

**Autism in N. Ireland:
The tragedy and the shame**

Mickey Keenan
School of Psychology
University of Ulster

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I would like to thank the members of SCPEO who selected me for this award. My initial reaction on hearing that I had won the award was to wonder if the BPS really understood the extent to which it may have inadvertently reinforced what some might call my disruptive behaviour. I guess we'll just have to wait and see what the future brings in terms of the behaviours that appear.

While I am personally very honoured and proud to receive this award I consider it also to be a significant acknowledgement of the contribution behaviour analysis can make to enriching the lives of a vulnerable group in our community. In my talk today I hope to share with you examples of the kinds of challenges facing parents of children with autism in N. Ireland. I have pulled together material from various places including a book produced with the help of parents, my opening address to the first conference in Applied Behaviour Analysis (ABA) in Ireland, and a response to the N. Ireland Task Group Report on Autism.

My presentation is organised into 3 main headings:

- 1 Background to my work on autism in the community
- 2 Essential features of ABA: What parents are being taught
3. Difficulties in getting support for ABA: The Autism wars

1. Background

For those of you not familiar with autism here is some background information:

"Autism" - a descriptive label for a developmental disability (often manifest before age 3) affecting verbal and nonverbal communication and social interaction. Other characteristics may include persistence in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

Autism is a spectrum disorder (ASD) - The symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Two children can have the same diagnosis but act very differently from one another and have very different skills.

Prevalence rates - The National Autistic Society (NAS) has calculated that prevalence rates lie anywhere between 20-71 per 10,100 (<http://w02->

0211.web.dircon.net/pubs/archive/prevalence.html). A recent article in The Scotsman noted the following: "Campaigners believe that Scotland is facing a crisis, with the number of cases of autism rising from one in every 2,500 of the population to one in 166 over the past ten years - an increase of 1,600 per cent." (<http://www.thescotsman.co.uk/index.cfm?id=261152003>)

If it had not been for a wonderful mum, Lynne, who worked diligently with me to bring out the best in her little boy, I would not have been actively involved in the area of autism today. When Lynne first came to me I found it hard to come to terms with her predicament. As an academic I was well aware that there were hundreds of journal articles detailing the success stories of behaviour analysis with autism (<http://www.behavior.org>). What I couldn't understand was why this mum was coming to me and not to a professional in the community? I was aghast to learn from her that there was nobody to whom she could turn. There was nobody who had sufficient knowledge of ABA to help her teach her son how to learn. So it fell to me, a behaviour analyst with no prior practical experience of working with autism to help her. Details of the success of our work together are contained in a book called *Parents' Education as Autism Therapists: Applied Behaviour Analysis in Context* and published by Jessica Kingsley Publishers (Keenan, Kerr, & Dillenburger, 2000). To give you an example of the kinds of difficulties faced by all parents of children with autism here are some extracts from this book on Lynne's little boy, Colin.

Colin's story

At his belated 18 months assessment the health visitor expressed a number of concerns. He did not respond to the hearing tests and it was difficult to physically keep him in the room for the assessment. The health visitor made reference to hearing loss, possible brain damage, and developmental delay.

Between the ages of 20 months and 3 years and 9 months Colin was seen by dozens of health professionals, e.g., several Community Medical Officers, audiologists, Ear, Nose, and Throat (ENT) 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. He had been assessed as having moderate learning difficulties and professionals were beginning to talk about Special Schools and Units. The Consultant Psychiatrist diagnosed Colin as having Asperger's Syndrome and Attention Deficit/Hyperactivity Disorder. Colin had very little language, only about seven or eight words, e.g., demands such as milk, drink, biscuit, or simple labels such as car and cup. He was extremely active, if restrained, e.g., holding his hand, carrying him, or using a child harness, he became extremely upset and it became a thoroughly aversive situation for the whole family. He depended on routine, e.g., he became upset if his mother varied the route to the Nursery School or parked in a different place. 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 internal doors. He did not respond to his name, he slept little, waking frequently and was very difficult to settle in bed again. He did not do what he was told and everything seemed a struggle. Below are the assessments given by professionals at various times during this period.

Table 1
Assessment by professionals

2 years Colin was assessed by a Speech and Language therapist as having a severely disordered communication development. Both comprehension and expression were severely affected. Self-distracting behaviour and echolalia were present.

3 years 9 months Four classroom observations highlighted a very pronounced lack of social awareness. “[Colin] pays scant regard or ignores group and class activities. He often wanders about the classroom oblivious to the main class activity. While peers in close proximity are reacting off each other [Colin] remains egocentrically preoccupied with the toy cars, having no urge to engage socially” (Educational psychologist report).

3 years 10 months Colin was assessed using the Childhood Autism Rating Scale (CARS). “The results specifically indicated a language delay, social aloofness, some degree of obsessiveness, poor adaptation to change, high level of activity and low level of attention control” (Educational psychologist report).

Despite my depiction of the inherent difficulties in the scenario where I was being asked for help by Lynne it wasn't exactly the same as the blind leading the blind. My expertise lies in my teaching skills. I knew that if I could teach her the principles of behaviour analysis that are integral to the design of specific interventions that she would eventually be able to design her own interventions, that she would become a skilled teacher for her own son. Basically I had to design an intensive course in ABA for Lynne.

Applied Behavior Analysis is the science in which procedures derived from the principles of behavior are systematically applied to improve socially significant behavior to a meaningful degree and to demonstrate experimentally that the procedures employed were responsible for the improvement in behavior. (Cooper, Heron, & Heward, 1987, p.14)

As you can see from these statements taken in January this year (age 11) from a report on his special educational needs Lynne and I facilitated some remarkable changes with our educational programs.

Colin is a very good-natured boy who enjoys the company of his classmates. He plays football and is very proud of being a member of the school quiz team. He has a great sense of humour He is a lively, enthusiastic, friendly boy who can articulate readily and most competently his needs and opinions. He has made excellent progress in understanding spoken and written information. He has an excellent expressive vocabulary and uses it appropriately in his spontaneous

language. His reading and thinking skills are well developed and he can use inference well. ... In school he contributes well to class debates and discussions. He has a wide general knowledge. He always listens well and absorbs the information presented.

From our early work together Lynne persuaded me to hold a couple of public talks to inform others about the techniques we had used. To cut a long story short, I ended up running classes in ABA on a voluntary basis for about 40 sets parents each month for about a year. Eventually we progressed to a charity status, the charity is called "PEAT" (Parents' Education as Autism Therapists).

For those of you who are not familiar with PEAT I feel it is best described as a school, a cross-community school in a divided society, a school run by parents for parents, a school without a roof, or without walls.

One of the main goals of our group is to persuade professionals and other parents that the practice of the science of behaviour analysis is long overdue in our community. We educate parents on how to use scientifically validated procedures for the benefit of their children. That is, we actively train parents how to teach their children how to learn.

A theme that continues to repeat itself with every parent who has turned to PEAT is one of 'overcoming obstacles', obstacles that are either conceptual in nature or of a more practical nature, or a combination of both. 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.

The biggest nightmare for any parent is the thought of harm coming to their children. I am sure also that all parents present here today have experienced at some time that awful angst at the thought of dying and leaving their vulnerable children unprotected. It doesn't bear thinking about how much more magnified this feeling is if a typically developing child is diagnosed with autism. In the early days of the group I learned a lot about the effects of autism on the family by talking to parents and observing them in their homes. I was deeply touched by the courage they showed in dealing with a number of things:

Diagnosis

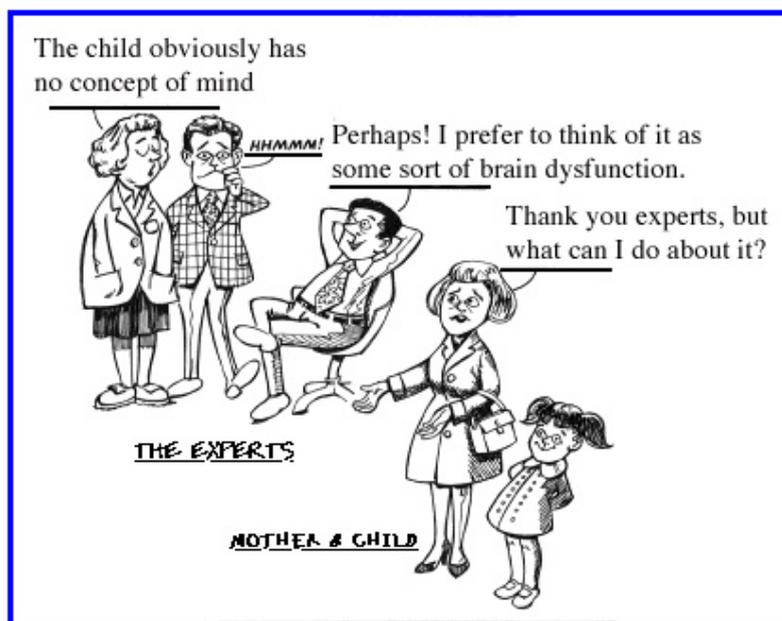
Firstly there were emotional difficulties in coming to terms with the diagnosis of autism in their child.

Practical

Entwined with this were the emotional difficulties associated with not being able to help in a practical way as their child, and in some cases the entire family, slipped further and further away from the dreams and expectations of a happy family.

Professionals

There were unintentional obstacles created by caring professionals who presented parents with a diagnosis but at the same time offered them no practical advice in the face of mounting difficulties. All parents identify with this scenario depicted in Figure 1.



Adapted from Martin & Pear (1992). *Behavior Modification: What it is and how to do it*. Prentice Hall

Figure 1: A typical experience for parents of children with autism

It is not my desire to be contentious for the sake of it by raising this issue. I am merely reporting a shared experience of virtually all of the PEAT members, an experience that chilled me to the bone when I first came across it and one that persuaded me to do whatever I could to help them.

Back to school

There were obstacles associated with the whole idea of studying again. Many, if not all were desperate for a short-term fix that would return them from the nightmare that had enslaved them. The last thing they wanted was to have to pick themselves up and go back to school.

Gauntlet

Having run the gauntlet of all of these difficulties these parents still rose to the challenge of organising themselves into a registered charity. This was done for the benefit of others despite the extra work they had undertaken in the management of their children's learning. As word gets around about what we are doing so PEAT expands. Currently there are about 100+ sets of parents in the group and a similar number of parents using ABA in schools in the South. Unfortunately we have only one full-time therapist, Stephen Gallagher, and one part-time therapist, John Calvert, who visit parents across the whole of N. Ireland doing a virtually impossible job. Both Stephen and John studied under me at the University of Ulster at Coleraine and it is their compassion for the plight of the

parents and children that helps to sustain PEAT in financially difficult times. At the time of writing this paper money has run out for Stephen which means that there is a potential crisis looming for the goals of the group. Without Stephen there will be no more PEAT group. Two other people who were central to establishing the movement that PEAT began were Bobby Newman from the Association in Manhattan for Autistic children and Ken Kerr from the Saplings school in Kildare. On behalf of Lynne and the other parents I would like to thank them both again.

For me personally, both as an academic and as father, it has been a humbling experience to have been involved with a group of individuals who battled hard to transform their love for their children into practical skills, skills that are guided by the rigours required by a science of behaviour. On the positive side we are now in a position where behaviour analysis is discussed in public meetings, both North and South of the border. Before this behaviour analysis was something that existed only for a small number of professionals or in the closed books on university shelves, to be opened in the event of an essay being needed for a course mark. In Figure 2 you can see the extent of interest in ABA across the whole of Ireland. Interestingly, although awareness of ABA originated with PEAT there are as yet no ABA schools in N. Ireland.

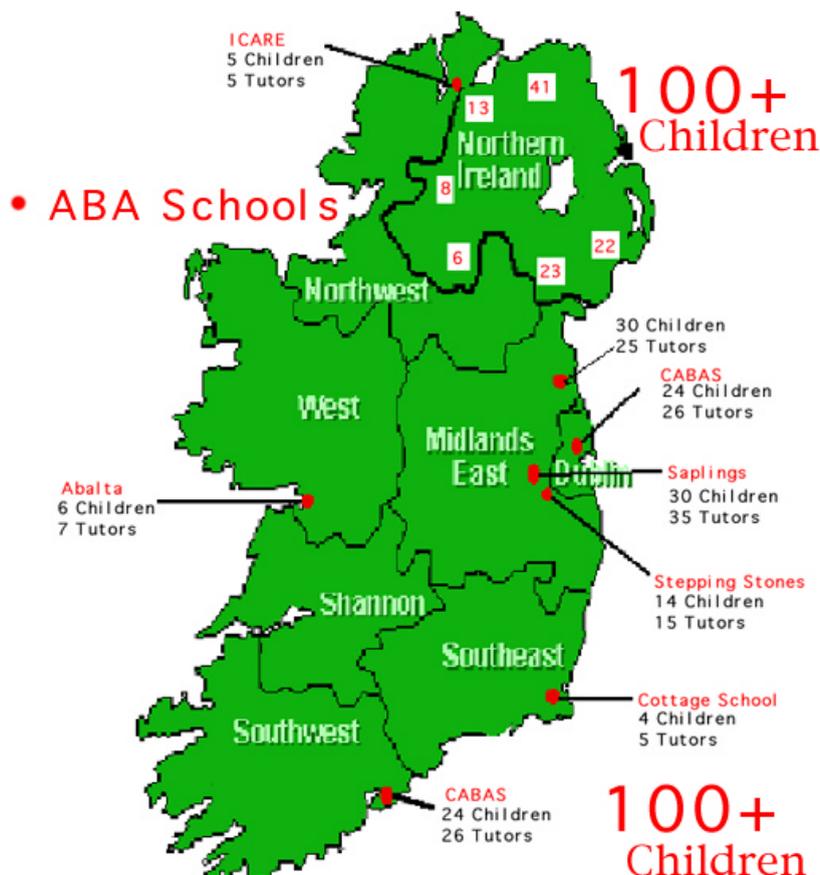


Figure 2: Numbers of children receiving educational programs in ABA in Ireland.

In spite of the progress we have made, for me the politics of it all is the most unexpected and stressful part of the path that has led me to here. The setting up of a new group is always bound to annoy others who thought they were the only ones who had the right to be in the driving seat. There wasn't much I could do about that. I was asked by parents to teach them what others were not teaching them. My personal commitment to continue hinged on the fact that the children always came first. But the politics don't just exist in the day-to-day affairs of community groups. In the heartlands of academia the situation for behaviour analysts is even more cut throat. This is something that I'll come back to later. Indeed such is the misrepresentation of the field generally that there are few psychology departments in the U.K. who make adequate provision for the teaching of ABA despite its proven record in a dealing with a wide range of social problems apart from autism and learning difficulties (e.g., Grant & Evans, 1994; Hudson & McDonald, ; 1991; West & Hamerlynck, 1992; Martin & Osborne, 1980; Martin & Pear, 2001; Mattaini & Thyer, 1996; Nietzel, Winett, MacDonald, & Davidson, 1977; Sanders & Dadds, 1993; Sidman, 1989; Sulzer-Azaroff, & Mayer, 1977).

2 Essential features of ABA: What parents are being taught

Before I outline very briefly some of the essential features of ABA that inspire me in my academic work and which guided me in my work with Lynne, I think it might be appropriate at this point to highlight some of the recommendations it has received elsewhere.

Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior. (Mental Health: A Report of the Surgeon General, 21st March, 2000, p. 5)

The California Department of Education (1997) concluded that "research has shown that intervention and educational programming based on the principles and practices of applied behavior analysis can produce rapid, complex, and durable improvements in cognitive, social-communication, play, and self-help skills. Application of behavior-analytic principles are very effective in replacing and/or reducing maladaptive behavior" (p. 67). (California Departments of Education and Developmental Services, Collaborative Work Group on Autistic Spectrum Disorders. (1997, July). Best Practices for Designing and Delivering Effective Programs for Individuals with Autistic Spectrum Disorders. Sacramento, CA: California Department of Education.)

The New York State Department of Health issued guidelines for the treatment of young children with an ASD [Autistic Spectrum Disorders; essentially someone who can be diagnosed as having autistic tendencies], stating that early and intensive behavioral intervention is at present the only appropriate treatment (New York State Department of Health, 1999). (New York State Department of Health, Early Intervention Program. (1999, May). Clinical Practice Guidelines: Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (ages 0-3 years). Albany, NY: Author.)

Statements like these are not made lightly, especially in view of their financial implications for staff training. Personally I still marvel at what Lynne and I achieved and what others are achieving through ABA. So what lies at the heart of ABA? Is it peculiar only to autism or does it apply to any other areas? The first thing you should note is that neither of the two A's in ABA stand for autism. Regarding it's relevance to other areas Martin and Pear (2001) said the following:

Applications are occurring with an ever-increasing frequency in such areas as education, social work, nursing, clinical psychology, psychiatry, community psychology, medicine, rehabilitation, business, industry, and sports. (p. 14)

It is impossible to do justice to the underlying philosophy of science that drives ABA in the time available so what I have done is to use a number of quotations that provide an overview of some of its essential features. Let me start with one from Bernard Guerin (1994). Guerin has written a book for social psychologists interested in taking the natural science perspective of behaviour analysis. He explains what behaviour analysis is at the start of his book by saying what it is not:

...behavior analysis is not at all like you have read and heard about it. It does not reduce everything to food and sex reinforcers, nor does it throw out the window all the good things like the mind or the self or theorizing or innate behaviors or thoughts or feelings or attitudes or the brain or information or emotions or symbolic behaviors or knowledge. These are straw-person arguments which both introductory and advanced psychology books promulgate. (p. 15)

The other quotations I turn to now come from an unexpected quarter. They come from the writings of Alan Watts. He was not a behaviour analyst, but someone who wrote extensively on Eastern Philosophies, in particular Zen Buddhism. Watts' writings provide remarkable parallels with the philosophy of radical behaviourism (Baum, 1994; Chiesa, 1994; Hayes & Brownstein, 1986; Keenan, 1997; Lee, 1988; Moore, 1980, 1981, 1985; Schnaitter, 1987; O'Donohue & Ferguson, 2001; Williams, 1986; Hardy).

In one of his books published in 1966 (*The book: On the taboo against knowing who you are*) he notes the following:

In Japan it was once customary to give young people about to be married a "pillow book." This was a small volume of wood-block prints, often colored, showing all the details of sexual intercourse. It wasn't just that, as the Chinese say, "one picture is worth a thousand words." It was also that it spared the parents the embarrassment of explaining these intimate matters face-to-face. (p. 3)

He then goes on to wonder what sort of book he might slip to his son or daughter. He suggests that it would have to be a book that discusses many of the things that have been the focus of religions –

the universe and man's place in it, the mysterious center of experience which we call "I myself," the problems of life and love, pain and death, and the whole question of whether existence has meaning in *any* sense of the word. (p. 5)

The conclusions of Watts are similar to those of behaviour analysis:

The root of the matter is the way in which we feel and conceive ourselves as human beings, our sensation of being alive, of individual existence, and identity. We suffer from a hallucination, from a false and distorted sensation of our own existence as living organisms. Most of us have the sensation that "I myself" is a separate center of feeling and actions, living inside and bounded by the physical body - a center which "confronts" an "external" world of people and things, making contact through the senses with a universe both alien and strange.

This feeling of being a lonely and very temporary visitors in the universe is in flat contradiction to everything known about man (and all living organisms) in the sciences. We do not "come into" this world; we come *out* of it, as leaves from a tree. As the ocean "waves," the universe "peoples." Every individual is an expression of the whole realm of nature, a unique action of the total universe. This fact is rarely, if ever, experienced by most individuals. Even those who know it to be true in theory do not sense or feel it, but continue to be aware of themselves as isolated "egos" inside bags of skin. (pps 8-9)

These next statements are more elaborate versions of a view also held by Skinner who noted that the skin does not separate you from the world but connects you to it.

The skin is always considered as a wall, barrier, or boundary which definitively separates oneself from the world -despite the fact that it is covered with pores breathing air and nerve-ends relaying information. The skin informs us just as much as it outforms; it is as much a bridge as a barrier. (p. 57)

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. (pps. 67-68)

But as things are, we define (and so come to feel) the individual in the light of our narrowed "spotlight" consciousness which largely ignores the field or environment in which he is found. "Individual" is the Latin form of the Greek "atom" - that which cannot be cut or divided any further into separate parts. We cannot chop off a person's head or remove his heart without killing him. But we can kill him just as effectively by separating him from his proper environment. (p. 69)

The analysis offered by Watts is echoed by behaviour analysis in so far as behavioural principles that have been formulated are anchored in terms that relate changes in an person to the context in which these changes are observed. Allied to this is a working definition of behaviour credited to Lindsley (1968; for comments on his paper see <http://members.aol.com/johneshleman/comment09.html> see also Malott, Whaley, & Malott, 1993) that is implicit in all applied work:

Behaviour is anything a dead person cannot do.

An unusual definition I am sure you agree, but in this simple sentence there is no scope for the usual misrepresentation of the discipline that supposedly regards people as black boxes, a point I'll return to later.

Next is a different kind of image I want to show you. Figure 3 is taken from my multimedia tutorial in behaviour analysis (Keenan & Dillenburg, 2000). I use it in all my talks with parents. It is called the 'behavioural stream'.

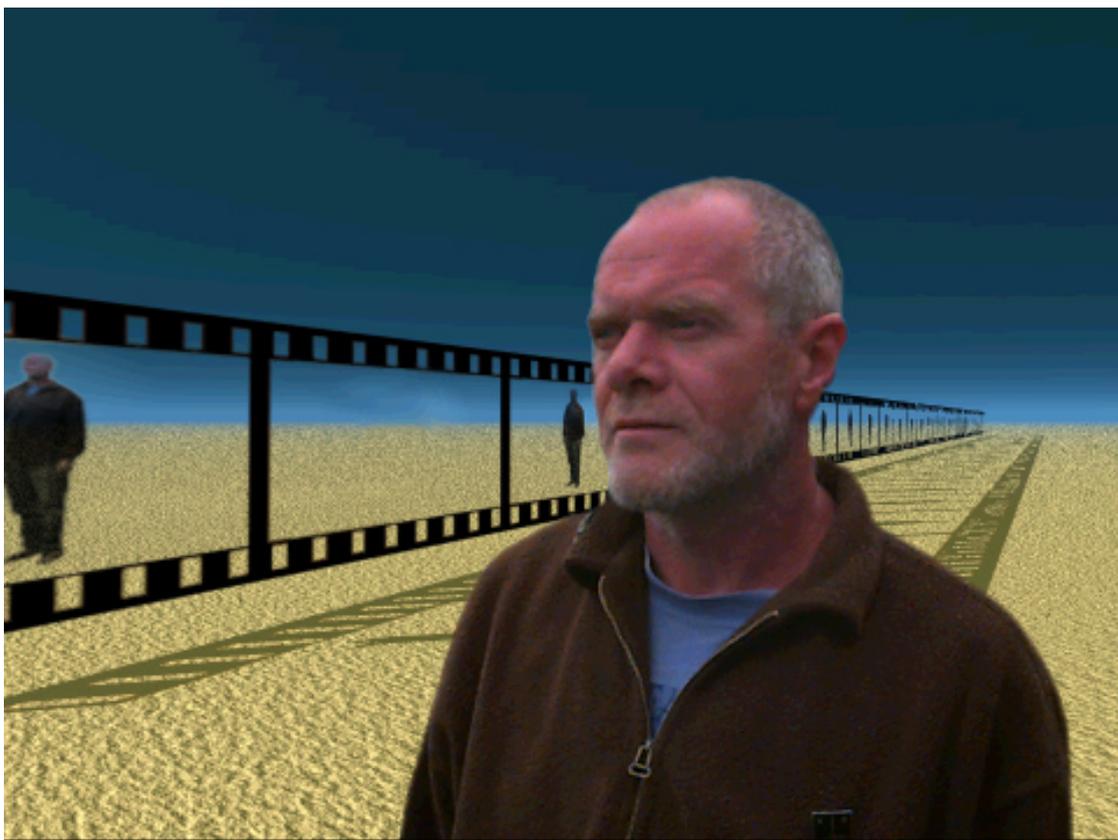


Figure 3: The behavioural stream

This figure shows the life of an individual to be a continuous process. Upon first meeting a person we observe only a snapshot in his/her life. What is happening 'inside' a person at the moment of observation is regarded as part of a one continuous process. Viewed this

way, data collected are regarded as measures of dependent variables that are functionally related to 'external' independent variables. In relation to a child with autism, acknowledging life to be a continuous stream has enormous implications for treatment designs. In a home program, for example, it translates into the practice of teaching a parent to shadow the developing child (i.e., the stream) in such a way as to be able to monitor very closely the changes in choreography that make up the fine detail of the child's interaction with his/her physical and social environment. When this choreography is in need of change, then practical steps are taken to see if this can be achieved. The questions that arise usually for parents and therapists include which aspects of the choreography to start with, and what to do next. Not surprisingly, behaviour analysis has developed and continues to develop guidelines to address these questions (Maurice, Green, & Luce, 1996). All the while, though, the 'research' conducted by behaviour analysts and parents in answering these questions hinges on methodology that many undergraduate psychology students in the U.K. and Ireland do not get taught, that is, single-case research methodology (Johnston & Pennypacker, 1980, 1993; Sidman, 1960). Again, this methodology is not restricted to the study of autism but its relevance to autism can be seen from the following quotation by Anderson and Romanczyk (1999):

One of the important characteristics of children on the autistic spectrum is uneven learning ability and skill levels. Thus, individualisation of intervention cannot be overstated. The specifics of programmes will be different for different children and must be sensitive to the child's needs. Thus, an important aspect of ABA is the introduction of procedures to quantify the child's behavior that can be used to create and evaluate individualised interventions. (p. 165)

Many of the mummies and daddies in PEAT and in other groups throughout Ireland and the U.K. now know about evidence-based practice (Dillenburger, 2003) and the value of experimentation. They know how to collect data on the educational programs they use with their children and they know how to assess the effectiveness of these programs. Although many are still not consistent in the application of their new science they still have a better understanding of principles of behaviour than many students who graduate with a degree in psychology.

So what does a home program look like? Table 2 provides an example of an ABA program that identifies various behaviours that may be targeted for change.

Table 2
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
Child imitates 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.
Child identifies objects and pictures.

Intermediate:

Child identifies rooms.
Child identifies emotions
Child follows two-step instructions.

Advanced:

Child follows three-step instructions.
Child discriminates concepts

Expressive Language

Basic:

Child imitates sounds and words.
Child labels objects and pictures.

Intermediate:

Child labels objects based on function.
Child labels gender.

Advanced:

Child labels categories.
Child retells a story.

Pre-academic Skills

Basic:

Child matches identical pictures
Child matches identical objects.
Child undresses.

Intermediate:

Child initiates for bathroom
Child washes hands.
Child puts on some clothes.

Advanced:

Child brushes teeth.

Child buttons clothes

To conclude this section, there is one outstanding issue that needs to be addressed in terms of parent training. It is the extent to which category mistakes in the form of mentalism impede the design of effective programs. Throughout the years I have been teaching behaviour analysis this is perhaps the one issue that is most difficult to deal with. I reckon it also lies at the heart of much of the misrepresentation of behaviour analysis (Morris, 1985; Nye, 1992; Skinner, 1977, 1985; Wyatt, 1990). My solution to teaching about it has been to use an animated cartoon character in my multimedia tutorial. In the animation the character, Adam, walks across the screen towards the image of a girl who turns her eyes to look at him briefly. Adam then begins to bounce a ball and at one point he burps. The girl beside him admonishes him for this rude behaviour and he blushes, stops what he is doing for a moment before continuing to bounce the ball. He

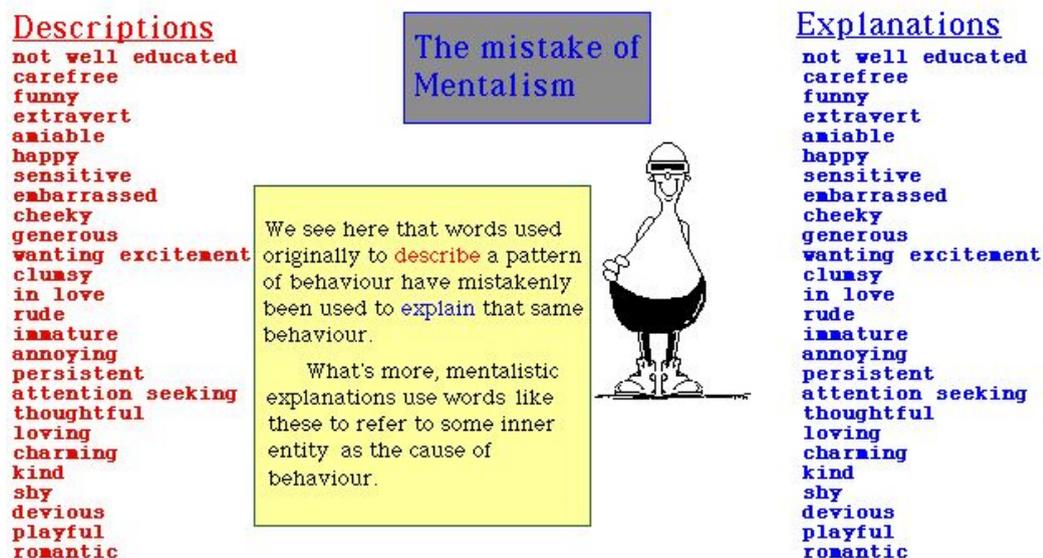


Figure 4: The mistake of Mentalism

burps again and is admonished again. After a moment he walks off the screen and returns with a flower which he gives to the girl. The animation finishes with them both smiling. As far as animations go this is not exactly Oscar material. However, parents are asked to jot down words they feel are appropriate to this character called Adam. When they are finished I rerun the animation again only this time I show the parents 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. More often than not the range of words obtained by the students matches the words used by the parents. At this point the mistake of mentalism is demonstrated by compiling all the words used and placing them on the left-hand side of the screen under the heading 'Descriptions'. That is to say, it is acknowledged that these words are indeed correctly used as descriptions of behaviour. The mistake of mentalism occurs

when any of these words are then used to explain behaviour. If they are used in this way a circular argument is mistakenly invoked giving the illusion of having supplied an explanation (Figure 4). There is an advantage of using a cartoon character in this instance. In a further twist of the animation Adam's head is opened up to reveal an empty space, not even a brain. Parents are taught that their use of words to explain his behaviour is an indication of how a language trap invents an inner explanation based on the circular reasoning of mentalism (see Holth, 2001 for a more detailed analysis of mentalism and category mistakes).

3. Difficulties experienced in getting Education Authorities to support ABA

Unfortunately for the parents in Ireland there are no university programs for teaching ABA to professionals. This is a serious problem because learning about ABA is more than just learning a few recipes for behaviour change (Walsh, 1997). Currently if it was left up to psychologists in Ireland who are not trained in behaviour analysis to indicate the essential features of behaviour analysis you would undoubtedly see something like this:

Though vast in quantity, the great majority of behavioural findings tell us little of worth about ourselves. In a sense, having denied the importance of subjective data, their findings appear limited, alien, even 'soul-less'. (Spinelli, 1989, p. 175)

Behaviourism also embodied the positivism of the Cartesian (from Descartes)-Newtonian tradition, in particular the emphasis on the need for scientific rigour and objectivity. Human beings were now being conceptualized and studied 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 was no place for these things in the behaviourist world. (Gross, 1995, p. 239)

Comments like these have found homes in many departments of psychology in the U.K.. However, they seriously misrepresent behaviour analysis. It is difficult to see how these comments fit in with Colin's progress. Did I really ignore those distinctive human qualities? Perhaps Colin is the only one who can answer this but I suspect the answer is fairly obvious. Students new to behaviour analysis should ask also how these comments match the following comments 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)

Parents usually persist with ABA programs for their kids because they hold no a priori assumptions about the philosophy of science underlying the science of behaviour analysis. Rather they see with their eyes the developments their children make. Figure 5

graphically represents the argument being made. In the picture the author is shown with his daughter. I prefer to see myself in the image on the left. Those who caricature behaviour analysis would see me in the image on the right.



Figure 5: Behaviourism views people as 'black boxes'.

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 is so rife in psychology departments in the U.K. and Ireland. It is such a shame that its developments are prevented 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. 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. One suggestion I would like to make is that the BPS produce a special edition 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.

To show you what happens when misrepresentation is perpetuated by people in positions of authority I would like now to address some of the politics experienced by families in the PEAT group. Initially, in my naivety, I thought that the Dept. of Education would support the work that is being done by PEAT. To date my contacts with the Dept. have not been encouraging. Let me read you an extract from a letter I received from the department on 24th August 2000. This extract is taken from a letter I received nearly a whole year after I first wrote to them outlining the scientific evidence supporting the effectiveness of behaviour analysis:

This department is mainly concerned with the education of children in school, although it is entirely possible for home tuition to be provided by teachers for children unable to attend school for a variety of reasons, mainly medical. Applied Behaviour Analysis methods, on the other hand, appear to be practised

outside the education system by people other than teachers and this again might tend to suggest that they fall outside this Department's area of responsibility.

But there are no teachers with the skills to set up ABA programs. It was shortly after I received this response that we decided to hold the first ABA conference in Ireland. One of our keynote speakers was Prof. Gina Green from the New England Center for Children. Prof. Green is a past president of the Association for Behavior Analysis and, at the time of the conference, Psychology To-day magazine nominated her as mental health professional of the year in the U.S.. U.S. Secretary of Education Richard W. Riley named The New England Center for Children as a recipient of the U.S. Department of Education's National Award for Model Professional Development. Citing efforts to improve teachers' expertise and raise student achievement, Riley stated, "These award winners exemplify what can be done to give teachers the best skills and knowledge".

A representative from the Dept. of Education in N. Ireland was invited to the conference by PEAT. However, after staying a short while to listen to Prof. Green's opening address he left without making contact with her. The Department of Education still has not contacted her despite the obvious benefits that would accrue from having her involved in a consultancy basis for ABA development in N. Ireland.

For a time I wondered if the obstacles I was encountering were merely over-interpretations stemming from paranoia on my part. However, in reality many families in PEAT struggle against a wall of misinformed and prejudicial views held by many professionals. This occurs to the extent that successful home programs for children are jeopardised because professionals at various schools refuse to embrace these achievements and engage in partnership with parents who are developing their skills in ABA. Currently, parents are now being forced to use the courts to gain funding for their home programs and to gain access to schools by independent observers to assess the provision being offered for their children. This is a drastic step for anyone to take but the parents have been left with no alternative. Similar steps have been taken by parent groups in British Columbia. There the Supreme courts made the following statement:

It is beyond debate that the appropriate treatment is ABA [Applied Behaviour Analysis] or early intensive behavioural intervention. (The Supreme Court of British Columbia, Docket C984120, 26th July, 2000, p.64)

My only way of making sense of these 'autism wars' is to consider the possibility that it is the 'evil empire of ABA' that is being fended off by people protecting the children from what they perceive as its abusive regimes. To support this contention consider the following. 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. Numerous letters of protest were delivered. In the North, the only way the PEAT group could get a response from the Dept. of Education as to why this was the case was through the help of a local group of politicians called the Women's Coalition. They raised the issue on the floor of the N. Ireland Assembly. The answer that came back was the following:

For manageability reasons, this Group was kept small.

The Task Group included members of two of the voluntary organisations who work in the area of autism but who have no expertise in ABA. The argument that 'manageability' was the major reason for excluding an ABA representative is disconcerting because a relatively large proportion of the report was given over to commenting on ABA, and getting it wrong. The views expressed in the report do not accurately reflect the current standing of ABA world-wide. Indeed the views expressed in the report may be harmful to budgeting decisions regarding the development and quality of ABA training in the community. They may impact also in a detrimental way on the support PEAT parents receive from professionals not trained in ABA.

The most blatant example of the Task Group's failure to provide an objective independent evaluation of therapies available is found in section 3.25.

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.

The inclusion of this statement in the report is unforgivable since there is no evidence of any kind to support it, and none were offered. The parents of the PEAT group were totally sickened by these statements which suggest that they would knowingly bring harm to their children. Time and again ABA-trained parents are told that learning must be fun for their children. Any possibility of abuse arises because of a poor level of therapist training rather than because of something inherent in ABA methodology or techniques. The report makes no informed recommendations about the level of training that is required for those purporting to be trained in ABA. This is a serious omission because without clearly defined criteria for determining standards of training children will be open to abuse that arises from incompetence. We can look to the States where some lessons have already been learned. There have been cases where people who have attended short courses in ABA then went on to present themselves as ABA-trained. To counteract this the Association for Behavior Analysis International (<http://www.wmich.edu/aba/>) is supporting moves towards a certification program in ABA that would protect the rights of children and other clients. Perhaps the BPS could align itself with this movement.

Another blatant example of how ABA was demonised in the report comes from the reference to the use of aversive procedures for dealing with difficult behaviours. As presented, the report serves as a warning to professionals not familiar with ABA to be wary of it because of potential damage to children. Parents in the PEAT group were outraged by these comments because they know this to be entirely untrue.

However, a patronising and deft stroke of the pen by the Task Group makes it difficult for a parent to criticise this view without being seen as someone who will opt for

anything, even potential damage to their children, as long as there was a glimmer of hope. To put the issue of aversives in perspective Sallows (1999 - Autism '99 conference) notes the following:

the reader may be interested to know that aversives were a generally accepted practice during the 1960's and 1970's. TEACCH, for example also advocated the use of aversives at that time. In their training manual, Schopler, et al. (1980), describe the use of "aversive and painful procedures" such as meal deprivation (p.121), "slaps or spansks on the bottom" (p.121), or "electric shock, unpleasant tasting or smelling substances" (p.122) as appropriate interventions if positive methods are ineffective. (p. 48)

Had an ABA representative been on the Task Group a more informed debate would have taken place and misrepresentation would not have appeared in a government sponsored report. This is a particularly serious issue because the goal shared by all professionals is the welfare of children who are relying on unbiased discussion about scientifically validated treatment. This point is made all the more poignant by the Task Group's reference to comments by a parent, Catherine Maurice, which gives the impression that she is opposed to ABA. Maurice (1999) wrote a highly influential book called "Let me hear your voice" in which she described her contact with ABA. It is difficult to reconcile the impression created in the report with the views she really holds. Maurice is a member of the Autism Advisory Board of the Cambridge Center for Behavioral Studies (www.behavior.org). In a recent address to this body she said the following:

There is widespread misunderstanding and distortion of the approach. Dozens of pseudo-scientific books and articles out there describe it as child abuse, a squelching of the spirit, a crushing of the soul. Treating the symptoms and not the "root cause," whatever that might be; a denial of the self, cruel, manipulative, dehumanizing, punishing, controlling; etc. etc. Moreover, even when people do not attack behavior analysis, they make glaringly ignorant statements about it, like "Oh yes, that's where they do discrete trials for forty hours a week." Or, "behavior management is for really low functioning kids."

And then gradually, I began to understand ABA more and more. I started to understand what it was: Not some dehumanizing control of people through a cynical manipulation of rewards and punishments, but rather the light of scientific exploration brought to bear upon behavior, and upon learning. ... What I do know, what I have seen with my own eyes, is the significant difference that Behavior Analysis is making in other children's lives, and in the lives of adults as well. What convinces me to keep speaking out is not even that I know some other children who have achieved normalcy. Rather, it is knowing that Behavior Analysis continues to help those that do not recover. As time goes on, I have seen many different rates of progress in children who are receiving behavioral intervention.

Catherine Maurice address to the
Cambridge Center for Behavioral Studies (CCBS)

Annual Board Meeting, Palm Beach, Florida, November 5, 1999

The support that Prof. Green and many other international experts in ABA have shown, and continue to show, for the development of ABA in Ireland were totally ignored by the Task Group. Instead, they relied extensively on the writings of an English professional, who coincidentally is no fan of ABA, as she made clear in her review of the PEAT book where she described the whole discipline as intellectual nonsense. Another curious fact is that the PEAT book was personally given to members of the task group and, although it has received international acclaim, it was not even referenced in the report.

The report makes a case also about the expense involved in ABA. However, cost-benefit analyses (US) were given to the Task Group. Each of these studies showed the substantial savings to be made when long-term care is no longer needed by children who have benefited from ABA. The conclusion from one of them was as follows:

"The principal conclusion from this preliminary cost-benefit analysis is that the cost savings substantially exceed the early intensive treatment cost for a candidate 3-year-old child with autism or ASD. This conclusion holds for a wide range of cost assumptions and discount rates." (Prepared for Harper Grey Easton, Barrister and Solicitors. Submitted by Columbia Pacific Consulting, 1550-650 West Georgia Street, Vancouver, B.C. V6B 4NB. December 7, 1999)

A cost benefit analysis for behavioural intervention versus traditional provisions (in special schools) for children with autism was also conducted in the U.K. by Parents for the Early Intervention of Autism in Children (PEACH) in 1997. Their findings showed that a typical home-based intensive behavioural programme was estimated at £17,000 per annum covering a 50-week period. In comparison a NAS school placement cost between £22,500 and £23,500 per annum covering a 38-week period. No mention of these reports can be found in the section on ABA..

Evidence-based practice is the hallmark of ABA. However, it is ethically imperative that practitioners who claim to offer ABA services can provide evidence of competency in this discipline. Our greatest concern centres around the issue of who defines what is appropriate training in ABA. The report makes no mention of this crucial aspect of quality assurance. This is a serious omission, especially in light of the fact that the people who wrote the report have not understood ABA properly. Potentially this omission opens the floodgates for people briefly acquainted with ABA to offer training that does not meet agreed international standards. Unfortunately this is already happening to some extent in our community. (For more information relating to Certification in Behaviour Analysis the reader should visit the following web site: www.behavior.org.)

Conclusion

In years to come this award will serve as a reminder for me of my efforts to inspire parents to be confident in the teaching of their children. Other memories that will forever be ingrained are reactions of professionals to what I have done. Amongst other things I

have been dismissed as a 'born again behaviour analyst'; I have been accused of belonging to a cult; I have been referred to as a trouble maker for not towing the line; I have been patronised for being very passionate about my work; and generally I have been viewed at times as a right pain in the backside. In spite of the alienation that I have experienced from BPS members in a variety of circles, I am determined that my commitment to helping others in my community will win out. I am concerned, though, for the parents. It is hard work doing what they do. In conclusion I would like to take this opportunity to encourage psychology students wishing to learn more about behaviour analysis to work alongside parents in well-monitored home programs. 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 active support of the BPS. I'll close my talk by giving you two examples that were brought to my attention of how equality of opportunity for children with autism can be unintentionally impeded by BPS members. A student interested in working with children with autism for her undergraduate dissertation produced a research proposal based on research on video modelling (Nikopoulos & Keenan, in press). Her proposed experimental design is shown in Table 3.

Table 3
A video modelling procedure for teaching skills

<p>Condition A Assess self-help skills in child with autism.</p>	<p>Condition B Show a 30-sec video of someone engaged in those self-help skills that are not in the child's repertoire.</p>	<p>Condition A Assess the effects of the self-help skills shown in video, i.e., determine if the child has learned these new behaviours.</p>
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Her psychology departmental ethics committee did not give permission for the study because they decided that "it constituted an intervention" and demanded that the research proposal be submitted to the main university research ethics committee for approval. In other words, a committee of psychologists decided that a procedure designed to teach a child new skills, especially a child with autism, should be considered as a clinical intervention. I wonder if a similar decision would have been made if the proposal had been designed to use video modelling to educate a typically developing child?

The second example also involves a proposed undergraduate dissertation that was viewed as a clinical intervention. The aim of this study was to teach a child with autism to follow a specific schedule for his morning routine. The study was thought by the student to have the added bonus of possibly reducing disruptive behaviours that tended to occur because there was no morning routine. Not only was ethical permission not given for the study by the student's departmental ethical committee, but an alternative suggestion that the parents be taught how to teach the child instead of the student doing it was also not permitted; teaching the parents was deemed to be a clinical intervention by proxy.

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. The logic of this position is that parents of the PEAT group, or other parents who understand also how to apply the principles of behaviour, should be considered as clinicians rather than parents simply because they are skilled at creating opportunities for learning!

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