

# Autism in Northern Ireland

# The tragedy and the shame

**A**T Colin's belated 18-months assessment the health visitor expressed a number of concerns about him. He did not respond to the hearing tests, and it was difficult to keep him in the room. The health visitor made reference to hearing loss, possible brain damage, and developmental delay. Over the next two years Colin was seen by dozens of health professionals – community medical officers, audiologists, ear, nose and throat specialists, speech therapists, psychologists, paediatricians, an occupational therapist, a physiotherapist, and several health visitors. Family life was severely disrupted because it was too much of a battle to take him visiting or shopping. Colin had been assessed as having moderate learning difficulties, and the consultant psychiatrist diagnosed him as having Asperger's syndrome and ADHD. He had very little language – only about seven or eight words. In nursery school he refused to join in story time or planned activities, preferring solitary repetitive play with toy cars, water and sand. At home he was seldom still and his parents had to lock windows and doors. He did not respond to his name and he slept little.

Now aged 11, Colin is an entirely



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different child. His school report describes him as 'a very good-natured boy who enjoys the company of his classmates... a lively, enthusiastic, friendly boy who can articulate readily and most competently his needs and opinions...[who] always listens well and absorbs the information presented'.

From being a child destined for an institution, Colin now can look forward to a happier and more fulfilled life. So how did I work with Colin's mum Lynne to achieve this remarkable transformation? I used applied behaviour analysis (ABA).

The Supreme Court of British Columbia has said:

*It is beyond debate that the appropriate treatment is ABA or early intensive behavioural intervention. (Docket C984120, 26 July 2000, p.64)*

So why is there an almost total lack of skills in our community to achieve what we did? Why do families struggle against a wall of misinformed and prejudicial views held by many professionals towards ABA? Why are parents being forced to use the courts to gain funding for their home programmes, and to gain access to schools by independent observers to assess the provision being offered for their children?

## What is ABA?

Lynne and I recounted our story in a book (Keenan *et al.*, 2000) partly written by parents from a charity we established in Northern Ireland called Parent's Education as Autism Therapists (PEAT). The mission

of this charity is to empower parents with skills in ABA – the 135 families in PEAT have only one full-time and one part-time therapist with the skills to help them. So what are parents being taught about ABA?

Cooper *et al.* (1987) defined ABA:

*...the science in which procedures derived from the principles of behavior are systematically applied to improve socially significant behavior to a*



Offering hope – But ABA is underused

## WEBLINKS

Association for Behavior Analysis:

[www.abainternational.org](http://www.abainternational.org)

Association for Science in Autism Treatment:

[www.asatonline.org](http://www.asatonline.org)

Behavior Analyst Certification Board:

[www.bacb.com](http://www.bacb.com)

Cambridge Center for Behavioral Studies:

[www.behavior.org](http://www.behavior.org)

US Surgeon General's Report on Mental Health,

Autism Section: [www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html](http://www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html)

*meaningful degree and to demonstrate experimentally that the procedures employed were responsible for the improvement in behavior.* (p.14)

Sounds simple enough, but somehow many psychologists have got the wrong end of the stick with 'straw-person arguments which both introductory and advanced psychology books promulgate' (Guerin, 1994, p.15). These include the idea that behaviour analysis reduces everything to food and sex reinforcers, or that it discards valuable psychological ideas like the mind, the self, innate behaviours, emotions and knowledge. Spinelli (1989, p.175) believes that 'the great majority of behavioural findings tell us little of worth about ourselves' and that 'in a sense, having denied the importance of subjective data, their findings appear limited, alien, even "soul-less"'. Gross (1995, p.239) describes behaviourism as the study of people as natural phenomena, 'with their subjective experience, consciousness and other characteristics, which had for so long been taken as distinctive human qualities, being removed from the "universe"', there being 'no place for these things in the behaviourist world'.

In fact, ABA certainly doesn't view people as 'black boxes'. Watts (1966)



## EDUCATIONAL CURRICULUM FOR A CHILD ON THE AUTISTIC SPECTRUM

### Attending skills

Basic:	Child sits in chair independently. Child makes eye contact in response to name.
Intermediate:	Child asks 'What?' when their name is called.
Advanced:	Child makes eye contact during conversation and group activities.

### Imitation skills

Basic:	Child imitates gross motor, fine motor, and oral motor skills and actions with objects.
Intermediate:	Child imitates a sequence of actions or sounds.
Advanced:	Child imitates peer play.

### Receptive language

Basic:	Child follows one-step instructions, and identifies objects and pictures.
Intermediate:	Child identifies emotions, and follows two-step instructions.
Advanced:	Child follows three-step instructions, and discriminates concepts.

### Expressive language

Basic:	Child imitates sounds and words, and labels objects and pictures.
Intermediate:	Child labels gender, and objects based on function.
Advanced:	Child labels categories, and retells a story.

### Pre-academic skills

Basic:	Child matches identical pictures and objects. Child undresses.
Intermediate:	Child initiates for bathroom, washes hands and puts on some clothes.
Advanced:	Child brushes teeth, and buttons clothes.

wrote extensively on Eastern philosophies, providing remarkable parallels with the philosophy of radical behaviourism (e.g. Chiesa, 1994; Keenan, 1997; O'Donohue & Ferguson, 2001). He expands on Skinner's view that the skin does not separate you from the world but connects you to it. Behavioural principles are anchored in terms that relate changes in a person to the context in which these changes are observed:

*Today, scientists are more and more aware that what things are, and what they are doing, depends on where and when they are doing it. If, then, the definition of a thing or event must include definition of its environment, we realize that any given thing goes with a given environment so intimately and inseparably that it is more difficult to draw a clear boundary between the thing and its surroundings.* (Watts, 1966, pp.67-68)

Another distinguishing feature of behaviour analysis is its emphasis on developing research methodology that monitors changes in an individual. 'Being a person' is an experience that extends across time, but research methodology taught to

undergraduate students typically hides this natural facet of our humanity by focusing on data collected in snapshots, and averaged across groups of people. In effect, the individual is sacrificed on the altar of group statistics. When dealing with autism, this means that professionals are not empowered with the skills necessary to assess the effectiveness of educational programmes intended to empower the individual.

Where single-case research methodology is employed (e.g. Johnston & Pennypacker, 1993), it has enormous implications for treatment designs. In a home programme, for example, it translates into the practice of teaching a parent how to shadow the developing child to monitor very closely the changes in choreography that make up the fine detail of the child's interaction with their physical and social environment. The box above shows how this would be put into practice in a typical ABA curriculum.

When this choreography is in need of change, then practical steps are taken to see if this can be achieved. Usually this involves a functional assessment that begins by defining the problem behaviour, then identifying possible causes of the behaviour, predicting when the problem behaviour will occur, and finally designing

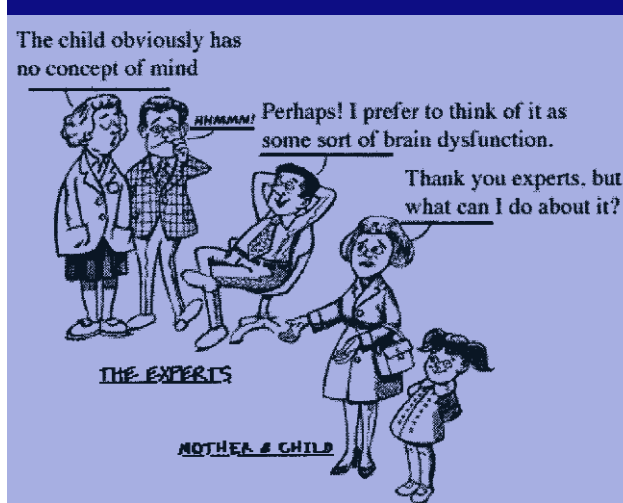
effective treatment programmes (see Desrochers *et al.*, 2002). The questions that usually arise for parents and therapists include which aspects of the choreography to start with, and what to do next.

Behaviour analysis has developed, and continues to develop, guidelines to address these questions (Maurice *et al.*, 1996; see also weblinks).

Another major issue that is addressed when teaching behaviour analysis to parents is the topic of 'mentalism' – the tendency for explanations to be formulated in such a way that references to historical and current contexts are omitted while fictitious entities are invoked instead (Moore, 1980, 1981); not to be confused with the practice of inferring intentions from behaviour. Parents are made aware of the extent to which mentalism impedes the design of effective programmes. Confusion on this topic lies at the heart of much of the misrepresentation of behaviour analysis (Morris, 1985; Skinner, 1977, 1985; Wyatt, 1990), and I have used an animated cartoon character to teach about it (Keenan & Dillenburger, 2000). In a short sketch 'Adam' walks across the screen towards a girl who looks at him briefly. He then bounces a ball and at one point he burps. The girl admonishes him for this rude behaviour and he blushes, stops what he is doing for a moment before continuing. He burps again and is admonished again. After a moment he walks off the screen and returns with a flower for the girl. Parents are asked to jot down words they feel are appropriate to Adam.

When they are finished the animation is rerun, only this time parents are shown similar words used by a class of 100 undergraduate psychology who were asked to do the same thing. In the animation these words appear on the screen to coincide with the behaviour being referred to. Words used include cheeky, rude, immature, attention-seeking, charming, shy, and extravert. The range of words produced by the students usually matches the words used by the parents. Next, all the words used are placed on the left-hand side of the screen under the heading 'Descriptions'. I then point out that these words are correctly used as *descriptions* of behaviour. The mistake of mentalism occurs when any of these words are then used to *explain* behaviour. In a further twist of the

**FIGURE 1** A typical experience for parents of children with autism



animation Adam's head is opened up to reveal an empty space – there is not necessarily any 'inner entity' causing the behaviour. In effect the animation reveals to parents that their use of words to explain his behaviour is an indication of a language trap (see Holth, 2001, for a more detailed analysis of mentalism and category mistakes).

**Autism wars**

When governments in the North and South of Ireland set up task groups to look at provision for autism, all ABA professionals were excluded from participating. The task group report produced in the North stated:

*Local professionals who work with young children suggested to Task Group members that they would have grave reservations about being involved in subjecting such young children to such an intense behavioural programme for fear of causing some kind of psychological damage. (Section 3.25)*

So we have a situation in which the 'evil empire of ABA' is being fended off by people protecting the children from what they perceive as its abusive regimes. In my view, the context for understanding this state of affairs can be traced to misrepresentations of behaviour analysis, as I outlined earlier. Views like these have found homes in many departments of psychology in the UK, and in the pages of *The Psychologist*. However, even a cursory glance at Colin's progress would suggest that something is not right here. Could Lynne and I have helped him if we had

ignored those distinctive human qualities? Perhaps Colin is the only one who can answer this question, but I suspect the answer is fairly obvious. Students new to behaviour analysis should ask also how these kinds of comments match the following statement by Skinner (1989):

*Methodological behaviorists, like logical positivists, argued that science must confine itself to events that can be observed by two or more people; truth must be truth by agreement. There is a private world of feelings and states of mind, but it is out of reach of a second person and hence of science. That was not a very satisfactory position, of course. How people feel is often as important as what they do. (p.3)*

In any case, parents new to ABA are not concerned with the various academic arguments surrounding behaviour analysis. Their primary concern is to find a scientifically validated treatment that helps their child. In many ways, membership of PEAT stems from a simple curiosity about what information has been denied to parents: 'Why didn't anyone tell us that something could be done, that I could do something?' These are words that continue to echo throughout the group, with many parents identifying with the scenario depicted in Figure 1.

Unfortunately for the parents in Ireland there are no university programmes for teaching ABA to professionals. In the rest of the UK the situation is similar, with very few psychology departments teaching it at the undergraduate level, despite its proven record in a dealing with a wide range of social problems apart from autism – for example, parenting, social skills, self-control, education, littering, and energy conservation (Grant & Evans, 1994; Martin & Pear, 2001), community (Martin & Osborne, 1980), social welfare policy, child maltreatment, teen pregnancy, youth violence, racism, and drug abuse (Mattaini & Thyer, 1996). According to the US Surgeon General, 'thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate

social behavior' (US Department of Health and Human Services, 1999, p.164). Other sources describe 'rapid, complex, and durable improvements in cognitive, social-communication, play, and self-help skills', stating that 'application of behavior-analytic principles are very effective in replacing and/or reducing maladaptive behavior' (California Departments of Education and Developmental Services, 1997, p.67).

It is difficult to reconcile parental involvement in ABA, and the evidence of its effectiveness, with caricatures of behaviour analysis by professionals. This issue needs to be confronted if we are to promote the development of ABA skills in our community. The contrast between the perspective of parents and the perspective of professionals fed on a diet of misrepresentation is unfortunate, and it is one of the reasons why I used the word 'shame' in my title. It is a shame that misrepresentation of behaviour analysis has prevented its developments from being shared with students who have an interest in helping others. It is such a shame that parents of children with autism have to bear the brunt of funding decisions that are informed by misinformation on ABA. In Britain about 100 local education authorities have funded ABA programmes for children with autism. Unfortunately, many of these decisions were forced through tribunals.

An added problem is the scarcity of undergraduate students with the requisite skills to help run these programmes. Maybe some day the rift between behaviour analysis and psychology will be repaired, so that more opportunities for cross-fertilisation of ideas can become a reality. Perhaps interested authors could band together to produce a special issue of *The Psychologist* showing the advances made in ABA. This might help to expose the inconsistencies between those who perpetuate myths about behaviour analysis, and those who use ABA in a compassionate way to facilitate meaningful changes in the lives of others.

## Conclusion

I would encourage psychology students wishing to learn more about behaviour analysis to work alongside parents in well-monitored home programmes. Not only would parents benefit from an extra pair of hands, but these new psychologists would be in a better position to dismiss the

misinformation that has misled many of their teachers in the past. While I am convinced that this is a simple and useful way to shepherd resources so that parents, children and students all benefit, I fear it will take a long time to achieve without the continued support by the BPS for the activities of its Standing Committee for the Promotion of Equal Opportunities (SCPEO).

Consider this example of how equality of opportunity for children with autism can be unintentionally impeded by BPS members. For her undergraduate dissertation a student proposed to teach a child with autism to follow a specific schedule for his morning routine. Not only was ethical permission for the study refused by the student's departmental ethical committee, but also a suggestion that the parents be taught how to teach the child instead of the student doing it was not permitted; teaching the parents was deemed to be a clinical intervention by proxy, and as such it was demanded that the proposal be forwarded to the university research ethical committee for approval.

Psychologists not familiar with ABA educational programmes are mistaken

when educational procedures are deemed to be clinical interventions. It really is a sad day for psychology when procedures designed to enhance a child's self-help skills cannot be seen for what they are – opportunities for learning. Clearly, any procedures that are specifically designed to facilitate changes in another person must be of the highest ethical standards; any social interaction falls within this domain. But the point is this. Educating a child to have commerce with the world is not in itself an ethical issue; it is the absence of appropriate education that is of ethical concern. If education is an ethical issue for children with autism then it should be so for all children in need of education. To single out children with autism in this way, perhaps because of adherence to a medical model, is to discriminate against them. The 'illness' is addressed first and not the child. It is issues like this that are the very heart of what SCPEO is all about.

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