Title: What helps to prepare children with High Functioning Autism/Asperger Syndrome for the social and emotional demands of mainstream Secondary Schools – Exploring pupils' perceptions.

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Submitted to The School of Education, University of Aberdeen in application for the degree of Master of Education.

Abstract:

Statistically, a high proportion of adolescents with Asperger Syndrome or High-functioning Autism (ASD) suffer from mental health problems. Neuroscientific research points to a link between ASD and mental disorders, suggesting a biological disposition of people with ASD to clinical depression, anxiety, OCD and related disorders. However, numerous studies and testimonies of people with ASD show that environmental issues, especially the school environment, contribute significantly to mental health problems, and literature also provides examples of good practice reducing the likelihood or severity of mental ill health.

This research was concerned with finding out from young people with ASD their views and experiences about what causes emotional upset at school, as well as what they find helpful in aiding their social-emotional wellbeing when moving from Primary to Secondary. For this purpose, in January 2009, all pupils attending mainstream Secondary Schools in the Highlands of Scotland were invited to participate in a survey questionnaire. Eleven pupils in four different locations took part in semi-structured interviews. The results are discussed in the light of literature and current legislation, leading to recommendations for practice.

appraisal of my Research Proposal. Finally a huge thank you to my headteacher, Moira Leslie, and her husband, Jim, for their continuous emotional and practical support. Without it I would not have persevered to the end.

Contents:

1) Introduction

The past decade has seen a steep increase in children being diagnosed with Autism Spectrum Disorders/Asperger Syndrome and there is hardly a school now which does not have a number of these pupils on their roll. According to NAS statistics, 1999 found 114 pupils with a diagnosis of ASD in Scottish Secondary schools compared to 825 pupils in 2005 (NAS, 2007); or 529 pupils in all (pre)school establishments in 1999, compared to 2561 pupils in 2005, according to Action for Autism (Scotland), 2006 (Robertson, 2009). Since the trend for mainstream education has allowed little specialist provision to be established and led to the closure or downgrading of special schools and units, these children usually find themselves in large classes with many peers and staff who have limited understanding of their condition and a curriculum and environment that, in many cases, does not suit their needs (Andron, 2001, Hesmondhalgh and Breakey, 2001, Sainsbury, 2000).

The majority of people with ASD are of average or above average ability, yet their different perception of the world and their idiosyncratic ways of social communication set them apart, often leading to misunderstanding, inappropriate treatment and rejection by peers (Smith-Myles and Adreon, 2001). Heightened sensitivity to sensory stimuli combined with limited pathways of sensory integration adds to the conflict experienced by most people on the Autistic Spectrum (Myles, Cook et al, 2000, and Williams, 1998). Whether it is mainly due to a biological disposition or environmental issues, such as the ones touched on above, or the interplay of both, statistics show an alarming number of young people with ASD suffering from Mental Health Problems (Barnhill, 2000, in Smith-Myles and Andreon, 2001, and Gillberg, 2002).

In fact, mental ill health is one of the biggest problems amongst people in Scotland today, with alcoholism, drug misuse, eating disorders and self-harm/suicide still on the rise (Dwivedi and Harper eds., 2004). The Public Health Institute of Scotland (2003) claimed that around 125,000 young people under the age of 19 were experiencing mental health problems, causing them daily difficulties in living, and according to Edwards, 2003, *"one in five children and young people in Scotland will suffer from clinically defined mental health problems during their school career"* (both figures quoted in Dunlop, Tait et al, 2009, p.115). The National Conference: *Promoting Mental Health in Schools,* Birmingham, 20.11.2008 painted a similar picture. It is therefore no wonder that government initiatives promoting Emotional Literacy, Health and Wellbeing and Pastoral Care and Nurture have become a priority in education (SEED, 2005 and 2008). In fact *"a new policy document 'Towards a Mentally Flourishing Scotland' (Scottish Government, 2007) has been published, and an action plan on this is expected."* (Dunlop, Tait et al, 2009, p.115)
Therefore, emotional stability and mental health can no longer be delegated to social and health services; that is, social and emotional factors have always been an integral part of the curriculum, as they underpin cognitive development and educational success, even though success has primarily been measured in academic outcomes (Hanko, 2003). However, in the new Curriculum for Excellence guidelines (HMIe, 2009), Health and Wellbeing, including mental health, are now given equal importance with Literacy and Numeracy.

To come back to the increasing number of pupils diagnosed with ASD and their specific vulnerability to mental ill health, many initiatives have recently sprung up to tackle their emotional and social needs. From raising awareness about ASD amongst educational staff and the general public, to specific schemes like Communication Groups, Play Schemes, Circle of Friends and Befrienders, much is currently being tried to help young people with ASD to experience greater wellbeing. There have been a few isolated studies and

many general observations evaluating the success of such initiatives, yet without definite conclusions (NAS, 2001, Sherratt, 2005 and Owens, 2008).

In The current climate of *Curriculum for Excellence* with the aim towards personalised holistic education (SEED, 2006) and the government's priority to increase mental health in young people (SEED, 2008), it makes it an important area for research and curriculum development. Personally, I am drawn to this study by my own experience as a Support for Learning teacher with Asperger Syndrome, preparing pupils with ASD for their transition from Primary to Secondary school. Also, as my base school is in the process of becoming an accredited *Nurture School,* taking steps to improve emotional literacy and wellbeing in staff and pupils, my work with pupils with ASD is embedded in the school's improvement plan.

Finally, it is hoped that my research will be of benefit to the wider educational community in Highland and beyond, enabling the participating pupils to reflect on their situation and to voice their experience, informing curriculum development by evaluating current practice and sharing outcomes with the Autism Outreach Team and a variety of educational professionals through the Highland Autistic Spectrum Education Network (HASEN) and the ASD Awareness Workshops I am frequently holding throughout the Highlands.

2) Literature Review

Autism Spectrum Disorder (ASD), including Asperger Syndrome, is characterized by the so called **Triad of Impairments**, comprising difficulties with social interaction, social communication and flexibility of

thought. This includes *"impaired, delayed or atypical interpersonal development and difficulty with forming, maintaining and understanding the social complexities of relationships; impaired and unusual language and communication, verbal and non-verbal; and rigidity of thought and behaviour, including ritualistic behaviour and delay or absence of pretend play"* (Scottish Society for Autism, 2005, p.1). ASD is a life-long disorder with an onset before the age of three years, though an official diagnosis is often given much later.

Recent advance in neuroscientific research indicates that ASD is the result of *"impaired temporal binding between local networks in the brain"* (Brock, Brown et al., 2002, p.210) due to a lack of certain neurotransmitters, which are necessary to carry messages from one area of the brain to another, thus interconnecting them. Impairment in this area leads to a lack of **central coherence**, which is *"the cognitive ability to bind together a jumble of features into a single, coherent object or concept"* (Frith, 1989, quoted in Belmonte, Allen et al., 2004, p. 9228). A weak Central Coherence can cause difficulty transferring skills from one situation to another by forming connections and sifting relevant from irrelevant sensory information, leading to problems with transference of skills and knowledge and therefore with change. Thus, the autistic mind interprets the world very differently from the neurotypically developing mind, leading to a unique experience of life and at the same time alienation from the life experience of the majority of people. I will look at the significance of this later.

The exact causes underlying ASD are not yet clear, but there is strong evidence for a genetic component. ASD is not linked to a specific IQ. Once it was thought the majority of people with ASD were below average IQ (Wing, 1971), probably arising from their inability to use verbal communication and thus reveal their intellectual potential. It is now widely acknowledged that ASD is more common in people with average or above average IQ (Barnhill et al, 2000, in Smith-Myles and Adreon, 2001, p.71) and numbers of pupils with ASD in mainstream schools confirm this. Nowadays, with targeted early intervention, most autistic children have good verbal communication skills by the time they start Primary School, yet the semantics of language usually cause them many problems, and misunderstandings are common.

Another important factor in ASD, which is gaining significance, is the difficulty with sensory integration.

> *"When I was an infant, my senses didn't work right and my response to light and sound and touch were not just meaningless, but too acute. I could not only not understand the world, but I also could not stand it",* explains Donna Williams (1996, p.1), a woman with Autism.

Some researchers have invented long check-lists of hyper- and hypo-sensitivity for people with ASD to identify causes for distress and areas of strengths (Bogdashina, 2003). I will return to the significance of these issues for the social and emotional well-being of young people with ASD.

Statistically, ASD affects four times more boys than girls, but from my experience as a teacher and from testimonies of members of the Autism Rights Group Highland I would argue that many girls remain undiagnosed because they do not exhibit the same strong behaviours as boys.

> *"We understand far too little about girls with ASDs because we diagnose autism based on a male conceptualisation of the condition."* (Attwood, quoted in Hill, 2009).

In her article, Hill (2009) cites Dr Judith Gould, a leading expert in ASD, accusing the medical profession of overlooking girls because of *"a stereotyped view... based entirely on how boys present with the condition, hence condemning them* (girls) *to lives of such misery that many resort to extreme self-harm and anorexia."* She and her colleagues estimate 2.5 boys per one girl on the Autistic Spectrum.

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According to the HMIe Report: Education for Pupils with ASD (2006, p.7), 1.5% of all pupils in the Highlands have a diagnosis of ASD, though the number in Primary Schools is about three times as high as in Secondary Schools (NAS, 2007 and Robertson, 2009). According to the above document, 72% of children with ASD in Scotland attend mainstream classes only (p.11). Again, the percentage in Highland would be higher due to lack of specialist provision. Taking into account this rate of prevalence, the majority of schools will always have several pupils with ASD on their roll.

In order to identify specific social and emotional needs of young people with ASD, we must come back to the three areas identified above:

- The unique experience of life in contrast to that of the majority of people
- The difficulties with the semantics of verbal communication
- The pain and anxiety caused by sensory integration problems.

Woodward and Hogenboom (2002), building on Rudolph Steiner's anthroposophy, describe Autism as a lack of ego-integration, which means the soul or eternal part of a person does not properly take hold of the body or incarnate into the physical part of a person, therefore leading to a failure to integrate and interpret sensory stimuli from both inside and outside one's body and thus to make sense of life and to connect with other people. They call it a *"reluctance to be born"* or *"a longing to remain in a spiritual pre-birth existence" (p.162).* This theory resonates with many people on the Autistic Spectrum (Williams, 1996).What to outsiders often looks like aloof self-centredness is in fact a lack of sense of self and a merger with one's environment.

> *"Real egocentricity as we understand it in our non-autistic day-to-day lives, seems to be lacking."*
> (Cumine, Leach et al, 2000, p.23)

Vermeulen (2001, p.54) talks about experiencing oneself as less coherent, i.e. different in various contexts, which makes it difficult to develop an identity of oneself.

In fact, many autistic children only start in middle childhood (around age 7-9) to refer to themselves as 'I' rather than their name, and even when this has been mastered, the concept might not really be understood. This weak sense of self makes it very difficult to understand one's feelings and therefore to deal with them appropriately. It stands in the way of empathising with other people's feelings and hampers any two-way interaction, since this requires both participants to be aware of themselves as distinct from the other (Williams, 1998). This is also referred to as **Theory of Mind**, which normally develops around the age of 3-4 years, when children start to become aware that other people's thoughts and feelings are distinct from their own. It enables them to look at situations from different points of view by putting themselves 'into someone else's shoes'.

> *"In 1985, a group of research psychologists (Baron-Cohen, Leslie and Frith) proposed that people with autism lack a 'Theory of Mind'."* (Cumine, Leach et al, 2000, p.19)

Although in some children with ASD this development does occur, yet much slower or later, in others it does not develop at all, leading to an inability to understand or predict others' behaviour, perspectives and intentions and to reflect on one's own (Scottish Society for Autism, 2005). Hence, many autistic children prefer solitary play or interaction with objects, which can be manipulated and interpreted and are therefore easier to understand than people. Apart from social isolation, this also has consequences for the intellectual development.

> *"A child unable to learn through shared understanding will have an over-reliance on rational thinking, which leads to an unbalanced view of the world."* (Sherratt, 2005, p.18)

Many programmes and therapies have been designed during the past years to help people with ASD gain better understanding of themselves and their feelings. Many children now benefit from such programmes or therapies sometime during their school career, and I evaluate some on pages 18-19. Although this greatly enhances their ability to make sense of life and communicate more effectively with others, the underlying sense of 'being an alien on planet Earth' still prevails. Their unusual behaviour often underlines this. Donna Williams (1996, p.124) has described autistic behaviours as *"instinctive attempts to compensate for, control or correct processing deficiencies in the brain".* In fact, much behaviour common in Autism, like the weaving in and out of one's hands like a figure-of-eight, have now been identified as instinctive attempts to integrate the left and right hemispheres of the brain (see Williams, 1996, p.68). It is important to note that

all behaviour, even the most bizarre, has a function, and whether it is voluntary or involuntary, is an expression of Autism which must be taken seriously.

Looking at underlying causes for distressing behaviour will often lead us to the pain and anxiety which accompany sensory integration problems. Hearing a wider range of frequencies than is considered normal for humans, or tuning in to background noise rather than the spoken words, can make it extremely stressful to follow verbal conversations or to listen to instructions, apart from the possibility of causing physical pain. The confusion created by taking in every little detail, yet not recognizing the whole picture (Frith, 1989), can be as frightening as being overwhelmed by smells and touch due to heightened sensitivity in these areas. These issues alone can lead to such distress that the only coping mechanisms available are fight or flight. As most autistic children learn during their early and middle years in Primary school that temper tantrums or running away and hiding are unacceptable behaviours, withdrawal into oneself is often the only option left.

Faced with all these difficulties, the high incidence of mental health problems in people with ASD comes as no surprise. Sainsbury (2000, p. 112) estimates that

"at least half of all people with ASD suffer from clinical depression at some point in their lives, often starting during the teens."

There are numerous examples of studies stating an alarming percentage of people with ASD suffering from depression, often to the point of suicide attempts (Wing, 1981, quoted in Sainsbury, 2000, p.112; Ghaziuddin et al, 1998, quoted in Deudney and Shah, 2004, p.2-3; Barnhill, 2000, quoted in Smith-Myles and Adreon, 2001, p.21).

> *"Kim et al (2000) also found depression to be more common in children aged 10-12 years with High Functioning Autism/Asperger Syndrome than in the general population of children of the same age",* while *"Grandin (2000) writes that, at puberty, fear was her main emotion. Any change in her school schedule caused intense anxiety and the fear of a panic attack."* (Deudney, 2004, p.2 and 5)

White, Oswald et al (2009) published a review of 40 research papers written between 1990 and 2008 on the prevalence, phenomenology and treatment of anxiety in young people with ASD, coming to the conclusion that

> *"anxiety and poor stress management are common concerns in clinical samples of children with autism spectrum disorders (ASD). Anxiety may worsen during adolescence, as young people face an increasingly complex social milieu and often become more aware of their differences and interpersonal difficulties."* White, Oswald et al (2009, p.1)

In fact, looking at it from a medical view point, based on recently identified correlations of affected areas of the brain in both mental health problems and ASD, one could speculate that anxiety and depression are part of the brain dysfunction in ASD (Belmonte, Allen et al, 2004, Ghaziuddin, 2005) and begin to seriously manifest during the hormonal changes of puberty. According to Gillberg (2002), High Functioning Autism and Asperger Syndrome show significantly high levels of comorbidity in relation to ADHD, OCD, clinical depression and Tourette's Syndrome, as well as associated problems, such as pre-occupation with death, eating disorders, states of profound confusion, phobias, catatonia, prosopagnosia (failure to recognise faces), personality disorders and apparent psychotic episodes. Given that many people with ASD have a tendency to perfectionism and are extremely honest, they often blame themselves for their inability to conform (Smith-Myles and Adreon, 2001), trying extremely hard to change what they cannot change: the core of their being. Feelings of rejection, including by their own parents, often disguised as well-meaning interventions, add to the burden (Sinclair, 1993).

Not surprisingly, the medication most commonly prescribed for people with ASD are anti-depressants and in some cases neuroleptics (Gillberg, 2002). As in clinical depression and OCD, the imbalance of certain neurotransmitters found in the cerebrospinal fluid, causing the increase in dopamine-breakdown products and decrease in noradrenalin-breakdown products, are equally found in Autism, and therefore medication acting as serotonin re-uptake inhibitors (SSRI) helps to stabilise mood, reduce obsessions and compulsions and calm anxiety and fear (Peters and Gillberg, 1999, Deudney and Shah, 2004).

However, biological causes alone are not enough to explain poor mental health in adolescents and adults with ASD, and therefore medication can only play one part in addressing the problem.

> *"It seems clear that biological tendencies to high levels of anxiety can only be exacerbated by living in an environment which, as viewed by a child with ASD, is often terrifyingly chaotic and unpredictable."* (Sainsbury, 2000, p.115)

For most autistic pupils, coping in a mainstream classroom is extremely stressful. The amount and close proximity of people, different activities and the multitude of sensory stimuli constantly puts these youngsters in overload, unless they find ways to isolate themselves from their surroundings by focussing inwards. In Secondary school, this is exacerbated by the many changes of classrooms, classmates and teachers and the need to shift attention from one subject to the next within a few minutes, whilst running the gauntlet of bewildering noise, the pushing and shoving of bodies and the confusing labyrinth of corridors. Also, *"social contact can generate anxiety as how to start, maintain and end the activity and conversation."* (Attwood, 1998, in Deudney and Shah, 2004, p.5)

One of the key findings of the Research Report by Wainscot, Naylor et al (2008, p.1) is that the teenage pupils with High Functioning Autism (HFA) and Asperger Syndrome (AS) in their study *"spent break and lunch times inside in quieter, more closely adults supervised areas of school"* than their non-autistic peers, which is not surprising, given the high stress level experienced by sensory overload and social demands. Other key findings in the above report state that in comparison with other pupils those with HFA/AS *"engaged in fewer social interactions during the school day, both in and out of lessons, and reported having far fewer friends."*

Yet most people with ASD long for social contacts, though many do not understand how to achieve real friendship. As Andron (2001, p.87) writes:

> *"They prefer to play with other Autistics, as they have more to share with each other."*

It is only natural that we feel drawn to others who are similar to us. However, special interests like steam trains, bird watching or collecting stamps, can also bring children together, not exclusively those with ASD. Personally, playing in the orchestra was my way of engaging with peers when I was in High School, while for one of my cousins it was a mathematics club.

Another reason for the onset of depression during the teenage years might be the fact that the majority of peers become rather intolerant to any kind of social deviance.

> *"The students in middle school seem to be more immature than the students in any other school that I have ever been to. They seem to enjoy harassing people a lot more than at other schools, by making fun of them and such. This can be extremely horrible, for you have to do your work and endure the stuff that other students do."*
> (John Oak, 9th grade student with ASD, quoted in Smith-Myles and Adreon, 2001, p. 141)

While younger children are generally more accepting of differences, the onset of puberty for many brings the need to belong to a distinctive youth culture which does not leave room for otherness. So if teenagers with ASD find a friend, it is often another social outcast (Sainsbury, 2000).

Smith-Myles and Adreon (2001, p.8) observe that *"the emotional maturity level for adolescents with AS is significantly below what is expected for their chronological age."*
Not understanding social cues or the hidden curriculum makes pupils with ASD an easy target for bullying. According to the National Autistic Society (NAS) survey **Make school make sense** (Batten, Corbett et al., 2006, p.17) *"Over 40% of children with autism have been bullied at school. Children with Asperger Syndrome are particularly vulnerable, with 59% of their parents reporting that they have been bullied."*
Asking the children directly, paints an even bleaker picture (see Reid and Batten, 2006a).

Professor Tantam, in his lecture on **The bullying of mainstream secondary pupils with Asperger Syndrome** (London, 20.9.2008) suggests that

> *"bullies bully to make others conform and are supported by their social group which values cohesion."* (p.34)

Apart from standing out for their sometimes bizarre behaviour, lack of social understanding and unconventional interests, children with ASD are often misled by sarcasm and teasing disguised as friendliness. The latter can have much more devastating effects on pupils' self-esteem and emotional health than outright hostility, as it is felt as betrayal.

> *"I thought they were my friends because they made me laugh and said nice things to me and then I found out that they were really making fun of me. I don't really know if I have any friends now. I think it's better not to trust anyone."* (C., personal conversation with the author)

The consequences of bullying range from damage to self-esteem, mental health and progress at school, to school phobia, social withdrawal, self-harm and suicide attempts. Many parents have felt forced to take their child out of school and either home-educate or find alternative placements. Also,

> *"because of the nature of autism, children on the spectrum may not be able to understand the motives of other children or may not have the social skills to handle difficult situations. This can mean that they are easily led or provoked by bullies."* (Batten, Corbett et al., 2006, p.17)

The NAS survey (Batten, Corbett et al, 2006) found that one in five children with autism and one in four with Asperger Syndrome has been excluded from school, usually on several occasions, often as a direct result of retaliation.

> *"Jenny suffered extreme mental bullying…and because of her poor social and language skills she lashed out. The school refused to address the issue and just excluded her."* (Batten, Corbett et al., 2006, p.17)

In some cases, teachers and other school staff also contribute to bullying, though usually in subtler, less open ways. Sarcasm, singling out someone's idiosyncrasies, refusing to make allowances for specific needs or differentiate lesson content can all aggravate pupils with ASD to the point of hitting out against others or themselves.

Bullying often goes unnoticed for a period of time, as many people with ASD do not know how to make sense of or express what is happening to them. One mother writes:

> *"Carl doesn't tell me when he is bullied. I have to figure it out, sometimes from bruises."* And another patent states: *"My daughter changed from being trusting, happy, un-self aware to being paranoid, depressed and suicidal."* (Reid and Batten, 2006b, p.3)

Since many people with ASD have difficulty understanding their emotions, they often do not express them in conventional ways. For example, instead of crying they might laugh or self-harm in response to emotional pain.

> *"The inability of people with autism to communicate feelings of disturbance, anxiety or distress can also mean that it is often very difficult to diagnose depressive or anxiety states."* (Howlin, 1997, quoted in Deudney and Shah, 2004, p.2)

The NAS survey (2006) identifies several areas where change is needed and can make a significant difference for pupils with ASD. I would put these areas into two major categories: a) the school environment, curriculum, staff and peers and b) the person with ASD.

> *"Inclusion is not about placing children with autism in mainstream schools and ignoring difference by 'treating all pupils the same'. It is about making appropriate provision to meet each child's needs and reasonable adjustments to enable each child to access the whole life of the school."* (Batten, Corbett et al., 2006, p.4)

It is imperative to acknowledge that each person with ASD has specific needs which require to be addressed by the curriculum. Not surprisingly, according to Batten, Corbett et al. (2006, p.3-7), 72% of parents whose autistic children are educated in resource bases in mainstream schools and 83% of parents whose children attend autism-specific special schools are most satisfied with their education compared to 30% of those with children in mainstream classes only. However, such provision is only available for a minority of children, especially in the Highlands. Therefore it is important to make appropriate adjustments for children with ASD in mainstream schools and classes. These would include

- The provision of quiet spaces or calm working environments accessible to pupils with ASD whenever they need it
- Appropriate seating arrangements within classrooms taking into account sensory sensitivities
- Help with moving around the school between classes, where needed
- Supervised break & lunch times and after school activities to incorporate pupils' special interests and needs
- Differentiation of lesson content and delivery, including setting homework and exams
- ASD awareness training for all staff, particularly Secondary School Subject teachers, who seem to have missed out in past years
- ASD awareness training for peers, which could be incorporated into PSD or Social Studies

(adapted from Batten, Corbett et al., 2006, p.28)

As for pupils with ASD, one of the greatest needs highlighted by parents and children alike is the provision of Social Skills Training.

> *"Social Skills Programmes help children with autism learn the social skills that other children develop naturally."* (Batten, Corbett et al., 2006, p.21)

However, many adults with ASD argue that before they were able to learn social skills, they needed to establish a sense of self. Hesmondhalgh (2001, p.104-105) in his counselling programme for students with ASD identifies three steps:

1. *"knowledge of self*
2. *knowledge and understanding of autism*
3. *the personal management of autism"*

I would argue that once a sense of self is emerging, social skills training can take place alongside the development of self-understanding and self-management, in fact, it can be mutually enhancing. It must be kept in mind, though, that most people with ASD have difficulty transferring skills from one context to another. Social skills are therefore best learned in real-life situations. To this end, Play-Drama (Sherratt, 2006), Lego Therapy (Owens, 2008) and similar approaches have recently been developed.

> *"Play-Drama is an intervention designed to help children on the autistic spectrum to learn about other people, about how to see through other people's eyes and how to communicate about shared ideas. It encourages flexible thinking, imagination and creativity in children who have difficulty in these areas."* (Sherratt, 2006, p1)

Lego-Therapy is based on the Empathising-Systemising theory developed by Baron-Cohen in 2002, which *"proposes that people with autism are impaired in empathising, but have preserved or even superior systemising abilities."* (Owens, 2008, p.2 of lecture notes.) Owens argues that since Lego is a systemising toy which appeals to many children, it lends itself as a medium to further collaboration. By putting children with and without ASD together into trios where each person has a distinct role (i.e. engineer, supplier, builder), the problem-solving activity has the potential to enhance social interaction and understanding of minds. Lego clubs based on this approach are currently set up in many Highland schools.

However, the kind of Social Skills Training often available for pupils in Primary Schools is not only delivered out of context, but often simply aims at eliminating autistic behaviour without trying to understand and address the purpose it serves. I have seen children being subjected to making eye-contact, which led to unnatural staring, since this was the best they could manage.

> *"There is an assumption that the ultimate goal is to help people on the Autistic Spectrum to fit into Non-Autistic structures and much time and money is poured unquestioningly into that goal. But teaching any human being to suppress or ignore their own natural systems in favour of those of the social majority might be 'functional' or 'practical', but is it healthy?"* (Williams, D., lecture, Manchester, 13.9.2008)

Other ways of supporting children with ASD in forming peer relationships, especially in Secondary Schools, are selected buddies or a Circle of Friends. A buddy, when carefully matched, can be a great help for students with ASD, not only as protection from bullying and to find their way around school, but also as someone who understands the hidden curriculum and social life of their peers and can act as a counsellor or go-between for the student with ASD.

A Circle of Friends is essentially a group of buddies who take turns to look after their *focus child* and meet regularly as a group with the pupil with ASD to identify problems, seek solutions and review progress. This can break down the social isolation often experienced by pupils with ASD in large Secondary Schools, as they come to know at least a few peers they can trust.

> *"When the Leicestershire Autism Outreach Team established seven different circles (around 1997) the results were very promising… Staff reported a range of benefits for the focus child involving:*
> - *improved social integration and higher levels of peer contact*
> - *reduced anxiety*
> - *improved behaviour"* (NAS, 2001, p.10)

Children who have already been traumatised by painful school experiences will need professional treatment, either concrete therapy (i.e. play, art) or cognitive therapy to release and explore feelings and to learn new ways of coping. While the former approaches are based on psycho-analytical theory, allowing the person to deal with their feelings in pictorial ways, Cognitive Behavioural Therapy is *"a technique for the treatment of mental disorder based on the concept that how people perceive the world and themselves influences their behaviour and emotions."* (HMIe, 2006, p.32)

Many people with ASD highlight the need to mix with other people on the Autistic Spectrum. Currently, the National Autistic Society is setting up Social Groups for adolescents with ASD (age 16-21) in various places throughout the country, including Inverness and possibly elsewhere in the Highlands. However, even younger children often benefit immensely from knowing that others experience the world in similar ways. I have seen friendships emerging during the Holiday Play Scheme for Autistic Children, and I believe it can be of great help to some youngsters to meet regularly in 'ASD Groups' within or out-with their school. Within school, such groups can be organised by the Support for Learning teacher, a member of the Autism Outreach Team or by an adult with ASD who understands from the inside-out what it means to live with the condition.

Where appropriate provision is in place, the lives of young people can be greatly enhanced, and with emotional stability they are able to make unique contributions to our society (Grandin and Scariano, 1986). But we still have a long way to go to ensure such provisions are available for every person with ASD.

While conducting the Literature Review, I encountered a host of personal testimonies from children and adolescents with ASD. However, the overwhelming majority were concerned with problems arising from bullying and inappropriate provision. Extensive search of websites, including the Scottish Autism Research Group (SARG), Scottish Autism Support Network (SASN), National Foundation for Educational Research (NfER), Department for Children, School & Families/ Research (DfES), National Autistic Society (NAS) and Scottish Society for Autism (SSA), for previous or ongoing research conducted with pupils with ASD, did not reveal materials of relevance other than the papers referred to in this text. Whilst finalising this dissertation, I was made aware of a very similar research project by Humphrey and Lewis (2008), a major part of which consisted of finding out directly from young people with ASD how they view their general experience of Secondary School, which I will discuss in detail in chapters 4 and 5.

Perhaps it is difficult for children and adolescents with ASD to understand the complexity of the situation they find themselves in at Secondary School and to identify their own emotions and triggers for these, as Lawson, an adult with ASD, describes:

> *"What if an individual cannot explain their emotional or physical experiences? What if, in fact, they are detached from such experiences because they have not been able to gather the information from their senses, experience and comprehension of such experiences?"* (Lawson, 2001, in Dunlop, Tait et al, 2009, p.114)

Perhaps individuals with ASD need to grow up and look back from a distance in order to see what was helpful and what was not. Therefore, originally, I wanted to invite adults with ASD as participants in this research, but since so many innovations have been introduced in education during the past decade, their experiences might not represent those of youngsters today. For this reason and the fact that there seems to be a gap in the research regarding studies of the perceptions of pupils with ASD (Humphrey and Lewis, 2008), I have set myself the difficult task of researching the views of Secondary School pupils with ASD in the Highlands of Scotland, concerning their social and emotional needs.

3) Methodology

Research Questions:

1. What are the pupils' perceptions of their social and emotional experience of Secondary School?

2. What strategies do they identify as helpful in order to cope with the social and emotional demands at school?

3. What implications does this have for ASD specific input during the transition process from Primary to Secondary School and beyond?

Eliciting pupils' perceptions

> *"Article 12 in the United Nations Convention on the Rights of the Child*
> *(United Nations, 1989) clearly identifies the right of children to express*
> *their views on matters that impact on them."*
> (Dockett and Perry, 2007, p.53)

As pupils are the consumers of education, it is imperative to take their views and experiences into account when evaluating the curriculum (Costley, in Lewis and Lindsay, 2000). Scott (in Christensen and James, 2000) argues that children are often left out as respondents to social surveys on account of their perceived cognitive inferiority, needing parents or professionals to speak for them. Yet children's very reasoning can reveal a very different picture of their experience and aspirations than the interpretation by adults involved with them.

> *"Once children have reached the age where they are able to process and respond to standard*
> *questions, they are also adept at controlling what they reveal."* (Scott, in Christensen and James,
> 2000, p.102)

Education for Citizenship, which includes giving children opportunities for practicing choice and reflecting on outcomes, is now enshrined in the Curriculum for Excellence. However, Faulkner and Woodhead (in Christensen and James, 2000) argue that even when we listen to children's views, we still interpret them from our adult perspective, unless we invite children into the research process. To this end, Lewis (in Fraser, Lewis et al, 2004, p.5) demands a *"shift from research **on** children and young people to research **with** children and young people."* She goes on to explore the power relations between adults and children in research, which depend in part on our concept of childhood and the roles ascribed to the participants. This leads researchers, like Kellett and Robinson (in Fraser, Lewis et al, 2004) to insist that children and young people should be involved in every aspect of the research concerning them, including the choice of research methods and analysis and interpretation of data. Even where this is not possible because of practical limitations, we have the duty to respect children and young people for their particular status and role, their insight as insiders, their personal knowledge of their daily struggles and unique solutions, their meanings and hopes they assign to their situation (Alderson, in Fraser, Lewis et al, 2004). However, Jones (in Fraser, Lewis et al, 2004) warns that tensions can arise between responsibility and protection, thus giving children

responsibility within research must not endanger them physically or emotionally, and it has to be clear that overall responsibility lies with the adult researcher.

> *"This is a power inequality that cannot be levelled out through superficial attempts at egalitarianism."* (Jones, in Fraser, Lewis et al, 2004, p.113)

Particular considerations are necessary when the research concerns pupils with disabilities. In emancipatory disability research, arguments have arisen concerning the validity of research undertaken by non-disabled researchers, as both methodology and underlying assumptions are derived from a world view which differs from that of those with disabilities (Lewis and Kellett, in Fraser, Lewis et al, 2004).

> *"Oliver (1997) claims that some research by able-bodied people is a violation of the experiences of disabled people, irrelevant to their needs, fails to improve their quality of life and sometimes even makes it worse.*" (Lewis and Kellett, in Fraser, Lewis et al, 2004, p.202)

This can, to a certain extend, be countered by acknowledging that the experts in the particular research are those who experience the disability. In this respect, it might be an advantage that I share the disability of those with whom this research is concerned (Kammer, 2007).

Perhaps due to the difficulties many young people with ASD have in understanding and articulating their social and emotional experiences (see pp.10 and 16), research in this area has only recently begun to take their views into account and is still largely based on parental and professional perceptions, although the right of children to be involved in decision making concerning themselves is clearly stated in the Education (Additional Support for Learning) (Scotland) Act (2004).

> *"Researching pupil perceptions is a potent way of challenging assumptions made about marginalized groups within education."* (Lloyd-Smith and Torr, in Lewis and Lindsay, 2000, p.60)

It might be argued, therefore, that not taking pupils' views into account when reviewing educational initiatives leads to a flawed outcome. Also, according to the above authors, pupils' attitude to school, teachers and authorities change dramatically when they are actively involved in decision making. However, they argue that children need to learn how to be reflective and make informed decisions by being given opportunities for practising choice and reflecting on the outcome.

Warren in Lewis and Lindsay (2000) holds that children like adults need to learn to question assumptions, to look at things from various angles and to acknowledge their limitations. These skills, however, are particularly difficult to master for people with ASD because of their lack of flexible thinking (Frith, 1989), which I kept in mind when designing and analysing the questionnaire and interviews, though I wonder whether we are in fact asking too much by expecting such a level of maturity during their teenage years. Nevertheless, it is of great importance to give a voice to those with whom this research is concerned, or in

other words to go to the primary source when investigating the social and emotional demands of Secondary School on pupils with ASD.

Research Paradigm and Strategies

> *"Researchers make methodological choices based on their assumptions*
> *about reality and the nature of knowledge that are either implicitly   present, or explicitly acknowledged."*
> (Avramidis and Smith, 1999, p.27)

According to Bryman (2004), some researchers argue that research strategies are closely linked to research paradigm. We can distinguish four major research paradigms based on philosophical ideas which underlie our thoughts and actions. Whilst Positivism claims to be driven by scientific methods, using empirical testing and generating objective knowledge, Interpretivism comes from the opposite angle, pointing to the complexity of social situations and human life and seeking to produce meaning rather than knowledge (Gephart, 1999). Critical Theory focuses on empowering those involved in the research with the aim to bring about change (Dash, 1993). Post-modernism or Post-structualism challenges any form of objective knowledge in order to explore the construction of alternative realities (Weiss and Wesley, 1999). Thus, all four paradigms are concerned with reality: Positivism seeking ultimate reality, while the others pursue constructed realities. Guba and Lincoln (quoted in Krauss, 2005, p.759) define paradigm as the *"basic belief system or world view that guides the investigation",* which leads Krauss (2005) to suggest that it is foremost a question of philosophy.

In the light of the above, I would place this research in the field of Interpretivism, acknowledging the complexity of social situations and human life and seeking to produce meaning rather than knowledge, as well as Critical Theory, which focuses on empowering those involved in the research with the aim to bring about change.

Although quantitative data are mainly associated with Positivism, as they present standardised, measurable outcomes, they do have their place in the other traditions, too, as long as we acknowledge that they are subject to interpretation and are only dealing with measurable facts, not processes, whereas qualitative data take longer to generate, are more difficult to analyse, but tend to be more context specific, process oriented and participant-centred (Avramidis and Smith, 1999).

I do not agree with the opinion held amongst some researchers that quantitative and qualitative methods of data collection should not be used together, as they obscure the epistemological and ontological aspects embedded in the paradigm. Bryman (2004) explains that a multi-strategy approach has often been employed in social research with the advantage of cross-checking the results of one method against those of

the other, as well as reaching larger numbers without losing depth. It also allows studying different aspects of an identified problem or question. Therefore, in the following research, I used both quantitative and qualitative data to supplement each other.

In order to invite all pupils with ASD currently attending mainstream Highland Secondary Schools to participate in the research, I decided to device a questionnaire, gathering quantitative as well as qualitative data, and to follow this up with semi-structured interviews with small groups of participants in four different schools, including at least one city and one rural school.

<u>Ethical Considerations</u>

> *"Research with human participants is an intrusive process."* (Lindsay in Lewis and Lindsay, 2000, p.3)

Lindsay goes on to say that even a simple task, like filling in a questionnaire, asks the participants to reflect on their situation and, by doing so, has an influence on their further life. Therefore, ethical considerations underpin every stage of the research, particularly when the participants are children (Alderson, in Fraser, Lewis et al, 2004).

> *"The British Educational Research Association (BERA) believes that all educational research should be conducted within an ethic of respect for persons, respect for knowledge, respect for democratic values, and respect for the quality of educational research (BERA, 1992:1)"* (Lewis and Lindsay, 2004, p.11)

The guidelines of the Scottish Educational Research Association (SERA, 2005) broadly identify 5 areas of concern:

- the research must be beneficial for the educational community and, when conducted with children, must be in their best interest
- it must comply with legal requirements, in particular concerning voluntary informed consent given by participants and, in the case of younger children, their guardians
- the methodology must be appropriate to elicit unbiased data, taking into account the level of ability and maturity of the participants
- confidentiality and anonymity, including data protection, must be safeguarded at all times
- participants have the right to be fully briefed about the aims, process and findings of the research

In this research, due consideration has been given to all of these points. The worthwhile- ness lies in its aim to give a voice to the young people whom it concerns and to inform development to improve their wellbeing. As a teacher, legal requirements always underpin my professional relationship with children. However, I am aware that, when eliciting emotionally sensitive information from young people, there is a tension between protecting their feelings and facilitating openness and sharing.

Concerning voluntary informed consent, I always shared the aims and process of the research with participants beforehand in writing, seeking written consent from both pupils and their guardians for face-to-face interviews and discussions, whilst being explicit in the guidance notes to the schools that pupils were free to opt out of the questionnaire, although ideally participants opt in, not out of research (Alderson in Fraser, Lewis et al, 2004), this would have been impractical.

Much thought went into devising the research tools, and at every stage I invited participants to contribute to it (Appendix 2). Also, a simplified version of the research report was composed and sent to all participating schools for dissemination to the pupils who took part in it (Appendix 15).

Considering confidentiality, I am aware of the potential dilemma arising from disclosure of material, especially in connection with bullying, which requires the researcher to take further steps, involving a third party. It is therefore imperative to seek information about reporting procedures in advance and to explain this to the participants beforehand (France in Fraser, Lewis et al, 2004). As the questionnaires were anonymous, this only applied to the interviews. Gathered data were at all times kept safe, interview tapes deleted after scribing their content and statements kept anonymous.

Much has been written about power issues between adult researchers and children/young people as participants (Christensen and James, 2000; Kellett, 2005; Lewis and Lindsay, 2000). The inequality might even be enhanced in a school (i.e. teacher/pupil) context.

According to Nunkoosing, 2005, p.699,

> *"the power of the interviewer rests in his or her authority as a seeker of knowledge and methodological expertise, and that of the interviewee as a more or less privileged knower."*

For research to be of value for the wider professional community, the researcher's honesty and impartiality are essential (Bryman, 2004), though it may be argued that our actions and interpretations will always be influenced to some extend by our own beliefs, opinions and experiences. However, being alert to this, reflective of ones own thought processes and openly sharing findings with colleagues and participants along the way to incorporate their views and interpretations (i.e. triangulation via collaboration), as I did throughout the process, helps to keep bias to a minimum.

Collaboration

At every stage during the research I worked closely with staff from my own and other schools, young people with ASD and their parents, Autism Outreach Highland and members of the Autism Rights Group Highland, sharing ideas, proposals and findings and seeking and incorporating their feedback, as described in various parts of the methodology, especially in 'Eliciting Pupils' Perceptions' and 'The Questionnaire'.

> *"Partnership and collaboration do not rely on sameness and equality, but on utilising differences"*
> (Lacey, 2001, p.140)

Collaboration with a wide variety of people is essential in social research to take into account different viewpoints, experiences, priorities and interpretations. This can, however, lead to conflicting advice and disagreements, which itself might be used constructively to open up discussion and lead to deeper communication. Phillips, Goodwin, et al (1999) believe that the real nature of disagreements result from people's interests and that in a climate of honesty and acceptance these interests can be revealed and explored to negotiate a win/win situation where nobody feels victimised at the end. Head (2003) makes a distinction between functional and deep collaboration, the former being shallower and only concerned with the smooth and efficient running of events, while the latter incorporates *"interconnectedness"* (p.51) of its members and *"a common sense of the task in hand"* (p.52). Whilst collaborating with colleagues, other adults and young people to devise methodology and research tools, as well as analysing and interpreting data, I was particularly grateful (though not pleased at the time!) for critical comments, challenging me to rethink theories and assumptions. The outcome of this research is therefore very much a joint project with the groups and individuals acknowledged at the beginning of this paper.

<u>The Questionnaire</u>

> *"The use of questionnaires with children seems to have received little attention in methodology texts. In contrast, teen magazines make frequent and apparently popular use of informal self-report questionnaires."* (Lewis and Lindsay, 2000, p.194)

The advantages of questionnaires are that they can be administered without the presence of the researcher, important when operating in a large geographical area like the Highlands. Consisting of mainly standardised questions, they are relatively easy to analyse, and as they can be completed individually, are usually favoured by participants and researchers who do not perform well in direct encounters, which applies to many people with ASD, including myself. They can also be repeated at different times and in different settings, allowing for comparisons to be made (Blaxter, Hughes et al, 2006). Disadvantages include constraints of mainly closed questions for quick, categorized interpretation, leading to descriptive rather than explanatory answers, and lack of opportunity to clarify questions or statements with the researcher. Also, I was slightly worried that administration by school staff might give rise to distortion, since they might interpret pupils' answers as reflecting their own or their institution's performance. To avoid this as much as possible, I guaranteed anonymity of responses, including pupils as well as their schools, and set this out in guidance notes for administering staff.

> *"A great deal of thought and planning goes into the design of a questionnaire in order to avoid bias and ensure participants have sufficient response choices to express their viewpoints accurately."* (Kellett, 2005, p.88)

However, even with the best intentions to avoid bias, the personal views of the researcher will always shine through in the design and analysis and the very reason for choosing the particular field. In addition, responses, too, are prone to bias, including, individual interpretation of questions and statements, social desirability of answers and context effects (Christensen and James, 2000).
Bryman (2004) advises to adopt the following structure for questionnaires:

1. Personal factual questions (i.e. age, gender, location)
2. Factual questions about school experience
3. Personal questions about attitudes, values, beliefs and experiences

This structure allows for an easy start, followed by engagement with personal experience and leading to sharing of personal opinions. For clarity and administrative ease, I divided the questionnaire into four parts.

The first part is concerned with facts about gender, age, location (i.e. mainstream classes, special unit/base or both) and choice. It is intended as an easy start for participants and an indicator of possible correlations between these facts and later statements.

The order of questions is important and has to follow a logical sequence (Scott in Christensen and James, 2000). I therefore set the scene in Part 2 by looking at possible problems encountered by the pupils, before evaluating tried solutions (Part 3) and finally rating the importance of what should be in place to avoid problems or to be equipped to deal with them (Part 4). Apart from the statements supplied by the researcher, each part invites the participants to add their own comments in case they differ from the statements provided or elaborate on these.

The first draft of statements was based on problems and solutions commonly found throughout literature, as well as personal experience as a pupil and a teacher of pupils with ASD.

In order for questions and statements to be relevant, clear to understand and sufficient to elicit participants' views, as well as to answer the research questions, I discussed the first drafts of the questionnaire (Appendix 4) with my tutor, colleagues and members of the Autism Rights Group Highland and a sample of Secondary School pupils with ASD.

The latter initially caused problems with access (Appendix 1-3), as two of the three invited pupils were not ready to participate, but another pupil was found who agreed to take part and we had a very fruitful discussion in their Learning Support Base. By then the questionnaire had already undergone many changes, including the written feedback of one of the two boys. As the other pupil was unknown to me, I was particularly grateful for the participation of his Support for Learning teacher, who by asking him to explain what he thought the statements meant found out what needed to be rephrased or added. She also helped me to formulate some guidance notes for administering staff and confirmed some practical details. The amended questionnaire was then trialled by the Children's Services Worker with three other Secondary School pupils with ASD and was found to be ready for use (Appendix 5-6). A copy was sent to every Learning Support Department of the 29 mainstream Highland Secondary Schools in early January 2009, allowing six weeks for administration. Numbering the return envelopes allowed me to follow up any non-returns. Each school was asked to photocopy the questionnaire for each pupil with ASD on their roll, after I had been discouraged from using electronic versions due to their unreliability. The six weeks time limit allowed for staff or pupil absences and weather related school closures, but ensured that the questionnaire would not be forgotten. I did, however, have to remind 16 schools at the end of February (Appendix 7). In March, I phoned those which still had not responded, but most failed to find the relevant person and they did not respond to let me know their reason for not participating in the research. By then I had begun the process of analysing the data and arranging follow-up interviews (Appendix 8-10).

The Interviews

"Skilful interviewing can help us understand other people's feelings about important issues and find out more about their perceptions and interpretations of situations." (Kellett, 2005, p.74)

The combination of questionnaire and semi-structured interviews was chosen to enable me to make systematic comparisons and generalisations, as well as giving a more detailed insight into the views of the participants. I used semi-structured interviews to provide a structure and to ensure that responses could be compared, but also allowing for individual elaboration.

The particular difficulties in interviewing pupils with ASD include possible difference in interpreting questions and answers due to literal understanding, also distractions in the environment, participants' preoccupation with details or other stimuli at the time of the interview and limited understanding of and ability to reflect on their feelings and experiences (Smith-Myles and Andreon, 2001). There are also general problems when interviewing children and young people, like peer pressure (in group interviews), tendencies to always agree or disagree, wanting to please or challenge the interviewer and not taking questions seriously (Bryman, 2004). However, interviews have the potential to explore people's experiences and views in greater depth, to give insight beyond the direct questions, clarifying issues arising from questionnaires and open unexpected avenues.

The context of the interview also has implications, for example what has just happened in the life of the interviewees, which affects their mood (Bryman, 2004). Conducting interviews at school can lead to an unconscious assumption that it is some kind of performance test with right and wrong answers. On the other hand, it can also provide security and stimulation for thought and discussion about school related issues, as many people with ASD tend to compartmentalise experiences together with the environment in which they take place (Vermeulen, 2001). For this reason, and also to help with access, I proposed to hold the follow-up interviews in the Learning Support Base of the participants' schools.

Because of the nature of ASD, showing so many highly individual facets, it can be very helpful to have somebody present who is familiar with the particular pupils and able to facilitate communication for those who would otherwise not be able to articulate their views, as I experienced during the discussion with pupils about the questionnaire design. However, the danger of having a member of staff from the particular

school present at the interviews lies in losing some of the pupils' original opinion by shifting the weight from their direct responses to the interpretation of their facilitator. In addition, pupils might feel inhibited to express themselves freely in the presence of a member of staff who might judge what they convey to the interviewer. These issues had to be addressed before inviting other adults to be present at the interviews, to assure as much as possible that their role was to facilitate, not to regulate pupils' responses (O'Kane, in Christensen and James, 2000). Alternatively, I asked staff to select pupils who were happy to meet me without support and who were able to articulate their views independently.

In order to keep to a manageable timescale and to facilitate discussion, I chose to undertake three group interviews with 2-4 pupils each and three individual interviews in four different regions: Inverness, Ross-shire, Inverness-shire and Lochaber. Group interviews have the potential to provide additional insight into social processes, the use of language and peer dynamics (O'Kane, in Christensen and James, 2000), although some pupils preferred a one-to-one setting. In the letter inviting pupils to take part in the interviews (see Appendix 5), I stated clearly their purpose, aproximal length, who else would be there, the content of the questions, how I would record what was being said, how the data would be used, how findings would be disseminated and possible outcomes, as well as assuring confidentiality and asking for consent.

To be able to concentrate fully on the interview process and reduce the possibility of omissions and errors, I tape-recorded most of the interviews. Replaying the tape to the participants straight afterwards (if they wish), allows them to comment on or clarify issues or to delete anything, although none of the participants took up this offer. After transcribing, the tapes were erased and all comments kept anonymous. The downside of recording interviews on audio-tape is that facial expression and body language are lost, and transcription can be a lengthy process. Some pupils also felt uncomfortable with the prospect of having their voice recorded, in which case I took notes as we went along. However, this interfered with the fluency of the interview and resulted in less accuracy and more omissions.

According to Bryman (2004), we have to acknowledge the potential for deception by the researcher, especially in interviews about personal issues and when trying to elicit deeper information. This can be quite unsettling for the participants and seen as invasion of privacy. Ongoing consent, i.e. being allowed to opt out at any point, has to be established, as well as remaining sensitive to the participants' needs. Probing for detail may, for example, lead to the pupil feeling obliged to invent a response. It therefore has to be made clear to participants beforehand that they do not have to elaborate on issues that upset them, unless they choose to (France, in Fraser, Lewis et al, 2004). Other ethical considerations, as already mentioned,

include the researcher's impartiality, especially when interviewing several pupils together, and honesty, including not making false promises. There is the possibility of legal obligations clashing with confidentiality, for example if a participant relays information which requires to be followed up (e.g. bullying). It is vital to point this out initially, even if it leads to pupils choosing to withhold certain information.

O'Kane (in Christensen and James, 2000) points out the importance of sustaining participants' motivation by ensuring that the interview is enjoyable, that questions are well matched to participants' conceptual and verbal skills and that they see the relevance of it for their life.

According to Roberts (in Christensen and James, 2000), some authors advise interviewers to hold back their own opinion in order not to influence the responses of the participants. Others, however, insist that the questions asked already lead in certain directions and that offering one's own opinion or experience can help to start discussion or to show empathy and thereby encourage the participants to share more. Also, *"interpretation* (of comments) *must be checked against the child's views"* (Lewis and Lindsay, 2000, p.196). This can be done by summarising what has been said or by 'routing', i.e. taking different routes or rephrasing questions in order to clarify answers (Scott, in Christensen and James, 2000).

Taking into account the limited attention span of many pupils with ASD and their preference to get on with the task rather than to digress into socialising, I anticipated that each interview would take no longer than 30-40 minutes. According to Mayall (in Christensen and James, 2000), it is important to maintain a balance between staying focussed and allowing for meaningful diversions. Edwards (in Fraser, Lewis et al, 2004) urges researchers to look at what participants bring to the interview, what is relevant to them and to empower them to share their knowledge and experience. Bryman (2004) adds the importance of paying attention not only to what, but how it is said, including intonation, body language, sighs, stutter etc., as it determines the meaning of the words. Consideration also has to be given to practical issues like seating arrangements (preferably in a circle) and ground rules, i.e. listening to each other without interrupting, not judging or making fun of what others say and giving everyone equal opportunity to participate (Costley, in Lewis and Lindsay, 2000).

Scott (in Christensen and James, 2000) argues that visual stimuli can aid motivation and discussion, though they also have the potential to distract, suggest or divert.

The Interview Schedule was carefully designed after analysing the questionnaires and taking all the above considerations into account. Before finalising it (Appendix 11), I took it through a similar process as the questionnaire, discussing it with colleagues and adults with ASD and trialling it with two young people with ASD.

All of the interviews went smoothly without upsets or conflicts and elicited valuable information (see sample in Appendix 13 and Collated Answers in Appendix 14). Two pupils in two different group interviews did not contribute much, despite ongoing encouragement from myself and other participants, but as my only contact with them was during the interview, I cannot tell whether this reflects their usual behaviour or was influenced by the interview set-up. One pupil in an individual interview became fixated by the recall of upsetting smells in the canteen and found it very hard to engage with the following questions. All the other pupils were very forthcoming with information and surprised me with their openness and their friendly, encouraging and empathetic interaction within the group interviews. The selection of the pupils by their teachers meant that each of them was deemed able to communicate without support, thus not making it necessary for other staff to be present. Also, I was grateful in each school to be given a quiet, undisturbed room in the Support Base, familiar to the participants.

Methods of Data Analysis

> *"Analysis is about the search for explanation and understanding, in the course of which concepts and theories will likely be advanced, considered and developed."* (Blaxter, Hughes et al, 2006, p.206)

Durrant and Holden (2006) state that the process of analysis has to take into account a complexity of issues, such as understanding one's own and other people's perspectives and interests, sifting the important from the unimportant, making theoretical and moral judgements and critically questioning the validity of findings. Being aware of the need for collaboration, I shared the data and the process of analysis with colleagues, other professionals and adults with Asperger Syndrome, which led to interesting discussions and enhanced understanding.

> *"Meaning does not simply present itself – sense has to be made of the information. It is not the data that tells the story, it is the researcher."*
> (Durrant and Holden, 2006, p.133)

Most data gathered through the questionnaire lent themselves to straightforward analysis as descriptive statistics, displayed in tables, charts and graphs (see Appendix 12). The next step was to assess the significance of these statistics, including the correlation between data from different parts of the survey and a comparison of gender and age groups.

After gathering all data from completed questionnaires into tables and listing all additional comments made by participants (see Appendix 12), I used the following coding methods:

Part 2: What do you find upsetting at school?
As used in some diagnostic tools, like the Dyslexia Screening Test, I doubled the scores given for "very much" to distinguish their weight from "a little", thus arriving at the numbers used for the graph in the following way: very much = x2, a little = x1, not at all = x0.

Part 3: What do you find helpful at school?
Here I calculated the percentage of answers given by those who experience the intervention, as this varied considerably, which I took into account when interpreting the data.

Part 4: What would you have needed to learn in Primary School for coping well with Secondary School?
Although stated clearly on the questionnaire, some pupils did not understand the intended scaling system and used numbers more than once or only numbered certain statements. However, the principal of the lowest number indicating the most important statement still applied, though with slight inaccuracy in the cases where statements felt as unimportant had not been numbered at all. For this reason, I was particularly interested in atypical data, i.e. scores of 1, 2 or 3 given by individuals to statements which statistically appeared as rated least important.

To look for gender and age differences, I then repeated the above process (part 2-4) by first sorting the questionnaires into groups of boys and girls and afterwards into age groups (12-13 years, 14-15 years and 16-17 years). This allowed me to find out specific problems, needs and strengths experienced by various groups of pupils, to make comparisons and speculate about reasons where significant differences occurred.

The numerical outcomes of the questionnaires were always complemented by the additional comments given by participants, which enabled me to look for supplementary information, emphasis and (in)consistencies. The information gleaned from the questionnaires served as the basis for the follow-up interviews.

Analysing interviews can be much more time consuming than analysing questionnaires, as the individual answers might differ widely from each other. Also, the process of the interview has an important bearing on what is being said, and despite clearly defined guidelines, the discussion might lead into unexpected directions. Blaxter, Hughes et al (2006, p.84) give a list of reflective questions for the researcher when evaluating interviews, including looking at the researcher's own thoughts, feelings, actions and reactions during the process, as it is impossible to take oneself out of the equation. Lewis and Lindsay (2000, p.216), advise to note *"the group consensus on key issues ... and where pupils are able to extend the discussion by the group interacting",* and finally to relate *"the content of discussion transcriptions to the original research questions."*

Jones (in Fraser, Lewis et al, 2004) suggests to look critically at what the participants emphasise, their feelings connected with problems and solutions and how they interpret situations and make sense of what is happening.

During the interviews I was particularly aware of the discrepancy between acting as a leader in order to glean relevant information to answer the research questions, while at the same time following the participants' train of thought and interaction. In addition, I felt the need to keep within a set time-scale of 30-40 minutes to maintain the participants' motivation and concentration. I therefore did not always engage in detail with participants' comments, especially when these elaborated on areas of personal interest, like Scottish music or the Scouts.

During the transcription of the interviews I noticed, by colour-coding each participant's verbal input (see Appendix 13), who had contributed much and who a little, and paid particular attention to discrepancies about interpretation of questions and answers and ways of interaction within the group, i.e. one answer or comment triggering another. I was also aware of times when my questioning had been too directive and where I could have gleaned more valuable information, had I encouraged the participant to explain their answer in greater detail.

In order to make the interview data manageable for systematic interpretation, I summarised statements and grouped them into certain areas, i.e. Change, Sensory issues, Attitudes of peers and staff (see Appendix 14). These, together with the tables, graphs and comments from the questionnaires, formed the basis for the following presentation and discussion of findings.

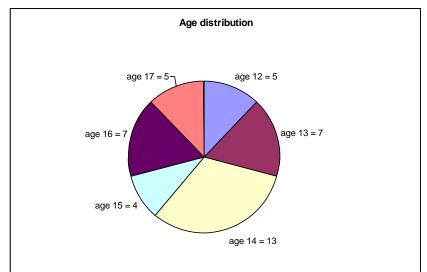# 4) Presentation and Discussion of Findings

"It is clear that listening to children, hearing children and acting on what children say are three very different activities, although they are frequently edited as if they were not." (Roberts, in Christensen and James, 2000, p.238)

Mayall (in Christensen and James, 2000) points out that giving children a voice can make them more reflective about their lives and is therefore a rewarding activity in itself. However, I would argue that, if no action results from their effort to share their unique knowledge, it will simply lead to frustration and a sense of betrayal.

As mentioned earlier, I hoped that the outcomes of the questionnaires and interviews would complement each other and build up a picture of the pupils' perceptions in the area of the research.

Part 1: Information about the participants

Of the 41 pupils who completed the questionnaire, 35 (=85%) were boys and 6 (=15%) girls. Because of the limited number of female participants, gender comparison has to be treated with caution. Issues of gender ratio in the diagnosis of ASD have already been discussed on p.8.

Age distribution

age 17 = 5   age 12 = 5

age 16 = 7   age 13 = 7

age 15 = 4   age 14 = 13

Age distribution was fairly equal, with the exception of 14-year olds who made up about twice the number of each of the other age groups (see diagram above). The high number of 14-year olds may have occurred by chance, or due to this age group more readily taking part in the research, as they were neither newcomers to the school, still trying to find their feet, nor tied up with studying for exams. It might also be connected to variations in diagnosis, which often depends on priorities and availability of knowledgeable staff, like Health Visitors, teachers or paediatricians, to detect signs of ASD and make informed referrals, which fluctuates due to priorities in education, the health sector and public concern in general.

All pupils but one attended mainstream classes with some time in a Support Base or Special Unit; 47% stating this was their choice, 33% their parents' choice and 20% not having had a choice. The reason for not being given a choice might be either that the school has a certain policy for all pupils with ASD or acts on recommendation by the previous Primary School. It may be that some pupils were not capable or deemed capable of making an informed decision, although schools have a legal obligation to consult with pupils and their parents on such matters (see p.22).

Those participating in the interviews were either happy with this class/base arrangement or felt that there was no satisfactory alternative available. One pupil mentioned that he had not known about the Base when he started Secondary School and was only referred to it when his problems in mainstream classes escalated. In many areas, the term *Support Base* and *Special Unit* are used interchangeably. The majority of schools, especially where the roll is no more than 200-250 pupils, do not distinguish between an ASD Base and a general Support Base. However, some larger schools acknowledge the need for separate provision for pupils with ASD from those with general Learning Disability (LD) and those with Emotional and Behaviour problems (EBD). As stated on p.8, the majority of people with ASD are of average or above average academic ability, and to group them together with pupils with LD might deprive them of appropriate educational opportunities. Although pupils with ASD often display challenging behaviour, the underlying reasons, as we have explored on p.11, are very different from those of pupils with EBD and therefore require a different approach. Most of all, pupils with ASD generally function best in a quiet, spacious and uncluttered environment, due to sensory integration problems (see p.13), which for many pupils with LD or EBD would lack the stimulation necessary for them to thrive. The need for ASD specific provision in all Secondary Schools is becoming more widely acknowledged (Dunlop, Tait et al, 2009), as the number of pupils with ASD is rising and mainstream teaching environments become harder for them to access due to increasing sensory over-stimulation as a result of new teaching methods, like co-operative learning and interactive technologies.

> "*For almost any other special need, the classroom only becomes disabling when the demand to perform a given task is made. For the child with autism, disability begins at the door.*" (Hanbury, 2007, quoted in Dunlop, Tait et al, 2009, p.80)

Summary:

- The unevenness in gender participation might be due to the prevalence of a diagnosis of ASD currently being 4 times higher in boys than in girls, as girls often go undiagnosed because they do not present with the same challenging behaviour patterns as boys (see p.8).
- Age distribution amongst participants was relatively equal with the exception of 14-year olds, which might be due to a higher number of this age group diagnosed with ASD or their greater readiness to participate in this research.
- All but one of the participants attended mainstream classes with some time in a Support Base or Special Unit, though in most cases not ASD specific, which for the majority was a combination of their and their parents' choice, while 20% felt they had not been given a choice.

<u>Part 2: What do you find upsetting in school?</u>

The table, graph and additional comments in Appendix 12, part 2 show which areas, indicated by the statements provided, the pupils identified as most upsetting in their daily life at school.

Looking at it from a purely statistical perspective, *Lots of changes happening at once* ranks highest, with *Too much work* and *Boredom* close on its heels, followed by *Being picked on or made fun of* and *Confusing home work assignments. No-where to get away from it all, Not having a friend, I feel I don't belong here* and *Getting lost in the buildings* had the lowest scores, indicating that they were least upsetting issues. Interestingly, girls ranked as most upsetting *Misunderstandings, Too much noise* and *Lots of changes happening at once*, placing *Too much work* and *Boredom* at place 9+10 (see Appendix 12, Gender Differences).
Not having a friend bothers significantly more 14-15 year olds compared to other age groups and a higher percentage of girls than boys (see Appendix 12, Gender Differences and Age Comparison). Possible reasons for this will be discussed on p.49-50.

Change:
As examined in detail in the Literature Review (p.7), due to a lack of central coherence many people with ASD have difficulty telling the important from the unimportant, therefore losing the picture of the whole when details are changing (Frith, 1989). It is not surprising that *Lots of changes happening at once* or changes in a general sense and changes of teachers featured so highly, both in the questionnaire and the interviews.
Two pupils mentioned during the interview a positive example of how they had been prepared for their teacher's maternity leave. They felt that without the preparation they would have had difficulty adjusting to the new teacher. However, many changes cannot be prepared for in advance, as they happen unexpectedly. The authors of the Autism Toolbox (Dunlop, Tait et al, 2009, p.124) point out the importance of predictability for pupils with ASD and that changes can lead to anxiety, inappropriate reactions, non-compliance and attempts to keep things the same. Even the impact of sudden unexpected changes can be lessened if this is acknowledged and pupils are given as much help as necessary to adjust to the circumstances, i.e. being told exactly what is happening, why and what is expected of them.

Sensory Issues:

Looking at the additional comments made on the questionnaires and the main concerns revealed in the interviews (see Appendix 14), sensory issues like noise, smells and crowded corridors were mentioned most often and with the strongest feelings. Perhaps if *Smells* and *Crowded corridors* had featured amongst the statements of Part 2, it would have led to a more accurate picture regarding their importance as negative factors.

> *"The sensory factors in a mainstream secondary school can be overwhelming for children with an ASD."* (Hesmondhalgh, 2006, p.65)

Hesmondhalgh (2006) describes the new building of the Secondary School with ASD provision, where he teaches, as having *"wider corridors, greater natural light and better soundproofing"* (p.65) which reduces pupils' sensory overload and therefore the stress and anxiety leading to challenging behaviour. According to Kluth, 2003, sensory overload can cause confusion, tiredness and even physical pain or shut-down.

Dunlop, Tait et al (2009) are very clear about the importance of the effect of the learning environment on pupils' wellbeing and point out the fact that modern classrooms and schools in general are likely to cause problems for pupils with ASD due to high sensory arousal and limited space. They suggest creating quiet areas within the classroom and school, but in practice this often proves impossible within the present building structures and classroom layouts. Also, as different smells cause different reactions in people with ASD, it is impossible to completely eliminate this cause for upset. It is, however, important to be aware of its influence on the general wellbeing of pupils with ASD and to allow them to express their feelings with regard to smells and to provide alternatives if possible (i.e. the use of disabled toilets, lunch outside or in the Base, choosing to sit away from people whose odour is causing distress).

Also, it can be helpful to allow pupils affected by crowded corridors to enter or leave classes ahead or after the main body of their peers, although this may cause them to miss out on introductions and conclusions of lessons unless conveyed in different form, for example through tapes or written notes.

Work:

Interestingly, *Too much work* and *Boredom,* which both scored highly on the questionnaire, were not elaborated on in additional comments, apart from one: *"At exam times, it feels that there is too much work."* It also did not feature in the interviews, even when I mentioned it specifically, though one pupil stated that *"in S1 everything seemed irrelevant, just nonsense, but not anymore".*

Because people with ASD make sense of the world differently from other people (see p.7), much of what stimulates or interests others has no appeal or meaning to them. In contrast, areas of interest are often explored in great depth and to the exclusion of everything else which would distract from it (Gillberg, 2002).

A major motivator for the majority of people lies in the interpersonal realm, i.e. wanting to please or challenge, to impress or compete, a drive which most people with ASD lack (see p.10). Thus, classes which provide stimulation for other pupils, either because of content or social value, can feel irrelevant and boring for those with ASD. Also, the way in which a subject is explored might not provide a logical structure for someone whose brain organises and processes information differently (Frith, 1989), hence creating a sense of chaos and the necessity to work things out one's own way. I would suggest that this is the main reason for upset caused by *Confusing homework assignments* and *Too much information in classes,* which affected almost as many participants as *Too much work* and *Boredom,* though to a lesser degree. Coping with the classroom environment can require so much energy that any additional demands are felt as 'too much work' (Sainsbury, 2000).

Misunderstandings:

In contrast, *Being picked on or made fun of* and *Misunderstandings,* i.e. teachers and peers not understanding the nature of ASD, was mentioned and elaborated on by several pupils during the interviews (see Appendix 14). This seemed to cause particular problems for girls. An older pupil, about to leave school, said: *"You get picked on, probably because other pupils don't understand Autism, certainly a lot of them. I never had any friends, in High School anyway. It would've been nice to, but I managed to live with it."* Another pupil felt that most teachers did not understand the nature of Autism and were underestimating his academic ability due to his social ineptitude. This is, in fact a common experience of people with ASD, due to a mismatch between social and intellectual ability (Andron, 2001).

Often, misunderstandings are the result of literal language interpretation (see p.7) and blunt honesty (see p.13). Several books have recently been published for people with ASD, explaining common metaphors (Welton, 2004) and the need for tact (Gray, 2000).

I have looked at the reasons for bullying on pp. 12-14. For most participants in the interviews this was not a big issue at present, but most stated that it had affected them at some point. Josh Muggleton, a teenager with ASD who suffered a breakdown after four years in Secondary School, reports:

> *"I needed a place of sanctuary when things got too much for me. I needed encouragement from the teachers, not threats. If the teachers had been properly trained in ASDs, they might have been able to help me cope."* (Muggleton, 2006, p.28)

Friendship Issues:

30% of participants were concerned about not having a friend, though most of them only a little. One interviewee said: *"It would have been nice to* (have a friend), *but I managed to live with it."*

Some people with ASD appear happy to be by themselves and uninterested in making friends or even actively avoiding contact, but although periods of withdrawal into their own world are for many essential to de-stress, most long for friendships, yet do not know how to initiate or uphold them (see p.14), as one participant stated:

> *"It isn't the case that pupils should be given a crash course on ASD, but rather to be taught the distinction between someone who won't socialise properly and someone who <u>can't</u>."*

Remaining Issues:

No-where to get away from it all affected about one third of participants and I will discuss the importance of an ASD Base on p.48. Equally, one third of participants stated, though only a little, *I feel I don't belong here* (see p.7-9 for possible reasons).

Getting lost in the buildings was only a problem for three participants. Many Highland Secondary schools have a roll of less than 300 pupils, while most larger ones have systems in place to assist newcomers (and others if needed) to find their way around the premises.

Summary:

- Changes, sensory issues (noise, smells, crowds) and a lack of understanding from staff and peers were felt by the majority of participants to be the main causes of upset in their school life, with too much work and boredom at times also playing an important part. This corresponds with many personal testimonies found throughout literature, i.e. Gerland (1997), Grandin (1995), Williams (1998), and with findings by Humphrey and Lewis (2008, pp.37-38).
- Some gender differences were noted, for example girls suffering more from noise, misunderstandings and not having a friend, while boys indicated too much work and boredom as bigger problems.
- Age comparison found that not having a friend matters significantly more to 14-15 year olds than to other age groups, which will be looked at on p.52.

In contrast to the study by Humphrey and Lewis (2008) conducted with twenty pupils with ASD from four Secondary Schools in England to find out their views and experiences of mainstream Secondary School, bullying was not a current issue for the participants in my research, though it might have been for non-participants (see p.66). Also, the importance of fitting in and being 'normal', which featured highly in their

research, was not an issue for my participants. Perhaps there is greater acceptance of diversity in Highland Schools and a more positive attitude towards ASD in general.

Part 3: What do you find helpful in school?

The table, graph and additional comments in Appendix 12, part 3 reveal what pupils experience as helpful for their emotional and social wellbeing at school and how much emphasis they place on certain statements and interventions.

Again, looking at the whole picture, *Having a friend or buddy, A Circle of Friends* and *An adult in school who understands me* are ranked by participants as most helpful, while *Interesting lunch- and after school clubs* and *A card to request time-out when needed* scored least importance.

Having a Friend:

Having friends, a buddy or Circle of Friends was seen as helpful by the vast majority (94%) of participants and elaborated on in additional comments and during the interviews. One such comment reads: *"Having friends who won't stereotype me",* while several pupils shared examples of good friendships and buddies during the interviews, like:

> *"The thing that seems really useful is having, like, some friends, because if you have at least one friend, you won't be walking alone around the school, because most people pick on the people who are by themselves."*

> *"When I was in first year, my buddy was very, very helpful. She was my map of the academy."*

Statements like these remind us of the difficulties faced by many pupils with ASD, i.e. loneliness, bullying, disorientation and being overwhelmed by the Secondary School environment, as examined on pp.11-16. Humphrey and Lewis (2008, p.34) observed that *"pupils' relationships with peers proved to be both a barrier and an enabler to their successful inclusion in school."*

Literature is abundant with quotes from people with ASD seeking acceptance for who they are.

> *"We would be fine as we are if only society would learn to be more accepting and empathetic toward the atypical."* (Holliday Willey, in Kluth, 2003, p.139)

> What we need is *"acceptance of diversity rather than compliance".* (Kluth, 2003, p.179)

> *"We should acknowledge differences, we should greet differences, until difference makes no difference anymore."* (Allen in Faherty, 2000, introduction)

Understanding Adults:

Equal importance was placed on teachers and other school staff to understand the needs and strengths of pupils with ASD and to accept their uniqueness. One girl explained what a difference a Support teacher had made to her, stating: *"She was one of the best I had. She took time to know me."*

Often children with ASD are more comfortable in the presence of adults than peers, as their behaviour can be more predictable.

> *"My son likes to be near a member of staff at break times, so he often spends them in his class tutor's 'den' and this keeps him out of the way of the bullies."* (Reid and Batten, 2006, p.6)

However, the HMIe (2006) document *Education for Pupils with ASD* states that many subject teachers in mainstream secondary schools felt they did not have enough understanding of ASD to support pupils adequately and deal appropriately with their unpredictable behaviour (p.27). The importance of including a basic course on ASD in the Professional Development of all school staff is also deemed essential by the authors of The Autism Toolbox (Dunlop, Tail et al, 2009).

Lunch/After School Clubs:

I noted that After-School-Activities were seen as significantly more important for girls than for boys (Appendix 12, Gender Difference) and questionnaire results showed significant variations between different age groups (see Appendix 12, Age Comparison):

- Age 12-13: 56% not at all, 11% a little, 33% a lot;
- Age 14-15: 16% not at all, 42% a little, 42% a lot;
- Age 16-17: 100% not at all important;

Interestingly, in Part 4, *Being part of a club that continues in Secondary School* was ranked least important for transition from Primary School and only three pupils (age 13, 14 &14) considered it third important out of eight statements (see Appendix 12, part4).

Significantly more 14-15 year olds being bothered by not having a friend compared to the other age groups suggests that this particular age group may be in greater need of organised clubs for socialising, while younger and older pupils have other ways of interacting with peers.

Time out:

I would like to note that 68% of pupils reported not having a time-out card, 44% not having interesting lunch clubs and 39% not having interesting after school activities, whereas the other areas were experienced by more than 85% of participants with the exception of a Circle of Friends 76%. However, since the

outcome is based on percentage of those who experience the statements and since extra-curricular activities and time-out cards were not mentioned in additional comments or stated as particularly helpful during interviews, it appears that these areas are in fact least important to pupils with ASD and are therefore least likely to be offered or implemented as much as other interventions by school staff.

Gender- and age comparison (see Appendix 12) revealed that time-out cards are more important for 12-15 year olds than for 16-17 year olds who experience more freedom in curricular choice and individual study time and reported that classes were quieter than in the early years of Secondary School as all pupils wanted to learn what was being offered in order to pass their exams. In addition, only one girl had experienced a time-out card and she regarded it as not at all helpful, although she and the other girls expressed suffering from classroom noise. In one interview, two girls stated in a rather resigned tone of voice that *"you just have to put up with it"*. This resonates with many teachers' experience that girls' needs are easily overlooked, as they are more likely to suffer in silence than to openly demand attention as is typical for boys (Hill, 2009).

One pupil commented that he was allowed to leave the class without a time-out card, but this had occasionally led to misunderstandings, as other teachers thought he had been expelled from class. It can also be difficult for pupils to know when exactly to make use of a time-out card, as they might not be able to understand their own emotions or how much they are expected to put up with before it becomes too much (see p.16). However, additional comments made on the questionnaire and elaborated on during interviews revealed the importance of being time-tabled to the Support Base, as well as it being available at break and lunch times and for time out. Two pupil comments read like this:

> *"The Base! It's good to start the day in the Base, to have friends in the Base and a lunch club where only Base kids are allowed."*

> *"It really helps to go out of class when it gets too noisy, to have the Base to go to for break and lunch time and when I need time out."*

Part 4: What would you have needed to learn in Primary School for coping well with Secondary School?

Finally, looking at the table, graph and additional comments in Appendix 12, part 4 gives an indication of pupils' priorities for interventions during their time in Primary School, which helps to prepare them for the social and emotional demands of Secondary School.

Learning ways of socialising and understanding myself better

These two statements were felt to be the most important aspects of preparation for coping well in Secondary School, regardless of age or gender. According to Frith (1989), children and young people with ASD need explicit teaching in order to learn to understand their own and other's mental states, to compensate for their lack of intuitively picking up social clues and to plan ahead for unexpected situations. The interviews revealed that about two thirds of children had been offered some form of Social Communication Group, either in or out of school, prior to their transition to Secondary School. However, the purpose of the intervention had not always been made clear to them. Several pupils also reported that they had not liked being grouped together with children with EBD, ADHD or general Learning Disability, as their needs were very different. Rated as most important, was the attitude of the teacher or leader, and several pupils related positive memories of out-of-school activities, like drama and outdoor education, provided by Autism specific services.

> *"Me and R. went to this thing after school in a big gym. It was by this guy, an actor. He was doing all sorts of things with us."*

Their statements emphasise the importance of staff offering social-emotional support to children with ASD to understand the nature of Autism and to have a positive attitude towards it.

Behaviourist techniques, like rewards, reinforcements and punishments, might act on the surface, but they never eliminate the underlying cause of the problem (Kluth, 2003).

It is also important to keep in mind that *"teaching people with autism out of the context in which the skills that are being taught are needed can be pointless"* (Graham. 2008, p.38), due to the difficulty with transference.

Jackson, a mother of several children with ASD, also states, rather provocatively:

> *"I maintain that communication is a two-way thing, as is social interaction, so surely it is both the misunderstood and the ones misunderstanding that are impaired?"* (Jackson, in Hesmondhalgh, 2006, p.9)

As pointed out on p.18, the ability to understand ourselves better and to socialise develops hand in hand, as the following statements made during interviews show:

> *"Understanding yourself better, especially if you have an ASD, makes it easier to learn ways of socialising because you know what it is."*

> *"I think it would have been a good thing if we understood ourselves better, because that way, if something is about to happen, we'd know better and be more self-controlled. I thought the other children were being immature and they were just bullying me for the sake of it. When I moved to Secondary School, I realised that's how most people act… I just figured it out by myself."*

One participant reported that Ceilidh dancing was her favourite way of socialising, while for another it was playing dodge-ball with the Scouts. This leads us back to the importance of structured social activities for some pupils with ASD, (see p.14).

Learning to calm myself and de-stress and Learning to recognize when I need time out were two other areas identified by the participants as important We have already noted the predisposition to anxiety related stress experienced by most people with ASD and the difficulty to recognize and verbally articulate feelings (p.12).

> *"I would sing my emotions because I was unable to explain it in words; words can be so cheap. I always knew exactly what song I would play on my way home from school after being bullied for just being me, for doing nothing but being different, I guess."* (Simon, 2007, p.14)

The importance currently placed on teaching Emotional Literacy (see p.5) acknowledges the need for all children to explicitly learn to recognize and articulate feelings, yet pupils with ASD do not necessarily respond to teaching which is geared towards neurotypically developing minds.

> *"Autism is a profound impairment of a person's ability to relate in the usual ways to other people and the world."* (Graham, 2008, p.38)

We therefore have to look for ways of helping children with ASD find their individual solutions for recognizing and dealing with stress, as some shared during the interviews:

> *"What I usually do, I put up my hand and I say that I need some breathing space and I can go out."*

> *"When I get lost, I kind of find a quiet place where I can think."*

Having a friend who goes on with me to Secondary School
This also features as a priority (see Appendix 12, part4). I have elaborated on the importance of friends on p.49. Most Secondary Schools take friendships into account when allocating classes, but as one girl stated during the interview:

> *"If you don't socialise in Primary School, you won't socialise in Secondary, not as other people will. I really made an effort in P6 and 7 to be nice and talk to people to make friends, although it was quite hard."*

To my surprise, **Other pupils being taught about ASD and Learning how to tell others about my ASD** was considered less important in statistical terms. However, pupils age 14-15 thought it more important that other pupils were taught about ASD than *Learning to recognize when I need time out,* and pupils age 16-17 thought it more important that other pupils are taught about ASD than *Having a friend* (see Appendix 12, Age Comparison).

In addition, looking at atypical responses led to the following findings:

Learning how to tell others about my ASD:
- 3 pupils found this most important (age 12, 14 & 16)
- 2 pupils found it second important (age 14 & 16)
- 3 pupils found it third important (age 14, 14 & 17)

Others being taught about ASD:
- 2 pupils found this most important (age 14 & 16)
- 5 pupils found it second important (age 14,14,15,16,16)
- 3 pupils found it third important (age 12, 13 & 14)

Being part of a club that continues in Secondary School:
- 3 pupils found this third important (age 13, 14 & 14)

The high score (see Appendix 12, part 4, table and graph) does not therefore do justice to the 20% of pupils who rated *Learning to tell others about my ASD* and the 25% of pupils who ranked *Others being taught about ASD* amongst the most important aspects. Furthermore, during the interviews, most pupils acknowledged the need for peers to become more understanding of ASD and more tolerant towards it. However, several pupils had negative experiences when trying to explain ASD to their peers, which might have led them to the conclusion that it was not a good idea. In contrast, the whole class of peers being taught about ASD by Autism Outreach or other knowledgeable staff was felt as most effective. One participant reported an example from Primary School:

> *"One day, when I was in P5, there was Mr B.* (Autism Outreach), *and he took the rest of the people apart from me and taught them what I had and everything. Some people did still make fun of me then, but most people didn't make fun of me anymore."*

My uncle, Dr U. Kammer, in personal correspondence of 10.12.2008, told me of an autistic pupil who attended the local grammar school in the 1970's. Through sensitive introduction by a competent teacher, his peer group showed exceptional understanding and tolerance of his autistic behaviours. He did not suffer from any form of bullying or mental health problems and was a successful scholar.

This shows that in fact, greater general knowledge and acceptance of ASD can make a big difference to the social and emotional experience of school for pupils on the autistic spectrum. Perhaps, many participants in the questionnaire survey found areas within themselves (i.e. understanding themselves and how to relate to others, dealing with stress and forming friendship) of greater concern than perceiving the need to educate others. Also, most pupils with ASD would probably have been taught that, being the odd ones out, it was up to them to change and adapt rather than trying to change the perception and attitude of the majority around them. One pupil, about to leave school, said at the end of the interview:

> *"I think the most important would probably be to tell others about Autism and Aspergers because they need to understand the stuff from the start to not getting the wrong end of the stick. It's probably best if it did come from the teachers. It was awful when I did mention it."*

Summary:

- *Learning ways of socialising and understanding myself better* were felt as the most important aspects of preparation for coping well in Secondary School, regardless of age or gender, and this was elaborated on during the interviews with pupils sharing their experience of various input given in this area both in and out of school. This corresponds with the recommendations made by Hesmondhalgh and Breakey (2001) and by Barnard, Prior et al (2000). Equally, HMIe (2006, p.30) states: *"Schools should ensure that pupils with ASD are given appropriate opportunities to gain an understanding of the social world they live in."*

- The nature of interventions to achieve better self-understanding and increase the ability to socialise was seen as less important as the attitude of the staff who were implementing them, in particular their acknowledgement that each person is unique and that autism has many positive aspects to it. Dunlop, Tait et al (2009, p.119) recommend that *"when engaging children and young people in social and emotional learning, you target their strengths."* Also, Reid and Batten (2006, p.32) report that the participants in their research *"talk about individual teachers or assistants who, through their understanding and support, have made a positive difference to their school life."*

- Due to the high level of anxiety experienced by many pupils with ASD, learning to understand one's emotions and to deal with stress was also rated as highly important, which ties in with the findings and recommendations of Hesmondhalgh and Breakey (2001) and Smith-Myles and Adreon (2001).

- Some participants reported negative experiences when trying to educate peers about their ASD and this might have been one of the reasons why it did not score much importance on the questionnaire, except for 20% of participants. However, the need for peers and staff to be taught about ASD in order to gain better understanding and greater tolerance for people on the autistic spectrum was acknowledged by the majority of pupils during the interviews. Humphrey and Lewis (2008) received similar responses in their discussion with participants and came to the conclusion that *"there must also be an acknowledgement of the need to intervene with the peer group… to challenge the attitudes and stereotypes that they often hold."* (p.33)
  According to Batten, Corbett et al (2006, p.42), *"Improved training and understanding of autism (for all school staff) was the biggest single response from families",* whilst HMIe (2006, p.30)

recommends: *"Continuous professional development at an appropriate level should be available to all staff in schools."*

- *Being part of a club that continues in Secondary School* was rated by most participants as least important. No evidence was found to support or contradict this.

Most findings are coherent with those of Humphrey and Lewis (2008) who, admitting *"lack of generalisation that can be made from such a small, exploratory study",* point out that *"commonalities between our findings and those of similar studies – e.g. Carrington and Graham, 2001 – suggest they are typical"* (p.43*)*.

5) Conclusion and Evaluation

Main Research Question:

- What helps to prepare children with High Functioning Autism/Asperger Syndrome for the social and emotional demands of mainstream Secondary Schools?

Sub-Questions:
- What are the pupils' perceptions of their social and emotional experience of Secondary School?
- What strategies do they identify as helpful in order to cope with the social and emotional demands at school?
- What implications does this have for ASD specific input during the transition process from Primary to Secondary School and beyond?

To return to the above research questions, the following **conclusions** can be drawn:

1. For the majority of pupils with ASD, too many changes happening at once and changes in general cause the greatest emotional upset in Secondary School, for reasons explored on p.7. Most pupils experience high levels of stress in mainstream environments caused by sensory issues, misunderstandings and peer pressure, while for many boys too much or seemingly irrelevant work adds to their difficulties.

2. Having a friend or buddy, a Circle of Friends and/or understanding adults in school was identified as most helpful in order to cope with the social and emotional demands at school. In addition, being offered time-tabled periods as well as chill-out time in a ASD specific Base, free of clutter, noise and interpersonal demands, was felt necessary in order to de-stress and gather one's thoughts.

3. The vast majority of participants felt that, starting in Primary and continuing in Secondary School, pupils with ASD should be offered specific input to address ASD related issues for better self-understanding, stress management and ways of socialising. This must be in a relevant context due to their difficulty of transferring skills (see p.7) and must be delivered by someone with personal interest in and positive attitudes towards people with ASD.

4. Most participants agreed on the importance of peers being taught about ASD to enhance tolerance and understanding, but this input must come from knowledgeable adults in order to make a positive impact. Likewise, all school staff (including subject teachers and Learning Support Assistants) should have a basic understanding of ASD, appreciate the implications of sensory issues and not confuse academic and social needs.

Current legislation and recommended practice, including Curriculum for Excellence, The Autism Toolbox (Dunlop, Tait et al, 2009) and The Education (Additional Support for Learning) (Scotland) Act 2004, point

the way ahead to ensure that pupils with ASD experience greater mental health. Graham (2008) makes it clear that the implications of the Disability Discrimination Act (1995, amended 2005) put responsibility on educators, employers and services to make adjustments and not to expect people with disabilities to conform in ways which are impossible for them.

> *"It is no longer right that people with autism should be told that they will be able to learn things and do things that they do not have the facilities for. Nor is it right that people with autism need to develop or learn 'coping strategies' – over and above those that all of us need."* (Graham, 2008, p.132-133)

Whether ASD is *"a disorder or a neurological difference that has been socially constructed as a disorder"* (Molly and Vasil, 2002, in Robertson, 2009, p.16), we have an obligation to provide each pupil with an educational experience to aid and not to hinder their well-being.

As the number of pupils with ASD is still rising and while modern school environments and new approaches to teaching and learning (i.e. co-operative learning, interactive technology, group teaching) cause more and more difficulties for pupils on the autistic spectrum, we urgently need strategies to alleviate stress and help to improve emotional well-being and social functioning.

Based on the outcome of this research, I would like to make the following recommendations:

- Every school, including Primaries, should have an ASD Base, which is spacious, uncluttered and quiet to provide a place where pupils with hypersensitivity to sensory stimuli can de-stress and work undisturbed. This ties in with the findings of Batten, Corbett et al (2006) who quote parents of children with ASD saying *"If I could make one change, I would attach an autism base to the school"* and *"I would put her in a quieter classroom"* (p.43). Humphrey and Lewis (2008, p.38) reported that some schools had *"certain areas (such as resource rooms or libraries) that were used as a refuge for pupils wanting to escape the 'chaos of the corridor'."*
- Every pupil with ASD should be offered time-tabled periods as well as chill-out time in the Base, since most of them need time-out for the above reason and may not be able to judge when to ask for it or how to relax in a busy environment. Dunlop, Tait et al (2009, p.88) acknowledge that *"pupils may become overwhelmed by environmental stimuli… and may, on occasion need time to withdraw and settle following upset."*
- All school staff should have a basic understanding of ASD and the implications of sensory issues and not confuse academic and social needs, in order to allow pupils to reach their academic potential. Humphrey and Lewis (2008, p.39) quote one pupil saying that teachers *"know about their subject but they know nothing about us with Asperger's syndrome."* Dunlop, Tait et al (2009, p.87)

state that *"Staff working with the pupil need to accept that these* (sensory processing differences) *are legitimate and often complex issues that impact on learning and learning behaviour."*

- All peers should have a basic understanding of ASD, taught by a knowledgeable adult (perhaps as part of PSE), to enhance tolerance and understanding, aid friendships and decrease bullying (see pp.58-59).
- Starting in Primary and continuing in Secondary School, pupils with ASD should be offered specific input to address ASD related issues for better self-understanding, stress management and ways of socialising to lessen the likelihood of mental ill health (see p.58).

These recommendations are largely consistent with those arrived at by other research in this field, i.e. Barnard, Prior et al (2000), Batten, Corbett et al (2006), HMIe (2006) and Dunlop, Tait et al (2009). In addition, they demand a *"suitably varied range of provision to meet the wide and varying needs of pupils with ASD"* (HMIe 2006, p.30), which is currently not available in most parts of the Highlands, and stress collaboration with parents and pupils to plan progression. Humphrey and Lewis (2008) also remind us that support given to pupils with ASD in mainstream classes should be unobtrusive, in order to avoid marking them out in front of their peers.

Although my research has been exclusively concerned with the experiences of pupils with ASD, many issues, such as friendships, relationship with staff, delivery of the curriculum and even sensory over-stimulation, are also relevant for other pupils. One might argue that mainstream education has been developed to cater for the needs of the majority of pupils, leaving those on the fringe, like gifted pupils, those with general or specific learning difficulties, certain medical or psychological disorders or from minority sub-cultures, to struggle to fit in (Sainsbury, 2000). If the idea of inclusion is born of the desire to eliminate differences and to fit everybody into the norm, it violates the basic human rights which it pretends to serve. Thus, for inclusion to be a positive experience for all pupils, individual differences must be welcomed and adequately catered for rather than seen as a defect to be corrected (Williams, 2008).

> *"A detailed consideration of the barriers experienced by some pupils can help us to develop forms of schooling that will be more effective for all pupils."*
> (Ainscow, 2008, in Dunlop, Tait et al, 2009, p.146)

If nothing else, it will enable the majority of the school population to widen their horizons by respectfully sharing their lives with people who think and act differently. Many others will probably benefit, too, as it has already been shown that sign-posting and buddy support in Secondary Schools, originally introduced to help pupils with Developmental Disorders, has been successfully expanded to support other pupils.

"There is a powerful lobby for inclusion philosophically and practically. However, there is also no doubt that achieving inclusive practice is both difficult and requires significant restructuring of provision and ideological commitment to implement." (Barnard, Prior et al, 2000, p.26)

It is my hope that this research paper will contribute to the achievement of true inclusion.

Evaluation:

According to Bryman (2004), when analysing data gathered in research, we have to pay attention to a variety of issues, such as casual connections between variables (interconnectivity), the specific social context and other factors in the environment, which all limit generalisation of outcomes beyond the group of participants. In addition, we have to acknowledge *"ambiguity about the direction of causal influence"* (Bryman, 2004, p.36), i.e. what causes what. Without follow-up research some years later, by which time the school population (participants) will have changed, the data gathered in this research are non-manipulative or static, which means we cannot measure changes brought about by interventions resulting from this research. Although external validity is strong when random groups are selected (Bryman, 2004), in this case all mainstream Highland Secondary school pupils with ASD only, replication of the research elsewhere would indicate whether the findings are generalisable (Lewis and Lindsay, 2000).

"People sometimes cynically suggest that social scientists find what they want to find or just convey the obvious." (Bryman, 2004, p.463)

I am very aware of the limitations of this research. Although I hoped that the majority of invited pupils would participate, the questionnaire and interviews might not have been the preferred vehicle of expression for some. As Ravet (2007) points out, we need to engage more concrete methods, like art, drama, play or general observations, to elicit the perceptions of those pupils for whom verbal expression causes difficulty. However, this would have been beyond the scope of this project.

Humphrey and Lewis (2008), whose research questions are very similar to mine, employed semi-structured interviews in conjunction with pupils' personal diaries. Although only five out of twenty participants recorded their daily school experiences for a whole month and another four pupils for a shorter period, this anecdotal evidence allowed for greater depth when analysing their experiences and unique interpretation of situations and motives, as well as their own reasons for actions and reactions and their underlying emotions. The specially designed diaries included prompts to aid pupils' focus and to ensure that both positive and negative experiences were recorded. As my research would also have benefited from this approach, I would include similar strategies if I was to repeat it.

As it turned out, of the 29 Highland Secondary Schools, 19 responded, with 41 completed questionnaires returned and 12 pupils reported as having declined to take part or not being invited due to parental or professional concerns. Despite great efforts, I was unable to establish the exact number of pupils with ASD currently on roll in Highland Secondary Schools. I therefore calculated the response rate in the following way: 19 out of 29 schools = 66% of schools responded. Of these schools, 77% of pupils with ASD took part by completing the questionnaire.

Some teachers only invited those pupils they deemed capable of understanding the questionnaire, while others only approached those who received some form of additional support. Two schools only returned one questionnaire each, although their pupil numbers suggest that they have more students with ASD on their roll. A whole geographical area did not respond, despite the fact that it contains a large number of pupils with ASD and boasts a special early years' provision for children with ASD. Following power-point-presentations about the research given in June to Principal Teachers of Support for Learning from Highland Secondary Schools and professionals involved with the Highland Autistic Spectrum Education Network, I approached several teachers of schools which had not responded to find out their reasons for it. Most of the answers concerned time constraints, staff changes, school inspection and the logistics of administration in the case of large numbers of pupils with ASD on roll, most of whom would have needed assistance with completion. In several cases the questionnaires were sent home and never returned. One teacher reported that his pupils did not see the relevance of it, as they were about to leave school. However, another teacher said:

> *"The questionnaire revealed things to me about my pupils that I hadn't thought of before, and I'd welcome it as a tool for regular use to check-up on how they're getting on."*

Some of the administering teachers informed me that the reason they had not approached certain pupils and the reason stated by pupils or their parents for not wanting to take part in the research was that thinking about these issues would upset them too much. Also, the pupils who were approached by their teachers and agreed to take part in the follow-up interviews were most likely those with good communication skills and the confidence to voice their opinion on the matters to be discussed. This leads me to speculate whether the views of pupils most in need of interventions were in fact not reached by this research.

The importance of collaboration with all stakeholders in the research was already discussed on pp.27-28. As mentioned earlier, I encountered difficulties in contacting relevant staff in those schools which did not respond to the questionnaire and only gleaned some of their reasons from those I managed to approach after

my presentations. Had I been able to engage them in dialogue beforehand, it might have led to wider participation.

Although I gathered much valuable information during the interviews, a more skilful interviewer (i.e. without ASD), not hampered by lack of spontaneous reaction and difficulty understanding the complexity of social/emotional issues, might have been able to extract further reasons for participants' answers as well as being more observant of underlying emotions. On the other hand, my own experience of ASD gave me the advantage to empathise with the participants' experiences of school and to better understand their ASD specific expressions during the interview process.

Data analysis proved to be a straightforward, though lengthy process once I had mastered the relevant computer software. In contrast to my linear interpretation, starting with the biological disposition of people with ASD to mental health problems, Humphrey and Lewis (2008) displayed their findings in "*a network of themes and categories*" (p.30), thus placing greater emphasis on interrelated aspects, like the desire for wanting to fit in, in order to feel better about themselves, influencing peer relationships and thus their mood. In my opinion, both models are relevant. However, my personal experience leads me to the conviction that underlying medical issues are at the base of emotional and social problems faced by people with ASD and therefore need to be addressed, rather than looking solely at environmental issues and interpersonal relationships when searching for solutions for improving mental health in young people with ASD.

At every stage of the research I was grateful for critical comments (and encouragement!) from colleagues of my own and other schools as well as members of the Autism Rights Group Highland. As mentioned on p.36, it is important to incorporate different views to widen possible interpretation and avoid bias (Lawson, 2001). Being an insider, i.e. having struggled with many similar experiences during my own school days due to my Asperger Syndrome, might have predisposed me to hearing only that which confirmed my own views. Therefore it has been imperative to compare my data and their interpretation continuously with other research findings and to look for possible explanations in the wider literature. This process sharpened my critical thinking and flexibility of thought, i.e. taking other people's views into account, which enhances my communication and collaboration with pupils and colleagues.

Thanks to Myna Dowds of Autism Outreach and Jane Baines, SfL Development Officer, I was able to feedback findings to a large number of staff from participating and other schools through power-point-presentations. Subsequent personal conversations revealed that the research was seen as valuable by many

colleagues, which made the hard work worthwhile. In fact, the research brought me in closer contact with many leading practitioners in the education of young people with ASD throughout the Highlands, as well as with pupils, resulting in mutual enhancement through sharing of experiences and ideas.

It is hoped to publish a copy of the Research Report on the website of the Scottish Autism Network Forum, the National Autistic Society, the Scottish Society for Autism and the Highland Autistic Spectrum Education Network. A short report of the research already appeared in the newsletter of the Autism Rights Group Highland (ARGH, Spring 2009) and Highland United for Good Mental Health (HUG, Summer 2009) and I am proposing to write up an article about the research for the University of Aberdeen Journal *'Education in the North'.*

References

ANDRON, L. (ed.), (2001). *Our Journey through High Functioning Autism & Asperger Syndrome.* London: Jessica Kingsley Publ.

AVRAMIDIS, E. and SMITH, B. (1999). An Introduction to the major research paradigms and their methodological implications for special needs research. *Emotional And Behaviour Difficulties: A Peer Reviewed Journal.* **Vol. 4,** No.3, pp.27-36.

BARNARD, J., PRIOR, A. and POTTER, D., (2000). *Inclusion and Autism: Is it working?* London: National Autistic Society.

BATTEN, A., CORBETT, C., ROSENBLATT, M., WITHERS, L. and YUILLE, R., (2006). *Make school make sense. Autism and Education: the reality for families today.* London: NAS.

BELMONTE, M.K., ALLEN, G., BECKEL-MITCHENER, A., BOULANGER, L.M., CARPER, R.A. and WEBB, S.J., (2004). Autism and Abnormal Development of Brain Connectivity. *The Journal of Neuroscience*, **24**(42): pp.9228-9231.

BLAXTER, L., HUGHES, C. and TIGHT, M. (2006). *How to research.* Maidenhead: Open University Press.

BOGDASHINA, O., (2003). *Sensory Perceptual Issues in Autism and Asperger Syndrome.* London: Jessica Kingsley Publ.

BROCK, J., BROWN, C.C., BOUCHER, J. and RIPPON, G., (2002). The temporal binding deficit hypothesis of autism. *Development and Psychology*, **14**, pp.209-224.

BRYMAN, A. (2004). *Social Research Methods (second edition).* Oxford University Press.

CHRISTENSEN, P. and JAMES, A. (editors) (2000). *Research with Children.* London: Routledge Falmer.

CUMINE, V., LEACH, J. and STEVENSON, G. (2000). *Asperger Syndrome: A Practical Guide for Teachers.* London: David Fulton Publ.

DASH, N. K. (1993). Research Paradigms in Education: Towards a Resolution. *Journal of Indian Education,* **19** (2), pp. 1-6.

DEUDNEY, C. and SHAH, A., (2004). *Mental Health in pople with autism and Asperger Syndrome.* London: National Autistic Society.

DOCKETT, S. and PERRY, B. (2007). Trusting children's accounts in research. *Journal of Early Childhood Research.* **Vol. 5,** No.1, pp. 47-63.

DUNLOP, A., TAIT, C., LEASK, A., GLASHAN, L., ROBINSON, A., MARWICK, H., (2009). *The Autism Toolbox.* Edinburgh: The Scottish Government.

DURRANT, J. and HOLDEN, G. (2006). *Teachers Leading Change: Doing Research for School Improvement.* London: Paul Chapman Publishing.

DWIVEDI, K.N. and HARPER, P.B. (editors) (2004). *Promoting the Emotional Well-being of Children and Adolescents and Preventing Their Mental Ill Health.* London: Jessica Kingsley Publ.

FAHERTY, C. (2000). *Asperger's… What does it mean to me?* Arlington, Texas: Future Horizons Inc.

FRASER, S., LEWIS,V., DING,S., KELLETT, M., ROBINSON, C. (editors), (2004). *Doing Research with Children and Young People.* London: SAGE Publications.

FRITH, U., (1989). *Autism: Explaining the Enigma.* Oxford: Blackwell Publ.

GEPHART, R. (1999). Paradigms and Research Methods. *Research Methods Forum,* **Vol. 4,** Summer 1999, Department of Management, University of Texas, Arlington.

GERLAND, G., (1997). *A Real Person.* London: Souvenier Press.

GHAZIUDDIN, M. (2005). *Mental Health Aspects of Autism and Asperger Syndrome.* London: Jessica Kingsley Publ.

GILLBERG, C., (2002). *A Guide to Asperger Syndrome.* Cambridge University Press.

GRAHAM, J. (2008). *Autism, Discrimination and the Law.* London: Jessica Kingsley Publ.

GRANDIN, T. and SCARIANO, M., (1986). *Emergence, labelled Autistic.* New York: Arena Press.

GRANDIN, T., (1995). *Thinking in Pictures.* New York: Vintage Books.

GRAY, C. (2000). *The New Social Story Book.* Arlington, Texas: Future Horizons Inc.

HANKO, G. (2003). Towards an inclusive school culture – but what happened to Elton's 'affective curriculum'? *British Journal of Special Education.* **Vol. 30,** No.3, pp.125-131.

HEAD, G. (2003). Effective Collaboration: deep collaboration as an essential element of the learning process. *Journal of Educational Enquiery.* **Vol. 4,** No.2, pp.47-62.

HESMONDHALGH, M. and BREAKEY, C., (2001). *Access and Inclusion for children with ASD.* London: Jessica Kingsley Publ.

HESMONDHALGH, M. (2006). *Autism, Access and Inclusion on the Front Line.* London: Jessica Kingsley Publ.

HILL, A. (2009). Doctors are 'failing to spot Asperger's in girls'. *The Observer.* 12.04.2009.

HMIe (2006). *Education for Pupils with Autism Spectrum Disorders.* Edinburgh: HMIe.

HMIe (2009). *Curriculum for Excellence.* Edinburgh: The Scottish Government.

HUMPHREY, N. and LEWIS, S. (2008). Make me normal: The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism,* 12/1, pp.23-46.

KAMMER, E. (2007). *Discovering who I am: Growing up in the sensory world of Asperger Syndrome.* Inverness: Brandon Press.

KELLETT, M., (2005). *How to Develop Children as Researchers.* London: Sage Publ.

KLUTH, P., (2003). *You're going to love this kid! – Teaching students with Autism in the inclusive classroom.* London: Jessica Kingsley Publ.

KRAUS, S.E. (2005). Research Paradigms and Meaning Making: A Primer. *The Qualitative Report,* **Vol. 10,** No. 4, December 2005, pp. 758-770.

LACEY, P. (2001). *Support Partnerships.* London: David Fulton Publishers.

LEWIS, A. and LINDSAY, G. (editors), (2000). *Researching Children's Perspectives.* Buckingham: Open University Press.

MUGGLETON, J., (2006). Square peg, round hole. *NAS Communications*, Autumn 2006, p.28.

MYLES, B.S., COOK, K.T., MILLER, N.E., RINNER, L. and ROBBINS, L.A. (2000). *Asperger Syndrme and Sensory Issues: Practical Solutions for Making Sense of the World.* Shawnee Mission (USA): AAPC.

NATIONAL AUTISTIC SOCIETY (no author identified), (2001). *Words will really hurt me. How to protect your child from bullying.* London: NAS.

NATIONAL AUTISTIC SOCIETY (2007). Statistics accessed at www.nas.org.uk.

NUNKOOSING, K. (2005). The problems with interviews. *Qualitative Health Research,* **Vol. 15,** No. 5, pp.698-706).

OWENS, G., (2008). *The use of Lego Therapy to enhance Social Interaction in Children with ASD.* Handout based on thesis (PhD). University of Cambridge.

PEETERS & GILLBERG, C., (1999). *Autism: Medical and Educational Aspects.* London: Jessica Kingsley Publ.

PHILLIPS, S., GOODWIN, J. and HERON, R. (1999). *Management Skills for SEN Coordinators in the Primary School.* London: Falmer Press.

RAVET, J., (2007). *Are we listening? Making sense of classroom behaviour with pupils and parents.* Stoke-on-Trent: Trentham Books.

REID, B. and BATTEN, A., (2006). *Make school make sense for me: children and young people with autism speak out.* London: NAS.

ROBERTSON, J.W. (2009). *Informing the public? UK newspaper reporting of autism and Asperger's syndrome.* Journal of Research in Special Educational Needs, **Vol. 9,** No.1, pp. 12-26.

SAINSBURY, C., (2000). *Martian in the Playground: Understanding the Schoolchild with Asperger Syndrome.* Bristol: Lucky Duck Publ.

SCOTTISH SOCIETY FOR AUTISM (2005). *Frequently Asked Questions.* Alloa: SSA.

SEED (2005). *The Mental Health of Children and Young People: A Framework for Promotion, Prevention and Care.* Edinburgh: Crown Copyright.

SEED (2006). *A Curriculum for Excellence - progress and proposals.* Edinburgh: Crown Copyright.

SEED (2008). *Curriculum for Excellence – building the curriculum 3.* Edinburgh: Crown Coryright.

SERA (2005). *Scottish Educational Research Association, Ethical Guidelines for Educational Research.*

SHERRATT, D., (2005). *How to support and teach children on the Autistic Spectrum.* Cambridge: LDA.

SHERRATT, D. (2006). *Play-Drama for children on the autistic spectrum.* Inverness: Highland Council Autism Outreach.

SIMON, (2007). Letter and Poem. *Aspereger United*, **49**, January 2007, p.14.

SINCLAIR, J., (1993). Don't Mourn For Us. *Our Voice* (newsletter of Autism Network International), **Vol.1**, No.3.

SMITH-MYLES, B. and ADREON, D., (2001). *Asperger Syndrome and Adolescence: Practical Solutions for School Success.* Kansas/USA: Autism and Asperger Publishing Company.

TANTAM, D. (2008). *The bullying of mainstream secondary pupils with Asperger Syndrome.* London: NAS International Conference, 19.-20.Sept. 2008.

TREVARTHEN, C., (2000). *Autism as a neurodevelopmental disorder.* Edinburgh: Harcourt Publ.

VERMEULEN, P., (2001). *Autistic Thinking – This is the title.* London: Jessica Kingsley Publ.

WAINSCOT, J., NAYLOR, P., SUTCLIFFE, P., TANTAM, D. and WILLIAMS, J., (2008). Relationship with peers and the school environment of mainstream secondary school pupils with Asperger Syndrome (high-functioning autism): A case-control study. *International Journal of Psychology and Psychological Therapy*, **8(1),** pp. 25-38.

WELTON, J. (2004). *What did you say? What do you mean?* London: Jessica Kingsley Publ.

WEISS, S. and WESLEY, K. (1999). Postmodernism and its Critics. *Anthropology 536.* University of Alabama's Anthropology Department's web page.

WHITE, S.W., OSWALD, D., OLLENDICK, T. and SCAHILL, L. (2009). *Anxiety in children and adolescents with autism spectrum disorders.* Research. Virginia Polytechnic Institute and State University, Department of Psychology.

WILLIAMS, D., (1996). *Autism – An Inside Out Approach.* London: Jessica Kingsley Publ.

WILLIAMS, D., (1998). *Autism and Sensing.* London: Jessica Kingsley Publ.

WILLIAMS, D. (2008). *Clashing 'Normalities'.* Lecture held at Manchester University, 13.9.2008.

WING, L., (1971). *Autistic Children.* London: Constable.

WOODWARD, B. and HOGENBOOM, M., (2002). *Autism – A Holistic Approach.* Edinburgh: Floris Books.

<u>Appendix</u>

Appendix 1: Letter to headteacher, inviting pupils for questionnaire design discussion

Elkie Kammer
SfL teacher
R. Primary School

28th October 2008

Mr S. D.
Headteacher
C. Academy

Dear Mr D.,

I am SfL teacher at R. Primary School and I am currently studying for a MEd Inclusive Practice with Aberdeen University. My research topic is:

What helps to prepare pupils with High Functioning Autism and Asperger Syndrome for the social and emotional demands of Secondary School.

Part of this research will form a questionnaire to be sent to all pupils with ASD in Highland Secondary Schools in January 2009.

I am enclosing a provisional questionnaire, which I would like to discuss with pupils with ASD before designing the final version. As I have worked with three of your pupils in the past (names), I would like to ask your permission to approach these pupils for their help. This would involve passing on the enclosed letters to them (see the pro forma attached for your information) and, once parental permission is given, to arrange a meeting with them for approximately one hour during the school day in November at C. Academy.

If you have any concerns or questions, please do not hesitate to contact me by e-mail: … or by phone at R. School (…).

Yours sincerely,

Appendix 2: Letter to pupils invited to questionnaire design discussion

Elkie Kammer
SfL teacher
R. Primary School

28th October 2008

C. Academy

Hello _____

I hope you are well and enjoying Secondary School (or at least part of it).

At the moment I am studying part-time for a Master of Education degree at the University of Aberdeen. This involves research about ***What helps to prepare pupils with High Functioning Autism and Asperger Syndrome for the social and emotional demands of Secondary School***.

Part of this survey will be a questionnaire sent to all pupils with ASD in Highland Secondary Schools in January 2009. I have started to make up this questionnaire, but would like to hear your opinion on it and what else to include or how to say things better.
For this reason, I would like to come to C. Academy one day in November for about an hour, to discuss the questionnaire with you and a couple of other pupils and to design the final version.
I would really value your opinion and hope you agree to take part. It would also be nice to see you again and to hear how you are doing.

If you have any questions, please do not hesitate to contact me, either by e-mail …or by phone at R. School (Tel…).

If you decide to take part in the discussion about the questionnaire, please, share it with your parents, sign the slip below and return it to me in the envelope provided.
I hope to hear from you soon.

With best wishes,

yours sincerely,

Appendix 3: Consent form for questionnaire design discussion

What helps to prepare pupils with High Functioning Autism and Asperger Syndrome for the social and emotional demands of Secondary School?

(A survey including all pupils with ASD in Highland Secondary Schools)

I agree to take part in a one-hour discussion with Miss Kammer and two other pupils at Culloden Academy in November 2008 to help design the questionnaire for this survey.

_____
        (pupil's signature)

I give permission for my son to take part in a one-hour discussion with Miss Kammer and two other pupils at Culloden Academy in November to help design the questionnaire for this survey. I understand that the pupils' names will be kept anonymous.

_____   _____
        (parent's signature)   (date)

Appendix 4: Draft questionnaire for design discussion

This is the draft questionnaire we will discuss.

You can read it and think about:

- **Are the suggestions relevant?**

- **Is it clear enough to understand?**

- **What else could we add?**

- **What should we change?**

This questionnaire is for all pupils with Autism or Asperger Syndrome attending Secondary Schools in the Highland Council Area.

Its aim is to find out your opinion of the social and emotional demands of school:
- what makes it difficult for you to cope
- what makes it better and
- what preparation helped or would have helped you for the transition from Primary to Secondary School.

The information will hopefully lead to making life better for pupils with ASD. So thank you for taking part in this survey. I will let you know of the outcome, once I have collected all the information.

Part1: About Yourself

a) Your gender: male ☐   female ☐

b) How old are you? _____

c) Are you attending mainstream classes?   Yes ☐   No ☐

d) Are you in a special class or unit?   Yes ☐   No ☐

e) Is this your or your parents' choice?   My choice ☐

My parents' choice ☐   We don't have a choice ☐

What do you find upsetting in school?

Please, tick one answer for each statement.

Statement	Very much	A little	Not at all
Misunderstandings			
Not having a friend			
Being picked on or made fun of			
I feel I don't belong here.			
Too much noise			
Crowded corridors			
No-where to get away from it all			
Getting lost in the building(s)			
Too much information in classes			
Confusing homework assignments			
Boredom			

Can you think of anything else? Write it here.

What do you find helpful in school?

Please, tick one answer for each statement.
If there is something you do not get (like a Home-School Diary or a Circle of Friends) leave that statement out.

Statement	Very much	A little	Not at all
Having a friend or buddy			
Having a Circle of Friends			
An adult in school who understands me			
Most teachers understand my needs			
A card to request time-out when I need it			
A quiet place I can go to			
Interesting lunch clubs			
Interesting after school activities			
Being allowed to work on my own at times			
Having a Learning Support Assistant			
Home – School Diary			

Can you think of anything else? Write it here.

What would be most important to learn in Primary 7 in order to cope well with Secondary School?

Please, number the statements in order of importance: 1 = most important, 2 = second important, and so on.

Understanding myself and my ASD better	
Learning ways of social communication	
Learning to recognize when I need time out	
Learning to calm myself and de-stress	
Learning how to tell others about my ASD	
Other pupils being taught about ASD	
Having a friend who goes on with me to Secondary School	
Being part of a club that continues in Secondary School	

Any other comments or ideas? Write them here.

Appendix 5: Guidance Notes for Final Questionnaire

Elkie Kammer
SfL teacher
R. Primary School

5th January 2009

Highschool/Academy
PT Support for Learning
Dear ………

I am SfL teacher at R. Primary School in Inverness and I am currently studying for a MEd Inclusive Practice with Aberdeen University. My research topic is:

What helps to prepare pupils with High Functioning Autism and Asperger Syndrome for the social and emotional demands of mainstream Secondary School.

Part of this research takes the form of the attached questionnaire to find out the pupils' own perceptions. It is sent to all Highland Secondary Schools and I would be very grateful if you take as many photocopies as you have pupils with ASD on your roll and administer it in school, if possible.

Some pupils might require an adult to go through the questions and statements with them and prompt them to think about possible answers. However, I would like to capture as much as possible the pupils' views and would like to assure you that whatever these views are, they do not reflect the performance of the school or staff.

All questionnaires will remain anonymous and the number on the return envelope will only be used to keep track of which schools have returned the questionnaires and who might need a reminder.
I would be grateful to receive the completed questionnaires by Friday, 20th of February.

If you have any concerns or questions, please do not hesitate to contact me by e-mail: … or by phone at R. School (…).

May I take the opportunity to thank you very much for your help and to remind you of the offer to hold a free ASD Awareness workshop at your school, if ever you wish.

Yours sincerely,

Appendix 6: Final Questionnaire (4 pages)

This questionnaire is for all pupils with Autism or Asperger Syndrome attending Secondary Schools in the Highland Council Area.

Its aim is to find out your opinion of the social and emotional demands of school:
- **what makes it difficult for you to cope**
- **what makes it better and**
- **what preparation helped or would have helped you for the transition from Primary to Secondary School.**

The information will hopefully lead to improving life for pupils with ASD. So thank you for taking part in this survey. I will let you know of the outcome, once I have collected all the information.

Part1: About Yourself

a) Your gender: male ☐   female ☐

b) How old are you? _____

c) Are you attending mainstream classes?   Yes ☐   No ☐

d) Are you in a special class or unit?   Yes ☐   No ☐

e) Do you ever attend the Support Department or Base?   Yes ☐   No ☐

f) Whose choice is this?   My choice ☐

    My parents' choice ☐   We don't have a choice ☐

Part 2: What do you find upsetting in school?

Please, tick one answer for each statement.

Statement	Very much	A little	Not at all
Misunderstandings			
Not having a friend			
Being picked on or made fun of			
I feel I don't belong here.			

Too much noise			
Crowded corridors			
No-where to get away from it all			
Getting lost in the building(s)			
Too much information in classes			
Too much work			
Boredom			
Confusing homework assignments			
Sudden changes of teachers			
Lots of changes happening at once			

Can you think of anything else? Write it here.

Part 3: What do you find helpful in school?

Please, tick one answer for each statement.

Statement	Very much	A little	Not at all	I do not have this
Having a friend or buddy				
Having a Circle of Friends				
An adult in school who understands me				
Most teachers understand my needs				
A card to request time-out when				

I need it				
A quiet place I can go to				
Interesting lunch clubs				
Interesting after school activities				
Being allowed to work on my own at times				
Having a Learning Support Assistant				
Home-School Diary				

Can you think of anything else? Write it here.

Part 4: What would you have needed to learn in Primary School for coping well with Secondary School?

Please, number the statements in order of importance 1 to 8:
1 = most important, 2 = second important, and so on, 8 = least important

Understanding myself better	
Learning ways of socializing	
Learning to recognize when I need time out	
Learning to calm myself and de-stress	
Learning how to tell others about my Autism or Aspergers	
Other pupils being taught about Autism and Aspergers	
Having a friend who goes on with me to Secondary School	

Being part of a club that continues in Secondary School	

Any other comments or ideas? Write them here.

Elkie Kammer
SfL teacher
R. Primary School
26thFebruary 2009

PT Support for Learning

Dear Colleague,

I am SfL teacher at R. Primary School in Inverness and I am currently studying for a MEd Inclusive Practice with Aberdeen University. My research topic is:

What helps to prepare pupils with High Functioning Autism and Asperger Syndrome for the social and emotional demands of mainstream Secondary School.

Perhaps you remember the questionnaire I sent to you in the beginning of January to find out the pupils' own perceptions on this issue. For statistical reasons, it is very important to give every pupil with ASD in all Highland Secondary Schools the opportunity to voice their opinion. As I have not heard from you, may I remind you of this survey and ask you, if at all possible, to carry it out at your school.

I would be grateful to receive the completed questionnaires as soon as possible.

If you have any concerns or questions, please do not hesitate to contact me by e-mail: … or by phone at R. School (…).

May I take the opportunity to thank you very much for your help.

Yours sincerely,

Appendix 8: Letter to PT Support for Learning, inviting pupils for follow-up interviews

Elkie Kammer
SfL teacher
R. Primary School

23rd February 2009

PT Support for Learning
High School / Academy

Dear Colleague,

Thank you very much for assisting me with the research for my MEd Inclusive Practice with Aberdeen University into

What helps to prepare pupils with High Functioning Autism and Asperger Syndrome for the social and emotional demands of mainstream Secondary School.

Having collected and analysed the questionnaires, my next step is to hold follow-up group interviews with 2-4 children with ASD in three different schools. I would like to invite your pupils to attend an interview with me at G. High School for about half an hour, if possible on a Friday (as this is my non-teaching day).

If you think this is feasible, would you please pass copies of the attached letter to the pupils and their parents, and once (hopefully) their permission is obtained let me know what time would be suitable for me to come and conduct the interview.

To give you some idea of the content of the interview, I enclose the interview schedule, which may also be passed on to the pupils.

If you have any concerns or questions, please do not hesitate to contact me by e-mail: … or by phone at R. (…).

May I take the opportunity to thank you very much for your help.

Yours sincerely,

Appendix 9: Letter to pupils invited to follow-up interviews

<div align="right">

Elkie Kammer
SfL teacher
R. Primary School

23rd February 2009

</div>

Dear_____

I am Support for Learning teacher at R. Primary School in Inverness and I am currently studying part-time for a Master of Education degree at the University of Aberdeen. This involves research about ***What helps to prepare pupils with High Functioning Autism and Asperger Syndrome for the social and emotional demands of Secondary School***.

Part of the research has been a questionnaire sent to all pupils with ASD in Highland Secondary Schools in January 2009, and I am very grateful that you took part in it.

Having collected and analysed the questionnaires, my next step is to hold follow-up group interviews with 2-4 children with ASD in three different schools. I would like to invite you to attend an interview with me at M. Academy for about half an hour on a Friday (date and time to be confirmed).

I would really value your opinion and hope you agree to take part.

If you have any questions, please do not hesitate to either contact your SfL teacher at school or to e-mail me at …

If you decide to take part in the interview, please, share it with your parents, sign the slip below and return it to your SfL teacher at school as soon as possible.

I am looking forward to meeting you.

With best wishes,

yours sincerely,

Appendix 10: Consent form for follow-up interviews

What helps to prepare pupils with High Functioning Autism and Asperger Syndrome for the social and emotional demands of Secondary School?

(A survey including all pupils with ASD in Highland Secondary Schools)

I agree to take part in an approximately 30-minutes interview with Miss Kammer and some other pupils at M. Academy in March 2009.

_____
(pupil's signature)

I give permission for my child to take part in an approximately 30-minutes interview with Miss Kammer and some other pupils at M. Academy in March 2009. I understand that the pupils' names will be kept anonymous.

_____   _____
(parent's signature)   (date)

Appendix 11: Interview Schedule (2 pages)

Interview Schedule

1. **Briefing**:
   - Introduction of participants
   - Setting the scene by repeating practicalities stated in the invitation letter, incl. asking for permission to audio-tape the interview and reminding participants that they can choose what to share and are free to opt out at any time.
   - Assure confidentiality, but be clear about legal obligations to pass on certain types of incidents.
   - Repeat rules, i.e. not interrupting others or deriding what they say.

2. **Giving opportunity for feedback about the questionnaire**:
   - How did you find the questionnaire in general? (Give out blank samples as reminders.)
   - Do you want to comment on the lay-out?
   - Was it easy to follow?
   - Were the questions and statements relevant to you?
   - Did you fill it in on your own or with adult help?
   - Was there anything missing?
   - Any thoughts you would like to share?

3. **Suggested interview questions:**

   - Look at the list of problems (Part 2). Is there anything you find particularly upsetting? Can you tell me a bit more about it?
   - Is there anything else that you want to share, which is not on the list? Please, tell me more about it.
   - Looking at Part 3, which of these things have you experienced so far?
   - What did you find helpful (sometimes helpful, not helpful) and why?

   - (Part 4) According to the outcome of the questionnaire, "*Learning ways of socialising*" and "*Understanding myself better*" are at the top of the list of things that pupils with ASD find important to help them with moving from Primary to Secondary school.
   - What opportunities did you have in Primary school to learn ways of socialising?
   - Were these opportunities enough?
   - What did you find especially helpful or unhelpful?
   - Can you think of other / better ways to learn how to socialise?

- What opportunities did you have to learn to understand yourself better?

- What worked best for you? What didn't work? What would you recommend?

- Is there anything else you find important for making transition from Primary to Secondary school easier?
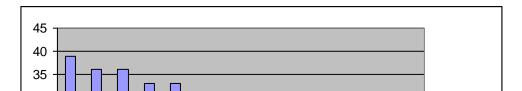
4. **Winding down:**

- Summarise what has been discussed.

- Offer to replay tape to give participants the opportunity to clarify statements, add or take away anything.

- Thank participants for taking part and let them know when/how outcomes of the research will be shared.

Appendix 12: Collated data from Questionnaire (15 pages)

Part 2: What do you find upsetting at school?

Not everybody gave a tick to every statement, hence variations in numbers.

Statement (1 – 14 corresponding to columns in graph)	Very much	A little	Not at all
1.Lots of changes happening at once	13	13	14
2.Too much work	9	18	13
3.Boredom	10	16	15
4.Misunderstandings	4	25	12
5.Being picked on or made fun of	11	9	19
6.Confusing homework assignments	5	23	13
7.Too much noise	5	19	17
8.Crowded corridors	6	16	20
9.Too much information in classes	5	18	18
10.Sudden changes of teachers	6	12	22
11.No-where to get away from it all	2	13	25
12.Not having a friend	3	9	28
13. I feel I don't belong here.	0	13	26
14.Getting lost in the building(s)	0	3	38

45
40
35

Code: numbers of answers were converted as follows: Very much = x2, a little = x1, not at all = x0 ;

Additional comments on Part 2:

- Strange smells, sometimes unhygienic toilets, classes sometimes too fast.
- At exam times, it feels that there is too much work.
- Been (being?) late.
- My teachers are keen for me to stay in school, but I am not so keen because of changes of teachers. It makes me less happy to be here.
- Crowding is an issue here – often during class changes the corridors are salmon-packed. A great issue to me.
- The Support Base often sports a smell of general un-hygiene, which is discomforting to me and especially my sister.
- People laughing at me watching the passing trains.
- Changes in a general sense; especially too many of them at once.

Part 3: What do you find helpful in school?

Statement (numbers corresponding to columns in graph)	Very much	A little	Not at all	I do not have this
1.Having a friend or buddy	24	9	2	6
2.Having a Circle of Friends	17	11	2	10
3.An adult in school who understands me	22	17	4	1
4.Having a Learning Support Assistant	19	12	5	5
5.A quiet place I can go to	18	11	8	4
6.Most teachers understand my needs	12	24	4	1
7.Being allowed to work on my own at times	14	16	9	2
8.Home-School Diary	12	14	9	6
9.Interesting lunch clubs	10	5	8	18
10.Interesting after school activities	8	6	11	16
11.A card to request time-out when I need it	3	3	7	28

Percentage of answers given by those who experience this

Additional comments on Part 3:

- Having friends who won't stereotype me.
- I can go without a time-out card.
- Very helpful to have a lot of leeway on deadlines; I do not have much useful spare time between four advanced higher subjects.
- There are more teachers in this school that understand my needs, but they are not in school.
- More friends, but not a large circle.
- Having time-tabled time in the Support Base with Mrs McD.
- I go to the Support Base at lunch times.
- I would like a stress ball.
- Most teachers understand myself; some of them don't even realise that I have autism (as mine is high functioning).

Part 4: What would you have needed to learn in Primary School for coping well with Secondary School?

Please, number the statements in order of importance 1 to 8:
1 = most important, 2 = second important, and so on, 8 = least important

The concept of numbering was not readily understood. Some participants gave numbers more than once. However, it still works out that **the lowest number indicates the most important statement**.

1. Learning ways of socializing	111
2. Understanding myself better	116
3. Learning to calm myself and de-stress	133
4. Having a friend who goes on with me to Secondary School	135
5. Learning to recognize when I need time out	150
6. Other pupils being taught about Autism and Aspergers	179
7.Learning how to tell others about my Autism or Aspergers	198
8. Being part of a club that continues in Secondary School	225

- Better Times tables teachings.
- Most of these were not really important to me.
- Not to be grouped together with pupils with ADHD or EBD.
- Learning how to approach and then speak to a teacher about a problem.
- Transition programme in place. One period per day in Base to catch up and de-stress and chat. (Information supplied by teachers of two different schools.)
- I don't feel able to number the above and don't want to think about it.
- What's the point – I'm already in Secondary School!
- It isn't the case that pupils should be given a crash course on ASD, but rather to be taught the distinction between someone who won't socialise properly and someone who can't.
- In Primary School I was quite hyperactive, after I went into Secondary, I lost those tendencies and was then able to focus my potential on education. In Primary it would have really helped me if I was given a sense of real achievement for completing work, instead of being suppressed and cornered by my 'support' teachers.
- If I had had time in (or known about) the Support Base from the beginning.
- My autism is actually fairly mild, and I have some trouble socialising at times. Other than that, there is nothing outstanding I have to say.
- I had very bad stress in first year and it wasn't realised until third term. So certainly stress recognition would have been very useful.

Gender Difference:

Part 2: What do you find upsetting at school?

Girls only

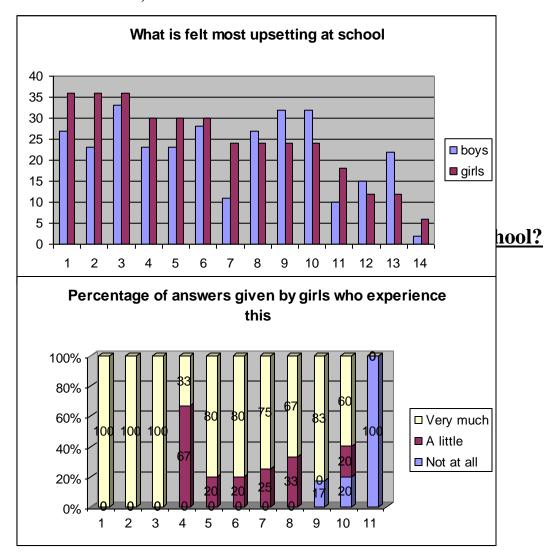**Key:** 1= Misunderstandings, 2= Too much noise, 3= Lots of changes happening at once,

4= Crowded corridors, 5= Too much information in classes, 6= Confusing homework,

7= Not having a friend, 8= Being picked on or made fun of, 9= Too much work,

10= Boredom, 11= I feel I don't belong here, 12= No-where to get away from it all,

13= Sudden changes of teachers, 14= Getting lost in the building(s);

To compare their answers to those of the boys in the study, I multiplied the above data by 6, as 6 times more boys than girls took part, and displayed them together in the following graph (the column numbers still represent the statements as listed above):

What is felt most upsetting at school

Percentage of answers given by girls who experience this

Key: 1= Being allowed to work on my own at times, 2= A Learning Support Assistant,
3= Having a Circle of Friends, 4= Most teachers understand my needs,

5= Home School Diary, 6= Interesting lunch clubs, 7= A quiet place I can go to,
8= An adult in school who understands me, 9= Having a friend or buddy,
10= Interesting after school activities, 11= A card to request time-out when I need it;

Percentage of answers given by boys who experience this

Key: 1= Having a friend or buddy, 2= Having a Circle of Friends, 3= An adult in school who understands me, 4= A Learning Support Assistant, 5= A quiet place I can go to,
6= Most teachers understand my needs, 7= Being allowed to work on my own at times, 8= Home-School Diary, 9= Interesting lunch clubs, 10= A card to request time-out when I need it, 11= Interesting after school activities;

Part 4: What would you have needed to learn in Primary School for coping well with Secondary School?

The lowest number indicates the most important statement.

Girls' answers

Key: In order of priority: 1= Understanding myself better, 2= Learning ways of socializing, 3= Having a friend who goes on with me to Secondary School,
4= Learning to recognize when I need time out, 5= Learning to calm myself and de-stress, 6= Being part of a club that continues in Secondary School, 7= Other pupils being taught about Autism and Aspergers, 8= Learning how to tell others about my Autism or Aspergers;
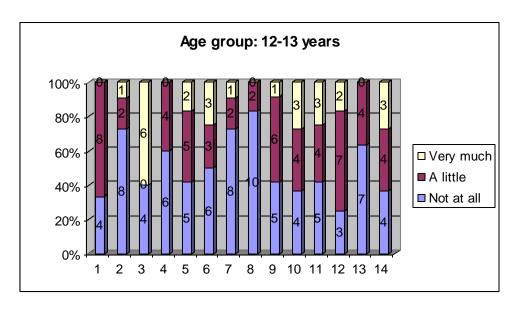
Boys' answers
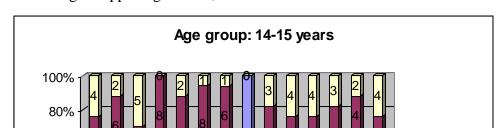
Age comparison

Part 2: What do you find upsetting in school?

(value inside columns = number of answers; first age group: 12 pupils, second age group: 17 pupils, last age group: 12 pupils)

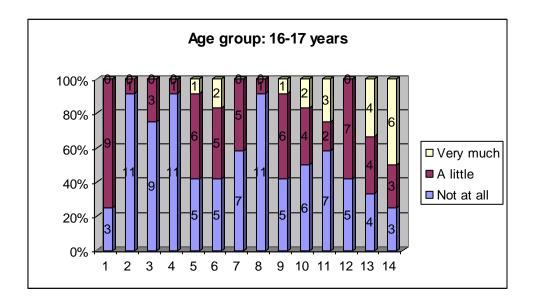**Key:** 1= Misunderstandings, 2= Not having a friend, 3= Being picked on or made fun of,
4= I feel I don't belong here, 5= Too much noise, 6= Crowded corridors,
7= No-where to get away from it all, 8= Getting lost in the building(s),
9= Too much information in classes, 10= Too much work, 11= Boredom,
12= Confusing homework assignments, 13= Sudden changes of teachers,
14= Lots of changes happening at once;

Key: 1= Misunderstandings, 2= Not having a friend, 3= Being picked on or made fun of,
4= I feel I don't belong here, 5= Too much noise, 6= Crowded corridors,
7= No-where to get away from it all, 8= Getting lost in the building(s),
9= Too much information in classes, 10= Too much work, 11= Boredom,
12= Confusing homework assignments, 13= Sudden changes of teachers,
14= Lots of changes happening at once;

Additional comments from the first age group (12-13 years) include:
- Being laughed at for watching trains
- Being late

Additional comments from the second age group (14-15 years) include:
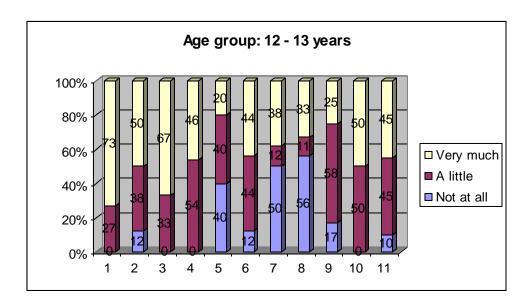- Changes in general and too many changes at once

Additional comments from the last age group (16-17 years) include:
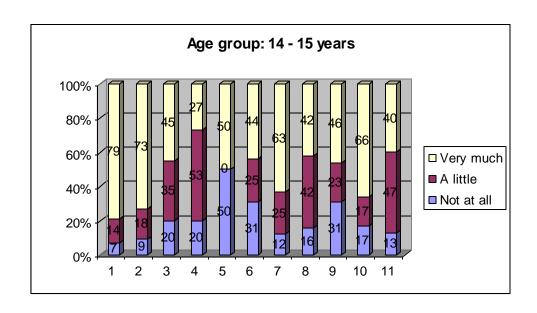- being bothered by smells (x2)
- crowds

- changes of teachers
- too much exam work
- classes sometimes too fast
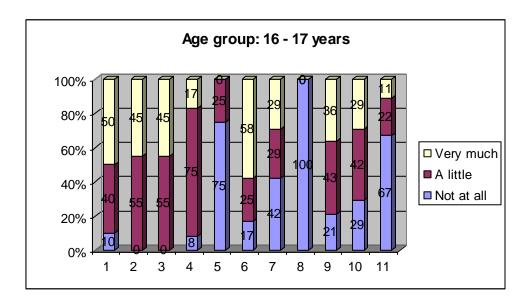
Part 3: What do you find helpful in school?

(value inside columns = percentage of pupils who experience this)

Age group: 12 - 13 years

Key: Statements: 1= Having a friend or buddy, 2= Having a Circle of Friends,
3= An adult in school who understands me, 4= Most teachers understand my needs,
5= A card to request time-out, 6= A quiet place I can go to, 7= Interesting lunch clubs
8= Interesting after-school activities, 9= Being allowed to work on my own at times,
10= Having a Learning Support assistant, 11= Home-School Diary;

Age group: 14 - 15 years

Key: Statements: 1= Having a friend or buddy, 2= Having a Circle of Friends,
3= An adult in school who understands me, 4= Most teachers understand my needs,
5= A card to request time-out, 6= A quiet place I can go to, 7= Interesting lunch clubs
8= Interesting after-school activities, 9= Being allowed to work on my own at times,
10= Having a Learning Support assistant, 11= Home-School Diary;

Additional comments from the first age group (12-13 years) include:

- Having time tabled time in the Support Base (x3)
- Lunch time in Support Base
- Talking with people when I'm sad or happy

Additional comments from the second age group (14-15 years) include:

- Most teachers understand my needs, though some don't know that I have ASD
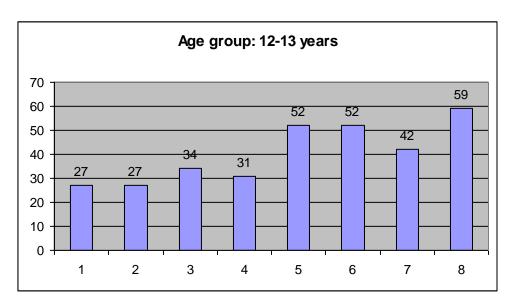
Additional comments from the last age group (16-17 years) include:

- I'd like more friends, but not a large circle
- Teachers who understand me being available
- A lot of leeway on deadlines

Part 4: What would you have needed to learn in Primary School for coping well with Secondary School?

(numbering statements according to importance, i.e. 1=most – 8=least)
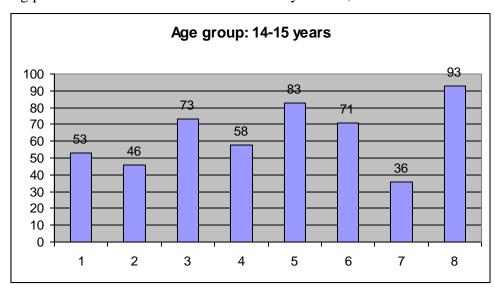
The lowest number indicates the most important statement.

Age group: 12-13 years

Statement	Value
1	27
2	27
3	34
4	31
5	52
6	52
7	42
8	59

Key: 1= Understanding myself better, 2= Learning ways of socialising, 3= Learning to recognise when I need time out, 4= Learning to calm myself and de-stress,
5= Learning how to tell others about my ASD, 6= Other pupils being taught about ASD, 7= Having a friend who goes on with me to Secondary School,
8= Being part of a club that continues in Secondary School;

Age group: 14-15 years

Statement	Value
1	53
2	46
3	73
4	58
5	83
6	71
7	36
8	93

Key: 1= Understanding myself better, 2= Learning ways of socialising, 3= Learning to recognise when I need time out, 4= Learning to calm myself and de-stress,
5= Learning how to tell others about my ASD, 6= Other pupils being taught about ASD, 7= Having a friend who goes on with me to Secondary School,
8= Being part of a club that continues in Secondary School;

Age group: 16-17 years

	Value
80	73

Additional comments from the first age group (12-13 years) include:
- Knowing about the Support Base right from the beginning
- Learning how to approach and speak to a teacher about a problem

Additional comments from the second age group (14-15 years) include:
- Learning to recognise stress

Additional comments from the last age group (16-17 years) include:

- It isn't the case that pupils should be given a crash course on ASD, but rather to be taught the distinction between someone who won't socialise properly and someone who <u>can't</u>.

Appendix 13: Sample interview script (6 pages)

<u>Interview Script, M. Academy, 13.3.2009</u>

E. = myself, A. (age 14) and R. (age 17) = pupils

Briefing and Winding down were not transcribed.

E.: How did you find the questionnaire in general, like the lay-out, was it easy to follow?
R.: Yes, it was very easy, straightforward… pretty good. I don't remember having a hard time writing it or anything.

A.: It's a very straightforward thing. It wasn't hard, really. I found it easy to answer. I didn't think: "O, I don't know what that means" or "some of that I can't understand".

E.: Did you feel it was relevant?

R.: Yes.

A.: Yes, I knew that's something we should know about and write down and stuff. Yes, I think it's relevant.

E.: Did you fill it in by yourself or did you have help?

R.: I just filled it in by myself. Did you?

A.: Yes.

E.: Did you feel there was anything missing? Would you have liked to see anything else?

R.: I don't think so.

A.: No, but I'm not really the expert. I just write it down and that's it.

E.: Do you sometimes get other questionnaires to fill in, like general surveys?

A.: About a month ago there was a questionnaire about Eco-schools… and I had quite a few questionnaires.

R.: I haven't actually had many questionnaires; not that I remember anyway.

E.: Let's have a look at the questions again. In Part 2, is there anything you find particularly upsetting?

R.: Any of these?

E.: Yes, or anything that isn't on the list. Anything that stands out for you.

R.: Probably this one "Crowded corridors". You got any, A.?

A.: Well, it's just that a lot of it I didn't really seem to have much of a problem with. You know, I was fine with it…. It didn't really mean much to me, most of it.

E.: Right, so you don't really find school upsetting at all.

A.: I find… It's just that I mostly go to school to see some of the friends I have. That's the thing that I like looking forward to. So, most of the stuff I get used to. Just, you know, it doesn't seem to affect me mostly.

E.: And you do have friends, which is good, because some people find they don't have a friend. Did you have friends when you came in, friends from your old school?

A.: I had a small amount. I wasn't like the popular one of the school. I tried not to make friends with the people who are just a bit like an idiot, really, not just anybody, you know, I try and pick my friends. But I didn't have that many friends, like five friends from last school.

E.: That's quite a lot! I never had more than one or two. (Everyone laughed.) What about you?

R.: Well, I remember… What, from this bit (points to Part 2)? There is this about the crowded corridors. What I don't like about that is often you can't tell where somebody is going to go, so it's a bit like crossing the road. And I often look at the ground, so I don't see their eyes, because to me they are all like strangers, so I don't like making eye contact, you know. So I just have to look at the ground and it's a bit awkward. And some days I'm walking beside somebody, like either of my SfL teachers, then I sort of lose them for a moment or two, because all these people are getting in between. It's just, you see…. And sometimes boredom can be a bit of a problem, but it's not something horrific. And, let's see… yes, lots of things happening at once. I don't like that either, because I think it's just a hassle.

A.: I think most people get affected by boredom. I wouldn't blame it on the school. You know, everything is too old; you want something new in it, because you just get bored of it. If you, like, do the same routine over and over and over again, you get bored.

E.: I think you are right, everybody has these phases, I mean everybody gets bored at times with whatever goes on, but there are some children who feel everything is irrelevant; they're just completely bored because they can't relate to it.

R.: Exactly, when I was in first year, I was like that. I thought most of it was just nonsense, you know.

E.: You would have liked to learn something different.

R.: Perhaps yes, I mean things like… Some of the things I thought were nonsense I actually find interesting now. For example, my favourite subject now is biology.

E.: I suppose, it's also as you move on you can choose more whereas in first and second year you just have to do…

R.: Yes!

E.: Ok, let's go to part three. I know there are quite a number of things that some people have never experienced, lie a buddy or Circle of Friends. Is there anything that you have never experienced?

A.: It's just, sometimes… It's just something that annoys me slightly is *Most teachers understand my needs*. It's just that sometimes they just go up to me and they explain stuff that I already know. I had one time, when I had an interview, and they gave me a 3-year-old's book to read and… I was just slightly ticked off… It's just. you know…

E.: They don't understand about Autism.

A.: Yes.

R.: Yes (nodding).

A.: The thing that seems really useful is having, like, some friends, because if you have at least one friend, you won't be walking alone around the school, because most people pick on the people who are by themselves. I managed to get a group of friends, like three or four, and I hang out with them in between time.

E.: They accept you as you are.

A.: They don't know. They just think: O, you are too smart to go to the Base!

E.: (emphatic) Yes! – And what about you, R.?

R.: I haven't had a buddy or Circle o Friends, but I've always had the Base. I pretty much know all the SfL teachers there… *Most teachers understand my needs*, that's true as well. So that's very helpful. – I never had a Time-out-card, and I'm very pleased to go to that room next door, you know, it's like a chill-out place.

E.: Can you go there whenever you need it?

R.: I don't really need it that much, but I suppose if it was getting hectic, then whoever I'm with, we just go out and… And I don't have the lunch club thing… Having a Learning Support Assistant is probably the most helpful, because… it's probably the way I got through it easier than I would otherwise.

E.: And has that person been with you the whole time?

R.: Yes. Not the same person all the time, but I've always got somebody. So that's very useful.

E.: And a Home-School-Diary is probably more for the parents to have the contact?

R.: Probably, yes. I don't know if I have that.

E.: What about you, A., did you ever get an LSA?

A.: No… we do get the support, like, helping people in the class and that, but to me… they don't seem to be relevant to me, because most of the time I do stuff by myself because I'm, like, smart enough to do stuff. They don't need following me about and stuff .

E.: So it depends if you have the need for it.

A.: Yes.

R.: Yeas, exactly.

E.: So you've actually answered my questions there. The only thing in part three, is there anything else that wasn't on the list that you really find quite helpful?

R.: Well, the only thing that I find quite helpful is, if there is a class that you don't go to, that you can go to the Base and do home work there. I find that easier than doing it at home. So when I get home, I have free time.

A.: I just thought, something that would help first, I think, just students – they should be learning, like, what Autism and Aspergers is, because some of them just think that it's things that make you dumb and that and most people think that I shouldn't be in the Base because I'm too smart. But they just need to understand what it is and how it works and that, so that way they don't upset anybody about it.

R.: We seem to be more book-smart than people-smart. I think that's just basically what it means.

E.: Yes, I always felt I learned most from books.

R.: Yes, I know.

E.: So you think people should actually be taught about Autism and Aspergers, because I'm actually about to do this with our P7s to give them an introduction to what it is. Just to explain to the whole class what it is and what it feels like. Yes, it is a disability because of the sensory over-stimulation and certain different ways of thinking, but at the same time it's a high ability because you've got pockets of intelligence and understanding and focus and all that which others don't have.

A.: Yes, it does get quite annoying… It isn't good if you're talking to someone… It's like going up to a brick wall, but if you think of people like Einstein, they had it and they were making history. You know, they should learn a bit more about it.

E.: Do you think it would be useful to do that with the P7s?

R.: It would be, yes.

A.: Yes.

E.: Now, if we look at part four, the ones chosen as most important from all the questionnaires so far were *Understanding myself better* and *Learning ways of socializing.* Actually, these were the two top ones. What do you think?

R.: yes, I think so. If you understand… I don't know when it was that I got the idea that I had Asperger Syndrome, but most of the time it was something that was just there and I didn't think about it that much. So it's useful, because then you understand, and understanding yourself better, especially if you have an ASD, makes it easier to learn ways of socializing because you know what it is…

A.: Yes… I was ok with the idea. It was almost a shock to me, but I was ok with it. My parents, they recognised something was different with me when I was little. They noticed seriously when I was in P5 and someone chucked my lunch box and I was really upset about it and the teacher sent a letter home. I think it would have been a good thing if we understood ourselves better, because that way if something is about to happen, we'd know better and be more self-controlled.

E.: Did you ever wonder why other people acted differently?

A.: I just thought, they were being immature and they were just bullying me for the sake of it. When I moved to Secondary School, I realised that's how most people act. They act like this, because they're trying to be funny, you know, if they're sarcastic they're just trying to be funny, not to take the mickey out of you. I just learned that they're just doing this because they're doing this, and I just figured how they act and that. So that way I can react to it.

E.: And how did you figure it out? Did you have anyone to talk you through it or did you just figure it out for yourself?

A.: I figured it out for myself, because I noticed that almost everybody, they're not all that serious. They always, like, play around… quite careless. Well, not really careless, you know, technically sort of. I just noticed that in them and I got used to them. They go up to you, like, pretending to fight you, but they're just joking about as a joke, and I just noticed that, because mostly everybody does that. I won't really do that sort of thing, but I noticed that they do it.

E.: So you figured things out by yourself rather than being taught.

A.: Yes, because if someone has to spell it out for me, it makes me feel as if …

R.: Rather, sort of stupid.

A.: Yes, as if I was in a bubble.

E.: What about you, R., what kind of opportunities did you have in Primary School to learn to understand yourself better and to socialise?

R.: Well, I don't remember having very many opportunities, well, there were opportunities to talk to people and that, but never in the light that I was autistic. It was very, sort of, un-serious. As a kid, I've always known I was a bit unusual, like A. said, I was highly strung, you know, but I've cooled down.

E.: Did you have any kind of Communication groups or Social Stories or something like that in Primary School?

R.: Well, I don't think so. I did have a few friends, though. But there was this thing, called Circle Time that we used to do when we were younger.

A.: What do you mean with Social Stories?

E.: We do this a lot with the little ones on the Autistic Spectrum, reading a stories that gives examples of, let's say, children mucking about and play fighting and then the child with Autism can see from the story that it's not meant to hurt.

A.: I don't think I got that sort of stuff. When I was in Primary, before figuring everything out, I just noticed that everybody… they didn't seem almost… they didn't betray people, but they always, you know, pretend to be my friend and then they turn their back away from me. And I didn't trust that many people because of it. And then I realised it wasn't them trying to turn their back on me, it was that I wasn't really… I didn't understand why they were doing it. So I couldn't really cope with that sort of stuff.

E.: What do you think would have helped you? When you think back to Primary School, especially P7, what would have helped you with the transfer to Secondary School?

R.: I think what really did help us, we did have a few visits here to see what it's like, I remember that. It was quite enjoyable, because I saw what kind of teachers we were having the next few years… and I think, possibly actually realising that you have an ASD and actually realising it properly.

E.: So you would find it helpful if people on the Autistic Spectrum were actually taught about it and from there on can understand themselves better?

R.: Perhaps, yes.

E.: Do you agree with that or…?

A.: Yes, yes, that would be it, yes. I'd sort of think that, you know, sometimes the SfL teachers, they treat everybody in the Base the same. They're always asking if they can help us out with a specific thing and they're not realising I don't always need the help, like with spelling or reading or such stuff.

E.: Do you think in the Learning Support Base they are so used to people who have academic needs that they can't really relate to people who are highly academic, but have quite different needs.

A.: Yes, I think they shouldn't treat everybody the same, because everybody isn't the same. The people with a higher ability, they shouldn't be brought down, but brought up to where they should be.

E.: Do you want to add anything, R.?

R.: Well, I think, A. has less of a hard time with the things that I do, academically, you know, like the problem I have with writing. If somebody writes it for me, it's a lot easier.

E.: But you've got the ideas for it.

R.: Yes, they're all there.

E.: Now, if you could give one hint, what would you have wished to get in Primary School to understand yourself better and being able to socialise and to integrate into Secondary?

R.: I think if there was something similar in a Primary School to what they have in a Secondary School, like the Learning Support Department, you know, or people… I don't remember hearing the word Asperger Syndrome in Primary School… So if it was something like that, something that would… or even an earlier diagnosis, because I got diagnosed when I was in Primary 4. Obviously that meant that in P1, 2 and 3, even though I had it, I didn't know.

E.: So if there was a Base in Primary School, what would you want in that Base? Just to have a quiet place where you can sit?

R.: Probably quiet, yes, and people like we got here.

A.: I just thought, in Primary School you think you could, like, have a specific, almost a new subject for those who have like Aspergers and Autism, maybe they should, like, teach them how to cope with High School, because it can be frustrating for them, because most of the time in Secondary School they teach academically, they don't really teach how to cope and talk to people and that… and that's the thing that makes them stand out, almost like a sore thumb, really, because they don't blend in. I'm not saying we need to blend in, but you need to be able to communicate with people and not look awkward. You want to be able to learn what it's like in the school. Most people who go to High School will be excited about it, while people with Autism they have, like, nerves, they'll be really anxious. So if they learned what High School will be a bit like, they'd understand, you know, they won't be hit hard by the amount of change it was and be able to get on with it a bit easier.

E.: Yes, I understand what you're saying. – Well, I gleaned a lot of excellent information from you and I think we're coming to an end. I just want to tell you how this is going to feed in to my research….

Appendix 14: Collated answers from the interviews

About the questionnaire:

All participants reported that they found the questionnaire easy to complete and the questions straightforward, relevant and not too personal. They could not think of anything that was missing. One person said that some questions he had struggled with a bit and had to think about, but there had been the option to ask the SfL teacher for help, though nobody had needed to make use of this.

Part 2: What do you find upsetting in school?

- Crowded corridors bother me a lot (expands on it)
- "Sometimes I get lost between classes; then I find a quiet place to think and remember where to go next."

- Getting lost at first
- "Noise and crowds can be an issue."
- I don't like noise, especially in the classes, children mucking about, teachers shouting

- Teachers shouting gives me a fright
- Too much noise, because I have funny ears and my class is really, really noisy
- Too much noise

- Smells can put me off, especially when they're cooking salmon in the canteen.

- Lots of changes happening

- Lots of things happening at once

- Being picked on

- Some pupils in classes make fun of me, but I don't bother about it

- "You get picked on, probably because other pupils don't understand Autism, certainly a lot of them. I never had any friends, in High School anyway. It would've been nice to, but I managed to live with it."

- "I didn't trust pupils, only my friends from Primary School, so they couldn't bother me."

- In S1 everything seemed irrelevant, just nonsense, but not anymore

- "Advanced Highers are pretty hard, but everybody finds it hard."

E: "Have you ever gone through a phase of high anxiety or depression? You don't have to answer if you don't want to."

M: "You really go through stuff like that. You get… I have some trouble sleeping and that and take some pills for it. It's probably common nowadays, even with people without Autism."

Part 3: What do you find helpful in school?
- Most important to have some friends

- To have some friends

- Having a friend

- One friend from Primary School

- Buddy in first year extremely helpful

- Having a Circle of Friends

- Friends in the Base

- The Base to go to and SfL staff, including interesting lunch clubs in the Base

- "The Base! It's good to start the day in the Base, to have friends in the Base and a lunch club where only Base kids are allowed."

- Most important to have the Base to go to and teachers and LSAs who understand me and help me; a place to chill out; periods in the Base to do my homework

- "To go out of class when it gets too noisy. The Base to go to for break and lunch time and when I need time out."

- Quiet lunch time in the Base

- Going to the library where it's quiet

- Teachers understanding my needs

- It's good that the teachers understand you

- Annoyed about teachers who don't understand the nature of Autism and treat me as if I was stupid.

- Teachers understand me and are very nice. I had an LSA in the early years.

- To have an LSA in class, as I easily forget stuff

- To have subject options (I opted out of P.E.)

- Sometimes I go to lunch clubs

- I used to go to a drama club at lunch until my ears picked up again

- I don't go to lunch clubs because they don't have what interests me

- It's easier here than in a large school; not so crowded

- Two children found home-school-diaries helpful to remind themselves and there parents of what they had done at school and of homework and deadlines, while two didn't make much use of them, one saying it was too confusing what page to turn to.

Part 4: What would you have needed to learn in Primary School for coping well with Secondary School?

- "I think it would have been a good thing if we understood ourselves better, because that way, if something is about to happen, we'd know better and be more self-controlled. I thought the other children were being immature and they were just bullying me for the sake of it. When I moved to Secondary School, I realised that's how most people act… I just figured it out by myself."

- "Understanding yourself better, especially if you have an ASD, makes it easier to learn ways of socialising because you know what it is."

- "Understanding myself better; just learn it yourself and come up with things of doing it your own way."

- "If you don't socialise in Primary School, you won't socialise in Secondary, not as other people will. I really made an effort in P6 and 7 to be nice and talk to people to make friends, although it was quite hard."

- One of the best ways for me to socialise is doing Ceilidh dancing.

- "The Scouts, I really made friends there because I like dodge ball, a thing the Scouts are good at."

- To calm yourself and de-stress and learning ways of socialising

- "You should learn, that when you feel stressed out or anything, come to the Support Base or just wait outside the classroom to cool down."

- Learning to calm myself and de-stress; I completely taught this myself.

- What you need most to learn: recognise when I need time out and how to calm myself and de-stress

- You should learn what to do in situations, like if you get bullied.

- A few visits to Secondary School beforehand to see what kind of teachers you get

- Earlier diagnosis; knowing I've got an ASD

- There should be an ASD Base in Primary School

- Better (academic) subject teaching in Primary School

- SfL staff should treat people according to their needs, understanding that you can be highly academic and have needs in other areas

- "In Primary School there should be a specific subject for those with ASD to teach them how to cope and talk to people and that."

- To learn what High School will be like and be prepared for the amount of change and be less anxious

- "High School is better than Primary. I felt lonely and invisible in Primary School. It was very stressful. I hated to buddy little ones when I was in P7. I like to be with my own age group in class."

- "I didn't have anything extra in Primary School, but my Mum talked to me about problems and helped me understand."

- "In Primary School there was a SfL teacher who did voice recordings about my likes and dislikes and what I wanted to do in future. She was a wonderful lady. She took time to know me."

- "I was in a group when I was in P6. It was kind of helpful. Me and R. went to this thing after school in a big gym. It was by this guy, an actor. He was doing all sorts of things with us." (D. Sherrat from Autism Outreach?)

- "I did get some help to understand myself and socialise, some of it outside school. I'd say it was helpful."

- "When you get into 6th year, you get along with everybody. You have the subject matter to talk about. But I'm not exactly friends with them, because I'm not really in contact with them like they are with each other."

E.K.: Do you think other children should know more about what it means to have Autism?

- "Yes, tell others of ASD, what it is, what it feels like."

- "Yes, so people understand more."

- "Yes."

- "Telling other pupils about ASD wouldn't make a difference."

- "A person who was my friend, I told her I had Autism and she started picking on me and told everybody. It didn't really work out."

- "I think it would be helpful, because then they can socialise with other people."

- "I think they would make fun of us."

- "I think the most important would probably be to tell others about Autism and Aspergers because they need to understand the stuff from the start to not getting the wrong end of the stick. It's probably best if it did come from the teachers. It was awful when I did mention it."

- "Students should be learning what ASD is and how it works, so they don't upset anybody about it."

- "One day, when I was in P5, there was Mr B. (Autism Outreach), and he took the rest of the people apart from me and taught them what I had and everything. Some people did still make fun of me then, but most people didn't make fun of me anymore."

Appendix 15: Report for Participants (10 pages)

Report for pupils who participated in the research about

what helps to prepare children with High Functioning Autism / Asperger Syndrome for the social and emotional demands of mainstream Secondary Schools:
Exploring Pupils' Perceptions.

Introduction:

- In Highland presently 1.5% of school age children have a diagnosis of ASD (=Autism or Asperger Syndrome).
- There are still 3 times as many pupils with ASD in Primary than in Secondary Schools, and the number of children being diagnosed with Autism or Asperger Syndrome is rising.

- The vast majority of pupils with ASD are in mainstream classes, as they are of average or above average academic ability.
- Girls are often overlooked because they are generally more introvert and display autistic traits in a different way from boys.

The main problems faced by people with ASD are

- The unique experience of life in contrast to that of the majority of people, which easily leads to misunderstandings and isolation.
- The difficulties with the semantics of verbal communication, which mainly affects social language, but also has an impact on other areas, for example following instructions or understanding jokes and sarcasm.
- The pain and anxiety caused by sensory integration problems, for example the effect of noise, crowds, smells or too much visual distraction.

Mental Health Problems:

- Many recent studies have shown high incidents of mental health problems in people with ASD, in particular anxiety and depression.
- Claire Sainsbury, a woman with Asperger Syndrome, estimates that "at least half of all people with ASD suffer from clinical depression at some point in their lives, often starting during the teens" (from *Martian in the Playground*, 2000, p.112).
- Other recently undertaken studies show an even higher percentage and also in many young people with ASD a tendency to Obsessive Compulsive Disorder, Eating Disorders and Self-harm.
- In fact, looking at it from a medical point, there is a biological link between mental health problems and ASD. In both of them, the same areas of the brain are affected. Therefore one could speculate that anxiety and depression are part of the brain dysfunction in ASD and begin to seriously manifest during the hormonal changes of puberty.

"It seems clear that biological tendencies to high levels of anxiety can only be exacerbated by living in an environment which, as viewed by a child with ASD, is often terrifyingly chaotic and unpredictable." (Sainsbury, 2000, p.115)

Apart from the sensory over-stimulation (noise, smells, crowds etc.), there are other issues that can make life difficult and stressful for people with ASD, for example peer pressure.

- While younger children are on the whole more accepting of differences, the onset of puberty for many brings the need to belong to a distinctive youth culture which does not leave room for otherness.

- The majority of teen-age peers become rather intolerant of any kind of social deviance.
- Youngsters with ASD often stick out because they do not understand the hidden curriculum, for example what is *cool* or *the in thing* and what isn't.

This survey was trying to find out more about these issues from pupils with ASD.

The three research questions which you helped to answer were

- What are the pupils' perceptions of their social and emotional experience of Secondary School?

- What strategies do they identify as helpful in order to cope with the social and emotional demands at school?

- What implications does this have for ASD specific input during the transition process from Primary to Secondary School and beyond?

Methodology or how I found out:

- Autumn 2008: based on Literature Review (= books, articles and papers written about this topic) and with the help of colleagues at school, my university tutor, members of the Autism Rights Group Highland (= adults with ASD) and pupils with ASD I designed a questionnaire.
- January 2009: the questionnaire was sent to all Learning Support Departments of Highland Secondary Schools, inviting all pupils with ASD to take part in the survey and have their say.
- March-April 2009: Follow-up interviews were held in 4 schools (Inverness, Ross-shire, Inverness-shire and Lochaber) with 11 pupils with ASD.

- 19 out of 29 schools = 66% of schools responded.
- Of these schools, 41 pupils (=77%) took part by completing the questionnaire.
- 35 were boys (=85%) and 6 girls (=15%)
- The age range was fairly even, though there was twice the number of 14 year olds than of each of the other age groups.
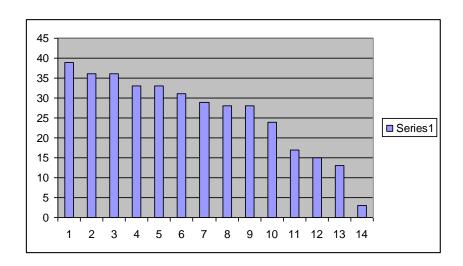
The questionnaire consisted of 4 parts:

- Part 1: general information about the participant (age, gender…)
- Part 2: What do you find upsetting at school?
- Part 3: What do you find helpful in school?
- Part 4: What would you have needed to learn in Primary School for coping well with Secondary School?

Outcomes:

- All, but one pupils reported attending mainstream classes and spending some time in a Support Base or Special Unit.
- Whose choice was this? 20% reported no choice, 47% my choice, 33% my parents' choice (some combination of my/my parents' choice).

Part 2: What do you find upsetting in school?

1. Lots of changes happening at once   2. Too much work   3. Boredom
4. Misunderstandings   5. Being picked on or made fun of   6. Confusing homework
7. Too much noise   8. Crowded corridors   9. Too much information in classes
10. Sudden changes of teachers   11. No-where to get away from it all
12. Not having a friend   13. I feel I don't belong here   14. Getting lost in the buildings

However, girls ranked as most upsetting misunderstandings, too much noise and lots of changes happening at once, placing too much work and boredom at place 9+10.

Not having a friend bothers significantly more 14-15 year olds compared to other age groups and a higher percentage of girls than boys.
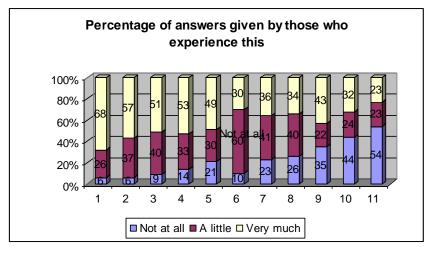
Additional Comments made on the questionnaire include

- Strange smells, sometimes unhygienic toilets
- Changes of teachers
- Crowded corridors
- People laughing at me watching the passing trains.
- Changes in a general sense; especially too many of them at once.

The main concerns revealed in interviews were

- Crowded corridors
- Too much noise in classes and elsewhere
- Getting lost between classes
- Lots of changes
- Smells (canteen, toilets)
- Being picked on or made fun of
- Teachers not understanding the nature of Autism, underestimating academic ability

Part 3: What do you find helpful in school?

Percentage of answers given by those who experience this

100

1. Having a friend or buddy   2. Having a Circle of Friends
3. An adult in school who understands me   4. Having a LSA   5. A quiet place I can go to   6. Most teachers understand my needs   7. Being allowed to work on my own at times   8. Home-School diary   9. Interesting lunch clubs   10. Interesting After School activities 11. A card to request time out when I need it

A time-out card was more important for 12-15 year olds than 16-17 year olds and not at all for girls.
After School Clubs were significantly more important for girls than boys and there was a difference between age groups:
  • Age 12-13: 56% not at all, 11% a little, 33% a lot;
  • Age 14-15: 16% not at all, 42% a little, 42% a lot;
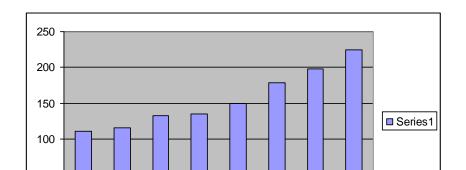 • Age 16-17: 100% not at all important;

Additional comments made on the questionnaire include

  • Having friends who won't stereotype me.
  • Being allowed to leave the class when I need to
  • Very helpful to have a lot of leeway on deadlines
  • Having time-tabled time in the Support Base
  • Going to the Support Base at break/lunch times.
  • Most teachers understand me; some of them don't even realise that I have autism (as mine is high functioning).

The interviews revealed these as most helpful:

  • To have friends or a buddy
  • The (quiet) Base to go to routinely and when needed
  • Understanding and helpful teachers and LSAs
  • Subject options (incl. opting out)

Part 4: What would you have needed to learn in Primary School for coping well with Secondary School?

The lowest number indicates the most important statement
1. Learning ways of socialising   2. Understanding myself better
3. Learning to calm myself and de-stress   4. Having a friend going on with me
5. Learning to recognise when I need time out   6. Other pupils being taught about ASD 7. Learning how to tell others about ASD   8. Being part of a club that continues in Secondary School

However, Learning how to tell others about my ASD:
- 3 pupils found this most important (age 12, 14 & 16)
- 2 pupils found it second important (age 14 & 16)
- 3 pupils found it third important (age 14, 14 & 17)

Others being taught about ASD:
- 2 pupils found this most important (age 14 & 16)
- 5 pupils found it second important (age 14,14,15,16,16)
- 3 pupils found it third important (age 12, 13 & 14)

Additional comments made on the questionnaire include

- Not to be grouped together with pupils with ADHD or EBD.
- Learning how to approach and then speak to a teacher about a problem.
- It isn't the case that pupils should be given a crash course on ASD, but rather to be taught the distinction between someone who won't socialise properly and someone who can't.
- In Primary it would have really helped me if I was given a sense of real achievement for completing work, instead of being suppressed and cornered by my 'support' teachers.
- If I had had time in (or known about) the Support Base from the beginning.
- I had very bad stress in first year and it wasn't realised until third term. So certainly stress recognition would have been very useful.

The interviews revealed in more depth the importance of

- Understanding myself and my Autism / Asperger Syndrome better
- Learning ways of socialising and making friends
- Learning to recognise stress and how to calm yourself

- Other children being taught about ASD by an adult who understands it
- An ASD Base in all schools, incl. Primary, and teachers who understand your needs and strengths

Social Communication Groups:

- About 2/3 of children had been offered this either in or out of school.
- They rated as most important: the teacher / leader taking time to understand me.
- Children were not always made clear about the purpose of interventions (or maybe didn't understand it at the time).
- Being grouped together with children with Emotional Behaviour Problems, ADHD or general Learning Disability did not work well.

Other pupils learning about ASD:

- Most pupils acknowledged the need for peers to become more understanding of ASD and more tolerant towards it.
- Several pupils had negative experiences when trying to explain ASD to peers.
- The whole class of peers being taught about ASD by Autism Outreach or other knowledgeable staff had very positive outcomes.

So what are the implications for schools? What needs to be done?

- Every school, incl. Primary Schools, ought to have an ASD Base, which is spacious, uncluttered and quiet.
- Every pupil with ASD should be offered time-tabled periods as well as chill-out time in the Base.
- All school staff (incl. subject teachers and LSAs) should have a basic understanding of ASD and the implications of sensory issues and not confuse academic and social needs.
- All peers should have a basic understanding of ASD, taught by a knowledgeable adult (could be part of PSE).

- Starting in Primary and continuing in Secondary School, pupils with ASD should be offered specific input (like special lessons or activities) to address ASD related issues for better self-understanding, stress management and ways of socialising.
- There are now many published materials available for all ages, but they need to be adapted, as each individual or group is unique and responds to different approaches.

<u>Conclusion</u>

- The number of pupils with ASD is rising rapidly.
- The tendency to anxiety, depression and other mental health problems is high in pupils with ASD.
- Modern learning environments are causing high levels of stress to pupils with ASD.
- Therefore it is essential that every school has an ASD Base available to those who need it.
- There is a great need for staff and peers to increase their understanding and tolerance of ASD.
- Pupils with ASD should be offered to enhance their self-understanding, stress management and ability to socialise in a meaningful way.

This has been reported in a power-point-presentation to Principal Teachers of Learning Support from all over Highland on 1st June 2009 and to Highland Primary and Secondary Learning Support Teachers and other school staff on 10th June 2009.

A full report of the research will we published on the website of the Highland Autistic Spectrum Education Network (HASEN) and the research section of the Scottish Autism Service Network (www. scottishautismnetwork.org.uk).

This short report is sent to all Highland Secondary Schools to be made available to read for pupils and staff and it will also be sent for information to the Director of Education.

A heart-felt thank you to all participants for taking the time and sharing your experience and ideas. Without you, the research could not have taken place. Hopefully, the recommendations will improve school life for pupils with ASD.