out and making noises.. and sometimes he will stop but sometimes he will just carry on and do it again. He just wants to see what reaction he will get from people and he does that [flapping gesture] with his hands as well.

T

The teacher attributes intent to Adam's actions, therefore it is perhaps unsurprising that her belief appears to be that he is perfectly capable of control, but 'wants to see what reaction he will get'. More surprisingly, perhaps, Carrie also mentions that she believes he likes to see the reaction to his behaviours:

If the children start to laugh, then obviously this encourages him further because he does like to get reaction from other children.

C

The teacher's account is however, quite balanced in that she has noted his popularity amongst his peers, and mentions how the other children in the class can burst into spontaneous applause if he is congratulated by her for

some achievement. She also believes that having a special needs student in the classroom can be beneficial to other children as this is a social lesson that they can learn:

That is a nice thing about having a child with special needs in the class, because it makes them more compassionate towards you, you realise that some children are different, people are different, some people have got special needs and I think that is really nice for them.

T

Adam's popularity among his peers was certainly evident during the observation. They included him fully in their quiet chatter, and offered help and advice on the task in hand. He was also responsive to them. This very much reflects the evidence provided by Adam's interview: that he appeared to value those children whose photographs he had taken, at times expressing a very warm liking for his friends.

The teacher's apparent rejection of a social model of disability, in her belief that Adam must adapt to the environment if he is to progress, is a little surprising given her expressed understanding of how some curricular modifications have worked to alleviate some of his problems. Her description of the very clear reciprocation between him and his peer group demonstrates that he is 'acceptable' to them, and not necessarily, perhaps, serving as a useful lesson in compassion.

3.5.4 Pilot Study Summary

The challenging pilot study has provided an alternative method for data collection from children on the autism spectrum who may have limited language. This has been a qualitative research problem since the publication of Kanner's *Autistic Disturbances of Affective Contact* (1943). It has been assumed that children on the autism spectrum, especially younger children with limited verbal skills, may not be able to offer insights into their emotional and social self. It is virtually unknown except for one recent study (Preece and Jordan, 2010) in which children of this age were asked questions but answers were often given by parents, to take direct oral interview evidence from an autistic child of this age.

It was an essential step on the route to discover how best to address this methodological problem of data collection from this population. This researcher has been cautious in including the interview data from Adam, as evinced by this method of data collection. However, given the caveat that this evidence involves a further and indirect interpretative stage in data analysis, it also contributes to the holistic data analysis process which is ultimately a discovery of the construction of meaning via the instrument, the researcher.

It is concluded that in general the Pilot Study revealed the research design to be fit for its purpose. Additionally by attempting data collection in this very complicated case of a verbally-challenged child by a projection technique

which used artefacts, the researcher was able to devise alternative methods of data collection for possible use with similar children in the main study.

The data analysis process and instrumentation examined in the pilot study were therefore employed in the main study. However, what is additional in the main study is a supplementary analysis, of the means by which participants communicated their views of the complex nature of autism. Although this was noted, to some extent, in the pilot study, and referred to in the 'Comments' notes made for the transcripts of Carrie, and of Adam's teacher, there were insufficient data available from these two participants alone, to conduct this supplementary analysis.

However, it was a lesson learned from the Pilot Study that complexities and contradictions existed in some accounts of beliefs. A consideration of the communication strategies of the participants is now presented as a useful adjunct to central thematic analysis of the Main Study.

Chapter 4: Findings

4.1 Introduction: lessons of the Pilot Study

The pilot study demonstrated that the four interview questions produced the level of response in teacher and parent that was hoped for. Responses could be usefully analysed through the methods employed. Therefore it was decided to retain these in the main study. They are:

1. What do you know about autism spectrum conditions?
2. Where did you gather that information from?
3. Do autism spectrum conditions lead to any problems?
4. Are autism spectrum conditions a disability?

It was decided that the alternative method of data collection employed with Adam would be used if any other student on the autism spectrum had difficulty in responding to the above questions, and that an ever-flexible approach should always be considered in 'interviewing' this particular group of students. Although the researcher had theoretical knowledge and practical of verbal difficulties in autism she had never imagined having to adjust the research design to the extent that was necessary in Adam's case. An important lesson of the pilot study was Yin's direction (2009:92) that it is sometimes advisable to use the most complicated case in the pilot study, as this is the one which is likely to challenge pre-determined data collection protocols.

Another lesson of the pilot study was the necessity to begin to analyse the data critically at the earliest possible moment. What was impressive, for instance was Carrie's in-depth knowledge of autism, and her ability to communicate this knowledge in an extremely organised fashion. A salient point noted by the researcher in her field notes on the bus back to town was that she did not say that she had learned about autism from her children or from personal experience, but from a variety of leaflets and radio programmes. The other striking issue was that her answers were almost too clear. The researcher noted, 'almost rehearsed' in the field notes

This was also evident when the transcript was returned and colour-coded. The highly organised delivery was visually clear in her transcript map. Bands of each colour, uniformly arranged, marked the transcript. It was only after noting this that the researcher decided to check all future interview transcripts for communication strategies in the participants, a decision which led to the development of a 'supplementary' analysis briefly mentioned in the previous chapter. This supplementary analysis was then used in assisting the analysis of the main study interviews. 'How' the content of the interview data was shared became a factor to consider in the memos made.

After the initial writing-up of findings the researcher discovered that Carrie was a regular presenter at voluntary organisations for parents of children on the autism spectrum. This would seem to explain the high internal consistency and organisation of her account. While this does not detract from her position

as informant, it is useful to note where communication patterns occur in data, and to question why they might occur. They can often provide insight into deeper underlying factors. This is the rationale underlying the working-up of a further layer to the first level of coding.

The codings were therefore extended in the Main Study to accommodate a synchronous illustration of *how* the information was given, where this was of interest, alongside *what* information was given. This can sometimes be used as the main tool of analysis, as in discourse analysis. Discourse analysis was not, as such, employed in this study. It is a method that requires adherence to certain protocols, and its employment determines research design.

The analysis undertaken here is based on an holistic system named *explication de texte*. While often thought to refer only to written text, it can be used with all forms of text including the visual, and speech. In English, it is called 'close reading' which again wrongly suggests a reliance on the written word. Arising from the French philosophical tradition, its imperative is to analyse the 'text' in its broadest and fullest sense. In simple terms, it examines the following, in iterative levels of analysis:

1. What is this saying?
2. What does it really mean?
3. Why do we think that it may mean this – what clues are given in *how* it is said and/or framed and/or presented?

4. What patterns/themes/salience emerge from the combination of 3 before 2 in a text-bound dimension?
5. What conclusions may emerge?

In several ways this analytical method is used in most qualitative data analysis, although 3 is rarely articulated in most forms of analysis. It is a good fit for case study in education, combining as it does the internal dynamics of bound systems with the appreciation of multiple societal influences on that system. It is also a good fit with the system-based theoretical framework of this study, the biopsychosocial framework.

The chapter now continues with a further presentation of the participants, in order to clarify which of these took part in the main study. Again, a clearer picture of the participants can emerge from the case history notes and the vignettes presented as Appendix 1.

It should be noted that the teachers have not been named but have been coded to show their relationship with the participants. Thus, Harry's teacher is coded HT, Lisa's teaching assistant as LT, Keiron's teacher as KT and Evie's as ET.

4.2 Participants

Fig 4.2.a Student Participants.

NAMES	Evie	Kieron	Harry	Lisa
Age	22	18	11	15
Siblings	1 younger brother (birth brother adopted into same family)	5 brothers, 7 sisters: brother to Lisa	2 younger sisters	6 brothers, 6 sisters: sister to Kieron
Diagnosis	Asperger's Syndrome	Asperger's Syndrome	Asperger's Syndrome	Autism spectrum
Age of Diagnosis	17	8	10	10
Parent	2 adoptive parents	Twice-divorced mother	Divorced mother, now remarried,	Twice-divorced mother
Additional Diagnosis/needs?	Previously diagnosed AD/HD	None	Previously diagnosed AD/HD inattentive	Gifted and Talented
School/college	City College of Further Education, studying BTech	City 6th form College, studying ICT AS Level	County High (10-14) school, previously City Secondary (11-16)	City Secondary, studying 11 GCSEs
Location	County location, large modern private estate	Inner city social housing	Outer city social housing now privately owned	Inner city social housing
Ethnicity	White British	Mixed race: White British/ Eurasian	White British	Mixed race: White British/ Eurasian

Fig 4.2.b Parents

PARENT NAME	Frank and Gill	Irene	Maggie
Parent to	Evie	Harry	Kieron and Lisa
Age range	55+	35+	45+
Number of children	2 adopted	3	13 from 2 marriages
Marital status	Married	2nd marriage	Divorced twice, now single
Work	Frank - Retired Works Manager	Former nurse, now clerical worker	Parent

Fig 4.2.c Teachers

TEACHER	ET	HT	KT	LT
Student	Evie	Harry	Kieron	Lisa
Age group	55+	30+	35+	35+
Status	Lecturer	Teacher	Teacher	Teaching Assistant
Subject speciality	Chemistry	Technical Design	ICT	Art
Education setting	College of Further Education	High School (10-14)	Sixth Form College	Secondary (11-16)
Qualified	BSc	BA (Ed)	BA (Ed)	
Teaching years	30+	2	11	10

A factor that could be relevant appeared in the initial scrutiny of the background detail of the teachers whom the participants themselves were at liberty to select. While three of these were qualified teachers, the member of staff chosen by Lisa was a Higher Level Teaching Assistant, whose expertise lay in supporting students on the autism spectrum in Art classes. It was not known at the start of data analysis whether this might be an important factor.

4.2.1 Data gathering

A problem encountered in the data-gathering from teachers was that Harry changed schools in the course of this study. On entering secondary level education he had enrolled at a school which had some level of support of students with special educational needs. However, only six months after he had entered the school, the local authority announced that the school was in danger of closure. Harry's mother, a local city councillor, believed that this would almost certainly happen.

She had also been concerned about the extent of the bullying which Harry had encountered in the school. Although he had good support within the school day, much of the bullying was occurring at unstructured times, particularly at break and lunch times. The combination of the two issues led Irene, his mother, to make the decision to enrol him in a different school.

The local educational authorities for the area in which this study was conducted have two different education systems in place. In the city, the secondary schools operate a move to secondary school at 11. This is then

followed by education from 11-16, and a third move is made at 16 into a city sixth-form college. In the county, an innovative system was introduced in the late 1950s. This involved primary school to the age of 10, followed by High school, to the age of 13/14 and education was completed at Upper School, which educated students from 14 to 18 years old.

Irene lives on the city/county boundary, and had chosen to enrol Harry in the city system. However, the problems which were faced by the projected closure of his secondary school, and the bullying issue, had forced her to rethink the future of his education. Her decision was to take Harry out of the city system and enrol him in an equally-accessible county High School, at the Easter of the year of this fieldwork.

As a consequence, Harry's evaluations, both in observations and in teacher interview, had to take place in a new school environment with a new teacher. The researcher had concerns about these changes, as there were logistical problems in accommodating them. There was also, clearly, a concern about interviewing a teacher before the end of a school year, who had been teaching Harry for a very short time. In the final weeks of the summer term the interviews and observations were concluded, in the new school. These data may therefore have been compromised by the enforced changes in Harry's schooling.

Methods and procedures of organisation and analysis of the gathered data will now be discussed.

4.3 Data analysis

It was decided that the method of data analysis used in the pilot study, analysing the data in relation to the research questions, produced useful outcomes. Therefore, this method of data analysis is used in the main study. However, since there were more participants in the main study, and since all these student participants, it was discovered, could be fully interviewed in the same way as parents and teachers, the transcripts could also be analysed as to the means by which participants offered their views, as suggested in **4.1**

4.3.1. Communication strategies and styles

It became clear, in full analysis of the data, that there were many confusions expressed in each participant's communicative strategies as they attempted to convey both the complexity of this issue of autism, and their sometimes internally-conflicting belief states. This was an inevitable, perhaps, result of the efforts to articulate their view of autism, a fluid developmental process, rather than a state, and one strongly situated or contextualised.

As a concept, autism is often poorly defined and understood and confusingly interpreted. Therefore a tentative supplementary examination of the data generated in this study lends itself to an investigation of how beliefs about this perhaps indeterminate or nebulous concept, autism, are formulated and expressed. The supplementary analysis does not seek to be definitive but is merely an attempt to capture nuances of certain complexities which were

evident in each participant's transcript, in this study. It represents this researcher's effort to outline the processes of representing, communicating and limiting or expanding complex and personally-held beliefs.

As this study is the first study to examine beliefs about the lived-life experience of autism from the perspective of this triad of stakeholders, operating within a framework of educational inclusion, some attempt to understand the way in which beliefs were framed and expressed, could be a useful addition to the primary thematic analysis. Therefore this first level of analysis, which is organised in relation to the four sub-questions, as discussed in **3.4.6**. However it is also accompanied, where this may be relevant, by a supplementary analysis of strategies employed in communicating beliefs, which is finally summarised in **Fig 4.3.3**

4.3.2 Data Analysis by Research Questions

Question 1. Do professionals and parents, and children on the autism spectrum regard autism as a deficit, or a difference, and is there any recognition of the skills and strengths and advantages of this condition?

Participants tended to refer to deficit by explanatory means, using what may be thought of as expert biomedical descriptions of autism:

the three identifying factors are lack of imagination, difficulties around social situations and can't remember the third one now but I know certainly it is things like language processing

one side of the brain hadn't developed during pregnancy or something happened, so the part of the brain that stops you doing things in Evie's case, didn't or allows you to do things

F&G

There is a strong sense that parents were attempting to find reasons to explain any apparent shortcomings that might be evident in their children. Few of the students used a deficit model at the outset and preferred to explain their condition with a brief reference to a cognitive difference, as in Kieron's case, 'it makes the brain make some things harder to learn than others' and in Harry's, 'I think it's to do with your way you think' before submitting statements about the way they themselves experience it.

Evie, unusually struggling to express herself in answer to the opening question said she felt 'on the spot', and, 'it's probably because it's the communication side of it.' Evie of all the students was apt to use a biomedical model frequently to explain her, at times, deficit view of her condition, as she did here, saying that 'it's the communication side of it'.

Lisa described autism using the pronoun 'they' but her explanation was highly personal nevertheless,

They are usually very talented in one area.....Umm I know that they are OK if they have schedules they are OK with, they do well?And it's near enough impossible to concentrate on something if they're not interested....

She then immediately reverted to the first person in reiterating what she had conveyed as explanatory, and her account became more clearly personal and experiential, as she continued, 'it means I can focus well, but only if I'm interested'.

Keiron's evidence, however, tended to a deficit account, and one that appeared to have strong elements of social construction. In reply to the researcher's question on how his autism had affected him, he delivered a brief numbered list, orally:

- 1. I can't read faces*
- 2. I don't know when to stop talking*
- 3. I am really annoying*

The statement, 'I am annoying' was repeated very often, throughout the interview. It might appear that describing himself as annoying, and as not being able to stop talking, is heavily dependent on what other people might have said to him or about him. He further also relies on a deficit model to speak about, 'you can't make decisions', and 'you over-react or you under-react' where the pronominal 'you' in these statements would be more

conventionally 'I', again reinforcing the possible social construction of these perceived deficits.

Teachers tended to try to avoid a deficit/biomedical model as explanatory, one in particular:

Ooh criteria um oh yes, well they have idiosyncratic behaviours and there is a check list, but I don't like check lists because it is trying to put people into boxes and Lisa definitely doesn't fit into the boxes as far as I can see.

LT

Despite this effort to see each child holistically and individually her discourse was not fully successful in avoiding any reference to a biomedical model:

And in every year group you have got not definitely diagnosed, but people who are somewhere on the spectrum, at least 5 or 6.

LT

While denying that there can be a 'check list' and insisting that every student has their 'idiosyncratic behaviours' the teaching assistant appears to believe that she can see patterns of behaviour which would justify a diagnosis, 'are somewhere on the spectrum'. Another contradiction was from Kieron's teacher, who, while also strongly resisting 'labels' for the students she encountered nevertheless used most of her interview describing her sister's

battles to have her children diagnosed with a number of different autism spectrum and related conditions:

the oldest is the girl who is dyslexic and dyspraxic and the second oldest is a boy who has dyslexia, Irlen Syndrome, ADHD and Tourettes

KT

The teachers who appeared to reject a deficit model perhaps more successfully were Evie's teacher, who, was quite tentative and exploratory in her account of her beliefs, and Harry's teacher, who, while referring to the 'traits' was mostly experiential and exploratory in her opening accounts, exploratory in the sense that much of her discourse was reflexive with, in this extract, little evidence of deficit, merely of difference:

Harry particularly likes his own routine and likes to know upfront what is going to be happening, he likes to get organised. I think that can be a trait of autism, that they need to know and have a set routine...it's to do with the routines again, I suppose, it's organising and getting things in order is quite a lot of it.

HT

This is not to say that this particular teacher was totally successful in avoiding referring to deficits. In fact, it is difficult to envisage that any response to the question, 'What is autism'? could avoid referring to the challenges faced by children who may 'struggle' as she describes it, in another part of her

interview, with some aspects of their condition. However, she appears to have a high degree of empathy with Harry, linking his behaviour to emotional/psychological needs, 'sometimes he wants to be reassured and asks lots of questions and things'. This may be because she has known Harry for only a short length of time, and is still analysing his actions and his apparent difficulties in order to try to understand how best to support him.

Whether or not autism could be regarded as a strength was strongly mediated by factors of cognitive ability, maturation and motivation in personal accounts. Lisa, who is also classed as Gifted and Talented, was happy to share her own awareness of her strengths, mediated by her certainty of her cognitive ability, 'If I know how to do it then I can do it faster than most people', 'I am good at calculations in my head and on paper,' 'generally good on tests', 'I usually do quite well' and 'one of my main talents is that I can retain information quite well'.

Frank and Gill were also aware of the factor of cognitive ability in what they describe as Evie's strength: her attention to detail and her keen rote memory. They perceive it as a particular gift in this extract from their interview in which they explain how they have learned about autism from watching television programmes, including one about Stephen Wiltshire:

the similarity for me would be their level of attention to detail so this young lad [Stephen Wiltshire, an autistic savant] could see a house and then paint it, or draw it and include all the detail. Evie can

remember lots of data, information that we've forgotten. I think the best way that that manifests itself is that she is very good at identifying moths, Evie will spend hours and hours sort of examining them and working out which one is which. But more often than not she'll remember that this is this pug or that is something else pug and she will remember it straight away. And so, that maybe just a something that people of her age can do but I don't think so. I mean, some experiences that people have got a good memory but she seems to have a particularly good recall of things like that. Which I guess is nigh to what this lad can do, so yeah.

F&G

Irene, in her accounting of Harry's autism also points to a strength in a concluding statement of an extract in which she initially appears to be talking about her son's limitations or deficits. This is an interesting section of her interview as it shows considerable slippage in positions, from an account of perceived deficit, in her son's rigidity of thinking, to a generalisable strength, although critical components are not totally absent. The important factors pointed to here are environmental (situated), maturational (better over time) and motivational (determination):

He challenges, everything is black and white, and he can't see that his view is that - his view. He is quite a science orientated person and he can't understand that when he comes up with a scientific theory, that it is absolutely fantastic and he is very able but it still is only a theory

because of his black and white attitude to things... Harry has phases where for three or four days he will need that black and white routine to be as rigid as it possibly can be and he will take comfort from that..... They have the tenacity and the sheer bloodymindedness to stay to a task that I suspect most of us wouldn't, and we wouldn't have made the scientific achievements that we have made without people who can lead life alone whilst they are involved in their fixations.

I

Irene appears to say that although Harry's rigidity of thought leads to socially-constructed environmental difficulties at present, nevertheless, in the future, in a different environment, the deficit she perceives could well be regarded as a strength: tenacity of purpose and perseverance, which could be regarded as motivational assets, as she understands. Her change of pronoun from 'him' to 'they' signals the shift in focus from the personal 'Harry' to the abstract 'people' although she retains to some extent the language of deficit – 'fixations', and 'lead life alone'. It is a particularly affecting extract.

Question 2. To what extent do teachers, parents and the children themselves identify the sensory and perceptual differences which are theorised to be essential features of autistic intelligence?

This particular question does not require the researcher overtly to examine the issue of deficit or strength, but to look at the accounts to discover whether

there is evidence of a belief of sensory difference. However, the notions of deficit and strength were also apparent in answering this question.

The parents, and several of the students, appear to be particularly concerned about sensory issues Lisa says, in her experiential account, 'I'm finding it difficult as I haven't been listening to the teacher because she has a voice I can't concentrate on'. Her sensory problem here is alleviated by a personal strategy, that of not listening. She expands on that statement, 'She has a sort of accented voice. I'm usually OK with most people with accents, but if they're talking for a long period of time, I find it hard to concentrate.' Later in the interview she discusses what makes her feel 'queasy' : 'Odd voices and the noises that hurt my teeth. I don't know why but certain sounds hurt my teeth' Colours, she says, are also difficult for her at times, 'I'm very bad at reading red paper...red paper is always this one specific shade of red...and I don't like that colour.' Her handwriting is poor, and she is angry that part of the English GCSE exam mark is given for handwriting.

Of eye contact she says, ' I do at some points, but mostly I don't. I have a lot of trouble when it's someone I don't like'. It is interesting that for her emotion is a qualifying factor in whether she is able to give eye contact. She also says that she has difficulties in operating in two modalities at the same time, '..they tell us to take notes but I'm watching something. If I start writing I'm going to forget what they're talking about'.

Lisa's views as expressed in her experiential account of her sensory differences appear to be more negative and more inclined to a deficit model than what was apparent in most of her interview, especially where she communicated most often what appeared to her to be an important factor, cognitive ability. In discussing her beliefs about sensory differences, however, she employs the language of deficit, 'I'm finding it hard', 'I find it difficult', 'I'm very bad at', 'I have a lot of trouble', 'I'm going to forget' and 'hurt'.

The very articulate and insightful views she offered about her sensory issues were enabled by her high level of intelligence, and while this can have a positive effect, it may also lead to some socially constructed misapprehensions that cognitive ability is the one factor that can lead to scholastic success or failure. High intelligence can be considered in isolation, rather than taking an holistic view of the balance of several interwoven factors in determining educational achievement.

Lisa's mother, Maggie, spoke at length about sensory problems, particularly with eating, dressing, sleeping, and using the telephone. She spoke of the accommodations that had been made for Lisa by her Primary School where she was placed, if necessary, in classes inappropriate to her age and achievement when she had difficulties with teachers who shouted. She also mentioned a perceived phobia, in Lisa, about stairs, partially easing as she grew older, 'that used to be a huge issue, well it still is, some stairs she can't cope with':

And then ones like Lisa that are really bright and intelligent, everyone looks at her and says 'Yeah well that one's normal, isn't she?' 'Cos they haven't spent more than two minutes with her, therefore they are all hugely surprised when something goes wrong. I painted the corridor of the stairs in the old house, as I really wanted to get rid of the colour, it needed doing. She sobbed on the sofa for two days and refused to move. I managed to prise her off to go to the toilet occasionally, and when I say two days sobbing, she managed to keep it up apart from when she fell asleep.

M

Lisa's 'phobia' about stairs may have played a part in the behaviour she claims that Lisa displayed on that occasion. However what is evident here is an additional factor of environmental change, and the emotional reaction to that, which is reported to have been produced in this case.

Lisa's teaching assistant also speaks in her account, of the sensory differences she has noted. These, according to her statements, have been socially constructed, in part:

Well they have all got different learning styles again...umm, auditory a lot of the time and they are all responsive to music, very repetitive, rock is a big thing for most students I work with.....I think for students who are high end, they can hear the rhythms and put them into mathematical patterns and they can see the music. I've had it

described to me by several students, and other students such as J find it a nice repetitive, soothing background presence but it helps them focus.

LT

While the social construction here is clear, 'had it described to me', there is the consideration of Lisa's cognitive ability which she describes as 'high end'.

Harry also mentioned sensory difficulties, photosensitivity, and a keen sense of hearing, while apologising for mentioning it as it sounded like 'bragging', but 'I have quite good hearing so little sounds do seem quite loud to me'. Evie, who has very evident motoric facial and body tics explained her sensory difficulties as, 'I am a jiggly person and I have actually got RSI in my left ankle from it!' while Kieron says that he fidgets constantly, as he believes it helps him concentrate. He also mentions that he can't 'read faces' but his mother extends that description, and says that Kieron is not merely unable to read faces, but also unable to recognise them, as are two of her other sons.

This expansion by Maggie is important. It brings into focus one of the issues which may mediate against the sharing with others a sensory difference that children on the autism spectrum experience. Generalising difficulties may possibly play some role in an understanding that what children on the spectrum may experience, perceptually, may be unlike the sensory perceptions of typical children, but they may not be aware of that fact. Awareness of sensory difference may be reliant on a number of different factors, including age, environment, and intelligence. Maggie said that she

was aware that Kieron was unable to recognise faces, but his own understanding was that he could not 'read' them.

Question 3. To what extent is there consensus and/or conflict among teachers, parents, and students as to desirable outcomes in intervention strategies for autism spectrum conditions and the means appropriate to achieve them. Where there is conflict, what is its nature?

It appears that there are believed to be many intervention strategies leading to an assumed desirable outcome in the case of the students involved in this study, their parents and their teachers, which is to succeed academically within a mainstream and inclusive educational framework. Kieron's teacher spoke of her own nephew in support of special unit primary education, 'he went to a special unit who were absolutely amazing with him. Really helped, leaps and bounds there, and now he is in mainstream school'.

A special school alternative was considered by Maggie, for Kieron, but rejected:

We actually looked at special school when Kieron was moving up into senior school. But having had a look round it, he was too clever for that. He would have loved it, they wouldn't have pushed him hard and he would have come out of it without any qualifications at all and he would have thoroughly enjoyed school. BUT he wouldn't have done much for the rest of his life. Indeed we were told that if he was too good

for some of the subjects what they would do was take him out of that school for those subjects and put him into a different school to take the ones he was good at. That would have meant that he was spending half of his time in the school that didn't know how to deal with him, and that's worse than spending your whole time in that one school.

M

Here she unpicked some of the dilemmas faced by herself and her child in the alternative to mainstream which she says was presented to her. The principal mediating factor here as she claims, was again cognitive ability which appeared to have great importance, 'he was too clever', and the alternative, placing him on a split school site, seemed to her to be unacceptable, even though she believed that the mainstream school 'didn't know how to deal with him'. Another factor was that in special education he would have left school, she believed, without any qualifications.

The issue of qualifications was given great weight by parents in their personal accounts:

It's been a bit of a mixed bag because I think what tended to happen was, her behavioural problems particularly when she was younger tended to mask any academic achievement partly because she was not at school on a regular basis. She was suspended for various periods of time and then.....errrm permanently excluded from a variety of schools, wasn't she?..... Umm but she was never entered

for anything like GCSEs although I think she did do a mock GCSE once and did very well, but the sadness was that had she been diagnosed and helped earlier on and then I guess she would have done OK in mainstream school with the right support structures and then she would have achieved academically quite highly.

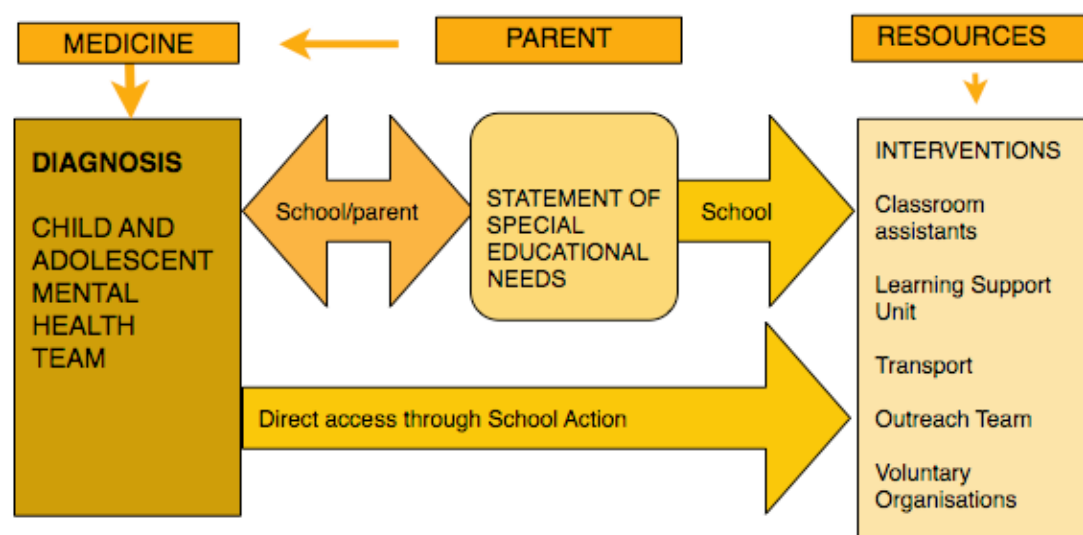
F&G

Frank, whose words these are, in offering an account of his own experience notes that Evie left mainstream school without any GCSEs, and believes that the reasons for this were mediated by Evie's behavioural problems which in turn led to official suspensions and exclusions. His perceptions of what has happened to her he expresses in emotional terms, 'sadness'. Another important factor in what Frank says here is that he draws attention to his belief that an earlier diagnosis may have led to earlier interventions: 'support structures'. It was a noted perception of the parents that in their experience the educational interventions necessary were strongly dependent on a diagnosis by health professionals although officially this is not a statutory requirement.

All parents in this study perceived the statementing process as being a linear progression towards access to interventions, in which their own input, they believed, was generally to secure a diagnosis. At that point, they claimed, the education system would listen to them about what they thought were their child's needs.

The diagram below (4.3.2) summarises their reported concerns. All parents believed that generally they were left out of any educational decision-making.

Figure 4.3.2 Parents' perceptions of accessing services



The diagram represents the summation of their views that educational interventions, represented in the right hand column were largely unavailable unless a doctor or Educational Psychologist agreed to a diagnosis. Frank later in his interview outlined what he believed might be a reason for this dependence on diagnosis, 'At that time she was just classed as a naughty child'. The biomedical explanatory terms might work, he believed, to over-ride any socially- or culturally-constructed assumptions. However, Maggie noted that there might also be a funding issue. She said, 'Lot of the time, they just don't want to see it because it demands funding and no one wants to stump up the funding' :

Only Kieron [has a statement], they looked at a statement for T, but left it very late and basically they didn't give him a statement on the grounds of 'Well he's coped this long'. We actually had an Ed Psych who assessed who said, 'Yes he needs a statement, but I can tell you now I won't manage to get you one'.

M

Of Maggie's seven children who have a diagnosis of autism spectrum conditions, then, she says that only one has a statement of special educational needs. In this study, Kieron, Harry and Evie have statements but not Lisa, the reason being, Maggie believed, because of her high intelligence, citing a paradox which she thinks plays its part, 'it's because they're intelligent that no one is ever going to know that they just can't get it out there'. However, despite not having a statement, Lisa's junior school was accommodating, Maggie says, in adapting the environment:

Lisa can't cope with anyone that shouts. The junior school were quite good about changing her teachers and put her in the wrong levels so she could have the right teacher which worked really well.

M

Of the interventions and support offered, Autism Outreach was mentioned by many participants. Evie's teacher (in a City College) noted that the outreach team provided some helpful training for the staff, but Harry's teacher (in a

County High School) says, 'We do have outreach people coming into the school but they normally just talk to the children, we haven't had anybody personally speak to me', which suggests that the services may operate differently. She also said that, 'we've had paperwork given to us on particular children but that's about it, nothing else as far as I'm aware'. Lisa's teaching assistant was of the belief that socially-constructed and experiential craft knowledge may be of more use:

I don't think the training is a great help....It was just one of the introductions to Autism, it's more useful working with the students and they will tell you.

LT

Of the parents, Irene's view of the outreach service is not without criticism:

[Outreach Service] have been involved and have tried to, you know, ask Harry how he can, you know, offload some of his anxiety through the day and at one point for a very short period of time, you know, he could go to there, he had got some of his fiddle toys erm, you know resources being what they are in school, it was not available for long. And I don't think he used it anyway.

I

She emphasised the temporary nature of this arrangement designed by the outreach service and organised by the school as an intervention into

alleviating Harry's perceived emotional reaction to the stresses of school. However, Frank and Gill praised their own outreach worker for providing them with insight into Evie's autism, 'I suppose the most information we have had is from [Outreach Worker], our GP didn't seem to know a fat sight about it'. Maggie also found the outreach team helpful, 'autism outreach who have come in and helped out sometimes, when there are problems, they've been useful, helping us liaise with schools and how to deal with it'.

The use and efficacy of teaching assistants was an intervention also mentioned by several of the participants. Lisa claimed to be embarrassed by one of hers:

I'm not really much for getting help, rather I wish they'd leave me alone so I can get on with it instead of giving me help that I don't need. Because they do give me a lot of help that I've never really needed. When I was in year 7 I had a mentor for ICT and she was sitting with me, they would ask a question and I would never raise my hand for a question. I just don't like to answer the questions, yeah? So she assumed I didn't know the answer and just gave me the answer which I consider to be cheesy. So I don't like that.

L

The issue of help was also mentioned by Kieron, who said, in reply to the question, 'What problems have you had at school?', 'There is one. When they give me support, they give me support for lessons where I don't need it...I'm

great with IT and IT is the only lesson where I have support.' Maggie on the subject of support from teaching assistants said. 'They all had some in some classes...But none had the one they really need. I mean Kieron used to have one for PE, but that was because it was making it safe for everyone else.' Harry was unique in this study as being the only student without a teaching assistant in any subject.

Lisa's reluctance to be too closely associated with a teaching assistant was also echoed by her teaching assistant, paradoxically, who believed that the use of teaching assistants can sometimes produce detrimental social consequences:

Sometimes students will be walking around with support and it is like a visible disability and Lisa absolutely hates it.....there was a member of staff before me who worked with her, who would say, "Let's go and sit in the library and do organisational skills" and she just hated being managed in that way.

LT

The teaching assistant's criticism of the use of this kind of support was clearly mediated by what she believed to be Lisa's emotional reaction to it. There was in Evie's teacher, too, a certain belief that the use of a support worker is not always necessary, 'But I must admit I find that I can manage Evie generally on her own without a support worker', although she immediately contradicted herself, 'although it is nice when she does have one on one note-

taking, I think that is the main problem'. Here there appears to be a conflict in her own beliefs between what she sees as her professional competence, and what she also understands as some useful support for those aspects of Evie's classroom environmental and sensory problems, in this case note-taking from the whiteboard, which do perhaps require further assistance.

The part played by the health services were also referenced in relation to interventions, especially as has been noted, as a means of securing diagnosis which might lead to statementing. However, other interventions appeared to be facilitated by health services, rather than education. Kieron reported that he had Speech and Language interventions, and Irene (see Case History) that Harry had physiotherapy and Speech and Language therapy. Frank and Gill also mentioned health services interventions as having, they perceived, a positive effect on Evie:

Social skills is a particular problem for her and the first time I picked up on anything like that was many years ago when she went on a Saturday morning, many Saturday mornings, to a social skills workshop at [Adolescent Psychiatric Unit] and that actually was the start of a process erm of slow and gradual improvement.... the best bit of education when she was younger was when she went to [Adolescent Psychiatric Unit] where they had an educational establishment attached and the people there who were doing the teaching obviously could understand that there were kids with, well it was an adolescent

psychiatric unit, but with issues, shall we say, so she learnt quite a bit there and actually got a qualification from there, didn't she?

F&G

According to the Case History given by the parents, Evie had been admitted as an in-patient to the psychiatric unit following self-harm in her teenage years. It was there that she had some educational input, a diagnosis of Asperger's Syndrome, and the social skills training to which they refer.

Question 4 How might the relationships between students on the autism spectrum and typically-developing students and others be characterised?

This question was especially productive of data. This is perhaps inevitable in that school is a social arena. Only Evie, of the four students, did not report being bullied. Again, this can be explained by the fact that she has perceived herself as a violent person, although she never calls herself a bully. What is especially interesting is Evie's descriptions of her 'violence' towards others in which she appeared to view others, the apparent victims of her violence, in an extraordinarily detached way, rather as objects:

she was stopping me going through the door, she had her hand on that door and I wanted to go through that door! Her hand had to move and that was the only way to make it move I think.

E

While she begins this retrospective account with a perceived view of her actions being directed towards a person with an intentional stance, 'she' and 'stopping', the perspective shifts to her own motivation and is strongly mediated by that, to the extent that the person is reduced to a 'hand', which 'had to move', a disembodied object which she perceived was in the way of her goal, 'wanting' to get out of the door, and the 'I think' brings the retrospective view into the present tense. It is a very complex motivational justification of sorts. It is also an example of generalising difficulties. Evie appears perhaps to be somewhat limited in perspective-taking.

Frank and Gill seemed to believe that Evie's problems as a child must have caused difficulties for other children, in that she would 'disrupt' the class:

I think you mentioned the word boredom. She's not particularly tolerant of things that she doesn't like, as you said, and erm if she was in one of her bad moods she would not only not do her own work but she would disrupt other children from doing their work which I guess from a teacher's perspective would be very difficult to deal with, in fact we know because she did all sorts of things, broke people's pens, pencils and a flute, smashed it once, and peoples glasses erm didn't she have something to do with some scissors once?

F&G

While they believe they understand the social effects of Evie's behaviour they are inclined to see emotion and motivation as factors to be taken into account,

but their account also draws on the classroom environment, generally, as an important contributory factor, for the teacher, for Evie, and for the other children.

Harry was bullied at school, but retaliated, finally, he claimed. Part of his problem at school, he explained, was that he liked to wear hats, and his hats were often removed by others and thrown about. A highly intelligent 11-year-old, he was markedly analytical and ruminative in all his responses in the interview, and appeared to be worried by the fact that he had attacked one of his bullies, a girl. He also described his fight at school with some detachment, at first, 'Someone decided to kick me and call me names and push me about. It started like that.' But his account is qualified by emotional insight, 'I just lost my temper'.

His mother, Irene, attempted in her interview, to define what she believed were Harry's social problems:

I think as well he can be quite aggressive, errrm, he does not have the coping mechanisms of dealing with people. It is quite difficult, I think this is where I start to think that were there mental health problems included, because he gets/feels very victimised, he feels like everyone is out to get him eerrmmm I think that is where a lot of his anger and anxiety comes from.

I

Her account resorted to some biomedical explanation, or exploration of the possibility of 'mental health problems', but this came within a framework which shifted constantly from the biomedical 'does not have the coping mechanisms of dealing with people' to a possible linkage to emotion as an important factor. She also gave a socially-constructed account which nevertheless has some reliance on a biomedical deficit model, 'he lacks the facial expression':

Certain children feed off Harry's differences and prior to him fighting would have bullied him because of them, but now we seem to have it, it's come full circle, whereas Harry is the person to be worried about now which is I don't think necessarily healthy either. And I think that comes down to the fact that they never really know because he lacks the facial expression, whether he is going to lose it or not. Because he has lost it in the past when they didn't see any signs, they now worry.

I

Kieron addressed the issue of his own social circumstances, both past and present, and repeated the statement, 'I am annoying' very often. His was the least garrulous of the interviews, the most gnomic. In reference to the bullying to which he claims he was subjected he said, 'it was bad in Year Five and in Year Six the atomic bomb went off '. When asked what the atomic bomb was his reply was, 'Umm, bullying again. It went back to it.' In reply to the question, 'Did you find changing to secondary school difficult?' he responded, 'Mmmm, well after going through continuous bullying, not much'.

His reply to the question, 'If you could change three things about yourself at school, what would they be?' the first item on the list was, 'The way people perceive me.' That is an interesting answer in view of his repeated mantra, 'I am annoying.' When questioned about *Every Child Matters* which was given orally and was therefore liable to misinterpretation, he may have misunderstood the question, believing it to be a question of morality, and the researcher may have made the wrong assumptions in the follow-up question:

Researcher: Right, OK, have you heard of EVERY CHILD MATTERS?

Kieron: Yes but I don't believe in it.

Researcher: Do you think you matter?

Keiron: Mmmm, I think I matter a bit

There is a considerable evidence of emotion as an underlying factor in the socially constructed beliefs, 'the way people perceive me', that Kieron seems to hold about himself.

Maggie, his mother, was more forthright in discussing her perceptions of the issue of Kieron's bullying. Her view reveals some anger at the emotional distress that bullying can cause:

The first time the school ever admitted to me that there was a bullying problem was when they had to call me in because they thought I might notice his split lip and bruised face! So at this point they had to call me in and tell me that there'd been a problem and they were still saying that they thought it was children playing roughly, copying 'Power Rangers'! They didn't mean to be hurting him, just because they had him down on the ground and kicking him in the head. 'There's nothing to be concerned about, they're only playing!'

I think if teachers were made to face on a regular basis the same things as the children, if all of the other staff picked on them, jumped on them, hit them, threw things at them, called them names every day, they wouldn't want to go into school.....it's the same as full-grown adults doing the same thing to us. I've heard children really stressed out by school and if they were adults and went to a doctor, they would be signed off work for two weeks sick, stress, no problem, but because they're at school, they have to get on with it.

M

Her daughter, Lisa, also referred to bullying, but it was of a different order and nature. This type of bullying, sometimes referred to as social exclusion or as informational warfare is more conventionally used by girls and women and is covert as opposed to overt:

Well it wasn't really the sort of bullying where everyone yells at you. It's sort of where everyone just kind of avoids you. It is just sort of like they point at you. There was a thing when they called 'crops' I am not sure what that was about but apparently I was always the one with it and if you touch that person then you got crops? [NB noticeably agitated voice] They say if you're wearing trainers, which obviously was a lie because all through year 6 I was wearing trainers and they said nothing. When I got to secondary school they don't do the whole crops scene, more physical assaults, but that was because I pushed them off when they tried to sit on top of me.

L

Lisa's teaching assistant agreed that Lisa had been bullied at secondary school, but appeared to believe that the reason that nothing positive was done to help was that the school's response would have been to invite Lisa to the Learning Support Unit at unstructured times in the day. She believed that Lisa would hate that as she didn't like to be associated with poorly-behaved students because 'she is very high functioning and she doesn't like to go up there' :

She has been bullied badly on occasions yes, she is very reluctant to tell anyone because their reaction would be, "Oh come on up to Learning Support for break and lunch", and basically she would just pace up and down outside in all weathers.

LA

There appears to be again a conflict between perceived gifted ability and a variety of needs of an autistic student, which may not involve that factor.

Harry spoke at some length about the nature of friendship, a subject which appeared to confuse him:

Harry: *I've got quite a few people that I am good with but then again they're friendly with people that I'm not good with. And it spreads out. If I'm not very good with someone and they have loads of friends, naturally they are going to sort of.....*

Researcher: *Pick on you?*

Harry: *No, not exactly. In a way, but in a way that I can't tell.*

Researcher: *Do they ignore you?*

Harry: *Mmm, I don't really mind if they ignore me. I don't really like them. Don't want anything to do with them.*

There is evidence of the development of some personal strategies here. Harry's interview was characterised by his dissection of social circumstances and actions and by his high degree of slightly confused self-awareness and awareness of others. His statements were strongly mediated by emotion. He had read a book about Asperger's Syndrome, 'to make sure that I wasn't

alone, because I felt lonely before.’ When asked about friendships he said that he had friends but ‘not proper...I like to call them friends but they’re not exactly friends’. He had determined this by asking others what constituted friendships, and had realised that none of the other students at school fell into the category defined by others as being ‘friends’.

However, at the end of the interview, he said that there was a boy in his class who asked him difficult academic questions that he, the boy, was struggling with. When asked if it made him feel good to know the answers and to give them to the boy he said, ‘It makes me feel like I am needed.’ In many ways Harry’s was the most poignant interview, as he was so much aware of his differences, and so anxious to experience forms of social acceptance. Harry’s social behaviour was also remarked on by his teacher in his new school:

coz L, one of the other boys, which he was really good friends with him at first but then Harry came up to me and asked me to ask L not to be so intense any more. I think he was a bit too on top of him, so then he had to back off a bit, but now they are sort of friends. At lunchtimes he is quite happy with the girls..... Sometimes he gets a bit too over the top, a bit silly. I think he must suddenly feel confident and then do something like hit one of the girls or does something silly and then they tell him off. I think he has gone a bit too far now but it is knowing the boundaries. Sometimes he doesn’t understand some of the boundaries, what is right to do and what is wrong to do.

HT

The teacher's perceptions reflect some of the confusions and complexities which are present in Harry's own account, and demonstrate that she has observed his social skills and noted where she believes he may be encountering difficulties in establishing friendships.

Evie's friendships are selected from neighbours, her football-playing, and her membership of a Christian group. That Evie may not have conventional friendships is an issue that she herself refers to in naming friends as either much older or much younger than herself:

....her husband died and we've been quite close for quite a while. She's a bit of a dirty stop-out now coz she keeps wanting to find a bloke, so she keeps going out and stuff... She's in her sixties I think, so she's older than me!! [Laughter] And my friend Kate is in her thirties, was married and has two kids but I go out with her. In fact I went out ice skating with her and my other friend so ...but they're not my age.

E

Evie's repeated use of the word 'but' in the final sentence reveals that she may have some awareness that her choice of friendships may differ from what is typical.

Social confusion is also noted by Evie's teacher as being a perceived problem:

Last year there was a student that she was particularly friendly with. The student lost her mother and I think Evie was very protective towards her. I think it was very much appreciated by that student. But obviously I think sometimes if other people have problems she can hone in on them and it becomes all encompassing for her.

ET

The teacher says that she has observed what she understands to be Evie's caring nature, but also expresses a reservation that she believes her to be rather overwhelming in her approaches to others.

Another problem for those on the autism spectrum may occasionally be caused by others, particularly those in positions of authority, perhaps not understanding their issues and needs. This was a view expressed by Harry who felt that one of his teachers also added to the social difficulties he faced by placing him as an object of ridicule. He claimed that she would rebuke him loudly and show his work to the rest of the class. He said, 'I'm sure she could have done it so as it was not in front of the whole class or she could have like many others given me a chance.' His awareness that her behaviour was not that which characterised most of his teachers is demonstrated by his statement that she could 'like many others' have given him a chance, although it is uncertain here what he means by 'a chance'.

This problem is one that one of Maggie's sons also encountered:

Tim used to get an awful lot [of bullying] and he used to have issues, he would be sent home because he was being sick physically and that was stress. He still gets a bit like that when he is stressed but he's not at school anymore so it doesn't really happen. When he moved up from Junior School that got worse and he was being sick in the classroom a lot of the time. I explained to the school, because he was missing so much school, because he was being sick, and what it was was a nervous problem. They dealt with this by giving him a bucket to carry around. Instead of being sick and we clean it, he had to be sick in the bucket and empty it himself. I'm sure you can imagine what that did for his social status?

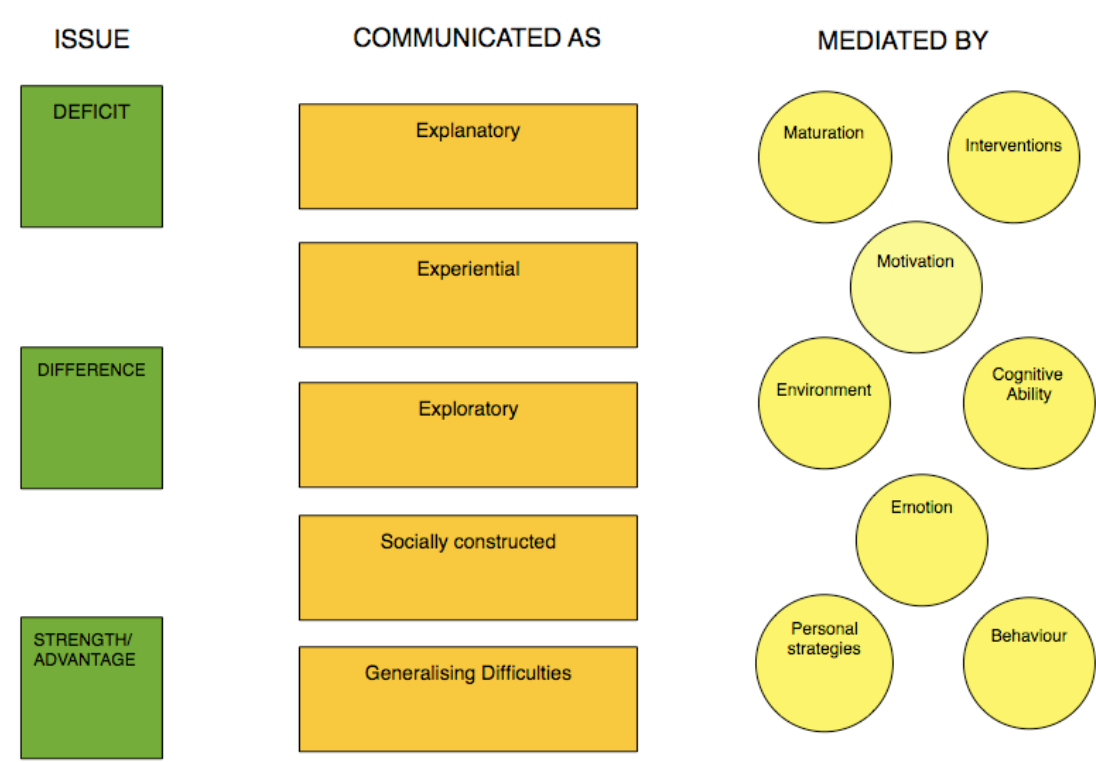
M

The school's solution to Tim's emotional problem, Maggie is claiming here, may have exacerbated rather than alleviated his problem and may have impacted negatively on his relationships with his peers. A claim frequently made by the students in this study can be summarised by Harry's insistence, 'I don't want to stand out'.

The analysis in this section has drawn heavily on an inquiry into how the 'what' of the interview data involved the 'how' of its expression, allowing the researcher insight into meaning. This supplementary but synchronous analytic investigation which involved 'how' memos in the data analysis process is now summarised, in the following diagram and explanation.

4.3.3 Communication strategies and styles summary

Fig 4.3.3. Communication strategies and styles



ISSUE The column on the left is strongly based on the question asked in supplementary research question 1, which was whether participants viewed the nature of the components of autism, in so far as they affected those on the autism spectrum as falling into one of three categories. Research supplementary question 1 was essentially the driver for all other questions. The following were clearly set out in that question, but formed the basis of many views expressed which could be classified as also answering research questions 2,3 and 4.

- **DEFICIT** – This is a position generally held in a bio-medical framework, although not confined to it, that autism represents a lack of expected or typical skills. This is the position taken by diagnostic criteria.
- **DIFFERENCE** – This is a relatively neutral position which seeks to define autism as different from typical or expected behaviours, but not necessarily defective by reason of that difference.
- **STRENGTH/ADVANTAGE** – This position notes any qualities in autism which might be thought to confer some form of advantage or strength.

COMMUNICATED AS The central column refers to the way the participants chose to frame and express their responses.

- **EXPLANATORY** This term was appended by the researcher to those communicative statements which sought to refer back to a believed expert, or widely-recognised source of information about autism. Most often, but not always, the explanatory form was used in conjunction with bio-medical explanations or definitions, as a kind of presumed objective reality, ie ‘This is what is known’.
- **EXPERIENTIAL** This communicative strategy was that most often adopted by all participants. It can be summarised in the phrase ‘in my own experience’ or ‘this is what I understand’.
- **EXPLORATORY** This was identified as a communicative style in which statements were questioned immediately after they were uttered, which gave the impression that the participant was unsure of the apparent

meaning he or she had constructed, or was seeking verification, either from a further reflexive interrogation, or from the researcher.

- **SOCIALLY CONSTRUCTED** While no means of communication can be totally free from social construction, as this is widely understood to be the underlying model of communication in general, in the case of this study the term was used to define those beliefs where a participant clearly expressed a view that had been significantly learnt from others, or a belief that they felt was generally socially acceptable or socially preferable. At times, social construction of an expressed belief, sometimes negative, was implied, rather than expressed, as can be seen in the analysis.
- **GENERALISING DIFFICULTIES** This term was rarely used in analysing the transcripts, but it is included in the category of communication, as it has a significant part to play in autism spectrum conditions and was evident in at least one important statement in the transcripts. It was used only to define those statements which revealed a problem in understanding the thoughts, feelings and beliefs of others.

MEDIATED BY This category, the third column, represents an attempt to define those factors which participants communicated as limiting, expanding, situating, qualifying or explaining what they described or expressed particularly in column one (deficit, difference or strength) often through the means of column two. Any number of these mediating factors could be included in any statement. These mediating factors might also be referred to in a loose rather than a scientifically precise way, as 'variables'.

- **MATURATION** was a recurring mediating factor. It was frequently used to account for changes in autism presentation at different stages in development.
- **INTERVENTIONS** The nature and effect of interventions was said by most participants to moderate certain possible behavioural outcomes.
- **MOTIVATION** Also known by the term conation, once believed to be the third function of mind (the other two being cognition and emotion) this embraces personal will, drive and volition. It is a central moderating factor evident in what is said by and of all participants on the autism spectrum in this study, and was seen to play a major role in the consideration of modifying outcomes.
- **ENVIRONMENT** This was a factor mentioned by all participants as being of crucial importance in establishing a situated reflection on autism. The relationship between autism and the environment in which it operated, whether this was a good or bad fit, was a major motif in all transcripts.
- **COGNITIVE ABILITY** Seen as a strength by most participants, cognitive ability, or intellectual capacity, appeared at times to work also as masking any possible problems which could be defined by a bio-medical model.
- **EMOTION** Emotional mediating factors were also evident in the data, as playing their part in constructing for participants an assumed notion of difference or deficit or strength. Emotions were seen as having positive or negative effects. The most commonly cited emotion as a mediating factor was anxiety.

- **PERSONAL STRATEGIES** These were most evident and expressed by the student participants or noted by their parents. Many students appeared to have adopted strategies which they believed enabled their survival or acceptance. One of the most common of these was 'I just ignore it'. Another was the tendency to 'zone out', or disengage attention.
- **BEHAVIOUR** Behaviour, as an expression of most of the above factors, was that judged, inevitably, as a presentation of what autism might involve, and often communicated as such.

Examples of some of the elements in the communicating strategies overall may be of assistance in enabling understanding of the complexities of responses. Explanatory as described above tended to adopt a biomedical or diagnostic pattern yet it was, in the transcripts, usually not set against but used alongside that which was Experiential and that which was Socially-Constructed. Exploratory was a means by which statements were questioned immediately after they were uttered. A participant who used several of these exploratory statements was Evie's teacher

I think that with Evie there are other problems as well like her attention seeking, or is that part of the problem itself? I suspect that probably all of these are tied up together and it's very difficult to see what fits in where? Yes. Mmm.

ET

A further category of communicated response was Generalising Difficulties.

The most striking of these occurred at the start of Harry's interview:

Harry

I think it is to do with your way you think

Researcher

Yes? So it is something to do with your mind, does your mind work differently from other people's?

Harry

I don't know other people's.

Harry's very literal and logical interpretation of, and communication regarding, the world around him, and therefore his apparently egocentric beliefs, was also referred to by his teacher and his mother.

The mediating factors were rarely stand-alone factors but several of them appeared to cluster together, often, and feed into each other. One mediating factor, motivation or conation was particularly evident in what is said by and of all participants on the autism spectrum in this study: 'sheer-bloodymindedness', 'they know their own minds', 'everything is black and white', 'tenacity', 'they all have their routines', 'got it into their head that

something is, and it is!', 'if it was something that interested her', 'I want to learn everything', 'very sure'.

Emotional mediating factors were also evident in the data, as playing their part in constructing a notion of difference or deficit or strength. Emotions were seen as having positive effects: 'If you can connect with them, they're friends for life', 'very caring', 'protective'. Yet there are negative emotional mediators, too: 'very aggressive towards people', 'get angry when they don't know what they're doing', 'if she was in one of her bad moods', 'self-harm', 'anxious', 'depressed', 'screaming and crying at the door every morning'. Just as participants appeared to believe that there could be extremism in motivational issues, so, too, there often appeared a similar 'black and white' belief associated with emotions.

4.3.4 Working within the conceptual framework

One of the essential factors in this study is the conceptual biopsychosocial framework. It recognises that it is important to examine how numerous factors in defining an educational need, or a disability, are personally constructed by groups of stakeholders and individual stakeholders within an inclusive educational framework. Initially, the data have revealed that there is one central issue, driven by the first research question, which is whether autism spectrum conditions are believed to be, by students, teachers and parents, a deficit, or a difference, or could have elements of strength. This basic question informs all other questions and can be examined under the other three questions.

What is presented, here, is an attempt to identify certain evident fluid internal and external constructions of the beliefs held by stakeholders, not only about the central deficit/difference/strength attitudes, but also how these are flexibly held, and also how stakeholders may see often conflicting or corroborating mediating factors in operation.

It should be understood that although for reasons of a systematic formulation of data analysis, issues are identified as falling broadly under the headings of the four research questions, what is evident from an overview, and what is presented, should not be defined as discrete. All issues, communicating strategies, and the positive and negative mediating factors, appear to be continually in flux, and sometimes contradictory in nature, as also they are occasionally consensual. This is, at heart, the essence of this biopsychosocial conceptual framework, which is why it has been chosen to represent the complex nature of autism spectrum conditions in relation to an inclusive educational framework.

This summarised supplementary analysis may offer further insights as exemplars of the nature of the complexities in attempting to communicate subjective views on the nature of autism. The nature of the supplementary analysis has been retained in the following discussion of emergent themes.

4.3.5 Emergent themes

Several themes emerged recurrently in an overall analysis of accounts. In the students' accounts were several repeated themes: bullying, 'difference', zoning out, special interests, and handwriting. In teachers' accounts, two issues were repeated. One was the issue of 'labelling'. Another was the observation that no two students on the autism spectrum are the same in the expression of their condition. The parents' observations were dominated by a sense of a lack of communication, between agencies and with them, and by exclusionary practices of various kinds and the long-term damage they believed might do to their children and to others on the autism spectrum.

Student Themes

1. Difference

An awareness of their difference was articulated by all students, although its expression was complex. Lisa expressed the distinction between lives of typically developing students and those with Asperger's Syndrome, 'they are half in the real world and half in their own world' and says 'I act weird.' She explains, 'they think it's weird the way I always sit by myself' and adds, later, 'I think weird is a compliment.' This is an interesting train of statements. Lisa's initial naming of 'they' rather than 'I', as discussed previously, places herself at a slight distance from what she claims to be and makes a clear distinction between 'real' and 'own' where 'Other' is constructed as real, and self is sometimes distinct from that .

This is a clearly expressed feeling of emotional and social alienation. Then there is the social construction of 'weird' which she recognises in that it is not a word she has originally applied to herself, but one she believes she has been given, socially: 'they think'. However, there is a reclamation of the word in the final comment, which has been mediated by a personal strategy of regarding it as, she says, a compliment.

Harry says that one of the problems that he has with his Asperger's Syndrome is 'it makes me stand out', adding, 'I don't like to stand out'. Kieron's mantra, as has been discussed is, 'I am annoying'. When asked what his reaction was to his diagnosis of Asperger's Syndrome he replied, 'Well it did explain a HELL of a lot! Like how come I was failing in English... and how come I was so annoying'. Kieron's view appears to be that the diagnosis was explanatory but that his view of himself, socially constructed, had already been determined. This is an important insight. Evie's expression of her awareness of difference is quite emphatic:

I know I am different, I know I am very different in fact I know I am extremely different but it is just like, the more you think you are different, the more you are, sort of thing. It's getting better as I am getting older as I am getting more wise.

E

Yet this difference, mediated by, as she judges, her maturation and growing wisdom, is largely unresolved as she says later: 'the only thing I would change in my life is the fact that I wish I could be understood and understand more'. She offers a very idiosyncratic celebration of her condition:

You see, I'm not female, I'm Aspergers.. I've got... you see when they have on the form, they should have male, female or Aspergers. I am not female or male, I don't want to be female and I don't really want to be male. I want to be like that [Aspergers]. They should have that [Aspergers] as one [of the gender categories]!

E

Evie is a particularly tomboyish young woman. She describes the difference in cognitive terms, 'I am logical, and not many female people are logical.'

The students' coping strategies in managing their differences are also referenced in their interviews with the common solution, in response to the failure of others to accept them, to ignore. Evie says, 'I tend to just ignore it':

But because I am Christian, I just follow that more than the Aspergers. We are just like, Ooh well I know that Aspergers is different and stuff but now I am not different, I just carry on as normal, sort of thing.

E

Lisa insists that she is not concerned about what others think about her, 'that doesn't actually bother me', and 'I just don't care any more', and explains her solitary behaviour as her own choice, 'I just tended to hang around by myself instead of people I was friendly with'. She also says she refuses to accept additional help because 'I don't like being treated differently to anyone else...I'm sure it would make my life easier but there are other students who could use that help,' Lisa's teaching assistant notes some features of Lisa's social competence which she believes can draw attention to her differences:

But she got bullied and she had her dress sense picked on quite badly as well. Because she does take non-uniform days literally! So it's a Red Nose day, she will come dressed up as whatever the character is, whereas other people put 'part' of it on!

LT

Harry, even though he has said he does not like to stand out, also claims like Lisa that solitariness is his own choice, 'I don't like being with other people myself', but with the emotional mediator occurring later: 'I felt really left out as I was not as good at sports as everyone else'. He answers the question of 'Do you get wound up [with other people] and manage not to show it?' with the familiar, 'No, I ignore it.' Like Lisa, he objects to what he sees as social injustice to those less capable than he is, citing SATs as one of the things he would change about school, because, 'There are some people in the class who can't pass'.

Maggie, the mother of Kieron and Lisa, has serious doubts about the need for her children to socialise which she equates with normalisation which may have a negative effect on their emotional well-being:

They try and force socialisation on them because that will make them more normal and it doesn't work. They just make them stress and stops them doing their work which they would excel at if they were just allowed to do the work part.

M

There appears to be some agreement in these accounts of difference and the ways it can be managed. Most appear to believe in 'ignoring' it. Harry and Lisa, when they rationalise, view social exclusion as a choice they have made, although Harry says that feeling left out is not comfortable for him. While he expresses a belief that he does not need other people, and resents being left out, he also appears to believe that he is happy to be with other people, albeit on his own terms. Both of these latter two also show a keen sense of social justice in appealing for help for others who may, perhaps, also feel or be 'different', and even more than they claim to feel they are.

2. Handwriting

Difficulties with handwriting are reported by, or of, all four students. It is an issue mentioned by Hans Asperger, as being a defining feature of autism. Poor handwriting was noted in all his subjects. Lisa references the injustice of

including handwriting as part of an English exam, and she later refers to herself as partially dyslexic, a condition she views as a 'bit of an impairment'. Harry also has difficulties with handwriting and his mother claims, using a biomedical explanation, that he was originally diagnosed as dyspraxic. He was, he says, as a younger child macrographic but is now able to make his writing smaller. He describes his progress in handwriting as, 'it started off as a scribble, then eventually it became words, and now it's only just readable'. The mediating factor here is maturation. He says that finds it difficult to write on lines and writes capital E and F the wrong way round and that has to attend literacy classes to try to correct this. Evie's perceived refusal to write notes in the absence of her scribe is mentioned by her teacher:

If there is a lot of writing to do then she will protest, too much writing and sometimes she will just sit there and cross her arms and refuse to write any more. I mean we do give out handouts but it is unavoidable that she can go through college without ever having to write things down.

ET

The teacher's belief here appears to be that Evie is being intentionally resistant, 'refuse to write any more', and her claim that she cannot go through the education system without taking notes is strongly mediated by environmental considerations.

Kieron did not offer any information on his handwriting, but this was supplied by Maggie, in her interview:

Researcher: *What's their handwriting like?*

Maggie: *Absolutely appalling*

Researcher: *Every one of them?*

Maggie: *Some of them are managing to write neat, Y [her oldest daughter] has got quite neat writing, she's one of my more able. A couple of the older ones have developed quite neat writing. Some of them are just not going to.*

M

[It should be noted, perhaps, that Maggie generally tends to use the word 'able' as 'socially competent' throughout her interview, rather than academically gifted.]

3. Zoning out

The theorised inability of many on the autism spectrum to sustain attention for any length of time is named 'zoning out' by both Harry and Lisa. Lisa says, 'in Maths I was always zoning out'. This she attributed to the voice of the teacher, which she says she deliberately blocked, as part of her personal strategies. Harry's account is environmentally mediated and claimed to be beyond his control. He says in the middle of his interview, 'Sometimes the

conversation goes off in my head'. On being asked what might cause him to lose attention he says, 'anything that happens'. On further questioning he reveals that he can become distracted by temperature, or by sounds, 'high-pitched or that are loud, even the ones that aren't so loud... I have quite good hearing so little sounds do seem quite loud to me.' Kieron describes his ability to concentrate as, 'I can only last for about five seconds and then I'm gone!' but does not elaborate on how and why this happens.

4. Special Interests

Some of the students' special interests were articulated and described in response to questions. Thus Evie was describing her rote memory for moths, 'I could probably identify almost 100 to 200 species of moths'. Kieron describes his collection of Manga comics, 'Mmmm Manga! I have about 200 books upstairs! I have to get rid of my books! If I kept all my books I would have around 300 to 400 and I wouldn't have enough room for them!' Kieron also excitedly mentioned his fondness for collecting parts of computers:

they were throwing out a PC that wouldn't work, they said I could keep it, but it wouldn't work. I got it to work!

K

One of Lisa's special interests is decorative boxes, 'I like to sort out and buy decorative boxes. I don't like them for certain things, I just buy a decorative box. I have quite a lot of them upstairs.' Most of the responses on special interests involve quantities as can be noted in Kieron's counting of his Manga comics. Harry's interview reveals his wide range of interests, and his one reservation, 'Most of all I like to talk about science, palaeontology,

archaeology, marine biology and all of them. Yes, I really like marine biology but I don't like squid.'

Special interests was also a perception of Lisa's teaching assistant, who chose to name these as 'switches' or 'obsessions':

Sometimes they're the most creative students in the class. But they need to sit in a certain place or they need certain amounts of help that they don't like to ask for; or they can't look at somebody because that is the person they don't like. Everybody who I've worked with who's on the spectrum has got a little obsession I call it, something that's their switch. Lisa's is Manga characters and literature and she's incredibly inquisitive about other things as well.

LT

What she named as an 'obsession' (deficit) at first, became a 'switch' and is neutrally placed as difference. Then, in the next sentence, it is framed as a strength: 'incredibly inquisitive'. This type of attitudinal slippage is a feature, as has been said, of the data from all participants. Harry's teacher also notes his inquisitiveness which she names as 'bizarre':

Ooh things like ummm, strange issues whether it's to do with the school and school policies as to the amount of money spent in education, things that I can't possibly answer. Or to do with.. the other day, he had a piece of paper and he put it into loop, he said 'Now

there's two sides, actually there are six sides to it, then he twisted it and said now there's 4 sides because it's a continuous loop, and he asked what is that called.....I don't know! Bizarre things like that and even though I know there is a word for it, I don't know!

HT

However, there was another way in which special interests revealed themselves, and this was in the hijacking of the interview by some of the participants. They selected to talk at length about one or more things which they required the researcher to listen to. This was particularly noticeable in the case of Harry and Lisa. Lisa wanted the researcher to discuss how to set up a poetry magazine, as another of her special interests is poetry. Harry wanted to talk about global warming, fossil fuels, riddles, and natural disasters. One of the teachers wanted to talk about her family. All three of these interviews were marked by the interviewees' desire at times to talk at, rather than to, the researcher. The researcher had become a captive audience.

Teacher Themes

1. Labelling

Most of the teachers spoke overtly about labelling. However they spoke about it in a slightly different way. Harry's teacher was keen to individualise each child and enable each to find their most comfortable way of learning without the low expectations that what she perceives as 'silly names' provides as

these may create barriers to self-esteem and motivation. She sees cognitive ability as the mediating factor, clearly naming this as 'he's intelligent':

Researcher: *Do you think autism is a disability?*

Harry's teacher: *No I don't think so, I wouldn't say so. I think it's just finding the right way to learn. Dyslexia and all the rest of it.... I think everyone can do what they want to, they've just got to work out their way of doing it. I think it's the same with all of them. It gets me so cross when they come up with these silly names for it everything all of the time and I think well no, everyone can do what they want pretty much as long as they find their way of doing it, it's perfectly....I mean he's intelligent, he's good with his work. There are certain things he needs to work on but he is perfectly capable, and it's just finding his way of doing the right thing and succeeding.*

HT

Lisa's teaching assistant is rather less positive and appears to express some doubts about the need to diagnose as autistic someone as 'high end' as Lisa generally. There is the slight suspicion here that she doubts the validity of Lisa's diagnosis or the need for it as Lisa is so academically capable. There is a strong sense of environmental factors as mediators in providing diagnosis or 'labels' :

I think my personal opinion is, if you've got someone who's been diagnosed and there's other people in the family or high awareness of, they've been diagnosed, but, if they were in a different family, it might have been missed and it's just their behaviour, their little oddities, which we've all got. So I think there's more people diagnosed and given a label than there probably is with a syndrome, title, whatever.

LT

She appears to believe that in labelling a child, there will then be low expectations of what they can do, which is a view expressed by Harry's teacher, however, she adds a further belief that diagnosis is a route sought by those whose children are failing due to largely familial factors:

They're not pushed very much, these students, the expectation of the school is so low and that is why I like them so much because they're going to achieve, they will achieve, because they can, why shouldn't they?Well I'm politically incorrect so I'm just going to say what I think now...I think there are loads and loads of kids who are diagnosed with stuff they don't have. I'm sorry but the amount of kids with AD/HD that suddenly get it in year 10 [laughs].... In my opinion, and this is probably why I'm downstairs [teaching assistant] and not upstairs [teacher].....five or six or more parents to the hundred kids on the register, a lot of it is family background, social economic, whatever the problems are, then the child is a problem at school, or for the family, or the doctor, and the diagnosis sooner or later happens.

The most internally contradictory interview on the subject of 'labels' was from Kieron's teacher, who, right at the beginning of the interview, said, 'I don't like labels', and complained about training sessions where people are described, she said, as 'typical dyslexia' and 'typical autism'. Yet, when she discusses her own familial experience, the slippage begins:

Well my nephew is 13 and they have been going back and forward, back and forward for years with him, about what is it. It's been said for years he was on the autistic spectrum, some people say he's too young to diagnose, other people say he's something different, but he has been recently, in the last few months they've said, yes, there you go, there is the label on your boy, he has Aspergers, which I think he also has some additional difficulties with communication on top of that.

Not only does she move across to a biomedical and deficit model, but she chooses to add her view on the 'label': that she thinks he has some additional difficulties with communication, too. She then lists the diagnoses that have been given to all her sister's children, without any question that they may be labels. She tends to the word 'is' to define the child by the diagnosis:

the oldest three all have learning difficulties, the oldest is the girl who is dyslexic and dyspraxic and the second oldest is a boy who has dyslexia, Irlen Syndrome, ADHD and Tourettes.....then there's the

third child who is either, or whatever you like to call it, on the autistic spectrum or diagnosed as Aspergers.

KT

She says of dyspraxia, 'my niece has it and they suspect I do as well'. The slippage in this interview came full circle at the end when in responding to a question about Oppositional Defiant Disorder she said:

*Ahh yes that's ringing a bell because I've heard two schools of thought on that. I've heard somebody say that **is** something, and then someone saying that we've done that because parents have to have a label on their child. This is what a psychiatrist has apparently told my sister but I don't know, obviously I have heard that second hand.*

KT

The 'label' issue is clearly a source of great confusion to this particular teacher. It is almost impossible to unpick her use of this word, as something that may be undesirable and the medical condition it describes may not exist or may be unnecessary, and the need to claim it as explanatory when the context, familial, appears to validate it.

2. No two are alike

The heterogeneity of the cohort is named as a factor by the teachers in this study. Evie's teacher is only at the beginning of her contact with the autism spectrum but expresses her experience:

...there was a chap a couple of years ago, again he had problems with concentrating and focussing on his work whereas with Evie, she produces the work, no problem. Someone outside may be putting pressure on her to do that whereas the person we saw a couple of years ago he did fall very behind with his assignments and had trouble organising himself. I don't actually think that is too much of a problem with Evie, certainly not as much of a problem with this chap a couple of years ago.

ET

Lisa's teaching assistant also offers the point of view that no two students on the spectrum are the same. With six years' close contact with these students, she has useful experience with them. In the lesson observed by the researcher, the teaching assistant was shared with a boy whose presentation was totally different from Lisa's. He talked incessantly, even to himself, and made weak jokes. His talk was commentary. He was also diagnosed with Asperger's Syndrome but was very different from the apparently lethargic and socially withdrawn Lisa, who only occasionally and reluctantly spoke to him, quietly. Lisa's assistant said in response to the question 'Are there any two alike?' :

No, no, no!! You can see if someone comes in and they've got something that a student is diagnosed with before, you can see the similarities maybe, but I wouldn't say they were alike. Because of their home environment or how they've been tutored in other schools or by other students, and that changes how you're able to help them. You may have a lot to get over first before you can help them.

LT

The teaching assistant expresses an opinion that these differences are produced by environmental factors, which form barriers to learning. This could be said to reflect a social model of disability.

Parental Themes

1. Communication issues

A belief that there were communication shortcomings, both in dealing with parents, and in interagency working, was strongly expressed by most of the parents. Frank and Gill referred to an initial failing, on the part of those who were charged with providing support, in providing information to them:

What's interesting is that a lot of the, I would describe them as authorities, education and people like that, didn't seem to know about Aspergers and they certainly didn't know how to deal with Evie, how she presented herself in terms of her behavioural issues. Mmmm, and I think

over a period of years, we've picked up bits and pieces about Aspergers and we've read books, and we've seen programmes about children with Aspergers who appear to be mmm 'worse' in inverted commas than Evie and some seem to be 'better' in inverted commas. So errm, no one has ever sat us down and said let me have half an hour about telling you all about Asperger's and all about autism and this is what it does and this is what will happen and this is how things will pan out over the years, no one has sat down and done that, particularly.

F&G

What is evident in this account is some anxiety about the meaning of the biomedical diagnosis in day to day living, and what might affect Evie's future prospects. These parents appear to feel that they have been placed in a position where information was in 'bits and pieces' which they had to 'pick up'. While this is a recurring theme in the parental accounts it is interesting that this means of securing useful information about autism is referred to by teachers, also. Harry's teacher says that she has learned about autism through picking things up, and Lisa's teacher tells of the usefulness of what students on the autism spectrum have told her. That could be said to provide a helpful additional experiential basis for educators but there is a sense in which parents may take from that lack of communication a belief that 'they didn't seem to know about Aspergers'.

However, in Maggie's case, she was provided with a pamphlet about Asperger's Syndrome when Kieron was diagnosed, which helped her realise that one of her older sons may well show those same characteristics.

However, she also claims that she experienced some difficulties in the communicative interactions between the health services and education. Her belief that diagnosis necessarily precedes school support is illustrated in her account of what happened to her youngest son:

His diagnosis through CAHMS was Global Delay and PROBABLY Autistic. But they never firmed up the 'probable' although Dr C had gone on to say that in other paperwork that he is Aspergers, and in a meeting, then, when the school said 'We don't think he has', she didn't pipe up and say 'Oh yeah, he has', she kept quiet about it. And some years later I actually got him a firm diagnosis of Aspergers, 'He definitely meets the criteria for this, it should have been done'. Dr X who is absolutely brilliant, said 'I don't mind treading on toes, you need this'. Absolutely brilliant, because then I managed to get him some help at school.

M

What is very interesting in the above is that although Maggie has a strong perception, referred to in the analysis of Question 3, that diagnosis must precede educational help, here she offers an experiential account which in part contradicts that. It is the 'school' in this account which overruled what a doctor, she says, had already written in a report. What is demonstrated here is that the roles of education and health in decision-making may not be as clear-cut as she might imagine, and that there may be other determinants in play and perhaps some environmental hegemony. Maggie also offers a further example of the weaknesses she perceives in the roles of other support

agencies, yet again involving communication shortcomings:

Social Services also came out and said, 'What help do you think you need?' 'What help is there?' and then [they] went away and when they came back they said, 'Well actually there isn't any. Have you spoken to the NAS?' I'd called them and said, 'Yes, and they said had I spoken to Social Services, and I said yes, they gave me YOUR number and everyone's', I said. They just pass the buck around and you don't really get any help anywhere. I am sure it must be there somewhere.

M

The perception that there may be communication problems between agencies and parents, and between agencies themselves as expressed by parents, is echoed in the interview given by Lisa's teaching assistant, in which she expresses a view that there may be intra-agency communications problems, also. Her account of the possible problems associated with employing a closely-attached teaching assistant for the child with ASC has already been referenced in her telling phrase, 'visible disability' She also mentioned the difficulty that may be posed by the school's expectations being too low.

However, what became more clear as the interview progressed was that she was critical of that particular school. She referred to qualified teachers as 'upstairs' which was presumably the location of the staffroom, and seemed not to identify with them. When asked about certain interventions her response was, 'A lot of these things they may know about upstairs, but I can

tell you they don't go on.' An example of this was, 'nurture groups, because we're supposed to have one here'. The suggestion was that there was misinformation about the school having a nurture group. She also, in reference to another intervention says, 'It isn't the right school to do it in [they] sit upstairs all day!' She also appeared critical of both the outreach service, and any parental worries that may have been shared with her. On the question of meltdowns she says, 'I keep getting them predicted for Lisa,' and said of an outreach worker 'she keeps telling Lisa she's going to have a breakdown when she goes to [sixth form college]' and:

so I think she struggles more with [the outreach service] - you may need to edit this!!! - and mum at home, and the school, what those three triangle elements want to do and what Lisa wants to do in the middle.

LT

It cannot be particularly useful for Lisa to be the subject of such perceived in-fighting, and while it is clear that Lisa is very close to this teaching assistant, having selected her as the one member of staff she wanted the researcher to speak to, LT appears to have a strong view of what is right for Lisa, and may perhaps have a proprietorial attitude towards her which could be seen as a barrier to other interventions.

2. Exclusionary practices

That Evie had been excluded from school, and that Harry had on several

occasions received fixed-term exclusions, and that Harry and Kieron had been home-schooled for a while was evident from the experiential parental accounts. In both cases they were home-schooled, it was claimed, because of the effects of bullying. There is evidence in these accounts of social and institutional exclusion of various kinds. Frank and Gill in a retrospective account of the difficulties Evie faced mention the factors associated with it, and the environmental factors which impinged upon it :

.... It's an impediment to her, it has been an impediment to her education for sure, impediment to forming friendships, big problem, so has it been an advantage or disadvantage? Overall it has been a disadvantage I would say... Our only hope is that.....mmm it's too late for Evie, but children who're diagnosed with Aspergers they get support and help that they want at a very very early stage. Err it was almost beyond redemption. The times we've said if only she'd been diagnosed earlier, she would have a much better education, she would have had all her GCSEs.

FG

While their belief that she has experienced considerable 'impediments' to her academic achievement, Frank and Gill also appear to believe that the exclusions which characterised her school career also impeded her social development, 'friendships'.

In some cases the exclusionary factors were framed in a within-child biomedical explanation where tensions appeared to arise between environmental expectations and a perceived feature of autism itself, leading to apparent self-imposed exclusion. Maggie refers to one of her older sons giving up his University course as a conflict between his perceived perfectionism and other elements which she identified as being in the nature of autism, and the social-academic environment:

He actually had to give up the University because he couldn't cope. It's not that he couldn't do the work because he's brilliant and all his friends that were passing the course were coming to him for help, but out of all the information you get on something, he can't learn to pick out the important stuff and that's quite a common problem, at least I found it to be. [You] just can't pick out what you actually need, and also that 'I've got to do it right'. You can't just hand in the work and that's good enough, it's good enough to get me a pass, it has got to be good enough for them. If they don't feel they've got everything in there then it's not right. So rather completely fail, just not do it at all.

M

Harry also claims to share this perfectionist tendency, 'I have a fear of making a mistake, that it's unfair to make mistakes in a lot of things', as does Lisa, 'I am such a perfectionist – I mean it never comes out perfect, full of imperfections.' Maggie's perceptions of the nature of perfectionism in her son are therefore shared by these two participants.

4.3.6 Key findings

1. There is evidence of opposed ideological thinking by all participants which appears to be at odds with any unifying theoretic. There was considerable internal slippage between what are viewed as theoretical positions on social as opposed to biomedical models of disability, often arising from an experiential position of some complexity.

This involved considerable confusion over whether elements of what they defined as autism could be considered to be deficits, difference or strengths. In some cases all three were cited for the same element. Many of the teachers, albeit in one case very confusedly, claimed to adopt what might be called a social model of disability, citing 'labelling' as a perceived problem.

One of these teachers appeared to believe quite strongly that environmental factors such as home background, socio-economic status, and differential teaching can play a leading part in the construction of difference in some children, which is then reframed and sought as a medical diagnosis. However, many family members felt that they should adopt a bio-medical stance as explanatory. This may be influenced by the fact that they claimed, against the officially-held position, that special educational needs are determined by a medical diagnosis, in their own experience.

2. All students in this study have complex responses to their autistic features and the way they are perceived. These involve, quite often, what appears to

be an emotional burden in carrying conflicting personal identity and social beliefs, considering themselves to be poorly understood, and sometimes mistreated, by others. All appeared very strongly aware of their 'difference' and the part they believed it played in their lives.

3. With the previous two findings in mind, the issue of 'labelling' appears poorly understood or poorly and confusedly expressed by those teachers who used the term. It may be a position espoused by them, a rejection of what may be thought of as an unacceptable deficit account of autism. However, they also appeared to place considerable value on what they perceived as cognitive ability in these students, thereby, by their accounts, rendering the need for labelling redundant.

This tended to work against the picture presented by the student participants in the study, who all claimed to be or feel different from other students, often in complex ways, which included several reports of being bullied or excluded. It also worked against their own awareness of sensory difference, despite the intellectual capability they may also have claimed.

4. There are several perceptions of conflicts of opinion between schools and families, and beliefs about communication shortcomings appear common. These parents can perceive that schools and colleges fail to listen to them, or their children, and fail to involve them in decisions, or operate in what they believe are their child's best interests. Often they said they felt excluded and discounted or poorly-informed.

One teaching assistant participant believed that there were also internal conflicts within school and expressed a belief in a within-school structural hierarchy which she thought both excluded and discounted her and her views.

5. Parents felt themselves to be poorly served by the professionals in their and their children's lives. They appeared to believe that those health, education and social services which are assigned to give them support were failing them and their children. Some viewed many of these support services as adversaries on occasion.

6. There was some evidence that the term 'autistic intelligence' could perhaps be of use in describing in a more fruitful and holistic way than currently adopted, the complex experiences of students on the autism spectrum. There was limited evidence that the Local Processing Bias cognitive pattern of 'autistic intelligence', as theorised in the Literature Review, could be explanatory of some of the cognitive, social and sensory differences recounted by the students.

7. There was some evidence that curricular and educational practices in general can be believed to be resistant to modification or change. This was a view expressed by several participants.

The Discussion Chapter, 5, will now examine these findings in more depth by linking them to any theoretical and evidential issues examined in the

Introduction, Literature Review, and Methodology to establish whether the findings can be considered reliable and coherent within the overall framework of the study.

Chapter 5: Discussion

5.1 Introduction

The aim and purpose of this chapter is to examine the findings in the light of the theoretical underpinnings of the Literature Review, and those presented in the general Introduction. First there will be an overview of the Methodology chapter, to examine some of the factors in the research design which may have enabled or weakened the production of useful data, and which may serve to explain any unresolved factors in the production of data.

5.1.1 Methodology and research questions

This study was very small scale ($n=11$) but employed a methodology which could produce data necessary to answer the research questions. Case-study, an intensive approach, appeared well-suited to examining the perceptions of this triad of stakeholders, as was the open nature of the questions posed. There was a wealth of useful data produced.

But it was the decision not to base the research on school premises but instead, to situate it in the home lives of the students and their parents, which marked this study as being productive of the insights which were enabled into the perceptions and beliefs of the participants. It is unusual to carry out educational research outside school premises and alters the field relations, in that it was possible for the researcher to resist being seen as an authority

figure, something which can occasionally work as a deterrent for those who are the source of the information. This also allowed ownership of the material to remain with the stakeholders, who were consulted and informed, and had a measure of control over data gathering, as they dictated which of their teachers they wished to be interviewed.

5.1.2 Data Analysis

The data were analysed under the headings of the four supplementary research questions (see **4.3.2**)

While the data analysis of under those headings appears in the previous chapter, it is the purpose of this chapter to blur the boundaries of those questions, somewhat, and to examine the main research question, '*How can autistic intelligence be recognised and accommodated within an inclusive educational framework?*' in the light of the findings, linking them to any theoretical evidence examined in the Literature Review, and discovering where any new theoretical perspectives might lie.

The supplementary and exploratory analysis of these data (see **Fig 4.3.2**) produced some unexpected findings, relating to the ways in which the various participants perceived and communicated the notions of deficit, difference or strength in autism, and the factors which appeared to mediate those views. What was unexpected is that there was little evidence of significant between-group polarity, except in the case of major innovative Findings set down in 1 and 2, and summarised in 3, which will be further discussed in this chapter.

However it should be noted these too, albeit to a lesser extent, were subject to the slippage and confusion that appeared to characterise individual views. The bio-medical theoretics of disability were presented alongside a socially-constructed view, often shifting apparently seamlessly within the discourse. This echoes a previous finding (Runswick-Cole, 2008) in which views were taken from parents attending Special Educational Needs tribunals, which was that far from categorising their child's needs and disability in terms of a powerful bio-medical theoretic, and seeking special educational provision, parents were noted to be pragmatic in their choices, shifting between stances.

While there are no direct comparisons between that study and this in terms of purpose, research question and participants, it is interesting to note that one similarity in researched perceptions: that this polarity may not be as established as it is believed sometimes to be. What was of note in this study was that all participants overwhelmingly chose an experiential communicative stance, even at times when they framed it as objective or bio-medically informed.

This, then, was the starting point of the supplementary data analysis, and is strongly supportive of the biopsychosocial conceptual framework of this study. Frith's (1992) view that autism, as a developmental condition, is mediated at all stages in any individual, by differentials of experience, motivation, maturation and compensation, was somewhat evident in the analysis of these data (see **Fig 4.3.1**)

5.1.3 Data analysis: principal research question

Analysis of the principal research question '*How can autistic intelligence be recognised and accommodated within an inclusive educational framework?*' will proceed according to the following subsections, as partially utilised to structure the Literature Review (2.1):

1. Is there any evidence that Asperger's expression 'autistic intelligence' is useful to considerations of this cognitive difference as presented in an inclusive education framework?
2. How is it recognised in an inclusive educational framework?
3. How is it accommodated?

It should be noted that in the following data analysis, it is difficult to separate these three questions from each other as each is dependent on the previous one. Therefore the analysis will proceed in a series of layers in which evidence from each part should be understood to contribute towards creating a progressively full answer to the main research question. The analysis is an iterative process.

5.1.4 'Autistic intelligence' as an explanatory descriptor of difference

What all participants in the study were apt to do was to perceive some of the positive qualities and strengths of autistic intelligence rather than label it as a deficit. Among those qualities noted was rote memory, an enquiring mind,

persistence and conation, which was unusual in itself as this particular quality is generally framed in the diagnostic criteria in negative terms as an adherence to repetition and routine. Yet it was seen as something of an advantage within an academic classroom environment. 'Works well' (ET), 'I retain information' (L), 'they know their own minds' (LT), 'inquisitive' (LT), 'I want to learn everything' (K), 'bizarre [questions]' (HT), 'tenacity' (I), 'he is brilliant' (M), 'Amazing memory' (F&G), 'I am logical' (E) were indications that as far as academic intelligence is concerned, those with average or above average intelligence may be thought to be able to succeed, despite being diagnosed on the autism spectrum.

Logic, tenacity, rote memory and a desire to learn are all factors contributing to academic achievement. It is these qualities which the teachers in this study seemed to believe would ensure success, and on which they based their positive statements:

with Evie she produces the work, no problem

ET

I think everyone can do what they want to, they have just got to work out their way of doing it

HT

they are going to achieve, they will achieve because they can, why shouldn't they?

It may be that teachers operating within this context may not share with parents and students an understanding of some of the negative effects which parents and students note. The drive towards perfectionism, leading to anxiety, may well be one of those factors, yet tangentially Harry's teacher has an opportunity to see his fear of making mistakes, and although noting part of it, appears not fully aware that Harry said he has a 'fear of making mistakes, that is unfair, to make mistakes':

you know when you are doing a handwriting piece...best piece, and I just sometimes presume that he should try his hardest and he said, 'You didn't say that!' I think yeah fair enough, I didn't point out that, yeah you should try your hardest but you know it is just trying to remember to say everything instead of just presuming.

While she is aware that his tendency to be very logical means that she cannot presume that he will realise that every piece of work has to be 'best piece' and described as such, the deeper layer of his resultant anxiety over a further failure to be perfectly correct may have been overlooked. This is a trait noted in Kaland et al (2007:90) as a possible explanation for poor performance on Embedded Figures tasks of their autism spectrum cohort. Those authors say that there may have been a tendency in these children to become anxious over committing errors, and therefore to give up, citing Soderstrom et al (2002) as suggesting that this is a personality trait which seems to

characterise those on the autism spectrum. Irene, Harry's mother, claims in her Case History notes that Harry had severe anxiety attacks starting in Year 4, with suicidal ideation, but that she was reassured by the mental health team at CAMHS that, 'children can't get depressed'. Research tends to counter that, with studies showing that severe anxiety and depression are common even in very young children on the autism spectrum (Lapota et al, 2010; Hurtig et al, 2009; MacNeil et al, 2009)

Another difficulty here, which again is noted in the literature and diagnostic criteria, but is subtle to recognise, is that Harry is taking his information purely from the words that are said. He has difficulty in interpreting paralinguistics, tone of voice, and, more particularly, facial expressions. He says he is unable to work out what people may be thinking or feeling from looking at them or listening to them and 'that is why I am always asking if they are annoyed'. Kieron also says 'I can't read faces', although his mother says that he fails to recognise them, a condition known as prosopagnosia (Grüter et al, 2008; Itier and Batty, 2009; Kätsyri et al, 2008) which is known to be a feature of autism spectrum conditions in a proportion of the group. Kieron is diagnosed with this. Difficulty in interpreting facial expression is one of the characterising features of deficits in social cognition which again is theorised to be an important factor in autism spectrum conditions.

Although teachers did not fail to note certain difficulties with social issues, they tended to resist ascribing too much importance to them, with Lisa's teacher and Harry's teacher foregrounding a liking for routine as

characterising the condition above everything. Evie's teacher noted that she tended to get up too close when talking, a characteristic which was noted during the researcher's observation, and that she was more voluble than the average student, asking and telling repeatedly. She gave a commonsense causality to this, describing Evie as 'attention-seeking' and sometimes overwhelming in her protectiveness of those she chose to befriend.

Harry's teacher, in noting some of his social difficulties again described them in commonsense terms, in that he could sometimes 'get silly' in playground in socialising with those who had chosen to befriend, the girls. Lisa's teacher was particularly resistant to the notion of social problems, despite relating that Lisa was badly bullied throughout her first years in the school. She spoke of, 'just help them to integrate and get on with the rest of them', and concluded 'Lisa has friends, she has a social group'.

Kieron's teacher, speaking from an experiential position as the aunt of a boy diagnosed on the autism spectrum appeared to be aware of some of the emotional difficulties that may arise from social failures, telling of a recent crisis in her nephew's life:

he has been doing pretty well until recently when he is being bullied, and he has hugely over-reacted and that has really upset him.. 'Cos he wants to kill the person who is bullying him, and part of him knew this was wrong and part of him didn't.

KT

Further discussion of the nature of social rejection, bullying, and its possible consequences, will be undertaken in the next section of this analysis.

What was theorised in the Literature Review was that sensory (local) processing may play an important part in social development, as social information is believed to be the most complex information to process. Therefore, this introductory view of a perceived understanding in these participants of the notion of autistic intelligence now progresses to discuss whether any issues were noted by any of the participants which might relate to sensory processing. Sensory difficulties and differences were noted by all students and parents and are a feature of children on the autism spectrum noted by many researchers including Kanner (1943) and Asperger, (1944/1991) and Ornitz (1974). Sensory processing differences have been mentioned as in need of further research (O'Neil and Jones, 1997; Leekam et al, 2007; Wiggins et al, 2009; Ashwin et al, 2009).

There was a consensus that orthography, as has been mentioned in Harry's case, above, was a serious difficulty for all four students, and in autism this is generally noted as a sensory integration problem involving the motor cortex and its connection to the prefrontal cortex (Beverdorp et al, 2001). All four of the students also claimed to be dyspraxic. Handwriting difficulty is noted in research in neurological conditions (Fuentes et al, 2009; Ben-Pazi et al, 2007; Adi-Japha et al, 2007; Mayes and Calhoun, 2007). Another theory connects handwriting ability with working memory. Where handwriting is not automatic the lack of orthographic-motor integration can claim too much of the working

memory, thus compromising the amount of memory available for composition purposes (Medwell and Wray, 2007). Evie's teacher noted Evie's difficulties, and her use of a scribe, but says that it is 'unavoidable' that she could get through college without writing things down.

Where Evie has severe orthography problems and also wears tinted lenses to enable her to read the whiteboard, Lisa's account, in which she discusses many of her sensory problems, which were unusually within her interview focussed on a deficit account, as referenced, includes a problem in taking notes in that she says she is unable to write and listen at the same time. This is another common sensory processing problem which is referenced in the literature.

A difficulty in processing information in more than one modality has been noted for some on the autism spectrum (Beversdorf et al, 2001). Jones et al (2003), for example, in a qualitative study of sensory processing difficulties expressed by five adult bloggers on the internet, quotes one of these, James, who uses almost identical words to Lisa in explaining how he can only use one sense modality at a time (2003: 118):

James used his hearing only to take in and record information in his memory:

Also, I can't take notes; I can listen or I can write, but not both ... Many of my teachers thought I was being lazy or inattentive because I didn't

take notes (and didn't look at them, and had a blank look on my face) but I was actually almost hypnotically focused on what they were saying.

Lisa says that she listens, then makes notes after she has left the classroom. This reliance on auditory rote memory, in her case, almost a form of mental recording, seems exceptional, and may possibly explain why she is unable to deal with loud voices, or heavily accented voices, which would, it could be theorised, interfere with her cognitive strategy of auditory recording.

Heightened audition or hyperacusis is a difference claimed by Harry, reflecting findings of studies on audiology and the very high percentage of hyperacusis in those on the autism spectrum, (Khalifa et al, 2004; Jones et al, 2009; Gomes et al, 2008; Rosenhall et al, 1999). This has been said to account for distractibility in some cases. Auditory distractions, Harry claimed, 'made the conversation go off in [his] head'. This brings into question the placement of a child on the autism spectrum in a large secondary school, which is by its very nature as described by Humphrey and Lewis (2008b) as 'noisy, bustling and often chaotic.' As suggested by a study by Menzinger (2009) special provision may need to be made for children with ASCs and hyperacusis in these environments. Dunn et al (2002) make similar recommendations.

What is interesting in analysing the accounts of students, teachers and parents, is that there appears to be little recognition of the students' claimed causal factors for sensory integration difficulties, and the claimed

compensatory strategies by students like 'zoning out' or using single channel rote memory, in attempting to adapt to the classroom environment, by teachers. This may be due to a number of reasons, chief amongst which could be that these students may have generalising problems and may not either know experientially, or communicate this even if they do have insight, that not all others share their processing difficulties. Some teachers may think as Lisa's teacher expresses, that it is just a personal idiosyncrasy rather than being part of the pattern of autism spectrum conditions. Maggie articulated this, when she reported countering a claim by teachers of one of her sons, that all children at times might have these difficulties. She said while she agreed, few other children had *all* these difficulties, arguably an identifiable and recognised pattern of difference.

This is an important point, and may be missed by teachers who, in this small study with its clear limitations, appear to have understandings and perceptions of certain saliences of autism spectrum conditions, and deal with those, but it is possible that they may not understand the full implications of the condition. It is possible that they may rely on a well-intentioned piecemeal rather than an holistic approach based on the emergent evidence of the data analysis in this study as revealed at this stage. The notion of autistic intelligence, with its strengths and its weaknesses, appears to be a construct which could be supported by some evidence from data. This is a tentative conclusion of this section of the analysis, which will need considerable further research corroboration or contestation. However, this section of the analysis gives some support to the term 'autistic intelligence' as being perhaps usefully

described as a cognitive difference, a pattern, which has evident sensory contributions, and may have social, emotional and communicative implications. Importantly, the data could be said to lend some support to the theorised cognitive nature of the presentation of Local Processing Bias as set out on pages **119-121**, as data reflect, in part, what was hypothesised in that section.

5.1.5 Negotiating recognition of this difference

The question of recognition of this putative cognitive difference has been dealt with in part in the previous section. It appears that although aspects of the presentation were noted by the teachers in this study, and in many cases recognised as being fundamental to autism itself, there may be a confused and poorly-understood attitudinal stance in the teachers which appears to stand in the way of genuine recognition of this educational need as it presents in schools. In fact, within this study, it does appear to reveal itself as a polarity of some significance. It is the conflict between the strongly-held belief in their own difference revealed by analysis of the student interviews, and the rejection by the majority of the teachers of 'labelling' (Finding 3).

The arguments here which are central to the issue of inclusion and disability are well-rehearsed, perhaps most tellingly by Booth (1992) and Söder (1992), an argument ultimately dismissed by Oliver (1991) as 'intellectual masturbation'. Söder (1992:269) makes a distinction between what he names as 'formal' labelling and the tendency of teachers to affix their own 'informal' (or non-) labels, as he names them. His argument certainly is in line with the

evidence from this study, where a non-label like 'attention-seeking' or 'obsession' or 'silly' appears preferred to the insight offered by examining the meaning of the diagnostic label.

An important relevance to this study is that the social aspects of schooling, including the choices by other children to exclude or bully those they perceive as different is what appears to have given rise in part to the emotional burdens these students and their parents claim they carry. This is also reflective of the finding by Jones and Fredrickson (2010) that where subtle cognitive difference occurs and is pervasive, students are less likely to be accepted by their peers if they appear more prosocial and appear to wish to make friends. This should perhaps be of concern.

Three of the four children in this study. Lisa, Kieron Harry, claimed they were bullied, as did their parents. This, they say, took various forms, not all of it physical. However, they and their parent(s) have strong perceptions of it. Research evidence is scanty although survey evidence is more congruent (Batten et al, 2006; Whitaker et al, 2007) with 53% of children with Asperger's Syndrome claiming to have been bullied (Batten et al, 2006). There are also two examples, from 19 students, offered in the Humphrey and Lewis (2008a) study, one from a graphic representation of a student's perceptions of his claimed bullying, another from a student's diary of what could be described as teasing by his peer group who suggest that someone wanted a date with him. Because of poor discrimination and coding of the children in this study, it was impossible to define whether this was the same student. One in ten parents,

in the Whitaker et al (2007) survey in that study, mentioned that their child was bullied, in the open-ended questions. Only half of the children had formed any friendship at school, and only one in five of the 'dissatisfied' parents felt that the children were accepted by their peers. Reducing bullying experiences for children on the autism spectrum at school has been said to be an important factor in reducing anxiety and depressive symptoms later in life (Rosbrook and Whittingham, 2010)

Apart from bullying, the negotiation of friendships was also cited in this study as being of some importance. Considerable evidence on his concerns about the nature of friendship were expressed by Harry in his interview. Researchers on friendships and ASC children are divided as to whether the child on the spectrum expresses more loneliness than typically developing children. Bauminger and Kasari (2000) note that loneliness was reported more often by their 22 participants, matched against 19 typically developing peers, and that it was more intense, although it was poorly understood by these children that friendship could relieve loneliness. In a Chamberlain et al (2007), study on social networks of 17 children with ASCs in mainstream schools and 380 classmates of these children, the children with ASCs did not report greater loneliness. Yet a weakness of the study, the authors say, was that it was self-selected, and these children, as noted, 'may have been highly motivated to demonstrate positive results' (Chamberlain et al 2007: 240).

Harry's teacher reported that he played more often with girls. This teacher's description of Harry's behaviour is consistent with that noted in a study of

friendships albeit with a younger age-group, that there may be a tendency of boys with ASCs to feel more comfortable and at ease with girls. Chamberlain et al (2007: 239) note:

Children with autism were more likely than their matched peers to have peer cluster connections with girls, suggesting that girls may be more likely than boys to take on a “care-taking” role among their classmates.

When the subject with ASC is a girl, it is possible that results on social functioning may be different. Girls are noted, as referenced in the above study, to have a greater social competence than boys. In girls, verbal IQ has been shown in one study to be a protective factor against social communication impairments, although this does not apply to boys (Skuse et al, 2009).

Evie’s perceived social competence is referenced by her teacher, particularly in relation to her care-taking qualities which her teacher describes as ‘protective’. However Evie says that she has no friends of her own age, but has friends who are older or younger. The tendency to make friendships with older or younger people is a recorded feature of Asperger’s Syndrome. Bauminger and Shulman (2003) record that in a friendship survey of (n=14) high functioning autistic children compared to (n=14) matched typically developing children, four of the children on the autism spectrum had younger friends, and one had an older friend, in contrast to the typically-developing children group, in which only one child had a friend outside their exact age-

group. Seven of the ASC group in that study had friends with special needs, many of these formed at school or through parent-to-parent contact. Mothers were seen as highly involved in encouraging their children on the autism spectrum to have friends and maintain the friendship. However in examining the social nature of the school setting, and the challenges said to have been presented to the students in that setting, we should return, again, to the argument on the social model of disability.

Söder (1992: 253) in reference to the way the social model of disability is employed within education, says 'oversimplified ideological application – with its assumption that disability would not have any impact on the lives of disabled persons in an integrated setting – is wrong'. In summary (:253) he claims that what critics of labelling are saying is that 'disability is unproblematic, just like any other characteristic and should not be dealt with in any special way' and calls for ethnographic research to determine whether these assumptions are correct. His account appears a little exaggerated, but there are some useful arguments. His final point that disability is related to the demands of a particular setting, ie that it is situated, are very relevant to this study, as is his observation that whether teachers choose to label or not appears to make little difference to the lived experience of their pupils. He points out, again in line with the findings of this study, that by the time a child enters school (and in the case of this study we should prefix the word school with secondary) s/he has already been socialised into disability.

All of the students in this study felt themselves to be 'different'. Lisa named herself as 'weird' and Kieron claimed he was 'annoying', Evie as 'I am different', and 'I am not male or female I am Asperger', and Harry as 'I don't want to stand out'. Some of these could be classed as reclamations of words from adverse comments, one is direct, one expresses perceived needs. All could be said to perceive in powerful terms some degree of alienation or isolation from others. On the other hand, most expressed a hoped-for degree of acceptance by others. Evie's hope was 'I wish I could understand and be understood more', Keiron's that he wished to be change the way others perceived him, Harry's, in reply to a question about how he was helping another student, 'It makes me feel that I am needed'.

The findings suggest a wealth of emotional problems in these children arising from their negotiation of 'difference' which appears to have been in part socially-constructed or reinforced by social construction. As for strategies to negotiate this perceived social difference, there is a uniformity of response from this small number of student participants. It is: 'ignore it'. This would not appear to be borne out by the number of utterances devoted to it, nor by the emotionality underlying some responses, nor by the wish to be perceived differently. It appears to be something that may resist an articulated desire to ignore. Some participants also named some teachers as contributing to that sense of exclusion and alienation, and official school exclusion is also claimed to reinforce aspects of perceived social deprivation by Evie's parents.

Booth (1992), in challenging Söder's views claims that he does not refer to the

experiences of real people or to examples of practice which may support or contest his argument. In an interesting passage from this paper (:272) one of the teachers Booth consulted says that the category 'child with disability' can be submerged within a culture of acceptance. This teacher says that in a poetry lesson about being afraid of the dark, one student asked his class teacher why some people were afraid of darkness. It was only at this point, she says that she was 'brought up short against his disability'. The boy was blind. Booth appears to be applauding the attitude of this teacher.

This teacher's response is very much in line with Harry's teacher's response about 'best piece' handwriting, and raises questions of whether students should be placed in the position of having to remind teachers, often in the hearing of their peers, that they are different. At best it may encourage a view from a peer, in Booth's paper, again written about in positive terms, that, 'I think it's more adventurous with people like that' [in the class]. It is important that his paper contains evidence from teachers and from typically-developing children, but none from a child with a disability.

Booth says that disability should be recognised without it becoming, 'the frame in which the whole personality of a pupil is frozen'. Against this argument should be placed the voice of the autism rights' activist and autistic, Jim Sinclair (1999 http://www.jimsinclair.org/person_first.htm), who says, 'It is only when someone has decided that the characteristic being referred to is negative that suddenly people want to separate it from the person.... I am autistic because I accept and value myself the way I am.' He argues that it

may be a neutral descriptor: 'this is me', and it may be others' perceptions which are somewhat at fault. This may lie at the heart of Kieron's wish to change 'the way others perceive me', and Evie's 'I wish I could be understood'. The removal of the label 'autistic' may paradoxically suggest that autism is a negative attribute, something that should not be mentioned, rather than a complex condition which can be understood.

Oliver (1991) may have a point to make in dismissing the arguments of both Booth and Söder. He says, 'A start can be made by not talking over our heads about issues that are irrelevant to our needs and by allowing us the dignity of deciding what we want to be called.' This is reflective of Sinclair's view. In dismissing the politicisation of these ideological arguments, Oliver asks people to pay attention to 'our needs' and 'allowing us the dignity of deciding'.

It is a clear message from this data analysis that perhaps the voices of those whose experience of disability and needs and difference is personal and social and emotional, may not be fully taken into account by an ideology which, in this small and geographically-limited study, appears to be tutored to reject labelling, but appears to resort to what Söder calls 'informal' labelling.

Norwich and Lewis (2007) claim that there may be advantages in educators referencing group differences. It may be useful in ensuring recognition, understanding and acceptance of what the students in this study strongly perceive as their difference. However, it should be emphasised that studies preceding this one have very rarely been strongly informed by the beliefs of

students on the autism spectrum about their condition within an inclusive educational framework, and what mediating factors may play a part in their understandings and beliefs. It appears to be important that, as advised by Oliver, there is some research into and recognition of what these beliefs may be.

5.1.6 Negotiating accommodation of this difference

All parents in this study reported some concerns regarding interventions for their children's educational needs and the means by which they were delivered. It is interesting to note that four major reports or surveys into parental attitudes about their child's happiness or otherwise at school were produced in the three years from 2006 to 2009. These were the surveys of Batten et al (2006) and of Whitaker et al (2007), the Inquiry of the Education and Skills Committee of the House of Commons into Special Educational Needs (HOC Education and Skills Committee, 2006) and the Lamb Inquiry (2009).

While the governmental reports were on special educational needs in general, there was strong reference to autism as being a matter of some concern. It should also be noted that the Warnock Report (1978) emphasised the role that parents play in their child's education, and that the Salamanca Statement (UNESCO, 1994:ix) encouraged governments to 'facilitate the participation of parents'. This is also reflected in Renty and Roeyers, (2006) Hodge and Runswick-Cole (2008); O'Connor, et al (2005) and Benson, et al (2008).

Where parents may believe, as they appear to in this study, that they have to take a clinical route in obtaining educational services (Howlin, 1998; Roades 2007) this may influence a theoretical position that autism can be seen as a bio-medical construct. That they may see services as adversaries, standing in the way of providing for their children's educational needs, as Maggie perceives, is strongly reflected in Valle (2009) where USA parents report how they had to battle for services for their children in meetings where, in one case, 16 professionals faced one parent, in a negotiating process which was perceived by the parent as overwhelming. This may contribute to a parental belief that their views are discounted or not sought.

Multi-agency working and cooperation, the route designated for parents of children on the autism spectrum is noted by research to be difficult to manage (Cameron, 1997; Brandon et al, 2006; Russell, 2003; White, 2006, Williams, 2004; Abbott et al, 2005; Featherstone, 2006; Percy-Smith, 2006; Carpenter, 2005; Preece and Mott, 2006; Montes et al 2009; Watling, 2004). Certainly there is some evidence in this study of a belief that schools and health services and social services do not appear to work successfully together nor do parents feel that information is always shared between agencies, or with them.

In one case, that of Lisa's teaching assistant, there was a belief that even within an institution, there may be poor lines of communication. She claimed that her views were probably not shared by the qualified teachers at the school. There is evidence of this belief in interviews with secondary school

students (O'Rourke and Houghton, 2008), and special needs teachers in a Humphrey and Lewis (2008b) study in which the special needs staff often referred to a rift and failures in communication with the mainstream subject teachers.

Maggie, and Frank and Gill, had seen or were seeing what they perceived as underachievement, in their child or children, due to what they believed to be failures in understanding or accommodations made for them. Ashburner et al (2010) found that the level of underachievement in typically-developing children, that is, the discrepancy between recorded intelligence and recorded academic results, was 8%. However, for children on the autism spectrum it was 54%, seven times higher, and this must be understood within the context that conventional intelligence tests may underestimate the true intelligence capacity of many of these children, as argued in Dawson et al (2007).

The Lamb Report (2009) appears to articulate the balance that needs to be sought between the hopeful views of some teachers in this study in rejecting the low expectations of these children which some schools may have, and in appreciating the need for adequate support to enable achievement. It refers (2009:35) to the need to couple 'an ethos....that focuses on high expectations for all pupils' with the provision of 'opportunities to develop social and emotional skills'. None of the schools referred to by parents or students in this study provided such an opportunity. In fact, the only social skills training that was cited, and cited as being useful, by Frank and Gill, was provided by a

psychiatric unit.

Where interventions were available and delivered, these often consisted of the deployment of teaching assistants in classrooms, sometimes in less than helpful ways. Lisa complained about one teaching assistant giving her the answers to questions, misreading the fact that she knew the answers but preferred not to put her hand up. Kieron complained that he was given a teaching assistant in lessons where he did not need one. Lisa's teaching assistant named the use of teaching assistants as making an invisible disability visible.

The deployment of teaching assistants in helping manage special needs students has been a subject of some controversy (Blatchford et al, 2009; MacBeath et al, 2006; Giangreco et al 1997; Malmgren and Causton-Theoharis, 2006; Werts et al, 2004; O'Rourke and Houghton, 2008) where they were found to be indispensable for classroom teachers, but could act as barriers to the special needs child being fully included within the classroom. Humphrey and Lewis (2008b) describe this as 'integrated segregation'. The Lamb Inquiry said that there was evidence that significant amounts of teaching assistant time was used to substitute for teacher time (Lamb, 2009).

Another theme which occurred in all participants' accounts was some perceived inflexibility in educational processes and procedures, although in the teachers' accounts this was not particularly seen as inflexibility but as 'this is what students are expected to do'. While the Code of Practice (2001)

encourages curricular adaptations few of those were made, or were perceived as adaptations even when it was clear from accounts that they had been made. Lisa was allowed, eventually, to spend her lunchtimes in the Art room. She had been allowed to move into different classes in primary school to avoid teachers with loud voices. Evie was allowed a scribe. Harry was allowed into school at lunchtime to have discussions with his empathetic class teacher. The greatest inflexibility was the insistence that these students should use handwriting, when iPad and other technologies are available and would make fewer demands on the students' claimed processing difficulties.

5.1.7 Summary

What is evident in this discussion of the findings of Chapter 4 is that there is considerable theoretical evidence to support certain aspects of the findings. In examining the question '*How can autistic intelligence be recognised and accommodated within an inclusive educational framework?*' based on the four supplementary research questions which formed the basis of the analysis in the previous chapter, there appears to be some support for the notion of autistic intelligence itself. It can be understood as a complexity of interactive factors which appear to present a learning style which has certain differential characteristics from the typical, whatever personality, psychological and social factors may influence its presentation. 'No two are alike' is a useful guide to its heterogeneous presentation, but is a truism that could be said to apply to all people, with or without a named disability.

Whether its nature should be regarded as a deficit is strongly debated, both in these findings and in the literature. There is research evidence, and evidence here, that it is believed to confer some advantages. However, there is also evidence that some of the students and parents perceive and acknowledge sensory deficits which may not be immediately apparent in a school environment, and which may interact less successfully with that environment and all it involves, to erect barriers to learning.

Also reflected in the literature is a debate over recognition and accommodation of this difference. The findings reveal the argument over the social or biomedical models of disability to be less polarised in experiential recounting of beliefs and understandings than appears to be presented in the literature. However, the poorly-understood question of labelling is central to the findings of this study, as their 'difference' was strongly perceived by these students. There was evidence that the argument presented by Söder, who claims that teachers themselves produce their own 'informal labels', has some support from these findings. The argument presented by Booth, which promotes a belief that disability is strongly socially-constructed, appears to have some support, also, but seems not to reflect the complexity of mediating interactions.

What may be absent from Booth's argument could be the question of whether positive teacher attitudes towards inclusion and mainstream placement alone can remove socially-constructed varieties of stigma, and bullying, social and official exclusion, and personal emotional burdens, from the lives of students

with autism and their families. As Bernstein said (1970) 'Education cannot compensate for society'.

There is also a question raised through these findings and discussion as to whether current educational practices have the sophisticated interactive and cohesive strategies, at every level of intervention, and throughout all agency policies, to implement successful change for these students. This possible change is conceptualised as resulting from their acceptance by all others in the educational social arena of school, leading to achievement in that perhaps challenging environment. Whether these students are presenting challenges to the system, or whether the system itself is creating challenges, is a question that should be asked. This issue will be dealt with more fully in the concluding chapter.

Chapter 6: Conclusion

6.1 Reflexive accounting

At this point it is necessary to revisit the aims of the study, and the structure of the study, to examine whether the total design enabled and made coherent those aims. This particular study was always a work in progress in which new meaning emerged at every stage and was subsequently incorporated, where it emerged. The thesis itself was regarded throughout as a flexible body of work which retained the plasticity to respond and change as further insights were gained. Every chapter has been through many processes of revision, some extremely intensive. The most intensive rewriting and redrafting work was undertaken after data, which produced unexpected findings, were examined and analysed. Most of these chapters have been through ten drafts.

Certain expectations were raised by the first draft of the Literature Review, which was completed initially on this researcher's prior knowledge of autism. What the data produced, however, was a series of major additions, extensions, changes, and new and previously unaccounted understandings to the fluid Literature Review, changing its focus and direction. The initial belief of this researcher that Theory of Mind explanations of autism were the most compelling, was reconsidered, and sensory issues emerged as appearing far more important in evaluating the nature of autism. The entire work has been instrumental in altering the prior beliefs and summations of autism spectrum conditions held by this researcher.

This is, or should perhaps be, the role of qualitative research. It exists to offer insights into the differentials between what we think we know and what we may learn, epistemologically, by deep investigations of lived-life experiences, from others. It should also be a reflexive, fluid process in which the researcher is open to and accepting of, the research experience itself. It has been so in this case.

It should also be noted that in the course of writing this thesis the rate of published papers on autism has increased far beyond expectations. Autism is itself a highly-evolving and very fast-moving area of study with at least 3,000 papers published each year. An iterative approach was necessary to keep pace with the wealth of new research material which appeared monthly. Although neuro-scientific evidence may be merely peripheral to the core foundations of this study, nevertheless it was necessary to read and understand those findings, too, and to incorporate them where necessary.

Finally, what should be taken into account is the necessarily innovative nature of this study. Rather than working in a known and well-researched field in which some guidance can be taken from prior studies, and those researchers who have gained expertise, this study has approached the subject of autism from a previously unexplored direction, that of a theorised 'autistic intelligence' based on the writings of Hans Asperger.

No previous research study has linked together this triad of stakeholders, to gain insight from students, their parents and their teachers on what they

believe to be the nature of autism. The study can both reflect and contest, in some tentative but illuminative ways, the evidence which has, to date, been gathered in a piecemeal fashion, by a variety of means and methodologies, from one or two parties in this triad, but never by all three in a qualitative study.

One of the issues facing researchers in autism is that they may have difficulties in taking evidence about social and emotional matters from the younger cohort of this group who may have semantic and pragmatic difficulties with social communication. It was therefore necessary in the course of this study to design a method by which it may be possible to take soundings from children with limited communicative and expressive language abilities.

It must be said that it is rare for a PhD thesis, written by a single researcher, working in relative isolation, to have attempted this degree of innovation in subject matter, method and design in order to uncover information which may be useful in catering to the educational needs of children with autism spectrum conditions in an inclusive educational framework. It is to be hoped that this exploratory research may inform the design of further, larger-scale qualitative research studies into this important issue.

6.1.1 The aims of this study

The study sought as its first priority to investigate the notion and nature of 'autistic intelligence', and whether this could be both recognised and accommodated within an inclusive educational system.

The naming of autistic intelligence rather than autism was in order to establish the nature of the research approach. The intent was to divorce autism from its connotations of disease or disorder, examining it not principally from the surface behavioural deficits which must be presented in diagnostic criteria for medical purposes, but to seek to clarify the nature of the cognitive difference which those with this condition appear to have. 'Cognitive difference' is the position recently taken by many researchers in this field in explaining the nature of autism. This is why it was also, here, named as an autism spectrum condition, rather than as an autism spectrum disorder. These modifications to nomenclature were important in establishing that the focus of this study was to facilitate understandings in educational practice.

6.1.2 The Literature Review

An important feature of this study was its lengthy examination of the known theoretical basis for the concept of autistic intelligence. What was discovered in the Literature Review was that over the years since Kanner and Asperger recognised autism, the theoretical underpinnings of this named and manualised disorder have converged to a great extent. Originally it appeared that three competing theories were offered: those of Theory of Mind, Weak Central Coherence, and Executive Dysfunction, with minor theories including Enhanced Perceptual Processing. Supported by neuro-scientific findings, a

consensus, discovered during the writing of this thesis, is developing, that over-and under-connectivity in brain circuits may be a core feature of autism, a theory named Local Processing Bias. The theory would appear to explain the sensory underpinnings of a way of thinking which may tend to prioritise perception over conceptualisation and editing for meaning-making. This in itself could support Asperger's term 'autistic intelligence' as being a useful term to employ when considering a means by which this difference could be understood by educators. The Literature Review revealed a wealth of theoretical support for such a concept.

6.1.3 Methodology

The study used an interpretive paradigm, in an effort to discover the perceptions of autism held by three groups of stakeholders: four students on the autism spectrum, their parents, and their teachers.

Although small in sample size (n=11), it allowed an in-depth exploration of beliefs and perceptions of the three groups, a noted feature of case-study research approaches which aim to reveal the understandings underpinning complex issues. Case studies are capable of reflecting multiple views, and identifying where gaps in perceptions and understandings might occur. Moreover, in order to enable greater reliability, the interviews with the students were not carried out on school premises. This placed the researcher in the home life of the students and their parents. This design element produced rich data.

6.1.4 The conceptual framework

As the primary focus of the study was social constructivist, rather than biomedical, the flexible biopsychosocial model was used throughout, as initially a position taken and promoted by Leo Kanner in his descriptions of what constituted autism. This model recognises any biological components of a divergence from what is typical, yet understands that many environmental factors interact with these, temporally, developmentally, and continually.

This theoretical position also recognises that to be blind to an invisible difference may not be a means to enable social justice. It can perhaps only be enabled by full recognition of the divergence which then allows for environmental accommodations to be made. This theoretical framework, it seemed, was the most logical way to scaffold an investigation into the nature of autism as cognitive difference, its possible challenges to conventional education, and the role that pedagogical adaptations were perceived as playing. An awareness of the biopsychosocial interplay of within-child factors with environmental elements was also illuminating in the examination of data and their analysis. This will be discussed later.

Throughout this study, a high degree of internal consistency was built around this theme of autistic intelligence as cognitive difference and its recognition and accommodation. The researcher wished to discover what the stakeholders thought, wished for, believed and perceived regarding education within an inclusive policy framework which has been adopted as one which

will enable all children to be included not merely in presence, which might be viewed as social tokenism, but in participation, acceptance and achievement.

6.1.5 Data collection and analysis

Data were collected, in part, by interviews with each participant, in which four questions were asked:

1. What do you know about autism spectrum conditions?
2. Where did you gather that information from?
3. Do autism spectrum conditions lead to any problems?
4. Are autism spectrum conditions a disability?

Following transcription and examination of the transcripts, data were analysed under the headings of the four research questions. However, what was noted at this stage was that answers to the first research question: *Do professionals and parents, and children on the autism spectrum regard autism as a deficit, or a difference, and is there any recognition of the skills and strengths and advantages of this condition?* underpinned an attitudinal stance, the motif of which permeated answers to all other research questions.

Whether autism was a deficit, a difference or an advantage was the issue which was prominent in all discourse from all participants, who used a variety of communicative styles and strategies to convey their views, and a variety of 'mediating factors' which were referred to as playing some part in moderating

in some way the differentials which were thought to impact upon the presentation of autism. As an illustrative supplementary analysis of the ways views and beliefs were held and expressed, this was interesting and illuminating for two reasons.

First, contrary perhaps to expectations, all participants, from all three groups did not hold one clear view which could be said to reflect a single theoretic, either that of a biomedical approach, or that of a social model, but all expressed their beliefs in complex and sometimes confused ways, at times contradicting what they had already said. All participants had considerable recourse to experiential report. In all transcripts there was constant shift between bio-medical and social models, between deficit and strength issues, and the interactions of variable elements such as maturation, motivation, cognitive ability and environment, in particular, were thought to be strongly influential in moderating or conveying beliefs on outcomes. It was this second element which appeared to reflect in some ways the biopsychosocial framework of this study, in which fluid interactions rather than static oppositions have proved useful in attempting to explore the complex condition of autism as a developmental condition, variously expressed according to temporal, personal or environmental factors, factors both personally intrinsic and extrinsic.

This illustrative supplementary analysis was employed, where appropriate, to underpin an analysis of responses to the four research questions from which certain thematic patterns emerged. These were further explored under the

overall research question, '*How can autistic intelligence be recognised and accommodated within an inclusive educational framework?*', where the issue of whether 'autistic intelligence' could be a useful term to express the complexity of ways in which autism challenges conventional educational practices could be explored, and whether this could be recognised and accommodated within an inclusive educational framework.

6.2 Significant findings

Significant findings were that the concept of autistic intelligence appears broadly to conform, according to what these participants in general believe, to the hypothesised theory of Local Processing bias. That is, it seems to be perceived as a cognitive difference which is distinct and atypical, and has a strong sensory/perceptual style of information processing, but may involve social difficulties, and perhaps unrecognised processing difficulties and some skills. It may be a useful term to use, in order to explain autism in a simplified yet holistic manner to educators.

Currently, there appears to be some resistance to recognition of this well-supported theorised processing style, with a general, if a tentative and evidentially-recounted only, assumption that average intellectual ability and personal strategies are sufficient to enable academic achievement. This view was expressed by most of the participants in this study, but was consistently strong in the teacher group. Intellectual ability was perceived to be the outstanding defining factor in scholastic success yet the accounts of all parents and all students were also replete with reported additional and poorly-

recognised difficulties in attempting to conform to social and sensory demands placed on them by schools. This was where gaps in beliefs and understandings were seen to exist. One of the aims of this study was to discover gaps in understandings.

Some teachers in this study appeared to hold a confused, and in the light of some contradictions noted in their accounts, not deeply-held, but perhaps loosely-espoused and rather glib view of 'labelling' theory. This may possibly stand in the way of a recognition of students' differential adaptations to school environments, which could theoretically in turn undermine attempts to accommodate difference.

Yet all students in this study had a clear and strongly-expressed, often emotionally-charged, view of their 'difference'. It was perceived as being the factor which alienated them from others and alienated others from them. As far as it is possible to determine the reason for this belief, it appears, in part, to be socially-constructed within and sometimes by a school environment, which their evidential reports say may have excluded them in some way. Parental reports and on occasion, teacher reports, appear to lend support to this view. Bullying was a perceived feature of most of their school lives, although in these particular accounts, this was more likely to occur at a primary and lower secondary level. Two students were officially excluded from school, one permanently, and two were home-schooled for part of their school career. Although students claimed that they ignored this alienation, they also strongly expressed a desire to change the way others perceived them.

An unexpected finding was that while there were some disagreements among the three groups of stakeholders about what autism meant and how best it could be accommodated within inclusive educational practice, many of them, including teachers, expressed beliefs about the inflexible and non-communicating way that educational services operate and their apparent powerlessness to change this. There was a clear perception in these teachers that the curriculum must be adhered to and could not be adapted to these students' needs, for instance in offering an alternative to handwriting, a finding that runs counter to guidance in the Code of Practice (2001).

Parents in general felt often that their views were discounted, that services were uncooperative with each other and with them, and that a burden of responsibility for their children's wellbeing was placed on them, with inadequate support or understanding. Many parents and students also expressed reservations about the deployment of teaching assistants as an intervention of choice to manage autistic intelligence. The teaching assistant interviewed expressed a belief that some schools tend to marginalise learning support staff, and believed that Learning Support Units were inadequate in supporting autistic intelligence.

Therefore, the two clear messages from this small group of stakeholders is that first there appears to be some consensual understanding of what may be described as autistic intelligence, with sensory/perceptual and social/communication factors impacting on information processing, despite

what is thought to be average or above average intellectual ability. The second is that the environment in which autistic intelligence may be required to operate, within an inclusive educational system, is in this study often perceived to be inflexible and at times even inimical to students with autism spectrum conditions. This would appear to be in complete opposition to what the inclusion agenda is said to provide.

An additional very significant finding emerged from the pilot study. It is that it may be possible, through the use of the projection techniques as outlined on page 239 or similar techniques, to take oral evidence from children on the autism spectrum whose communication skills may be limited. Although they may not be able to offer conventional verbal insights into what they feel and believe or why, they may be able to communicate in indirect ways how and what they feel. The methodological innovation developed here may be of considerable use to further research on children on the autism spectrum.

6.3 Limitations of research

This research, as in many cases of research studies in autism, was very small scale, which could be said to be a limitation. However, design methodology can help make even small-scale studies capable of generating useful illuminative data which are often absent from the literature on autism. While surveys are useful, and while this study in several ways bears out the findings of some of them, they are limited to questions which have been pre-prepared

and are less likely to produce insights into the lived world of beliefs and understandings as the substrate for the way people act.

This can only be done by exploratory qualitative studies. This particular exploratory study was, however, weakened by its restricted methods of data collection, and its restricted interview schedule, weaknesses which should be addressed if any further similar study is proposed. The keeping of diaries by student participants could be usefully employed and longitudinal studies with a repeated interview schedule would be most helpful.

In addition, the sample investigated was particularly heterogeneous. While this seriously limits strong claims to transferability, what should be said is that in a small and diverse participant group, as this was, one would not have expected, perhaps, the degree of consensus which appeared to arise on some issues. That was a striking finding, although it may be influenced by geographical limitations.

Another possible limitation of this study was that two of the children were siblings, therefore only three parents were interviewed rather than four. While the inclusion of their mother, with what is clinically described as a 'multiplex' family, was valuable in some ways in generating data which ranged over a long period of time and over a number of different perspectives, as she discussed many of her family of 13 children, the fact that this participant was mother to two of the children in the study led to the exclusion of a possible

other whose beliefs and understandings may have been quite different. An additional point of view may have improved the trustworthiness of the data.

It was also, as referenced, a limitation of this study that all participants were from the same relatively small geographical area. The policies and practices claimed as encountered by participants in this study may be very different from those encountered in other local authorities or over a larger range of local authority schools.

6.4 Implications for further research

Some of the implications of the findings in this study might usefully be explored further, as suggested above, especially those findings which were unexpected, or particularly strongly felt or believed. The questions which might be raised by larger scale further studies could usefully be:

- Is the employment of the term autistic intelligence useful in the training of teachers?
- How do perceived sensory/perceptual processing differences in students with autism spectrum conditions impact upon performance in and engagement with schools?
- What strategies might be useful in enabling students on the autism spectrum to negotiate their 'difference' among their peer group and find acceptance within it?

- What intervention alternatives to the use of teaching assistants to assist those on the autism spectrum are there in UK secondary schools?
- Does the use of assistive technology such as word processors improve the classroom performance of students on the autism spectrum who claim to have handwriting problems?
- What might be the ways to improve the participation of children on the autism spectrum, and their parents, in educational decision-making, and how could their views be obtained?

6.5 Summative review

There was a belief among stakeholders that currently the systems in place for first recognising, and then accommodating what might be thought of as autistic intelligence in inclusive education are largely inadequate. However, there was considerable confusion in formulating and expressing views on why this might be, or how recognition and accommodation could be negotiated. One of the barriers to an understanding of this complex problem may lie in an espoused and poorly-understood adherence to a rejection of 'labels' by some teachers in the study.

Whether that view is widespread among teachers cannot be known because of the limitations of this small-scale study, but such a view, even within this small and geographically-situated sample, has several implications. It implies

that a label attached to a form of atypicality can be thought to be a necessarily unacceptable indication of deviancy, rather than often a neutral, or even helpfully informative, indication as to what interventions might accommodate that pattern of difference. Rejecting this label can promote a reluctance to engage in further professional development to investigate what the label might mean. It may lead to conforming to a normalising agenda in which expectations of typicality may be promoted, thus standing in the way of imaginative adaptations and flexibility. Moreover, it cannot be helpful for students who claim to be aware of their difference, and to have been made aware of it, in part, by others, sometimes with serious emotional implications, to have that difference denied or ignored. It is significant that many of the children in this study claim to have been bullied within an educational environment in which some teachers may consider that their own apparently confused rejection of labelling is a panacea to what may sometimes be peer and official rejection of the students themselves.

An important factor in assessing the trustworthiness of this study is that its main findings are broadly reflected in a larger scale (n=40) three-year ESRC-sponsored study undertaken by the University of Manchester, 2008-2010, the results of which have been disseminated in a series of seminars and on a website http://asdinclusion.info/ASD_Inclusion/Seminar_presentations.html in February 2011. While that study was schools'-based, rather than home-based, and did not specifically seek the views of parents, many of its conclusions are very similar to those generated here. Social problems, including peer rejection, bullying and isolation, resulting in part from a lack of

awareness in others of what autism constituted and a failure to accommodate difference, were strongly noted in that study. Also noted were the effects of the condition on learning. Although sensory difficulties did not feature in the complexity noted in this study, 'poor motor skills' was noted by teachers of those students. An important factor examined was the students' attempts to negotiate difference, an issue strongly highlighted in this study.

In a recent report from the National Foundation for Educational Research, the authors (Wilkinson and Twist, 2010:15) conclude: 'In order to promote equal opportunities and achieve a truly inclusive educational environment, teachers, therefore, require a level of knowledge about the specific educational and assessment needs of ASD pupils'. This conclusion is very much in line with the conclusion of the current study.

Teacher knowledge about autistic intelligence and its possible impact on educational achievement, rather than rejection of labelling, is the bedrock on which true inclusion could be built. Recognition is crucial. Then, there may be a need for schools to constantly adapt their practices in line with a student's requirements, rather than expecting adaptations from those who may have significant difficulty in making them. A tolerant understanding of, and working with, the concept of autistic intelligence may enable the 'difficulties' these children present to the 'school system' to be resolved. It may encourage the notion that the difficulties may be mutual in nature and open to mutual remediation.

Appendix 1: Case Histories

1. Family A

Adam is 7 years old, and lives with both his parents, and a brother, Ben, who is 12, in a modern detached house in a semi-rural location on the outskirts of a Midlands' city.

Ben was diagnosed with classic autism after regressing, in language and social skills, from the age of three, and attends a special unit for children with an autism spectrum condition. He is now non-verbal, has a high-pitched hum, Ben was diagnosed at the age of 4, and this in turn led to an early diagnosis for Adam, at around the same age, although his diagnosis is 'on the Asperger side of autism').

Adam is verbal, and a good reader, although there are some serious pragmatic limitations to his language skills. He is sandy-haired, freckled, a joyful child with a ready smile, and a tendency to squeak when laughing. He flaps his hands noisily when excited. He attends mainstream primary school.

I interviewed his mother, to obtain case history. She explained that Adam could not roll over by the age of six months, but would indulge in what she called 'moleing', a word of her own invention, which she demonstrated by lying face down on the carpet and moving her arms and legs in a horizontal star jump. He was making no effort to walk by the age of 14 months. She was convinced from when he was six months old that he also had autism, and that he appeared likely to be more autistic than his brother. He finally walked at 22 months and began to talk at age two. His eye-contact was intermittent, and he rarely used his finger to point either to share or to request.

Adam has a statement of special educational needs, which gives him a full-time teaching assistant, and lunchtime supervision.

2. Family B

Evie is 22 years old, and lives with her adoptive parents, and her birth brother in a large detached house on a genteel housing estate in a rural town close to a Midlands' city.

Her adoptive parents, Frank and Gill, had first adopted her brother, who is two years older and had originally been fostered by family relatives while she had been placed in foster care until the age of 15 months with a single mother

foster parent. At this stage her birth father was jailed for sexual relationships with some of his older children and it was decided that the children were no longer safe with the mother. Frank and Gill were asked if they would be willing to adopt her, in addition to her brother.

Frank and Gill enjoy a very comfortable socio-economic status. Both are very capable people in their early 60s.

Evie is tomboyish in appearance, and wears tracksuits and carries a sports bag. She has short dark hair, and a very attractive face, despite her tendency to androgyny both in dress and manner. She has a range of very evident facial and verbal tics.

She talked and walked at age-appropriate times, and was both talking and walking by the time she was adopted. Her problems were evident at the start of school, when her parents who had believed her waywardness and tantrums were trauma-related were called in to see the educational psychologist.

At school Evie would destroy both her own and other children's work, and at home had what her parents described as 'tantrums' in which she would foam at the mouth.

A relocation and promotion for Frank brought the family to the Midlands, and the added disruption appeared to have worsened her behavioural difficulties. She was excluded several times, but in her final year at primary school had a

teacher who was extremely organized and gave her 'stability, attention, and control' and her behaviour improved. She was referred to a psychiatrist who diagnosed probable AD/HD and prescribed imipramine which eventually seemed to help with her insomnia. At the same time she was given a statement of special educational needs which did not cover lunchtime supervision, and at these unstructured times of day she was liable to behave badly.

Gill and Frank describe her Upper School experience as 'dreadful' and she had 'no help'. She was formally excluded. After leaving school with no exam grades, she began a Foundation course at a College of Higher Education, but attacked another student with a piece of wood. In a final incident a meeting was called about her and two members of staff attempted to stop her as she was trying to get to another staff member whom she liked and she pushed into them, causing one to fall to the floor and injure her back. She was asked to leave.

In the years since leaving school she was seeing a psychiatrist and was eventually referred to a residential unit for children with severe mental health problems after she had taken an overdose of pain-killing drugs. As an in-patient she made several attempts to abscond, and was self-harming, but was given a little schooling and some social skills training which appeared to help her. It was also here that an informal diagnosis of Asperger's Syndrome was made. A formal diagnosis of Asperger's Syndrome was made when she was

19. She also had a diagnosis of dyslexia for which she now wears tinted lenses in her glasses so that she can read the whiteboard.

For the last two years she has been taking a BTEC National Diploma course in Applied Science, and is currently achieving a Distinction, in a college of Higher Education where she has 'great support' from teaching staff and her own NAS- appointed teaching assistant who acts as a scribe for her during classes.

3. Family C

Harry is the 11-year-old son of a City Councillor and former nurse, Irene. They live with his two younger sisters aged 6 and 7, and Irene's second husband, Jeff, in an ex-Council property on a council housing estate on the borders of the city and its surrounding county.

Harry is very slight, awkward, prudish and almost genteel, with a marked impassive stillness of face and body, a quiet monotonous voice, a tendency when we meet to try to pull his viscose shorts over his knees as he sits and speaks, and an adult gravitas, although a rapid and sometimes stumbling vocal delivery. Throughout our interview, he never laughed, or smiled, and constantly tried to control the interview away from the questions I was asking, to the subjects he wanted to talk about. Sometimes, he was unable to listen,

visibly engaged in 'zoning out' with a blank lateral stare, losing the thread of the conversation or the question. His eye contact was variable.

Irene is the only member of her immediate family not to have been diagnosed with schizophrenia. She says that she knew from the age of two that Harry was on the autism spectrum but that she had to evidence this, and from that time kept a record of his developmental problems. He was diagnosed with a squint before he went to school,

She says that Harry walked at 10 months, although he was a 'toe walker' for many years, did not speak, nor babble, nor communicate generally, and did not use proto-declarative pointing. He opened and shut his hands to ask for things he wanted. At the age of 33 months he first spoke, saying, "I don't want that, I want a piece of toast." From this first communication, he 'never shut up', although he asked constant questions about things she could not answer. He asked about barometric pressure and where the winds came from. At play-group and school he would not play with others, he 'didn't do friendships'. He built Lego in neat repetitive colour-defined lines and cubes.

From the age of seven, he was assessed by occupational therapists, and found to have poor fine motor skills, because, it was said, 'he tries to do it too quickly'. He was diagnosed as dyspraxic. He has seen five different specialists, including Speech and Language therapists and orthopaedics for his walking stance. He is reported to have sensory issues which differentiate him from his typically developing peers. These include visual defensiveness to

bright lights, the tendency to see colours in peripheral vision, times when he can see perfectly and weeks when his vision is impaired, tactile defensiveness against wool, labels in clothes, water on his head, unusual reactions to heat and cold, oral defensiveness to food textures and will chew food until it is 'liquidised'.

He had developed serious anxiety problems. In Year 4 he was described as presenting 'challenging and anti-social behaviour' at school, and was correcting the teachers. Towards the end of this school year he began school-refusing, self-harming, head-banging, thumping and scratching himself, and biting his inner arms. He would ask, 'How bad is it going to be in the morning?', and developed what Irene called 'black thoughts' saying that she would be better without him and that she would have more time to be with his two younger sisters. Around this time he befriended a boy who felt 'different' and was bullied, a state of affairs that Harry felt very angry about as he said it was 'unfair'. The friendship appeared to stabilise his mood for a while, but then this boy began to shut him out, and then began to bully him. Harry's mood disorder worsened. He asked his mother how many tablets he would need to take to die, and how much water would he need to ensure that he drowned himself.

After a series of assessments at the Child and Adolescent Mental Health Unit (CAMHS), the paediatrician gave a diagnosis of ADHD (Inattentive type) and Asperger's Syndrome. Irene was given family support to help her understand the key features of these conditions. He was given a short course of cognitive

behavioural therapy (CBT). At this point, as he was beginning to respond to treatment with Concerta (methylphenidate) and CBT, the doctor who had diagnosed him and prescribed for him left CAHMS. The new team did not believe in any 'within-child' mental health issues in children of Harry's age, and took the position that any apparent problems in these children were caused by inefficient parenting. The CAHMS team had told her that 'children can't get depressed'

Harry, following the withdrawal of his ADHD diagnosis and medication had to be home-educated, although he was unable to concentrate or settle. Eventually he returned to school, where a very structured, helpful, and rigid teacher was able to engage with him, and provide him with security and understanding. During the two years from the onset of his mood disorders, Irene had been applying for a Statement of Special Educational Needs. The assessment was refused three times, despite the fact that from the first refusal she began to catalogue and record, efficiently, all his problems at school and at home. His school told her that as far as they could see, his needs were not evident and that he was behaving most of the time at school quite well, although most of the other children with educational needs were attaining at a lower level.

Because her request for Harry to be assessed had been refused three times, she applied to a SENDIST (Special Educational Needs and Disability Tribunal) for a decision on whether Harry should be issued with a statement. The Tribunal was set for 9th of July, 2007. Irene was elected as Councillor in

late June, 2007. The Local Authority capitulated, before the Tribunal date, but after the election, and decided to assess Harry for a statement of special educational needs. Throughout this protracted negotiation between school, the Local Authority, and Harry, Irene was a Governor at Harry's school.

4.Family D

Kieron (19) and Lisa (16) are two of the 13 (ages 28 to 7) children of Maggie, who has been married twice and is now a single parent. All 13 of the children are mixed-race (Asian/White British and Eurasian/White British). Maggie is White British. Only three of her children do not have a diagnosis of dyslexia or autism spectrum condition. One, attending Art College in another city, is also M/F transgender. Two of the others have been designated Gifted and Talented, including Lisa who also has an autism spectrum diagnosis.

Maggie left home when she was 16, taking literally her mother's instruction to 'get out' and was for a time homeless. She describes herself at school as 'that weird kid' and says that she went to school to escape home and vice versa. She is gentle, very intelligent, thoughtful, and extremely capable, a loving mother who describes her life with her children as, 'I collect kids.'

The family is housed by the Housing Association in a 6-bedroomed house which was formerly an hotel, and is run-down, but adequate. The siblings, to are Netta, 7, awaiting an autism diagnosis; Owen, 8, diagnosed with global developmental delay, probably autism; Polly, 10, who is awaiting a possible

diagnosis of Asperger's Syndrome; Queenie, 12, diagnosed with an autism spectrum condition who is also Gifted and Talented; Lisa; Rachel, 17, undiagnosed and 'copes'; Kieron; Simon, 20, diagnosed with an autism spectrum condition and chronic depression but the most intelligent of her children who is unable to face life outside of their home; Tim, 22, diagnosed with Asperger's Syndrome, who dropped out of University after the second year of his physics degree; Una (formerly Robert), 24, diagnosed with hyperlexia, dyslexia and dyspraxia, currently studying photography; Victor, 25, dyslexic, who studied computing; Winnie, 27, dyslexic, but a successful graduate; and Youssef, 28, undiagnosed, in work, and able to live away from home but who returns regularly for food and to have his washing done.

She was first very aware of Kieron's problems from birth. He had problems with eye contact, and his speech was indistinct, becoming too fast when he was excited or upset. Kieron had tics, flapped, and enjoyed turning round in circles, and the development of speech was late. He had grommets in his ears at the age of eight. At this time he was very badly bullied at school and eventually had to return home for lunch because of his problems in unsupervised times. The school took little notice of her concerns, telling her that 'the children are just playing,' and 'he screams so loud, that's why they pick on him.'

Kieron is overweight, casually-dressed with a round face, unkempt, with a humorous manner, and an engaging personality, and who likes Yugioh and Manga magazines, was eventually diagnosed with an autism spectrum

condition at the age of eight, shortly after which Tim was also diagnosed, followed by Simon. He was offered a statement of special educational needs for 25 hours support per week, but actually had no help at the Primary school. None of the other children was ever offered a statement of special educational needs, even after diagnosis, and in the case of Tim, the Special Educational Needs Coordinator 'didn't want to know'. Kieron is now at Sixth Form College where he is trying to pass English GCSE, and is studying AS Level Applied Computing, with a pass at the first stage of BTEC giving him a four GCSE equivalent.

Lisa was assessed as Gifted and Talented at Primary school, although Maggie says she was uncoordinated and 'klutzy'. She was slow, and slow to talk as a toddler, but now has recognised gifts in Maths, Science and poetry. She has no sense of organisation and no sense of what timetabling demands are. She was eventually diagnosed with an autism spectrum disorder at the age of 10. She is intense, talkative when engaged, leans forward to engage in discussion and is very animated, with the same moon-like face as her brother but is not significantly overweight. She is not well-groomed. Conversationally she is what might be called demanding, wanting to divert the conversations to what she wants to know.

Maggie says of her children that the system has failed all of them. She is convinced that failures in the diagnostic process held back all her children from making progress, and that deficiencies and delays and controversies within the system are harmful. Her attempts to find diagnosis were guided by

an imperative towards psychological explanations of her children's difficulties. She says the psychologist and psychiatrists failed to note her younger children's problems as they decided they were 'learned behaviour'.

Appendix 2: Observations

Lisa observation

Lesson: Art. Overviewing year's coursework folder

Teacher: Walking round room, stopping when asked to help, but is generally taking down displays from the walls and clearing up the room. 6 tables of students. Teacher does not approach Lisa or James (he has Asperger's Syndrome). Lisa's Teaching Assistant sits between James and Lisa and appears to be the one who directs them, and is working *for* James rather than with him.

Other students: 20

Seating: Lisa sits with her back against the window on one of the large tables, the last person on this side. Teaching Assistant sits next to her but at right angles to her at the bottom of the table. James sits next to the Teaching Assistant. Lisa sits with her back towards the students sitting on her side of the table, curled in her chair. She pays attention only to the Teaching Assistant, and occasionally James who talks compulsively, and twice to another large girl sitting with her back to the window at the next table.

Field Notes.

Lisa appears to be totally self-contained, almost remote, quite passive, rather ungainly but seemingly unaware of others, or, in fact, herself.

Her face is generally expressionless. James talks at her continually about his various IT interests. He commentates on his own every move and makes private jokes which he finds very funny. Lisa is detached, in a world of her own. The other students in the class appear more mature and are all engrossed in what they're doing. Lisa, by contrast, appears not to engage. She goes over to the computer alone, without signalling that she is about to do that. The Art Room overlooks a beautiful garden. It's a quiet room. There is music playing from a CD player. Lisa, on her return, asks, 'All right, James?' She has a US accent. James has pedantic language, 'that was rhetorical' and 'with all due respect'. Lisa clearly enjoys the exchanges she has with her Teaching Assistant, and becomes a little more animated during these. They appear to have good rapport. She drifts away at the end of the lesson, having apparently done little work.

Kieron observation

Lesson: IT completing coursework.

Teacher : Walking round helping all students.

Other students: Maximum of 10

Seating: Kieron sitting alone on one side of a double-sided station. All other students sitting opposite, quietly chatting at times while working.

Field Notes:

Kieron quietly concentrating. Initial appropriate but infrequent asking for help. No personal vanity – spilling out of his t shirt and track suit bottoms. Very quiet lesson. Keiron yawns. Some calling out and joshing by other boys. Kieron fidgeting, leaning right back and slouched. Foot and leg jiggling almost continually. Noticeably separate from others and working on a stand-alone computer. Scratches frequently – arms and head. Also cracks his fingers. When teacher leaves, briefly, other students chat and joke. Kieron's hand movements are noticeably stiff and deliberate. He seems eventually to need more help than most and his speech defect (a mumbled lisp) is more evident. Someone asks him for help while teacher is out of the room. Finishes early and leaves. Appears to be in his own world. As he leaves he is talking and singing quietly to himself.

Evie observation

Lesson: Chemistry

Teacher : Generally teaching from the whiteboard, but circulates to look at the outcomes of experiments during practical work

Other students: 17

Seating: Evie sits at the front bench. Her scribe sits next to but behind her and talks to her, and makes notes. There is a sense that her scribe barriers her and is very protective of her.

Field Notes:

Evie is loud and excitable, almost 'showing off' as she pointedly brings me a beaker of water. She has heaped a quantity of sports' equipment on one neighbouring stool (her left). Her scribe sits on the right, but behind her. There is an Asian girl, her lab partner also on her right. She clearly enjoys taking charge, for instance handing out the day's worksheets. She wears her own lab-coat, and has red-tinted lenses in her glasses. She talks incessantly, at high volume, and seems very laddish, and very comfortable with taking to the boys and joshing them. She is unable to settle, wriggling, fidgeting and looking for her pen. She is left-handed and noticeably gauche when she writes and walks. She seems not to respect personal space and gets very close to the teacher when talking to her. She appears to have a real interest in what she is learning, working well with her partner, although it is evident that she is using her partner as something of a lackey. At one point she asks the teacher, 'Did you have to attack me? I'm your best student!' At another point she tells the teacher, 'You need to get your glasses on!' She constantly argues with the teacher, although not aggressively. The teacher is very calm and measured, not taking offence or standing on her dignity. Towards the end of the lesson, she decides to change out of the outer clothes she is wearing and into the sports' clothes from the bag. Throughout the lesson the scribe writes all her notes, although Evie does look at the whiteboard as the teacher is writing on it. There is something rather larger than life about her spirit and attitude.

Harry observation

Lesson: Graphics

Teacher : Circulating constantly, also helping students retrieve items from the store room. She is very quietly in control.

Other students: 22

Seating: Harry sits at the back of the room at a large table on which there are some other students, mostly girls. There are large windows along the left and right of the room, which is very bright.

Field Notes: This is a practical lesson, in which the students complete the term's work, either in collecting items they have designed and made, or in writing up any notes they may have to finish. Harry is very neatly dressed. It is noticeable that while many students are active and circulating around the room, sometimes engaging in chat, or asking each other for help, Harry has placed himself at a distance from them. He appears impassive. While others are engaged on practical tasks, drawing, printing, and using the computers, he seems to be the only one who writes, painstakingly, for the entire lesson. Occasionally he makes contact with the teacher, showing her his work. However, he has far more teacher contact than any other student, and far less peer contact. Although not entirely solitary, as he does briefly respond when spoken to (twice, each time by one of the girls at the table), he seems detached. He shows no facial expression, and very little movement. He is curiously still and appears curiously alien. There seems to be good rapport with his quietly-spoken and friendly teacher. From time to time he stares blankly out of one or other of the windows. He leaves at the end of the lesson without saying goodbye to anyone except the teacher to whom he hands in his work.

Appendix 3: Words' List

Do you recognise these words or expressions?

1. Hyperlexia
2. Circle of Friends
3. Stimming
4. Theory of Mind
5. Special Interests
6. Irlen lenses
7. Mirror Neurons
8. Meltdowns
9. Every Child Matters
10. Sunderland Protocol
11. Statement of Special Educational Needs
12. Autistic Intelligence
13. Dyspraxia
14. DAMP

15. Executive Dysfunction
16. SENCO
17. Early Intensive Behavioral Therapy
18. Sally-Anne Test
19. ODD
20. Facilitated Communication
21. Central Coherence
22. SALT
23. Savant skills
24. Weschler Tests
25. Neural Pruning
27. Semantic Pragmatic Disorder
28. The AQ test
29. TEACCH
30. MMR

Appendix 4: Example of worked-up transcript extract

Frank and Gill

Frank and Gill

M = male

F = female

M

Testing, testing, 1,2, do you think that is working? Mmmm well it's not working too well, so get it close to your mouth!

Researcher..... [FIRST QUESTION]

Now what I want to find out today is what you know about Autism Spectrum conditions, you can include Asperger's Syndrome and the whole lot, what you know

F

Not a lot I suppose

M

Well we know about Aspergers, and I think before Evie was diagnosed with Aspergers we had seen some programmes on people with autism, there is a particularly famous young lad who can [*microphone dropped*], oooh blimey, a particular famous young lad who erm, I think glanced at the Houses of Parliament for 30 seconds and then sat and sketched it and he's become quite a notorious

artist so that was down to his autistic spectrum or autism as it was described as
but really, I suppose our main experience of it is through Evie, and how it
manifests itself in her

ROKKIT ROKKIT 24/9/10 14:33

Comment: 1. External informant - media

ROKKIT ROKKIT 24/9/10 14:34

Comment: 1. Personal informant - familial

F

Which is quite different to the boy we've just been talking about,

ROKKIT ROKKIT 24/9/10 14:40

Comment: 1. Heterogeneity/contrast

M

Yes

Researcher.....PROBE

In what way?

F

Because she just comes across as someone who's just a bit naughty, or at least
she used to do

ROKKIT ROKKIT 24/9/10 14:38

Comment: 4. Assumptions by others/peers

ROKKIT ROKKIT 24/9/10 14:38

Comment: 1. Deficit/deviance

ROKKIT ROKKIT 24/9/10 14:41

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ROKKIT ROKKIT 24/9/10 14:41

Comment: 1. Mediation –
time/maturity/development

ROKKIT ROKKIT 24/9/10 14:42

Comment: Group similarities

ROKKIT ROKKIT 24/9/10 14:41

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M

Well there are some similarities in the sense that clearly that lad has a peculiar
gift in many ways, because he can glance at something and then retains that in
his memory and can actually transfer that image onto paper. Evie can't do that

F

But an amazing memory

ROKKIT ROKKIT 24/9/10 14:43

Comment: 1. Strength/ similarities - rote memory

ROKKIT ROKKIT 24/9/10 14:42

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M

An incredible memory erm and the similarity for me would be their level of

attention to detail, so this young lad could see a house and then paint it, or draw

it and include all the detail. Evie can remember lots of data, information that

we've forgotten. I think the best way that that manifests itself is that she is very

good at identifying moths, little brown moths, and can remember what they are,

and I can't remember what they are, maybe because I'm getting on a bit, I don't

know [laughter]

ROKKIT ROKKIT 24/9/10 14:44

Comment: 1. rote memory - attention to detail

ROKKIT ROKKIT 24/9/10 14:43

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ROKKIT ROKKIT 24/9/10 14:45

Comment: 1. Rote memory/similarity

Researcher.....PROBE

Can she remember the names?

M

Ooh yes, yes, and if I showed you the moth identification guide, you'd realise

what a skill that is!

ROKKIT ROKKIT 24/9/10 14:46

Comment: 1. Recognition of strength

ROKKIT ROKKIT 24/9/10 14:45

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Researcher.....PROMPT

I do, really

M

Mm because she is ummm, there's a moth family called pugs and the moth guide is by a guy called Bernard Skinner and one of the plates in the book that has got I think 90 different species of pug on it and if you happen to catch some, because we trap them in the back garden, Evie will spend hours and hours sort of examining them and working out which one is which. But more often than not she'll remember that this is this pug or that is something else pug and she will remember it straight away. And so, that may be just a something that people of her age can do but I don't think so, I mean, some experiences that people have got a good memory but she seems to have a particularly good recall of things like that. Which I guess is high to what this lad can do, so yeah.

Researcher.....SECOND QUESTION

Has anybody told you about Aspergers Syndrome or Autism or anything?

F

Mmmm not really I don't think, do you? We sort of pick stuff up as we go along really, we have, I suppose the most information we have had is from [Outreach Worker], our GP didn't seem to know a fat sight about it.

M

What is interesting Barbara, is that a lot of the, I would describe them as authorities, education and people like that didn't seem to know about Aspergers and they certainly didn't know how to deal with Evie, how she presented herself

- ROKKIT ROKKIT 24/8/10 14:50
Comment: 1. Strength recognition – also joint and shared interest therefore also 4.
- ROKKIT ROKKIT 24/8/10 14:46
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- ROKKIT ROKKIT 24/8/10 14:49
Comment: 1. Perseverance or perseverance?
- ROKKIT ROKKIT 24/8/10 14:46
Formatted: Not Highlight
- ROKKIT ROKKIT 24/8/10 14:52
Comment: 1. Further claim to individual strength.
- ROKKIT ROKKIT 24/8/10 14:46
Formatted: Not Highlight
- ROKKIT ROKKIT 24/8/10 14:54
Comment: Connection fully made – strength and skill as component of difference and links familial with known 'autistic'
- ROKKIT ROKKIT 24/8/10 14:54
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- ROKKIT ROKKIT 24/8/10 15:20
Comment: 3. Tentative, seeking confirmation of lack of direct information
- ROKKIT ROKKIT 24/8/10 15:29
Comment: Expansion of the above, plus further reference to media (see above with the connection with Stephen Wiltshire) so also 1. Also feeling that they were left to deal with this in an undirected way – 'pick stuff up'
- ROKKIT ROKKIT 24/8/10 15:36
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- ROKKIT ROKKIT 24/8/10 15:36
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- ROKKIT ROKKIT 24/8/10 15:36
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- ROKKIT ROKKIT 24/8/10 15:23
Comment: Role of Outreach team
- ROKKIT ROKKIT 24/8/10 15:27
Comment: Role of family doctor – querying a lack of knowledge rather than lack of support
- ROKKIT ROKKIT 24/8/10 15:36
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- ROKKIT ROKKIT 24/8/10 15:36
Formatted: Highlight
- ROKKIT ROKKIT 24/8/10 15:27
Comment: Belief that services were less than knowledgeable
- ROKKIT ROKKIT 24/8/10 15:36
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in terms of her behavioural issues, mmmm, and I think over a period of years, I think you've said Gill. I think they ummm, we have picked up bits and pieces about Aspergers and we've read books, and we've seen programmes about children with Aspergers who appear to be mmm 'worse' in inverted commas than Evie and some seem to be 'better' in inverted commas. So erm, no one has ever sat us down and said let me have half an hour about telling you all about Asperger's and all about autism and this is what it does and this is what will happen and this is how things will pan out over the years, no one has sat down and done that particularly.

F

We know it is not curable, it is something you have to live with but we understand that the older you get the better you can deal, with, the person who has it, the better they can deal with it themselves.

M

And I think in Evie's case, that is actually presenting now because she is calmer generally, mmm well saying that, she will be a monster tonight but erm as she has got older she has matured and more able to deal with things herself.

Researcher.....PROBE

Do you know what it is?

- ROKKIT ROKKIT 24/9/10 15:32
Comment: Further iteration of 'believed failures from 'authorities', couched in surprisingly biomedical terms: 'presented herself' and 'behavioural issues'
- ROKKIT ROKKIT 24/9/10 15:33
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- ROKKIT ROKKIT 24/9/10 15:35
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- ROKKIT ROKKIT 24/9/10 15:38
Comment: Retention - 'picked up' this time more diminished 'bits and pieces' media influence. Coded 1/3
- ROKKIT ROKKIT 24/9/10 15:33
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- ROKKIT ROKKIT 24/9/10 15:37
Formatted: Highlight
- ROKKIT ROKKIT 24/9/10 15:45
Comment: Confusions arising perhaps from heterogeneity?? How do we sort this out ourselves?
- ROKKIT ROKKIT 24/9/10 15:43
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- ROKKIT ROKKIT 24/9/10 15:47
Comment: Again, a gentle complaint about lack of information sharing
- ROKKIT ROKKIT 24/9/10 15:47
Formatted: Highlight
- ROKKIT ROKKIT 24/9/10 15:49
Comment: Information or experience? Not explained

- ROKKIT ROKKIT 24/9/10 15:49
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- ROKKIT ROKKIT 24/9/10 15:51
Comment: Mediating effect of maturation and self-direction - again, information or experience? So involves perhaps 3

Appendix 5: Example of Quotes and Notes

Question 4: Students

Quotes and Notes Question 4 STUDENTS

EVIE

I get on better with older people and younger, and if I am socialising with older people, great, I can do all sorts, go out for days things like that. Which I do do, but having said that I didn't socialise badly when I went out in half term, I think it's improving but I don't have anyone I would exactly say a friend of my own age. All my friends I think are adults especially Margaret.

ROKIT ROKIT 1/10/10 17:25
Comment: of Harry

ROKIT ROKIT 1/10/10 17:25
Comment: again experience and maturation

She is my friend her husband died and we have been quite close for quite a while because of him because he got hurt and she keeps ?? She is a bit of a dirty stop out now coz she keeps wanting to find a bloke, so she keeps going out and stuff (laughter)

ROKIT ROKIT 1/10/10 17:25
Comment: unusual friendship

She is in her sixties I think, so she is older than me!! Laughter

And my friend Kate is in her thirties, was married and has two kids but I go out with her. In fact I went out ice skating with her and my other friend so ...but they are not my age.

I think I was known as the class clown

ROKIT ROKIT 1/10/10 17:26
Comment: laughed at?

everyone just thought I was a little rat bag. Dunno I think that the parents of the kids alienated them from me, because they made their own perceptions as opposed to letting the kids decide.

Someone would move my bag and I bit him, because he had my bag and I didn't want him to have it and other things like that.

ROKIT ROKIT 1/10/10 17:28
Comment: There seems to be little social understanding of negotiating

And I was doing mum's hanging basket with her.

Researcher. Ooh right.

Evie. And my dad, we were actually working as a team!

ROKIT ROKIT 1/10/10 17:28
Comment: Sounds surprised

I wish I could be understood and understand more.

ROKIT ROKIT 1/10/10 17:29
Comment: Two-way understanding as mediating

KIERON

I am getting on better with people at school, last year a guy knocked a can of coke out of my hand and then punched a hole in the wall and now we are the best of friends

ROKKIT ROKKIT 1/10/10 17:30

Comment: maturation

I got bullied

ROKKIT ROKKIT 1/10/10 17:30

Comment: bullying of all students and Maggie and Irene

I am really, really annoying, everyone knows that!

ROKKIT ROKKIT 1/10/10 17:31

Comment: again reclaiming 'annoying' or parroting?

I think my teachers like me, it's the students I hate, not all of them

But like I say I'm annoying!

ROKKIT ROKKIT 1/10/10 17:31

Comment: But of earlier and later comments

I

ROKKIT ROKKIT 1/10/10 17:31

Comment: I am annoying

Yea but now I have a great time!

ROKKIT ROKKIT 1/10/10 17:32

Comment: maturation

Mmmm.....(pause) it was bad in Yr 5 and yr 6 the atomic bomb went off

Researcher

Where was the atomic bomb what was it?

Umm bullying again, it went back to it

Do you/ did you find changing to secondary school difficult?

Mmm, well after going through continuous bullying, not much

ROKKIT ROKKIT 1/10/10 17:33

Comment: Bullying seen as a social perception of difference

It was annoying to start off with but quite easy to cope with afterwards

ROKKIT ROKKIT 1/10/10 17:34

Comment: Annoying again but maturation

If you could change three things about yourself at school, what would you want to change?

The way people perceive me.

ROK0T ROK0T 1/10/10 17:35
Comment: As annoying?

HARRY

I am good if they are a lot younger or older

ROK0T ROK0T 1/10/10 17:47
Comment: Cf Evie

Researcher

Right

With my own age it is hard

ROK0T ROK0T 1/10/10 17:48
Comment: As above

How do you see other people? As a help or a problem?

Difficult, some people are actually a help, some people aren't

I don't often like being with other people myself

ROK0T ROK0T 1/10/10 17:48
Comment: Cf Lisa

I like to call them friends but they're not exactly friends

B

How do you know they are not exactly friends?

I asked people

ROK0T ROK0T 1/10/10 17:49
Comment: Nature of friendship begins here

I have one in ?? I am not exactly sure, but they are what I think a friend would be.

ROK0T ROK0T 27/9/10 16:01
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Like, don't know the best way to put it, if you are feeling pretty down because you have got told off for something that you have not done, I do that, but it is not all my fault (B laughs) it helps you get clear about it.

ROK0T ROK0T 27/9/10 16:02
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ROK0T ROK0T 1/10/10 17:50
Comment: Nature of friendship continued

And yes I have got a friend he is autistic

Sort of. I think we are on different waves but we are still friends, we got quite a lot in common apart from the things that are different in autism

ROKKIT ROKKIT 27/9/10 16:02

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ROKKIT ROKKIT 1/10/10 17:57

Comment: In common, and 'different'

Well, the thing is I think he is rude

ROKKIT ROKKIT 27/9/10 16:03

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B

Are you rude?

Mmm well I don't like him talking about

B

Oh I know what you mean now, anything to do with human bodies?

ROKKIT ROKKIT 27/9/10 16:03

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Well any body, you don't like anything to do with bodies, so you feel more comfortable when you are fully clothed and you don't want any discussion about it

C

This is the lowest I get (pointing to shorts)

ROKKIT ROKKIT 27/9/10 16:03

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B

Right that is the lowest you get

C

ROKKIT ROKKIT 27/9/10 16:03

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My sisters get rude

ROKKIT ROKKIT 1/10/10 17:57

Comment: 'rude' is a big issue

I read it to make sure that I was not alone, because I felt lonely before

ROKKIT ROKKIT 1/10/10 17:59

Comment: Nature of friendship, and difference so Q1 as well as Q4

I am not going to say to everyone else leave me alone

ROKKIT ROKKIT 1/10/10 18:01

Comment: Appears quite confused about friendship

Mmm well, Sun, I grow quite close to my hats, to keep out of the sun so they used to take them and chuck them about but eventually in year 5 which was last year,?

ROKKIT ROKKIT 1/10/10 18:01

Comment: bullying

So as well as getting bullied in school, do you bully others?

Mm, not in school but I don't think I bully anyone but I don't know because whenever I ask they say things and I don't know if they are saying them to make me happy.

ROKKIT ROKKIT 1/10/10 18:02

Comment: Do they mean it?

Do you fight?

Yea couple of times yea

B

And why do you fight?

Mmm well if someone say annoys me, insults me, well not as in friends but in people who really really annoy me.....

In the past?

Yea, that is what I mean.....I got in a fight

B

What happened? Tell me the story

Well I was in year 5, I tried to get home. Someone decided to kick me and call me names and push me about, it started like that, I just lost my temper

B

What did you do?

I can't exactly remember, what I remember why she (because it was a she) started it, got my head and put my arm like.....(he demonstrates)

B

Yes an armlock

And I started kicking, then ?? ?? I don't remember anything else

ROKKIT ROKKIT 1/10/10 18:03

Comment: Bully/victim

Umm no I was brought back to school and I had to go to extra detention I don't have a perfect reputation at school

Why?

I don't exactly know, I have got quite a few people that I am good with but then again they are friendly with people that I am not good with. And it spreads out if I am not very good with someone and they have loads of friends, naturally they are going to sort of.....

B

Pick on you?

No not exactly, in a way but in a way that I can't tell

ROKKIT ROKKIT 1/10/10 18:04

Comment: Genuine difficulty expressed in the way to interpret others' actions

Do they ignore you?

Mmm, I don't really mind if they ignore me. I don't really like them. Don't want anything to do with them.

ROKKIT ROKKIT 1/10/10 18:04

Comment: Contradicts a number of earlier remarks

something you have done wrong, would she show the rest of the class or would she just pick on you?

LISA

they generally don't like hanging around other people

ROKIT ROKIT 1/10/10 18:16

Comment: Also Q1 Look at pronominal use – of Kieron and also Livie discussing her 'violence'. Talking about self but using third person. Generalising from personal knowledge to make a universal rule.

Well I don't hang around with the horrible people ??? which I consider to be a good thing

ROKIT ROKIT 1/10/10 18:16

Comment: also Q4 – sees social avoidance as a strength and has now taken up 1st person

RESEARCHER

Does, do any of the kids give you problems?

Well that is funny, that doesn't actually bother me, what people think about me doesn't

ROKIT ROKIT 1/10/10 18:18

Comment: see also Harry

RESEARCHER

Do people think you are weird?

ROKIT ROKIT 1/10/10 18:18

Comment: strong notion of difference

Yes,

RESEARCHER

Why?

Because I act weird

RESEARCHER

In what way?

Well they think it is weird the way I always sit by myself, ohh I do have friends there but when I am in lessons I sit by myself, I prefer to do that and I have a thing about where I sit sometimes.

ROKIT ROKIT 1/10/10 18:18

Comment: contradicted by observation

ROKIT ROKIT 1/10/10 18:18

Comment: similar to the place for everything issue

bullying was more of a problem when I was younger not that it happened much in B

RESEARCHER

Why doesn't it bother you as much now?

I don't know. I just don't care anymore. I think weird is a compliment.

ROKKT ROKKIT 1/10/10 18:19

Comment: Maturation and reclamation

It depends on which lesson I am really. I never stray away in science but that is because Mr Lally is really strict and I do not want to cross him.

ROKKT ROKKIT 1/10/10 18:22

Comment: Curious sense of what she can get away with and what she can't. Also, cf Harry, has noted some social rules

RESEARCHER

So what about friendships? Have you got any close friends, do you want friends?

Friends with Kelly in school and she is friends with people who I become friends with because she is friends with them.

ROKKT ROKKIT 1/10/10 18:22

Comment: Cf Harry

RESEARCHER

And is this the first real friend you have had or did you have friends when you were.....

I've had different friends through different schools. I just tended to hang out by myself instead of with people I was friendly with, until this year where I tend to hang out with Kelly and that.

ROKKT ROKKIT 1/10/10 18:22

Comment: Strongly individual, expresses solitariness as a choice

RESEARCHER

And Maths?

I think I probably will but that is just a subject that I can do and I don't like not taking ?? classes, or not science because after key stage 4 science starts to get more complicated and then you can please your mum and be a doctor or something.

ROKKT ROKKIT 1/10/10 18:23

Comment: Curious notion of why we do what we do - please your mum

Well it wasn't really the sort of bullying where everyone yells at you. It's sort of where everyone just kind of avoids you. It is just sort like they point at you. There was a thing when they called 'cogs' I am not sure what that was about but apparently I was always the one with it and if you touch that person then you got cogs? (Lisa is

speaking VERY rapidly now, noticeably agitated!) They say if you're wearing trainers which obviously was a lie because all through year 6 I was wearing trainers and they said ??

RESEARCHER

And no-one was allowed to touch, nobody was allowed to touch you or go near you because you had clogs?

Yeah

RESEARCHER

And if anyone came near you, they would catch it?

No - if they touch

RESEARCHER

If they touch you?

Yea but weird not in a good way

RESEARCHER

Not like you're weird, but unpleasant weird

Yeah

RESEARCHER

Right

ROKIT ROKIT 1/10/10 18:24
Comment: Social bullying

When I got to B they don't do the whole clogs scene, more physical assaults, but that was because I pushed them off they tried to sit on top of me, more people.

ROKIT ROKIT 1/10/10 18:25
Comment: Physical bullying

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