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Knowledge Exchange Seminar Series (KESS)

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Science that could improve the lives of people with autism is being ignored

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Given the economic and social costs of autism in our community (Knapp, Romeo, & Beecham, 2009) it is imperative that the government is correctly informed about effective treatment options. This presentation describes how a science with proven effectiveness for helping children with autism has been demonised and marginalised in our community (Keenan, 2015). The consequence is that government policy has been misguided and parents are denied access to skills that could help them and their children. At the same time, there is evidence that professionals at both universities in N. Ireland who offer training in this science have experienced obstacles preventing them from sharing their expertise. At the heart of this issue is a culture of misinformation that is propped up by gatekeepers who refuse to countenance the possibility that their limited understanding of this science is undermining the integrity of government institutions, and that they are doing a terrible disservice to families devastated by the diagnosis of autism. The science in question is Applied Behaviour Analysis, better known by its acronym as ABA.

Science and Policy

To set the scene for the following discussion, here are some comments about the relation between science and policy by Douglas (2009):

In the ideal image of science, scientists work in a world detached from our daily political squabbles, seeking enduring empirical knowledge. Scientists are interested in timeless truths about the natural world rather than current affairs. Policy, on the other hand, is that messy realm of conflicting interests, where our temporal (and often temporary) laws are implemented, and where we craft the necessary compromises between political ideals and practical limits. This is no place for discovering truth.

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Ethics and competence

The potential import of scientific findings for policy decisions is underscored by the ethical guidelines of the British Psychological Society (2009) in relation to professional competence of those claiming expertise in science. Section 2.3 of their ethical guidelines recognises the importance of acknowledging limits to professional competence. Specifically, it is said that Psychologists should do the following:

- (i) Practice within the boundaries of their competence.
- (ii) Engage in Continued Professional Development.

Another scientific discipline, Physics, considers the issue of competence in science to be of central importance for policy makers:

As a general rule, in matters concerning physics, the Institute of Physics in Ireland would seek to have appropriately qualified physicists represented on any review panel which might be reporting on 'findings from physics'. (*Institute of Physics in Ireland, personal communication*)

Policy informed by those familiar with ABA

This section contains comments by government representatives and professional bodies outside of N. Ireland on the value of the evidence base produced by researchers in the field of Applied Behaviour Analysis (Dillenburger, 2016).

"Over 30 [45] years of research demonstrate the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior." (Surgeon General, USA, 1999)

"There is sufficient evidence to categorize ABA as **medical** therapy rather than purely **educational**". (U.S. Office of Personnel Management Benefits Review Panel, 2012)

In Capitol Hill testimony, the 60,000-member American Academy of Pediatrics publicly endorsed the use of ABA treatments. (AAP, June 2012)

The Kennedy Krieger Institute and Johns Hopkins University School of Medicine (2017) provides comments from a range of organisations in the USA :

The American Association on Intellectual and Developmental Disabilities (formerly the American Association on Mental Retardation), the oldest and largest interdisciplinary organization of professionals concerned with intellectual disability and related disabilities, designated ABA-based procedures for the treatment of behavioral problems with individuals with intellectual disability and related disorders as "**highly recommended**." (Rush & Frances, 2000)

Current Opinion in Psychiatry

"Interventions based on applied behavior analysis have the strongest empirical basis, although there is some evidence that other therapies have promise." (Sturmey, 2002)

The [Centers for Disease Control](#) said "... notable treatment approach for people with an ASD is called applied behavior analysis (ABA). ABA has become widely accepted among health care professionals and is used in many schools and treatment clinics... ."

Several states have assembled task forces comprised of parents and professionals to develop guidelines and position statements. These committees identified ABA procedures as representing best practices.

Currently in the USA, 45 States (+ District of Columbia and the US Virgin Islands) have introduced legislation to ensure that parents have access to Applied Behaviour Analysis in their Health Insurance (Autism Speaks, 2017). In other words, on 47 separate occasions, the research evidence was reviewed and it was concluded that there was sufficient evidence to warrant the introduction of new laws in support of making ABA available to parents.

International standards of training in Applied Behaviour Analysis

The Behavior Analyst Certification Board (BACB; www.bacb.com) is an international, non-profit corporation, that has established universal/international standards for the field. The main office is in the USA, but the credentials are defined by the field worldwide, and have worldwide applicability. Masters level (BCBA) and Doctoral level (BCBA-D) qualifications involve 1500 hours of behaviour analytic practice under the supervision of a BCBA (at least 5% direct supervision). The BACB examination takes 4 hours and has a pass rate of 50-70%. The BACB Fourth Edition Task List (2017) is organized in three major sections that include *Basic Behavior-Analytic Skills*, *Client-Centered Responsibilities*, and *Foundational Knowledge*. When working with individuals, no single intervention is used in a one-size-fits-all approach. Instead, the general model used is the Scientific Method. Central to the scientific method is

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the fact that any decision about which procedures are to be used is guided by the needs of each individual. Decision making also evolves with the progress of each child when the goal is to maximize his/her potential.

ABA in N. Ireland

Task Group Report

When governments in N. Ireland and in the Republic of Ireland set up task groups to look at provision for autism (Task Group, 2002), ABA professionals were excluded from participating. Numerous letters of protest were delivered but ignored. In N. Ireland, the only way parents trained in ABA could get a response from the Department of Education as to why ABA professionals were not included, 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 other voluntary organisations who work in the area of autism but who had no expertise in ABA. The argument that manageability was the major reason for excluding ABA professionals is particularly disconcerting because a relatively large proportion of the final report was given over to commenting on ABA, and getting it wrong. The views expressed in the report did not accurately reflect the standing of ABA worldwide. Indeed, the views expressed in the report were harmful to budgeting decisions regarding the development and quality of ABA training in the community. The most blatant example of the failure to provide an objective, independent evaluation of available interventions, 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. (Task Group, 2002)

The inclusion of this statement in the report was unforgivable since there was absolutely no evidence whatsoever to support it. The statement was based on personal views and preconceived ideas of people unfamiliar with ABA. Parents trained in ABA were totally sickened by the suggestion that they would knowingly bring harm to their children. ABA-trained parents know that for learning to be effective it must be fun.

Another blatant example of how ABA was demonised in the Task Group report came from the reference to the use of aversive procedures for dealing with difficult behaviours. As presented, the report served as a warning to professionals not familiar with ABA to be wary of it because of potential damage it would cause to children. Parents trained in ABA were outraged by these comments because they knew them to be untrue. However, a patronising and deft stroke of the pen by the Task Group made it difficult for a parent to criticise this view of ABA without being seen as willing to 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 proper historical perspective, Sallows (1999) noted 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, "slaps or spanks on the bottom", or "electric shock, unpleasant tasting or smelling substances" as appropriate interventions if positive methods are ineffective. (p. 48)

Had an ABA professional 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 rely on unbiased discussion about scientifically validated treatments. 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 was opposed to ABA. Maurice wrote a highly influential book called "Let me hear your voice" in which she described the amazing progress her children made thanks to 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) and in an address to the board she said the following:

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. (Maurice, 1999)

Autism Strategy (2013-2020) and Action Plan (2013-2016)

As mandated by the Autism Act NI (2011), a cross-departmental group was set up to develop the Autism Strategy (2013-2020) and Action Plan (2013-2016) for N. Ireland. Intriguingly, none of the N. Ireland University autism professionals were included in the project team that was tasked with developing the Autism Strategy. Consequently, none of the wide-ranging University autism training programs or research was included in the Autism Strategy document or in the Autism Action Plan. In fact, the only mention of a university was in one very brief sentence related to widening participation of students with autism at Ulster University; QUB is not mentioned at all! A direct consequence of this exclusion is that the wide-spread misinformation about ABA continues to be propagated.

Evidence of a Minister being misinformed

Applied Behaviour Analysis (ABA) is one of many commercially available interventions for children with autism (Minister for Education, 2009)

This statement raises serious concerns because it is clearly misinformed. Furthermore, not only is ABA viewed as NOT being a science, it is viewed as NOT being child-centered and therefore not able to address the unique needs of each child. All of this is in contradiction to the summary of the scientific method used by ABA when working with individuals, and to the training standards outlined by the BACB. It comes of little surprise, then, to learn that training for most psychologists in the UK does not include extensive training in scientific methods that focus on individuals. This point is illustrated by comments from a leading Educational Psychologist in N. Ireland with key responsibilities for autism:

What is a scientific study without random assignment to groups? (Hughes, 2008, p. 444)

This comment is distinctive in its lack of awareness of scientific practices within ABA that use alternative methods to those espoused by Hughes; for a review of scientific procedures without allocation to groups see Gast and Ledford (2014). There is another issue, however, associated with the kinds of research methods mentioned by Hughes. This is of particular concern when ABA is mistakenly regarded simply as a method/intervention. Randomised Control Trials (RCT) are revered as the gold standard for assessing interventions. Conclusions about the effectiveness of ABA is criticized because of the lack of RCTs. It is inappropriate, however, to submit a science to scrutiny by using RCTs (Keenan & Dillenburger, 2011). If this were not the case, we would have the absurd position of advising politicians not to invest in training in Clinical Psychology, Educational Psychology, Speech Therapy, Occupational Therapy, etc. as well as Applied Behaviour Analysis because RCTs have not been conducted with them¹.

Child-centred

The distorted view of ABA within government circles has an additional layer of confusion. The use of the scientific method as applied to individuals is frowned upon and mischaracterized as NOT being child-centered BECAUSE it uses the scientific method. This makes for an anti-science perspective that should ring alarm bells for parents and politicians.

The Task Group on Autism concluded that "Interventions should be child-centred rather than method centred, and should address the observed and unique needs of the child." I continue to accept this view and, therefore, do not promote one type of intervention over another. (Minister for Education, 2010)

In effect, what is being said is that it is inappropriate to use the scientific method! As if this was not damning enough, the ministerial quotations above contain yet another problem that has had a major impact on how ABA is viewed in N. Ireland. This problem comes under the heading of a 'category mistake' (Chiesa, 2015) and this mistake permeates all that is written about ABA within government policy documents. To explain this problem, Figure 1 shows the distinction between a science and an intervention. Those not trained in ABA place the science in the wrong category. That is, they put it in bottom of the diagram along with the list of interventions. Doing this then justifies the decision not promote one type of intervention over another. In other words, an illusion generated by a category mistake forms the basis for decisions NOT to invest in ABA despite the wealth of evidence for the effectiveness of this science.

¹ A different kind of example puts reliance on RCTs for decision making into perspective and it is the fact that there have never been any RCTs conducted on the value of using parachutes!

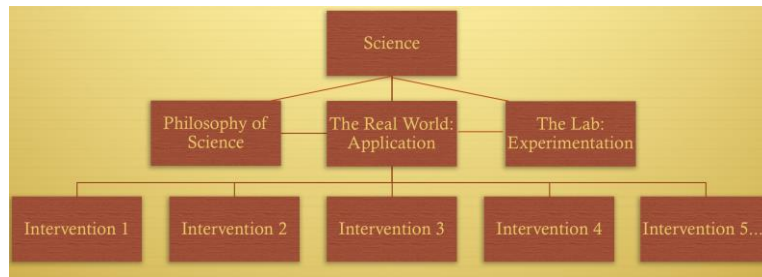


Figure 1: Avoiding category mistakes when distinguishing between Science and Interventions.

To fully appreciate the seriousness of misrepresenting ABA as an intervention, or as a commercial product, or as a methodology, instead of recognizing it as a science, the category mistake above is made here with Medical science using the same logic that is used against ABA.

Each child with an illness has his/her own individual needs and it would be inappropriate to invest in only one thing like Medical science.

The extent of the ignorance about the scientific status of ABA is clear from responses to a simple question, “Is ABA a science?”, sent to the Special Education Team, Access, Inclusion and Well-being Directorate, Department of Education:

To answer your queries the Department of Education is involved in education policies for children between 3-19 therefore it would not be for us to determine whether ABA is recognised as a science. (*personal communication*)

Another perversion of the argument against investing in ABA appears from Research Autism (2017), a major charitable organisation that informs the National Health Service on autism interventions in the UK:

Because there are many different interventions, programmes and techniques used to help individuals with autism which incorporate the principles of applied behaviour analysis it is not possible to provide a ranking for applied behaviour[al] (sic) analysis as a whole.

That’s like saying ‘*Because there are so many different ‘interventions’ developed by medical science, we can’t give a recommendation on this science as a whole!*’. A similar mistake has been made by the National Institute for Clinical Excellence (2013) when they concluded that there was no evidence to support the use of ABA. As with Research Autism, none of the members in this review panel had sufficient training in ABA to be able to interpret its research methods and findings appropriately; an ethical complaint has been lodged with the President of the British Psychological Society.

To help bring this issue of the scientific status of ABA into perspective, here are comments from two former Presidents of the Association for Behavior Analysis International (<https://www.abainternational.org/welcome.aspx>):

Although there are several journals devoted to the science of behaviour analysis, the two primary journals are the Journal of the Experimental Analysis of Behavior and the Journal of Applied Behavior Analysis. Both are highly rigorous 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 Friman, PhD, Clinical Professor of Pediatrics, University of Nebraska Medical Centre, *Personal communication*)

Eclectic approach

The category mistake discussed above has spawned further inconsistencies in the way the evidence base for autism treatment is mishandled. On one hand, it is said that it would be wrong to invest in only ‘one thing’ like ABA, while on the other hand it is argued that it is better to invest in ‘one thing’ called an eclectic approach, even though there is no supporting evidence for its effectiveness. Over the years, repeated requests have been made to the Department of Education for the scientific evidence to show an eclectic approach to be equal to or superior to the evidence base for ABA. The answer each time is that there is NO evidence base for preferring an ‘eclectic approach’. Yet, an eclectic approach is the preferred policy. This only makes sense when one is seduced by the illusion born out of the category mistake described above:

ABA is only one intervention/methodology that cannot handle individual needs, so best to adopt an eclectic approach.

Not only is this argument seriously flawed, it raises major ethical issues because there is scientific evidence to show that an eclectic approach is actually damaging to children (Howard et al, 2005).

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N. Ireland Autism Strategy Research Advisory Committee (NIASRAC; 2012)

When this committee was established there was a specific statement included in its Terms of Reference in **Bold**:

“In carrying out its research advisory role the Research Advisory Committee will not seek to espouse or promote a particular methodology in the care and/or treatment of people with autism.”

No scientist worth his/her salt would ever make such a recommendation to a research committee. Imagine, for example, if one method could be found to treat all cancer cases successfully. Surely, this method *should* be espoused by a committee. In the current context of misinformation about ABA, one can only presume that this statement in the terms of reference was designed to keep recommendations for ABA at bay; of course, this is based on their understanding of ABA and not ABA per se.

In terms of committee members, the committee sought nominations from various agencies, including both universities in N. Ireland. Queens' University Belfast (QUB) nominated, from their Expert Directory, Prof. Dillenburger who co-ordinates the MSc ASD at QUB and who has extensive research experience in autism. It so happens that the only person with a focus on autism on Ulster University's Expert Directory is Prof. Keenan, a behaviour analyst with numerous awards for his work in the field of autism:

2002	Award for Promoting Equality of Opportunity. <u><i>The British Psychological Society</i></u>
2002/2003	Distinguished Community Fellowship. <u><i>Ulster University</i></u>
2005	Personal Achievement Award. <u><i>New York State Association for Behavior Analysis</i></u>
2006	Elected Fellow of the <u><i>British Psychological Society</i></u>
2008	Award for Public Service in Behavior Analysis. <u><i>Society for Advancement in Behavior Analysis</i></u>
2014	Michael Hemmingway award. <u><i>Behavior Analyst Certification Board</i></u>
2015	International Dissemination of Behavior Analysis Award. <u><i>Society for Advancement in Behavior Analysis</i></u>
2015	First International Advocacy Award. <u><i>Autism Speaks</i></u>

He was not nominated to sit on this committee. His exclusion was due to an intervention by the Department of Health out of consideration for what was said to be the views of the Chairperson of the *N. Ireland Autism Strategy Research Advisory Committee* (who is also CEO of AutismNI; see below for related issues), as outlined by an email correspondence obtained under the Freedom of Information Act in Figure 2:

From: Jendoubi, Christine [mailto:Christine.Jendoubi@dhsspsni.gov.uk]
Sent: 21 November 2012 15:37
To: McKenna, Hugh
Cc: Deazley, Peter
Subject: MCHPA and other things....

Hello Hugh

It was good to see you again at Hillsborough. A couple of things:



The other thing I was wanting to talk to you about was the Autism Strategy Research Advisory Committee. This committee has not got off the ground yet and I am intending to write to both yourselves and QUB to ask for a nominee to sit on it and I was wanting to take your mind on whom I should be writing to in both institutions. At UU should it be you or your replacement as Dean of Life and Health Sciences? I was hoping it would be you so that I could have a quiet word and ask what the chances are of your nominating Roy McConkey, whom the Committee Chair, Arlene Cassidy, would very much welcome, as you can guess, as well as ourselves....

I asked Wendy who your equivalent was in Queen's and she suggested a couple of names but thought I'd be better asking you directly.

Much appreciated!

Christine Jendoubi (Mrs)
Director, Mental Health, Disability and Older People Policy | Department of Health, Social Services & Public Safety | Room C4.1, Castle Buildings, Stormont Estate, BELFAST BT4 3SQ Tel: (028) 90522388 (Dialnet 22388) | Blackberry: 07870509576 | Fax: (028) 90520574

Figure 2: Letter obtained under the Freedom of Information Act.

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Health Minister visits Autism Speaks

Following the presentation by Prof Lori Unumb, *Vice President, State Government Affairs*,



Autism Speaks, at the CBA/QUART Conference at Queen's University Belfast on 20th Sept 2013, where she outlined the history of the developments of State legislation to ensure ABA-based intervention is funded for children and young people diagnosed with autism

(<http://www.mediator.qub.ac.uk/ms/Quart/DrLorriUnumb3.mov>), Mr

Poots, then Health Minister, was invited to a meeting at Autism Speaks headquarters in New York. Mr Poots and colleagues attended this meeting on 23rd Oct, 2013. Given the current climate of hostility towards ABA, this was a significant event. Surprisingly, though, the

response to a Freedom of Information Request for a copy of the minutes of that meeting indicated that no minutes were available.

Parents and students respond

Two parents speak out



Liz Boyle - Full video here: <https://tinyurl.com/jaw6xn1>



Edel M^cGuinness- Full video here: <https://tinyurl.com/zsvjll5>

Petition



Petitioning Chair of Autism Strategy Group Maura Briscoe and 2 others

Provide the choice of ABA-based interventions for children with ASD in Northern Ireland.

Louise O'Neill
Belfast, United Kingdom

ABA (Applied Behaviour Analysis) is not a "treatment" for autism, but the scientific discipline from which principles of behaviour are uncovered which can give both children and adults new skills and ways of engaging with others. It's perhaps best known in working with children with autism.

A petition signed by almost 3000 people worldwide was submitted to the N. Ireland government by a parent in 2013. The petition asked that government should "Provide the choice of ABA-based interventions for children with ASD in N. Ireland". To date, nothing has come of it! Although the petition was signed by the world's largest autism organization, Autism Speaks, an influential local charity, AutismNI, did not sign it and nor was AutismNI proactive in sharing the petition with its members so they could decide for themselves whether or not to sign it. Students studying ABA to Masters level at Ulster University invited Arlene Cassidy, the CEO (who received an honorary doctorate from the university), to explain this response because it didn't make sense to them given their training in ABA. The invitation was declined. When the Course Director of the Masters course in ABA at Ulster University followed up this response by the CEO with a letter urging her to reconsider her decision given the importance of the career decision made by students, a complaint was made against him to the university.

Parent training

To offset the lack of support for ABA in the community, Prof. Keenan, at the request of parents, established a charity in 1997 called *Parents' Education as Autism Therapists (PEAT)* (www.peatni.org). Their mission was to train parents in ABA and their ultimate goal was to disband once statutory authorities assumed responsibility for training parents. Against all the odds, this group of parents have produced significant achievements. Together with Prof. Keenan and Prof. Dillenburger (2000) they published the first book in Europe on ABA for parents. This book has since been translated into Japanese and German, with a Greek translation in progress. In

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2016, PEAT received the family support organization of the year from NI4Kids (<http://www.ni4kids.com/familyawards/2016winners.aspx>). With the help of the Big Lottery and European funding from the Leonardo Lifelong Learning Program, PEAT also produced the first online multimedia training program in Europe for teaching ABA (www.simplestepsautism.com); Prof. Keenan's work in leading this project resulted in an award in 2015 from the *Society for Advancement in Behavior Analysis* (www.stamppp.com). This platform offers training in practical solutions for teaching children with autism. It has now been translated into 8 European languages with another in preparation for parents in the Czech Republic, paid for by their national health insurance. PEAT provides practical solutions to problems parents face in rearing a child with autism such as reducing severe challenging behaviour, reducing anxiety related behaviours, increasing food acceptance, increasing functional speech, reducing severe high levels of self-stimulatory behaviours, and helping increase social interaction with peers. These are just a few examples of practical results that surpass investment in education on autism awareness alone. PEAT helps approximately 500 families per year with direct service provision in family homes, school settings, or through delivering training for those both living with and working with individuals with autism right across N. Ireland. PEAT receives referrals from statutory services on an almost daily basis. These referrals have come from Educational Psychologists, Clinical Psychologists, Child and Adolescent Mental Health Services (CAMHS), Social Services, GPs, Educational Welfare Officers, Autism Intervention services, as well as other government funded autism charities. In spite of all of these achievements, this parent-led ABA charity has received no statutory funding in its 20-year existence, and its highly qualified ABA professionals can often be found on street corners with buckets making collections for their wages so they can continue to provide a solution-based education to families.

Conclusion

I would like to take this opportunity to thank the organisers of the KESS events. Policy should always be fully informed by scientific evidence and these events provide an opportunity for this flow of information to happen. Unfortunately, as you have seen, there are many problems that need to be addressed in the area of autism. The term *Institutional Discrimination* refers to unequal treatment that is entrenched in basic social institutions resulting in advantaging one group over another. This presentation has exposed *Institutional Discrimination in N. Ireland* by showing how unaccountable bureaucrats and other professionals with limited understanding of the science of Applied Behaviour Analysis have misinformed our Ministers about it. They are guilty of perpetuating myths about this science (cf. Heward, 2003) and their role as gatekeepers has resulted in international standards of best practice being denied to some of the most vulnerable in our community (Dillenburger, McKerr, & Jordan, 2014). This discrimination is so entrenched that I hold little hope of this presentation making a difference to future policy decisions. Peter and Hull (1994) noted that a primary purpose of a hierarchy within an organisation is to preserve itself. Unfortunately, parents in N. Ireland, and in the UK generally, have found that their only hope of arresting control away from people who bring politics into science instead of letting science inform policy is to take legal action (ABAA4all, 2017) against them.

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