

The Philosophy and Practice of SPECTRUM – A New Kind of Parent Support Group

Jane Pearson

Jane Pearson has a son of 28 who was diagnosed with Asperger's Syndrome (AS) as a teenager. She has worked with parent support groups in Colchester since 1997, mentors university students with AS and teaches a certificated course on AS at a local college. She feels strongly that early diagnosis and intervention is the best way forward for children on the autistic spectrum if they are to learn how to adapt themselves to our world. At the same time she feels we need to adapt ourselves to their world as they have much to teach us about perception, dedication and sensitivity.

Summary

There are a number of support groups for parents of children with social communication difficulties but they tend to concentrate on reaffirming for the parent just how difficult life is with an autistic spectrum child. This article describes a new initiative which aims to concentrate on what can be done by the parent to make a difference to the way their child understands the world and to improve their child's behaviour.

Introduction

In June 2007, a new kind of parent support group was set up in Colchester. We called it SPECTRUM because it was intended to support parents with a child with some kind of social communication difficulty, typically on the autistic spectrum. The group was set up by a number of people who cared for such children professionally – educational and clinical psychologists, a specialist teacher for autism, individuals representing Children and Adolescent Mental Health Services, Extended Schools Co-ordinators, a Special Educational Needs Co-ordinator and an Asperger Syndrome mentor. Initial funding came from all Colchester schools through the Extended Schools Co-ordinators. In 2009 a second SPECTRUM group was established in Clacton and, in January 2010, another will start up in Harwich.



The people behind SPECTRUM (Jane is on the left)

Our philosophy

SPECTRUM's publicity asks readers if their child finds it hard to make friends, if he/she gets really upset over small changes, or very involved with certain toys, activities or routines; whether he/she finds it hard to respond to other people's feelings, has unusual interests or can seem over-anxious. Superficially this collection of problems may sound trivial but there is nothing trivial about the difficulties these children have to deal with.

Social communication difficulties cause children distinct problems. Their communication is hampered by language delay, including speech impediments, and difficulty in understanding the body language and facial expression of other people. The normal give and take of conversation is beyond their grasp and they do not process the spoken word quickly. This means they often miss the point of verbal instructions. For them it must be like inhabiting a foreign country whose language they do not speak fluently. In addition, they do not learn social skills through play as neurotypical toddlers do and these skills remain undeveloped. Social conventions often baffle them. As soon as they begin school they are found to lack basic social skills and, without a diagnosis, this may be blamed on irrelevant causes such as poor parenting.

Unless their condition is properly understood these children suffer rejection, humiliation and self-doubt

for most of their waking hours. This causes stress and anxiety which may develop into associated depression or aggression. When these children are understood they will usually relax and flourish and their natural skills come to the fore. The earlier the process of assisting the child to respond positively to the world and to other people begins, the better for the child.

The parents also face difficulties. The child's difficulties may not be diagnosed or understood. Without a diagnosis understanding and support may well be hard to find. However, many parents discover that a diagnosis does not necessarily achieve instant understanding and support. A parent who feels their child is misunderstood and maligned may respond with anger or denial, neither of which usually helps the child.

SPECTRUM is non-political and leaves lobbying to other specialist groups. Instead, we try to encourage our parents by helping them to understand why their child behaves as he/she does and suggesting strategies that they could try to improve behaviour and avert problems. Generally, these strategies do not come from a textbook but from the collective wisdom of the parents themselves. Collectively, parents in SPECTRUM represent a good deal of experience of (diagnosed and undiagnosed) autistic spectrum children and young adults of all ages up to 30, some having other adult family members somewhere on the spectrum. No-one has experienced all the problems but everyone has experienced some of them. This is the nature of autistic spectrum conditions.

Once beleaguered parents feel the group's support and realise that there are some tried and tested remedies, their confidence usually grows and they begin to feel more optimistic. For a parent with a seven-year-old struggling at school it is very reassuring to see examples of older children in the group who are surmounting their difficulties and achieving a reasonable independence as adults.

Practice

SPECTRUM is unusual among parent support groups in having enduring professional input. Some parents appreciate the opportunity to talk to a professional in the relaxed setting of a parent support group. At the same time the professionals learn from the group of parents some of the difficulties they encounter which would not normally be raised in a clinic appointment. The professionals are as likely to serve the coffee as they are to hold forth on the science of child development.

The SPECTRUM meetings are planned by a small committee of professionals and parents. The parents also manage the finances, do fundraising and outreach work of various kinds including workshops and school visits. For instance, we have run a number of

social stories workshops where we introduce parents to the ideas behind the technique and then set about writing stories for different problems. It is very gratifying and uplifting for the whole group when a parent reports success with modifying their child's behaviour after having attended a workshop and trying out a story at home.

The combination of parents and professionals generally works smoothly. Given the difficulties that exist for agencies and professionals in providing the support that is needed when budgets are limited and diagnosis is not always straightforward, it is not surprising that differences of opinion are sometimes aired. However, a culture of honesty in the committee promotes acceptance of individual points of view. A recent example of this kind of difference occurred over the subject of bullying in schools. Although the county has a compendium of anti-bullying strategies to which the professionals could refer, the fact remained that almost every parent in the group had a child who was being seriously bullied at school despite the policy. This just demonstrates what a difficult problem bullying is to address and how much denial there may be at all levels within a school and outside it. We are still discussing how SPECTRUM might be able to draw attention to this, perhaps by devising workshops that could assist recognition of bullying and how to combat it.

SPECTRUM makes no distinction between parents who have a diagnosis for their child and those who do not. For genuine reasons, it is often difficult to arrive at a diagnosis for children with social communication difficulties. For many parents with such a child, diagnosis can be a long-drawn-out process during which there may be breakdown of trust resulting in frustration and anger. While we recognize and sympathise with parents in this position, for SPECTRUM the important point is how to help parent and child devise strategies to deal with the problems they are both having on a daily basis at school and at home. Unfortunately, having a diagnosis is not a magic solution for these daily problems. The system is overstretched, parents feel they have to 'fight' for the help they receive over and above dealing with the daily difficulties of helping a child with high stress levels and with insufficient social understanding (in both the child and society!).

SPECTRUM's aim is also to enable parents to meet and support each other with the assistance and advice provided by professionals. The agenda is set by the parents who also help to organize and lead the meetings. At each meeting we address a problem that the parents have agreed they want to talk about. After a 'warm-up' activity we quickly collect the kinds of problems we have experienced in connection with the topic. After a break for coffee we spend the rest of the meeting collecting the ideas of the group, things that

have worked for us, ideas that might work, including reasons why certain strategies are seen to work better than others. We also recommend helpful books, toys and appliances. After the meeting we collect together our strategies and construct a SPECTRUM resource which is handed out at the next meeting. Once in a while we evaluate the success that has resulted using a simple questionnaire and recorded group discussion.

“WINDING-DOWN” and DEALING WITH WORRIES!

Often a child needs a quiet calming down period with a story. This seems obvious but is a good way of “switching off” a child’s busy mind from the day and distracting them onto something else, particularly if it is their favourite story or special interest subject.



Some children need to hear about their “daddy’s” day and can repeatedly ask the same questions over and over again. Try getting dad to record this onto a tape/disc so the child can listen over and over again.

OR



try using a timer for each person to talk about their day in order to deter from repetitive questions. Possibly get each family member to say something “good”, “bad” and “OK” that happened to them in their day.

Try recording favourite stories onto a tape, disc or MP3. As, often, children request the same story over and over again. They are then able to listen for as long as they need before hopefully dropping off to sleep!



Part of a SPECTRUM resource on managing sleep problems

A recent topic for discussion was sleep problems. In an hour’s discussion we came up with seven pages of suggestions of ideas to try at home. The problems that parents were having ranged from their child’s failure to fall asleep to anxiety about external circumstances such as weather or fireworks, to early waking and wandering. The seven page resource that was written following the discussion began with ways to calm a child and sooth or remove anxieties which included bedside photographs of his mother and a hanky sprinkled with her scent to clutch. There were many practical tips for excluding outside noise or, alternatively, finding a way to make it less scary.

Then there were physical solutions including radio, internet white noise downloads and weighted blankets.

There were many ideas around discussing the worries of the day in such a way that they, too, were ‘put to bed’. These also included physical objects such as worry dolls and talking bears. Then there was a list of ideas to retrain a child into good sleep habits. Finally there were social stories written to explain to the child why sleeping was a good idea and to give information about what the rest of the family was doing while he/she was asleep in bed. For some children this information does the trick. SPECTRUM is fortunate in that one of the committee members is particularly

knowledgeable and experienced in the writing of social stories. We believe these are a very useful strategy to use to help our children understand the world.

What is the secret of SPECTRUM's success?

SPECTRUM is a positive and upbeat group. We believe firstly that most problems can be helped with appropriate strategies and secondly that both parents and children benefit from success. The benefits include, not only problem solving worked on together in the family, but also the fact that, in working on problems and finding solutions, both parent and child can feel more positive and hopeful about the future.

We see the varying ages of the children as a bonus in that parents of younger children can learn from the experience of those whose children are older. New parents are often very sensitive to the uplift they feel in their first meeting, the sense that they are not alone and that there are real solutions to be found for their present difficulties. Strategies work with children young and old provided some basic rules are followed. Many of these rules are no more than good parenting practice and the professionals in the group are expert at demonstrating these and explaining the reason. Some are counterintuitive and some are not designed for instant results. Nevertheless they are tried and tested.

Most of the group have a strong sense of their child's value and potential and are frustrated that this is not recognized by the outside world. This loving pride finds its voice in every meeting.

Contact

drjanepearson@hotmail.com