Volume 2

November 2003

THE JOURNAL OF AUTISM TASMANIA INC.

Autism News

Welcome to our Members

Welcome to the second issue of the new-look Autism News; I hope that you enjoy it

Inside is an interesting range of articles selected for you by the Editorial Committee.

Often it is difficult to find articles suitable for newsletters and the Committee is always looking out for items which will interest, inform and stimulate our readers.

Especially prized are original items submitted by our own members and I would like to thank Alice Minchin who submitted her insightful book review for this issue.

I would also like to encourage you, our members to put pen to paper over the holidays and to share your experiences, trials and or tribulations with other members - or if you find an article, book or journal of particular interest, please let the Committee know so that we can share it with our readers

Happy reading

Cheryl Scott Editor

Think Different?

Autism researcher Simon Baron-Cohen on "mindblind" engineers, hidden pictures, and a future designed for people with Asperger's.

Interview by Oliver Morton reprinted from Wired magazine www.wired.com/wired/archive/9.12/baron-cohen_pr.html

Sally has a marble. She puts her marble into the box, and then she goes outside. Anne comes in, takes the marble out of the box, and puts it in her basket. When Sally comes back, where will she look for the marble?

By the age of 4 or so, most children who watch this scenario played out by puppets - including children with Down's syndrome and other developmental problems - know the answer. But some do not. They do not understand that what they know and what Sally knows are different, that Sally has a mind of her own. The children who expect Sally to look in the basket, because they know that's where the marble is and can't

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Inside this issue:

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believe that she doesn't, are the ones likely to be diagnosed with autism or its relative, Asperger's syndrome.

Simon Baron-Cohen, a tall, soft-spoken clinical psychologist at the University of Cambridge, has spent two decades studying autism - how to help the people disabled by it and what the syndrome tells us about normal minds. Baron-Cohen is interested in the brain and in genes (his group at Cambridge is collaborating with geneticists in new studies of Asperger's syndrome), but his key interest is in minds: their workings, their malfunctions, their origins, and their care.

From the beginning, his work has been centred around what's called a theory of mind - that is, an innate ability to understand other people as having feelings, intentions, and pictures of the world that are not the same as our own. A theory of mind is a basic requirement for empathy or, for that matter, deceit. And according to an approach to autism that has become increasingly influential in Britain over the past decade or so, a theory of mind is what people disabled by autism and its related conditions lack. They are, in Baron-Cohen's nicely coined word, "mindblind." More recently, Baron-Cohen has looked at another aspect of the autistic mind: a proclivity for systemising - for understanding and constructing rules-based systems to explain our experience. To understand the social world, such rules are a poor replacement for a theory of mind; to understand the natural world, they are very useful.

It is another focus of his research, though, that has made Baron-Cohen an occasionally controversial figure. In 1997, he and his colleagues looked for and found some evidence of a link between autism in children and a propensity for engineering in their parents. Further work with students at Cambridge has suggested that engineers, mathematicians, physicists, and computer scientists have a way of thinking that is quantifiably "more autistic" than that of their peers in the humanities, arts, and social sciences. To some, this sounds like a medicalised stigmatisation of nerdiness. Others fear that linking children's disabilities to their parents' inclinations is a new way of blaming the parent. Baron-Cohen rejects this. He argues that linking the styles of thinking that society has come to value is helpful, not harmful. Minds come in different shapes just as bodies do, and we must learn to accept that. Indeed, we must learn to value it.

***Wired**: How common is autism?*

Baron-Cohen: Current studies suggest that the incidence is about 1 in 200 children for all disorders in the autism spectrum. That's much, much higher than the textbooks quote: Textbooks say 4 in 10,000.

Why the gap?

It's probably due to growing public awareness. Also, we're now looking for children at the higher end of functioning, children with autism who have normal intelligence. In the past we tended to look in special schools or in child psychiatric clinics for children with learning disabilities and a range of other problems; nowadays we look in the community at large.

Is there a danger that broadening the definition of autism might trivialise the problems of those with profound disabilities, equating a severe disorder that requires lifetime care with something much milder?

A PhD student with Asperger syndrome might be just as disabled as a person with learning disabilities and classic autism. Both may end up in need of considerable support, though of different kinds. The people being diagnosed at a rate of 4 in 10,000 needed more clinical support than the 1 in 200 diagnosed today. But I'd be hesitant to say that those cases were more severe.

Autism spectrum disorders are linked to other problems: Most of the people we see in our Asperger clinic for adults also suffer from clinical levels of depression. At any point on the spectrum, a diagnosis of Asperger is only given if the symptoms are causing a significant impairment to how someone functions. So "mild" cases, which don't really interfere, should not be diagnosed at all.

You argue that people with autism lack an innate capacity to draw inferences about what others know or think or feel - a "theory of mind." Is this ability separate from the ability to think about the world in general?

One of the papers I've written with colleagues describes three individuals who have Asperger syndrome. One won the Olympiad in physics and math right through his teens, and when presented with a physics or math problem he could solve it very, very rapidly. Yet he couldn't decode facial expressions of emotion in photographs. The second was a professor of mathematics, the winner of the equivalent of the Nobel Prize for math, the Fields Medal. No difficulties at all in abstract reasoning, but given photographs of facial

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expressions that somebody without any mathematical ability could read easily, he performed significantly below the average level. The third example was a computer scientist who could write programs without any effort at all, but again, just looking at a face, he couldn't tell what a person was feeling. It can't be a general problem that's affecting the mind as a whole. It must be a specific deficit.

These ideas have helped you develop tests for autism that can be administered surprisingly early in a child's development.

Yes, the Checklist of Autism in Toddlers is used by doctors and health visitors during the routine 18-month checkup, looking for the absence of two key behaviours that should be there if the child is developing normally. One is the pointing gesture; normally children point at things to communicate. Autistic children don't do that. If they point at all, it's to request something, but a normal child will point just to share interest, as if to say, "Look at that." The pointing gesture is a great piece of evidence for the theory-of-mind approach because, when you point at something, you have to take into account that somebody else may not have seen what you've seen, that somebody else may be interested to see what you've seen. It's about sharing minds.

The other key behaviour is pretend play. By that age, in normal cases, children are pretending in an imaginative way. They'll pick up an object and attribute properties to it that it doesn't have; they'll pretend a pen is a spoon and feed themselves. In children with autism, their play is much more reality-based. They're interested in how things work.

So if they want to play with a telephone, they'll pick up a telephone.

Yes, but they won't have an imaginary dialogue - they'll try to figure out what the buttons do.

Parents sometimes say they feel that the autism begins after this stage of development. If the problem is innate, how do you explain that?

It could be that around the time of joining a peer group, between 18 months and 2 years old, the child increasingly recognises that he or she doesn't understand the dynamics of even a small social group - three or four kids - and gives up trying. The other thing is language development. In the normal case, children learn words in a very social way; they hear a new word, "tape recorder," and see that the speaker is looking at that object on the table, and they're able to work out that the word they just heard must map onto that object as opposed to another one.

And people with autism don't do that.

No. They don't use the direction of people's gazes as a cue to breaking the code of language.

Does this sort of insight help parents and caregivers?

It immediately suggests a method of special education or intervention. If the child isn't naturally learning how to recognize people's feelings and how to attribute intentions, then he or she will benefit from being taught those things in a very stepwise way. We've produced a book aimed at teaching primary-school children this way. Now we're developing a CD-ROM that will contain photographs of actors producing every known human expression of emotion with their faces and voices. It will be like having an electronic encyclopedia of emotion to consult.

So by being explicit enough about things, one can get feelings across?

For many individuals with autism, when it's pointed out to them that they have hurt somebody's feelings, they feel very bad about it. But they wouldn't know how to avoid doing it in the future without formulating an explicit rule.

Along with mindblindness, you've studied the propensity in people with autism to systemise. But the idea that there might be a trade-off between these two abilities - between having a theory of mind and having a capacity to imagine or construct rule systems - sounds odd. The mind's not a zero-sum game.

It's not that there is necessarily any trade-off or compensation. The new look at autism just suggests that there are two factors, not one. There are difficulties in "mind reading," and at the same time, possibly independently, an intact or even superior talent for understanding systems.

But if the two are truly independent, why do they crop up together?

It may be true in the case of autism that if you start off with a deficit in terms of empathy or mind reading, you've just got more time to devote to understanding the world by systemising.

So the enhanced systemising could be a response to the primary deficit, like upper body strength in a paraplegic using a wheelchair.

Yes, that might be.

Autism is now seen as largely genetic in origin. But that leads to a seeming contradiction: One would expect genes that cause the disability not to be

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very good at getting transmitted to future generations.

Everything seems to be conspiring against the genes to persist, because they're interfering with social relationships, which are usually a prerequisite for reproduction. But if the genes for autism are persisting in the gene pool, it may be that in milder forms attributes of autism are adaptive. They're maladaptive in some circumstances - in conditions where social sensitivity is important - but they may be very adaptive in other environments, for example where high systemising might be needed.

This led you to look at the parents of people with autism, and in some early research you found that, like their children, these parents are better than average at "embedded figures" tests, which involve picking specific geometrical shapes out of complex pictures. Did that surprise you?

I was impressed by the degree of talent. Among both individuals with high-functioning autism or Asperger and their parents, many are super-fast at spotting details. You hardly have time to get the experimental materials out on the table before they've spotted the target. You've hardly managed to get the stopwatch going. The normal brain, as it were, takes much longer.

Do you think they are doing the same thing someone with a normal brain does, only faster, or performing a different sort of visual search?

It's impossible to know just from these studies. In a different task, called the block design task, where you have to construct a pattern from individual elements, autistic people are faster irrespective of whether or not the design they're copying has been pre-fragmented, whereas normal people find it easier with the pre-fragmentation. In the person with autism, the brain may already be seeing the part and be less distracted by the whole, and in the person without autism the brain may have to set aside its picture of the whole to analyse the detail. There may be two different strategies at play.

Would that explain aspects of autism beyond the visual realm?

Some people have suggested that when it comes to understanding the social world, it pays to be good at gestalt processing, because the social world is not about attention to detail - it's about a broad-brush approach. It's not about the fact that a person's hand is moving through space and you're tracking it frame by frame; it's about the global interpretation that he wants a drink. So it could be that all the theory-of-mind problems are just a downstream consequence of difficulties in getting the gist, getting the gestalt.

Further work on the relatives of children with autism showed that the parents had a more-than-chance likelihood of being engineers, compared with the parents of children with Tourette's syndrome or Down's syndrome.

Yes, there was significant over-representation of engineering among the fathers and grandfathers. The rate was about 12 percent, whereas, in the general population among males, the rate of engineering is about 5 percent. So that is statistically significant, but it has to be treated with caution. It is easy to misinterpret the result, saying there is a strong link between being an engineer and having a child with autism, whereas in fact all it shows is that 12 percent of fathers, rather than 5 percent, worked in engineering.

Does this mean that only the father's genes count?

No. Most of the mothers worked in the home and so we don't know what path they would have followed. There's no evidence for a link to sex as yet.

Is there other evidence for a link to engineering?

We did a study of students, in Cambridge, split between the natural scientists and the humanities students. The study looked at the likelihood of having a relative with autism. And what we found was that the students in the disciplines of mathematics, engineering, and physics had a higher likelihood of having an autistic relative - a sibling or a parent's sibling, or a first cousin. We asked about other conditions, too, to check that we were controlling for reporting bias, but we found that autism was the only disorder, among a set of six, that was significantly associated with disciplines that require a talent for systemising.

How have your colleagues in engineering reacted to this?

We've had a mixed reaction. A professional magazine for engineers picked up the story, and we had one or two letters that suggested this was simply perpetuating an image of engineers as socially inept. But we had a lot of letters from people saying, for example, that they had an autistic child and that they had engineering going back many generations in their families. So it was bound to be a sensitive issue, which is why we're at pains to stress what you can and can't conclude from this.

Can you conclude that engineers, physicists, mathematicians, and the like have a higher

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relative risk of a child with autism?

No, because we haven't done that study. All we've found is that if you take a group of people studying engineering, they tend to score slightly higher in terms of number of autistic traits, but we don't know that they are at greater risk of having a child with autism.

Surely, though, that is the implication of the finding that children with autism are more likely to have an engineer as a parent.

That is why I draw attention to it being only 12 percent; 88 percent of the fathers of children with autism are not engineers, and it probably follows that the majority of engineers have no link with autism.

If parents have some attributes associated with autism, does that have any developmental effects on the autistic child?

Possibly, but that may not be bad. Let's say there was a father who had quite an obsessive interest in, I don't know, bird-watching. He could tell you not just the names of all the species that tend to migrate through his part of the world but when they migrate and patterns of coloration and all that. If the child had a similar way of thinking - liked to collect information on a category of the world in a complete way - you could have a very beautiful opportunity for a father and a son to go out bird-watching, with their minds working in a very similar way. A normal child, on the other hand, might get quite bored.

What are the implications of finding certain professional aptitudes linked to autism?

Mainstream education expects children to be all-rounders, to be good at socialising on the playground and good in the classroom at doing math and science. That's just unrealistic - children come in all shapes and sizes. So part of what has to happen is a change in expectations. None of us are all-rounders, especially when we get to higher levels and can't maintain every skill at an equivalent level.

Are there role models for people with autism?

A lot of people with autism haven't yet come out or been recognised. There are people who suspect that Bobby Fischer has autism, and he may be a good role model for chess players. It's very hard when you don't have definite diagnoses, and it's irresponsible to be diagnosing at a distance; a diagnosis takes a proper clinical assessment.

So I guess I can't ask about Bill Gates. There's been a suggestion that Sherlock Holmes might be a candidate - great at systemising, not misled by the seemingly obvious gist of the situation.

It's a nice example, but all you can do is speculate.

If you can't be drawn to speculate about that, how about this: Computers make some parts of the world more rules-driven; does that mean the world is becoming a better place in which to have an autistic disorder?

Yes. There's a niche now for people with that sort of profile. There always was a niche, otherwise the genes would have died out, but maybe that niche is now much more accessible.

Family Relationships

Editor's note: The quotes (in bold) in the original article were printed alongside the main content of the article. Published with permission from the Association for Children with Disability, Victoria, publication "Helping You and Your Family", September 2000 issue.

Taking care of yourself and your family relationships is just as important as taking care of your child. You are a family first. Try to reach out to each other and communicate from the start – it will be worth it in the long run.

Couples/Partners

"When the going got really tough (with our son) we were both so exhausted it was hard to find the energy to care for each other. We made a rule that we had to talk to each other at least once a week about something not to do with disability. It seemed to help."

Having a child with a disability places a high level of stress on couples/partners. Some relationships will deepen and strengthen in love and commitment. Being aware of these extra stresses requires a degree of maturity, self-assurance and support. It is important to talk to each other about your feelings. Give each other support.

Sadly, many relationships don't survive the pressure and they break down. Sometimes parents get to the stage where they need to blame something or someone and because there is no-one else to blame, they blame each other.

Each partner will grieve and come to terms with the child's disability in different ways and in their own time. They also have different strategies for coping with stress. Men and women share and demonstrate emotions differently. Generally women find it easier to share their feelings and this makes it easier for them to ask for help or join a parent support group.

There can be enormous financial pressures. One partner may have to stop work or forgo their career to care for the child.

For any successful relationship, there is a need for commitment, good communication and mutual support. For good communication, recognition of each other's needs as well as your child's, is critical.

Sole Parents

"One part of being a sole parent that I enjoy is being in charge of all the decisions. I get all the support I need from my friends and family."

When it comes to making decisions for your child, being a sole parent can be a lonely experience. You might need to be particularly focused to ensure you use all the other supports available to you eg. extended family, other parents, friends, services,etc.

Extended Family

Grandparents, uncles, aunties, cousins. Sometimes we underestimate the extent to which extended family members are willing to help and support. Don't be too 'too proud' to ask for help. Usually extended family members will themselves feel better if they can help you in some way.

Mothers

All families have choices about how to divide and share responsibilities. In many families it is the mother who has the greatest responsibility for the care of children. Many women go into 'supermum' mode and forget their own needs. It is important to be sensible about how much you can do on your own. Don't feel ashamed to ask for help. You will probably be able to be more of a 'supermum' if you are getting some help and support.

Fathers

"I often feel guilty about being at work, knowing what my partner is coping with at home. I know in my case that being at work is much easier than being at home."

It can be very difficult for fathers. Some find it hard to be involved with their children because of work commitments. Many fathers experience a sense of guilt about the amount of time they spend at work while their partners are coping with difficulties at home. Others become workaholics – hiding from their feelings by being constantly busy at work.

Quite often fathers miss out on mutual support. They tend to have less access to parent support groups because the meetings are during the day, or they feel the women in groups don't welcome them or they don't feel comfortable discussing their own feelings.

Many fathers are not as experienced or as confident about sharing their personal feelings and they don't feel as if they can let it all out.

Much of male culture is about a concept of strength that undermines a genuine sharing of feelings between men. They feel stressed but don't know why. It can gnaw at them without them understanding why.

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With changes in community attitudes, men tend to be more involved in parenting these days. A supportive and understanding man can be a great source of assistance in sharing the tasks of looking after children (or taking the primary caring role at home).

Brothers and sisters

"It's hard for Mum. She has to spend so much time looking after my brother she doesn't have much time left over for me."

Care must be taken not to sacrifice the needs of the other children in your family. The extra attention required by your child with a disability may be interpreted by brothers and sisters as favouritism.. It may create tensions between siblings and feelings of rejection in non-disabled children.

Explain to siblings, at their level of understanding, what the situation is. They can be a great help. Be alert to your other children's needs. Inform them. Include them in your decision-making.

Give each child their own area of responsibility and their own special time alone with you. It can be difficult, but it is very important. You are a family first, second and last, and the thoughts, feelings and needs of siblings cannot be overlooked.

Difficulties you may encounter

Many factors can place pressure on relationships between parents. These include denial of grieving, different coping styles, the tendency to 'blame', and breakdown in communication about feelings and needs.

One or both parents may work to breaking point without recognising their own needs.

There are also difficulties faced by siblings of the child with a disability; jealousy and feelings of rejection are common reactions.

Strategies that may work for you

"I started to breathe easier on meeting other mums of kids with disabilities and the kids themselves. With those meetings came hope, new suggestions, enlightening stories, real empathy. These people really knew where you were at! Now I could start to really do something for my son. The chains that bound me in my hellish pessimism began to fall away."

Look after yourself.

Talk to your partner and family about feelings and needs. It does help to be open and share your feelings and thoughts.

Make sure you have someone to confide in, and share your experiences. Parent support groups have sympathetic listeners.

Fathers need to know who to trust and how to share their feelings.

Fathers should be encouraged to develop suitable support systems, including meeting other parents/ fathers with similar family situations.

Taking care of yourself and your family relationships is as important as taking care of your child.

Seek professional advice from your doctor or a counsellor if you have difficulties coping.

Make sure you have breaks from your child. Time out is crucial; ask friends and relatives or use a respite care service.

For couples, take time out together.

Set goals not only for your child, but for yourself and the family.

Share tasks, providing a role for all members of your family.

Encourage non-disabled siblings to talk about their feelings, and work out ways to support them.

Give each child their own area of responsibility and their own special time alone with you.

Ideas to think about

No family is perfect.

Looking after yourself is not an 'optional extra'. It must be part of the overall plan for your family if you want to last the distance.

"I used to feel guilty about this thing they called respite. I don't any more. It gives us time to just relax and talk – to recharge the batteries. Respite – I need it, we need it and I don't feel guilty about it one bit."

Stress, Relaxation and Intellectual Disability

Published with permission from the Disability Services Information and Education Newsletter June 2003

Stress!! Ask anybody and they'll tell you that stress is the cause of a lot of our woes in this modern world. We live too fast, we don't know how to slow down, relax, smell the roses. Stress makes our bodies sick and our minds full of angst. Perhaps it was always so but we just used to refer to it as worries, problems or difficulties instead of stress.

The groundwork for the modern meaning of "stress" was laid around the turn of the 20th Century by Walter B. Cannon, who described the physiological phenomena which occurs when a person is faced with a threat. The autonomic nervous system fires up to prepare the body to flee or to fight which is great, when you need it but puts a serious drain on your physical and mental capacities if overused.

Herbert Benson (1975) described the natural antidote to the stress response. He called it the "relaxation response" and showed how you can restore calm in your body by assuming the opposite postures and responses to what you use in a panic situation. For example, when we're stressed we breathe rapidly, tense our muscles and clench our fists in preparation for action. If you do the opposite and breathe slowly, drop your shoulders, uncurl your hands and stretch your limbs out, then you can help to override the stress response and calm down.

There are various techniques and styles of bringing about the relaxation response including progressive muscle relaxation where the person first tenses each part of their body and then relaxes it and focuses on the difference in the feeling in the muscles. Research into using such techniques to reduce stress for people with intellectual disabilities has not always been positive or conclusive. However, two modified forms of progressive muscle relaxation have been shown to reduce anxiety in individuals with mild or moderate intellectual disability (Lindsay & Baty 1986: Richard et al 1984.)

One of these techniques, called Abbreviated Progressive Relaxation, has been shown to significantly and substantially reduce disruptive behaviour in adults with an intellectual disability, (McPhail & Chamove 1989). This study involved three weeks of fairly intense training, with results which were immediate and cumulative and especially impressive for reducing physical and verbal aggression. However three months after training, with no further input, individuals displayed the same disruptive behaviours as prior to training.

Lindsay & Baty (1989) compared the use of Abbreviated Progressive Relaxation (ART) and another technique called Behavioural Relaxation Training (BRT) with groups of adults with moderate and severe intellectual disability. With BRT there is no tensing of muscles first or focusing on internal states of tension. Instead, the subjects are given a demonstration of unrelaxed posture and behaviour and then shown the relaxed versions and asked to imitate the latter. Subjects are given assistance and feedback to assume postures correctly.

In this study, although both groups improved on rated anxiety, the BRT group improved significantly more than the ART group. BRT may be a better relaxation technique for those with intellectual disability because the instructions are simpler, individuals are assisted by the instructor and there is no confusion with having to tense muscles first or to conceptualise internal states.

The authors were wary, however, of relaxation techniques for those with intellectual disabilities being used simply to produce a passive state, and believed that changes in relaxation states should then be used to enhance the individual's abilities.

Lindsay & Morrison (1996) showed that BRT could have a positive effect on the cognitive abilities of individuals with severe intellectual disability. In a study comparing BRT with a

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control group who were read stories, those in the BRT group showed a constant and significant increase in task performance levels on digit span tests and incidental learning tasks. The implications are that the amount of information processing and the quality of learning may be enhanced by relaxation therapy.

So there are some promising results on relaxation techniques for this group, who, due to their disability, are unrelentingly faced with stresses. It seems that simple relaxation techniques which are modelled well and done consistently seem to have a good effect on behaviour and cognitive abilities.

At the very least, the best way to help others to find some peace is probably to start with ourselves. So, breathe slowly, uncurl those fists and bend over and smell that rose.

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A case for teaching Functional Skills

Extract from TASH Newsletter Dec 1987 re: older brother Daryl who was 18 years old and had attended special education all his life , including some years of 'individual instruction'
Daryl can do lots of things he couldn't do before!

He can put 100 pegs in a pegboard in less than 10 minutes with 95% accuracy.
But he can't put coins in a vending machine.

Upon command he can 'touch' nose, shoulder, foot, hair & ear. He's still working on wrist, ankle and hips.
But he can't blow his nose when needed.

He can do a 12 piece big board puzzle with 100% accuracy and colour an Easter Bunny and stay in the lines!
But he prefers music, but was never taught how to use a radio or record player.

He can now fold paper in halve and even quarters.
But he can't fold his clothes.

He can put the cube in the box, under the box, beside the box and behind the box.
But he can't find the rubbish bin in McDonalds and empty his rubbish into it.

He can sort blocks by colour, up to 10 different colours.
But he can't sort his clothes: whites from colours for washing..

He can say his ABCs and tell me names of all the letters of the alphabet when presented on a card in upper case with 80% accuracy.
But he can't tell the men's room from the ladies' room when we go to McDonalds

He can string beads in alternating colours and match it to a pattern on a DLM card.
But he can't lace his shoes

I guess he's just not ready yet.

Why inclusion for autism spectrum disorder students not always the best option

Portions of this article have been excerpted from: Gary B Mesibov and Victoria Shea, "Full Inclusion and Students with Autism", Journal of Autism and Developmental Disorders Vol 26, No.3, 1996
Reprinted from Autism Awareness midyear 2003 edition

"Inclusion" is a term used describe the practice of teaching a student who has a disability in a regular classroom, with or without support, and using the regular curriculum, with or without modification. Inclusion advocates typically assert that each child has a right to be included at all times, and that necessary support services and accommodations to the child's impairment must be made within the regular education classrooms. Some even go as far as saying that this should occur even when parents do not want this or when the child is evidently not coping with the inclusion program.

Inclusion advocates support the view that the segregation of children by diagnosis or impairment is not in the best interests of the child because these children are denied access to normal experiences needed for normal development and that segregation results in adequate education services.

Inclusion should be distinguished from "integration" which describes the practice by which a student who has a special educational need receives instruction appropriate to individual needs in an appropriate educational environment (for example, a special education unit) and joins their mainstream peers for the remainder of their educational program. "Integration" is motivated by the student's educational best interest and occurs only when the student is capable of successfully participating in regular planned activities within the regular education class.

Does inclusion work for all autism spectrum disorder students?

One mother described her autistic son's experience in a mainstream class in Victoria.

> *My god what is that damn smell she has on; I can't breathe! Wow, what pretty colour eyes she/he has. Damn they should get that mole looked. And all the while they're talking to me; my mind wanders off*
>
> *Then usually I say, "You should get that mole looked at;; I just blurt it out then think 'DAMN' shouldn't have said that! That's INAPPROPRIATE. Those lights, those fluoros. There's one where we have our meetings and it drives me mad it really buzzes but no one else seems to mind and the noise of the air conditioner running and that clock on the wall – tick, tick, tick –drives me nuts too, but no one else. If I really want to hear someone I have to tell myself to listen and concentrate really hard on what they're saying then move it around in my head a bit till I figure out what they actually mean. It gets very tiring and sometimes I still get it wrong. I'm always being yelled at.*

Why inclusion will not always work for autism spectrum disorder students

Students who have an autism spectrum disorder have a range of individually unique cognitive, social, sensory, and behavioural problems. These include limited and disordered language skills, unusual sensory processing, difficulty combining or integrating ideas, difficulty interpreting the underlying meaning or relationship of events they experience, problems processing multiple sensory stimuli, resistance to unpredictability and change, and difficulties understanding social situations. Many students with autism, moreover, perceive their environments differently from children with other disabilities or their non-disabled peers. They may find the noise of a regular classroom to be distracting or even painful, the colourful materials distributed throughout the classroom to be over stimulating, and/or the physical organisation of the classroom inadequate for identifying where to go and what to do. As a result, students who have an autism spectrum disorder often experience considerable sensory-perceptual difficulties, confusion and anxiety in the classroom, leading to disorganisation, agitation and, in some cases, even aggressive outbursts.

Regular classrooms are language rich, socially

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complex environments, in which students are exposed to many distracting and challenging stimuli (loud noises, distractions, smells) and many challenges — either in terms of language or socially. A regular classroom and typical teaching techniques simply cannot be modified enough for many students who have an autism spectrum disorder, to overcome the barriers created by autism spectrum disorders.

Experience has shown that until students who have autism spectrum disorders become relatively adept at expressive and receptive language use, understanding basic social interactions and managing distractions, regular classrooms are unlikely to provide a nurturing learning environment. As a result, an important educational strategy for autism, is to structure environmental conditions so that students can attend to and comprehend instructions. These manipulations can include the use of individual and visually bare work spaces, physical harriers that separate play and work areas, predictable routines, very small groups or individual instruction, and reliance on visual and gestural communication. These modifications cannot be easily made in regular classes. Moreover, many traditional educational techniques and settings, appropriate for other students, are particularly ineffective for students with autism because these settings and approaches simply do not - and cannot - address the unique needs and unique impairments that are experienced by students who have an autism spectrum disorder.

The mis-match between the learning needs of students who have autism spectrum disorders, necessitated by the nature of autism, and the regular classroom environment has been demonstrated in over 40 years of experience in various programs, such as TEACCH.. These programs are tailored to the specific needs of students who have autism spectrum disorders. These programs have demonstrated that students who have autism spectrum disorders need special instruction that addresses their specific deficits and presents information in ways they comprehend. Programs, such as TEACCH, have shown that educating students who have an autism spectrum disorder requires individually designed settings and programs that address the developmental deficits that characterise this disability. Regular classrooms, at least initially, cannot do this; and for some students a regular classroom will never provide an environment conducive to education.

The conclusion is clear: the characteristics unique to students who have an autism spectrum disorder means that most of them require specialised instructional techniques, in addition to access to specialised settings. To the extent that regular classrooms cannot adjust to the special needs of many students with autism, the inclusion model limits the appropriateness of the education that students who have autism spectrum disorders would receive under that model.

The Goal of Education for Students who have Autism Spectrum Disorders:-

In addition to the specific nature of autism spectrum disorders and the difficulties faced by developing appropriate educational programs in a regular classroom, a related issue is the goal of education for students who have autism spectrum disorders. The explicit goals of an educational program should be adult independence and community membership to the greatest extent possible. The less supervision adults who have an autism spectrum disorder need, the more community options they have to meet their residential, vocational, health, and recreational needs. Thus, developing independence should he a very high priority for students who have an autism spectrum disorder.

To become independent, these students must develop the approach of looking for information in their environments, rather than watching familiar adults and waiting to be told what to do. When teachers can design and organise student environments, they can teach the students to look for and understand routines, visual cues, and organisational strategies. Starting in self-contained classrooms, organised to teach students who have autism spectrum disorder, so called autism or Asperger's friendly, makes it easier for many of these students to learn productive, independent routines.

In contrast, in a regular classroom, events change too rapidly for a student who has an autism spectrum disorder to develop consistent routines or any confidence in their ability to understand environmental cues. Students who have an autism spectrum disorder often continue to look to

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teachers for cues on what they are supposed to do and do not become independent actors. Placing students who have an ASD in integrated settings, therefore, can make it difficult for them to develop independence. Thus, even if students with ASDs are helped to function adequately in regular classrooms, learning new skills and having no behaviour problems, they may not be developing fundamental skills for independent functioning in adulthood.

Rather than being driven by a theory, it is best to design educational program so that they

- provide individualisation of program (which includes selecting the setting that best addresses that student's disability and educational needs);
- rely on empirically-based approaches rather than ideologically-based philosophies, and
- are based on treatment and education that begins with and emphasises an understanding of the problems of autism spectrum disorders and the particular difficulties that a particular student may experience.

Inclusion does not work for every student who has ASD. The reason is simple: students who have ASDs have difficulties that provide a barrier to learning in a regular classroom. Students who have an ASD require specific instruction and settings that enable them to manage their impairments, so that as their skills develop; they may be able to participate in the dynamics of a regular classroom. Otherwise, they simply will not understand what is going on. This is why the availability of a variety of settings is crucial, that range from autism spectrum disorder specific classes in special schools, autism specific learning support units to supported integration in mainstream classes, as well as highly structured, intensive specialised classrooms for ASD students and specialised, focused programs (eg. social skills) for ASD taught on a withdrawal basis for defined periods of time.

In all cases, the setting in which a student is placed should be determined by the child's best educational interests, as measured by how a particular setting will enable the student to learn most effectively; those skills necessary to live as well as and as independently as they can - and in the way they want. ,

Is there any such thing as "mild autism'? *Adapted from Autism News, May 2003* ".

Sometime Asperger's syndrome is described as "a mild form of autism". We suggest that such terms are not accurate because they convey the impression that the different difficulties that a person who is said to have "mild autism" are in some way qualitatively less than a person who has "severe autism". Such descriptions convey false impressions about the nature the difficulties people who have autism or Asperger's and their experience of these conditions. Such descriptions minimise the very real difficulties faced by people who are said to have "mild" autism or Asperger's. Increasingly, this translates into fewer services or less support.

It is easy to see how the term came to be used. When we compare a "high functioning" person (another term that we do not particularly like) with, for example someone with very little language and an accompanying intellectual disability, their difficulties may seem mild in comparison.

However, in terms of the impact on everyday life, the cognitive, social, and communication impairments of the high functioning person with autism, may very significantly affect the life of even the most "high functioning" person. Their lives may be burdened with anxiety, frustration, anger, confusion or depression to such an extent that their capacity for independent living is severely restricted. The support so called "high functioning" people require is no less important for their independence and safe living than the support for a person who has a different range of difficulties which are apparently more severe.

Of course, there is a continuum within the autism spectrum, with some people having more severe disability than others; that is not disputed. The point is simply that even those with good language skills, who on first meeting may seem quite capable, have deficits that can have a major effect on their everyday lives and their ability to live independently without some degree of support.

USING SOCIAL STORIES Reprinted from the Western Australian Association Newsletter

What are Social Stories?

"A Social Story is a short story that describes a situation in terms of relevant social cues and common responses, providing a student with accurate and specific information regarding what occurs in a situation and why."

The quote is from Carol Gray, who first defined Social Stories early in 1991, presenting a specific format for their use as educational tools for people with Autism Spectrum Disorders.

Why do we need Social Stories?

People with autism have impaired "theory of mind" ability. This is the skill to attribute thoughts, beliefs and perspectives to other people e.g. to predict what other people are likely to be thinking, or what they might know or believe. Social Stories are written to provide people with autism with the information they may otherwise lack. Also, because individuals process information presented visually much more effectively than information presented verbally, information provided in this format is more readily understood. *A visual symbol of praise may be far more meaningful for children who have Autism Spectrum Disorder than its verbal counterpart.*

People with autism often have difficulty determining the relevant issues, in a given situation, and are likely to become distracted by irrelevant details. The Social Story will, ideally, guide the reader enabling him/her to focus on what is relevant.

When do we use Social Stories?

We often use social stories when there is a problem, but seldom think to use them to celebrate an achievement, or to acknowledge something that the person who has autism typically does well. Carol Gray suggests that at least half of all social stories should be used for this purpose. She points out that "written praise may be far more meaningful for children with Autism Spectrum Disorder than its verbal counterpart."

Social Stories can tell who, what, where and why

Social Stories can tell the person: who is involved, where a situation occurs, what is happening, how it happens, and why. Often the why concept is the one most difficult for the person with autism to understand. Because non-autistic people understand most social situations fairly easily; we often assume that people with autism share our knowledge about a particular situation. Frequently, however, this is not the case.

For example, a mother recently complained that her son always talked 'at' her, while she was on the phone. She found it very irritating because she could not process two conversations at once. She assumed that "Joe" understood that this was the case and that he was just being difficult because he did not like her talking to someone else. When she told Joe that she could only understand one person speaking at her, he was surprised. He learned to wait provided that she told him explicitly that she was also talking to another person.

How do I Introduce Social Stories

Social Stories are a tool to help the person to cope with a difficult situation. Introduce Social Stories when the individual is calm. Use a calm, factual introduction, e.g. "I have a story about snack time", or whatever topic is relevant to the situation. A social story should not be used as a vehicle to tell off a person for poor behaviour. If used in this way, it is likely to be avoided and will be of very limited benefit.

How do I write Social Stories?

Carol Gray's website www.thegraycenter.org. gives precise directions for composing social stories. She suggests that there are four different kinds of statements that should be included in a helpful social story.

Descriptive sentences are statements of fact eg. "sometimes at the checkout we have to wait in line". The reason we include what might seem like the obvious is, because these are social rules which are not always obvious or

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understood by the person with autism. Quite often, simply supplying this information helps the individual to understand the situation more clearly and thus respond more appropriately.

These statements are often paired with sentences which assist the person in perspective-taking, a skill very difficult for the person with autism. Perspective sentences spell out all the elements in a situation which are often hidden to the person with autism eg. “my teacher will be pleased if I put my hand up when I want to talk.' Finally, we have directive sentences. These tell the individual how they can appropriately respond in the situation. For example, “At the checkout I can wait with Mum or Dad”.

The primary aim of social stories is to provide information which non autistic children of a similar age know automatically and to help the individual understand social situations which they frequently find unfathomable. The story should be made up of a number of components (See Gray's website listed above). The story overall should provide the person with a solution to a situation which they have experienced as difficult..

Your own creativity

When we read books and articles talking about different kinds of sentences in a social story, they can make the process seem overly complex. However, this should not be the case. You will be a successful story writer if you keep the following points in mind

- Keep the story brief.
- Make sure the language is at the person's level. Most of the examples provided here assume that the individual with autism has a good, basic command of language. However, good social stories can be produced using far simpler language and many children (and adults) can benefit from pictures to accompany the text.
- Remember, part of the reason social stories work is that they provide information visually. The individual needs to see, not just hear, their story. Don't introduce too many new stories at one time.
- Review stories frequently. Seeing a story just once is unlikely to change the situation.
- Allow the person access to their stories. For some individuals, their collections of social stories can become their “social reference manual” to help them deal with difficult situations.

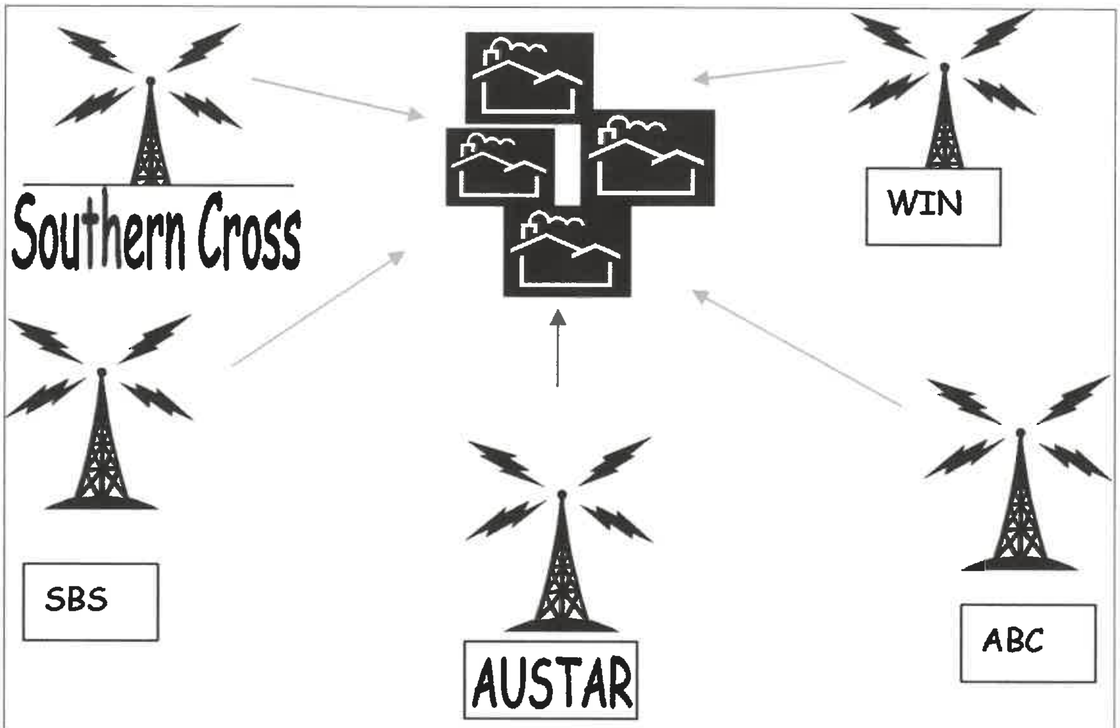
Supporting the person who has autism

It is very important for those supporting people with autism, to understand the extent of these deficits and the distress they can cause the person who becomes aware of their difficulties. It is very important to use concrete language which does not leave anything to the imagination. Also, be prepared to review teaching material, or the way you interact with these issues in mind.

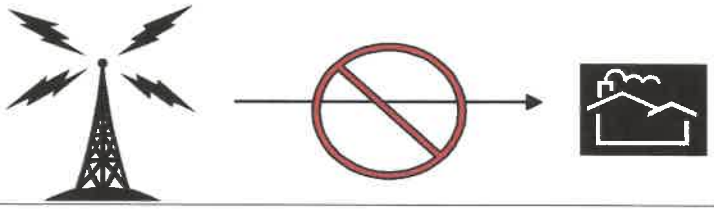
A Sample social story – When the TV doesn't work

Here is an example of a Social Story written to offset the panic of the TV not working

WIN, Southern Cross, SBS, ABC and Austar are all TV stations. They all have big towers to send the programs to the TVs in people's houses.



Sometimes things go wrong with the TV stations.
That stops the TV program from getting to the people's TVs.



The TV picture goes white and the TV makes a funny noise. xxxx doesn't like it when there is no picture or proper sound on the TV.
There is nothing wrong with the TV in our house.
It is the TV station that is not working properly.
The people who work at the TV station know how to fix the things that go wrong. Sometimes they can fix them quickly.
Sometimes it takes a long time.
We have to wait for the people at the TV station to fix the problem.
When it is fixed, we can see the TV program again.
We need to wait quietly.
We can watch another station or do something else until the TV station is fixed. It will be OK

THE JOURNAL OF AUTISM TASMANIA INC.

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Contact the **Autism Tasmania Family Support Coordinator,** Rose Clark on 6423 1086 or 0407 320 048

Book Review by Alice Minchin (aged 12)

THE CURIOUS INCIDENT OF THE DOG IN THE NIGHT-TIME

This intriguing novel was written by Oxford based author, Mark Haddon. Mark Haddon (author, illustrator, screen writer) has written fifteen children's books. The Curious Incident of the Dog in the Night-Time was first published this year.

The main setting of the story is a house in Swindon, not far from London, where fifteen year old Christopher lives with his father. The story is narrated by Christopher. Christopher has Aspergers syndrome, a form of high-functioning autism. He has a brilliant photographic memory, he can understand maths and science, but he can't understand other people, or other people's feelings.

Christopher's favourite (recurring) dream is about the whole world being infected by a strange virus. You catch the virus from looking people in the eyes and understanding what they say or how they feel. Then you die. Soon, only special people are left in the world: people who don't look at people's faces and don't understand how other people feel, people like Christopher.

Christopher likes dogs. Dogs don't have complex feelings, only happy, sad, angry. Christopher is devastated when he finds his neighbour's dog has been 'murdered'. He decides to find out "who killed Wellington" and write a murder mystery novel. But being a detective isn't easy, it involves TALKING TO STRANGERS.

Christopher's mother is 'dead'. She has been 'dead' for the past four years. But then Christopher discovers a box full of letters. If his mother is dead, how come the letters keep coming?

The main theme is about understanding the world from the perspective of someone with Aspergers Syndrome. The irony is, the reader understands more than the narrator.

This sad and funny novel, which really gets inside the Aspergers mind set, is a deadly accurate piece of writing. As the sister of a nine year old boy with autism, there were many behaviours that I could recognise and relate to.

I recommend this book for ages twelve to adult, particularly those who are related to or know, someone on the autism spectrum. (Of course, it would be an engrossing and educational read for those who are unfamiliar with autism.) I'd give it 10/10 for its amazing accuracy.

Alice Minchin