'Where can we be what we are?': the experiences of girls with Asperger syndrome and their mothers

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Editorial comment

There is a growing literature on girls and women on the autism spectrum. In the past, prevalence data has suggested that there are many more males than females on the autism spectrum and studies which have included both genders have often not focused on the particular needs of girls and women. It is thought by some that we are failing to identify and diagnose many girls with autism because they present differently and do not fit the existing diagnostic criteria – which have perhaps been largely based on the male presentation of autism and Asperger syndrome. This paper by Catriona Stewart presents some of the findings of her doctoral study which focused on four girls diagnosed with Asperger syndrome (AS). She reports their views on their lives at school and home and also considers their mothers' experiences. From this it appears that schools and services still have much to do to recognise the stress that both the girls and their families experience and to take appropriate and effective steps to address these. She lists some recommendations for schools on how to make their school lives less stressful and more enjoyable.

Introduction

Previous research into anxiety in people on the autism spectrum (Volkmar et al, 2005) has been primarily directed towards the assessment of interventions rather than on the experiences of anxiety per se. The lack of standard assessment tools for anxiety, as for depression (Stewart, 2006) in this population poses methodological challenges. For example, tools such as Beck's Youth Inventories (BYI) (Beck et al, 2005) or Spence's Child Anxiety Scale (SCAS) (Spence et al, 2003) have limitations in measuring these children's status and progress as reported by the children themselves.

In response to the methodological challenges involved, an interpretive case study approach was adopted and innovative data collection methods were developed. The 'In My Shoes' (IMS) interview software (Calam et al, 2000) was used to interview girls with Asperger syndrome (AS) and online diaries were created.

Interviews were also conducted with the girls' mothers. A thematic analysis was carried out with reference to the pedagogical model of interpretive or hermeneutical phenomenological research as described by Van Manen (1990). Emerging themes from each group were examined.

Themes

'Where can we be what we are?' sums up what the girls felt – that they were rarely able to be themselves. They felt different and did not feel their needs were met at school and were also often in conflict with their families. For the girls' mothers, an essential theme of 'no more than a breath away' sums up the struggles and disappointments of the past, their present difficulties and their fears for the future, for their children and for themselves.

Literature review

Young people with AS often have elevated levels of anxiety and other mood disturbances when compared to neurotypical (NT) peers (Kim et al, 2000; Gillot et al, 2001; White et al, 2009). Qualitative and interpretive research has increased in recent years, but has mostly focused on parental experiences. Issues around disclosure of diagnosis, discrimination, concerns for the future and mental health problems such as anxiety, disrupted self-identity and low self-esteem have been identified (Humphrey and Lewis, 2008; Huws and Jones, 2008).

Until very recently, the ratio of males to females with AS has been thought to be about 10:1 and almost all existing research has been carried out on males. Although some studies have included females, gender differences are rarely explored. That girls do make up a significant number of those with autism has recently come to attention and a small number of books on girls and women with autism have now been published (eg Attwood, 2009; Nichols et al, 2009; Simone, 2011). However, there is still a paucity of research and little qualitative information describing the experiences of girls with autism AS, with the exception of autobiographical books such as those by Gerland (2003); Grandin (1995); Holliday-Willey (1999); Sainsbury (2000); and Lawson (2007), for example.

The families involved in the study

There were four families in total involved in the study. Two of the girls were 15 years old; one was 14 and the fourth girl was ten. In three of the four families the girls were living with just their mother and siblings. The three single parent families were living in difficult circumstances and the fourth family had taken a pronounced drop in their economic and social position due to the daughter's difficulties. Three of the girls attended mainstream state secondary schools; and one was at a specialist school. One of the girls was a school refuser; another was close to becoming a school refuser and was reported to be self-harming; two were reported as being physically volatile on occasions and all suffered from insomnia. All were described as 'bright', with high or even very high school marks and at least one of them was artistically talented. The mothers and girls were interviewed and the girls were also asked to keep a diary (see *Appendix 1*).

Findings of this study

This study found that girls often experienced emotional outbursts with physical expression, such as pushing. One mother said she was becoming wary of confrontation with her daughter as she was getting bigger and stronger. Self-harming behaviours (eg, hitting their own head violently, or 'cutting') and school refusal were also major concerns for some of the girls' mothers. Others reported their daughters' social isolation and potential physical and emotional vulnerability.

It has been suggested that adolescent girls with AS may manage to negotiate the social demands of the school environment in different ways to boys, by using one or more of a number of strategies, such as finding a protector and mentor (Attwood, 2006). Girls with AS are also more likely to receive extra-curricular training in drama or dance, which helps the development of imitation skills and pretence. These can then be used to help girls with AS to 'blend in', sometimes described as 'cloaking and shadowing mechanisms' (Attwood, 2006) or as 'masquerading' (Carrington and Graham, 2001). This may give them surface sociability, but they often lack the deeper social understanding required to be socially successful. These girls have been described as:

> '… like a swan, appearing to the onlooker as gliding serenely and gracefully across the water while paddling furiously underneath the surface …' (Ludlow, 2004)

Personal experience of girls on the autism spectrum supports this; the effort and consequent exhaustion when demands for social interaction have been high should not be underestimated. These girls need a 'room of their own' and peace, quiet and 'time out' to recuperate and just 'be themselves'.

Additionally, adult women with AS have reported feeling pressurised, judged or excluded on the basis of their apparent lack of feminine characteristics or for displaying male behaviours (Faherty, 2002; 2006). One participant found that her personality and interests – Monty Python, film animation, film score music, the films of Tim Burton – set her apart as 'odd' and different in both her family and her school culture. She was artistically talented and academically very able. She would probably have got on well with older adolescent boys.

The impact of sensory perceptual differences

The importance of sensory and perceptual differences in people with AS has been noted by clinicians and researchers over the decades since AS was first described by Kanner (1943); Asperger (1944 cited 1991); Rimland (1964); and Volkmar et al (1996). The particular sensory and cognitive processing style in individuals with autism may lead to behaviours viewed as bizarre or pathological by others. Temple Grandin described her childhood autistic behaviours as intelligent, adaptive responses to what she experienced as a chaotic and often painful world (Sacks, 1995). There are criticisms that the perceptual differences of autism are often regarded as being limited to sensory hyper or hypo sensitivities. The profound effect that these sensory differences can have on behaviour and performance, are poorly acknowledged and understood (Bogdashina, 2004).

The increased social and academic demands required at secondary school have been cited as key factors in raising anxiety in adolescents with AS (Capps et al, 1995; Attwood, 2006). In other research (Humphrey & Lewis, 2008) the school environment itself has been identified as a source of considerable stress. Clarity about what is asked of them and a fair adherence to rules by teachers and other students is a recurring feature of the girls' concerns. As they worked to establish a system of rules that allowed them to function (ie systems of behaviour relating to logic, sustainability, cause and effect, predictable outcomes, fairness), the girls were expected to function in a world of people whose behaviour often did not adhere to those rules. The girls expressed a desire to do well, a willingness to comply; frustration at the marginalisation of their needs; sadness at being judged and excluded; anger at a school system which they saw as inconsistent and obstructive and a fear of failure.

Feelings of being different

From special consideration having to be made before any attempt to join in after-school or extra-mural activities, to where they sat in class, the girls were identified as 'different' which often caused them to be marginalised and targeted by their peers. As adolescents, action had sometimes been taken to help at school but this often led to them being singled out even further as 'different' and as a target for bullies. They attracted sometimes extreme and unpleasant attention from others, including physical assault. Elevated physical injury fears have been reported in children and young people with AS (Kim et al, 2000; Gillott et al, 2001; Russell and Sofranoff, 2005). In the context of the experiences described, anxiety around physical safety has a reasonable foundation. Additionally, anxieties around personal safety led to the girls taking little exercise or part in extra-mural activities. Weight gain added to increasingly low self-esteem. The social isolation and bullying described by the girls in this study (and also their mothers) reflect previous findings that children with AS report more loneliness than typically developing peers (Bauminger et al, 2003). Some recommendations on how they might be better supported at school are given in *Appendix 2*.

Somatic disorders

Sensory sensitivity was allied to the somatic disturbances experienced by the girls. Some of the girls suffered from chronic insomnia, which had a profound impact on their own and their families' daily lives. In one case, there was difficulty in sharing a room with an elder sister. For the girls their difficulties in sleeping led to a kind of 'vicious circle' where their anxiety would increase throughout the evening at the prospect of not being able to sleep, so that by the time it was bedtime, they were so anxious that there would be fights or tears. Adults with autism report anxiety about waking up during the night as they often have negative thoughts and cannot easily get back to sleep.

Transient and puzzling muscular pains were also a feature. The pains caused further anxiety when the girls had no way of assessing the cause or seriousness of their discomfort. For example, a sore ankle meant discomfort and frustration for one girl, while for her mother it was merely an excuse to avoid school. The principle of shared horizons suggest that both may be true – the strange and flitting pains both very real and uncomfortable AND an excuse not to go to school. For the girl, these pains were perhaps a physical representation of the anxiety and fear caused by her school experiences.

There were ongoing issues for the girls with physical sensitivity to fabrics and labels. In one case, the inability to cope with the noise and chaos at lunchtime meant the girl went without eating or drinking at school.

The girls' somatic disorders included:

- 'Fuzzy, buzzy head'

- Headaches

- Insomnia

- Transient muscular skeletal pains

- Gastrointestinal (GIT) disturbance

- Itching and eczema

- Irritability

- Apprehension

The most disturbing for the girls and their families was insomnia. Perhaps the most difficult area was the impact of their sensory and perceptual differences on their lives at home and their relationships with their families. Although their mothers were aware of the processing and sensory differences experienced by their daughters, being aware did not necessarily ameliorate the impact on their daily lives.

Family dynamics

The family home was not seen as somewhere the girls could be themselves, in comfort or security. Some reported a lack of personal space, quarrels with siblings and feelings of loneliness and insecurity. The impact of having a child with AS within the family can pose real demands on parents and siblings: Gray (2001, 2003), Allik et al (2006) and Woodgate et al (2008). Stress-related, impaired quality of life for mothers, more than for fathers has been reported (Allik, 2006; McGrath, 2006).

Sensory issues extended to personal contact, as well as to reactions to fabrics and other materials, inevitably impacting on the girls' relationships with other people. This applied to family members as well as others. For example, one mother said:

'She didn't like me hugging [her younger sisters]. If we were sitting, she didn't really like that, but if you tried to give her a cuddle she didn't like it.'

Although the dynamics operating within some of these families may reflect typical family behaviour, emerging evidence has suggested that adolescents with AS experience 'normal' levels of conflict within the family as more threatening than is usual (Kelly et al, 2008). There was grief on occasions where the girls felt misunderstood by parents or siblings. Concern, anxiety

and a genuine belief that they were the least preferred children of their parents was expressed by the girls in this study who had siblings. Two of the families had experienced parental separation during the process of gaining a diagnosis for their daughter. All the girls in the study were sensitive to the possibility of rejection from their parents.

The mothers' concerns

Adolescence has been identified as a crucial time for those with AS, with the levels of change in all areas of their lives – social, academic, emotional and physical – increasingly challenging. This study adds to previous findings in this area. It found the school environment to often be unsupportive and damaging to their sense of identity and self esteem. Nichols et al (2009) have reported that:

'… bright girls often notice the gap between their intellectual abilities and what they are able to achieve in day-to-day life. Many of the girls in our group report that the future looks very scary.' (Nichols et al, 2009, p 164)

Anxieties around perceptions of a 'scary future' were reflected also in the experiences described by the girls' mothers. This study highlights the impact on mothers of having an adolescent child with AS and their increasing anxieties for the future – their own future and that of their daughters. There were sometimes difficulties in relating to their 'different' daughters. The mothers also perceived their children progressively failing to meet the levels of developmental 'normality' they would wish for and which would give some assurance of a positive future for them.

Low levels of confidence in relation to their abilities to effectively parent were expressed by all of the mothers in this study and experiences of feeling torn between their AS girls and their other children. Material resources were crucial as being able to accommodate their different children's needs for their own space was not always possible. Feelings of grief, loss and isolation have been previously identified in parents of children with autism. The mothers also felt torn between accommodating their AS children as they were and wanting them to be happy, and the powerfully motivated desire for their children to conform so that their future place as an adult in society could be assured. The process of diagnosis for the mothers in this study was often protracted, taking up to seven years in one case.

Mothers reported feeling judged as they struggled to find a meaningful explanation for their children's problems. Raised awareness of the prevalence of girls with AS should help ease this process.

Concluding comments

This study found that girls with AS do indeed experience anxiety which manifests in a variety of ways, including chronic insomnia, regular emotional outbursts, self harm and school refusal. That girls with AS experience ongoing intolerance and marginalisation in the mainstream school setting is apparent. Furthermore, their unusual and specific sensory and perceptual characteristics are often not addressed in these settings. The school environment, from the classroom setting to the common social areas, the corridors and stairs and the dining rooms, often cause high levels of stress and anxiety, inhibiting the girls' abilities to function comfortably and leading to the consequential anxiety-provoked somatic symptoms.

These findings add to what is understood about the impact on family dynamics and especially on how those dynamics are influenced by the ability of the family to meet the specific needs of the child with AS. Home was not always experienced in this study as a safe place to be, but sometimes challenging and painful for the girls and for their families.

Impairments in social communication skills have been linked to the development of depression and anxiety disorders in this population (Kim et al, 2000; Gillot et al, 2001). The consequences of these impairments can be far reaching. It has been reported that in adulthood, high functioning individuals with autism are less likely than their typically developing counterparts to live independently away from home, to marry or have friendships, to complete college courses or to work independently (Howlin, 1998; Marwick et al, 2005). The challenge to understand and intervene in social communication and interaction in autism is therefore undeniable; the right educational setting must be effective, not in removing the autism, but in creating a good environment for the girls' development.

Barnard, Prior and Potter's (2000) report 'Inclusion and Autism: is it working?' shared parental perspectives on inclusion and made 16 recommendations including that awareness of autism should be part of the continuing professional development of all educational professionals; that local authorities should make autism-specific help available to mainstream schools whilst maintaining choice of autism-specific schools, and that all interventions should be made in a context of meeting the individual needs and rights of pupils with autism.

The HMIE report commissioned and published in 2005 in Scotland (Marwick et al, 2005) was done in response to the Standards in Scotland's Schools Act 2000 (Scottish Executive, 2000), a report entitled, *Moving to Mainstream* (Scottish Executive Education Department, 2003) which revealed some of the budget costs of an inclusive model of education and the Education (Additional Support for Learning) (Scotland) Act 2004 (Scottish Executive, 2004). Lack of appropriate services and insufficient special education facilities were identified UK wide almost two decades ago but this situation does not appear to have been resolved (Heiman and Berger, 2008). An inclusive approach to education aimed at fostering independent participation in education and society supported by the legislation detailed above can only succeed through the allocation of appropriate resources. Perhaps even more cogent however, is that such resources should be directed towards an approach to inclusion that is truly based in insightful understanding. The experiences of the participants in this case study suggest that such understanding and therefore the appropriate support still is not sufficient, at least in parts of Scotland.

Difficulties in addressing the needs of all members of the family was a commonly experienced aspect of having a child with AS. For the families with girls with AS, loyalties were often challenged as mothers were 'torn between' the love for their child or sibling; their fears at 'not being normal' and facing a future of marginalisation. For the girls, being judged for expressing their needs, anger at having their needs ignored, anxiety over conflict with and between family members and feelings of rejection were expressed, while the mothers experienced exhaustion, feelings of isolation and fears for the future.

Legislation cannot alone reconcile inequality of resources, either material or personal; it can help to raise awareness of these inequalities however and implement steps to address them. This study highlights an existing need for greater support for families with children with AS.

That support should firstly take the form of appropriate, efficient, speedy diagnosis which should now be easier and less traumatic. Individuals with AS may have mixed responses to a diagnosis (Holliday-Willey, 1999; Molloy and Vasil, 2004; Murray, 2005) as may their families and peers (Huws and Jones, 2008). Responses by individuals to a diagnosis will also be mediated by how that diagnosis is thought to affect their future: new opportunities, to join support groups, to find places on college courses established to cater for their specific needs, to be understood and accepted by their immediate community, to look forward to finding a workplace niche that suits their skills and talents, are the kinds of positive outcomes hoped for.

The girls in this study were found to be exemplary in the strength of their characters and their achievements, despite the challenges they experience in their daily lives. There is high risk of these lives not achieving the level of fulfilment or contribution to society commensurate to their abilities which should be possible with the right kind of recognition and support. Without that, we are all deprived – the girls, their families and society as a whole. The building of both school and social communities that value diversity and actively implement policies that support that diversity in real life may perhaps be judged to be idealistic or at the least ambitious. The benefits, however, not just for families and individuals involved in AS but for society overall are potentially invaluable.

Action needs to be taken to ensure positive futures for these girls. There should be a commitment to providing dedicated college and university or vocational training places. There is currently no existing comprehensive data, in Scotland at least, as to the numbers of school leavers with AS overall. The only data that does exist is incomplete and limited to entry into further and higher education. A clear picture of what happens to these young people after they leave school is currently unavailable. Career guidance and ongoing career and life support should be implemented through these transitional periods and beyond.

References

Allik, H, Larsson, J O and Smejde H (2006) Health-related quality of life in parents of school age children with Asperger syndrome or high-functioning autism *Health and Quality of Life Outcomes* 4 (1), 1.

American Psychiatric Association (APA) (1994) *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM IV)* Washington, DC: American Psychiatric Association.

Asperger, F (1944) [Die 'Autistischen Psychopathen' im Kindesalter] *Autistic personality disorder in infancy* translated by Frith U (1991) *Autism and Asperger syndrome* Cambridge: Cambridge University Press.

Attwood, T (2006) *The complete guide to Asperger's syndrome* London: Jessica Kingsley Publishers.

Bauminger, N, Shulman, C and Agam, G (2003) Peer interaction and loneliness in high functioning children with autism *Journal of Autism and Developmental Disorders* 33 (5), 489–507.

Bogdashina, O (2004) *Communication issues in autism and Asperger's syndrome: Do we speak the same language?* London: Jessica Kingsley Publishers.

Calam, R M, Cox, A D, Glasgow, D V, Jimmieson, P and Groth Larson, S (2000) Assessment and therapy with children: Can computers help? *Child Clinical Psychology and Psychiatry* 5 (3), 329–343.

Carrington, S and Graham, L (2001) Perceptions of school by two teenage boys with Asperger's Syndrome and their mothers: A qualitative study *Autism* 5 (1), 37–48.

Emerson, E, Graham, H and Hatton, C (2006) The measurement of poverty and socio-economic position in research involving people with intellectual disability in L M Glidden (Ed) *International Review of Research in Mental Retardation* New York: Academic Press.

Faherty, C (2002) *Asperger's syndrome in women: a different set of challenges?* Available from www.autismtoday.com (accessed 18 April 2012).

Gillberg, C (2005) Presentation to University of Strathclyde, Conference.

Gillot A, Furniss F and Walter A (2001) Anxiety in high-functioning children with autism *Autism* 5, 277–286.

Grandin, T (1996) *Thinking in pictures and other reports from my life with autism* New York: Vintage.

Gray, D E (2001) Accommodation, resistance and transcendence: three narratives of autism *Social Science & Medicine* 53, 1247–1257.

Gray, D E (2003) Gender and coping: the parents of children with high functioning autism *Social Science & Medicine* 56, 631–642.

Haslett, C, Chilvers E R, Hunter, J A A and Boon, N A (1999) *Davidson's principles and practice of medicine* (18th edition) Edinburgh: Churchill Livingston.

Heiman, T and Berger, O (2008) Parents of children with Asperger syndrome or with learning disabilities: family environment and social support *Research in Developmental Disabilities* 29 (4), 289–300.

Howlin, P (1998) *Children with autism and Asperger syndrome – a guide for practitioners and carers* London: Wiley.

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, 23.

Huws, J C and Jones, R S P (2008) Diagnosis, disclosure and having autism: An interpretive phenomenological analysis of the perceptions of young people with autism *Journal of Intellectual and Developmental Disability* 33 (2), 99–107.

Jardine, K M (2008) *What meaning does raising a child with autism have for parents? A Qualitative Exploration* unpublished thesis Edinburgh: The University of Edinburgh.

Kanner, L (1943) Autistic disturbances of affective contact *Nervous Child* 2, 217–250.

Kelly, A B, Garnett, M, Attwood T and Petterson, C (2008) Autism spectrum symptomatology in children: The impact of family and peer relationships *Journal Abnormal Child Psychol*ogy 36, 1069.

Kim, J, Szatzmari, P, Bryson, S, Streiner, D and Wislon, F (2000) The prevalence of anxiety and mood problems among children with autism and Asperger syndrome *Autism* 4, 117–32.

Lawson, W (1998) *Life behind glass* Australia: Southern Cross University Press.

Little, L (2002) Peer victimization of children with Asperger syndrome disorders *Journal of the American Academy of Child and Adolescent Psychiatry* 40 (9), 995–996.

McGrath, P (2006) Psycho-social issues in childhood autism rehabilitation: A review *International Journal of Psychosocial Rehabilitation* 11 (1), 29–36.

Marwick, H, Dunlop, A W and MacKay, T (2005) *Literature review of autism for HM Inspectorate of Education* Glasgow: National Centre for Autism Studies.

Midence, K and O'Neill M (1999) The experience of parents in the diagnosis of autism: A Pilot Study *Autism* 3 (3), 273–285.

Molloy, H and Vasil L (2004) *Asperger Syndrome, adolescence and identity* London: Jessica Kingsley Publishers.

Murray, D (2005) *Coming out Asperger: diagnosis, disclosure and self-confidence* London: Jessica Kingsley Publishers.

Murray, D, Lesser, M and Lawson, W (2005) Attention, monotropism and the diagnostic criteria for autism *Autism* 9 (2), 139–56.

Nichols, S, Moravcik, G M and Tettenbaum, S P (2009) *Girls growing up on the autism spectrum* London: Jessica Kingsley Publishers.

Public Health Institute of Scotland (PHIS) (2001) *Autistic spectrum disorders, needs assessment report* Glasgow: National Health Service (NHS) Scotland.

Russell, E and Sofronoff, K (2005) Anxiety and social worries in children with Asperger syndrome *Australian and New Zealand Journal of Psychiatry* 39 (7), 633–638.

Sacks, O (1995) *An anthropologist on Mars* London: Picador.

Sainsbury, C (2000) *Martian in the playground: understanding the schoolchild with Asperger's syndrome* London: Sage Publications Ltd.

Stewart, C (2011) *Hermeneutic phenomenology: Experiences of girls with Asperger's syndrome and anxiety and Western Herbal Medicine* PhD Thesis Edinburgh: Edinburgh Napier University.

Van Manen, M (1990) *Researching lived experience: Human science for an action sensitive pedagogy* Albany, New York State: University of New York Press.

Volkmar, F, Pau, R, Klin, A and Cohen, D (Eds) (2005) *Handbook of autism and pervasive developmental disorders* (3rd edition) New York: John Wiley & Son.

Weibe, R F (1990) *Revisiting autism and Asperger's syndrome: Building family and school communities that value diversity* unpublished PhD Thesis Ottowa: Simon Fraser University.

White, S W, Oswald, D, Ollendick, T and Scahill, L (2009) Anxiety in children and adolescents with autism spectrum disorders *Clinical Psychology Review* 29, 216–229.

Willey, L H (1999) Pretending to be normal: Living with Asperger's syndrome London: Jessica Kingsley Publishers.

Wing, L and Gould J (1979) Severe impairments of social interaction and associated abnormalities in Children: epidemiology and classification *Journal of Autism Developmental Disorders* 9 (1), 11–29.

Woodgate, R L, Ateah, C and Secco, L (2008) Living in a world of our own: The experience of parents who have a child with autism *Qualitative Health Research* 18 (8), 1075–1083.

Woolf, V (1929; 1989) *A room of one's own* New York: Harcourt Brace & Co.

Appendix 1: Data collection

The interviews

Two in-depth interviews were conducted with each participant girl and each mother within an interpretive phenomenological model.

A modified version of the 'In My Shoes' (IMS) interview software was used to carry out the initial interview with each girl and was referred to in the second. This was designed to provide a neutral point of focus and to make it easier for the girls to describe their experiences. It also provided a baseline for each girl's emotional vocabulary. This technique made the initial interview more prescriptive than is usual within an interpretive method, but did support the girls' ability to relax and provided insight into their lived experiences.

An example of the IMS emotions palette.
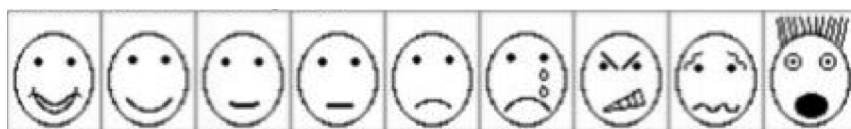
The participant was invited to consider the Emotions Palette and label each expression in turn with a word or words they felt most closely described the expression on the face. If they did not know what any facial expression meant, they were asked to leave the space for the label blank. This palette was used throughout the IMS interview.

The IMS software logs all entries made during the course of the interview. These logs were printed and used as text within the data analysis. The interviews were also recorded and the recordings transcribed verbatim for analysis.

One primary question was asked of the girls' mothers, with supplementary questions as appropriate throughout the course of the interviews. The question asked was: 'Life for everyone involves some levels of stress and challenges on a daily basis. How do you see your daughter in her experiences of daily life, with all its usual challenges and stresses?' The interviews with the mothers each took between an hour and an hour and a half. All the interviews were recorded and the recordings then transcribed verbatim.

The diaries

The girls were also asked to make use of an online diary in the form of a password-protected interactive webpage provided by the universities online system. The page contained a small indicative scale of what the girl felt about her experiences of that day (1 very good – 5 very bad) and the space to write her own comments. The entries were then sent direct to the researcher's email address. The entries were treated as text and included in the data analysis and also provided information that was then discussed during the girls' second interviews.

Examples of diary entries:

date time

xx.xx xx.xx **name:**   Lottie

radio: 2 (This number refers to the scale, 2 = Good)

comments: I'm good at the moment. I had some herbal stuff and it's not bad.

date time

xx.xx xx.xx **name:**   Lottie

radio: 3 = OK

comments: I've had a good day but I tried to do my science homework and I couldn't answer a single question because I was off when my class was doing the topic it's about. I can't believe my teacher shoves homework in my face expecting me to know everything about it!

Appendix 2: Recommendations for schools in supporting girls with Asperger syndrome

Attention should be paid to the following:

1. Awareness of the impact of noise and disruption in the classroom.

2. The need for clear and specific instructions.

   For example, A teacher might say:

   'Write down the answers to these 6 questions written on the blackboard – you may answer them in any order you like.'

   It might be useful to add:

   'If you don't know which one to start with, then just start with Number 1 and carry on to the next in order.'

   If a teacher wants the student to read a book at home, do not say:

   'You might like to read this book at home.'

   Instead say**:**

   'I want you to read this book at home by 30 March.'

3. Issues of safety are paramount for these girls.

   Reassurance and protection should be provided around the school, in the corridors as the students move from class to class.

4. Quiet, safe places should be provided for them for lunchtimes and free periods or breaks and on their way to school and back.

5. Settings for sports and PE classes, with noisy, communal changing facilities can be extremely challenging for girls with AS. Quiet, private changing areas can help.

6. Awareness training for all members of the school, teaching and support and admin staff and other students.

7. Find areas of excellence and specific skills; build on them as paths to further learning, increased self esteem, and improved position within their peer groups (see Sam Goldstein's www.raisingresilientkids.com); give them defined jobs to do, for example helping the teachers prepare for art or physics classes

8. After-school activities could be made more AS-friendly (eg, invite pupils with AS to come early to a drama class to allow a 'settling in' period before others arrive; give them a role within the group).