

# Autism: State Sponsored Child Abuse?

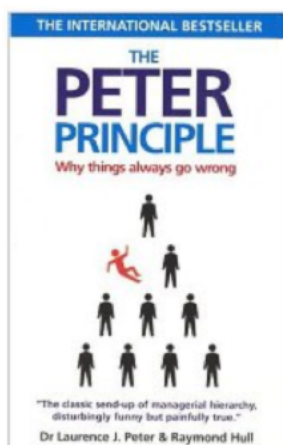


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The blurb at the back of the book *The Peter Principle* reads as follows:

"Ever wondered how that bunch of idiots got control of your office/factory/shop? They, as we all know, could not organise a booze-up in a brewery, but what we did not know was how they got to the top. The answer is supplied in *The Peter Principle*".



The exasperation expressed above is one that is only too familiar to the parents of children with autism. Being dependent on people in authority to make decisions that impact positively on their struggle with autism, they have run headlong into the Peter Principle in action. And as you will see, those in control of Education and Health have a lot to answer for.

I am a Board Certified Behaviour Analyst, Fellow of the British Psychological Society, and Distinguished Community Fellow at the University of Ulster. I became familiar with the destructive impact of autism in the family when a friend of mine, a GP, introduced me to a

family that was in serious trouble. Their child was not developing as his brother and sisters had done. At that time in Northern Ireland I had heard that it was not unusual for families afflicted by autism to be offered bereavement counselling. Although this struck me as a rather odd 'solution' to the problem, it did serve to underscore the devastating impact on the family. Dealing with autism can be like losing a child, every parent's nightmare.

I worked voluntarily with that child and the family over the course of a year. Now, some years later that young man is studying for a degree at University. The story of our work together is contained in the book *Parents' Education as Autism Therapists* that has been translated into Japanese, and is currently being translated into German and Hindi. A video clip of the young man delivering the opening talk, a talk he penned himself, to a conference in 2005 is available in a 3-part presentation on YouTube: <http://www.youtube.com/watch?v=LFVykFNOGdw>



Together with parents in Northern Ireland who got to know the science of Applied Behaviour Analysis (ABA) through workshops I delivered, we set up a parent-led charity to educate other parents about this science. Called PEAT ([www.peatni.org](http://www.peatni.org)), this charity has since developed a multimedia tutorial called **Simple Steps** that is currently being translated into 8 languages with the help of the

European Commission's Life Long Learning Programme, Leonardo, in a project called STAMPPP, (Science and the Treatment of Autism: A Multimedia Program for Parents and Professionals). The current version of the tutorial is available here: [www.simplestepsautism.com](http://www.simplestepsautism.com)



This tutorial teaches parents about the scientific method, the method that lies at the heart of all the natural sciences taught at universities. And where the natural science of ABA has been used to treat autism, extensive international research literature shows it to be effective. The National Standards Project, for example, when commenting on Established Treatments concluded:

“The overwhelming majority of these interventions were developed in the Behavioural Literature” (<http://www.nationalautismcenter.org/nsp/findings.php>)



Just as I worked with parents in Northern Ireland, I have sought to offer assistance to parents in the Republic and I have watched, exasperated and incredulous as they have suffered at the hands of the same bureaucrat led misinformation and crushing refusal to engage with fact that has so stymied progress in the North.

Prior to the establishment of PEAT, there were no university courses in ABA to train professionals. Over the years, numerous international conferences were held to inform the public about the science and on each occasion government ministers were invited to hear leading figures in Behaviour Analysis explain why parents wanted this science for their children. **No Irish minister ever accepted an invite to attend any of these conferences!**

Should it matter if an Education or Health Minister doesn't attend a science conference?

The short answer is 'Yes!' and politically, this is where the story becomes intriguing

and extremely worrying because of issues that have arisen with transparency in government practices. This story has been rumbling on for some time (see my YouTube presentation mentioned above), but recent events have brought it to a head and I think at last we have uncovered the nub of the problem.

It appears that unaccountable bureaucrats, just as happened in the North, are misinforming government ministers in the Republic. Members of the government in the Republic were fully behind parents before they became the ruling party. Now, having been fed on the same diet of misinformation as the previous government, they have changed their position completely. The result of this misinformation is that all of the ABA schools in the Republic have been forced to close with nothing more than lip service now paid to ABA. As an example of the misinformation, I have taken some information from a flyer that has been created by a parent in the Republic and circulated to politicians.

The parent wrote to the Department of Education and Skills with a simple question: **“Is ABA a science?”** He wanted to understand why his child and so many others were being denied access to effective autism treatment, access which the government has wasted €20 million in legal fees trying to prevent. The nail was hit squarely on the head!

Bear in mind that Masters level training in this science is now available in Trinity College, NUI Galway, NUI Maynooth and in both universities in Northern Ireland. Here, then, is the response obtained:

*“You have asked whether Applied Behaviour Analysis is a science...The Report of the Task Force also frequently refers to Applied Behaviour Analysis as an approach and contains significant and comprehensive commentary on this approach. In the light of this, the Department continues to hold the position that ABA is an approach. I see no reason to reconsider this position.”*

Special Education Section, Department of Education

Firstly, Ireland’s Task Force on Autism (2001) never asserted that ABA was not a science. Secondly, contrast that response from the Department of Education with other responses received from professionals trained in the science being discussed and contained on the flyer:

***“ABA is a Science...**Applied behaviour analysis is the science in which tactics derived from the principles of behaviour are applied systematically to improve socially significant behaviour and experimentation is used to identify the variables responsible for behaviour change.”*

William L. Heward, Ed.D., BCBA-D, Professor Emeritus, Special Education Program College of Education and Human Ecology, The Ohio State University, **Past President of the Association for Behavior Analysis International**

***“Although there are several journals devoted to the science of behaviour analysis, the two primary journals are the Journal of the Experimental Analysis of Behaviour and The Journal of Applied Behaviour Analysis. Both are highly rigorous and technical journals with strong citation indices. But all of this is well established fact and what surprises me is that any educated person would question it.”***

Patrick C. Friman, PhD, Clinical Professor of Pediatrics, University of Nebraska Medical Centre, **Past President of the Association for Behavior Analysis International.**

***“Of course Applied Behaviour Analysis is a science. There exist decades of well controlled research documenting the benefits of ABA for a broad array of challenging behaviours and skill acquisition goals.”***

Sandra L. Harris, PhD, Executive Director, Douglass Developmental Disabilities Center, **Rutgers University , Board of Governors Distinguished Service Professor Emerita**

The parent who produced the flyer made contact with the professionals above. If the Department of Education had contacted professionals trained in this science they would NOT have produced the answer they did produce.

To add to the intrigue, none of the professionals who teach at universities in Ireland were consulted on the question that was raised. Even the Division of Behaviour Analysis within the Psychological Society of Ireland was not consulted. When the chair of the division was approached by the parent he got this answer:

***“The field of study that is behaviour analysis, and of which applied behaviour analysis (ABA) forms part, is a science.”***

Professor Julian C. Leslie. Head of Research Graduate School, Faculty of Life and Health Sciences, University of Ulster

Alarmingly, the people who were asked to answer the question for the Department of Education may also have had influence with government practices in Northern Ireland; we are still trying to ascertain this possibility.

The significance of the continued struggle of parents to get government support for investment in ABA is best understood when seen in the context of international developments and a recent decision on State Law in California which means that insurance providers must meet the cost of ABA therapy for its customers (so far some 29 US States have passed similar legislation):

<http://www.fiercehealthpayer.com/story/blue-shield-retroactively-covers-autism-treatment/2012-02-03>

***“By taking this action, the Department of Insurance has put the entire health insurance industry in California on notice that denials of coverage for behavioral health treatment, including ABA therapy, must stop,” said Commissioner David Jones. “Existing state law requires and has required health insurers to provide coverage for autism; we will continue to vigorously enforce that law and expect other health insurers to comply immediately.”***

As other countries embrace the science of ABA as an effective intervention for children with autism, Ireland's Department of Education continues to insist that the earth is flat.

In Ireland, the misinformation about the nature of ABA is rampant on both parts of this island. To suggest that it is NOT a science and to then base government policy on such misinformation is surely a serious legal issue. This point was raised at a presentation I gave in the Dáil with a parent to the Fine Gael Committee on Education.

In Northern Ireland a former Minister for Education described ABA as '*one of a number of commercially available treatments for autism*'. In Scotland, when such misinformation about ABA found its way into government documents I worked with a parent who eventually managed to get these documents withdrawn by the Scottish government who subsequently corrected the misinformation. The same thing happened in New Zealand when the Department of Education became aware of serious inaccuracies in the depiction of ABA in a government sponsored report. The section on ABA was completely rewritten by professionals trained in this science. Surely the same should happen in the Republic and surely the government has a responsibility to hold its advisors to account.

In the title to this essay I inserted a question mark at the end. I did so because I believe that people within governments on both sides of the border in Ireland do not intentionally abuse children. Nevertheless, incompetence in their actions has resulted in the abuse of children diagnosed with autism and their families and this incompetence fits well with The Peter Principle.

The central argument in The Peter Principle is that people rise to their own level of incompetence within organisations. Put simply, it is often the case that the few competent bureaucrats and managers who do exist in one job don't stick around long because they are soon promoted to a job that they are unable to perform properly. How else can you explain why a Department of Education does not do its homework properly and does not consult with appropriately qualified and experienced professionals in relation to the question asked of them by a parent?

#### Recommendations

1. All TDs who care for the welfare of children should insist that an investigation begin immediately to expose the reason why professionals not trained in ABA are being consulted in preference to international organisations representing the science of ABA.
2. Professional bodies in ABA outside of Ireland should be consulted to ascertain the extent of the misrepresentation of ABA contained in the Report of the Task Force. **TDs might not know that the only person representing ABA on this Task Force was a parent of a child with autism. This would not be allowed to happen with any other scientific review.**
3. Insurance companies in the States who have been exposed to unbiased evidence on the effectiveness of ABA should be consulted so as to understand why they have agreed to drop their resistance to providing coverage for ABA.