

# HOW I PROVIDE A SERVICE FOR YOUNG PEOPLE WITH ASPERGER SYNDROME

WHAT KIND OF SERVICE DO YOU PROVIDE FOR YOUNG PEOPLE WITH SOCIAL COMMUNICATION DIFFICULTIES? IS THIS DRIVEN BY NEED, EVIDENCE AND VISION, OR STAGNATED BY HISTORICAL FACTORS AND OTHER PRIORITIES?

HERE WE HAVE TWO EXAMPLES OF HOW IMAGINATIVE AND THOROUGH PLANNING AND A FOCUS ON CLIENTS' NEEDS CAN CHANGE THE LIVES OF YOUNG PEOPLE WITH ASPERGER SYNDROME AND THEIR FAMILIES.

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## LET'S GET ON

FACED WITH INCREASING REFERRALS OF OLDER CHILDREN IN MAINSTREAM SCHOOL WITH SOCIAL COMMUNICATION DIFFICULTIES, CAROLINE BABER, ANN CLEMENCE, KAREN FORD AND RUTH WATSON DEVELOPED A PACKAGE OF CARE THAT HAS BENEFITED THE DEPARTMENT AS WELL AS THE YOUNG PEOPLE AND THEIR FAMILIES.



*l-r: Ann Clemence, Ruth Watson, Caroline Baber and Karen Ford*

**H**istorically our speech and language therapy paediatric department has offered a one-off assessment / advice package to students in mainstream secondary schools. An increasing number of such referrals querying social communication disorders (50 over a two month period) caused us particular concern, as often these students had no previous contact with the department. The numbers had a negative impact on waiting lists for initial assessments at community clinics.

These young people were experiencing considerable difficulties coping in school; a number were excluded or attending school on a part-time basis, they were generally quite isolated from their peer group and often perceived themselves to be victims of bullying. Many were receiving support via CAMHS (Child and Adolescent Mental Health Services) for anxiety, depression, anger management and other behavioural issues.

A survey of our therapists identified some concerns with this policy of 'advice and closure' whilst recognising the need to match service delivery to staffing levels. The assessment / advice package was very time consuming. Less experienced staff required considerable levels of support, and it was also felt to be unsatisfactory for therapists to acknowledge these clients' difficulties and then close their case. Families felt unsupported by the service.

We set up a pilot project to see if the department could offer these children social skills therapy in a relaxed and sociable context. The project, facilitated by four therapists, offered 16 children and their parents 16 weeks of contact, two of which were needed for pre-assessment and two for post-assessment. We also allocated five sessions for planning and evaluation; although this is not practical in the long-term it gave us the time we needed to reflect and revise. Parents and children made their own way to the venue which was convenient for bus and rail travel.

Initial baselines were established using:-

- a student questionnaire based on Let's Get On (*Improving Social Skills*)
- a parent questionnaire developed from the above
- five minutes of video recording assessed on a pragmatic observation checklist (based on Johnston *et al.*, 1991).

The students identified 'having a friend' and 'anger management' as their main concerns. The parents identified their main concerns about their children being lack of friends and difficult behaviour. The pragmatic observation profile logged a complete lack of any of the following behaviours in the students:

- asking for clarification
- telling others when they made an error
- making choices
- expressing feelings.

During our first session it became apparent that the parents also required our support and we decided to meet this need by running a parents' group alongside the children's groups. A more formal and structured format evolved for the children's groups as they required greater direction to achieve the set objectives and enable greater participation. It was also necessary to divide the group into smaller more manageable groups and this was done with the intention of returning to the large group format by the end of the course. ►

**Figure 1 Case example: Toby**

Toby was struggling to cope with his pending transition to secondary school and his mother was finding his behaviour difficult to manage. When the groups started, Toby and his mother were both very anxious about the whole process. On the first evening Toby was unable to enter the room with the other students and sat crying in an office. To his credit, and his mother's, they persisted in attending. Toby initially could not cope with even a small group as he found it impossible to accept anyone else's point of view or interest. He struck up a relationship with one other boy with the support of one key therapist. Toby was able to cope in this restricted pair and begin to target some of the issues that caused difficulties for him.

Once Toby was secure the next hurdle he had to cope with was a change of therapist which he managed really well. This surprised his mother who had anticipated that Toby would not want to work with any of the other therapists and felt that, prior to the groups, Toby would have found this change of significant adult too much to accept. Other children were gradually added to the initial pairing without any problems. The final success came when Toby was able to join the large group and to continue attending and enjoying it in this large, noisy and busy environment, interacting equally well with any of the other young people or supporting therapists.

During the course of the groups Toby announced that for the first time ever he had a friend. His mother observed that Toby felt safe at the group and therefore did not feel he had to compete for attention. Toby's

mother felt that the group helped Toby to understand his diagnosis and in fact he was able to explain to a teacher that he had Asperger syndrome and that was why he found some things difficult in class. This was a significant step forward as Toby had previously felt any difficulties arose from other people's problems. The successful outcome of giving this message did wonders for Toby's self-confidence and self-esteem. Toby's mother also noted that Toby had a better understanding of appropriate social behaviour and this was demonstrated when Toby was able to go to the dentist and cooperate with a basic examination for the first time!

We noted that Toby's turn taking and listening skills improved. He was better able to accommodate others' interests and this allowed him to behave in a more age appropriate way restricting 'immature' behaviours to time outside of the more structured group context. In his final assessment we observed Toby as able to ask yes / no questions, initiate conversation, establish a topic, make choices and express feelings. These behaviours had not been established at initial assessment. Having a friend and being able to participate in a bigger group resulted in a more confident, mature and happy boy and a reduction in 'complaints' about school and from school staff. Toby's mother really appreciated being able to make friends with parents "from other Asperger families". Toby and his mother now attend the parent-run social group and mum says Toby has coped "better than expected" with his first year at secondary school.

Two groups were set up initially according to assessment of need. This arrangement was still not suited to those students who had significant difficulty and one group was split again to accommodate two students as a pair (see case example in figure 1). After the first term it was possible to merge these smaller groups resulting in one group (A) for the Year 6 students and another (B) for the Year 7-9 students. They ran from 16.30-17.30 and 17.30-18.30 respectively.

The groups targeted behaviours that the students had identified at assessment. Group A followed a programme of social skills activities, pragmatic game boards (including "Say and Do" – *Positive Pragmatic Game Boards*) and games encouraging social interaction for the first term. Group B followed a programme of social skills activities, more focused activities to address anger management (including "Breaking the Chains of Anger" game) and games encouraging social interaction. These objectives continued into the second term and both groups also worked on self-awareness, awareness of others and developing friendship skills.

The parent group identified the areas they wanted information about: state-menting, behaviour management, understanding autistic spectrum disorder, family support, occupational therapy, the National Autistic Society, teachers' perspectives. We arranged a programme of short talks from appropriate speakers to cover these areas. The parents also spent time sharing their own experiences and coping strategies.

Both parents and children valued the opportunity to talk about the difficulties they coped with on a regular basis.

## Outcome

So what was the outcome? Qualitatively there were significant improvements. The group proved a useful means of confirming / correcting a diagnosis. The students "loved" the peer contact they found within the group and for all of them it was the first time they felt they had a friend. Some of the students discovered they went to the same school and some were even in the same class. This knowledge and peer support helped students improve their self-image and self-esteem as measured pre / post group. The students were happy to acknowledge their diagnosis and enjoyed talking about it with one another.

Parents reported students being able to explain their difficulties to subject teachers and other class members, reflecting their increased confidence. They particularly commented on the pleasure the children had gained from regular peer support and how important this contact was. The parents, supported by the East Kent National Autistic Society, have consequently established a weekly social group where students can go to enjoy a variety of activities with their friends, and families can meet up. (The group is known as the Thanet Autistic Zone.)

Quantitatively the results were rather mixed. The student questionnaires indicated an apparent increase in their problems with social interaction, although we would argue that this reflected the students' increased awareness of their difficulties with social interaction. Analysis of the pragmatics observation profile, however, showed clear differences between pre- and post- group assessment. There was improvement in all areas. Behaviours that

had not been observed in any of the students at pre-group assessment were now emerging (for example seeking clarification; establishing a topic).

Analysis of the parents' questionnaires showed no significant changes in their perceptions of their child's presenting difficulties. All the parents however demonstrated greater understanding of the nature of those difficulties that previously had been interpreted as bad behaviour. The parents also commented on increased confidence in interacting with and managing their children.

## Exhausting and exciting

For us as a team this project was exhausting and exciting. It allowed us to trial a package of care which promises to be an effective and satisfactory means for managing this client group. The project furthered a sense of team working within a newly formed team and less experienced staff were able to work alongside and learn from more experienced colleagues.

Consequently we have now allocated four outreach sessions to support and extend this work monitoring groups as assessment / diagnostic tools for children with queried social communication disorders. Four groups have been held since the pilot, and follow-up groups will be offered to children across different localities in the Trust which will allow us to reach more families and address our service concerns of imbalanced waiting lists caused by this client group. The content of the group activities will allow therapists' concerns to be addressed.

Liaison with our colleagues in education and health is earmarked as a priority as we would like to have a multi-agency approach to this work. At the request of one of our school clusters we have arranged a full day conference in autism. We have also developed a training package to offer to our local secondary schools to raise staff awareness and understanding of this client group. We plan to deliver this along with our school cluster colleagues.

The families' weekly social group has continued to meet at another venue and they have taken on full responsibility for this group. This is an invaluable and much needed resource for the area, and we refer new clients to this group.

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## Reference

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## Resources

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- *Breaking the Chains of Anger* is available from Incentive Plus, [www.incentiveplus.co.uk](http://www.incentiveplus.co.uk).
- Let's Get On (*Improving Social Skills*), Northumberland County Council, is also supplied by Incentive Plus.
- "Say and Do" Positive Pragmatic Game Boards, by Gill & DeNinno, available from Taskmaster, [www.taskmasteronline.co.uk](http://www.taskmasteronline.co.uk)
- For a copy of the programme for group B parents, e-mail [avrilnicoll@speechmag.com](mailto:avrilnicoll@speechmag.com)

# ASPERATIONS 4 U



OVER THE PAST FIVE YEARS, JANE BAKER HAS SEEN HER VISION OF A COMMUNITY-BASED, PARENT-RUN, SPECIALIST FACILITY FOR YOUNG PEOPLE WITH ASPERGER SYNDROME AND THEIR FAMILIES BECOME A REALITY. HERE SHE EXPLAINS WHY HER ENTHUSIASM AND PASSION FOR THE 4 US MODEL IS AS STRONG AS EVER.

Six years ago I had a conversation with a parent of a 14 year old recently recognised as having Asperger syndrome. She spoke movingly of the isolation and misunderstanding that the family had endured over many years and how, despite wanting a friend for a long time, her son had only just found one.

That set me wondering. Who do you choose as your friends? People who think like you do? People with similar life experiences? People who understand you easily? People you don't need to explain basic differences to? People who accept you as you are and love you despite your foibles?

So, if you had a strongly systemising brain (Baron-Cohen, 2004) as people with autistic spectrum disorder and Asperger syndrome have would you choose someone with an empathising brain as your close friend? You might, but probably you'd go for someone with whom you clicked because you instinctively knew how they ticked.

And if you were a parent of a child with specific challenges would you be interested in meeting similar parents regularly?

With these thoughts in mind, I was motivated to bring such families together back in January 2000. I was lucky to work with a manager who supported initiatives, and with colleagues who were enthusiastic and passionate about providing a different service to this client group. Since then the group has evolved from a speech and language therapy-led group at the local medical practice into a parent-run organisation (since January 2003) that meets in a Youth Centre at the heart of the community.

The South Devon Asperger's Group follows what I have called the 4 us Model and is about social inclusion for children with Asperger syndrome and pragmatic difficulties, and support in the community for their families. The children refer to it as 'Asperations'.

The 4 us Model has four components

1. Support group for parents of children with Asperger syndrome and pragmatic difficulties. A place to talk and listen to others who understand, to gain moral support from others with similar experiences and emotional responses, to share problems, and to explore solutions and coping strategies. It includes a resource library, and talks and problem-solving with multi-agency professionals from Child and Family Guidance, Child Health Directorate, social services, health, education (outreach teams and special educational needs co-ordinators), National Autistic Society and Parent Partnership. Sessions for the parents on relaxation, yoga and so on are planned.
2. Youth group for the children.
3. Sibling group with a play worker, having fun and also responding to their needs.
4. Social communication skills groups run by speech and language therapists using group interaction games and role-play to teach specific skills in context.

We also provide training and help to set up similar groups in other settings. There are two groups (5+ years and 11+ years) running on different days after school 4.30pm – 6.00pm term-time only. They are held at Kingsteignton Youth Centre which has the facilities to cater for all four needs at the same time.

Although there is no transport available, there is a nearby bus stop. The sibling group (run by a play worker), the parents' support group, resource library / speakers (run by the parents) and the communication skills groups offered by the speech and language therapists all meet at the same time in the same building. This makes it much easier for the families to access the service. We all get together for the final 30 minutes so the children with Asperger syn-

drome can have their Youth Club (run by the youth leader) together with their siblings, and the speech and language therapists are available to talk to the parents, give feedback, pass on new information and so on.

One hundred and ninety families have been involved in this initiative since it started. Currently 53 families attend either regularly or spasmodically. Some come every other week, others once a month, others every week depending on their circumstances. Sometimes families stop coming for a while and then reappear when they need to or when it has become possible or convenient again.

Amongst other things, parent volunteers provide a regular newsletter, maintain the resource library, befriend new families, provide refreshments, develop leaflets, collect donations and club fees, apply for grants, approach local businesses for donations, run raffles, fundraise, liaise with other local groups and the National Autistic Society, supervise the pool table and photocopy new information. In other words, as the South Devon Asperger's Group, they manage 'Asperations'.

## Funding

The initial funding for the speech and language therapy time came from within existing resources as a pilot. After a year the parent-led committee succeeded in getting funding from various bodies such as Awards for All, South West Foundation Grant, Teignbridge Primary Care Trust, Zero plus 14 and other local charities. This fundraising now covers the running costs of the venue (£15 a session), and the speech and language therapy, play worker and nationally qualified youth worker time (in total £38 per hour) as well as equipment when required.

Regular questionnaires to parents and children ensure that current needs are being met and allow for future development. The latest initiatives are to apply for charity status, and to run a holiday play scheme for the 11+ group.

So why is the 4 us Model needed? Children with Asperger syndrome have specific difficulties in understanding the rules of social interaction (Attwood, 1998). They want to make friends but can't 'read' other children, and often their attempts end in failure. They may have difficulty in controlling their anger and do not understand how this affects other people. They may be hypersensitive to criticism, and be unable to tolerate teasing as they take language and situations very literally. They do not understand sarcasm. They are often hypersensitive to noise and large crowds. They are often described as loners, always on the outside, feeling like "aliens in the playground" (Sainsbury, 2000). Other children often do not want to play with them and, as a result, they become isolated and excluded. They can become easy targets for bullies, most especially because of the way they respond to the teasing.

When the child with Asperger syndrome is the only child in the family, often the whole family becomes isolated and misses out on the normal socialisation of childrearing. The child does not get invited to birthday parties and the parents don't get included in social gatherings by default. Some children are home educated and have few opportunities to mix with other children.

The 4 us Model aims to counter all these disadvantages by

- a) Acknowledging that the parents are the experts in bringing up their children.
- b) Enabling parents and children to learn that they are not alone, so reducing isolation and empowering families.
- c) Acknowledging the support the parents, siblings and children can give to and receive from each other through offering opportunities to share experiences and information.
- d) Ensuring siblings get some attention for themselves.
- e) Providing a safe place where children with Asperger syndrome can learn the rules of social interaction in a systematic way in a communication skills group led by a specialist in communication (speech and language therapist).
- f) Giving the children the opportunity to practise these skills in a community setting and to explore their emotions / feelings, new friendships and ways of behaving. Through learning how to repair mistakes and try again in a non-judgemental environment until they have practised, learnt, and gained the confidence to use these social communication skills and coping strategies in everyday life and at school, we hope they will become properly included in the community.
- g) Helping the children understand why they are 'different' while enabling real friendships with others who 'think' like they do, so they have the experience of truly belonging to a group of people who understand. ▶

Figure 1 Samples of feedback from evaluation questionnaires

**1. Parents: Why do you come to the group?**

"It's the only place I actually feel safe with my two Asperger children. They have learned a huge amount in pragmatic communication skills from Jane's work, social integration, self-esteem and inclusion for the children and us. Some weeks I support others and other weeks I am supported. It works and it's a break. Thank you."

"I needed somewhere that I could meet and talk with people that had children like mine. Also somewhere that my child could mix with children like himself and feel at ease.....I feel as if I am no longer the only person with a child that suffers from Asperger's. Also when my son does have a bad time coping at the group people understand and do not judge. My life feels less stressful having somewhere to go once a week."

"For my son to develop better social skills and perhaps friendship, support for myself and his sister – so she can understand that other people have problems with their siblings."

"It's professional and especially geared to autistic children, so they gain the maximum benefit from the therapy. Also any problems they are experiencing in everyday life can be discussed. Helps them deal with life in general."

"Because I'd go insane if I didn't. Gregory doesn't feel the odd one out here and is not bullied. I get a lot of input from other parents and useful information."

**2. Parents: What do you find most useful about the group?**

"I have learned more from the support network in the group about Asperger syndrome and coping strategies than anywhere else (with all the agencies that are supposed to help / be on our side but seem to only hinder and cause stress!!! i.e. local education authority system, social services etc.) I feel supported by the parents and I have learned so much from the speakers."

"We all understand the children in our group with no sideways looks."

**3. Parents: What do you find least useful, or what would you like changing?**

"It takes an hour by bus and I would prefer a similar facility to be available locally."

"I don't like the amount of time / effort spent fundraising to pay for facilities, the constant form filling to acquire funds as well as supporting our children on a daily basis."

"I find it least useful when the social communication skills groups aren't running as my child can get over excited in the hall and it's hard to calm him down afterwards – but he is getting better."

**4. Young people: Why do you come to the group?**

"Because I do."

"Because I've got Asperger's."

"Because Mum makes me! Also because I enjoy the environment and like the people."

"I want to make friends!"

"I come to the group because sometimes I have behavioural problems, but mostly I just come for fun."

**5. Young people: What do you find most useful about the group?**

"Meet new friends, have fun. I don't like it when the others shout loud. I want the others to be a little quiet."

"I like seeing everyone and I like listening to people's news."

"To do exsparmets."

"It's nice that everyone who has Asperger syndrome can get together and be cooperative."

- h) Catering for the significant number of children in the group who are school refusers, or have home tuition directly as a result of their difficulties with peer interaction at school. This is often the only opportunity for these isolated children to meet, play and interact with their peer group. Some have learnt to avoid their peer group at school. They need a process for learning and change to enable them to overcome their isolation. They will not learn this without systematic intervention because of the very nature of their condition.
- i) Encouraging good self-esteem and addressing the fact that depression in teenagers with Asperger syndrome is common (Wing, 1981; Attwood, 1998; Sainsbury, 2000; Ghaziuddin, 2005). Being part of a group, understanding who you are, why you are different, how you are the same as other people, and having fun with like-minded individuals will help counteract feelings of depression and the sense of not belonging.

There have been no facilities for the families and individuals with Asperger syndrome in our area in the past as it is only recently that their difficulties have been recognised by professionals and the general public. In my experience, there is still widespread ignorance and myth surrounding the condition. Getting together should help empower families and educate professionals and the wider public, and so enable an understanding - and therefore acceptance - of people who are 'different'.

The All Party Parliamentary Group on Autism's Manifesto (see [www.nas.org.uk/nas/jsp/polopoly.jsp?d=159&a=2411](http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=159&a=2411)) aims to ensure that, by 2013, "All children and adults with autism will have access to leisure facilities and meaningful activity tailored to their needs and interests. This should be shaped in a way that promotes social inclusion and, where appropriate, should involve family members and friends" and "All children and adults will be supported to develop their social skills and understanding." True inclusion is our ultimate goal.

There is a massive need for this type of provision locally (see figure 1). Many parents cannot access the group because it is not local to them. Why don't we help them set up this model throughout the country?

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To accompany this article, copies of Jane's supporting documentation *Steps in Setting up the 4 us Model*, *Draft Group Constitution*, and *The 4 us Model leaflet: Social Communication in Context* are available on [www.speechmag.com](http://www.speechmag.com). Jane will discuss the social communication groups in more detail in a future article.

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