Aims and scope

The *Good Autism Practice* Journal (GAP) has been set up to meet the needs of practitioners and parents living or working with individuals with autism spectrum of all ages. The journal is multi-disciplinary in scope for professionals in services provided by health, social services and education as well as parents and individuals with autism spectrum.

The aims of the journal are to:

- provide a platform to discuss and share good practice
- disseminate good practice
- encourage a reflective and evaluative approach to the provision of services

Submission of papers to the Journal

If you wish to submit a paper, please read the notes at the back of this Journal for ideas on the content and formatting. If it is focussed on children on the autism spectrum, please email it to Dr Glenys Jones at g.e.jones@bham.ac.uk or send it to the School of Education, University of Birmingham, Edgbaston, B15 2TT. For papers with a focus on adults on the autism spectrum, please email these to Elizabeth Attfield at: elizabetha@autismwestmidlands.org.uk or send them to autism.west midlands, 18 Highfield Road, Edgbaston, B15 3DU.

Glenys Jones
Elizabeth Attfield
May 2010

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National Council for Special Education in Ireland: a review of evidence on educational interventions (available at www.ncse.ie)

ACER website:
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Editorial

There is a strong focus in this issue on the response of families to having a child on the autism spectrum and the ways in which professionals can work to support parents and siblings. Dr Clare Boorn, an educational psychologist, writes about two pieces of work. The first sought to identify the factors which lead to resilience and well-being in families and the second evaluated the benefits of running a short series of workshops on autism for parents. Katy Flynn and her colleagues from different disciplines also ran workshops for parents following diagnosis. Many services now offer parent training and so it is of interest to read these accounts to compare the content of the sessions and the potential outcomes. Then the paper by Julie Cooke and Catrin Semmens, based at a specialist school for children on the autism spectrum, write about the needs of brothers and sisters and how they might be supported. There is a growing literature on how to support siblings but still not enough initiatives offered by services or schools for these children. This paper is therefore welcomed as it provides ideas on how to work with siblings who may not know one another but who have a common bond in having a brother or sister on the autism spectrum. The workshop sessions described provide a forum for enhancing their knowledge of autism, discussing their feelings and developing strategies to manage some of the situations they face.

There are two papers looking at challenging behaviour – one by Amanda Appleby Payne which is a case study of an eleven year old boy. He had been excluded from his previous school for behaviour which staff were not able to manage. In such cases, it is important that education is restored promptly and effectively so that the child does not get out of the routine of leaving home to attend school or another base. This paper shows how staff at a school for children with moderate learning difficulties worked successfully with his parents to gradually introduce him to this new school. A thorough assessment and understanding of his needs and ways to motivate him to attend and engage successfully were vital to his success and the incidents of behaviours which challenged staff were reduced significantly in his new environment. A second paper by Jane Lawson considers the challenges to students on the autism spectrum who attend university. She argues that, just as in school, these students can be blamed and sanctioned for behaviours which are a direct result of their autistic differences. They are expected to understand procedures and social conventions just like neurotypical students and when they behave and react differently, this is viewed as anti-social, defiant, or careless and disorganised, when it is better viewed as a natural reaction to sensory overload, confusion, anxiety or a lack of social understanding. There is a need to educate university staff about autism and fellow students so that adjustments can be made to expectations and the teaching and social environments to enable students to thrive and achieve. Dr Nicki Martin also writes about higher education in her paper on preparing students on the autism spectrum for their PhD viva. She makes the point that the strategies suggested would also be very helpful to all students during this process.

There are two papers on specific interventions. One paper is on SCERTS (Social Communication, Emotional Regulation and Transactional Support) by Jan O'Neill and her colleagues and the other is on an intervention designed to help children to eat and drink a wider range of foods. SCERTS was developed by Prizant, Wetherby, Rubin and Laurent (2003) and is designed to develop communication skills. It has a focus on how adults can support and scaffold communication in terms of how they communicate and the situations they set up at home and in other settings. Data are presented on the effects of the introduction of SCERTS with four children on the autism spectrum within a special school. The paper by Joanna Gill and Maria Gleeson, both of whom as speech and language therapists, describes the work they did with eight children who attend a special school in Ireland. They ran a five-day 'Food is Fun' week at the school during the summer holiday and engaged in play and sensory activities involving food, based on McCurtin's work (2007). Successes were reported for each child in terms of the goals that their parents and therapists set together, some children making more progress than others. The Editors of the GAP Journal would be very interested in receiving more papers on this topic as eating difficulties challenge parents and professionals alike.

Call for papers for the GAP Journal on services and provision for adults

It is well known that there is much more literature on issues relating to children and a great need for more to be written about effective services for adults. The passing of the Autism Act 2009 required the Government to produce a strategy for adults on the autism spectrum and this was published in March 2010. In addition, statutory guidance from the Government for local authorities and health bodies in England is to be published by 31 December 2010.

The Editors of the Journal would really like to hear from people about the impact of this new legislation and about successful schemes and services to support autistic adults in terms of support to live, work and study as independently as possible and to enjoy a good quality of life.

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Elizabeth Attfield
May 2010

The SCERTS model: Implementation and evaluation in a primary special school

Jan O'Neill, Lisa Bergstrand, Karen Bowman, Katherine Elliott, Leslie Mavin, Sue Stephenson and Claire Wayman, Sunderland, UK

Editorial comment

An increasing range of educational, communication, behavioural, sensory, and relationship-based interventions for children on the autism spectrum are being used, both in special and mainstream school settings. As yet, there is limited evidence for the efficacy of many interventions (Jordan, Jones and Murray, 1998; Francis, 2005; Autism Intervention Research Trust, 2006–2010; Parsons et al, 2009), but there is an emerging consensus on what constitutes good practice (eg NIASA, 2003; SIGN, 2007; DCSF, 2009). This paper evaluates the implementation of the SCERTS model (Prizant et al, 2003) with four pupils on the autism spectrum within a primary special school. The author, Jan O'Neill, a Senior Educational Psychologist, makes the point that SCERTS encompasses many of the key principles of good practice and can be seen as a way of working with children which alters the culture of the school and adult style, rather than as a single intervention. An excellent analysis has been made on the effects of the introduction of SCERTS based on data on the children's progress and the views of all the professionals involved in the work.

Introduction

There has been a strong emphasis in the past few years on developing tools to monitor and track the progress that young people make across many areas of their development. P Scales, Performance Indicators for Value Added Target Setting (PIVATS) and National Curriculum data are now being widely used to monitor progress at individual, local and national levels. While more precise data on children's academic progress is now routinely collected and monitored, fewer assessment tools are available to help measure progress in relation to the development of specific skills, such as communication and social skills, and these are not usually linked to a framework for the delivery of a specific curriculum.

P Scales and PIVATS are seen as limited in their ability to adequately assess and monitor development in relation to specific social communication and behavioural skills, particularly in relation to children on the autism spectrum. IQ scores are often used as research outcome measures (Cohen, Amerine-Dickens and Smith, 2006; Smith et al,

2000; National Research Council, 2001) but there are concerns that these lack ecological validity; they do not measure:

> '... *meaningful changes within natural learning environments, do not address the core deficits in the autism spectrum and are particularly problematic for young children.'* (ASHA, 2006, p 16)

Connor (2003) identified some ways in which a young person's progress, in relation to the autism spectrum could be measured and this led us to developing a profile for children with a diagnosis. Within this profile we tried to identify those specific skills that we wanted to address in the delivery of our curriculum within a specialist primary school for young children on the autism spectrum. Access to training using the SCERTS (**S**ocial **C**ommunication, **E**motional **R**egulation and **T**ransactional **S**upport) model developed by Prizant, Wetherby, Rubin and Laurent (2003) led to us implementing a small-scale pilot within a primary special school.

Primary special school

Columbia Grange is a primary special school for children on the autism spectrum and/or learning difficulties and also the base for the local multi-agency Autism Outreach Team. It is recognised as an 'outstanding school' in its most recent Ofsted inspection in 2008 and there is a strong commitment to ongoing development with an emphasis on multi-disciplinary work within the school.

The rationale for choosing the SCERTS model was to:

- explore whether this was a meaningful framework to assess, monitor and track pupil progress for children on the autism spectrum
- set relevant targets based on consultation with families
- identify targets that address the key areas of difficulty associated with the autism spectrum
- develop reflective practice and a collegiate approach within the multi-agency team
- adopt a model that is grounded in evidence-based research

The SCERTS model

The SCERTS model is a non-exclusive framework for delivering a curriculum specifically designed to address the key areas of difficulty experienced by young children on the autism spectrum. It has a significant research basis. The SCERTS manual devotes a chapter to considering the evidence to support the view that the model is consistent with evidence-based practice (Prizant, Wetherby, Rubin, Laurent and Rydell, 2006). They acknowledge that research evidence can vary in terms of methodology and have developed a table of current research findings that support one or more domains of the SCERTS model. These research findings include randomised clinical trials, quasi-experimental group treatment designs, single case experimental designs and case-control, cross-sectional or longitudinal descriptive group research designs.

As an inclusive framework, the SCERTS model can incorporate a wide range of different interventions and approaches (eg Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH, Schopler and Mesibov, 1995); Picture Exchange Communication System (PECS, Bondy and Frost, 1994); and Intensive Interaction (Nind and Hewett, 1994) and allows for specific goal setting that relates directly to the key areas of difficulty recognised in the triad of impairments.

The development of SCERTS is heavily influenced by the work of Vygotsky (1978) with the need for the identification of the 'zone of proximal development' which clarifies the emerging skills. Learning is viewed as socially mediated with an emphasis on social partners who provide appropriate scaffolding to enable the child to successfully learn and acquire skills.

Key principles of the SCERTS model

The key principles of the model are as follows:

- Fostering spontaneous, functional communication should be viewed as the most critical educational priority for children on the autism spectrum
- Goals and activities should be developmentally appropriate and functional, relative to a child's adaptive abilities and the necessary skills for maximising enjoyment, success and independence
- Natural routines across, home, school and community environments provide the educational and treatment contexts for learning
- All behaviour is viewed as purposeful
- Social partners are viewed as much a part of the problem as part of the solution

Long-term positive outcomes for young children on the autism spectrum are seen as directly related to the development and achievement of functional social communication skills. Research suggests that early intervention that directly targets joint attention, imitation and play abilities appears to support the development of social and language skills for these children (Watson and Flippin, 2008).

The core domains of the SCERTS model focus on **S**ocial **C**ommunication, which has as its stated aim: 'helping a child to be an increasingly competent, confident and active participant in social activities' and **E**motional **R**egulation, which focuses on 'supporting a child's ability to regulate emotional arousal' (Prizant, Wetherby, Rubin, Laurent and Rydell, 2006). If a child has a weak capacity to self monitor their physical arousal and emotional state they are less likely to be able to attend to and access social interactions and learning opportunities.

The SCERTS model places equal weight on the role of **T**ransactional **S**upport in terms of the interpersonal support a social partner can give and the range of environmental supports such as visual and sensory strategies to support learning and emotional regulation.

Core domains of the SCERTS model

The core domains are:

- **Social Communication** – goals to help the child be a competent, confident and active participant in a social world. To achieve this a child needs to develop competencies in two key areas: **Joint attention** and **Symbol Use**
- **Emotional Regulation** – the capacity to self monitor levels of physical arousal and emotional states in terms of **Self Regulation** and **Mutual Regulation**
- **Transactional Support** – This includes the adjustments made by the communicative partner in terms of their interpersonal skills and adjustments made to the environment to foster positive learning outcomes

Interpersonal Support and Learning Support (environmental support)

The SCERTS model identifies three partner stages at which a child may be interacting in a social world, and observational assessment and target setting is directly linked to the identified partner stage. These partner stages are:

- **Social Partner** – where a child is using fewer than three words or phrases (which may be spoken, signed, pictured, written words or other symbolic system) referentially, regularly and with communicative intent
- **Language Partner** – where a child uses more than three words or phrases (which may be spoken, signed, pictured, written words or other symbolic system) referentially, regularly and with communicative intent
- **Conversation Partner** – where a child uses at least 100 words or phrases (which may be spoken, signed, pictured, written words or other symbolic system) referentially, regularly and with communicative intent and can use at least 20 different word combinations that are creative

Once a child's partner stage has been agreed, detailed observations take place across a range of settings within school, home and the community using the SCERTS Assessment Process (SAP).

Multi-disciplinary roles and processes

Within the multi-disciplinary team, discussions took place as to our relative roles. We were all involved in the initial process of carrying out observations to inform the assessment and target setting process, and considered it vital that this should be a shared and joint activity. Gradually, individual roles developed

with a strong commitment to regular meetings to share and support the ongoing process. The Specialist Speech and Language Therapist acted as the co-ordinator for the assessments and implementation of the SCERTS framework.

After the multi-disciplinary team training, several issues were highlighted. These included discussions around a pilot study, the identification of pupils and staff, whole-school training and translating the observational assessments into meaningful targets. The process gradually developed with a commitment from the Headteacher to explore funding to support ongoing training and protected time for staff to implement the model.

Process of implementing the SCERTS model

There were several actions to take to implement a pilot of the SCERTS model into school practice, as follows:

- Initial multi-disciplinary team joint implementation training
- Pilot agreed: four pupils; two at Social Partner stage and two at Language Partner stage
- Consultation with families
- Whole-school INSET
- Multi-disciplinary team observation, video, target/goal setting using the SCERTS manual
- Individual targets discussed and agreed with families
- Baseline and interim scores collected on SCERTS and Vineland Adaptive Behaviour Scales II assessment
- Monthly meetings
- Ongoing INSET with whole-school staff
- One-day consultation with Emily Rubin (SCERTS co-founder)
- Multi-disciplinary team visit to San Diego to review practice which is embedded in mainstream practice
- Evaluation: semi-structured interview with members of the multi-disciplinary team and reflective analysis with whole-school staff
- Analysis of assessment findings
- Setting-up of regional support group to discuss and share ways of developing the implementation of the SCERTS model

Method

Initial observations were carried out with the four identified pupils across a range of settings; involving transitions from one activity to another and in consultation with family members. Baseline

assessments were agreed within a multi-disciplinary assessment process using the SCERTS framework and the Vineland Adaptive Behavior Scales II (Sparrow, Cicchetti and Balla, 2005). Social Communication, Emotional Regulation and Transactional Support targets were agreed for the four pupils and staff and these were displayed in classroom settings. Interim assessments were carried out without reference to baseline scores after one year using the SCERTS and the Vineland Adaptive Behaviour Scales II (Sparrow, Cicchetti and Balla, 2005).

A semi-structured questionnaire was used to elicit views from members of the multi-disciplinary team and a reflective analysis activity was arranged with the whole-school staff.

Data on pupil progress

Raw score data from the baseline and interim SCERTS assessment indicated that all four pupils made progress in all four skills areas; Joint Attention, Symbol Use, Mutual and Self Regulation domains (see *Figure 1*).

Figure 1: SCERTS progress data for all pupils (after 12 months)
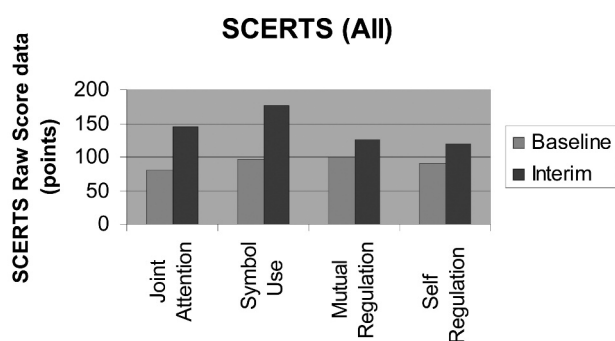
Individual pupil data from raw scores showed significant gains against all identified targets and the greatest gains against Joint Attention and Symbol Use domains (see *Figure 2*).

Similarly raw score data for individual pupils showed gains in the Communication and Socialisation domain from the Vineland Adaptive Behaviour Scales II (Sparrow, Cicchetti and Balla (2005) (see *Figure 3*).

Multi-disciplinary questionnaire

Members of the team were asked six questions relating to the pilot study. They were asked to write their responses and in addition they participated in a structured interview.

Staff understanding of autism spectrum following involvement with the pilot study

Several staff spoke about their increased understanding of the concept of emotional regulation and the importance of recognising their own roles in relation to supporting children when they were dysregulated. Specific behaviours had in the past often been viewed as 'part of autism' but everyone in the team spoke of a better understanding and a need for more open-ended reflection on the possible purposes and meaning which could be attached to the 'behaviour'.

Sensory issues were also highlighted with staff expressing a greater awareness of the benefits of a sensory curriculum. Across different disciplines such as speech and language therapy, occupational therapy and educational psychology there was a greater shared understanding, particularly with regard to the use of language used in describing needs and targets. Some of the comments made included:

'More aware that all behaviour is purposeful, has meaning. Not just their autism.'

'Think a lot more about sensory issues and regulation levels and the impact this has on a child's communication and learning.'

'More aware about need to focus on the passive children and encouraging opportunities for spontaneous communication.'

'Our behaviour affects their behaviour.'

Changes in practice

All staff were able to identify changes in their practice and for the speech and language therapist, the occupational therapist and educational psychologist this had resulted in training and liaison with professional colleagues within the local authority. They referred to the following changes:

'Greater use of visual supports, more detailed within task schedules.'

'More sensitive in giving children time and space, more child-centred approach.'

'Greater acceptance of some children's need for sensory equipment such as twiddlers, not removing these!'

'More liaison with Occupational Therapist (OT) and the Speech and Language Therapist (SALT)'

Figure 2: SCERTS progress data for individual pupils after 12 months

Figure 3: Vineland II progress data for the individual pupils after 12 months
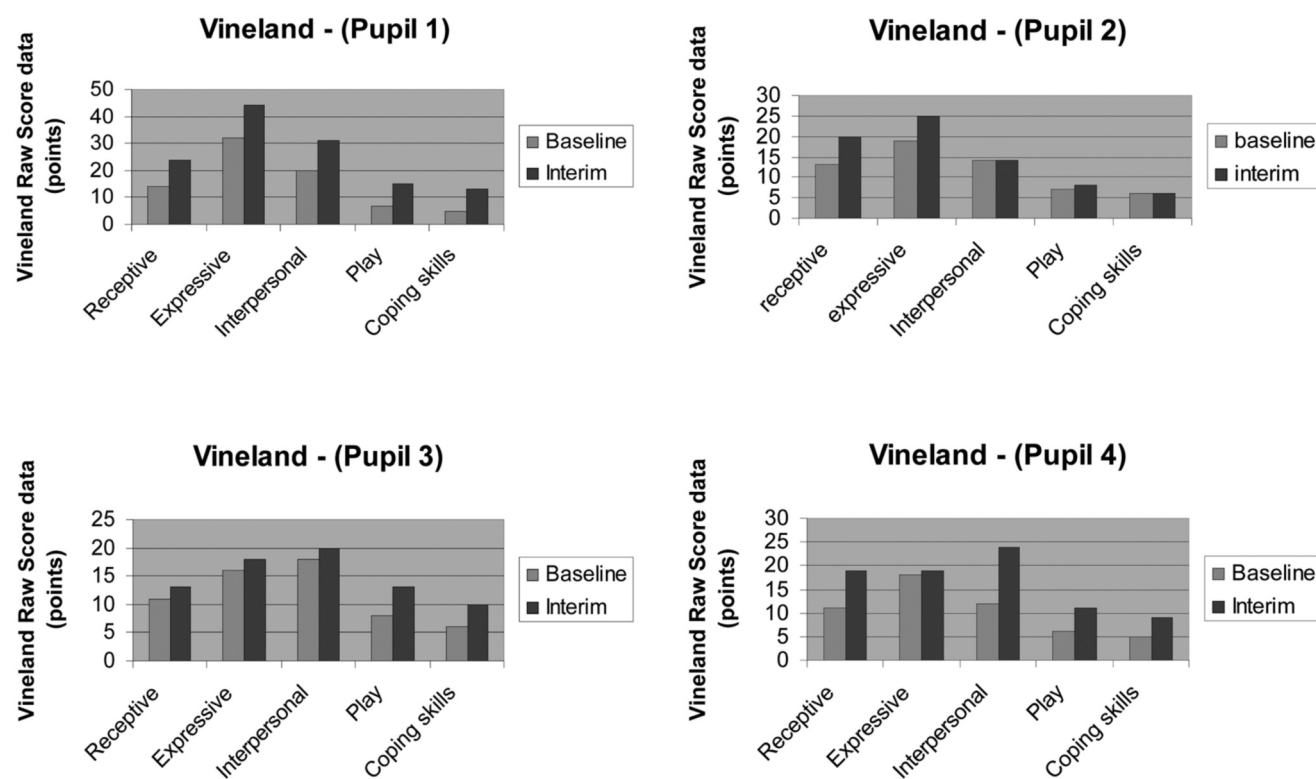
'Regular OT/sensory sessions embedded in school day, sensory activities more evident in the classroom, small trampets.'

'More developed sense of key worker with children in school and classroom setting.'
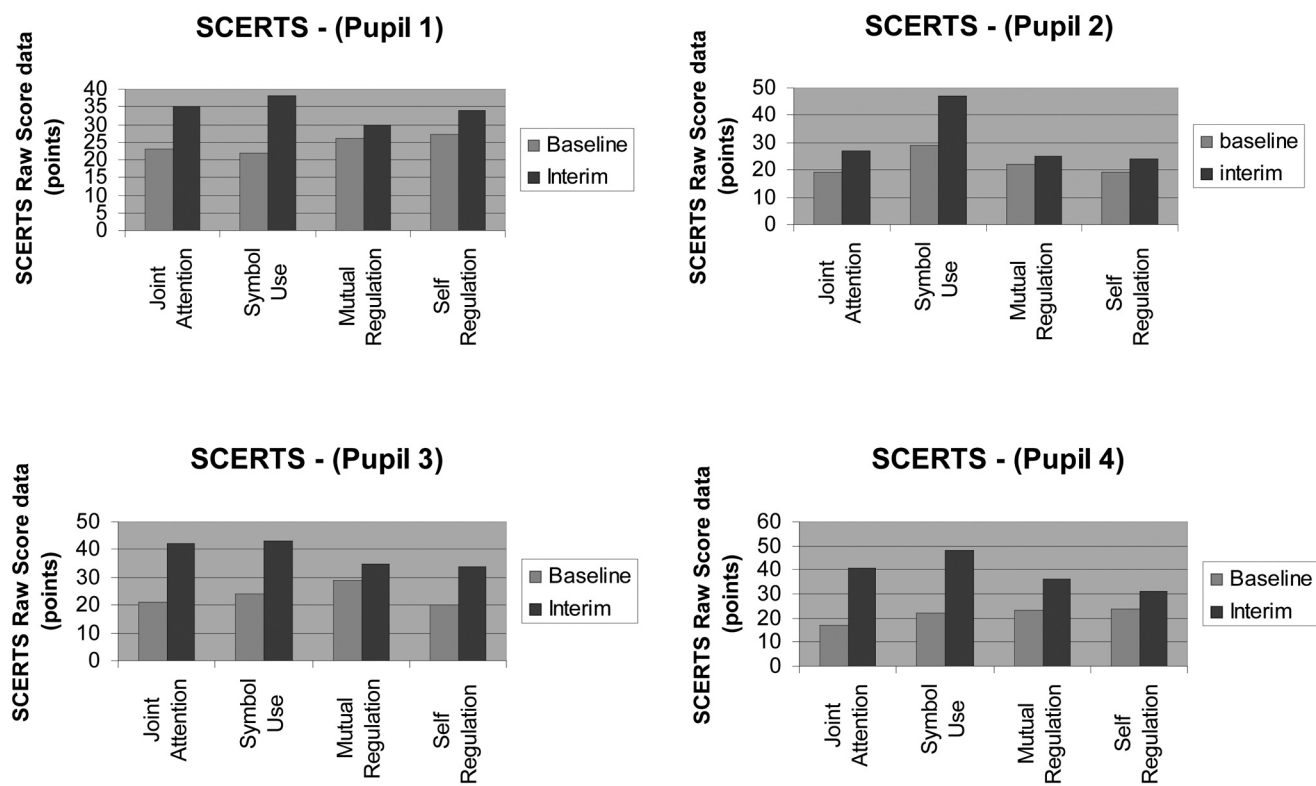
'Much more ready to acknowledge and respond to children's spontaneous bids for communication.'

'More focus on transitions between activities.'

'Greater use of ICT, whiteboards, making the curriculum more meaningful.'

'More interaction opportunities built in for children during learning activities.'

'Better monitoring of classroom practice.'

'Less anxiety about allowing for interruptions in curriculum delivery.'

Issues identified in using SCERTS

Several staff spoke about time constraints and the need for a team approach in terms of implementing the pilot. They had to learn how to observe and do the assessments; needed protected time; and felt the model needed to be whole-school and cascaded to staff. One said it involved a mind shift in thinking about behaviour and the autism spectrum and another said it raised their awareness of shortcomings in the curriculum.

Development and use of additional resources

Everyone involved spoke about an increased use of resources and in many instances personalised resources had been created. Many of these were then being shared across settings. One made more use of visual and concrete supports for teaching using toys and puppets; another used emotional key rings giving examples of choices; and staff commented on their own emotional states and used differentiated visual timetables more.

Links to existing practice

The adoption of the SCERTS model was seen as a significant part of the ongoing process within school to adopt a reflective analysis approach to continued development. The school culture encourages a reflective and exploratory view of teaching and learning and there has been an increased emphasis on the role of occupational therapy within school. Speech, language and communication tasks are now embedded within the school day, and not seen as separate, withdrawal work with the speech and language therapist. There has also been a development of teams within school for specific tasks, and less reliance on hierarchical model of management within school systems. The approach to behaviour management has also changed.

Next steps

Work to be done in the future includes making SCERTS part of whole-school practice, using the SCERTS model to enhance work on transitions between classes and between phases of education, creating greater links with parents and developing the use of SCERTS at the Conversational Partner stage. It is also planned to liaise with other settings in the region, to share practice and develop consensus for codings on observations and assessments and to develop a more meaningful curriculum for the children.

Comments from staff on the impact of SCERTS

Protected time was given within school to provide regular twilight sessions with all school staff. At the end of the academic year a session was planned to encourage a process of reflective analysis. Staff were asked to respond to three questions and to share examples of their practice in the classroom. Strategies which worked well were:

- allowing children to emotionally regulate themselves (eg colouring/doodling for older pupils)
- children using adult's photos to get their attention
- OT and sensory integration
- self regulation when overload occurred in class
- within-task schedules for more verbal children
- sensory integration. Greater use of visual props/resources during teaching activities
- use of OT room when needed
- more symbols being available
- children allowed to move around the classroom more

At a whole-school level, the changes in practice seen were:

- more appropriate expectations of children (eg allowing them to sit at back in assembly)
- staff accepting autistic behaviours
- children now able to sit longer with a desired objects
- change in teaching styles
- staff more patient and waiting. Listening to child's requests or forms of communication more

• children accessing different areas in school (eg library, quiet area)
• use of toys/twiddles
• classes seem to be trying to meet the individual needs of children more
• children generally happier in school – much fewer episodes of children severely dysregulated
• greater use of visual supports – photos and relevant timetables

Changes observed in the pupils
The pupils seem to be calmer and more focused on tasks and more ready to learn. They appear more aware of their own needs and using regulations as and when required. Some are seeking out adults to request more and there is more communication from children who are non-verbal. Some children were picking up on their own and others' emotions more and better able to self regulate.

Concluding comments
The core domains of the SCERTS model can be viewed as supporting some of the key principles in educating children on the autism spectrum recommended by documents such as the National Research Council (2001) – that is, on social functioning, peer relationships, spontaneous communication and language, and the acquisition of competence in natural contexts (eg classroom, home). Using the SCERTS model has resulted in a greater awareness of the need to honour pupil's spontaneous bids for interaction.

The prevalence of anxiety and behavioural difficulties including self injurious behaviour is well documented in the literature on the autism spectrum (Cox and Schopler, 1993; Kim et al, 2000; Gillot, Furniss and Walter, 2001; Tantam, 2000; Matson and Nebel Schwalm, 2007) and the impact on families and carers can be significant. Targets within the Emotional Regulation domain which focus on self and mutual regulation seek to address difficulties in coping with dysregulated behaviour both from a carer's perspective and also in terms of helping the young person develop their own personal coping strategies. It can be argued that the development of successful regulatory strategies will impact positively on an individual's long-term mental health and emotional wellbeing. Use of successful regulatory strategies also enable a young person to access learning opportunities more effectively.

The Transactional Support domain emphasises the role we play as mediators and provides a potentially non threatening way to help teachers, support staff and everyone working with a young person on the autism spectrum to reflect on the best ways of providing effective scaffolding. The role of the learning environment and quality of social interactions are seen as key in social learning theory and instructional scaffolding (Vygotsky, 1978; Wood, Bruner and Ross, 1976) and this theoretical work has influenced the development of the Transactional Support domain. Flynn (2005) discusses the role of Vygotsky's learning theories in relation to autism and proposes a situated dynamic assessment model. The advantages that he states in using such a model bear strong comparisons with the SCERTS model.

Reflective practice at both a personal and systems level is seen as key to professional development (Schon, 1983; Kolb, 1984) but there are often significant constraints within school systems in providing regular and meaningful opportunities for staff to engage in this practice. Implementation of the SCERTS model has provided a framework for encouraging reflective analysis and practice within a school setting. The use of video clips of children for the SCERTS assessment process has provided a relatively non-threatening means of engaging professionals in reflective enquiry as to their own roles as mediators. In general this has been very positive with the whole-school now participating in video analysis.

The use of the SCERTS model has actively encouraged the development of positive multi-agency working within the school. Access to implementation training as a team was important in enabling team members to support each other through the early days. The development of a shared vocabulary and an increased understanding of each other's roles was supported through involvement in the pilot. It has also supported collaborative and non-hierarchical ways of working with roles and responsibilities evolving as the process developed. SCERTS also provided a vocabulary for shared and jointly owned targets which had not existed prior to the pilot.

Liaison with families and carers has been seen as a strength in school and recognised as such in the recent Ofsted report. However, involvement in the pilot has highlighted our sometimes limited perspective about a child's experiences beyond the school day. It has helped strengthen relationships and is recognised as an area for further development.

SCERTS has enabled us to collect more specific data about pupil progress in relation to specific skill areas

which relate to social difficulties seen in autism. This is now incorporated within our annual review information and is replacing the use of PIVATS in relation to the personal and social development skills.

Some initial concerns about the use of the SCERTS model focused on how well it would complement existing practice. Within Columbia Grange school a range of approaches, strategies and interventions are used to support the learning environment and there were some concerns as to whether SCERTS was just another approach. As a framework the SCERTS model aims to support the inclusion of specific targets into all areas of the curriculum and is not dependent upon specific activities or approaches. In practice, targets were initially agreed at specific points in the day but there is evidence that staff are now more aware of referencing these targets throughout the day.

Reflection on the use of the SCERTS model has encouraged us to think about our school curriculum and to question how meaningful it is to our pupils. Adoption of literacy and numeracy strategies has not always translated into the most meaningful activities. Discussions have taken place about literacy activities in school and there is a commitment to creating personal books based on real experiences with greater use of visual symbols to support learning.

In conclusion the SCERTS model has allowed us to focus in detail on individual pupils, to explore their strengths, to identify emerging skills, and to liaise and collaborate more meaningfully with their families and carers. As a framework it is both child-centred but also system-sensitive. Meaningful targets can be introduced and embedded in all aspects of the curriculum and early concerns that it might mean wholesale changes to the curriculum have not materialised. Its use has encouraged ongoing reflective practice and has contributed to whole-school development.

Our future developments include the gradual inclusion of all pupils on the SCERTS model with increased liaison with families and carers. Use of the model is also extending to our special secondary school and we are participating in a regional SCERTS interest group.

References

American Speech-Language-Hearing Association (2006) *Guidelines for speech-language pathologists in diagnosis, assessment and treatment of autistic spectrum disorders across the lifespan* available from www.asha.org (accessed 21 April 2010).

Bondy, A and Frost, L (1994) The Picture Exchange Communication System *Focus on Autism and Other Developmental Disabilities* 9, 3, 1–19.

Cohen, H, Amerine-Dickens, M, and Smith, T (2006) Early intensive behavioural treatment: replication of UCLA model in a community setting *Journal of Developmental and Behavioral Pediatrics* 27, 145–155

Connor, M (2003) Monitoring and reviewing early behavioural intervention in autism (Lovaas) *Educational Psychology in Practice* 19 ,1, 21–30.

Cox, R D, and Schopler, E (1993) Aggression and self-injurious behaviors in persons with autism: The TEACCH approach *Acta Paedopsychiatry* 56, 2, 85–90.

DfES (2002) *Autistic spectrum disorders: good practice guidance* London: DfES.

Francis, K (2005) Autism interventions: a critical update *Developmental Medicine & Child Neurology* 47, 493–499.

Flynn, S (2005) A sociocultural perspective on an inclusive framework for the assessment of children with an autistic spectrum disorder within mainstream settings *Educational and Child Psychology* 22, 1, 40–50.

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

DCSF (2009) *Inclusion development plan: supporting pupils on the autism spectrum* available from www.standards.dcsf.gov.uk/nationalstrategies/node/165037 (accessed 21 April 2010).

Jordan, R, Jones, G and Murray, D (1998) *Educational interventions for children with autism: a literature review of recent and current research* London: DfEE.

Kim, J A, Szatmari, P, Bryson, S, Streiner, D L and Wilson, F J (2000) The prevalence of anxiety and mood problems among children with autism and Asperger syndrome *Autism* 4, 2, 117–132.

Kolb, D A (1984) *Experiential Learning: experience as the source of learning and development* New Jersey: Prentice-Hall.

Matson, J L and Nebel-Schwalm, M (2007) Assessing challenging behaviors in children with autism spectrum disorders: a review *Research in Developmental Disabilities* 28, 6, 567–579.

NIASA (2003) *National Autism plan for children: plan for the identification, assessment and diagnosis of autistic spectrum disorder* London: NAS.

Nind, M and Hewett, D (1994) *Access to communication: developing the basics of communication with people with severe learning difficulties through Intensive Interaction* London: David Fulton.

NRC (2001) *National Research Council educating children with autism* National Academies Press available from www.books.nap.edu (accessed 21 April 2010).

Prizant, B, Wetherby A, Rubin, E and Laurent, A (2003) The SCERTS model: a transactional, family-centred approach to enhancing communication and socio-emotional abilities of children with autistic spectrum disorder *Infants and Young Children* 16, 4, 296–316.

Prizant, B, Wetherby, A, Rubin, E, Laurent, A and Rydell, P (2006) *The SCERTS model: a comprehensive educational approach for children with autism spectrum disorders* Baltimore: Brookes.

Research Autism *Autism Intervention Research Trust 2003–2010* available from www.researchautism.net (accessed 21 April 2010).

Schön, D (1983) *The reflective practitioner* Basic Books: New York.

Schopler, E and Mesibov, G (1995) Structured teaching in the TEACCH approach in E Schopler and G Mesibov (eds) *Learning and cognition in autism* New York: Plenum Press.

SIGN (2007) *Sign Guideline Number 98 – Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders* available from www.sign.ac.uk/guidelines/published/numlist.html (accessed 21 April 2010).

Smith, T, Groen, A D and Wynn, J W (2000) A randomized trial of intensive early intervention for children with pervasive developmental disorder *American Journal on Mental Retardation* 5, 4, 269–285.

Tantam, D (2000) Psychological disorder in adolescents and adults with Asperger syndrome *Autism* 4, 47–62.

Vygotsky, L S (1978) *Mind and society: the development of higher psychological processes* Cambridge, MA: Harvard University Press.

Watson, L and Flippin, M (2008) Language outcomes for young children with autism spectrum disorders *The ASHA Leader, American Speech – Language - Hearing Association.*

Wood, D, Bruner, J and Ross, G (1976) The role of tutoring in problem solving *Journal of Child Psychology and Psychiatry* 17, 89–100.

From exclusion to inclusion: Planning for successful reintegration into a special school

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Editorial comment
Some pupils on the autism spectrum are excluded from both mainstream and special schools as a result of challenging behaviour. It is important that their education is restored promptly and effectively by placement at an alternative school or by a special individualized programme, preferably implemented outside their home, so that the child does not get out of the routine of leaving home to attend school or other base. This paper gives an account of how staff at a school for children with moderate learning difficulties worked successfully with the parents of an eleven year old boy to gradually introduce him to school, following exclusion from another special school and a short period at a pupil referral unit.

Introduction

Research evidence has shown that pupils on the autism spectrum are more likely to display challenging behaviour in comparison to children with learning impairments (Dixon et al, 2008; Dominick et al, 2007), children with psycho-pathology (Matson and Nebel-Schwalm, 2007) and typically developing children (Nicholas et al, 2008). School age children on the autism spectrum often present behaviours such as self-injurious behaviour, non-compliance and repetitive or ritualistic behaviours (Baghdadli et al, 2003; Kiernan and Kiernan, 1994; McClintock, Hall and Oliver, 2003; Murphy, Hall, Oliver and Kissi-Debra, 1999). Severe and chronic behaviour difficulties, correlate with reduced access to both educational and social opportunities (Anderton et al, 1992; Matson and Wilkins, 2007).

Over the years there have been many definitions of challenging behaviour. Early references make no distinction between the behaviour and the person, phrases such as 'maladaptive behaviour' or 'aberrant behaviour' suggest that the person is abnormal or unable to adapt to situations (Jones and Porter, 2008). Today, it is recognised that a person's behaviour is a product of factors internal to the person and factors in their external environment.

So, Blundell and Allen (1987) suggest that:

'… such behaviours represent challenges to service rather than problems which individuals carry around with them.' (p 14)

These may be deemed as:

'… behaviour of such an intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to the use of ordinary facilities'. (Emerson, Kiernan, Alborz, Reeves, Mason, Swarbrick, Mason and Hutton, 1987, p 8)

When referring to pupils on the autism spectrum, it is recognised in the literature that there is a strong relationship between the personality of the individual, their behaviour and the environment. Challenging behaviour is not in itself a direct result of autism. There will be many different factors which contribute to challenging behaviour and it is unlikely that there is ever a single cause. Whitaker (2001) bases his approach to dealing with challenging behaviour on three main assumptions, as follows:

- *'There is a significant learned component in most forms of challenging behaviour and what has been learned may be "unlearned"*
- *Challenging behaviour almost always means something*

- *Understanding the behaviour helps us to change it.'* (p. 14)

Managing pupils with these complex needs requires an understanding of the pupil, of autism and of the functions of their behaviour.

Andrew

Andrew (fictitious name) was admitted to the school at the age of 11 years. He has a diagnosis of autism and Attention Deficit Hyperactivity Disorder (ADHD) and is one of three boys in his family, all of whom are on the autism spectrum. He began his education in a school for pupils with moderate learning difficulties in the authority. As he became older he began to present with more challenging behaviour. Several incidents were reported and a number of temporary exclusions occurred ending with a fixed term exclusion following a serious assault on the headteacher. He transferred to a pupil referral unit (PRU) for an eight-week placement at the end of which it was recommended that he attend the Autism Base at a school for moderate learning difficulties called Greenfields (fictitious name).

Greenfields has pupils aged from 4–16 years on roll. As the teacher-in-charge of the Autism Base, discussions took place between myself and other members of the Senior Leadership team and the authority's SEN team on how Andrew's integration was to be managed. Due to the long-standing history and the practicalities of integrating Andrew into an existing base with other pupils on the autism spectrum, the plan needed to be carefully drawn up and managed. The Autism Base had seven pupils, two of whom frequently displayed challenging behaviour but who were settling well into the Base. It was recognised that Andrew could potentially change the dynamics of the group, so work began on preparing the existing pupils in preparation for Andrew's visits. Liaison with staff at his previous placements took place to gather a picture of Andrew. Once information had been gathered, he was invited on an initial visit with his parents to Greenfields school. It soon became apparent that he would require input and liaison with other agencies to facilitate a successful induction. Information revealed that Andrew presented with behaviour that needed to be addressed before induction could take place. He had previously displayed some sexualised behaviour towards women and had a history of negative experiences with people on the transport to and from school. After long negotiations, it was finally agreed to provide his own transport with the same male escort and driver. Training and advice

was given to both adults concerned and a risk assessment highlighted Andrew's potential challenges on the journey. Daily communication was established between home, transport and the school. This continues to be monitored and reviewed termly.

It was vital from the outset that good communication and understanding was arranged with Andrew's parents. Their past experiences had led them to lose confidence in the education system and good relationships and trust needed to be re-established. As arrangements were made with the family, it was also made very clear to all involved that this would be a team effort and that Andrew was part of that team. Expectations were high and Andrew was involved in discussions concerning past incidents and asked that he learnt to trust the adults working with him. Any physical harm to staff would be unacceptable. It is the ethos within the Base to use strategies to empower individuals to be in control of their actions in a positive sense, by establishing very early on possible choices in behavioural responses. Hewett (1998) says the emphasis needs to be on positive approaches to teaching pupils how to behave appropriately, rather than on adults controlling a pupil's behaviour. Every opportunity is used to model, discuss, hypothesise, imagine situations, or talk about something that has happened and how it should be dealt with next time. Using Intensive Interaction strategies (Hewett and Nind, 1998), pupils are shown respect and empathy, helping them to build and develop basic trusting relationships with the staff.

Part of the success of managing the integration of pupils on the autism spectrum into Greenfields school has been due to understanding the function of behaviour and to work towards self advocacy. Self advocacy can be seen as a relationship in which it is the professional's responsibility to:

- *'invite and value the person's self-expression*
- *offer choices and develop decision making skills*
- *act as an information resource about rights and opportunities*
- *give support as the individuals make changes, accepting mistakes and inappropriate behaviour as part of the learning process.'*
(Mittler, 1996, p 284)

It is important to emphasise at this point that as manager of the unit, there is a very positive ethos of 'Lets try … and if it does not work, let's try something else!' Approaches are eclectic, but at all

times consistent for each pupil and professional and managed with the utmost respect and awareness of both adult and pupil safety. My previous work in an autism-specific school, with severely autistic pupils, most of whom were non- verbal, had shown me that such pupils used alternative forms of communi-cation, including severely challenging behaviour. As a result, I felt confident to lead the Base team in finding the reasons behind Andrew's negative profile, and to implement appropriate strategies to enable him to access both his curriculum and his peer group.

With these approaches in mind an induction programme began, with just hour long visits to the Autism Base within Greenfields school. The physical environment of the classroom has been purposefully designed and created specifically for pupils on the autism spectrum. It is a small but carefully arranged room, using screens and furniture to create zoned areas. It is a low arousal room, with minimal visual displays. It has a maximum capacity for eight pupils, with three permanent staff (a Specialist Teacher and two Learning Support Assistants (LSAs)), all of whom are Team Teach trained (Team Teach Ltd, Founder George Matthew, 1997). The main approach is TEACCH (Treatment and Education of Autistic and Related Communi-cation Handicapped Children, Schopler, 1971). All pupils have their own individual work-station area with a variety of visual timetables and symbolic communication boards. Elements of the physical environment such as space, lighting, seating, noise, and appropriate furniture are carefully considered, as sensory issues are known to be a major contributory factor to challenging behaviour (Bogdashina, 2003; Myles, Cook, Miller, Rinner and Robbins, 2000). Symbol support is created by the 'Writing with Symbols' (Widget Software Ltd) programme that has helped the team create purposeful, augmentative communication systems.

Andrew's hourly visits were designed to create a positive and successful experience of life at school. On arrival he was introduced to his 'own space' and followed a visual timetable of short, but easily achievable, activities, using the work/reward system. Several 'choice' activities were selected and agreed and a reward system was put in place. Andrew proved easy to motivate as he had a number of special interests on which to base his rewards. He particularly liked Scooby Doo and Caspar the Ghost. He was allowed to bring in a few Scooby Doo books and was allocated time to share his interests with staff. (This is a timed activity using egg timers and

a symbol of the character that is chosen as a choice activity. Andrew is then allowed ten minutes to talk about his special interests). Sanctions and rewards are used constantly as part of the consistent practice in the Base. Whilst intensive, they are effective, as the pupils receive immediate feedback on their actions. Adjoining the classroom there is a purpose built area that is a 'safe space' for pupil withdrawal. It is a multi purpose space that is used for withdrawal and calming, and it is also a sensory and therapy room. It was important that this space was built into Andrew's routine from the start. It was felt whilst getting to know him, should his anxiety levels rise, he could withdraw himself or be instructed to move to this safe place. This was modelled to Andrew, during his visits, whilst he was happy and calm, to prepare him for the time when it was needed. Photographs of the room were used in discussion with Andrew allowing him the choice to have 'time-out' if he became overwhelmed. Safe withdrawal was practised and modelled in preparation for times of anxiety.

Through a series of observations it became apparent that one of the functions of Andrew's behaviour was to control his environment and opt out of specific activities. He had achieved this previously through physical force. He had a very low self esteem, particularly in curriculum areas, where his learning difficulties led to large gaps in his basic Literacy and Numeracy skills. When challenged, he would begin to opt out and then become challenging. Carr and his colleagues have researched the relationship between communication and challenging behaviour (Carr and Durand, 1985; Carr, Newsom and Binkoff, 1980). Their detailed observations revealed that, as for Andrew, challenging behaviour may be used as a means of escaping specific situations. They use the term 'escape-motivated aggression'. We used a variety of approaches to reduce this behaviour including 'differential reinforcement'. Precision teaching (Lindsley, 1991; West and Young 1992) was established by a trained LSA to begin to build on the academic foundations that were missing. Opportunities for success were rewarded and built upon. This in turn led to improved co-operation and self esteem. Andrew also displayed ritualistic behaviour around his special interests. On arrival, these were with the characters Scooby Doo and Casper the ghost. Time was set aside for him to discuss these at several times throughout the day, using egg timers. Staff positively engaged with Andrew during this time, modelling conversation skills and gradually reducing these times to twice daily. His special interests remain a dominant feature

and continue to be respected and utilised fully, whilst at the same time he needs reminding regularly that there are specific times of the day that he is allowed to discuss these. Currently he loves to draw card captors (These are characters that he invents and draws himself on small strips of paper and they are based on the Pokemon characters. Each character has a special skill which is represented in the names he gives to them.). This activity is long standing and overwhelms him at times. Periodically he is engaged in discussions of how to manage this himself and agreements have been made with him to leave large quantities of these drawings at home, and just having an agreed number at school.

Quite early on during induction sessions, Andrew would demonstrate intolerance to noise, would appear tired and would talk to himself. He said that he had imaginary friends who came to school with him and during times of anxiety he would talk to them. The functions of these behaviours were to distract himself and cope in challenging situations. After implementing symbol support, including 'noisy', 'I need space', 'I need help' and reward systems in place for these, a self regulatory system was introduced to help him monitor his own levels of anxiety. These took place as virtual boxes in his head. The phrase 'How are your boxes?' was used to address levels of anxiety. Andrew is very much a visual learner and thinker. He was able to communicate, whether these were 'full', 'half full' 'just a little bit' or 'fine'. The choice of phrases came from Andrew, described to us and then used accordingly. This strategy continues to work successfully in communicating his level of anxiety. When the boxes are filling up, opportunities are given to withdraw to the safe place, using ten-minute timers to empty the boxes. If the intervention is soon enough, this time is adequate and then Andrew is able to return to the task. Andrew was empowered to manage and regulate his own levels of anxiety, given a successful means to communicate this and a safe place in which to manage it.

With these strategies embedded in practice, Andrew's sessions at school were slowly increased, and he was able to stay on task and focus his attention for longer periods of time. The day was very gradually and carefully extended when we felt he could manage. He was of course always prepared in advance for this and negotiations with his parents and transport were ongoing to facilitate this. The more we got to know Andrew, the more we were aware of how complex his needs were. He presents as a very personable, polite, and well-mannered boy

(eg he will open and hold doors for you), and appears to be very sociable to unknown adults. As his time in school extended, his contact with staff outside the Base began to widen. It was therefore imperative to give all staff in school an overview of the complexity and depth to Andrew's personality and idiosyncrasies. All school staff were informed of his potentially challenging behaviour and everyone was alerted to Andrew's issues with close proximity and inappropriate, often sexualised, behaviour. This was not to create a sense of fear, but to make staff aware of these issues.

Work then began in the Base on social communication and his understanding of physical proximity. The Child and Adolescent Mental Health Service (CAMHS) also began working alongside us in school with weekly sessions to reinforce this. These targets were incorporated into bi-annual Individual Education Plans (IEPs) and progress was discussed at Parents' Evenings and Annual Reviews. A multi-agency approach developed as speech therapy was introduced. Targets were set and incorporated into daily practice. The focus on these sessions was social communication, using visual support materials from Black Sheep Press and we built on these during timetabled, social skills sessions. Opportunities were created to relate learning to experience allowing feedback and self monitoring opportunities.

Following work on feelings, where exaggerated emotions were modelled frequently, feelings charts were implemented and used on arrival in the morning and throughout the day as needed, enabling the pupils to express their emotions. Role play activities and visual presentations enhanced work in this area and helped Andrew begin to link feelings and emotions to situations. A colleague visiting from the authority's Autism Outreach team, commented on the success of this practice. She could see that the work we were doing was constant throughout the day, embedded in the curriculum. Our consistent approaches were being used within lessons and during all transition times. No opportunity for learning or transference of skills was overlooked; it was used and maximised to the full.

As a team we had identified over time both the internal and external factors that were contributing to Andrew's behaviour that had previously been labelled 'challenging'. A factor that lay outside the educational setting was his irregular sleep pattern. Research by O'Reilly (1995) demonstrated that the challenging behaviours of a man with severe

learning disabilities were more severe when preceded by a night of disturbed sleep. This was evident in Andrew. His parents had expressed their concerns regarding the use of medication for their son, and understandably preferred not to use any. We discussed the impact that fatigue was having on Andrew's access to school, which was significant as he would often arrive irritable and short tempered. It was also delaying the extension of his school day to full time as after lunch he would become very tired and found it hard to manage the curriculum demands. The use of melatonin was discussed and parents then approached their consultant requesting this. Over several months this medication began to improve and regulate Andrew's sleep pattern. There was a noticeable improvement in his ability to further access the curriculum. Sleep deprivation had been a significant contributory factor to his 'challenging behaviour'. To date, this can still cause irritability, and occasionally Andrew will still opt out.

As the Base consisted of pupils from a variety of year groups, (Years 5, 6 and 7), it had become increasingly more challenging to present an academic curriculum to meet all these pupils' needs. Whilst individualised learning for Literacy and Numeracy was achievable and an alternative curriculum covering social skills training, play skills, communication and interaction was highly successful, it was my long term aim to make the provision for the pupils more inclusive. Whilst the intervention with Andrew was intensive and consistent, the time would come for him to move out of the Autism Base to a class in the main part of the school.

This began in September 2009. Andrew is currently in Year 8. He continues to have LSA support and the Autism Base remains a safe base for him. He arrives slightly later than the rest of the school in the morning and is prepared for the day. He accesses his own timetable and prepares himself for his lessons. At any point in the day he may withdraw to the safe space if needed, but is always expected to return to task when able. In order to facilitate this, staff that now teach and support Andrew were given advice and strategies that have been used successfully. The LSA support is one of the familiar staff from the Base and she manages and advises Andrew throughout the day. Each day I will have some contact with him and I maintain links with all outside agencies to ensure consistency. Since September, there has been one incident of challenging behaviour towards staff, which is a considerable reduction since his arrival.

This was managed and discussed and functional alternatives were taught.

As a teacher of pupils with autism and Inclusion Manager for Greenfields School, I am aware that further staff training now needs to be implemented. Whilst Andrew is largely being educated successfully at our school, staff would benefit from a greater depth of understanding of autism to continue to meet his and other pupils' needs. Part of the School Development Plan is to use the Inclusion Development Programme (IDP) (DCSF, 2009) for autism to do this. Andrew also highlighted the need for improving whole school communication issues, establishing designated meeting times to hand over crucial information on pupils.

Further work will be needed to approach the subjects of puberty and sex education for Andrew and as he reaches Key Stage 4 access to college courses will need planning, preparing and implementing carefully. There is still much work to be done, but significant progress has been made. The most rewarding aspect of working with Andrew has been enabling him to have control over his own behaviour and learning giving him elements of choice back in his life. He continues to find aspects of school life a challenge, but he enjoys coming to school, has positive relationships with staff and selected peers and whilst we are always cautious to manage him sensitively, he remains far less 'a challenge' than was initially presented.

Concluding comments

To conclude, the key element in the process of understanding Andrew and the behaviour he was presenting was to discover the function of his communication. Establishing positive relationships with him was crucial as he had received so much negativity that we had to help him relearn how to behave in a variety of situations. The environment was key in facilitating these changes and provided a structured and consistent approach, thus eliminating a lot of triggers for anxiety. Like Whitaker (2002), we find that teaching individuals new skills, skills that give access to the outcomes the pupils prefer, successfully reduces challenging behaviour. As part of our intervention the new types of learning were providing access to communication, using augmentative and social communication approaches, and improving Andrew's self management skills. Establishing a multi agency approach, allowed Andrew to access the support he needed outside our setting. Transport to school had previously been such a negative part of his school day that the change

in this alone was significant. Termly meetings continue with the transport team to ensure that Andrew remains on single transport with the same escort and driver, as this is so crucial to his success. Maintaining consistent strategies, with agreed expectations and a positive school ethos will help Andrew continue to successfully access his appropriate curriculum. We have developed a mutually respectful working relationship with Andrew. Despite his initial reluctance to co-operate, he has realised that there are adults who do have a good understanding of how he sees the world around him and he is more accepting that they are there to help him. He is part of a successful team, which continues to be on a journey that will hopefully lead him to successful inclusion into society and that will enable him to have a happy and fulfilling life.

As Whitaker (2001) says:

'In a nutshell, "challenging behaviour" is behaviour that challenges – whether it is a challenge to our understanding, our own well being or our child's or else to our ability to carry out our responsibilities as parents or professionals.' (p 4)

Andrew presented us with several new challenges, one to provide a successful education for a previously 'hard to place pupil', two, to change the opinions of those who came into contact with him, and finally to provide him with an appropriate academic and social curriculum to which he was entitled. To date it gives me great satisfaction to say that this has been achieved, and whilst we admit to facing further challenges ahead, the process of understanding and enabling Andrew to manage his behaviour has been successful. He therefore now presents as a pupil that is far less of a '*challenge'*.

References

Anderson, D J, Laken, K C, Bradley, K H and Chen, T (1992) Social integration of older persons with mental retardation in residential facilities *American Journal on Mental Retardation* 96, 488–501.

Baghdadli, A, Pascal, C Grisi, S and Aussilloux, C (2003) Risk factors for self-injurious behaviours among 222 young children with autistic disorders *Journal of Intellectual Disability Research* 478, 8, 622–627.

Bogdashina, O (2003) *Sensory Issues and autistic spectrum disorders* London: Jessica Kingsley.

Blunden, R and Allen, D (1987) *Facing the challenge: An ordinary life for people with learning difficulties and challenging behaviour* London: Kings Fund.

Caldwell, P (1998) *Person to person: Establishing contact and communication with people with profound learning difficulties and extra special needs* Brighton: Pavilion Publishing.

Carr, E G and Durand, V M (1985) Reducing behavioral problems through functional communication training *Journal of Applied Behavioral Analysis* 18, 111–126.

Carr, E G, Newsom, C D and Binkoff, J A (1980) Escape as a factor in the aggressive behavior of two retarded children *Journal of Applied Behavioral Analysis* 13, 101–117.

Clements, J and Zarkowska, E (2000) *Behavioural concerns and autistic spectrum disorders explanations and strategies for change*: London *Jessica* Kingsley Publishers.

Dixon, D R, Kurtz, P F and Chin, M D (2008) A systematic review of challenging behaviours in children exposed prenatally to substances of abuse *Research in Developmental Disabilities* 29, 483–502.

Dominick, K C, Davis, N O, Lainhart, J, Tager-Flusberg, H and Folstein, S (2007) Atypical behaviours in children with autism and children with a history of language impairment *Research in Developmental Disabilities* 28, 145–162.

Emerson, E, Kiernan, C, Alborz, A, Reeves, D, Mason, H, Swarbrick, R, Mason, L and Hatton, C (1999) The prevalence of challenging behaviours: a total population study. *Research in Developmental Disabilities* 22, 1.

Grandin, T (1995) *Thinking in pictures and other reports from my life with autism* New York: Double day and Vintage Books.

Harris, J, Cook, M and Upton, G (1996) *Students with severe learning disabilities who present challenging behaviour* Kidderminster: British Institute of Learning Disabilities Publications.

Hewett, D (1998) Challenging behaviour is normal, in: P Lacey, and C Ouvry (Eds) *People with profound and multiple learning disabilities: A collaborative approach to meeting complex needs* London: David Fulton.

Hewett, D and Nind, M (1998) *Interaction in action: reflections on the use of intensiveinteraction* London: David Fulton.

Jones, G E and Porter, J (2008) *Challenging behaviour and autistic spectrum disorders: Unit 1: A context for understanding challenging behaviour* Birmingham School of Education: The University of Birmingham.

Kiernan, C and Kiernan, D (1994) Challenging behaviour in schools for pupils with severe learning difficulties *Mental Handicap Research* 7, 3, 177–201.

Lindsley, O R (1991) Precision teaching's unique legacy from B F Skinner *Journal of Behavioral Education* 1, 253–266.

Matson, J L and Nebel-Schwalm, M (2007) Assessing challenging behaviours in children with autism spectrum disorders: A review *Research in Developmental Disabilities* 28, 567–579.

Matson, J L and Wilkins J (2007) A critical review of assessment targets and methods for social skills excesses and deficits for children with autism spectrum disorders *Research in Autism Spectrum Disorders* 1, 28–37.

Matson, J L, Wilkins, J and Macken, J (2009) The relationship of challenging behaviours to severity and symptoms of autism spectrum disorders *Journal of Mental Health Research in Intellectual Disabilities* 2, 29–44.

McClintock, K, Hall, S and Oliver, C (2003) Risk markers associated with challenging behaviors in people with intellectual disabilities: A meta-analytic study *Journal of Intellectual Disability Research* 47, 6, 405–416.

Mittler, P (1996) Preparing for self-advocacy, In: B Carpenter, R Ashdown and K Bovair (Eds) *Enabling access* London: David Fulton.

Murphy, G, Hall, S, Oliver, C and Kissi-Debra, R (1999) Identification of early self-injurious behaviour in young children with intellectual disability *Journal of Intellectual Disability Research* 43, 149–163.

Myles, B S, Cook, K T, Miller, N E, Rinner, L and Robbins, L A (2000) *Asperger syndrome and sensory issues: practical solutions for making sense of the world* Kansas: Autism Asperger Publishing Company.

National Research Council (2001) Educating children with autism committee on educational interventions for children with autism, in C Lord and J P McGee (Eds) *Division of behavioral and social sciencesand education* Washington, DC: National Academy Press.

Nicholas, J S, Charles, J M, Carpenter, L A, King, L B, Jenner, W and Spratt, E G (2008) Prevalence and characteristics of children with autism spectrum disorders *Annals of Epidemiology* 18, 130–136.

O'Reilly, M F (1995) Functional analysis and treatment of escape-maintained aggression correlated with sleep deprivation *Journal of* Applied Behavior Analysis 28, 225–226.

O'Reilly, M F, Sigafoos, J, Lancioni G, Rispoli, M, Lang, R, Chan, J, Machalicek, W and

Langthorne, P (2007) Manipulating the behavior-altering effect of the motivating operation: Examination of the influence on challenging behavior during leisure activities *Research in Developmental Disabilities* 29, 3, 333–340.

Schopler, E (1971) Effects of treatment structure on development in autistic children *Archives in General Psychiatry* 24, 415–421.

West, R P and Young, K R (1992) Precision teaching, in R P West and L A Hamerlynck (Eds) *Designs for excellence in education: The legacy of B F Skinner* Longmont, CO: Sopris West, Inc.

Wing, L (1976) *Early childhood autism: clinical, educational and social aspects* (2nd edn) Oxford: Pergamon.

Whitaker, P (2001) *Challenging behaviour and autism: Making sense – making progress: A guide to preventing and managing challenging behaviour for parents and teachers* London: NAS.

Whitaker, S (2002) Maintaining reductions in challenging behaviour: A review of the literature *British Journal of Developmental Disabilities* 49, 94, 15–25.

The development and evaluation of a support group for siblings of children on the autism spectrum

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Editorial comment

Parents often express concern about the effects on their other children of having a brother or sister with autism or Asperger syndrome. The literature suggests that there are positive effects (as evidenced in the two articles which appeared in the October 2009 issue of the GAP Journal). There are also potential difficulties for them in terms of getting their fair share of their parents' attention and in having their play and life disrupted. There is a growing literature on how to support siblings but still not enough initiatives offered by services or schools for these children. This paper is therefore welcomed as it provides ideas on how to work with siblings who may not know one another but who have a common bond in having a brother or sister on the autism spectrum. The workshop sessions described provide a forum for enhancing their knowledge of autism, discussing their feelings and developing strategies to manage some of the situations they face.

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Introduction

The siblings of children on the autism spectrum may have increased care responsibilities, less parental attention, decreased self esteem and feel socially isolated (Wolf, Fisman, Ellison and Freeman, 1998; Williams, 1997). Further to this, outside of their families, siblings may experience limited access to information about the child's condition, negative peer reactions and disruption in social activities (Blue-Langer, 1996 in Lobato and Kao, 2002). Badger (1988 in Evans et al, 2009) described that siblings of children with learning disabilities are susceptible to feelings of guilt and resentment and are at risk of developing psychological problems, behaviour difficulties and are more vulnerable to illness. The siblings of children on the autism spectrum confront unique challenges. They are likely to encounter negative reactions from the public due to the repetitive and unpredictable behaviour of their sibling, who may appear as a typically developing child, as well as having to cope with the uneven profile of skills and the difficult behaviours of the child (Margan, 1998 and Royers and Mycke, 1995 in Smith and Perry, 2005).

Consequently support for the siblings of children on the autism spectrum is needed yet is often overlooked. This need to provide for brothers and sisters is identified in the guidance and regulation of the Children Act 1989. With reference to disabled children, it states that:

> *'… the needs of brothers and sisters should not be overlooked and they should be provided for as part of a package of services for the child with a disability.'*

Also the Government review *Aiming High for Disabled Children: better support for families*, launched in May 2007, reviews services for disabled children and their families. It recommends:

> *'Focused, effective support early in life and at key transition points, with early support for disabled children and their families, which promotes emotional and social development for disabled children and their siblings, to help improve outcomes for all.'* (p 9)

There is much evidence that sibling support groups are able to encourage the emotional and social

development of siblings of children with disabilities. Evans and colleagues (2001) evaluated the efficacy of sibling support groups designed to help brothers and sisters discuss and explore their relationships with their sibling with learning difficulties. They found that the siblings had increased self esteem, greater knowledge of their sibling's needs, and better coping strategies and emotional adjustment. The charity Sibs reports that there are common themes indicated by siblings who have attended groups across the country, as well as their parents. The immediate short-term themes include increased confidence, improved family dynamics, increased understanding of the disability, increase in play between the sibling and the disabled child, increase in siblings talking about issues with their parents and use of coping strategies at home. The long-term themes include prevention of mental health problems, prevention of behaviour problems and improved academic performance (see www.sibs. org.uk).

Many studies of sibling support groups evaluate the effectiveness of the group. For example, Evans et al (2009), using the Family Relations Test (Bone and Anthony, 1985) identified that the siblings in their study had greater involvement with their sibling with a disability. Further, using the Culture Free Self Esteem test (Battle, 1981), it was demonstrated that the siblings' self esteem increased post-group. D'Arcy et al (2005) studied 16 siblings of children with disabilities who had attended a sibling support group (Sibshops). They used semi-structured interviews and the Piers-Harris Children's Self-Concept Scale (Piers, 1986) and found that there was a dramatic increase in the siblings' reported discussions around their feelings and they had improved coping strategies. While these studies describe the methodology of their research, the aims of the groups and some of the content of the workshops, they do not provide enough detail to replicate the sibling support group for those wishing to develop their own.

An aim of this study was to provide a detailed model for a support group for siblings of children on the autism spectrum, which may act as a guide for those seeking to set up their own sibling support group. Another aim was to evaluate the effectiveness of the group by measuring any changes in the siblings' knowledge of the autism spectrum, as well as parental feedback.

NORSACA Sibling Support Group Model

The sibling support group model used in this study was originally developed by Professor Elizabeth Newson and Julie Davies (Davies, 1994). The concept of the model was to explore both the positive and negative aspects of having a sibling on the autism spectrum, how to cope and where to go for additional support and advice. Newson and Davies devised a workshop manual which combines a mixture of small group work, whole group discussions, games, presentations and drama. The model forms the basis of a sibling support group which is delivered annually by NORSACA (Nottinghamshire Regional Society for Adults and Children with Autism) (a regional autism charity) and funding is received from charitable trusts. The group is run by assistant psychologists and supervised by senior staff within NORSACA. Prior to the start of the group the assistant psychologists attended safeguarding training, which is critical, given the nature of the group and potential disclosures. Evaluation questionnaires are sent to parents and children who attend the group every year, and on the basis of this evaluation, the model has been refined slightly.

Sibling Support Group 2009

To recruit participants for the group, leaflets and posters advertising the group were sent to local organisations involved in the lives of children on the autism spectrum and their families. Parents who contacted NORSACA expressing an interest were asked to complete a questionnaire. Fifteen questionnaires were returned and 12 siblings were chosen to take part in the group. The decision process was based on the perceptions of need and the composition of the group.

The sample consisted of 12 children (eight girls and four boys), all of whom had a sibling on the autism spectrum. There were nine sets of parents. In three cases, two siblings from the same family participated, one set of these siblings were twins. The siblings ranged in age from 8–12 years. Eight of the 12 siblings had a younger sibling on the autism spectrum and for the remaining four children, their sibling was older. The children on the autism spectrum (seven boys, two girls) ranged in age from 4–14 years and were diagnosed with either autism or Asperger syndrome.

Methods

Prior to the start of the workshops, consent was gained from parents of all 12 siblings. The parents also completed a detailed questionnaire to provide

the group leaders with information about the sibling and his/her family, as well as emergency contact details. The questionnaire posed questions about areas such as the understanding and expressive abilities of the child on the autism spectrum, any materials previously used by the parents to explain autism, any issues that concerned the parents about the sibling's adjustment to their brother/sister's difficulties, parents' reasons for encouraging their child to participate in the workshops and any doubts or concerns that parents had regarding the workshops.

The children attended the group for eight weeks between 6.30 and 8.30 pm, covering each topic detailed in the workshop outline (see *Table 1*). There was a 30-minute break during the session. The group was held at one of the NORSACA school sites The venue was ideal because it had a large area for group discussions, games and small group/paired work. There was also a garden outside with play equipment for use during break times and a separate meeting room which was used by parents who stayed for the session. This gave the parents an opportunity to meet other parents and relax.

Table 1: Workshop outline

Workshop 1	Getting to know each other
Workshop 2	Difficult times with our brothers and sisters. Enjoying ourselves with our brothers and sisters
Workshop 3	What it is like to have Autism/Asperger syndrome
Workshop 4	Explaining to others
Workshop 5	Being treated differently
Workshop 6	Feelings about our brothers and sisters
Workshop 7	Thinking about the future
Workshop 8	An outing – eg bowling, ice skating

At the first (pre-test) and seventh (post-test) workshop all siblings completed a sibling knowledge poster (see *Table 2*). Parents were sent a parental evaluation questionnaire one week after the workshops had finished and eight of the nine of these were returned (see *Appendix 1*).

Table 2: Workshop 1: Knowing me knowing you posters

- Ask the siblings to bring a photograph of themselves and their sibling to the group.
- Make posters using these photographs and ask the siblings to write about themselves and their siblings, including their likes and dislikes and their siblings.
- Ask the siblings to then share these with the rest of the group.
- This gives the group an opportunity to learn something about their fellow group members and their siblings.

Measures
Knowledge of autism and their sibling
The children were asked to make a poster detailing everything they knew about autism or/and Asperger syndrome. They were told they could write and draw on their poster and were provided with large coloured paper, felt tipped pens, stickers and glitter glue. They were given approximately 20 minutes to complete their poster. All children completed the posters independently, although some siblings asked for help to spell particular words. The siblings were told to write 'I don't know' on their posters if, after thinking about the topic, they did not have anything to write. For two other activities used within workshops, see *Tables 3 to 6*).

Parental evaluation
The parental evaluation is a 12-item questionnaire developed by NORSACA. It combines closed and open questions, referring to the practicalities and content of the group. It has been used to evaluate the group in previous years and the results have been sent to the group funders to demonstrate its value.

Results and discussion
Knowledge of the autism spectrum
To evaluate the siblings' knowledge of the autism spectrum, their pre-test and post-test posters were compared. On the pre-test posters, seven siblings wrote what they knew about autism, four siblings wrote *'I don't know'* and one child decorated a picture of his brother. For the post-test poster, 11 children wrote what they knew about autism and one child described their sibling. Eleven children showed an increased knowledge.. The child that described their sibling in the post-test poster rather than indicating what they knew about autism, had written several points about autism in the pre-test poster. Therefore it was unclear whether this child showed an increased knowledge of autism.

The development and evaluation of a support group for siblings of children on the autism spectrum

Table 3: Activity in Workshop 2: Spider's web and 'super flies'

Discuss the concept with the children that having a difficult time with their sibling can feel like being stuck in a spider's web with nowhere to go. Give each child a bug template and ask them to write a difficult time on the bug and then decorate it. Once the siblings have finished, asked them to attach their bugs to a spider's web (made from string glued onto a large piece of card). Discuss the sibling's difficult times. Then perhaps after a break, introduce various coping strategies that could be used during difficult times (eg ignore, distract, bargain, avoid it, ask mum/dad). These could be explained to the siblings as Super Flies who can rescue them when they are in need.

Siblings' response:

The siblings identified difficulties such as:

'When it's bed time my sister never lets me sleep,'

'At school when he starts shouting, swearing and hitting his teacher because it makes me feel really bad when he gets held down.'

The siblings seemed to relate very well to this activity and seemed to find reassurance in sharing difficulties with each other. The siblings reported that they had tried using the 'super flies' to help them manage situations at home after this session. Following this activity the siblings identified positive times with their siblings such as:

'When we went swimming.'

'When we play on the trampoline together.'

Table 4: Activity in Workshop 3: The rules game

The aim of this game is to help the children understand how it may feel for their siblings if they don't understand social rules.

For this game:

• One person is asked to leave the room and wait while the rest of the group make up a rule.
• The person then joins the group again, without knowing the rule.
• The person then has to try and guess the rule that had been created.

Some examples of rules were:

• touch your legs only while you are walking
• touch something electrical
• only touch things that are red

The person who does not know the rule feels excluded and confused because they don't understand what is going on and this helps them to appreciate how their sibling might be feeling.

Table 5: Activity in Workshop 4: Aunt Blabby

Ask the siblings to write a letter to an Agony Aunt (Aunt Blaby) about a time when they had to explain autism to someone. Group leaders then reply to these letters with ideas about ways to explain autism and give these to the siblings in the following session.

Siblings' response:

The siblings seemed to enjoy the opportunity to honestly share their irritations. The siblings raised issues such as:

'When friends are at my house and my brother takes his clothes off.'

'When he gets mardy at KFC.'

'My sister keeps screaming in shops and everybody stares at her.'

Table 6: Activity in Workshop 6: Feelings Fish

Write a feeling on a fish template, and decorate it. Put the fish into a 'pond' and ask each sibling in turn to use a magnetic rod to catch the feelings fish. Then ask the sibling to talk to the group about a time then they felt the feeling written on the fish they caught.

Siblings' response:

Siblings were able to think of good and bad feelings but found it more difficult to discuss times when they felt that feeling.

Listed below are comparisons of pre-test and post-test posters from three siblings.

Sarah (name has been changed)

For her pre-test poster she wrote, '*Autism is something that makes people not understand as well as others*' and drew a picture of her sibling. For the post-test poster, she split the poster into two sections, labelling them, Autism and Asperger's. On each side she drew a triangle and labelled the three points 'social', 'rigid' and 'language' to indicate the triad of impairments found in children with autism and Asperger syndrome. She then described both autism and Asperger syndrome. Examples are listed below:

Autism

'*People are born with autism.*'

'*Makes people not understand as well as others.*'

'*You may not tell they have autism until they're 1–2 years old.*'

Asperger syndrome

'*Asperger's means you have one or two special talents.*'

'*Asperger's is like autism.*'

'*You can't catch autism.*'

Jessica

Jessica wrote 'I don't know' on the pre-test poster and drew a picture of their family. On the post-test poster, she listed the coping strategies that had been taught in the second workshop; 'bargain, nip it in the bud, ignore, ask mum and dad and distract'. Further to this, she wrote:

'*Autism is you don't understand a lot of things.*'

'*Trouble learning.*'

'*Trouble talking and making friends.*'

'*Repetitive.*'

'*You need a lot of time to get it in your head.*'

Samantha

Samantha wrote 'has difficulty playing' and 'can't talk' on her pre-test poster. On her post-test poster she drew a triangle and labelled it with 'social', 'rigid' and 'speech' and wrote beside it 'three main points to autism'. The sibling also wrote:

'*Autism is when a child struggles to speak in the early ages. Also they don't mix in groups as well as we do. My brother likes sensory things. Rigid means they like to repeat things lot of times.*'

Parental Evaluation
Practicalities

All parents felt that the group was held at a convenient time of the year and at an appropriate day and time. One parent commented that they would have liked the duration to be longer, the rest were satisfied with the number of sessions.

Content

Parents were asked to indicate their expectations of the group and whether they were satisfied that these had been met. All but one indicated that their expectations had been met. Some examples of parent expectations are listed below:

'*To understand that other children are going through similar lives to us. To help her express how she feels without me being there.*'

'*To learn more about autism, how it manifests and why their sister does the things she does.*'

'*I wanted her to express her inner feelings that she perhaps couldn't to us (fears) and to realise other children have similar experiences.*'

All parents felt that their child/children enjoyed the workshops. One respondent wrote, '*She couldn't wait to go each week*!' All parents indicated that there had been positive outcomes from the group and none felt there were any negative outcomes. Two sisters from the group joined another siblings group (at the school that their sister attends) shortly after the last workshop. Some examples of positive outcomes are listed below:

'*She has more patience with her brother now.*'

'*He knows his brother is like other autistic people.*'

'*She understands why she has been treated differently.*'

Parents were also given space to write any additional comments*:*

'*Incredibly worthwhile.*'

'*It was nice for me to meet and sit at times with the other parents and chat, whilst the children were in the group.*'

'*She got some really positive ideas to take away with her as well as making new friends.*'

Discussion

Comparisons of the pre-test and post-test knowledge of the autism spectrum posters indicated that 11 of the siblings showed an increase in knowledge. All parents were satisfied with the practical elements of the group. There were common themes in the parents' expectations of the group, these included: meeting other children with similar experiences, sharing their feelings and learning more about the autism spectrum. There were also common themes in parental report of positive outcomes of the group; increased understanding of autism, increased patience with their sibling and increased understanding of why they may be treated differently.

The aims of this study were to describe a model for a sibling support group in order to encourage and guide other individuals and organisations to develop their own. A further aim was to evaluate the effectiveness of the group by measuring knowledge of autism. The robustness of this measure is limited somewhat by not having a control group. However, the siblings did show greater knowledge of autism and parental evaluations indicated that the group had been a valuable experience for the siblings and they had enjoyed it very much. The siblings were able to share their experiences, express their feelings, learn about autism in a supportive environment, advise each other in problem-solving and to have fun.

Considerations for future practice

Although the sibling group model described has successfully shown its value for siblings and their parents, there are some changes to the model which could be considered. During the workshops, many siblings reported that they wanted the group to continue past eight weeks, indicating that they enjoyed attending and found it helpful. In addition, discussions with group leaders indicated that they found that the workshop in which they focused on increasing children's understanding of autism was quite rushed. They said the siblings appeared to become tired quickly due to the amount of information they were given. Therefore, it may be useful to increase the workshop duration to ten weeks, so that the information about autism could be divided between two workshops. A further issue raised by the group leaders which they had foreseen to such an extend related to behavioural difficulties within the group. The group leaders felt that setting clear boundaries and rules for the group was very important as well as referring back to these regularly.

Size of the group

A further consideration relates to the size of the sibling group. It is important to have a large enough group to be able to split up to work in smaller groups or have the opportunity to have team games. However, it is important that the group are able to have group discussions in which everyone is concentrating and listening to each other. A large group can make this aim more difficult to achieve. The NORSACA sibling group model suggests a group size of eight to twelve. After discussions with group leaders, it was felt that ten as a maximum group size would allow for successful whole group discussions, as well as smaller group work.

Composition of the group

It is important to consider carefully the selection of the children at the outset, in particular, the age and gender of the children as well as the age of the sibling on the autism spectrum and their diagnostic profile. The most successful group may be where the children have most in common, for example, the siblings on the autism spectrum being closer in age. The problems and difficulties encountered by the children are likely to be markedly different if their sibling is under five or an adolescent, for example. This may make it more difficult for the group to relate to each other's experiences. Further, children with younger siblings may not be emotionally ready to think about future challenges that their sibling, themselves and their family might face as their brother or sister gets older. There did seem to be a group divide between the younger and older members of the group, which was sometimes difficult as there were activities that appealed to the younger group more than the older group and vice versa. The younger group for example, had more difficulty writing their Aunt Blabby letters.

Concluding comments

As the literature demonstrates, siblings of children on the autism spectrum are likely to develop psychological problems and behavioural difficulties (Badger, 1988 in Evans et al, 2009). Therefore while the support group demonstrated positive outcomes, in order to ensure the effects of the group are maintained and developed in the long term, further support is needed. A future development of the model may be to offer the siblings post workshop support, such as an Internet forum. By using this, the siblings could continue to share their experiences, work together to overcome challenges and maintain their friendships. For siblings/parents and anyone else interested in this area, the authors would like to refer to the sibs website (www.sibs.org.uk).

References

Battle, J (1981) *Culture free self esteem inventories for children and adults* Seattle, WA and Windsor: NFER Nelson.

Bene, E and Anthony, J (1985) *Family relations test: Children's version* Windsor: NFER Nelson.

Cox, A H, Marshall, E, Mandelco and Olsen, S (2003) Coping responses to daily life stressors of children who have a sibling with a disability *Journal of Family Nursing* 9, 4, 397–413.

D'Arcy, F, Flynn, J, McCarthy, Y, O'Connor, C and Tierney, E (2005) Sibshops: An evaluation of an interagency model *Journal of intellectual Disabilities* 9, 1, 43–57.

Davies, J and Newson, E (1994) Supporting the siblings of children with autism and related developmental disorders. In P Mittler and H Mittler (Eds) Innovations in family support for people with learning disabilities Chorley, Lancashire: Lisieux Hall.

Department of Health (1991) *The Children Act 1989 Guidance and Regulations: Volume 6 Children with Disabilities* London: HMSO.

Evans, J, Jones, J and Mansell, I (2001) Supporting siblings: Evaluation of support groups for brothers and sisters of children with learning disabilities and challenging behaviour *Journal of Learning Disabilities* 5, 1, 69–78.

Faux, S A (1993) Siblings of children with chronic physical and cognitive disabilities *Journal of Pediatric Nursing* 8, 5, 305–317.

Labato, D and Kao, B (2002) Integrated sibling-parent group intervention to improve sibling knowledge and adjustment to chronic illness and disability *Journal of Paediatric Psychology* 27, 8, 711–716.

Piers, E V and Harris, D B (1986) *Piers-Harris Children's Self-Concept Scale, Revised manual* Los Angeles: Western Psychological Services.

Sibs, Developing a service for siblings of disabled children, available from www.sibs.org.uk/uploads/files/Developing%20services%20for%20siblings%20of%20disabled%20children_2.pdf (accessed 21 April 2010).

Smith, T and Perry, A (2005) A sibling support group of brothers and sisters of children with Autism *Journal on Developmental Disabilities* 11, 1, 77–88.

Appendix 1: Parental evaluation questionnaire

FINAL EVALUATION

The following questionnaire aims to give you the opportunity to express your thoughts and feelings about the siblings group. We encourage honest replies as we hope to use your suggestions to improve future siblings groups. The questionnaire is completely confidential so you can feel free to say exactly what you think.

Practicalities

The following questions are related to the practical aspects of the group. Please circle either **Yes** or **No** where this choice is provided. We also encourage you to use the spaces provided to add any comments you wish to make.

1 Was the Siblings Group held at a convenient time of the year for you? YES NO

2 The Siblings Group was held on a Wednesday, was this day appropriate for you? YES NO

3 The group was held between 6.30pm and 8.30pm, did you find this convenient? YES NO

4 How satisfied were you with the length of the sessions (2 hours)?

5 How satisfied were you with the duration of the groups (8 weeks)?

6 Do you have any other comments regarding the practical aspects of the group?

Please use this space, and overleaf if necessary, to comment.

Content Evaluation

The following questions are related to the content of the workshops.

7 How did you expect your child to benefit from attending the group? (eg learn more about sibling's difficulties, make friends, help him/her talk more about feelings towards their sibling etc). Please give details:

8 How satisfied were you that your expectations were met?

9 Did you feel that your child enjoyed attending the siblings group? YES NO

10 Have there been any positive outcomes which you think have been a result of your child attending the group? YES NO

11 Have there been any negative outcomes which you think have been a result of your child attending the group? YES NO

12 Do you have any other comments you would like to make about the group?

Supporting families post-diagnosis: An evaluation of parent workshops

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Editorial comment

The authors of this paper worked as a team to deliver a series of five workshop sessions to parents of children on the autism spectrum. Katy Flynn and Jemma Tosh are Assistant Psychologists, Dr Latha Hackett is a Consultant Child and Adolescent Psychiatrist, Dr Sam Todd is a Clinical Psychologist, Dr Caroline Bond is an Educational Psychologist and Alison Hunter is a Speech and Language Therapist. Given that autism has implications for many areas of a child's development and daily living, it is good practice for professionals from different disciplines to work together with families. Consistent messages and advice can then be given across services. The Manchester Autism Sessions were developed in response to a growing need for family support and information. This paper describes the workshop sessions and an evaluation of these to inform future work. Many services now offer parent training on the autism spectrum following diagnosis and so it is of interest to read this account and compare the intervention and outcomes with others.

Introduction

The prevalence of autism and Asperger syndrome has been increasing over the past two decades (Parner, Schendel and Thorsen, 2008; Baird et al, 2006; Bryson, 2003). In 2008, the Central Manchester Foundation Trust Child and Adolescent Mental Health Service (CAMHS) completed a departmental audit that showed a seven-fold increase in the diagnosis of children on the autism spectrum in the last five years. This could be due to heightened public awareness and diagnostic substitution, where children who would have previously been diagnosed with learning disabilities, are now being diagnosed with autism. This increased prevalence places autism as the second most common developmental disability, the most common being mental retardation (Parner, Schendel and Thorsen, 2008).

Giving parents access to information about their child's condition can raise confidence in their parenting skills and reduce feelings of blame and guilt (Dreier and Lewis, 1991). Information about the condition, as well as strategies and techniques to help understand and manage the child are equally important (Lukens and McFarlene, 2004). The National Autistic Society's (NAS) review of disabled children's services states that:

'… as the number of children with disabilities such as ASD increases, these changes need to be reflected in practice.' (NAS, 2006, p 2)

A Government framework for service-user participation is summarised in *Our Health, Our Care, Our Say* (DoH, 2006). This outlines a new direction for the health service and a central goal is to design services around the needs of the patient, by providing service users with a 'voice' that enables them to shape provision improvements. The National Service Framework (NSF) for children and young people emphasises that families' views should be 'valued and taken into account in the planning, delivery and evaluation of services' (DoH, 2004, p 87). Client satisfaction evaluation forms are a very effective way of doing this (World Health Organisation [WHO], 2000).

The workshops

The Manchester Autism Workshops were developed in response to this growing need. Although professionals from different disciplines undertake assessment and provide intervention for children and their families, parents and carers do not usually get the opportunity to discuss issues at length with this multi-agency team. By equipping parents/carers with knowledge about current issues, behavioural

strategies and services available, these sessions aimed to empower and train parents/carers to help their child in the best way possible. The workshops also provided parents/carers with the invaluable opportunity to meet other parents/carers who have recently been through the diagnostic process with their children.

Five sets of workshops for parents were held between October 2007 and 2008 with a total of 59 parents. Each workshop series consisted of five weekly sessions. These workshops offer parents/carers a chance to understand more about the autism spectrum from specialists in disciplines including psychiatry, psychology, education, speech and language therapy, paediatrics and outside support services (eg MAP (Manchester's Multi-Agency Partnership for disabled children and young people) and the NAS. Parents/carers had the opportunity to ask questions, take part in discussions and to meet other parents/carers.

The parents completed an evaluation form after each session and a whole course evaluation form at the end of the final session. They also rated their understanding of the autism spectrum at the beginning and end of the workshops.

The participants
CAMHS professionals were asked to refer parents/carers whom they believed to be suitable for the workshops. Parents/carers were then sent a letter with information about the sessions and an application form to fill in and send back, if they wished to attend. A total of 115 parents were invited to take part in the workshops, and 59 (51 per cent) took up the invitation, of which 43 parents attended

Figure 1: Ethnicity of families
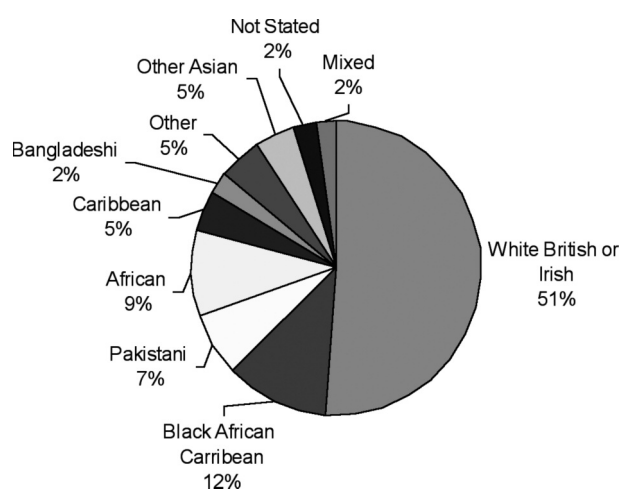
three or more sessions. Half of the participants were White British or Irish (see *Figure 1*).

Two-thirds of the parents had a child with a diagnosis of autism and a third had a child with Asperger syndrome.

Workshop contents
The workshops consisted of five half -day sessions that were run weekly. Each session was run by a different professional, as follows:

- **Session 1:** Understanding autistic spectrum disorders (Child Psychiatrists)
- **Session 2:** Education: Understanding and working with the education system (Educational Psychologists)
- **Session 3:** Communication: Enabling your child's communication and understanding (Speech and Language Therapists)
- **Session 4***: Behaviour: Understanding and managing behaviour (Clinical Psychologists and Community Paediatricians)
- **Session 5:** Further resources for you and your child
            (NAS, Disabled Children's Team etc)

Analysis of the evaluation data
Parents' views on the workshops were collected using anonymous questionnaires. At the end of each session they were given a feedback form containing five questions asking about what was useful and what could be improved. At the end of the final session parents/carers were given a whole course evaluation form containing five questions asking about what was useful and what could be improved. At the start of the first session, and the end of the final session, they were given a questionnaire asking how well they felt they understood five areas, corresponding to the five session topics.

Findings
The parents reported a significant increase in their understanding of ASD. They also rated the workshops as 'useful', giving mean scores between 4.3 and 5, with 5 representing 'completely agree' on a Likert type scale. They also said they would recommend this course to others, with mean scores between 4.8 and 5 (see *Table 1*).

In response to the question, 'Did the course cover what you wanted to know?' nineteen parents said 'yes', four parents said 'mostly' and one parent said 'no' as she wanted to know more about education.

Table 1: **Mean response to statements presented to parents***

Statement	Group 2	Group 3	Group 4	Group 5
The course was useful to me	4.8	4.8	5	4.3
I would recommend this course	4.9	5	4.8	4.8

Ratings: 1= completely disagree to 5 = completely agree.

* Group 1 completed a slightly different whole course evaluation form, so they are not included in this section of the analysis.

Parental evaluations were generally positive with 48 per cent of all comments about aspects of sessions that parents found useful and 16 per cent were general, positive comments (see *Figure 2*).

Parents found information about different services and support particularly useful and one parent said, the sessions 'informed me of helpful agencies I was unaware of'. They also frequently commented on the benefits of being in a group and how this made them feel less alone. Some stated that their understanding of the education system had improved and that they were now aware of 'the support available within the educational system' and the 'school's obligation towards children with special educational needs (SEN)'.

About a third provided suggestions for improvements suggestions and stated other topics they would have liked to have been covered. The most frequently suggested improvement concerned 'more time' and for the sessions to be 'longer'. Parents would have also liked more on topics already covered, such as behaviour and the causes of autism, as well as new topics such as how to help siblings cope. Some parents also suggested that parents'

Figure 2: Percentage of parents who made positive and negative comments and who could suggest improvements

experiences be included in the workshops, in addition to the general examples and case studies.

Consistent with previous research, the parents described their sense of loneliness prior to attending the group (Levac et al, 2008). Some parents stated that this was the 'first time' they had had the opportunity to meet other parents of children on the autism spectrum. The way in which parents described their experiences changed over the five weeks. Parents who originally used the pronoun 'I' began to use terms such as 'we' and 'our'. This suggests that parents came as separate individuals but over time became a group with shared experiences.

Parents also said they were relieved to know that their child wasn't 'different' and that they were the same as other parents in the group. This was in stark contrast to their experience outside of the group, in schools and society as a whole, where their child is in the minority and therefore 'different'. Two parents said:

'My son is not different.'

'Other children are like my son.'

Levac et al (2008) also reported that parents find such groups a safe haven from a critical world'. Another parent said it was a relief to 'realise that it was nothing to do with me.'

Additionally, the construction of ASD as a medical disorder, provided comfort to many parents. It helped them to separate the child from the behaviour, and to externalise the problem. One said, 'that explains why he acts different' and another said, 'how they act is because of the syndrome.' This enabled parents to empathise with their child, rather than feel challenged by their behaviour. One said, 'I learnt that he sees the world differently' and another parent said, 'I had no idea what it must be like for her, now I can make a start to try and understand.' This resulted in parents being able to change their

behaviour towards their child. For example: 'I don't shout ... as much,' and 'I am calmer and more understanding.'

In gaining knowledge about the autism spectrum, as well as the support of the group, parents appeared empowered and able to confront challenges more effectively and more assertively. Three comments from parents were:

> *'I know the rights of our children and what our children are entitled to.'*

> *'I know how to begin the difficult process of getting the school to be more aware of her child's needs. I learnt how to start the wheel turning.'*

> *'I feel I could go away immediately and know where to start'*

Discussion
These workshops were run by the Social Communication Assessment and Intervention Team (SCAIT), which is made up of multidisciplinary professionals who are highly experienced in providing interventions for children on the autism spectrum and their families. Parents of these children generally consider help and support from professionals extremely important (Renty and Roeyers, 2006). It was therefore predicted that these sessions would help to meet some of the parents' needs for information and support.

The workshops also provided parents with peer support. This can help parents with the demands of caring for a child with a disability (Trivette and Dunst, 1992). At the end of some workshops parents swapped phone numbers, and further longitudinal research might explore the lasting benefits of meeting other parents/carers going through the same things at such a difficult and emotional time.

By evaluating the responses of five sets of workshops we hoped to gather information which could be generalised. However, the sample size was small and was taken from a Central Manchester population, which limits the extent to which these results can be generalised. In addition, only half of those invited chose to take up the workshop invitation so they were a self-selected group and therefore more likely to be positive about the experience. Further research should explore the reasons as to why almost half the families did not respond to the invitation to join the workshops. This is clearly an issue worthy of investigation. Services

need to have a range of options for parents as 'one size' will not fit all families. Some parents will still be coming to terms with their child's diagnosis, and the workshops may not have been offered at the right time for some parents. Some parents who did not opt in originally made contact at a later date to let us know that they now felt ready to participate in a workshop. A question for careful consideration, best left to the judgement of the clinician, is the length of time between a child being given a diagnosis and their parents/carers being invited to these workshops. Some parents will prefer individual sessions from professionals visiting them at home or in a school or clinic setting. Others may prefer to have written information and others will have literacy and language problems which are a barrier to such workshops.

In addition, all studies on parent training or any intervention which asks for parents opinions are constrained if the parents only have experience of one form of training or intervention. A stronger design would be to have the same parents experience two or three different types of training or to have three separate groups of parents evaluate three different types of training, for example.

Many parents did not feel they had enough time to talk between themselves, so a suggestion for future groups would be a longer break or time at the end for parents to socialise and share experiences if they wanted to. This suggestion could be extended by arranging for all professionals involved to attend a question and discussion session the end of the workshops. Also, an increase in small group activities would be valued as sessions that incorporated these received very positive comments.

Parents/carers were understandably very positive about aspects of sessions that they could directly relate to their child and current situation. Similarly, parents/carers were critical when sessions were not relevant; 'due to my children's ages it didn't help.' In line with Government frameworks (DoH, 2004; DoH, 2006), we have since altered the sessions to make sure that they are more relevant for families. We have since run groups that target specific families, such as groups for a specific age range, for children with additional learning disabilities and groups for higher functioning, older children.

Although there are strengths in having different professionals delivering each of the five sessions, there may be drawbacks too – as they may not all know the content of previous and future sessions and

the opportunity to develop a relationship with one or two professionals over a five-week period is not possible. A way round this would be to have one of the multi-disciplinary team present throughout the five sessions to give continuity. A further issue is whether it is preferable to have five sessions, each having a very different topic – as in the workshops described here – so that parents get some information on a range of topics – or whether to have five workshops on the same theme (eg communication; understanding behaviour). These questions would be worthy of further study.

A further suggestion for future groups would be to organise a pre-group coffee morning, approximately a month before the workshops began. This would give professionals and parents/carers the opportunity to meet, and discuss the individual needs of families. Professionals would then have the opportunity to plan their sessions with individuals in mind, and this would hopefully improve the relevance of sessions. Parents' own examples could be used to illustrate points, where possible. Future workshops have already been planned to take comments into consideration, plans include having more community based venues with a crèche, and one group will run as a whole-day session (instead of weekly workshops). Despite these proposals there is still scope for further development.

Concluding comments

This study evaluated five sets of workshops for parents. These received positive feedback, including a significant increase in self-reported understanding of the autism spectrum. The workshops provided information, as well as informal peer support. Considerations in the future would be to make sure that workshops are relevant to the families' specific situations, and include additional topics such as managing siblings. It would also be useful to provide more time for parents to talk to each other, either before or after sessions.

References

Baird, G, Simonoff, E, Pickles, A, Chandler, S, Lucas, T, Meldrum, D and Charman, T (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP) *The Lancet* 368, 210–15.

Bryson, S (2003) About 3 in every 1000 US children in large metropolitan areas may have autism or related developmental disorders *Evidence Based Mental Health* 6, 73.

Department of Health (2004) *National service framework for children, young people and maternity services: core standards* available from www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089099 (accessed 21 April 2010).

Department of Health (2006) *Our health, our care, our say* available from www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453 (accessed 21 April 2010).

Dreier, M and Lewis, M (1991) Support and psychoeducation for parents of hospitalised mentally ill children *Health & Social Work* 16, 1, 8–11.

Holtkamp, K, Herpertz-Dahlmann, B, Vloet, T and Hagenah, U (2005) Psychoeducation for parents of adolescents with eating disorders: the Aachen program *Eating Disorders* 13, 4, 381–390.

Levac, A, McCay, E, Merka, P and Reddon-D'Arcy, M (2008) Exploring parent participation in a parent training program for children's aggression: understanding and illuminating mechanisms of change *Journal of Child and Adolescent Psychiatric Nursing* 21, 2, 78–88.

Lukens, E and McFarlene, W (2004) Psychoeducation as evidence-based practice: considerations for practice, research and policy *Brief Treatment and Crisis Intervention* 4, 3, 205–225.

National Autistic Society (2006) *Treasury review of disabled children's services* available from www.hm-treasury.gov.uk/d/cypreview2006_nationalautisticsociety.pdf (accessed 21 April 2010).

Parner, E, Schendel, D and Thorsen, P (2008) Autism prevalence trends over time in Denmark: changes in prevalence and age at diagnosis *Archives of Pediatrics & Adolescent Medicine* 162, 12, 1150–1156.

Renty J and Roeyers H (2006) Satisfaction with formal support and education for children with autism spectrum disorder: the voices of the parents *Child: Care, Health and Development* 32, 371–385.

Trivette, C and Dunst, C (1992) Characteristics and influences of role division and social support among mothers of preschool children with disabilities T*opics in Early Childhood Special Education* 12, 367–385.

World Health Organisation (2000) *Client satisfaction evaluation* (workbook 6) available from www.emcdda.europa.eu/attachements.cfm/att_5868_EN_6_client_satisfaction_evaluations.pdf (accessed 21 April 2010).

Addressing the feeding and dietary issues of children on the autism spectrum by running a 'Food is Fun' week

Joanna Gill and Maria Gleeson, Ireland

Editorial comment

The authors are both Speech and Language Therapists who work in a special school for children with autism and learning difficulties in Ireland. In this paper, they describe the work they did with eight children to extend the range of foods they tolerated or ate and to encourage them to eat independently. They ran a five-day 'Food is Fun' week at the children's school during the summer holiday and engaged in play and sensory activities involving food, based on McCurtin's work (2007). On the face of it one might question the likely efficacy of having an intensive focus on an area which children find difficult. Successes were reported for each child in terms of the goals that their parents and the therapists set together, some making more progress than others. The Editors of the GAP Journal would be very interested in receiving more papers on this topic as eating difficulties challenge parents and professionals alike.

Introduction

The school has an eclectic approach using a combination of interventions including Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) (Schopler and Olley, 1982) and Applied Behavioural Analysis (ABA) (Lovaas, 1987). Although the school promotes a healthy eating policy, and participates in the 'Food Dudes' scheme (Horne et al, 2004), some children do not eat healthily and do not take part in the 'Food Dudes' activities. Schreck et al (2004) maintain that many children on the autism spectrum have significant dietary problems and that 72 per cent of these children eat a narrower range of foods than typically developing children. Piazza and Roames (2008) use the term 'feeding disorder' to describe dysfunctional eating which occurs in childhood. They describe children with feeding disorders as displaying:

> '… a wide variety of behaviors such as refusal to eat, refusal to eat certain types or textures of food, dependence on a limited or developmentally inappropriate source of nutrition (eg bottle dependence in a three year old), and skill deficits such as inability to self-feed.' (p 471)

We had concerns regarding the feeding disorders of some of the children attending our school, as one child, Aidan (name changed) was still dependent on a bottle at the age of ten, and another child, Bernadette only fed herself with dry finger food, and insisted that her mother spoon fed her with breakfast and dinner. Latif et al (2002) discuss the importance of iron in brain functioning and the implications of a high milk and low red meat diet of many children on the autism spectrum. Lozoff et al (1992) conclude that early iron deficiency may result in impaired cognitive abilities, decreased attention span, reduced learning capacity, and neuromotor dysfunction. We had concerns that some of the children at school may be underperforming academically as a result of their eating regime. We therefore thought it was important to support these children to overcome some of their anxieties around food and to eat a wider range of foods.

Ledford and Gast's (2006) comprehensive literature review suggests various reasons for feeding problems in children on the autism spectrum, such as:

> '… concentration on detail, perseveration, impulsivity, fear of novelty, sensory impairments,

deficits in social compliance, and biological food intolerance.' (p 153)

Stewart and Latif (2008) suggest there may be a lack of integration of sensory signals in the brain associated with textures, tastes and smells which leads to feeding difficulties. Schwarz (2003) divides the feeding difficulties of children on the autism spectrum into two groups: behavioural feeding disorders, such as gagging, choking, and expulsion with no medical basis; and sensory-based feeding problems, where children have aversions to particular textures. Maladaptive feeding behaviours may be inadvertently maintained by parental anxiety, communication difficulties and a reinforcement of negative feeding practices.

After attending a one-day workshop on *Eating, Drinking, and Swallowing Management* we decided to run a 'Food is Fun' week in August 2007. This would allow children repeated and varied opportunities to desensitise themselves to food, with familiar staff, in an autism-friendly environment for two and a half hours a day over five days.

Aims
The aims of the 'Food is Fun' Week were to:

- increase confidence in being near food without the fear of having to eat it (eg touching, washing, cutting and smelling different foods)
- offer an experience of food play: painting with food colours, making food collages, making food dough shapes and other messy play
- expand the children's knowledge and experience of food; food games, role play of restaurant and shop situations, and cooking

Strategies used
Strategies used were individual to each child, and included:

- TEACCH (Schopler and Olley, 1982) strategies such as visual schedules and First/Then cards were used with all children; and different activities took place in specific areas, so that the children had some environmental clues as to what would happen next
- Sensory breaks and activities such as cycling, walks, and deep pressure were used with the children with greater sensory needs to reduce anxiety, following ideas from Bundy et al, 1991) (see *Appendix 1*).
- Reinforcers such as toys, books or favourite foods were used to support the children to

participate in activities which they found challenging
- Token economies were used with some children, where they earned one token for each activity they participated in, and then cashed in their tokens for a prize from the surprise box; the number of tokens needed for this prize increased as the week went on
- Social stories (Gray, 2000) were used to prepare children for attending the week and for new activities
- Oral desensitisation was used to increase tolerance of new foods/textures, progressing from fingers to hand to arm to neck to cheek to nose to mouth to tongue following ideas from Chapman Bahr (2001)
- Food chaining: expanding a child's food repertoire by slowly linking the features of an accepted food to that of a target food as recommended by Fishbein et al (2006)
- Collaboration with the children's parents and support around goal-setting

The children
Aidan was a nine year old boy with a diagnosis of autism and moderate learning difficulties. His diet consisted solely of fortified milk in a baby's bottle (at home) and small fruit yogurts (at home and at school). He only ate pink yogurts, such as raspberry and strawberry. He had been seen regularly throughout his childhood by a dietician. Several attempts had been made to introduce new foods to his diet, but these had been unsuccessful. He was anxious and fearful around food, and only ate yogurts which he had opened himself. He had no set eating time, eating his yogurts in school when he wanted to. At home he helped himself to yogurts during the day, and took his milk in a baby bottle at breakfast time and on going to bed. He exhibited a variety of challenging behaviours such as head-banging on the floor, dropping to the floor without head-banging, head-butting staff, spitting, screaming and throwing objects. Aidan talked a lot about foods such as pizza, chocolate and fruit, but never ate them, or even touched them. He refused to sit at the same table as other children when they were eating, and he did not sit with his family at their meal times. His parents' main goal was to expand his food repertoire.

Bernadette was a ten year old girl with a diagnosis of autism and moderate learning difficulties. Since early childhood she had been on a casein and gluten-free diet. Although she finger-fed herself a variety of crunchy, salty carbohydrate snacks, she insisted

that her mother spoon-fed her with breakfast and dinner. Breakfast was a rice porridge made with soy milk, and dinner was mashed potato with meat or fish or chicken and vegetables pureed through it. She showed very little interest in other people's food, but sat at the table at mealtimes in school and in the short-term care unit. At home, she preferred her mother to feed her in the living room while the TV was on, away from the rest of her family. Her parents' main goals for Bernadette were that she should become independent in feeding herself at breakfast time and that she ate a wider variety of textures.

Cormac was a ten year old boy with a diagnosis of Hunter's syndrome with profound hearing loss. He had been on a casein- and gluten-free diet for about 18 months. His mother had concerns because he recently refused to eat some of the new foods which he had initially eaten on first introduction, such as home-made bread. He was also refusing to eat meat. Although he ate some crunchy carbohydrate snacks, his mother was concerned about their salt content, and much of his food was therefore home-made. His mother said Cormac did not eat wet or runny foods.

Damian was a 12 year old boy with a diagnosis of autism, moderate learning difficulties and a sensory modulation disorder. He exhibited challenging behaviours in the form of pinching staff, pinching himself and picking at himself to cause bleeding. He body slammed into walls at regular intervals. He had been on a gluten- and casein-free diet for several years. There was a history of food intolerance, reflux and gagging since infancy. Damian's foods of choice were crunchy, salty carbohydrate snacks, but he also ate toast with butter and honey, and dry cereals.

Eoin was a ten year old boy with a diagnosis of autism and severe learning difficulties. He was born 12 weeks prematurely and was tube fed for two weeks while in an incubator. He was then bottle fed and continued to use a bottle until he was five years old, and ate pureed commercial baby food. He ate a variety of sweet and/or crunchy carbohydrates, such as rusks, digestives, chocolate digestives, crisps and buns. Eoin licked peanuts but did not swallow them.

Fergal was an eight year old boy with a diagnosis of autism and mild learning difficulties, whose twin brother also attended the 'Food is Fun' week. Fergal had formerly been on a gluten- and casein-free diet, but this was abandoned after six months because he ate only potato waffles and chips. Fergal's foods of choice were waffles, chips, chicken nuggets, dry

white toast and dry cereal; he occasionally ate fish fingers. He was very reluctant to have his face washed and to eat warm food. He gagged on the presentation of new foods.

Gerry is Fergal's twin. He also has a diagnosis of autism and mild learning difficulties. He had also tried the gluten- and casein-free diet. Gerry's diet was somewhat wider than his brother's and included chicken nuggets, fish fingers, cheese strings, spaghetti with meat sauce, carrots, dry cereals, chips, pasta, savoury rice and occasional potatoes.

Harry is an eight year old boy with a diagnosis of autism. He was moving to a mainstream school in the following September and his mother was concerned about his limited range of food, and felt that his poor diet might stand out in his new educational setting. He ate pizza, chips and chicken nuggets. He disliked having his face washed and his teeth brushed. Harry could tolerate the tips of his fingers getting dirty in art and play activities.

Methods
Parent Questionnaires
All the parents completed a number of documents prior to the food week. These documents were taken from *The Fun with Food Programme* devised by McCurtin (2007).

- *A Case History Form* which explored the feeding and nutritional history from birth to the present day and any physical and medical issues of relevance
- *Food and Eating Rating Form which* rated behaviours at meal times on a scale of 1–5, such as the time taken to eat a meal and behavioural reactions to food
- *Food Independence Questionnaire* which examined the child's level of feeding independence (eg use of utensils, sitting to eat)
- *Taste and Textures Form where* the parents list the foods the child eats and the frequency of their consumption

Meeting with the parents
On completion of the above documents, the second author (MG) met with the parents, all of whom were mothers, to discuss feeding difficulties; set achievable goals; outline the strategies we intended to use; and identified motivating reinforcers. JG and MG videoed themselves acting a role play for parents in Year 1 to identify inappropriate/ appropriate strategies and interactions, such as not secretly adding food to yogurt or mashed potato; not

Table 1: Goals set for the children

Child	Year 1 Goal	Year 2 Goal
Aidan	Tolerate messy food play Eat other colours of yogurt	Tolerate messy food play Eat soup
Bernadette	Eat breakfast independently Taste and eat apple	Eat main meal independently Eat banana
Cormac	Eat runny food	N/a
Damian	N/a	Eat soup Desensitise oral area
Eoin	N/a	Taste banana Tolerate messy food play
Fergal Gerry Harry	N/a	Eat fruit Handle food; chop vegetables Make jelly Make pizza

making extravagant promises or threats; not taking photographs of a child eating; not saying 'just one more spoon' then giving another three; not pleading; using 'first then' cards; giving appropriate praise; leaving new food within sight of the child to accustom them to the idea; playing music to keep a calm atmosphere; and sitting at the table. The mothers' concerns were varied. They were worried about their children's nutrition, but also about social limitations in not being able to take their children to restaurants and parties.

Goals set

Goals were collaboratively set with the parents for each child (see *Table 1*). Although the parents had initially focused on setting specific goals around eating, our priorities as speech and language therapists (SLTs) were that the children should be able to tolerate food play and participate in food activities such as shopping games, and so most children had dual goals. Each child's anxiety around food was taken into account; they had the opportunity to participate minimally; goals were reviewed daily, and adjustments were made in small increments.

The 'Food is Fun' week

The 'Food is Fun' week ran for five days at the school, using four different classrooms during August for two and a half hours a day, from Tuesday to the following Monday. We deliberately spanned a weekend so that their response to food at home over the weekend could be reported back to us on Monday by the parents.

Children involved

In Year 1, Aidan, Bernadette and Cormac were involved. In Year 2, Aidan, Bernadette, Damian, Eoin, Fergal, Gerry and Harry were involved. Fergal, Gerry and Harry were very verbal children and presented with different sensory needs to Aidan, Bernadette, Damian and Eoin. For this reason, the children were split into two groups. Group 1 comprised Aidan, Bernadette, Damian and Eoin and their programme was quite similar in both years. Group 2 (Fergal, Gerry and Harry) worked at a more advanced level, and much of their work targeted practical food handling such as washing and chopping a variety of fruit to make a fruit salad; or washing, chopping and grilling vegetables to make a French bread pizza, as well as tasting these foods.

Staffing

In Year 1, we had three staff for three children: Aidan required 1:1 staffing, and Bernadette and Cormac worked together with one member of staff. The third staff member prepared and cleaned up after activities – a vital role. Staff rotated roles. In Year 2, we had two groups. Group 1 consisted of four children with more sensory and behavioural needs who required 1:1 staffing, and Group 2 consisted of three children who were more independent and required two staff between them. Group 2 (staff and children) helped to prepare some activities for Group 1, and did some of the clearing up.

Costs

In Year 1, the Parents and Friends Association of the school funded the Food is Fun Week; the

costs came to €150. In Year 2, we asked each parent to contribute €20 and the Parents and Friends Association made up the balance. The total cost was €280.

Activities over the course of five days
Our ambition was that everything that the children did for the two and half hours would be connected with food; if they were painting, they were using food colours, if they were doing a jigsaw puzzle, it was a puzzle of food, if they were singing, they were singing food songs. We changed the names of some activities to give a food theme, so if children needed some deep pressure activity, we called it 'Hot Dog', rather than 'roll in a blanket'. Staff even wore T-shirts with fruits on them! However, in Year 1, Aidan found a black and white line drawing of a bicycle

(as used in his schedule) and stuck this on his schedule without us noticing, so we felt obliged to deliver on this, as we had not immediately removed it. With hindsight and with the benefit of an Occupational Therapist's input, we realised that he did need some physical activity, so it was fortuitous that he planned it for himself! In Year 2 we included more physical and sensory activities: bounce on the Peanut Ball for some activities, Hot Dog Press, and Find with Fingers on the Physio Ball (see *Appendix 1* for further examples of sensory activities).

There was a gradual movement over the five days from dry to wet textures, and the children were required to manipulate and play with a variety of consistencies (see *Tables 3 to 7*). However, the children did not all progress at the same rate, and

Table 2: Activities over the course of five days Group 1, Year 2

Time	Day 1	Day 5
2.00	Lunch (brought from home)	Lunch (brought from home; sit together to eat)
2.15	*Aidan*: sensory room	*Aidan*: bike
	Damian: walk playground	*Damian:* walk playground
	Bernadette and Eoin Find with fingers	*Bernadette and Eoin* Find with fingers
	Butter beans from raw rice	Tinned mandarins from cooked rice
2.30	Food Lotto (cards)	Food Lotto (real food)
2.20	Food trialling session 1	Food trialling session 9
2.45	Dough play: gluten-free flour	Dough play: mashed banana
2.55	Songs (five chocolate rice cakes in the baker's shop)	Songs (five fat sausages sizzling in a pan)
3.00	Smells: lemon, ketchup, coffee	Smells: lemon, vanilla, coffee, onion, cinnamon, curry
3.10	Food art: collage; make glue from flour and water: stick on dry pasta shapes, beans	Food art: face painting: chocolate sauce, strawberry sauce, custard
3.20	Sensory walk dry	Sensory walk wet
3.45	Hungry Caterpillar story: first two pages, apple and pear; each child to use green sock puppets, touch each fruit to puppet's mouth	Hungry Caterpillar story : whole story, each child to touch each fruit to puppet's mouth and own lips
3.50	Whipped cream messy play with fingers	
4.00	Food trialling session 2	Food trialling session 10
4.10	Find with fingers	Find with fingers
	Butter beans from raw rice	Tinned mandarin from soya yogurt
4.20	Match pictures of fruit to real fruit	Picnic outside
		Snack and smell fruit/put to lips fruit salad made by children in Group 2
4.30	Home	Review with parents; home

Table 3: Progression of sensory walk over five days

Day	Texture	Examples
1	Dry	Raw rice, kidney beans, chick peas, pasta, flour, oatflakes, popcorn, peanuts, cornflakes
2	Sticky	As above; add raisins and sugar
3	Moist	Remove raw rice, beans, pasta; keep others. Replace with cooked cold rice, cooked cold pasta, thawed frozen peas, cold baked beans
4	Wet	Remove all dry foods where possible. Keep raisins, sugar, cold cooked rice, cold cooked pasta, thawed peas, cold baked beans, add yogurt, porridge, jelly
5	Wet, different consistencies	Remove raising and sugar. Keep wet foods. Add minestrone soup, noodle soup

some activities needed to be presented at the same level for a few days before moving on.

The sensory walk
The sensory walk involves filling rectangular washing up bowls (large enough for both feet to fit in at one time) with different food textures. The children were required to walk through the different bowls, and then have their feet washed at the end. It is quite a messy procedure, and requires space.

Find with Fingers
'Find with Fingers' uses deep bowls, from which children have to take one target item (butter beans) at a time from the base food (raw rice) and fill the individual sections of an ice tray with them. The size of the ice tray increases so that over the week the children had to pick up more pieces of the target food, using a pincer grasp. Children were encouraged to alternate their hands, so that both hands were used.

Dough Play
Children were required to squeeze, roll and use shape cutters to cut different shapes with the different textures, using both their hands.

Food Trialling
In this desensitisation activity, we applied food to different parts of the student's upper body. The purpose of this activity is for the children to become familiar with the appearance, smell and texture of a new target food before putting it to their mouth or tasting it, but they were under no pressure to proceed further than they felt comfortable. Some children did not get beyond the elbow, others swallowed a tiny amount of a new food: soup, banana or a new flavoured yogurt.

Results
In year 1, in terms of the activities and the logistics, we found the children benefited from regular, scheduled physical activities such as a walk, playground, running around, and calming breaks

Table 4: Progression of 'Find with Fingers' over five days

Day	Texture	Examples
1	Dry/Dry	Butter beans from raw rice
2	Smooth/Dry	Halved grapes from raw rice
3	Sticky/Sticky	Orange segments from cooked rice
4	Slippery/Sticky	Banana slices from cooked rice
5	Slippery/Wet	Peach slices from custard

Table 5: Progression of 'Dough Play' over 5 days

Day	Consistency	Examples
1	Smooth/Dry	Gluten-free flour and water, food colouring
2	Smooth/Sticky	Mashed potato, food colouring
3	Wet/Dry	Cornflour and water 'gloop', food colouring
4	Sticky	Roughly mashed banana
5	Slippery/Sticky	Smoothly mashed banana, food colouring

Table 6: **Progression of 'Food Trialling'**

Session	Part of body
1	Finger tips
2	Palm of hand
3	Back of hand
4	Upper surface of lower arm
5	Elbow
6	Neck
7	Cheek
8	Nose
9	Lips (very brief touch)
10	Lips (a few seconds)
11	Lips (as though applying lipstick)
12	Teeth (very brief touch)
13	Tongue tip (very brief touch)
14	Tongue Blade (very brief touch)
15	Put target food on spoon and hold in child's mouth, but no expectation that child should swallow it
16	Child to swallow miniscule amount of target food

from the activities. One-to-one staffing was vital. The programme would have failed if we had not been able to access a third person at short notice. We also needed more time for preparation and clearing up than we had anticipated. Separate rooms were needed and used for different activities

Children's progress
Aidan
Over the five days, Aidan was quite resistant to taking part in many of the activities and had to use his chosen reinforcer, the bike, frequently, to encourage him to participate in activities. But, he did make progress. His tolerance for food on his hands increased, he became more used to certain smells and he was able to sit at a table where a variety of foods was present. He took part in the dry elements of the sensory walk, but refused to dip his toe into the wet sloppy foods. Similarly, he was able to remove the dry items from dry foods in the 'Find with Fingers' activity, but not from the wet foods.

Follow up from year 1
In collaboration with Aidan's Cass Teacher and Occupational Therapist, we initiated a food chaining programme to move Aidan from yogurts through to other desserts such as crème caramel, custards, mousses, fruit purees, and jellies to rice pudding. In Year 2, Aidan came to the 'Food is Fun' week again and he was able to participate in every activity, which was real progress. His tolerance for messy play had improved and he took part in the 'Sensory Walk', and 'Find with Fingers'. He was on a token economy to earn reinforcers, and he worked well on this. His challenging behaviour was greatly reduced. He tolerated 'soup-painting' on his face and tongue, and this continues to be worked on in class. At the time of writing, he takes three spoonfuls of soup twice daily in school, followed by a yogurt of any flavour.

Bernadette Year 1
By day three, Bernadette was feeding herself independently with porridge at breakfast time. By day five, she tolerated apples in her mouth, but did not swallow them. She showed increased tolerance of messy play, and participated in 'Find with Fingers' and the 'Sensory Walk'. She is pre-dominantly non-verbal, but was heard to say: 'Oh no, not the jelly!', the second time it was presented to her to walk through, but she went through it nonetheless! Since the first food week, Bernadette has continued to eat her breakfast independently, but she required her mother's presence in the room, and much verbal encouragement.

Bernadette Year 2
In year 2, we changed the time of the 'Food is Fun' week from morning to afternoon to facilitate Bernadette's new goal of eating her dinner independently, because she was used to being spoon-fed her main meal at lunch time during the holidays. She ate her dinner independently from Day 2; and successfully extended her taste range to include a new flavour of soy yogurt, which continues to be part of her diet. She also tasted two spoons of chocolate flavoured soy yogurt, but has not continued this. She cut and played with a banana, and tolerated it on her tongue, but did not swallow it. She tolerated strawberry sauce and chocolate sauce. She participated in all activities, but still showed some reluctance for walking in jelly. At the time of writing, she slices and licks bananas, but does not swallow these.

Cormac Year 1
It became apparent during the week that Cormac exhibited different behaviours in school from at home. During 'Food Week' he willingly tried yogurts, custards and smoothies, all of which he did not eat at home. He participated cheerfully in all activities, even the messiest 'Sensory Walk', and appeared to have no difficulties. This duality of behaviours between home and school is often seen in autism. We considered his food aversion to be mild and that he did not need to attend the 'Food is Fun' week in Year 2.

Damian
He participated very well in messy play of all types, albeit for a short time. He required a sensory break after each activity (see activities in *Appendix 1*). By Day 4, he tolerated soup in his mouth from a spoon, and from his own fingers, but spat it out within 4 seconds. He stayed calm throughout the activities. He painted strawberry, chocolate and toffee sauce on his face and licked his lips. At the time of writing, he chews and swallows bananas, and swallows three spoons of soup with a grimace, but does not object. Damian has eaten one small piece of peach, and eats custard and strawberry and chocolate sauces regularly.

Eoin
He required a lot of encouragement to participate in any new food-related activity. First/Then cards were used to motivate him; he earned a small piece of chocolate digestive for each activity he undertook. By Day 5, he picked up the smell canisters independently, and held them under his own nose and sniffed them. He tolerated banana on his tongue; he tolerated strawberry, chocolate and custard on his face; he complied with the sensory walks, and he touched fruit independently in the Find with Fingers and matching activities. At the time of writing, Eoin has eaten small pieces of banana on occasions.

Fergal
He found it very difficult to tolerate messy play and required a lot of prompting. A star chart was used to encourage him, and he earned a 'surprise' when he got three stars for trying new food in his mouth. By Day 5, he took part in the 'Sensory Walk', and used both hands to play with cream and sauces. He reluctantly tasted apple, pear, nectarine, strawberry, cheese on toast and strawberry jelly, and was only motivated by his reward.

Gerry
He was extremely reluctant to participate in any of the activities the first day, and screamed for much of this first session. However, from Day 2, he earned tokens and enjoyed getting his surprises. His behaviour improved hugely. By Day 5, he was willingly eating pear, nectarine, strawberry, banana, cheese, bread and cheese on toast; he tolerated messy play without demanding the instant wiping of his hands. He occasionally gagged when taking fruit out of custard with his fingers. At the time of writing, Gerry continues to eat fruit most days.

Harry
He required a lot of verbal encouragement and a star chart to participate. He became more tolerant of messy hands, but still avoided this if possible. He refused to put his hands or feet into the very wet textures. By the end of the week, he had tasted apple and pear, and cheese on toast. His mother reports that he continues to eat apples and to make and then eat cheese on toast at home.

Group 2 overall results
All three boys had an increased understanding of healthy and unhealthy foods, and participated in cooking and other food preparation activities

Concluding comments
From our experience of the past two years**,** we believe the 'Food is Fun' weeks have been of great benefit to children who present with food and feeding difficulties. All eight children made progress with regard to the tolerance of food in their environment: All eight children can now participate in messy play, whether food or non-food in nature. Six children achieved their eating goals, and continue to extend the repertoire of food eaten. Seven out of eight parents felt they had an increased understanding of the strategies we used with their children to support feeding; they felt their children had benefited from the week. Following on the success of food chaining with Aidan during the year, we recommend tailored food chaining plans for children with severely restricted diets.

Integral to the success of the week was the diversity of techniques used from different interventions in autism, such as ABA, TEACCH and Sensory Integration. The high ratio of staff to children was vital to the success of the programme. The benefit of having the active participation of an Occupational Therapist was shown in Year 2, where her sensory interventions reduced the incidence of challenging behaviours (see *Appendix 1* for ideas).

Addressing the feeding and dietary issues of children on the autism spectrum by running a 'Food is Fun' week

References

Bundy, A, Lane, S and Murray, E (1991) (2nd edn) *The sensory integration theory and practice* Philadelphia: Davis.

Carle, E (1974) *The very hungry caterpillar* London: Puffin.

Chapman Bahr, D (2001) *Oral motor assessment and treatment: ages and stages* London: Allyn & Bacon.

Fishbein, M, Cox, S, Swenny, C, Mogren, C, Walbert, L and Fraker, C, (2006) Food chaining: a systematic approach for the treatment of children with feeding aversion *Nutrition in Clinical Practice* 21, 182–184.

Gillberg C and Coleman M (2000) *The biology of the autistic syndromes* Cambridge: Cambridge University Press.

Gray, C (2000) *The new social story book* Texas: Future Horizons.

Horne, P J, Tapper, K, Lowe, C F, Hardman, C, Jackson, MC and Woolner, J (2004) Increasing children's fruit and vegetable consumption: a peer-modelling and rewards-based intervention *European Journal of Clinical Nutrition* 58, 12, 1649–1660.

Kennedy, M, McCurtin, A and Murchu, D (2007) *Workshop on paediatric eating, drinking and swallowing* Limerick University.

Latif, A, Heinz, P and Cook, R (2002) Iron deficiency in autism and Asperger syndrome *Autism* 6, 103–114.

Ledford, J and Gast D (2006) Feeding problems in children with autism spectrum disorders: a review *Focus on Autism and Other Developmental Disabilities* 21, 153–166.

Lovaas, O I (1981) *Teaching developmentally disabled children the me book* Baltimore: University Park Press.

Lozoff, B, Jimenez, E and Wolf, A W (1992) Long term developmental outcome of infants with iron deficiency *New England Journal of Medicine* 325, 687–94.

McCurtin, A (2007) (Ed) *Fun with food programme* Bicester: Speechmark Press.

Piazza, C and Roames, S (2008) Assessment of pediatric feeding disorders in J Matson, F Andrasik and M Matson (Eds) *Assessing childhood psychopathology and developmental disabilities* New York: Springer.

Schwartz, S M (2003) Feeding disorders in children with developmental disabilities *Infants and Young Children* 16, 317–330.

Schopler, E and Olley J G (1982) Comprehensive educational services for autistic children: the TEACCH model, in C R Reynolds and T R Gutkin (Eds) *Handbook of school psychology* New York: Wiley.

Schreck, K A, Williams, K, and Smith, A F (2004) A comparison of eating behaviours between children with and without autism *Journal of Autism and Developmental Disorders* 34, 433–438.

Stewart, C and Latif, A (2008) Symptomatic nutritional rickets in a teenager with autistic spectrum disorder *Child: Care Health Development* 34, 276–278.

Appendix 1

Activities suggested by the Occupational Therapist to regulate children during the 'Food is Fun' Week by providing tactile and deep pressure sensation and proprioception.

- Rolling a large ball over a child's back and legs
- Vibration pillow applied to legs and arms
- Bouncing on a large ball
- Rocking in a rocking chair
- Weighted blanket on the child's lap
- Rolling a child in a weighted blanket
- Weight-bearing activities: rolling over the ball/carrying heavy bags, boxes etc
- Safe space: quiet calm area they can retreat to
- Controlled pace walk in a quiet area
- Running in the PE Hall
- Brushing
- Massage
- Theraputty
- Theraband

An investigation into behaviours which challenge at university: The impact of neurotypical expectations on autistic students

Jane Lawson

Editorial comment

Jane Lawson has worked with adults and children on the autism spectrum for 10 years in a range of provision including residential, outreach, supported living, FE college support, and primary education. For the last six years, she has worked in Higher Education at three different Universities, in one of which she instituted and managed a mentor system for autistic students which has been running for four years. In this paper, Jane argues that students on the autism spectrum are expected to understand and function within environments (in this case universities) which are set up to be understood by neurotypical students. The responses and behaviours of autistic students to academic and social demands are interpreted using a neurotypical lens and so often misinterpreted, with sanctions applied rather than support. Lawson makes the point that staff at the university need to understand the factors which might lead to autistic students behaving or reacting in a non-neurotypical way and to put in support that enables these students to engage in activities and to thrive in a university environment.

Introduction

Bogdashina (2006) cites Muskie's (1999) definition of 'neurotypical syndrome' which he says is:

'… a neurological disorder characterised by preoccupation with social concerns, delusions of superiority, and obsession with conformity. Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one.' (p 8)

This is written with humour and is based on current definitions of the autism spectrum. In this essay, neurotypical and autistic are each understood to be constructs which serve to identify the normative (neurotypical) and the non-normative (autistic) populations. The aim of this paper is to show that although 'challenge' is often characterised as being a result of cognitive, social or emotional difficulties on the part of the autistic student, the challenge of the normative or neurotypical (staff, student or environment) presents an equivalent and often unrecognised challenge to students on the autism spectrum.

Emerson et al's (1987) definition of challenging behaviour is:

'… behaviour of such an intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to the use of ordinary facilities.'

However, in line with more recent uses of the term, this paper understands 'challenging behaviour' to be contextually defined: an outcome of an interaction of factors and a social judgement rather than 'an objective, scientific diagnosis' (Clements and Zarkowska, 2000, p 32). Thus, when investigating autistic students' behaviours that challenge, it is important to identify the significant factors in the higher education context, the social judgements which are made and to understand how these can contribute to behaviours perceived to be 'challenging'.

The challenge of university life

First year students are expected to make a quick transition to independent living, often away from home and to take responsibility for themselves and their actions. This leap to independence comes with variable training, dependent upon input from their families and work done by their previous schools, with new students thrust into an environment where they are expected to live with their peers, pay bills and otherwise manage their money, clothe and feed themselves, take care of their personal hygiene, appropriately interact with university staff (admini-strative, academic, ancillary) and students (in classes, residences and societies), master academic conventions, manage their work and engage in a social life.

The university is an alien environment for the majority of new students (freshers) most of whom have not long turned 18, have been living at home with their parents and who have not had the experience of managing their lives without direct support. As their career progresses, they will face new challenges such as living in off-campus accommodation, being expected to undertake new academic tasks with a greater expectation of independent learning and problem-solving (eg longer projects, group work), to undertake work placements and build a CV, and prepare for their post-university career. Each of these transitions is accompanied by a set of expectations of typical development through a process of skills and knowledge acquisition. Social judgements, including judgements of academic ability, are made by staff of students and by students of each other, throughout this university career. These are invariably founded in neurotypical standards and expectations, both of the ways in which the skills and knowledge are delivered and acquired and also the ways in which skills and knowledge are expressed (eg in academic writing, verbal interaction, engagement in group activities). As Grace and Gravestock (2009) argue:

'The need for students to develop as independent learners is both fundamental to academic success in HE and essential to subsequent professional success …This involves a high level of self-awareness and the ability to monitor their own learning and performance.' (p 49)

Students who do are not able to meet these demands may thus be unsuccessful.

The hidden curriculum

Some of these standards and expectations are overtly conveyed: rules for living in halls of residence, timetables of attendance at lectures, dates when work has to be handed in, for example. Underlying them all, however, is what has been described as the 'hidden curriculum': a set of expectations of behaviour and performance in the academic domain which is taken-for-granted by the majority. Sambell and McDowell (1998) describe it thus:

'The term 'hidden curriculum' is widely known and used but encompasses a broad range of definitions. It is an apposite metaphor to describe the shadowy, ill–defined and amorphous nature of that which is implicit and embedded in educational experiences, in contrast with the formal statements about curricula and the surface features of educational interaction.' (p 391)

Smith and Simpson (2001) suggest:

'The hidden curriculum includes skills, actions, modes of dress, and so on, that most people know and take for granted. Every school and every society has a hidden curriculum. This unspoken curriculum is the one that causes challenges and, indeed, grief for those with AS.' (p 280)

Thus student participation and performance in higher education is judged in contexts where the rules of engagement are opaque and difficult to negotiate. This is problematic for all students, but particularly so for autistic students.

'Students who have little experience of the particular university culture they are in may struggle to understand and to find a way through unspoken, often long-established customs … An explanation of systems and processes is therefore essential if we are to reduce undue distress and uncertainty.' (Grace and Gravestock, 2009, p 2)

If distress and uncertainty are generated for neurotypical students, then for those who are on the autism spectrum, it is clear that higher education will be more problematic. Grandin and Barron (2005) suggest that neurotypical students learn the hidden curriculum through the application of a 'social sense' which they are born with and through observation and interaction. In the context of the university, it can be argued then, that students pick things up (more or less) from discussion with their peers and older students, and from watching what others do. On the other hand, Grandin and Barron

(2005) suggest that people on the autism spectrum are more likely to learn from direct experience and explicit, visual explanation. Thus, for an autistic student, the unarticulated set of culturally accepted rules may be impossible to learn and their interaction with peers is likely to be more limited, so they have less opportunity to observe and discuss conventions with others.

University rules: Which behaviours are acceptable and in what context?

Students at university are expected to learn and abide by the rules of academic and social life. Challenges to the rules are expected and other rules made in anticipation of this. For example, if a student disagrees with an awarded mark, there will be a procedure for them to challenge this. Academic error is accepted as a possibility. If a student disobeys the rules of their hall of residence (eg they set off a fire extinguisher after a night at the Students Union), there will a procedure for them to be punished and reprimanded. Disobedience/prank is an anticipated element of student life and thus a behaviour within the normative range. Students on the autism spectrum can be unduly upset and very anxious and angry with peers when they blatantly break the rules at university (not understanding that this is part of being a student). This can then cause ostracism and ridicule from their fellow flat mates and peers and result in further social isolation.

So it is very hard for autistic students to understand when others' break or bend the rules. All behaviour is judged within its social context and it is knowing and understanding how rules change with context that is so hard for them to grasp and to learn what is OK or is not OK and when.

Support, not sanctions, when students on the autism spectrum appear to break expected, neurotypical conventions at University

Writing about autism and further education, Breakey (2006) argues that:

'Currently, there is assumed to be a level of tolerance in Western society which allows for comparatively broad and flexible boundaries to social norms, which are continually being renegotiated in some areas. Tolerance is however, only extended within certain limits, and behaviour which strays too far beyond the tolerable limits is judged as "inappropriate", "deviant" or "perverted". Social norms are therefore inextricably linked to conformity, with the

dominant members of society requiring conformity to their views.' (p 156)

Taking this back into the university setting, an autistic student who does not attend a class because the lights in the room are bright and there is no window, who speaks at great length in seminar groups, who tells his fellow students their views are stupid or wrong, who constantly taps his pen on his desk (or cannot bear another doing this), or who sends e-mail after e-mail to a lecturer about a particular question or topic, will be seen as behaving beyond the normative: as being deviant or presenting challenging behaviour. This position beyond the normative is described by an adult with autism, in Prince-Hughes (2002):

'As autistic students, our internal needs and motivations are often at odds with the physical environment of the university and many of its social and emotional demands. Behaviours that are "normal" to us (talking long and enthusiastically about our special areas of interest, disregarding personal appearance and sometimes hygiene, speaking plainly rather than censoring our thoughts) and our coping mechanisms (such as small rituals, a need for continuous clarification, and attachment to comfort objects) make us stand out as odd and sometimes unwelcome members of the university community.' (pp xvii–xviii)

The social and emotional demands of the university lay as much, if not more heavily, in the context of residential life and expectations of normative student sociability and management of the tasks of daily life (eg shopping, cooking, washing). For the neurotypical student, reciprocity, co-operation, tolerance of others and communal living and working may be difficult to come to terms with and will generate challenges for them, even though they will 'work out' the rules and negotiate a manner of living with their peers. For the autistic student, where learning has to be through explicit instruction and clarification and where routines and self-orientation make communal living and working a source of anxiety and perhaps fear, student social life and management of daily tasks are particularly challenging. As Wendy Lawson, an adult with Asperger syndrome explains,

'... I have huge problems with being disorganised, getting lost, using public transport, understanding others, and just the practical interactions of social situations. I think many of you might be

saying "so what, I do as well". I know the neurotypical individuals might have issues in these areas but I would suggest to you that it is the degree of the 'issue' that separates us.' (Lawson, undated, p 3)

This is supported in the responses of autistic students to the question of what they found most difficult at university in Beardon and Edmonds' Aspects Consultancy Report (2007) where social and interactional issues were identified as being key areas. Examples given were:

' misreading people and being misread'

'mostly … day-to-day living, having to do everything for myself without support or help (eg eating, getting dressed, washed etc.)' (p 166)

Individual reactions to social 'outsiderness' and difficulties with self-management are highly variable and will to some extent depend upon the personality of the individual concerned. However, they can be profound. Social rejection can lead to depression, and a retreat into comforting, imagination-based activities (eg computer games, withdrawal, or the development of an 'arrogant disregard' for others, each of which has the effect of further isolating the individual (Attwood, 2006).

Sensory sensitivity and responses
Bogdashina (2003) refers to the way in which sensory information is differently processed, interpreted and analysed by the brain, causing differences in the way the autistic student feels and reacts to sensory stimuli. It is now widely recognised that differences in sensory processing do indeed affect many students on the autism spectrum and can be crucial in understanding their behaviour and reactions to situations. An autistic student may have difficulties for example in a seminar discussion, where noise levels can be high, and people will raise voices and speak over one another. The student's response to this might be to leave the room, or to become angry with the student or staff member which may then be viewed as insensitive, rude and unacceptable. Breakey (2006) suggests that staff need to appreciate the effects of sensory over-load and that measures be taken to produce low-arousal environments to create a more inclusive environ-ment. Then adjustments do not have to be made for a particular student who might otherwise be excluded from an experience or singled out as being different or difficult.

These issues are supported by my own experience with autistic students and also from autobiographical accounts of people with autism such as Donna Williams (1998). These show that sensory perception plays a crucial role in anxiety and subsequent behaviour which may be perceived by others as challenging.

A difference in attention
Wendy Lawson (2007) argues that autistic people are generally monotropic which she defines as,

'… having the ability only to focus in on one aspect of communication, or upon one interest or activity at one time …' (p 33)

For Lawson, monotropism affects both how she conducts her academic work and also how she is perceived by others. The differences she identifies relate to difficulties with change between places and over time, shift of attention from one topic to another, interpreting language literally, and in '*experiencing events … as separate and exclusive*' (p 37) rather than having a common link or being related in some way

Additionally, she links monotropism to being self-orientated (only focused on one's own interests), distinguishing this from a neurotypical view of self-orientation as 'selfishness'. Lawson (2007) suggests that it is not possible to be selfish or intentionally rude and hurtful if you do not have an understanding of how your behaviour or actions impact on another's feelings and emotions. The mis-reading that students can fear from their peers and staff can, in all probability, be linked with this difference in relating to and interacting with others, together with autistic students' difficulties with imagining the effects their actions may have.

Perfectionism
A further and significant psychological trait associated with autism is that of perfectionism. This can have devastating effects on a student's time management, stress and energy levels. Tammet (2006), an autistic adult, explained how perfectionism affected his studies:

'Whenever I wrote, I poured over every letter and full stop. If I noticed a smudge or error I would rub everything out and start over. This streak of perfectionism meant that I sometimes worked at a snail's pace, finishing a lesson in a state of near exhaustion, yet with little to show for it.' (Tammet, 2006, p 63)

My experience of working with autistic students has been that this is a very common trait and that exhaustion and anxiety have adverse effects on the students' wellbeing, their behaviour towards others and their own behaviours, for example producing self-injury, comforting actions or OCD behaviour. This can also explain the late submission of work, missing information in lectures/seminars and the difficulty peers and lecturers have in understanding and accommodating this behaviour.

When describing her initial disclosure to the disability services department at a university she attended, Lawson identifies how her monotropic way of thinking, processing information and her sensory perception, presented challenges to learning.

'... I was very fortunate: I had a person who was willing to listen. "Wendy, what difficulties do you experience?" she asked me. I said that is was very difficult to listen to a lecture and take notes at the same time. I explained that I wasn't good at doing two things at once. "Oh, that's easy," she said. "We'll get you a note-taker." I also told her how I get lost easily and didn't cope with finding my way round or with lots of noise, lights and people. She assigned me to a peer-support person, who showed me around campus and waited to assist me in locating places. I was also allowed to take exams in a separate room to the other students, given extra reading time and allowed to check with the invigilator that I had the right understanding of the questions.' (Lawson, 2006, p 205)

This is a good example of how quite simple reasonable adjustments which address both the cognitive and environmental factors which challenge autistic students, can reduce the problems university presents for autistic students. Grace and Gravestock (2009) argue that:

'We cannot be "difference blind" and we need to recognise the diverse needs of the different students in our programmes in order to help any student with a particular need. But we also need to celebrate and truly engage with these differences in a positive and constructive way. (p 2)

Had Wendy been required to 'change herself' and be the 'independent learner' which university usually demands, then the challenges would have been significant and possibly ended in her having to withdraw from the programme.

University staff may have significant concerns about making reasonable adjustments or devising support strategies for students. Whitaker (2006) suggests that:

'Anxiety about how the majority of the class will perceive any form of "special treatment", particularly if this is framed as "tolerating" lower standards of behaviour, is often at the root of resistance to implementing required management strategies.' (p 139)

Such anxieties privilege neurotypical behaviours as 'correct' and others as inherently deviant, or at least inferior: a view which establishes normativity as a neutral position and a natural standard.

Effects of past trauma

A final issue of particular significance is the effect of past trauma on the behaviour of autistic students. Clements (2005) maintains that:

'Traumatic life events can have a major and dramatic impact on human emotional stability and behavioural functioning ... more often the effects are seen where there is repeated exposure to highly aversive experiences – repeated teasing and bullying, repeated harsh treatment ... It is a sad fact that people with autism are more vulnerable than others to systematic abuse.' (p 27)

David Andrews (2006), an adult with Asperger syndrome, discusses the effects of bullying during his school years which resulted in a nervous breakdown, followed by treatment which identified his biology as the problem and not the abuse he was subjected to. He cites the continuing effect this has had on his mental health, his sense of self-efficacy and his feeling less valued than his professional peers. He goes on to say that,

'... mental health problems for the Asperger autistic person do not arise from the biochemistry of autism but that, rather, they arise from how he or she experiences society. Society, as yet, is not an inclusive organisation.' (p 106)

The implications here for the ways in which universities respond to neurodiversity is evident: perceptions of autistic students as inherently deviant or challenging and the university as a neutral, normative institution to which they must adapt (or be adapted) can have significant adverse impacts.

Concluding comments

To conclude, it is important for staff to understand how autism affects a person's ability to understand and follow procedures and to live and work with fellow students. Non-neurotypical reactions or behaviours need to be seen not with a neurotypical lens but with an autistic lens. Where behaviours are inappropriate or may lead to work being judged unacceptable, then clear, explicit guidance is required to support that student to understand what needs to be different and how that might be achieved. Sensory factors, together with modes of teaching and expectations of typical academic and social development within the teaching areas (eg lecture theatres, seminar rooms, laboratories) are likely to make it very difficult, and sometimes impossible, for an autistic student to work within that environment. The same is true within social and living areas and adjustments need to be made to enable the student to access and manage to work and live in these areas. We have to engage with the autistic people to make the mutual connection (Lawson and Murray, 2007).

A willingness to make explicit the hidden curriculum, to de-mystify the university and also to provide support within the social domain would improve the chances of autistic students having a positive experience of university life. Behaviours and actions which stem from natural responses to what for an autistic student may be aversive, confusing or anxiety-provoking should not be perceived as behaviours which are out of order and in need of sanction, but to be an indication that support, adjustments and explanations are needed to enable the student to study and enjoy university life. Universities need to review and adapt their teaching, learning and social practices to include all students, including those who are non-neurotypical, not institute specific means of adapting the individuals to existing practices.

References

Attwood, T (2007) *The complete guide to Asperger's syndrome* London: Jessica Kingsley.

Beardon, L and Edmonds, G (2007) *ASPECT consultancy report: a national report on the needs of adults with Asperger syndrome* Sheffield: Sheffield Hallam University, Autism Centre.

Beardon, L and Edmonds, G (2008) *Asperger syndrome and social relationships: adults speak out about Asperger syndrome* London: Jessica Kingsley.

Breakey, C (2006) *The autism spectrum and further education: a guide to good practice* London: Jessica Kingsley.

Bogdashina, O (2006) *Theory of mind and the triad of perspectives on autism and Asperger syndrome: a view from the bridge* London: Jessica Kingsley.

Bogdashina, O (2003) *Sensory perceptual issues in autism and asperger syndrome: different sensory experiences – different perceptual worlds* London: Jessica Kingsley.

Cigman, R (Ed) (2007) *Included or excluded: the challenge of the mainstream for some SEN children* Oxford: Routledge.

Clements, J (2005) *People with autism behaving badly: helping people with ASD move on from behavioural and emotional challenges* London: Jessica Kingsley.

Clements, J and Zarkowska, E (2000) *Behavioural concerns & autistic spectrum disorders: explanations and strategies for change* London; Jessica Kingsley.

Emerson, E (1995) *Challenging behaviour: analysis and intervention in people with learning difficulties* Cambridge: Cambridge University Press.

Grace, S and Gravestock, P (2009*) Inclusion and diversity: meeting the needs of all students* Oxford: Routledge.

Grandin, T and Barron, S (2005) *Unwritten rules of social relationships: decoding social mysteries through the unique perspectives of autism* Texas: Future Horizons.

Lawson, W (undated) *Adolescents, autism spectrum disorder and secondary school* available from http://mugsy.org/wendy/asschool.htm (accessed 21 April 2010).

Lawson, W (2007, reprint) *Understanding and working with the spectrum of autism: an insider's view* London: Jessica Kingsley.

Murray, D (ed) (2006) *Coming out Asperger* London: Jessica Kingsley.

Whitaker, P (2006) 'Why's it all so difficult? Sharing the diagnosis with the young person' in D Murray (Ed) *Coming out Asperger* London: Jessica Kingsley.

Murray, D (undated) *Discussion paper on eugenics and diversity: the importance of conserving diversity is widely recognised in the 21st century; it applies to humans too* available from

www.autismandcomputing.org.uk/eugenics_and_neuro diversity.en.html (accessed 21 April 2010).

Murray, D and Lawson, W (2007) Inclusion through technology for autistic children in R Cigman (Ed) *Included or excluded: The challenge of the mainstream for some SEN children* Oxford: Routledge.

Nichols, S, Moravcik, G M and Pulver Tetenbaum, S (2009) *Girls growing up in the autism spectrum: what parents and professionals should know about the pre-teen and teenage Years* London: Jessica Kingsley.

Paxton, K and Estay, I E (2007) *Counselling people on the autism spectrum: a practical manual* London: Jessica Kingsley.

Prince-Hughes, D (Ed) (2002) *Aquamarine blue 5: personal stories of college students with autism* Ohio: Swallow Press/Ohio University Press.

Purkis, J (2006) *Finding a different kind of normal: misadventures with Asperger syndrome* London: Jessica Kingsley.

Porter, J and Jones, G (revised by Thomson, S) (2008)

Challenging behaviour and autistic spectrum disorders unit 1: a context for understanding challenging behaviour Birmingham: University of Birmingham.

Sambell, K and McDowell, L (1998) The construction of the hidden curriculum: messages and meanings in the assessment of student learning *Assessment & Evaluation in Higher Education* 23, 4, 391–402.

Smith-Myles, B and Simpson, R L (2001) Understanding the hidden curriculum: an essential social skill for children and youth with Asperger syndrome *Intervention in School and Clinic* 36, 5, 279–286.

Smith-Myles, B and Southwick, J (1999) *Asperger syndrome and difficult moments: practical solutions for tantrums, rage, and meltdowns* Kansas: Autism Asperger Publishing Co.

Tammet, D (2006) *Born on a blue day* London: Hodder & Stoughton.

Minimising the stress of the PhD viva for students with Asperger syndrome

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Editorial comment
Dr Nicola Martin is Head of the Disability and Wellbeing Service at the London School of Economics and has particular expertise on students with autism and Asperger syndrome. This paper explores the issues for students with Asperger syndrome when dealing with their PhD viva and makes recommendations on how they might be supported. Nicola makes the point that vivas are stressful for all students and that many of the strategies suggested could be of use to other students during this process.

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Introduction
The guidelines here have been influenced directly by participatory research with students who have Asperger syndrome (AS), and from the insights of writers who have AS (Arnold, 2003; Beardon and Edmonds, 2007; Beardon, Martin and Woolsey, 2009; Grandin, 1996; Hughes, 2007; Lawson, 2001, 2003; Madriaga et al, 2008; Madriaga and Goodley, 2009; Martin, 2008; Martin et al, 2008; Murray, 2006; Woolsey, 2007). The Premia Project (2007) reviewed the literature on vivas which demonstrated, unsurprisingly, that '*many candidates approach the viva with high levels of anxiety*.' So, other students without AS would also benefit from support.

Benefits of clarifying the process for all students
There are at least three potential benefits of routinely telling ALL candidates and not just those with a recognised disability, about the way the viva will be structured and in explaining the possible outcomes and procedures clearly, rather than assuming understanding: Firstly, positioning a particular group of candidates as 'other' is avoided ('othering' is the term used by disability academics such as Richards, 2008). Secondly, those who are reluctant to ask seemingly obvious questions, will not have to ask. Anyone who does not need the information (which could be presented in a simple leaflet) could choose to discard it, while those who really do need it, but may be too afraid to ask, can be spared anxiety and /or embarrassment. Thirdly, students who have the label of AS but do not identify with it positively, are more likely to derive assistance from information which does not mention the condition (Martin, 2008).

Asperger syndrome, stereotyping and individuality
Stereotyping around AS, which many with the condition find offensive, creates images of genius, inflexibility, obsessiveness and poor social and communication skills (Arnold, 2003; Hughes, 2007; Lawson, 2003; Murray, 2008). The film *Rain Man* and the novel, *The Curious incident of the Dog in the Night* (Haddon, 2003), did much to perpetuate this idea (Fleischer, 1989). In reality, if you have met one person with AS, you have met one person with AS, and individuals do not conform to stereotypes (Beardon and Edmonds, 2007). A common misconception that AS is a mental illness also persists (Beardon, 2009). An individual with AS may well acquire an additional mental health difficulty, often anxiety or depression (Attwood, 2007; Beardon and Edmonds, 2007), but AS in itself is a neurological difference which does not have to lead to mental illness. Beardon (2009) and others argue that episodes of mental ill health often arise as a result of poor services or negative experiences in a world which is hostile to difference.

While people with AS have many positive characteristics, including the capacity for immense hard work, and a high level of interest and originality around their academic discipline (Baron-Cohen, 2000; Asperger, 1944), other aspects of AS are challenging, particularly in unsympathetic contexts (Beardon and Edmonds, 2007; Madriaga et al, 2008). Difficulties with social communication; understanding the perspective of others; flexibility to build on experience to cope with change and work out what to do in novel situations; and sensitivity to the sensory environment are common characteristics

of AS (Bogdashina, 2003; Happe et al, 2006; Howlin et al, 2000). Organisation and the ability to prioritise can be compromised particularly in the face of ambiguity, therefore clear communication is essential (Attwood, 2007). Low self esteem is frequently a feature of AS and this may manifest itself in perfectionism (Beardon, 2009; Martin, 2008; Murray, 2006). Sensitivity and planning can enable the student to showcase their originality and ability in the context of the viva. Lack of sensitivity and disorganisation will inevitably disproportion- ately disadvantage candidates who are less robust, including (but not exclusively) those with AS.

Ability, application and (exceeding) expectations

It is not necessary to be a genius to have AS. Diagnostic criteria identify the requirement to be of at least average intelligence (Gillberg, 2002; Leekam et al, 2000). Students who have come to the point in their academic career where they are about to take a PhD viva have clearly demonstrated intelligence and application. Candidates who have AS are likely to take their work seriously and personally and may well find criticism difficult to deal with, possibly as a result of low self esteem which often persists despite high levels of achievement (Beardon and Edmonds, 2007).

Self esteem, failure and standards

Multiple instances of bullying and social exclusion are common life experiences for people with AS, especially during adolescence, and it is hardly necessary to rehearse the potential for damage to the ego that can result (Attwood, 2007; Beardon and Edmonds, 2007; Tantam, 2000). Students who have AS and have gained a university place have often massively exceeded the expectations of parents, teachers and others (Madriaga et al, 2008), therefore those who have got to PhD viva stage are likely to be exceptionally invested in the notion of succeeding and likely to suffer greatly if they fail.

Careful preparation for the eventuality of failure is essential and support needs to be built in should it occur. Perfectionism can be a real issue which can cause a great deal of unhappiness (Martin, 2008) and an MPhil is highly likely to feel like a failed PhD. Brabazon and Fearn (2009, p 31) remind university staff that '*behind every failed doctoral candidature is a person tragedy*'. There is not a research base to support the contention that failure of a PhD candidate with AS would be felt more acutely but without wishing to appear dramatic the author invites readers to reflect on some of the comments

about suicidal feelings from people with AS in Beardon and Edmonds (2007). Edmonds, herself, a very high achieving author with AS (and a post- graduate student) has now, very sadly taken her own life. While academic standards cannot be compromised, the personal tragedy of failure because of an inability to navigate administrative and social communication hurdles is avoidable.

Communication is a 'two-way street'

The communication style of many candidates with AS does not easily match the demands of the PhD viva and it is necessary to look at the preparation of both students and staff (without compromising academic standard) as indicated by the Disability Discrimination Act 2005, Part 4 and Disability Equality Duty (2006). Students with AS are likely to find ambiguity, figurative language and some aspects of social communication hard to cope with (Attwood, 2007; Beaumont and Newcombe, 2006; Bogdashina, 2005; Premia Project, 2007). Ambiguous arrange- ments and unclear questioning can precipitate anxiety and exacerbate stress in what is already a stressful situation. (Beardon and Edmonds 2007; Martin et al, 2008). A stressed student may behave in a way which is socially awkward, for example, by appearing agitated or not making eye contact easily. Putting the candidate in a position where they are more anxious than they need to be should be avoided, but accepting agitated behaviour as a manifestation of anxiety rather than any form of 'challenging behaviour' is helpful (Beardon, 2009).

Telling the student that they should shake the external examiner's hand and then sit down might assist them to work out what they are expected to do socially, in those first awkward seconds. The student does not need to sit particularly still, or look at the examiner, for example. Pauses and thinking time may be necessary, and an examiner who calmly waits is less stress inducing than one who interrupts a necessary, reflective silence. An examiner who is prepared to be straightforward with questioning, and to rephrase and clarify is most helpful for the student who has AS (and arguably also for someone who is, for example, being examined in a second language).

Give explicit instructions – state the obvious

It is advisable to state the obvious (without being patronising), as a very stressed candidate is less likely to pick up on subtle clues in verbal and body language (Beardon and Edmonds, 2007). For example, these are all examples of obvious statements which can smooth the process:

'The viva will start when I ask you the next question.'

'This is the last question.'

'The viva is now over and you can leave the room.'

Theorists refer to deficits in 'central coherence' which relates to the ability to prioritise or identify the salient issues within the bigger picture (Baron-Cohen and Swettenham, 1997). This may lead to the candidate going off at a tangent and the examiner needing to refocus the question clearly. Statements like:

'I do not want you to focus on that particular detail of your methodology, I want you to consider the broad application of your findings …'

may seem rather directive but may well be necessary if the candidate begins to perseverate on a seemingly irrelevant point. The Premia Project (2007) provides guidance on accessible vivas for candidates with a range of impairments and recommends that the examiner devises questions early on in the viva which the candidate will be more confident in handling.

Administration and organisation

Often individuals who have AS find aspects of personal organisation and prioritisation challenging. Some psychologists attribute this to a core deficit in executive function (Baron-Cohen and Swettenham, 1997). The PhD viva is preceded and followed by form filling. It may be this aspect of the process which becomes the focus of intrusive worry, so smoothing the path could help the candidate to concentrate on the academic concerns. Practical, sensitive support with form filling, fee paying and all the necessary administration, and clearly written instructions about what has to be done, by when, is highly recommended. Confidence could be severely damaged by any sort of comment which implies that the candidate is performing poorly in the arena of paperwork completion. Something as simple as an admin. tick list to work through could enhance self assurance in candidates with or without AS. Brabazon and Fearn (2009) provide systemic practical guidance on supporting all students in their attempts at navigating administrative aspects of the whole PhD experience. When procedures work effectively at a systemic level, the requirement for 'special' arrangements is greatly reduced (Adams and Brown, 2006). Post-viva arrangements are equally critical, including clear feedback and action planning around rewrites and resubmission or, in a worst case scenario, failure. Following up communication in writing is vital.

Disclosure of disability

If a candidate does not want to disclose that they have a disability or condition, this should be respected (Beardon et al, 2009). Such students may agree to communicate their requirements to the External Examiner without using a label. A statement can be produced by the student, with assistance from a familiar and trusted person, as required, which says something like '*because I am not a neurotypical student*', or '*as a result of a specific learning difference*', I require the following adjustments (Martin, 2007). Many university services have official forms which could lend themselves to the production of this sort of document for the attention of the External Examiner.

Flexibility and sensitivity

As difficulties in being flexible can be a characteristic of AS, a reasonable degree of flexibility may be required by the institution (without compromising academic standards, of course). Prior to the viva, the thesis may have been presented in an unconventional style. Help along the way to assist the student to understand what is expected in terms of how to structure and present work may be required. Supervisors should expect and plan for the necessity to offer additional time and input to the student during the preparation of the thesis. The DDA 4 (2001) describes an anticipatory duty towards reasonable adjustments for disabled students, so additional tutorial time may be required.

If the appearance of the final thesis is unusual or unconventional, provided it fulfils the standards required, it may be necessary for supervisors and examiners to be flexible about this. The External Examiner is likely to be more empathic if s/he is made aware in advance of this. Some people with AS are highly sensitive to the sensory environment (Bogdashina, 2003; Martin et al, 2008), so the room chosen for the viva will need to be carefully considered. A supporter or advocate may need to sit just outside the door for moral support for one student with AS. Others might feel patronised by this, so this would need to be an individual adjustment, not a rule). More rest breaks than usual during the viva may be necessary. The idea of breaks would need to be discussed in advance with the

student so that they are prepared for these. Providing a drink of water is often a very easy and reasonable adjustment.

Some students with AS are poor sleepers (Beardon and Edmonds, 2007) so if it is possible to negotiate the most helpful time of day for the viva to take place this should be considered. Encouraging candidates to have a meal and a drink in advance of what is likely to be a draining experience, and allowing them to take a drink in with them would be beneficial for those who would not automatically remember to do so when under stress. Students cannot readily engage in higher order activities, such as giving of their best in a viva, when they are tired, hungry, thirsty, the wrong temperature, anxious or feeling that they do not belong.

Students who do disclose they have Asperger syndrome
Legally, reasonable adjustments are required if the student has disclosed to a member of staff (DDA 4, 2001). It is quite possible though to have worked with a PhD student who has AS over several years without the condition being identified or diagnosed (Beardon and Edmonds, 2007). If AS has not been discussed with the student before, it is probably too late to raise the issue when the viva is looming, although it would not be too late to respond with appropriate adjustments. It is important not to assume that a clinical diagnosis could be obtained quickly, or that this would be desirable at a very stressful time. Practitioners able to offer adult diagnosis are few and far between, the issue of funding such assessments is unresolved and post-diagnostic support is usually required but often lacking (Beardon and Edmonds, 2007; Martin et al, 2008). Those who know the student well, such as the supervisor(s), should be able to assess the student's needs and what modifications might be needed relating to the viva.

The following form of words could possibly be helpful for opening up a discussion with a candidate who does not want to talk about AS.

'You are more likely to be successful if you tell the external examiner about aspects of the way you communicate which he or she might find unusual so that they can ask you questions in the most helpful way'.

Absolute caution is urged as self esteem can be very fragile. For someone more comfortable with the label it may be possible to say,

'Shall we work on a statement which tells the examiner about your AS and the way it affects you so that she or he can think about the best way to work with you in the viva'.

Feedback from the viva
Timely, clear feedback is as important as the preparation for the viva, and the viva itself. Written feedback needs to be made available, preferably later the same day. The candidate needs to be able to leave the room with a sense of achievement and an understanding of what they need to do next. Appropriate support may well be necessary to assist the student with the practical, academic and emotional implications of the information they are given, particularly if the news is not as good as they had hoped.

Recommendations
1   Routinely well-organised administrative systems including written guidelines and appropriate support with form filling are essential. Building this into the system minimises the requirement for students to disclose that they have a disability related difficulty with personal organisation. Not all students with AS (and other impairments) are prepared to disclose.
2   If the candidate is comfortable doing so, it may well be helpful for them to disclose either that they have AS, or that they have specific access requirements, prior to the viva. It may be useful for some individuals to prepare a short statement for the external examiner (with assistance if needed) explaining their access requirements (for example quiet, uninterrupted thinking time between question and answer). This will help the external examiner, who is meeting the student for the first time, to focus on academic concerns and not be put off at all by any behavioural manifestations of stress. While this suggestion may work for one individual it may heighten the stress of another. It is a suggestion not a rule.
3   To reduce anxiety, familiarisation with the layout of the room in advance is likely to be helpful. People with AS can experience sensory sensitivities so it is worth checking that the space is comfortable. It is advisable to provide drinking water and make sure the temperature is appropriate. Again, candidates without AS, or any 'label' may also find this helpful and making the practice ordinary minimises the danger of 'othering'.
4   The candidate should be told approximately how long the viva is going to last, who will be present, and the follow-up to the viva. The

opportunity for a break may need to be built in and arrangements for how this is organised need to be worked out in advance (e.g. that they will be accompanied if they leave the room). A brief written note on this will provide something to refer back to.

5   It is useful to acknowledge to the candidate that everyone is nervous to an extent when taking their viva and this is not specific to (or 'special' about) students with AS. The student may feel that being anxious is a personal failing, and then become anxious about being anxious.

6   Specific advice about what can be taken into the room would be useful. In a non-patronising way it would help if the candidate was advised to have something to eat and drink and to go to the toilet in advance of the viva.

7   In a situation where an external examiner and a supervisor are going to be in the room together, the rules of engagement need to be made very clear. The candidate may struggle with an unspoken assumption that it is not necessary to include the supervisor in conversation or to look at them, unless this is stated specifically.

8   Some people with AS make unusual eye contact, especially when stressed. The candidate might worry about this in the viva context (especially if they have had the experience of people insisting on eye contact). They should be reassured that it does not matter and (with their permission) the external examiner may be briefed and advised that this should not be taken into account.

9   Ambiguous questioning may fluster the candidate and s/he should be provided with specific strategies to seek clarification, such as saying, '*Please will you repeat /rephrase the question'*. The examiner should be encouraged to ask short clear questions and to give time to respond, and to ask supplementary questions if further elaboration is needed. Having the opportunity to practise asking for clarification so on is likely to put the candidate at ease.

10   The examiner may be briefed to use phrases like, '*I'm going to stop you there and ask you a slightly different question on the same theme'* if the candidate is going off the point. Questions like, '*Can you say a little more about that'* might be ambiguous (and could elicit a yes or no response) therefore a degree of prompting may be necessary. The candidate should be briefed that the examiner may use such strategies (which could be demonstrated in a practice session).

11   Post-viva feedback needs to occur as soon as possible and be very specific and sensitive. Many candidates who have AS are perfectionists and have low self esteem, despite being high achievers. The candidate needs to leave the feedback session knowing exactly what they have done well, and what they need to do in order to complete. It is also important to spell out that it is usual to have to make some amendments (a topic which should have come up during viva preparation). All feedback should be followed up in writing ASAP and by the agreed date. The candidate will certainly be waiting anxiously for this communication and may over interpret any delay.

12   Assistance should be made available for any follow-up action and the candidate will need this to be clarified in writing, and discussed carefully, in order for them to avoid doing unnecessary rewriting

13   If the candidate fails their PhD, it is essential that a safety net is put in place. An MPhil is likely to be perceived as a fail and very careful discussion, on more than one occasion, around the merits of this award, will be necessary.

14   The candidate may find it useful to have an advocate with them when the feedback is discussed and should be given this option.

References

Adams M and Brown S (Eds) (2006) *Towards inclusive learning in higher education: developing curricula for disabled students* London/New York: Routledge.

Arnold L (2003) *Neurological difference page* available from www.larry-arnold.info/Neurodiversity/index.htm (accessed 21 April 2010).

Asperger H (1944) Autistic psychopathy in childhood: a translation of the paper by Frith in U Frith (Ed) (1991) *Autism and Asperger syndrome* Cambridge: Cambridge University Press.

Attwood T (2007) *The complete guide to Asperger's syndrome* London: Jessica Kingsley.

Baron-Cohen, S (2000) Is Asperger's syndrome/high functioning autism necessarily a disability? *Development and Psychopathology Millennium Edition* 489–500.

Baron-Cohen S and Swettenham (1997) Theory of mind in autism: its relationship to central coherence in D Cohen and F Volkmar (Eds) *Handbook of autism and pervasive developmental disorders (*2nd edn) London: John Wiley and Sons.

Beardon, L (2009) *Asperger syndrome and mental health* London: Jessica Kingsley.

Beardon L and Edmonds, G (2007) *ASPECT Consultancy Report: a national report on the needs of adults with Asperger syndrome* available from www.shu.ac.uk/autismcentre (accessed 21 April 2010).

Beardon L, Martin N and Woolsey, I (2009) What do students with Asperger syndrome or high functioning autism want at college and university: in their own words *Good Autism Practice Journal* 10, 2, 35–43.

Beaumont R and Newcombe P (2006) Theory of mind and central coherence theory in adults with high functioning autism and Asperger syndrome *Autism The International Journal of Research and Practice* 10, 4, 365–382.

Bogdashina O (2003) *Sensory perceptual issues in autism and Asperger syndrome: different sensory experiences – different perceptual worlds* London: Jessica Kingsley.

Bogdashina, O (2005) *Communication issues in autism and Asperger syndrome – do we speak the same language*? London: Jessica Kingsley.

Brabazon, T and Fearn, H (2009) Doctoring the system: improving the structures that support doctoral students can turn around completion *Times Higher Education* 22 October 2009, 31–36.

Buzan T (1974) *Use your head* London: BBC.

Disability Discrimination Act 2005, Part 4 London: Disability Rights Commission.

Disability Equality Duty (2006) available from www.direct.gov.uk/ded (accessed 21 April 2010).

Fleischer L (1989) *A Barry Levinson film, Rainman: a novel based on a screenplay by Ronald Bass and Barry Morrow* London: Guild Publishing.

Gillberg C (2002) *A guide to Asperger syndrome* Cambridge: Cambridge University Press.

Grandin T (1996) *Thinking in pictures and other thoughts on my life with autism* New York: Vintage Books.

Grandin, T (2003) *Animals in translation* London: Bloomsbury.

Haddon, M (2003) *The curious incident of the dog in the night time* Oxford: David Fickling Books.

Happe, F, Booth, R, Charlton, R and Hughes C (2006) Executive function deficits in ASD and AD/HD: Examining profiles across domains and ages *Brain and Cognition* 6, 11, 25–39.

Howlin, P, Baron-Cohen, S and Hadwin, J (2000) *Teaching children with autism to mind read* Chichester: John Wiley and Sons.

Hughes, P J (2007) *Reflections: Me and planet weirdo* London: Chipmunka Publishing .

Lawson W (2001) *Understanding and working with the spectrum of autism: an insider's view* London: Jessica Kingsley.

Lawson, W (2003) As a woman with Asperger syndrome *Autism Asperger Publishing Company Newsletter* May /June 2003 available from www.asperger.net/news letter_mayjune03lawson.htm (accessed 21 April 2010).

Leekam S, Libby S, Wing L, Gould J and Gillberg C (2000) Comparison of ICD10 and Gillberg's criteria for Asperger's syndrome *Autism: The International Journal for Research and Practice* 4, 1, 11–28.

Madriaga, M, Goodley, D, Hodge, N and Martin, N (2008) *Experiences and identities of UK students with Asperger syndrome* available from www.heacademy.ac.uk/events/detail.researchseminar/08 feb (accessed 21 April 2010).

Madriaga, M and Goodley, D (2009) Moving beyond the minimum: Socially just pedagogies and Asperger's syndrome in UK higher education *International Journal of Inclusive Education* 1–15.

Martin, N (2007) Personal Statements. Helping transition to further education and employment *Good Autism Practice Journal* 8, 2, 17–21.

Martin, N (2008) *REAL services to assist students who have Asperger syndrome* NADP Technical Briefing 4/2008.

Martin, N, Beardon, L, Hodge, N, Goodley, D and Madriaga, M (2008) Towards an inclusive environment for university students who have Asperger syndrome *The Journal of Inclusive Practice in Further and Higher Education* 1, 3–15.

Murray, D (2006) *Coming out Asperger: diagnosis, disclosure and self confidence* London: Jessica Kingsley.

Premia Project (2007) *Making research education accessible: an accessible viva* available from *www.premia.ac.uk* (accessed 21 April 2010).

Richards, R (2008) Writing the othered self auto ethnography and the problem of objectification in writing about disability and illness *Journal of Qualitative Health Research* 18, 12, 1717–1728.

Tantam, D (2000) Psychological disorders in adults and adolescents with Asperger's syndrome *Autism*: *The International Journal of Research and Practice* 4, 1, 47–63.

Valentine, J (2002) Naming and narrating disability in Japan, In M Corker and T Shakespeare (Eds) *Embodying disability theory, disability and postmodernism* London: Continuum.

Woolsey, I (2007) *Patterns of social and educational support for students with Asperger syndrome/high functioning autism in Further and Higher Education in the United Kingdom* available from www.shu.ac.uk/ autismcentre (accessed 21 April 2010).

Parents' responses to having a child on the autism spectrum: Issues, challenges and ways to address these

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Editorial comment

The response of parents and families to having a child on the autism spectrum varies from family to family and at different times and stages of the child's life. It is important to consider the factors which lead to positive well-being and those factors which appear to distress and disable the family. In this study, Dr Clare Boorn, an Educational Psychologist, conducted two studies. The first explored the reactions and views of 23 mothers with children on the autism spectrum, using a rating scale. The second looked at the effects of running a group for six mothers and three fathers which provided information on the autism spectrum and gave the opportunity for sharing ideas and discussion. The findings and methodology will be of interest to all those who work with families and to other parents of children on the autism spectrum.

Introduction

The first study explored the perceptions of parents who had a child on the autism spectrum, with a particular focus of exploring resilience within their own family. There were 23 parents in this study. Eight children were of primary age and attended two different special schools (5 boys; 3 girls). The remaining 15 children attended the different mainstream schools; 11 of primary age (8 of whom were boys) and four boys in secondary school. Parents' views are a vital source of information and family resilience is a growing area of inquiry. The Lamb Report (2009) highlights how parents need to be listened to more and the systems around them robust in supporting families and helping children progress. The CAHMS review, *Keeping Children and Young People in Mind,* (DCSF and DoH, 2010) refers to supporting families in having:

> '… *clear information, access to suitable and accessible services, and to receive high-quality support at the time when they need it.'* (p 5)

Raising a child on the autism spectrum can be a life-changing event. This study aimed to explore parents' views about some of the daily challenges they face as well as the positive experiences that are evident. It was clear however from the early stages of the first study that some parents who lived in rural areas had limited opportunity to network with other parents and would like to meet as a group to make friends, build relationships and share ideas. The first study was therefore followed by a second study which created a support group for a sub-sample of parents in the first study. A series of workshops was set up at a local Children's Centre with the aim of introducing some of the materials presented through the Inclusive Development Programme: Supporting Pupils on the Autism Spectrum (DCSF, 2009) as well as helping parents to problem solve through a 'Solutions Circle' intervention (Wertheimer, 1995).

Outcomes for children on the autism spectrum depend on many factors but one is the nature and extent of the difficulties presented by the autism; another is the resilience of the rest of family in responding to stress. Investigating factors which may contribute to families becoming stronger is crucial, particularly in directing professionals and external agencies in the planning and organisation of resources within a community.

Literature review

Numerous studies have been conducted to explore resilience within families. The common themes that emerge identify the diversity of coping mechanisms that many families use which include:

• the extended family
• resources within the community and the services received by young children with autism and their families (Kohler, 1999)
• access to knowledge and skills

However, for many families the daily stresses and ability to cope depends on the individual child, particularly in terms of behaviour and emotional demands (Hastings, 2002). Coping strategies and parental attitudes play a significant role as to how motivated a parent might be in accessing resources within the community. Parents' belief systems and attributions about having a child with special educational needs are likely to determine the parents' level of readiness to engage with external agencies and other parents within the community. For many parents, stress, low mood and low expectations about their child's future are contributory in determining outcomes. The social and emotional adjustment of other family members is also important. As acknowledged in Pottie and Ingram's (2008) study on stress, coping, and well-being in parents of children with autism, a higher level of daily positive mood and well-being is often connected with emotional and helpful support and interactions around the family. The study concluded the importance of identifying interpersonal processes that improve psychological well-being and emotional health, as well as directing future parenting interventions.

Bayat (2007) investigated factors which increase resilience in families. These included parents having a positive understanding of their child's disability and access to resources. Furthermore, effective parents held a positive perception of life in general as well as gaining spiritual strength. The concept of optimism and expectation drove many adults forward and helped them to reframe challenging periods in their life. The King et al (2006) study explored the belief systems of families with autism and Down syndrome. Focus groups were used to gather data with a number of themes emerging. Parents' priorities altered over time, with many changing their way of thinking. Although some parents 'grappled with lost dreams', positive adaptation was evident, with parents being able to share their hopes and beliefs for the future.

Professionals must recognise that not all families demonstrate confidence and optimism. This may relate to some having limited internal resilience, and reduced protective factors within the family system and the extended community. Coping mechanisms and parental attitudes are key factors in determining parent's emotional health and ability to cope. Adjusting to changes, developing self knowledge, understanding and seeking support within the locality is likely to enhance a family's ability to deal with everyday challenges.

The factors influencing adjustment in the families of children on the autism spectrum have been investigated by Henderson and Vandenberg (1992). This study reported on:

• the severity of the child's disorder (stress)
• the mother's social support (resources)
• their perceived locus of control (perception)

Resilience studies are important in encouraging external agencies to become part of the social support network for parents of children on the autism spectrum. The nature of parental attributions reflects the particular difficulties associated with parenting such as uncertainties regarding cause and their likely outcomes and future lives. Positive family adaptation (Bristol, 1987) is predicted by the adequacy of social support. Families of children on the autism spectrum can work towards identifying, as well as implementing, those strategies which from research have shown can lead to better adaptation, thus increasing their own resilience. Professionals can help in this process.

Study 1: Exploring mothers' reactions to life with a child on the autism spectrum

Sample

Twenty-eight mothers took part in this study, all living in one local authority. They were each asked to complete a rating scale and 23 mothers (82 per cent) returned these. For the purposes of the study, the family was defined as the immediate family unit, that is, mother, father, and siblings, rather than aunts, uncles, grandparents. It was made clear that all information would be treated confidentially and the mothers did not have to include their name or background details. An explanation of the study was shared prior to sending the rating scale through focus groups or when meeting a parent in school.

The rating scale

A blank space after the word 'child' was used to remind the parent to think only of their child with

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autism. Parents were also asked to read each statement and tick (✓) the one response that best described how much they agreed or disagreed with each statement: *Strongly Disagree, Disagree, Agree, Strongly Agree.*

Results

Table 1: **Mothers' responses to statements on the effects of the child in the family (n = 28)**

Statement	Reply	Percentage of mothers
Since the diagnosis of my child with autism, my family and I have learned about others with special needs	Yes	83
	No	17
As a result of the diagnosis of my child with autism there has been some positive changes in my families life	Yes	63
	No	37

Table 2: **Mothers' responses to resilience within the family**

Since the diagnosis of autism, I consider my child to be:	Strongly Disagree	Disagree	Agree	Strongly Agree
what gives me common ground with parents		4	46	50
responsible for my increased sensitivity to people		13	52	33
what gives our family a sense of consistency	17	29	42	8
the reason I am more productive	13	25	52	8
the reason I budget my time better		17	50	33
the reason I am able to cope better with stress and problems	8	8	58	25
what makes me realise the importance of planning for my family's future			46	52

Table 3: **Mothers' responses to resilience within the family**

As a result of the diagnosis there has been some positive changes in my family's life. The presence of my child:	Strongly Disagree	Disagree	Agree	Strongly Agree
is an inspiration to improve my job skills		17	63	21
helps me understand people with differences		8	42	50
is a source of pride because of his/ her achievements			25	8
cheers me up		21	38	42
renews my interest in participating in different activities		42	33	25
makes us more in charge of ourselves as a family		38	58	4
helps me take things as they come		21	54	25

Table 4: Mothers' responses to resilience within the family

As a result of the diagnosis the positive changes in my families life have been that:	Strongly Disagree	Disagree	Agree	Strongly Agree
my circle of friends have grown larger	38	42	21	4
I have someone who shares responsibility for doing several tasks around the house	21	25	38	17
my social life has expanded by bringing me into contact with other parents	42	33	25	
I am more compassionate		13	79	8
I have learned about autism		13	38	50
my family is more understanding about special problems	4	8	67	21
our family has become closer	8	25	50	17
I have learned to adjust to things I cannot change	13	8	58	21
my other children have learned to be aware of other peoples needs and their feelings	13	8	54	25
I have many unexpected pleasures		13	50	38
I am more accepting of things	8	17	62	13

Table 5: Mothers' responses to resilience within the family

Because of my child with autism:	Strongly Disagree	Disagree	Agree	Strongly Agree
my family enjoys spending time together		33	42	25
my family has the support we need to relieve stress	29	25	42	4
my family members have some time to pursue their own interests	25	21	38	17
my family members have friends or others who provide support	8	33	42	17
my family has outside help available to us to take care of the special needs of our child	38	29	33	
my family is able to handle life's up and downs		17	50	33
there is sufficient support for him/ her to make progress at school		33	63	4
my family has a good relationship with the service providers who work with our family members with autism	8	38	54	
there is sufficient support for him/ her to have friends	17	50	33	

Parents' responses to having a child on the autism spectrum: Issues, challenges and ways to address these

Table 6: Mothers' responses to resources they considered would make a difference to their family

- More help in the home- strategies on managing behaviours
- More programmes on TV. /DVD on how to implement strategies
- Networking with parents
- Schools having a greater understanding of some of the complexities and anxieties faced by families
- Holiday clubs/ short term respite/ after school support packages
- More public awareness
- Managing transitions into schools
- Liaison with Schools
- A helpline
- Finding a specialised nursery/ school during the holiday breaks.

Table 7: Mothers' responses to the day-to-day challenges they faced

- Contact with external agencies
- Child care
- Going on holiday
- Christmas period is a difficult time which makes it hard for the rest of the family
- Neighbours and the community- sometimes feeling alienated
- Day-to-day jobs
- Getting employment that is flexible
- Understanding the diagnosis, explaining it to a child and family
- Consistency amongst family in managing behaviours
- Having friends around
- Going out as a family/ partner and having special time
- Day-to-day stresses- wanting to find an answer to why my child has autism
- Once a diagnosis has been made, sometimes it feels like there is less people to speak to and less support available.

Table 8: Mothers' responses to the support they received within the home setting

- Grandparents and extended family
- Neighbours
- Flexibility with job
- Relying on siblings to help and volunteers
- External agencies support EPS, AOR, and HV.

Key findings from Study 1: Exploring family resilience

Many families said they were confident in accessing information since the diagnosis of their child. Although the majority of families felt there had been some positive changes since the diagnosis, a small number (n=5) considered there had not. A number of families believed they had a common bond with other families and were more sensitive towards others. A significant number of parents felt they budgeted their time better and were more able to cope with stressful situations. They felt it was important to plan ahead for the future.

The majority of parents felt the diagnosis of autism had improved their employment skills, led to a better understanding of people with differences and obtained a sense of pride when their own child achieved. As a family, many felt more compassionate in their views and took opportunities to learn about autism. On the whole families were more accepting of problems and had become closer as a family system. Many made adjustments to manage change and siblings were felt to be more observant to other people's feelings and difficulties. Despite the challenges, the families considered that they had time for unexpected pleasures and were more accepting of situations around them.

Interestingly, their ratings on friendships and networking were less positive. Many families considered that their friendship circles had lessened since having a child diagnosed with autism. Their social life had reduced. Also, many families felt that their child with autism did not have opportunities to spend time with other children. Mixed views were also apparent with regard to accessing support. Some parents felt they did not have the mechanisms around them to relieve stress at times and that there were limited opportunities for other family members to access outside help.

Parents on the whole welcomed more help on managing behaviours within the home setting. Although they had the opportunity to access resources through the media (TV, DVD, CD), parents welcomed being taught specific skills for their *unique* child. Parents often sought opportunities to network with other families within the community, to have a closer liaison with schools. Holiday periods were frequently a time for concern with many seeking advice, respite or on knowing what clubs/ school activities were available for their child.

Day-to-day challenges were variable. Some families took the view that they had limited contact with

external agencies. Other felt alienated and on their own at transitional periods such as school holidays. Living in a community made them more aware of challenges such as what the neighbours might think of them with a child with autism. One family said that she felt conscious of leaving the house with her son as the local neighbours could demonstrate intense negativity towards them.

Returning to work could also be a problem for some. Like any family with childcare considerations, finding an employer sympathetic towards being flexible in the work place could present a number of issues. One parent said that getting her child to school in the morning was a traumatic time and this often affected her when she arrived at work. Other families acknowledged that although they were more aware of what a diagnosis meant, it was sometimes difficult to explain this to other family members. Some families welcomed support from external agencies, especially with extended family members (eg grandparents, siblings, teenagers). Consistency in managing behaviours amongst family members was a point of concern for some.

Overall many families said that although they felt more resilient as a family unit, once a diagnosis had been made it felt as if there were fewer agencies and support packages around them, particularly when a child started school.

Study 2: The parent workshops

Having undertaken Study 1, the next stage was to set up a pilot project with *hard to reach parents*. The researcher had become increasingly aware that some rural parents often did not access resources. This second project aimed to empower those parents in the locality and enable them to feel more aware as to what was going on in their local community and school. The community team comprised two outreach workers and a teacher from the autism outreach team and the researcher (an Educational Psychologist). The focus of the content of the project was the Inclusive Development Programme Autism Spectrum (IDP) (DCSF, 2009) materials and sharing resources/resilience examples within the sessions. The local GP surgery had heard about the project and directed some parents to the sessions. Leaflets were distributed to mainstream schools inviting families with a child with autism to attend. A summary of the content was offered for four weekly sessions and all were free of charge. The venue was based in a Children's Centre. There were six children in this sample (four of primary age, two of

secondary age and five of whom had a Statement of Special Educational Needs).

Three planning sessions took place with the Educational Psychologist, Autism Teacher and Outreach workers. It was agreed that the sessions would be a mixture of information giving, a demonstration of the use of resources and strategies, and a problem solving activity based on the technique 'Solution Circles' (Falvey, Pearpoint et al, 1997). The sessions were to be informal with an emphasis on parents feeling relaxed, getting to know each other and to begin to network over the weeks.

Outside speakers included a specialist teacher talking about sensory processing, a teacher demonstrating the use of Social Stories (Gray, 1994) and a member from a specialist centre to highlight some resources within the community. Each week the room was set out with chairs arranged in a semi circle to aid discussion. Display boards and tables allowed parents to review resources at their own leisure. Back ground music was included as parents arrived and tea, coffee and cakes arranged throughout the morning. Nine parents attended each session (six mothers and three fathers).

Prior to the workshops, the parents were asked to complete a self-evaluation checklist to allow the course deliverers to gain an insight into what parents viewed as their strengths and weaknesses in terms of knowledge and skills.

Workshop content
The IDP materials (DCSF, 2009) were used as a basis to inform parents about the new materials being disseminated within the local authority as well as national directives. Areas covered in the workshops included:

An understanding of what is autism: The key components highlighted that the autism spectrum is diverse and covers a range of subgroups but all have needs in common, as well as strengths and interests. The biological basis and diagnostic process was also discussed including the dimensions of intellectual development and severity of autism. School issues were explored where parents and professionals discussed the challenges, which could lead to anxiety, and challenging behaviours.

Social and emotional understanding, communication and language of a child with autism were explored in terms of the difficulties with

socialisation and interaction. Many children may have problems understanding the rules of social engagement, communicating emotions and recognising the feelings of others. The session was interactive with parents exploring literal interpretations using a card game and the effectiveness of Social Stories as a visual tool to support children and young people at all developmental stages. The adults were encouraged to review how they communicated with their own child and how they interpreted responses.

Flexibility of thought and behaviour was discussed and demonstrated through the use of video and resource materials that could support a child at transitional points (e.g. holidays, starting a new class or a school). Parents also had the opportunity to explore how they supported their child with change, decision- making, and routines. Parents were keen to share their child's special interests and how at times these could be used as a motivator.

Some parents wanted to talk about *transition* to a new school/class/place as often they experienced challenging behaviours within the home setting. Parents felt this was often a time when they needed a higher level of support. In pairs, parents were encouraged to undertake small role play examples and then to consider how they might use the resources on display (eg a transitional passport, circle of friends, social stories, a visual timetable, and a tactile sensory object).

In another session that explored *Sensory Perception*, parents were extremely interested in the theoretical knowledge and underpinning as to why many children experienced difficulties when processing information within their environment. Parents shared how their own child could demonstrate over sensitivity or under sensitivity in certain senses or show different tolerance to stimuli. The outside speaker offered an insight into the complexities by showing slides on brain development as well as video clips on individual sensory profiles. In addition, parents had the opportunity to explore the sensory checklist within the IDP materials and to reflect on how a similar checklist could be used within different settings. Parents could create a sensory profile for their own child if this was an ongoing area of concern. The knowledge of sensory processing issues could further support parents when communicating with the school/ class teacher. Over the course of the four weeks parents were encouraged to share their knowledge of their own child and the successful strategies they implemented.

Through the use of the IDP material parents were informed about curriculum priorities and inclusive practice within the school setting. Video clips were used and discussions encouraged with regard to potential difficulties in certain subject areas, as well as the many strengths and areas of interests that their child demonstrated. Parents were shown how to pre tutor their child with a subject, to help them understand the specific terms and rules of an activity before it happened. Revision, homework and exams were areas where parents often highlighted concerns and the difficulties in sharing this with schools at times.

'Solution Circles'
During the sessions, parents not only received a range of information specific to autism, they were also able to problem solve and network with each other which had been a key objective in parents supporting each other. Parents were introduced to 'Solution Circles' – a 30-minute creative problem solving process for getting unstuck. This was demonstrated as a short and powerful tool with an emphasis on *community capacity*. In other words, it could support parents in any community or work place. The course deliverers, with parent's permission, chose a problem that had emerged during discussion and then were encouraged to practise and demonstrate skills within the group. Some of the issues for the solution circles sessions included:

'I always shop on line but would like to go to a large supermarket but because my child causes so much disruption I feel stressed and stay at home.'

'Each year we go on the same holiday, same place and I would dearly love to try somewhere new and to have my other children experience a different place.'

'When I try and sit down and do homework with my child he goes mad. He hates doing work at home and I know he has to do it now he's at secondary school. I don't know how to start and whether I shouldn't do anything. I feel really upset sometimes.'

In the 'Solution Circles' assigned roles were given. These included:

• Problem Presenter (focus person/ parent) presenting a problem to the group:
• Facilitator (and time keeper) facilitating the management of the circle
• Note Taker
• Observer

The following steps were explained and undertaken when a problem was discussed at the end of the session:

Step 1: (five minutes).The parent had up to five uninterrupted minutes to outline the problem. The facilitator introduced the parent and kept structure and time and made sure no one interrupted. The recorder took notes. The facilitator then asked the parent to present their problem while everyone else listened.

Step 2: (five minutes). The facilitator summarised the problem and asked the group to brainstorm- to throw in some initial ideas. Everyone was encouraged to contribute ideas about creative solutions based on what they just heard. The process facilitator made sure everyone had a chance to give their ideas.

Step 3: (five minutes). Time to explore and clarify the problem and ask questions were further encouraged. The facilitator emphasised a focus on the positive points.

Step 4: (five minutes). The problem presenter (parent) and the group decided on how first steps could be achieved within the next three days. At least one step was to be initiated within 24 hours. This was critical as research shows that unless a first step is taken almost immediately, people do not change or implement a strategy.

The facilitator volunteered to phone the parent within three days and to discuss if they had been able to take their first step and to see how they were getting on. Finally the group did a round of words to describe the experience and the recorder gave the record of notes to the parents.

Final session
The final session with the parents reviewed what we had learnt as a group, celebrating the skills and knowledge that had been demonstrated but also giving recognition to the skills the parents had already, prior to the course. Parents expressed a close bonding with many other parents within the group and viewed how they wanted to continue connecting with each other in the future. Telephone numbers were exchanged. It was also helpful to have a representative from a local charity to share with parents how they were able to address the needs of local people. This charity provides education; care and support in local settings offering a diverse range of services tailored to individual families. Parents were asked to complete the self- evaluation checklist that had been completed prior to the workshops in order to check their knowledge again once the workshops had finished.

Results

Table 9: Parents' self-evaluation ratings prior to the workshops (n = 9 parents)

Percentage of parent responses to statements	Very Confident %	Confident %	Limited Confidence %	No Confidence %
I can explain what autism is to my family and friends.		22	33	44
I understand what the triad of impairments is and how they affect my child.	11	11	55	22
I recognise that autism affects children in different ways.	11	55	11	22
I am aware of how a child with autism may have sensory processing difficulties (smell, sight, touch).	11	22	55	22
I know how to adjust my communication style to facilitate interactions with my child.	0	33	44	22
I understand that a child with autism can have an uneven profile as they develop.	0	55	22	22
I have opportunities to meet other parents with autistic children and to learn new ideas.	0	22	44	33

Parents' responses to having a child on the autism spectrum: Issues, challenges and ways to address these

Percentage of parent responses to statements	Very Confident %	Confident %	Limited Confidence %	No Confidence %
I understand how my child with autism may have difficulty with social understanding.	22	44	22	11
I adjust my language to help my child understand spoken instructions.	22	44	22	11
I know that a child on the autism spectrum may have difficulty with change and in predicting what might happen next.	11	55	22	11
I know how to put structure and predictability into unstructured times.	0	33	44	22
I have knowledge of how my child on the autism spectrum might be affected across subject areas at school.	0	22	44	33
I know the people within school from whom I can get advice and support regarding my child on the autism spectrum.	11	33	33	22
I know how to access information on the autism spectrum within the community.	0	22	44	33
I know how to extend the play skills of my child with autism.	11	22	33	33

Table 10: Parent self-evaluation ratings after the workshops (n = 9)

Percentage of parent responses to statements Confidence	Very Confident %	Confident %	Limited Confidence %	No Confidence %
I can explain what autism is to my family and friends.	44	55		
I understand what the triad of impairments is and how they affect my child.	33	55	11	
I recognise that autism affects children in different ways.	33	66		
I am aware of how a child with autism may have sensory processing difficulties (smell, sight, touch).	66	22	11	
I know how to adjust my communication style to facilitate interactions with my child.	22	66		
I understand that a child with autism can have an uneven profile as they develop.	88	11		
I have opportunities to meet other parents with autistic children and to learn new ideas.	100			
I understand how my child with autism may have difficulty with social understanding.	77	22		
I adjust my language to help my child understand spoken instructions.	11	77	11	

Percentage of parent responses to statements	Very Confident %	Confident %	Limited Confidence %	No Confidence %
I know that a child on the autism spectrum may have great difficulty with change and in predicting what might happen next.	88	11		
I know how to put structure and predictability into unstructured times.	66	22	11	
I have knowledge of how my child on the autism spectrum might be affected across subject areas of school.	77	22		
I know the people within school from whom I can get advice and support regarding my child on the autism spectrum.	77	22		
I know how to access information on the autism spectrum within the community.	100			
I know how to extend the play skills of my child with autism.	22	55	22	

Review of findings from Study 2

Having delivered the sessions it was apparent from the ratings on the checklist that all parents felt better informed in explaining what autism was to family and friends particularly in terms of the triad including sensory processing difficulties, and how autism could affect individual children in different ways. Initially, many parents considered they had a basic understanding and had access to information through the internet but the sessions allowed for an open discussion around unique children, uneven profiles and the strengths that all had.

What was particularly apparent was that all parents welcomed networking with each other. The sessions were not about highlighting difficulties and deficits but rather diversity and strengths. Parents felt more able to consider how they could adjust their interactional style and language to help their child but also how to implement structure and consistency.

In addition, all parents felt much more informed about the school curriculum and were able to view the challenges that could emerge across subjects. A notable discussion point was the homework with one adult commenting 'it would be great if someone could come up with an alternative name as it causes so much reaction in our house!' Parents felt more confident to know what the role of the SENCO was in school and to understand the code of practice of SEN as well as the statementing process. Parents commented on having a home school liaison book and therefore felt uncomfortable to seek further

assistance. It was pleasing to also observe how informed parents were from listening to the an Outreach Worker who discussed resources in the community and indeed how these could be tailor-made for individual families.

The pre- and post-evaluations showed a positive shift on all dimensions. This is not uncommon when individuals attend a course but from observation, parents had a forum to ask questions, to discuss concerns and to learn from each other. The 'Solution Circles' as an intervention was a strategy that parents wanted to develop further and to have other opportunities to explore issues as they arose. In many ways four sessions only allowed the parents to have a brief experience, but it was recognised that this workshop was a pilot and aimed to help the course deliverers to consider how the project could be extended further in the community.

Qualitative data highlighted that parents wanted to continue meeting, as friendships had started to be established. Many reported on how useful it would be to extend the course to grandparents and siblings as well as their own child with autism. One parent asked how shops in the locality could be better informed in terms of being autism friendly as this for her was an area of ongoing concern. Furthermore, another parent asked if there would be opportunities to learn how to play with her child and to have more fun. She tended to follow a manual guide and tried to offer ongoing consistency and structure but yet she yearned for a floppy day where

she had the confidence and skills to interact more effectively. Such feedback from parents provided a wealth of information for future courses.

Concluding comments

From reviewing Study 1, it was evident that by listening to parents and obtaining their views as to some of the challenges but indeed the strengths they had within their own system, this opened up a gateway to considering those parents who may not have protective mechanisms around them. How could vulnerable families be reached, supported and encouraged to work with each other? The second study allowed this to take place through a pilot project with the view that psychology could support the relationships of individuals in a community, to address common issues and to seek to understand and to enhance quality of life for all. The project had a strong focus on prevention and early intervention as a means to solve problems, and to help parents feel more empowered with the view that the environment could also be modified around them. Face-to-face communication with parents, treating them as equal partners with expertise in their own children's needs was crucial in establishing and sustaining confidence, as pointed out in the Lamb inquiry (DCSF, 2009).

This pilot study further demonstrated an example of an evaluation undertaken by an educational psychologist working alongside other agencies. The impact on outcomes for *parental confidence* formed a key part of the process allowing for parents to have a *stronger voice* and opportunities *to access* the information that they needed. It aimed to build on com*munity strengths* encouraging parents to support each other but also to be scaffolded within a multi agency network.

Over the years there has been much research centred on identifying the risk factors and approaches that do not work well for families. Looking ahead, in contrast, there need to be more studies that focus on good practice within multi agency systems, as well as identifying specific protective factors that constitute positive relationship building in communities and the processes where intervention programmes have made an impact.

References

Bayat, M (2007) Evidence of resilience in families of children with autism *Journal of Intellectual Disability Research* 51, 9, 702–71.

Bristol, M M (1987) Mothers of children with autism or communication disorders: successful adaptation and the double ABCX model *Journal of Autism Development Disorder* 17, 4, 469–86.

DCSF and DoH/Children's Mental Health Teams (2010) *Keeping children and young people in mind – full government response to the CAMH*S London: DCSF/DoH.

DCSF (2009) *The Lamb Inquiry: special educational needs and parental confidence*, London: DCSF

King, G, Baxter, D, Rosenbaum, P, Zwaigenbaum, L and Bates, A (2009) Belief systems of families of children with autism spectrum disorders or Down syndrome *Focus on Autism and Other Developmental Disabilities* 24, 1, 50–64.

Keller, C and Nicolls, R (1991) Coping strategies of chronically ill adolescents and their parents *Int Disabil Studies* 13, 4, 138–40.

Kohler, F (1999) Examining the services received by young children with autism and their families: A survey of parent responses *Focus on Autism and Other Developmental Disorders* 14, 150–159.

Henderson D, and Vandenberg B (1992) Factors influencing adjustment in the families of autistic children *Psychol Report* 71, 1, 167–175.

Pottie, C and Ingram, K M (2008) Daily stress, coping, and well-being in parents of children with autism: A multilevel modeling approach *Journal of Family Psychology* 22, 6, 855–64.

Accredited courses in Autism

compiled by Stephanie Robinson

Note: This list is not exhaustive. If you know of other courses which are not mentioned here, please write to the editors

Institution	Qualifications	Delivery	Duration/Credits	Assessment methods	Entry requirements	Details from
Strathclyde University Glasgow	Postgraduate Certificate in Autism Postgraduate Diploma in Autism Masters in Autism	Campus, evening; outreach course possible within Scotland. Distance course likely	All at M level Four modules; 60 credits 8 modules; 120 credits 180 credits	Each module has 3,000 word assignment or equivalent	Normally a first degree or equivalent, plus relevant experience in autism; accreditation for prior formal and experiential learning may be given; multi-professional intake	Aline-Wendy Dunlop Senior Lecturer and Course Director University of Strathclyde Jordanhill Campus 76 Southbrae Drive Glasgow G13 1PP
University of Cumbria	University Certificate in Autism Postgraduate Certificate in Autism		Level H, 60 credits Level M, 60 credits			Dr Steve Mee (Steve.Mee@cumbria.ac.uk)
Lancaster University/ Autism Initiatives	Practical Approaches to Supporting Children and Young People with an ASD *stand-alone module or Advanced Professional Studies	Autism Initiatives in Crosby Other venues	Six × 180 minute sessions	NVQ Level 3 Masters level: 5,000 word assignment	Experience of working or living with a person with autism	Sharon Hanner Education Outreach Autism Initiatives 7 Chesterfield Road Crosby Merseyside L23 9XL
University College of Worcester/ autism.west midlands	Certificate in the Education of children with Autism – offered at undergraduate level and at Level M	Taught in various locations across the Midlands and at University of Worcester	Three module course. Module 1:30 hours taught; Module 2: action research project in own time+ tutorials; Module 3: independent study	Three × 3,500 word assignments	Aimed at anyone working and/or living with ASD. Degree required for Level M	Elizabeth Attfield Training Department autism.west midlands 18 Highfield Road Edgbaston Birmingham B15 3DU 0121 450 7576 training@autismwestmidlands.org.uk

Institution	Qualifications	Delivery	Duration/Credits	Assessment methods	Entry requirements	Details from
autism.west midlands operating as a BILD satellite centre	Learning Disabilities Award Framework Autism Unit at Level 2 and 3 Accredited by Open College Network	Delivered in various venues in the West Midlands	Two days teaching	Completion of assessment booklet	To be working/supporting children or adults with autistic spectrum disorder	Julie Keen Training Department autism.west midlands 18 Highfield Road Edgbaston Birmingham B15 3DU 0121 450 7576 training@autismwestmidlands.org.uk
Univerisity of Birmingham, School of Education	University Certificate (ASD) Certificate in Higher Education (ASD)	Web-based with support from regional tutor	One year, PT, 60 credits Level C Two years, PT, 120 credits Level C	Portfolio of work based on practice for each module	No formal qualifications required other than normally expecting two years' relevant experience of working with or caring for children or adults with autism.	Karen Guldberg School of Education University of Birmingham Edgbaston Birmingham B15 2TT k.k.guldberg@bham.ac.uk
University of Birmingham, School of Education	Advanced Certificate in Autism (ACE) (Level H)	Distance education or campus, 1 year, PT	For distance course materials posted with six tutorials with a regional tutor and other students throughout the year, plus two study weekends	Three × 3,000 word assignments	For Level C Professional qualification (eg in teaching, social work or nursing) and at least 2 years'relevant work experience with children or adults	Reception School of Education University of Birmingham Birmingham B15 2TT 0121 414 4866 E-mail: education@bham.ac.uk
	BPhil in Autism (Level H)	Distance education or campus, 2 years, PT		Four × 3,000 word assignments, plus a dissertation of 10,000 words	OR	
	Postgrad Cert (Level M) in Autism	Distance education or campus, 1 year, PT	Campus Tuesday evenings from 5–8pm at Birmingham University	Three × 4,000 word assignments	At least two years' FT study in higher education and at least 2 years' relevant work experience with children or adults	
	Postgrad Diploma (Level M) in Autism	Distance education or campus, 2 years, PT		Six × 4,000 word assignments	For Level M, as for Level C, but a first degree or advanced qualification needed	
	MEd (Level M) in Autism	Distance education or		Five × 4,000 word assignments and a	In exceptional cases, long experience may be considered in an APEL	

Institution	Award	Mode	Structure/Duration	Assessment	Entry requirements	Contact
	These awards are available for those working with ADULTS or CHILDREN with ASDs, but the course on ADULTS is only available by distance	campus, 2 years, PT		research module plus a dissertation of 15,000 words	arrangement for Level C entry	
Sheffield Hallam University	Certificate in Understanding Autism	Campus	Six units over two years, one evening a week. Units may also be taken individually 120 credits	Combination of written assignments and oral presentations	Ability to work at University Level 1 and an interest in autism	Professional Development Programme School of Education Sheffield Hallam University Collegiate Crescent Campus Sheffield S10 2BP 0114 225 2306 OR Nick Hodge/Luke Beardon 0114 225 5645
	Diploma in Autism	Campus	Five units over two years, one evening a week		QTS and an interest in autism	
	Postgraduate Certificate in Autism	Campus	Two units over 12 months, one evening a week		Normally a degree and an interest in autism	
	Postgraduate Diploma in Autism	Campus	As Postgrad. Cert but four units over two years		Normally a degree and an interest in autism	
	MA (Autism)	Campus	Four units, plus a dissertation, over approx. three years		Normally a degree and an interest in autism	
Sheffield Hallam University/The National Autistic Society	Post Graduate Certificate in Asperger Syndrome	Off campus, various sites around the UK	Two units over one year. Unit 1: three days over a six-week period; Unit 2: Work-based learning with tutorial support	Written assignments	Normally a degree and an interest in Asperger syndrome	Luke Beardon 0114 225 5645 The National Autistic Society 0115 911 3363

Institution	Qualifications	Delivery	Duration/Credits	Assessment methods	Entry requirements	Details from
University of Hull	University Foundation Award Level 4 in QA Higher Ed National Qualifications Framework	St Luke's School Scunthorpe	One evening a week during term time for three terms	Portfolio of assessed work and an assignment of 3,000 words	For classroom assistants, teachers or parents. No formal entry requirements	Jenny Burnett Centre for Lifelong Learning University of Hull 49 Salmon Grove Hull HU6 7SZ 01724 844560
University of Wales, Newport School of Education	Postgrad Cert in Autism Postgrad Diploma in Autism Masters in Autism	Part-time evenings only; Full-time day and evenings	Four taught 30-credit modules at Level M plus 60 credit dissertation one to two years FT 3–5 years PT	Each taught module has a 5,000 word assignment. Dissertation is 15,000 to 20,000 words	A first degree or relevant experience in autism	Chris Heard University of Wales School of Education PO Box 179 Caerlon Campus Newport NP18 3YG

Book reviews

Title:

Boy Alone: A Brother's Memoir

Reviewed by:
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Birmingham

Author: **Karl Taro Greenfeld**
Year of publication: **2009**
Published by: **Harper Collins**
ISBN: **978-0-06113-666-5**
Number of pages: **368**
Cost: **£14.99**

Many practitioners will be familiar with the trilogy of books written by Josh Greenfeld in the 1970s and 1980s: *A Child Called Noah*, *A Place for Noah*, and *A Client Called Noah*. Based on his own diaries, they chronicle the Greenfeld family's journey through the then almost non-existent world of schools and services for children with autism as his severely affected son Noah grew into his teenage years. Greenfeld's acerbic and sometimes combative narrative portrayed a family in crisis.

Noah's brother, Karl, was a vividly drawn character in these books, and has now revisited his family's experience from a sibling's perspective, updating the story now that both brothers are middle-aged men. This account sheds more light on topics that the elder Greenfeld was unable to discuss in detail, such as Noah's rejection from Ivar Lovaas's programme at the University of California due to lack of progress. He very ably discusses the roadblocks to setting up services and finding decent personnel that blighted the life chances of autistic children at the time. There are sections that will make thought-provoking reading for today's practitioners as well. His family was on the receiving end of a long line of '*evangelical educators or careerists who saw in the Noahs of this world a ticket to academic or professional success*,' Greenfeld writes: '*When it became obvious that Noah could absorb a dozen miracles before manifesting any loaves or fishes, these types would lose interest*' (2009, p 147).

Greenfeld makes it clear that growing up with a severely autistic sibling coloured his life choices in many ways, and in the early years those were often negative. Support groups for siblings were unknown

at the time, and the stigma attached to autism (and the need for his parents to literally create and run their own schools and services) isolated his family and created a difficult internal dynamic within which Noah was necessarily the main focus. Karl describes being torn between feelings of tenderness and responsibility on the one hand, and resentment on the other. He frankly discusses the rebellious behaviour he chose as a teenager and young adult, including becoming a disciplinary problem at school and constructing complex fantasy worlds, and eventually drug use, petty theft and vandalism.

And yet it was his compassionate side that won out, eventually allowing him to move into mature adulthood with a successful career and happy family life. He is now his brother's guardian – but the outcome for Noah, he explains, has been much less positive. Until the state of California changed its policies on care for disabled adults a few years ago, Noah was incarcerated in a series of state institutions once his parents were no longer able to manage him alone due to their own age and ill health. In this uncaring system, despite his family's best efforts, he was physically and sexually abused, and drugged for behaviour control. He learned to use pre-emptive aggression to keep staff and fellow inmates at bay. Although Noah is now in a community setting, these defensive behaviours remain, and he has lost many of the skills his parents worked so hard to help him learn.

The final section of the book I found problematic – it involves a tricky piece of writing in which Greenfeld plays on the 'cure' narrative to prove a harsh point. Some readers may find that his effort

goes too far. Like his father's books, Greenfeld's is a blunt and honest account of living with autism, but without an adequate support system for either people with autism or their families. It makes for sobering reading.

Title:

Working with Adults with Asperger Syndrome: A Practical Toolkit

Reviewed by:
Damian Milton, MA, BA (Hons), PGCE, IfL (Member)

Authors: **Carol Hagland and Zillah Webb**
Year of publication: **2009**
Published by: **Jessica Kingsley**
ISBN: **978-1-84905-036-4**
Number of pages: **156**
Cost: **£29.99**

This book has been designed as a resource for practitioners supporting adults with a diagnosis of Asperger syndrome (AS) through the use of practical advice and case vignettes. The development of the book was supported by an NHS Trust and Surrey Social Services, and it is primarily for the use of health and social care professionals. It is suggested by the authors that a greater awareness of the problems faced by AS adults can make a huge difference to their lives. The authors contend that the advice given is easy to apply in practice and uses a person-centred approach. Despite this intention, the text fails in this regard for a number of reasons.

The book is divided into ten sub-sections ranging from communication difficulties to mental health. Within each section a number of problems are highlighted for consideration (over 50 in total), without mention that a condition of AS could also provide potential benefits or areas of strength, nor how these might be used to compensate for areas of potential weakness. The case vignettes used are not direct quotes from AS adults, but composites drawn from the authors' experiences, thus effectively silencing the AS 'voice' from speaking on its own terms. This leaves the power to define firmly in the hands of the professional onlooker, and denies a person-centred approach by making generic portrayals stand in for authentic experience.

Both the authors have worked as clinical psychologists in the field of learning disabilities.

Their experience, however, may be unduly entrenched within this tradition, leading to conclusions based on their perceptions of a minority sample: those with AS who have come to the attention of health services. The authors only use three references as evidence in support of their techniques, and use an outdated nomothetic, cognitive model, framing AS adults as suffering from a developmental disorder, pathologically deviating from an idealised norm. The book does recommend some useful activities (eg social stories, circle of friends), yet interprets the use of these through a distorted lens.

Despite giving a caveat that all AS people differ from one another and that a practitioner should get to know the individual in their care, the book proceeds to describe AS people using sweeping universalisms: as sharing a number of typical behavioural characteristics; as inevitably talking at length, 'driving others away as a result'; lacking Theory of Mind (without referencing Simon Baron-Cohen or his critics); not realising 'they' are getting things 'wrong'; upsetting others; incapable of picking up hints; easily distracted (even from special interests); unable to know when a 'white lie' is called for; behaving in ways that are 'unusual to the rest of us'; and rigid and unimaginative. They are further described as people whose behaviour can result in bullying; whose characteristics will make them unattractive to others; who would put 'their needs first every time'; and as unable to be taken at face value in their exclamations:

'*If you find that a person with AS repeatedly says things like "you don't understand," this can be their way of telling you that they are confused and struggling with the conversation.*' (Hagland and Webb, 2009, p 28)

It could equally be that you, in fact, do not understand.

By defining AS adults as a disordered 'other', the authors construct a notion that AS adults are incapable of self-determination or analysis, and that their problems must be managed by professional outsiders in order for them to live more appropriately in 'normal' society. As an adult with a diagnosis of Asperger syndrome, this reader found the text to be highly stereotypical, and potentially damaging when in the hands of under-trained practitioners. I would recommend that this book be read as a guide on what not to think and how not to act when supporting those on the spectrum. With increased funding to be awarded to the training of health and social care staff outlined in the government's autism strategy, one can only hope that the training materials used are of a higher standard and take on board the voices of AS people themselves.

Title:

Disabled Church, Disabled Society: The Implications of Autism for Philosophy, Theology and Politics

Reviewed by:
Dr Mitzi Waltz,
Lecturer in Autism Studies,
Autism Centre for Education
and Research, University of
Birmingham

Author:	**John Gillibrand**
Year of publication:	**2010**
Published by:	**Jessica Kingsley**
ISBN:	**978-1-84310-968-6**
Number of pages:	**224**
Cost:	**£22.50**

Gillibrand is an Anglican priest in Wales, a theologian, and the parent of a severely autistic son. In this book he tells his family's own story briefly, using it as a jumping off point for a thought-provoking discussion of how the realities of caring for his son have impacted his theology. He writes passionately – sometimes angrily, when discussing how both church and state have fallen short – of how '*Adam's life has...taught me the absolute priority of care and kindness, indeed of love, over all things, and over all other values*.'

From a theological point of view, Gillibrand highlights and decries ways in which the Anglican tradition continues to see disability as a consequence of sin, 'original' or otherwise. His lengthy interpretation of the Biblical passages often used to back up this belief are enlightening, detailed and challenging. He considers a wide variety of later viewpoints that challenge (or buttress) traditional views, ranging from medieval mysticism to 20th century philosophy. This is all written in a highly accessible way, and should be of interest to anyone who wants to engage with the 'big questions' about autism, disability, and ethics. His use of Jacques Derrida's work to critique some of the foundational issues in Western philosophy in relation to autism is particular clearly written – something of a feat, given that Derrida is notoriously complicated to read.

Gillibrand concludes with an intriguing political turn, in which he explores how a properly thought through Judeo-Christian ethic should impact social services and supports, as well as societal attitudes. This is a particularly important read for individuals working in religious institutions, including those providing pastoral care in faith schools or teaching Religious Education, but will be of interest to many others as well.

Book reviews

Title:

Practical Behaviour Management Solutions for Children and Teens with Autism – The 5P Approach

Reviewed by:
Amanda Appleby Payne,
Inclusion Manager,
MLD School

Author: **Linda Miller**
Year of Publication: **2010**
Publisher: **Jessica Kingsley Publishers**
ISBN: **978-1-84905-038-8**
Number of pages: **175**

Linda Miller is a chartered educational psychologist and chartered scientist with a specialism in autism and related disorders. She currently works as Operations Director for the UK-based Eagle House Group and has more than 25 years' experience in education. She has worked closely with schools and parents, providing consultation and assessments, advice on behaviour management and given support to schools in developing policy and provision. Linda has also played a key role in developing local authority autism policy in the UK and contributed to the national Autism Good Practice Guidance.

One of the greatest demands on parents and professional when caring for children and young adults with autism is the challenge they face when managing a wide variety of behaviour. The aim of this book is to provide a *'How to do it'* framework for behaviour intervention with the focus on prevention and establishing long term change. It reinforces good autism practice throughout.

The 5P approach brings together a number of elements which provides an overall strategy for successful behaviour management. These include:

• Organising an appropriate environment
• Teaching new skills and coping strategies
• Preventing and diverting behaviour
• Dealing directly with behaviour difficulties

The book consists of seven chapters that are easy to read with clear explanations and what I particularly liked was the constant reference to individuality. Chapter 1 gives an overview of the understanding of the nature of autism and the implications this may have in relation to behaviour. Chapter 2 follows with good autism practice suggestions for establishing autism friendly environments and introduces the 5P traffic light approach. Chapter 3 finally introduces

the 5P approach giving a general overview, identifying the five elements involved as:

• Profiling
• Prioritising
• Problem Analysis
• Problem solving
• Planning

Chapter 4 is dedicated to the final phase of planning for intervention and includes a photocopiable intervention framework record. Included in this are flowcharts to help staff/parents identify the behaviour that needs addressing but also some feelings management charts to use with the young person. These are colour coded and follow the traffic light system of green, amber, red. I have used very similar resources with pupils allowing them to be involved successfully in the management of their own behaviour.

The final chapters (5, 6 and 7), and the most useful I feel, give additional guidance and supporting materials, including case studies. Examples of observation frequency charts, visual resources and strategies for behavioural intervention are what I feel practitioners will find most helpful. The four case studies show the 5P approach in action and how it can be used successfully.

This practical book is a useful resource for parents and professionals who have already experienced a young person with autism, it reinforces good autism practice, but it is nothing new. Professionals new to autism will need to read further into the subject (references are given for further reading) and find more detailed examples on how to create an effective working environment. I would recommend it to my colleagues in an MLD setting and it would be useful for SENCOs in mainstream schools to use in supporting teaching staff.

Notes for contributors

Aims and content of the publication

1   The aim of the journal is to publish examples of good practice (or an analysis of the issues affecting practice) in working with, or supporting, individuals with autism spectrum and their families throughout their lives. This does not imply 'best' practice, but practice that is judged to be innovatory or helpful for others to know about. Papers should not previously have been published nor be under consideration elsewhere.

2   Each paper submitted will be refereed by at least one anonymous referee as well as by the editor.

3   Length of papers. Each issue will aim to have around four or five papers of between 3,000 and 4,000 words, plus two or three papers between 1,000 and 2,000 words. There may be photographs, diagrams and tables.

4   The journal will also take reviews of books, vidoes, educational or in-service packages, computer programs and TV programmes related to practice. These will normally be commissioned by the editor, so voluntary reviews should be checked with the editor before submission.

Form in which papers should be submitted

5   Papers may be submitted as an electronic attachment or in paper form.

6   Authors should provide two title pages. One should contain the names, affiliations, full mailing address plus telephone, fax, e-mail address. The second title page should contain the title only. This is so the referee(s) will not be able to identify the author(s) when refereeing.

7   Please number all the pages except the title pages and include any acknowledgements, an address for correspondence; main text; references; appendices.

8   Articles submitted for publication must be word processed or typed in double spacing throughout (including all notes and references), on one side only of white A4 paper, with generous left- and right-hand margins. Pages should not be stapled. Titles and section headings should be clear and brief and maximum of three orders of heading.

9   Quotations. Lengthy quotations (exceeding 40 words) should be displayed and indented in the text. These are not to be encouraged. It is the author's responsibility to check all quotations for infingement of copyright and to obtain formal permission to use the quotation formal.

10   Tables and figures should have short, descriptive titles, and be clearly numbered. All footnotes to tables and their source(s) should be typed below the tables. Column headings should clearly define the data presented.

Confidentiality

11   It is the responsibility of the author(s) to ensure that all those who have contributed to the paper or the work presented are acknowledged and that they have given their written permission for the article to be published. The names of all individuals, schools, establishments, local authorities, towns and cities should be changed or omitted, so that they are not identifiable.

References

12   The references should be listed alphabetically in full at the end of the paper, in the following style:

Happé, F (1995) *Autism: an introduction to psychological theory* Cambridge, MA: Harvard University Press.

Hobson, R P (1989) Beyond cognition: a theory of autism, in G Dawson (Ed) *Autism: nature, diagnosis and treatment* New York: Guilford.

Sigman, M D, Kasari, C, Kwon, J and Yirmiya, N (1992) Responses to the negative emotions of others by autistic, mentally retarded and normal children *Child Development* 63 (3), 796–807.

In multi-authored articles, the names of all authors should be given in the reference list.

13 Language and terminology. Jargon, or unnecessary technical language, should be avoided. Wherever possible, use non-discriminatory language that places the person first (eg 'adults with autism' rather than 'autistic adults') and is not sexist (eg does not assume that all children are boys, all teachers or support staff women) nor racist.

14 Abbreviations. As far as possible, avoid initials, except for terms in common use. Abbreviations that are common enough to be in the dictionary (eg IQ and USA) are acceptable.

15 Copyright will be the publisher, BILD. Authors will be obliged to sign a form indicating their acceptance of this.

16 Paper copies or e-mail attachments should be sent, as explained on the Aims and scope page to Dr Glenys Jones or Elizabeth Attfield.

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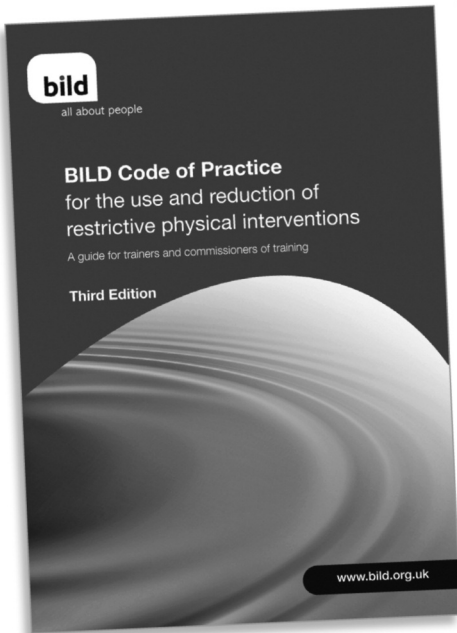
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Booking forms and further information for each event is available on request. Please e-mail <u>Jennie@autismcymru.org</u> or call 02920 463263.

22 June	**Seminar:**	**Thinking and Autism**
	Speaker:	**Kate Sliver and Andrew Grainger of Autism Initiatives**
	Venue:	**Glyndwr University, Wrexham (13.00–16.00)**
	Cost:	**Professional £45, Parent of child with ASD £10**

Thinking and Autism:

In this workshop, Kate will discuss further the benefits of developing thinking skills and share some approaches that they use at Autism Initiatives and talk about how these have been helpful to people. This was previously presented at the World Autism Congress, where it was enthusiastically received.

20 Oct	**Seminar:**	**Intensive Interaction**
	Speaker:	**Dr Dave Hewett**
	Venue:	**Glyndwr University, Wrexham (9.30–4.30)**
	Cost:	**Professional £105, Parent of child with ASD £35**

Intensive Interaction:

This very popular seminar looks at meeting the fundamental communication needs of people who have severe learning difficulties and/or autism.

16 Nov	**Seminar:**	**Positive Behavioural Support and ASD**
	Speaker:	**John Clements**
	Venue:	**National Botanic Garden of Wales, Carmarthen**
	Cost:	**Professional £105, Parent of child with ASD £35**

Positive Behavioural Support and ASD:

This inspirational seminar will examine current practice in relation to positive behavioural support and autism spectrum disorders (ASD); exploring approaches that are not only effective, but help the individual to move on from behavioural and emotional challenges.

****

Important dates for the diary: 20, 21 and 22 June 2011 is **Wales' 4th International Autism Conference** – further details to follow.

More training will arise throughout the year, if you would like to be added to Autism Cymru's mailing list please e-mail your details to Jennie's e-mail address above.