

Concept Paper

# How 'Fake News' Affects Autism Policy

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**Abstract:** Since autism was first recognised, prevalence has increased rapidly. The growing economic as well as social cost to families and society can only be mitigated by effective interventions and supports. It is, therefore, not surprising that there is much heated debate and most governments have developed public policies to address the management of autism. This paper describes how well-known 'propaganda' techniques, that have become prevalent in the helping professions have been used to influence autism policies by spreading 'fake news' about the scientific discipline of Applied Behaviour Analysis (ABA). Over the past 40–50 years, meaningful evidence has accrued showing that interventions based on ABA can help people with autism reach their potential. In view of this, nearly all of North America has laws to mandate that ABA-based interventions are available through their health care systems. In contrast, across Europe there are no such laws. In fact, the National Institute for Health and Care Excellence (NICE), the body guiding health and social policy in the UK, concluded that it could not find any evidence to support ABA, and therefore could not recommend it. This paper addresses the reasons for these diametrically opposed perspectives.

**Keywords:** applied behaviour analysis (ABA); autism; policy; public health; RCT; misinformation; propaganda; fake news

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Autism spectrum disorder is a complex neurodevelopmental disorder that affects 1% to 3.5% of the global population [1,2]. The economic costs to society associated with autism are immense, running at £32 billion per year in the UK and \$180 billion in the United States, more than heart disease, stroke and cancer combined [3]. The personal and social cost of autism for those directly affected and their families is difficult to estimate, however, it is safe to say that it is considerable. While some argue that autism is mainly a manifestation of neurological diversity [4], others describe a lifelong condition, often with a rather bleak trajectory [5,6]. Recent research has shown that much can be done to help individuals achieve optimal outcomes [7,8].

In this paper, we discuss first how autism policy in North America is informed by findings from the natural science of Applied Behaviour Analysis (ABA). Then, using case studies from the UK where training in this science is not widely available, we illustrate how the spread of misinformation about the science prevents it from playing a key role in autism policies.

While a universally agreed definition of public policy may not be possible, it is clear that policy decisions are an important part of social governance. The U.S. Department of Education's Center for Civic Education [9] defines public policy simply as whatever

Government (any public official who influences or determines public policy, including school officials, city council members, county supervisors, etc.) does or does not do about a problem that comes before them for consideration and possible action.

Public policy decisions identify the objectives relating to the health, morals, and well-being of the citizens of the country in which these policies apply. In fact, public policy, legislatures, and courts 'seek to nullify any action, contracts, or trust that goes counter to these objectives even if there is no statute that expressly declares it void' [10]. However, for many reasons, health policy has always been political. In fact, it is probably impossible to keep politics out of health policy [11–15].

Gambrill [16,17], whose research focusses on evidence-based social care and critical thinking, used the term 'propaganda' for the way in which political games play out within the helping professions.

There is a fog that has been generated by corporate interests and organizations attempting to sell their services and products to desperate or poorly educated consumers. (p. 1)

More recently, the term 'fake news' [18] has become the favoured vernacular to describe information that is 'deliberately fabricated and published with the intention to deceive and mislead others into believing falsehoods or doubting verifiable facts' [19]. Researchers are now beginning to take the phenomenon seriously [18,20,21].

The rise of fake news highlights the erosion of long-standing institutional bulwarks against misinformation in the internet age. Concern over the problem is global. .... A new system of safeguards is needed. ([22], p. 1094)

The field of autism research and practice is not immune to propaganda or fake news as defined here. In order to increase the likelihood that effective, scientifically validated interventions are available for individuals with autism, it is essential that public policies are based on accurate, up-to-date, peer-reviewed, and critically appraised research data [23]. For this to happen, scientists and policy makers have to work together [24].

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.

Without reliable knowledge about the natural world, however, we would be unable to achieve the agreed upon goals of a public policy decision. ... Science is essential to policymaking if we want our policies concerning the natural world to work. ([25], p. 3)

Apart from making sure that policy is based on factually accurate information, government advisors are expected to adhere to ethical standards and codes of practice. For example, for psychologists, Section 2.3 of the British Psychological Society's [26] ethical guidelines acknowledges the limitations of professional competence in the various fields of psychology by stating that psychologists must:

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

Other scientific disciplines (e.g., physics) have similar regulations for their members when representing the discipline at policy levels. They consider the issue of competence in science 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*)

## Science and Autism Policies in North America

There is extensive evidence that interventions based on Applied Behaviour Analysis are more effective than other procedures for supporting individuals on the autism spectrum [27–29]. In North America, parents of children with autism lobbied successfully for government representatives and professional bodies to examine this evidence [30,31]. As a consequence, public policies in support of the use of Applied Behaviour Analysis were developed. For example, the US Surgeon General [32] concluded as early as 1999 that:

Over 30 years of research demonstrate the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.

Subsequent to this statement, continued research provided supporting evidence of the effectiveness of ABA-based interventions, and now with nearly 50 years of accumulated evidence, other organisations have adapted similar policy recommendations. For example, the U.S. Office of Personnel Management Benefits Review Panel [33] declared the following:

There is sufficient evidence to categorize ABA as medical therapy rather than purely educational.

Furthermore, the 60,000-member American Academy of Pediatrics [34] and the New York State Department of Health [35] publicly endorsed the use of ABA-based interventions for those affected by autism.

In Canada, policy makers came to similar conclusions and consequently most Canadian territories have laws to ensure that ABA-based interventions are available, although in some cases this is tied to an age or a time limit [36]. Justice Kiteley [37] of the Ontario Superior Court of Justice clarified the importance of ABA for children's rights and freedoms:

The absence of ABA means that children with autism are excluded from the opportunity to access learning, with the consequential deprivation of skills, the likelihood of isolation from society and the loss of the ability to exercise the rights and freedoms to which Canadians are entitled.

Autism Canada [38] found that '[t]here are no known negative effects of the ABA approach' and consequently, the right of children to benefit from ABA-based protocols also penetrates education policy in Canada. For example, the Department of Education in Ontario put forward a policy/programme memorandum [39] to school boards

To support their use of applied behaviour analysis (ABA) as an effective instructional approach in the education of many students with autism spectrum disorders (ASD). This memorandum establishes a policy framework to support incorporation of ABA methods into school boards' practices. The use of ABA instructional approaches may also be effective for students with other special education needs.

In the USA, 45 States (as well as the District of Columbia and the US Virgin Islands) have introduced legislation to ensure that those affected by autism have access to ABA-based interventions through their health care system [40]. 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 to make ABA-based interventions available [41]. Lobbying for the remaining US States to adopt similar legislation continues [42]. In effect, ABA-based interventions now are considered gold standard and have become 'treatment as usual' in most of North America [7].

This progress in the USA was made possible because of the significant number of well-trained behaviour analysts who were able to present accurate information to government bodies. The Behavior Analyst Certification Board [43] provides international standards for training behaviour analysts at pre-degree (RBT), bachelor's (BCaBA), Masters (BCBA), and Doctoral levels (BCBA-D).

These qualifications involve extensive theoretical as well as strictly supervised practical training and a rigorous final examination.

Board Certified Behaviour Analysts (BCBA) work in a wide variety of areas, including education, disability, communications, gerontology, social work, and organizational management. Their work adheres to seven defining dimensions of ABA: It is applied to problems of demonstrated social importance; it has measurable behavioural outcomes; it uses systematic analysis to demonstrate that specific procedures produce specific effects; procedures are technologically described well enough to be replicated; it is conceptually compatible with behaviourism; it uses effective procedures with strong, socially important effects; and it achieves generality from the outset to ensure longevity of effects [44]. When working with individuals, no single intervention is used in a one-size-fits-all approach. Instead, the scientific method is used [45]. Central to the scientific method is the notion that decisions about procedures are guided by, and evolve with, the progress of the learner. There is no 'normalising agenda'<sup>1</sup> [46], but instead the goal is to work in partnership to arrange educational experiences that maximise the individual's skills levels. Doing so increases behavioural repertoires and choices and alleviates obstacles to independent living [47].

### Science and Autism Policies Elsewhere

The vast majority of verified training courses in ABA are offered in the USA [43]. In contrast, there is a lack of well-trained behaviour analysts in other parts of the world, though the number of non-US courses is growing. Not surprisingly therefore, the picture with regards to autism policy elsewhere in the world looks quite different to North America [48]. For the most part, ABA is not mentioned in public policies. Furthermore, there is evidence that academics at universities who offer training in ABA have experienced obstacles in sharing their expertise [49]; see also, video testimonials by professionals from Iceland, Italy, Sweden and the Netherlands [50]. An example from Italy illustrates the general problem that arises when behaviour analysts are excluded from government reports regarding reviews and recommendations of autism interventions:

A good example is the Linea Guida 21, a guideline on effective treatments for autism recently published by the Italian Istituto Superiore di Sanità (ISS), a research branch of the Italian Ministry of Health. This guideline asserts that behavioural interventions are most effective in autism treatment. However, because no behaviour analyst, academic or professional trained in ABA, was on the scientific board that evaluated the research, the guideline report contained worrying examples of confusion between the science, procedures, models and protocols for intervention. ([48], p. 169)

In fact, there is evidence of historical bias against ABA as Todd pointed out:

Unfortunately, most misconceptions about behaviorism, ... will be difficult to correct because they owe more to "academic folklore" than to scholarly analysis. This academic folklore is passed from textbook to textbook and from teacher to student as unquestioned fact. The misconceptions are so well accepted that genuine critical investigation is brought to a halt. ([51], p. 117)

It can be argued that as a result of this level of misinformation some government advisors have breached the ethical standards of their own professional bodies by claiming to have sufficient

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<sup>1</sup> Implementing an ABA program is not something that is 'done to someone', rather it is something that is 'done with someone'. The goal is to provide opportunities for an individual to acquire skills that increases opportunities to make choices in life. Keenan [46] commented on the misinformation that is circulated about this goal: 'It is considered a perversion by some to encourage parents to employ the principles of behaviour in the context of educating their children with autism. Using insights from behaviour analysis, it is argued, is something to be discouraged. ABA is caricatured as NOT being person-centred and it is also argued that designing experiences based on awareness of the influence of [laws of learning] to educate someone necessarily involves coercion, and that the science is guilty of forcing people to conform to one view of the world.' (p. 7)

expertise in ABA when evidently this is not the case [52,53]. Furthermore, when a significant lack of knowledge about ABA is evident in staff training [54] it is nearly inevitable that public autism policies are misinformed [48].

In Northern Ireland, for example, historically policy makers refused to engage with behaviour analysts [55,56] and hence their understanding of ABA remains limited with the consequence that people with autism and their families are denied access to ABA-based supports [48]. At the heart of the problem lies misinformation that is maintained by gatekeepers whose limited understanding of ABA is undermining government recommendations [57]. This misrepresentation of ABA has spawned many inconsistencies in the way the evidence base for autism support is handled. 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 the 'eclectic approach' [49,58].

Over the years, parents of children with autism and professionals repeatedly requested the Department of Education in Northern Ireland to show them the scientific evidence of the eclectic approach to be equal to or superior to ABA-based supports [59,60]. The answer has been that there is no evidence for an eclectic approach. In fact, eclectic interventions repeatedly have been shown to be less effective than ABA-based interventions [28,29]. Yet, autism policies are either based on the notion that there is not enough evidence for specific autism interventions, without specifying what evidence would be considered 'enough' [61], or they explicitly favour an eclectic approach [55].

Gambrill [17] outlined a number of specific propaganda strategies that are implicit in the spread of misinformation and we illustrate how these are used in the context of policy decision making with regards to evidence-based autism interventions:

1. Preparing uncritical, incomplete research reviews related to a practice or policy;
2. Ignoring counter evidence to favoured views and hiding limitations of research;
3. Ignoring or misrepresenting well-argued alternative views and related evidence;
4. Arguing ad hominem (attacking the critic) rather than ad rem (responding to the argument). (p. 8)

#### **1. Preparing uncritical, incomplete research reviews related to a practice or policy**

When governments in Northern Ireland and in the Republic of Ireland set up task groups to guide policy in relation to autism interventions [55], professional and academic behaviour analysts were excluded from participating regardless of repeated parental requests to have them included [62]. Despite the fact that the first book on parent education in ABA had been published at that time [63] and a copy of this book had been given to all Task Group panel members, information provided by the book was ignored. The final report did not include a single reference to the book and, instead, included a caricature of ABA [62,64]. At the same time, a discernible preference for one specific autism intervention programme (namely, the TEACCH programme; [65] was apparent throughout the report, despite the lack of evidence supporting this particular programme [66]. Indeed, the views expressed in the Task Group report have been obstructive to the development and quality of ABA-based interventions in Northern Ireland and in the Republic of Ireland. The most obvious example of the failure to provide an objective, independent, evaluation of available interventions is found in Section 3.25 of the Northern Ireland report:

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. ([55], p. 38)

The Task Group report did not provide any evidence to support this statement. Examples of incomplete reviews related to the description of different ABA-based procedures and the reference to the use of physical punishments for dealing with difficult/challenging behaviours [55]. This left the reader with the impression that these procedures were standard practice in modern day ABA-based interventions overlooking the long history of behaviour analysts developing and promoting positive reinforcement-based interventions [67]. To put the issue of use of aversives or punishment in its

proper historical perspective, Sallows [68] noted that many autism interventions included aversives in the past that would be considered unethical today:

... the reader may be interested to know that aversives were a generally accepted practice during the 1960s and 1970s. TEACCH, for example also advocated the use of aversives at that time. In their training manual, Schopler et al. [69] describe the use of 'aversive and painful procedures' such as meal deprivation, 'slaps or spansks on the bottom', or 'electric shock, unpleasant tasting or smelling substances' as appropriate interventions if positive methods are ineffective. ([68], p. 31)

Had a well-trained behaviour analyst been on the Task Group, a more informed debate could have taken place and these and other kinds of misrepresentation would not have appeared in a government-sponsored report. The fact that they did is regrettable, especially since the goal shared by all professionals is the welfare of those they serve. More importantly, misrepresentation of ABA in Government sponsored reports in the UK were repeated, over 15 years later, as Case example 1 shows.

#### **Case example 1:**

The UK's National Institute for Health and Care Excellence [70] provides landmark reviews on which UK government relies to allocate £millions of funding for health and care services (e.g., NICE guidelines led to over £400 million being allocated to in support of mental health through the Improving Access to Psychological Therapies programme (IAPT; [71]).

NICE's role is to 'improve outcomes for people using the NHS and other public health and social care services' by:

- Producing evidence-based guidance and advice for health, public health and social care practitioners.
- Developing quality standards and performance metrics for those providing and commissioning health, public health and social care services.
- Providing a range of information services for commissioners, practitioners and managers across the spectrum of health and social care [70].

In their guidance for panels, NICE states explicitly that assessors should rely on randomised controlled trials (RCT) and systematic reviews to establish what is to be considered evidence-based practice in various clinical areas (see [45] for a discussion on the misapplication of RCTs).

In the NICE review of the research evidence for the management and support of children with autism [72], they concluded that Applied Behaviour Analysis (ABA) is a general approach to intervention that can involve a wide range of behavioural strategies and can be used to change behaviours across multiple domains (p. 29). Yet, they did not recommend the use of ABA for the following reason (NB: this statement was repeated 6 times in their response to consultation):

During guideline development, there was evidence from randomised controlled trials (RCT) and systematic reviews about psychosocial interventions to improve the core features of autism. However, none of this evidence was about ABA. ([73], pp. 1, 7, 8, 10, 21, & 23)

NICE [72,74,75] did not include any credentialed behaviour analysts in their review team (e.g., with Masters or Doctoral training in ABA) who could have explained that ABA is in fact a science and not simply a general approach to intervention, and that it is entirely inappropriate to assess a science using RCTs. Indeed, when asked about expertise in ABA in the Guidelines Committee, NICE argued, that '[a]lthough the Guideline Committee did not include professionals with an internationally recognised qualification in behaviour analysis, they were familiar with ABA and the research' ([76], p. 1). Despite requests, no definition was offered as to what was meant by being 'familiar', nor is there a NICE policy of regarding people familiar with a scientific discipline as being equivalent to people fully trained in that scientific discipline [77].

NICE's 4-year review of NG170 re-asserted that 'ABA was not recommended in the guideline' ([73], p. 1), because most of the evidence for ABA comes from single-case experimental designs (SCD).

Given that NICE panel members had no internationally recognised training in ABA, the decision to dismiss the findings from a science in which they are not trained constitutes a serious breach of ethical standards in both the Medical Research Council and the British Psychological Society. Both these organisations specifically point out that professionals should not operate outside their area of expertise.

When behaviour analysts are side-lined in major Government reviews, it is not surprising, that autism reviews repeatedly report ABA-based interventions incorrectly [56,78].

In some European fora, incomplete research reviews of ABA-based interventions are also prevalent. For example, at the Autism-Europe International Congress in Budapest, Howlin [61] asked what has been learned in 70 years of autism research. There was no mention of the extensive body of research on ABA that has informed health care legislation in the USA described earlier. The growing research on long-term maintenance of improved quality of life [8,27] and the analyses of positive social return on investment from using ABA-based interventions [79–83] are also problematic for incomplete reviews of autism research [84].

## 2. Ignoring counterevidence to favoured views and hiding limitations of research

Apart from misrepresenting ABA, UK government policies and reports also ignore counter-evidence and hide limitations of research related to their preferred stance on eclecticism. A good example is the response to the Autism Act (Northern Ireland) (2011), that mandated the development of a cross-departmental Autism Strategy (2013–2020) and Action Plan (2013–2016) [85,86].

The project group tasked with drawing up these two documents also did not include any credentialed behaviour analysts (despite parents' protestations and requests); in this case, they did not include any academics at all. Consequently, none of the wide-ranging local University autism training programs were mentioned, neither in the strategy nor in the action plan, despite the fact that Northern Ireland's universities offer extensive undergraduate and post-graduate training in autism as well as behaviour analysis. The reports, however, did include extensive references to favoured agency-based training providers without pointing out their limitations. Moreover, none of the extensive autism research carried out at Northern Ireland's universities was mentioned either (e.g., [50,86]).

Case example 2 provides a case in point of how counter-evidence was ignored and limitations of research were not documented at a Ministerial level.

### Case example 2:

In 2013, the Minister of Health in Northern Ireland accepted the invitation to open an international autism conference at the local Russell Group University. At the conference, he met one of the keynote speakers, Dr. Lorri Unumb, Vice President, State Government Affairs, Autism Speaks [42]. Dr. Unumb invited the Minister to a meeting at Autism Speaks Headquarters in New York, USA, to familiarize him with the history of the State legislation for ensuring ABA-based intervention is funded for children and young people diagnosed with autism.

The Health Minister, along with a number of colleagues attended the meeting in New York, USA, on 23 October 2013. Given the absence of policy to provide ABA in Northern Ireland, this was a significant event. Surprisingly, though, no-one was ever properly informed about what was said at that meeting and, in response to a Freedom of Information Request for a copy of the minutes of that meeting, it was revealed that no minutes were available. No change in policy occurred.

Baldwin's [87] comments are relevant here:

Science has evolved over many centuries to become an integral part of modern society, underpinning our health, wealth, and cultural fabric. Yet scientific evidence is often willfully disregarded by politicians worldwide. They often cherry pick or ignore the science when it does not accord with their political agenda. We have seen 'alternative facts' supplant scientific and other evidence bases in this 'post-fact' era.

When the Minister for Health eventually convened the Northern Ireland Autism Strategy Research Advisory Committee (NIASRAC), nominations were sought from various agencies, and, after significant lobbying, the two local universities were included this time. However, here again, irregularities occurred. Instead of allowing them to nominate freely, an email intervention was sent from the Department of Health to one of the universities [88], in which there was an explicit request for a particular non-behavioural emeritus faculty member to be nominated to the committee. The email asked for 'a quite word' stating explicitly that the Chair of the NIASRAC would appreciate the nomination of this person [88]. The university complied and consequently the only autism expert in their Directory of Experts, a credentialed, world-renowned behaviour analyst who held multiple awards for his work regarding autism, was excluded from the committee.

The whole process of setting up the NIASRAC took so long that the inaugural meeting took place after the completion of the Autism Strategy and Action Plan. In other words, because the Autism Strategy and the Action Plan already had been submitted to the Minister for signature, NIASRAC missed the opportunity to inform the Minister about counter-evidence and limitations of research regarding the favoured and recommended 'eclectic' model.

### 3. Ignoring or misrepresenting well-argued alternative views and related evidence

The previous case examples showed how autism research reviews in the UK were uncritical and incomplete and how counter-evidence and limitations were ignored. Buried within this position is a distorted view of the scientific method that is used in ABA.

The Task Group on Autism [55] stated that interventions should be child-centred rather than method centred and should address the observed and unique needs of the child. No-one would argue with this statement. However, when ABA is misrepresented as a single, 'one size fits all intervention' it is viewed as not being child-centred. For example, the Minister of Education made the following statement:

Applied Behaviour Analysis (ABA) is one of many commercially available interventions for children with autism [89].

When ABA is characterised in this way by a high-ranking government official, parents and other politicians will not recognise this as misinformation. To emphasise this point, a subsequent Minister for Education reiterated the view that ABA was not a scientific discipline:

I continue to accept this view and, therefore, do not promote one type of intervention over another [90].

These assertions ignore the scientific method used in ABA [45] and the internationally recognised training standards mentioned earlier [43]. ABA is not understood as a science, but rather, is viewed as one method or one intervention amongst many, unable to address the unique needs of each child.

The question that arises, then, is the following: How come consecutive ministers are so badly misinformed? It comes as no surprise to learn that most of the ministerial advisors have little or no training in ABA [54] and the scientific methods that underpin individualized ABA-based interventions [48]. This point was illustrated by comments in the High Court Dublin, when the Northern Ireland Department of Education's lead educational psychologist with responsibility for autism was called as witness against a child with autism that required ABA-based interventions. During cross examination, she was singled out in the following way:

in terms of her professional convictions, insofar as she has a principle or a broadly-based objection to ABA, in that she has never recommended it for anyone, and also in terms of the fact that she has been retained by the Department in very many cases, and the same issue has arisen, and her attitude has been the same on every occasion. ([91], p. 10)

In other words, it could be argued that the Department kept employing the same witnesses and advisors, because they knew that a 'broadly-based objection to ABA' would support their case. The lack of understanding of the nature of scientific research is explicit in a letter to the editor of the membership journal of the British Psychological Society, *The Psychologist*:

What is a scientific study without random assignment to groups? ([52], p. 444)

At first sight, this may sound familiar. In many medical circles, random allocation (i.e., Randomised Controlled Trial; RCT) is revered as the gold standard for assessing medical interventions, but the ethics and practices of using RCTs are more complicated when used for evaluating social or psychological interventions [92,93]. There are many scientific procedures for evaluating these kinds of interventions without random assignment to groups (see [94]).

As with other inductive sciences, including personalised medicine, the key research methodologies of ABA are single-case experimental designs (SCD), also referred to as single-system research designs. These research methods are increasingly recognised as key to evidencing the effectiveness of psycho-social interventions. For example, one of the main resources of autism related information for the NHS,

Research Autism ([95] see under key publications), cites the What Works Clearinghouse's (WWC) Technical Standards on SCDs [96]. WWC concludes that 'SCDs are adaptations of interrupted time-series designs and can provide a rigorous experimental evaluation of intervention effects' (p. 1).

Of course, no-one would argue that it is appropriate to submit a whole scientific discipline to scrutiny by RCTs [45]. But this is precisely what Hughes [52] and NICE [76] demand when they say they cannot recommend ABA because there are no RCTs evaluating ABA. That is the same as someone asking other natural scientists (e.g., biologists, physicists, or chemists) to run RCTs to assess their disciplines, a request that would appear rather strange to these scientists.

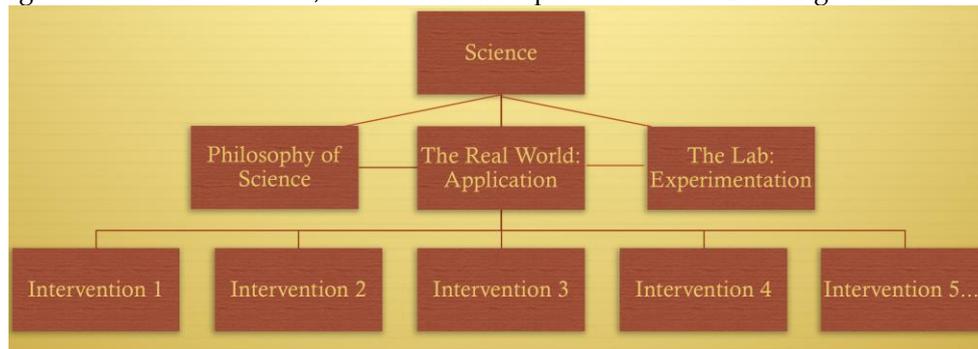
In this context, we conducted a brief literature search for RCTs and systematic reviews for a number of scientific disciplines to determine the feasibility of this request. Table 1 provides a summary of the findings. Results indicate that there are no RCTs or systematic reviews of any of these scientific disciplines. For example, there are no RCTs or systematic reviews to support the use of medicine (as indicated by 'none available' in the Table 1). Therefore, following the logic of NICE [76] or Hughes [52], none of these scientific disciplines should be used or recommended! Obviously, this does not make sense.

**Table 1.** Major disciplines involved in public health policy and the evidence base to support them.

Discipline	RCTs and Systematic Reviews
Medical Science	None available
Dentistry	None available
Pediatrics	None available
Audiology	None available
Nursing	None available
Pharmacy	None available
Radiology	None available
Speech-Language Pathology	None available
Occupational therapy	None available
Psychology; clinical; educational	None available

The call for RCTs to assess a science (e.g., ABA) contains a major category mistake [97]. To explain this, Figure 1 shows the distinction between a science and an intervention. Those who call for

RCTs on ABA place the science of ABA in the wrong category. That is, they put it in the bottom row of the diagram as one intervention, rather than the top row as the overarching science.



**Figure 1.** Avoiding category mistakes when distinguishing between science and interventions.

To fully appreciate the implication of misrepresenting ABA as simply one intervention amongst many, instead of recognizing it as a science, the following sentence makes the same category mistake with regards to medical science:

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 next case example demonstrates the problems that occur when category mistakes involving ABA permeate government policy and practice:

#### Case example 3:

In April 2012, the Northern Irish Minister for Health appointed the CEO of a local autism charity to establish and head up the Northern Ireland Autism Strategy Research Advisory Committee (NIASRAC). The Terms of Reference (TOR) for this committee were drafted prior to the committee being established and included the following statement:

**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.** (sic)

When the committee eventually discussed the TOR, questions about this statement were overruled and the statement remained unchanged. It remains unclear why the committee chair felt it was necessary to include such a statement in the TOR, clearly limiting the reach of the committee. However, when viewed against the background of the recurring category mistake of ABA as ‘a particular methodology’, it becomes clear that this statement was included to ensure that ABA would not be recommended in the care and/or treatment of people with autism, regardless of the evidence reviewed by the committee.

Eventually, after four years of service, the only behaviour analyst on the committee, a Russell group university professor, resigned amidst serious concerns about the management of the committee. As a consequence, the Government’s Permanent Secretary of the Department instructed the Chair to pause the activities of NIASRAC, until full discussion with the Minister could be arranged.

Notwithstanding the motivation behind the statement in the TOR, no leading scientist would or should make such a limiting recommendation to any kind of research committee. Imagine, for example, if one method could be found to treat all cancer cases successfully. Surely, this method should be espoused by any research committee charged with advising Governments in the care and/or treatment of people with cancer.

The extent of the misrepresenting of evidence about the scientific status of ABA becomes apparent from responses to a simple question, ‘Is ABA a science?’ This question was sent to the

Special Education Team, Access, Inclusion and Well-being Directorate, Department of Education in Northern Ireland. Their answer was not a simple 'Of course it is!' Instead, they said:

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*)

This response is not entirely surprising when Research Autism [98] the main informant for the National Health Service (NHS) on autism interventions in the UK states the following:

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 behavioural (sic) analysis as a whole.

In contrast, Dr. Patrick Friman, Clinical Professor of Pediatrics, University of Nebraska Medical Center and former President of the Association for Behavior Analysis International states:

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. (*Personal communication*)

#### 4. Arguing ad hominem (attacking the critic) rather than ad rem (responding to the argument)

Finally, when all attempts to suppress a non-favoured argument are exhausted, the last propaganda strategy is to attack the messenger [17].

The next case example illustrates what happened when students of professionally verified MSc in ABA [99] invited the person who had received an honorary doctorate for services to autism from their university [100] to give a talk to clarify the absence of support for ABA of her organisation.

##### Case example 4:

In 2013, parents of children with autism submitted a petition to the Northern Ireland government requesting that government should 'Provide the choice of ABA-based interventions for children with ASD in Northern Ireland' [101]. Although the petition was signed by almost 3000 people worldwide including the world's largest autism organization (i.e., Autism Speaks), an influential local charity was not proactive in sharing the petition with its members, thus depriving its members of the information contained in the petition.

Subsequently, students from the MScABA at a local university invited the CEO of this charity, who held an honorary doctorate from their university, for a meeting. The students requested an explanation for the charity's lack of support for parents wanting ABA, because it did not make sense to them given what they had learned about this science in their studies.

The CEO declined the invitation to speak with the students. When the Course Director of their Masters course followed this up with a letter urging her to reconsider her decision not to meet with the student, given the importance of the career choice made by these students, he was informed by his university management that an official complaint had been made against him.

(NB: There has been no response from Government to the petition).

This example is particularly intriguing given that students had made the request for a meeting because they wanted to learn from her. This was important to them, given that they had made the decision to base their professional career on ABA. The complaint against the Course Director was evidence of Gambill's [17] forth propaganda strategy of attacking the messenger rather than engaging with the argument.

A similar situation arose when senior academics, including a professor who is on the autism spectrum, were appointed by the British Psychological Society (BPS) to conduct a review of the 2006

British Psychological Society guidance for psychologists working with children and young people on the autism spectrum [102].

#### Case example 5:

In 2014, the BPS sought Statements of Interest from all members to form a panel to review the BPS guidance for psychologists working with children and young people on the autism spectrum. A Chair, who was a well-known University Professor, himself on the Autism Spectrum, as well as a further three panel members (including 2 more University Professors) were selected from the applicants. Together the panel represented three regions of the UK as well as a European and an 'insider' perspective, thus meeting requirements of Public and Patient Involvement (PPI) [103].

Over the subsequent two years, the panel provided numerous drafts, responding to and integrating extensive, at times intemperately-worded feedback from the BPS membership. Eventually in early 2016, the Chair asked for the final revised document to be re-circulated one final time for comments to the BPS membership prior to publication. However, the BPS deemed this to be unnecessary. The Professional Practice Board signed off the final document and it was posted on the BPS webpage [102]. The url was disseminated and shared widely via the BPS twitter feed (dated 31 August 2016, 08:15).

The revised document included updated information related to autism, including a section on adults with autism and, due to the evidence discussed elsewhere in this paper, the following paragraph was added relating to distinctive contributions of psychologists:

Interventions in autism must, of necessity, vary according to the specific needs of the individual on the autism spectrum. However, multidisciplinary teams working with individuals with ASDs should include at least one psychologist who possesses specific competencies and skills, in addition to other relevant personnel, such as occupational therapists, mental health workers etc.

In the UK, psychological treatment for ASD has traditionally been offered by a psychologist, however, behaviour analysis-based intervention should be supervised and/or delivered by Board Certified Behavior Analysts (BCBA). Most BCBA's have a background in psychology and it is noted that a growing number are part of/lead multidisciplinary autism teams. Note that this document does not recommend that BCBA's should supplant psychologists, but recognises their contribution to the supervision and/or delivery of interventions, depending upon the specific needs of the individual client.

The BPS received a large number of messages about the report. Many parents and professionals enthusiastically welcomed it (e.g., ABAA4ALL [104]). However, there were also some critics and the BPS decided to yield to them and immediately withdrew the guidelines from their webpages, without consultation or notification of the review panel or the public.

After some correspondence between the panel members and the BPS to try and resolve this situation and reinstate the document (after all it had been widely consulted on and signed off by the BPS only weeks earlier), the BPS's handling of the situation led to the panel chairman stepping down from this role as review chairman as well as tendering his resignation from his longstanding membership of the BPS!

Subsequently, the BPS convened a 'consensus meeting' in London, inviting those who had objected to the revised document as well as the remaining review panel members, none of those who supported the new guidelines were invited to attend. There was no parent or PPI representation. Given that the chairman, himself on the autism spectrum, had resigned he did not

attend. During the meeting, there was significant hostility against ABA and the role of BCBA's. In fact, at one point the review panel was accused of having led an attempted 'coup d'état for ABA'.

As a result of this meeting, the BPS decided to set up a new 'Autism Task & Finish Group' and proposed this to be chaired by a retired academic, well-known for her lack of support for ABA. This panel was to produce a completely new document using a new set of procedures. Both the previous 2006 and the revised version of the BPS autism guidelines have been deleted from the BPS webpages [102].

Rather than automatically being included in the new group, as agreed at the London meeting, the original review panel members were asked to re-apply to sit on the new review panel. Having lost confidence in the BPS handling of evidence, none of the original review panel members were prepared to sit on the new panel.

One of the attendees at the London meeting, who is a university Professor, a Board Certified Behaviour Analyst-Doctoral (BCBA-D), a Fellow of the BPS, and the recipient of many international awards for his work in autism, including the BPS Award to Promoting Equality of Opportunity [105] was so appalled by the handling of the situation that he returned his Equality of Opportunity Award.

### 3. Conclusions

The focus of this paper was to make the reader aware of the link between the science of behaviour analysis and the politicking found in health policy making in the field of autism. The problems that arise when public policy is guided by misinformation or 'fake news' [20] about a science do not apply only to Northern Ireland or the UK [106–108]. Elsewhere, parents of children with autism, professionals who want to deliver ABA-based services, and academics who teach the science have similar experiences [109]. Within discussions of politics and science, Lupia [12] recognised that this scenario is not uncommon:

Members of the scientific community share a frustration: many attempts to communicate science are badly received. This frustration is particularly evident in politicized environments. (p. 14048)

Problems with the accurate dissemination of information about ABA have a long history [110]; also see [111,112]. Baum [113] explained that the origins of these problems can be traced to the very idea that such a science could exist in the first place:

All that is genuinely controversial about behaviorism stems from its primary idea, that a science of behavior is possible. At some point in its history, every science has had to exorcise imagined causes (hidden agents) that supposedly lie behind or under the surface of natural events. (p. 1)

To offset the lack of support for ABA in public policy, parents have taken control. They set up their own initiatives to ensure that they can avail of ABA-based interventions for their children. For example, in Portugal, parents set up the parent led charity MyKidUp [114], in Germany, parents started the Münster Early Intervention in Autism initiative (MIA; [115]), and in the Czech Republic parents set up the Czech Society for Behaviour Analysis [116,117].

In Northern Ireland, parents established a charity in 1997 called Parents' Education as Autism Therapists [118]. PEAT's mission is to train parents in ABA with the ultimate goal of ensuring that statutory authorities assume responsibility for this work. Against all the odds, PEAT has generated significant achievements. They published the first book in Europe on ABA for parents [63] and were made the 'Family Support Organization of the Year' [119].

Importantly, PEAT has joined parents, professionals and academics to educate others about the science of Applied Behaviour Analysis. With a grant from the Big Lottery and extensive European funding from the Leonardo Lifelong Learning Programme, they produced the first online multimedia

ABA training program in Europe for parents [120]. This platform offers training in practical solutions for teaching children with autism. The SimpleSteps platform has been translated and adapted to 10 European languages [50]. Most of the development of this platform was funded through local or European Union funding, though the most recent adaptation in Portugal was possible due to funds raised directly by parents of MyKidUp and the Czech adaptation was resourced by the largest Czech Health Insurance company.

While governments remain reluctant to engage in evidence-based practices, SimpleSteps provides practical solutions to problems faced by parents when rearing a child with autism. For example, it teaches parents how to support their child to increase functional speech, how to manage food acceptance, how to improve social interaction with peers, how to reduce severe challenging, self-stimulatory, or anxiety related behaviours. Most importantly, SimpleSteps ensures that parents have easy access to accurate and scientifically validated information.

Policy on social, educational, and health interventions should always be fully informed by scientific evidence. Unfortunately, as outlined in this paper, at times the use of propaganda strategies [17] has resulted in public policy decisions that are based on ‘fake news’ [121]. This is not to say that the science of behaviour analysis does not value legitimate criticisms [109,122]. However, parents of children with autism increasingly reach the conclusion that self-help [104] and/or legal action [123–126] is the only way they can safeguard the rights of their children to have access to educationally and medically necessary supports and interventions [127,128], thus protecting their children against people who bring politics into science instead of using science to inform public policy.

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