

When public policy is guided by misinformation: A case study in the consequences of fake news

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Abstract

Since autism was first recognised, prevalence has increased rapidly. The growing economic as well as social cost to society can only be mitigated by effective interventions and supports. It is therefore not surprising that most governments have developed public policy documents to address the management of autism. Over the past 40-50 years, meaningful evidence has accrued showing that interventions based on the scientific discipline of Applied Behaviour Analysis (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 the 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. In particular, it examines what happens when health and social care policy is misinformed about effective autism intervention.

Keywords: Applied Behaviour Analysis, Autism, Policy, Randomised Controlled Trials, Fake News.

Autism spectrum disorder is a complex neurodevelopmental disorder that affects 1% to 3.5% of the global population (Dillenburger, Jordan, McKerr, Lloyd, & Schubotz, 2017; Dillenburger, Jordan, McKerr, & Keenan, 2015). 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 (Buescher, Cidav, Knapp, & Mandell, 2014). 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 a lifelong condition, often with a rather bleak trajectory (Howlin, Savage, Moss, et al., 2014), recent research has shown that much can be done to develop individual optimal outcomes (Fein, Barton, Eigsti, et al., 2013; Orinstein, Helt, Troyb, et al., 2014).

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38 In this paper, we discuss first how autism policy in North America is informed by
39 findings from the science of Applied Behaviour Analysis (ABA). We then examine
40 why, in Europe, knowledge of this science is not widely available and how, as an
41 unfortunate consequence, misinformation about the science has prevented it from
42 playing a key role in autism policies. Using case studies from the UK, we then
43 illustrate how well-known propaganda methods have played a central role in
44 influencing public policy decisions.

45 While a universally agreed definition of public policy may not be possible, it is clear
46 that policy decisions are an important part of social governance. The U.S.
47 Department of Education's Centre for Civic Education (2018) defines public policy
48 simply as whatever

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

53 Public policy decisions identify the objectives relating to the health, morals, and
54 well-being of the citizens of the country in which these policies apply. In fact, public
55 policy, legislatures, and courts 'seek to nullify any action, contracts, or trust that goes
56 counter to these objectives even if there is no statute that expressly declares it
57 void' (Business Dictionary, 2018).

58
59 To ensure that effective, scientifically validated interventions are available for
60 individuals with autism, it is essential that public policies are based on up-to-date,
61 peer-reviewed, and critically appraised research data (Heward, 2003). For this to
62 happen, scientists and policy makers have to work together (Ainscow & Chapman,
63 2017).

64
65 In the ideal image of science, scientists work in a world detached from our
66 daily political squabbles, seeking enduring empirical knowledge. Scientists
67 are interested in timeless truths about the natural world rather than current
68 affairs. Policy, on the other hand, is that messy realm of conflicting interests,
69 where our temporal (and often temporary) laws are implemented, and
70 where we craft the necessary compromises between political ideals and
71 practical limits. This is no place for discovering truth.

72 Without reliable knowledge about the natural world, however, we
73 would be unable to achieve the agreed upon goals of a public policy
74 decision. ... Science is essential to policymaking if we want our policies
75 concerning the natural world to work. (Douglas, 2009)

76

77 Apart from making sure that policy is based on factually accurate information,
78 government advisors are expected to adhere to ethical standards and codes of
79 practice (Peter & Hull, 1994). For example, for psychologists, Section 2.3 of the
80 British Psychological Society's ethical guidelines (2009) acknowledges the limitations
81 of professional competence in the various fields of psychology by stating that
82 psychologists must:

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

85

86 Other scientific disciplines (e.g., physics) have similar regulations for their members
87 when representing the discipline at policy levels. They consider the issue of
88 competence in science of central importance for policy makers:

89

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

94

95 **Science and autism policies in North America**

96 There is extensive evidence that interventions based on Applied Behaviour Analysis
97 are more effective than other procedures for supporting individuals on the autism
98 spectrum (Eikeseth, Smith, Jahr, & Eldevik, 2002; Howard, Sparkman, Cohen, Green,
99 & Stanislaw, 2005; Howard, Stanislaw, Green, Sparkman, & Cohen, 2014). In North
100 America, parents of children with autism lobbied successfully for government
101 representatives and professional bodies to examine this evidence (California
102 Departments of Education and Developmental Services, 1997; Maurice, 1999). As a
103 consequence, public policies in support of the use of Applied Behaviour Analysis
104 were developed. For example, the US Surgeon General (1999) concluded that:

105

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

109

110 Subsequent to this statement, research continued to provide supporting evidence of
111 the effectiveness of ABA-based interventions, and now with nearly 50 years of
112 accumulated evidence, other organisations have adapted similar policy
113 recommendations. For example, the U.S. Office of Personnel Management Benefits
114 Review Panel (Autism Speaks, 2012) declared the following:

115

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

118

119 Furthermore, the 60,000-member American Academy of Pediatrics (AAP, 2007) and
120 the New York State Department of Health. (2011) publicly endorsed the use of ABA-
121 based interventions for those affected by autism.

122

123 In Canada, policy makers came to similar conclusions and consequently most
124 Canadian territories have laws to ensure that ABA-based interventions are available,
125 although in some cases this is tied to an age or a time limit (Autism Society Canada,
126 2004). Justice Frances Kiteley (2005) of the Ontario Superior Court of Justice clarified
127 the importance of ABA for children's rights and freedoms:

128

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

133

134 Autism Canada (2018) found that '[t]here are no known negative effects of the ABA
135 approach' and consequently, the right of children to benefit from ABA-based
136 protocols also penetrates education policy in Canada. For example, the Department
137 of Education in Ontario put forward a policy/programme memorandum (PPM-140,
138 2007) to school boards

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

145 In the USA, 45 US States (as well as the District of Columbia and the US Virgin
146 Islands) have introduced legislation to ensure that those affected by autism have
147 access to ABA-based interventions through their health care system (Autism Speaks,
148 2017). In other words, on 47 separate occasions, the research evidence was reviewed
149 and it was concluded that there was sufficient evidence to warrant the introduction
150 of new laws to make ABA-based interventions available (The Kennedy Krieger
151 Institute and Johns Hopkins University School of Medicine, 2017). Lobbying for the
152 remaining US States to adopt similar legislation continues (Unumb, 2013). In effect,
153 ABA-based interventions now are considered gold standard and have become
154 'treatment as usual' in most of North America (Fein et al., 2013).

155

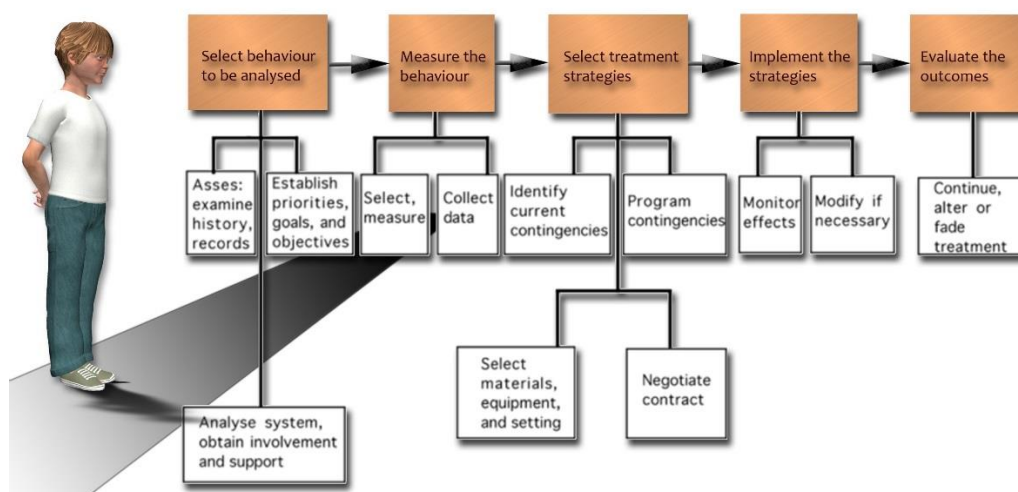
156 This progress in the USA was made possible because of the significant number of
157 well-trained behaviour analysts who were able to present accurate information to
158 government bodies. The Behavior Analyst Certification Board (BACB, 2018)

159 provides international standards for training behaviour analysts at pre-degree (RBT),
 160 bachelor's (BCaBA), Masters (BCBA), and Doctoral levels (BCBA-D). These
 161 qualifications involve extensive theoretical as well as strictly supervised practical
 162 training and a rigorous final examination.

163

164 Board Certified Behaviour Analysts (BCBA) work in a wide variety of areas,
 165 including education, disability, communications, gerontology, social work, and
 166 organizational management. 'Genuine ABA interventions have all the defining
 167 features of ABA and are designed and overseen by appropriately credentialed
 168 professionals' (APBA, 2017). When working with individuals, no single intervention
 169 is used in a one-size-fits-all approach (Dillenburger, 2011). Instead, the scientific
 170 method as shown in Figure 1 is used. Central to the scientific method is the notion
 171 that decisions about procedures are guided by, and evolve with, the progress of the
 172 learner. There is no 'normalising agenda'³ (Keenan, 2016), but instead the goal is to
 173 work in partnership to arrange educational experiences that maximise the
 174 individual's skills levels. Doing so increases behavioural repertoires and choices and
 175 alleviates obstacles to independent living (BACB, 2018).

176



177

178

179 **Figure 1:** The scientific method applied to individuals (reprint permission granted,
 180 Keenan et al, 2014).

181

182

183

³ '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.' (Keenan, 2016, p. 7)

184

185 Science and autism policies in Europe

186 The vast majority of verified training courses in ABA are offered in the USA (BACB,
187 2018). In contrast, there is a lack of well-trained behaviour analysts in other parts of
188 the world, though the number of non-US courses is growing. Not surprisingly
189 therefore, the picture with regards to autism policy in Europe looks quite different to
190 North America (Keenan et al, 2014). For the most part, ABA is not mentioned in
191 public policies. Furthermore, there is evidence that academics at universities who
192 offer training in ABA have experienced obstacles in sharing their expertise
193 (Dillenburger, 2011; see also, video testimonials by professionals from Iceland, Italy,
194 Sweden and the Netherlands, STAMPPP, 2013). An example from Italy illustrates
195 the general problem that arises when behaviour analysts are excluded from
196 government reports regarding reviews and recommendations of autism
197 interventions:

198

199 A good example is the Linea Guida 21, a guideline on effective treatments
200 for autism recently published by the Italian Istituto Superiore di Sanità (ISS
201 2011), a research branch of the Italian Ministry of Health. This guideline
202 asserts that behavioural interventions are most effective in autism treatment.
203 However, because no behaviour analyst, academic or professional trained in
204 ABA, was on the scientific board that evaluated the research (Moderato
205 2012), the guideline report contained worrying examples of confusion
206 between the science, procedures, models and protocols for intervention.
207 (Keenan et al, 2014, p. 169)

208

209 It can be argued that some government advisors have breached the ethical standards
210 of their own professional bodies by claiming to have sufficient expertise in ABA
211 when clearly this is not the case (Hughes, 2008; Jordan, 2001). The result is that
212 misunderstandings flourish (Fennell & Dillenburger, 2016). Consequently, across
213 Europe public autism policies frequently are based on misinformation and 'fake
214 news' (Keenan et al., 2014).

215

216 In Northern Ireland, for example, the government has refused to engage with ABA
217 trained professionals or academics (Dillenburger et al., 2014) and hence their
218 understanding of ABA is very limited and inaccurate (Keenan et al., 2014) with the
219 consequence that people with autism and their families are denied access to ABA-
220 based supports. At the heart of the problem is a culture of misinformation that is
221 propped up by gatekeepers who refuse to countenance the possibility that their
222 limited understanding of a science in which they are not trained is undermining the
223 integrity of government recommendations (Keenan, 2015). The misrepresentation of
224 ABA is pervasive and has spawned many inconsistencies in the way the evidence
225 base for autism support is handled. On one hand, it is said that it would be wrong to

226 invest in only 'one thing', like ABA, while on the other hand it is argued that it is
227 better to invest in 'one thing' called the 'eclectic approach' (Dillenburger, 2011).

228

229 Over the years, repeated requests were made by parents of children with autism to
230 the Department of Education in Northern Ireland to show them the scientific
231 evidence of the eclectic approach to be equal to or superior to ABA-based supports
232 (Keenan, 2017). The answer has been that there is no evidence for an eclectic
233 approach (Keenan, personal communication). In fact, eclectic interventions
234 repeatedly have been shown to be less effective than ABA-based interventions
235 (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Howard, Stanislaw, Green,
236 Sparkman, & Cohen, 2014). Yet, autism policies in most of Europe are either based
237 on the notion that there is not enough evidence for specific autism interventions,
238 without specifying what evidence would be considered 'enough' (Howlin, 2013), or
239 they explicitly favour an eclectic approach (Keenan et al., 2014).

240

241 In order to maintain the status quo, well-recognised propaganda strategies have
242 been used against the use of ABA that include the following:

- 243 1. Preparing uncritical, incomplete research reviews related to a practice or
244 policy;
- 245 2. Ignoring counterevidence to favoured views and hiding limitations of
246 research;
- 247 3. Ignoring or misrepresenting well-argued alternative views and related
248 evidence;
- 249 4. Arguing ad hominem (attacking the critic) rather than ad rem (responding to
250 the argument. (Gambrill, 2012, p.8)

251

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

253 When governments in Northern Ireland and in the Republic of Ireland set up task
254 groups to guide policy in relation to autism interventions (Task Force, 2001; Task
255 Group, 2002), professional and academic behaviour analysts were excluded from
256 participating despite repeated parental requests to have them included (PEAT,
257 2002). Despite the fact that the first book in Europe on parent education in ABA had
258 been published at that time (Keenan, Kerr, & Dillenburger, 2000) and a copy of this
259 book had been given to all Task Group panel members, information provided by the
260 book was ignored. The final report did not include a single reference to the book and
261 reported what can only be described as a caricature of ABA (Morgan, 2008; PEAT,
262 2002). At the same time, a discernible preference for one specific autism intervention
263 programme (namely, TEACCH) was apparent throughout the report, despite the
264 lack of evidence supporting this particular programme (Warren, Veenstra-Vander
265 Weele, Stone, et al., 2011). Indeed, the views expressed in the Task Group reports
266 have proven to be harmful to the development and quality of ABA-based
267 interventions in Northern Ireland and in the Republic of Ireland. The most blatant
268 example of the slating of ABA and the failure to provide an objective, independent

269 evaluation of available interventions, is found in Section 3.25 of the Northern Ireland
270 report:

271

272 Local professionals who work with young children suggested to Task Group
273 members that they would have grave reservations about being involved in
274 subjecting such young children to such an intense behavioural programme
275 for fear of causing some kind of psychological damage. (Task Group, 2002,
276 p. 38)

277

278 The Task Group report did not provide any evidence to support this statement.
279 Other examples of serious misrepresentation were confusions between different
280 ABA-based procedures and a reference to the use of physical punishments for
281 dealing with difficult/challenging behaviours (Task Group, 2002). Insinuations that
282 these procedures were standard practice in ABA-based interventions ignored the
283 long history of behaviour analysts developing and promoting positive
284 reinforcement-based alternatives (Dillenburger & Keenan, 1994). To put the issue of
285 use of aversives or punishment in its proper historical perspective, Sallows (2000)
286 noted that many autism interventions included aversives in the past that would be
287 considered unethical today:

288

289 ... the reader may be interested to know that aversives were a generally
290 accepted practice during the 1960s and 1970s. TEACCH, for example also
291 advocated the use of aversives at that time. In their training manual,
292 Schopler, et al. (1980), describe the use of 'aversive and painful procedures'
293 such as meal deprivation, 'slaps or spansks on the bottom', or 'electric shock,
294 unpleasant tasting or smelling substances' as appropriate interventions if
295 positive methods are ineffective. (p. 31)

296

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

304

Case example 1:

The UK's National Institute for Health and Care Excellence (NICE, 2017a) provides landmark reviews on which UK government relies to allocate £millions of funding for health and care services (e.g., NICE guidelines lead to over £400 million being allocated to in support of mental health through the Improving Access to Psychological Therapies programme (IAPT; NICE, 2017b).

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. (NICE, 2017a)

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 Keenan & Dillenburger (2011) 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 (NICE, 2013), 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. (NICE, 2016, pps 1, 7, 8, 10, 21, & 23)

NICE (2012) 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 was in fact a science and not simply a general approach to intervention, and that consequently, 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' (NICE, 2013b, 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 (NICE, 2017a).

NICE's 4-year review of NG170 re-asserted that 'ABA was not recommended in the guideline' (NICE, 2016, 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.

305

306 Clearly, behaviour analysts were being side-lined in major Government sponsored
307 reviews. It is not surprising therefore that Governmental autism reviews cover ABA
308 incorrectly (Dillenburger, McKerr, & Jordan, 2014; Morris, 2009).

309

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

311 Apart from misrepresenting ABA, UK government policies and reports also ignore
312 counter-evidence and hide limitations of research related to their preferred stance on
313 eclecticism. A good example is the response to the Autism Act (Northern Ireland)
314 (2011), that mandated the development of a cross-departmental Autism Strategy
315 (2013-2020) and Action Plan (2013-2016) (Northern Ireland Executive, 2014).

316

317 The project group tasked with drawing up these two documents also did not include
318 any credentialed behaviour analysts (despite parents' protestations and requests); in
319 this case they did not include any academics at all. Consequently, none of the wide-
320 ranging local University autism training programs were mentioned, neither in the
321 strategy nor in the action plan, despite the fact that Northern Ireland's universities
322 offer extensive undergraduate and post-graduate training in autism as well as
323 behaviour analysis. The reports, however, did include extensive references to
324 favoured agency-based training providers without pointing out their limitations.
325 Moreover, none of the extensive autism research carried out at Northern Ireland's
326 universities was mentioned either (e.g., BASE Project, 2016; STAMPPP, 2013).

327

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

330

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, (Unumb, 2013). 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 colleagues attended the meeting in New York, USA, on 23rd Oct, 2013. Given the absence of a 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 (2017) 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 wilfully 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.

331

332

333 When the Minister for Health eventually convened the Northern Ireland Autism
334 Strategy Research Advisory Committee (NIASRAC), nominations were sought from
335 various agencies, and, after significant lobbying, the two local universities were
336 included this time. However, here again, irregularities occurred. Instead of allowing
337 them to nominate freely, an email intervention was sent from the Department of
338 Health to one of the universities (Jendoubi, 2012), in which there was an explicit
339 request for a particular non-behavioural emeritus faculty member to be nominated
340 to the committee. The email asked for 'a quiet word' stating explicitly that the Chair
341 of the NIASRAC would appreciate the nomination of this person (Jendoubi, 2012).
342 The university complied and consequently the only autism expert in their Directory
343 of Experts, a credentialed, world-renowned behaviour analyst who held multiple
344 awards for his work regarding autism, was excluded from the committee.

345

346 The whole process of setting up the NIASRAC took so long that the inaugural
347 meeting took place after the completion of the Autism Strategy and Action Plan (see
348 Case Example 3). In other words, because the Autism Strategy and the Action Plan
349 already had been submitted to the Minister for signature, NIASRAC missed the
350 opportunity to inform the Minister about counter-evidence and limitations of
351 research regarding the favoured and recommended 'eclectic' model.

352

353 **3. Ignoring or misrepresenting well-argued alternative views and related** 354 **evidence**

355 The previous case examples showed how autism research reviews in the UK were
356 uncritical and incomplete and how counter-evidence and limitations were ignored.

357 But buried within this sorry state of affairs is yet another propaganda ploy that
358 results in ABA being frowned upon along with a distorted view of the scientific
359 method.

360

361 The Task Group on Autism (2002) stated that interventions should be child-centred
362 rather than method centred and should address the observed and unique needs of
363 the child. No-one would argue with this statement. However, when ABA is
364 misrepresented as a single, 'one size fits all intervention' it is viewed as not being
365 child-centred. For example, the Minister of Education made the following statement:

366

367 Applied Behaviour Analysis (ABA) is one of many commercially available
368 interventions for children with autism. (Ruane, 2009)

369

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

374

375 I continue to accept this view and, therefore, do not promote one type of
376 intervention over another. (O'Dowd, 2010)

377

378 These assertions ignore the scientific method used in ABA (Figure 1) and the
379 internationally recognised training standards mentioned earlier (BACB, 2018). ABA
380 is not understood as a science, but rather, is viewed as one method or one
381 intervention amongst many, unable to address the unique needs of each child.

382

383 The question that arises, then, is the following: How come consecutive ministers are
384 so badly misinformed? It comes as no surprise to learn that most of the ministerial
385 advisors have little or no training in ABA and the scientific methods that underpin
386 individualized ABA-based interventions (Dillenburger et al., 2014). This point was
387 illustrated by comments in the High Court Dublin, when the Northern Ireland
388 Department of Education's lead educational psychologist with responsibility for
389 autism was called as witness against a child with autism that required ABA-based
390 interventions. During cross examination, she was singled out in the following way:

391

392 in terms of her professional convictions, insofar as she has a principle or a
393 broadly-based objection to ABA, in that she has never recommended it for
394 anyone, and also in terms of the fact that she has been retained by the
395 Department in very many cases, and the same issue has arisen, and her attitude
396 has been the same on every occasion. (High Court Dublin, 2006, p. 10)

397

398 In other words, it could be argued that the Department kept employing the same
399 witnesses and advisors, because they knew her 'broadly-based objection to ABA'

400 would support their case. The same educational psychologist made her lack of
401 understanding of the nature of scientific research explicit in a letter to the editor of
402 the membership journal of the British Psychological Society, *The Psychologist*:

403 What is a scientific study without random assignment to groups? (Hughes,
404 2008, p. 444)

405
406 At first sight, this may sound familiar. In many medical circles, random allocation
407 (i.e., Randomised Controlled Trial; RCT) is revered as the gold standard for
408 assessing medical interventions, but the ethics and practices of using RCTs are more
409 complicated when used for evaluating social or psychological interventions
410 (Nardini, 2014; Smith & Pell, 2003). There are many scientific procedures for
411 evaluating these kinds of interventions without random assignment to groups (see
412 Gast & Ledford, 2014).

413
414 As with other inductive sciences, including personalised medicine, the key research
415 methodologies of ABA are single-case experimental designs (SCD), also referred to
416 as single-system research designs. These research methods are increasingly
417 recognised as key to evidencing the effectiveness of psycho-social interventions. For
418 example, one of the main resources of autism related information for the NHS
419 Research, Research Autism (see under key publications, 2010), cites the
420 What Works Clearinghouse's (WWC) technical standards on SCDs (WWC, 2010).
421 WWC concludes that 'SCDs are adaptations of interrupted time-series designs and
422 can provide a rigorous experimental evaluation of intervention effects' (p. 1).

423
424 Of course, no-one would argue that it is appropriate to submit a whole scientific
425 discipline to scrutiny by RCTs (Keenan & Dillenburger, 2011). But this is precisely
426 what Hughes (2008) and NICE (2013) demand when they say they cannot
427 recommend ABA because there are no RCTs evaluating ABA. That is the same as
428 someone asking other natural scientists (e.g., biologists, physicists, or chemists) to
429 run RCTs to assess their disciplines, a notion that would receive short shrift from
430 any reputable scientist.

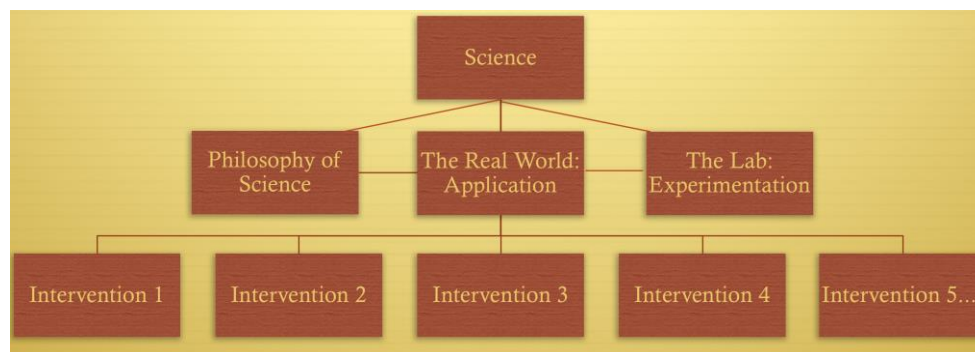
431
432 In this context, we conducted a brief literature search for RCTs and systematic
433 reviews for a number of other scientific disciplines to determine the level of support
434 for their use. Table 1 provides a summary of the findings. Results indicate a
435 complete lack of any RCT or systematic review evidence to support the use of any of
436 these scientific disciplines. For example, there are no RCTs or systematic reviews to
437 support the use of medicine (as indicted by 'none available' in the Table 1).
438 Therefore, following the logic of NICE (2013) or Hughes (2008), none of these
439 scientific disciplines should be used or recommended! Obviously, this does not
440 make sense.

441
442

443 **Table 1:** Major disciplines involved in public health policy and the evidence base to
 444 support them
 445

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

446
 447 The call for RCTs to assess ABA contains a major category mistake (Chiesa, 2005). To
 448 explain this, Figure 2 shows the distinction between a science and an intervention.
 449
 450



451
 452
 453 **Figure 2:** Avoiding category mistakes when distinguishing between science and
 454 interventions.

455
 456 Those who call for RCTs on ABA place the science of ABA in the wrong category.
 457 That is, they put it in the bottom row of the diagram as one intervention, rather than
 458 the top row as the overarching science. To fully appreciate the seriousness of
 459 misrepresenting ABA as simply one intervention amongst many, instead of
 460 recognizing it as a science, the following sentence makes the same category mistake
 461 with regards to medical science:

462
 463 Each child with an illness has his/her own individual needs and it would be
 464 inappropriate to invest in only one thing, like *medical science*.

465

466 The next case example demonstrates the problems that occur when category
467 mistakes involving ABA permeate government policy and practice:
468

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 most likely 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 outlining 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, until full discussion with the relevant Minister.

469
470 Notwithstanding the motivation behind the statement in the TOR, no leading
471 scientist worth his/her salt would or should make such a limiting recommendation
472 to any kind of research committee. Imagine, for example, if one method could be
473 found to treat all cancer cases successfully. Surely, this method should be espoused
474 by any committee charged with advising Governments in the care and/or treatment
475 of people with cancer.

476
477 The extent of the ignorance about the scientific status of ABA is clear from responses
478 to a simple question, 'Is ABA a science?'. This question was sent to the Special
479 Education Team, Access, Inclusion and Well-being Directorate, Department of
480 Education in Northern Ireland. Their answer was not a simple 'Of course it is!'.
481 Instead, they said:
482

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

487
488 This response is not entirely surprising when Research Autism (2017), the main
489 informant for the National Health Service (NHS) on autism interventions in the UK
490 states the following:

491
492 Because there are many different interventions, programmes and techniques
493 used to help individuals with autism which incorporate the principles of
494 applied behaviour analysis it is not possible to provide a ranking for applied
495 behavioural (sic) analysis as a whole.

496
497 In contrast, Dr Patrick Friman, Clinical Professor of Pediatrics, University of
498 Nebraska Medical Center and former President of the Association for Behavior
499 Analysis International states:

500
501 Although there are several journals devoted to the science of behaviour
502 analysis, the two primary journals are the Journal of the Experimental
503 Analysis of Behavior and the Journal of Applied Behavior Analysis. Both are
504 highly rigorous journals with strong citation indices. But all of this is well
505 established fact and what surprises me is that any educated person would
506 question it. (Personal communication)

507
508 **4. Arguing ad hominem (attacking the critic) rather than ad rem (responding to
509 the argument)**

510 Finally, when all the other propaganda ploys have been used against a non-favoured
511 argument, all that is left is to attack the messenger.

512
513 The next case example illustrates what happened when students of a professionally
514 verified university-based Masters course in ABA (MScABA) asked the person who
515 had received an honorary doctorate from their university for clarification about her
516 lack of support for ABA. The person in question was the CEO of a large local autism
517 charity who also held the secretariat for the Governmental All-Party Group for
518 Autism.

519

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' (<https://tinyurl.com/ybq59299>). 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 did not share the petition with its members, thus depriving its members of the information pertained 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 proactive support for parents and 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 she had made an official complaint against him.

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

520

521 This example of attacking the messenger is particularly intriguing given that
522 students had made the request for a meeting because they wanted to learn. This was
523 important to them, given that they had made the decision to base their professional
524 career on ABA. The complaint against the Course Director obviously deflected from
525 the need to explain the absence of pro-active support for ABA.

526

527 A similar situation (described in Case example 5) arose when senior academics,
528 including a professor who is on the autism spectrum, were appointed by the British
529 Psychological Society (BPS) to conduct a review of the 2006 BPS guidance for
530 psychologists working with children and young people on the autism spectrum
531 (BPS, 2018).

532

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 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) (NIHR, 2017).

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 (ow.ly/tvtC303hxqe). The url was disseminated and shared widely via the BPS twitter feed (dated 31/08/2016, 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. Parents and professionals enthusiastically welcomed it (e.g., ABAA4ALL, 2016). However, there were also some critics and the BPS decided to yield to them, rather than the many positive comments from parents, and immediately withdrew the guidelines from their webpages, without consultation with 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. There was no parent or PPI representation (given that the chairman, himself on the autism spectrum, had resigned). During the meeting, there was significant hostility against ABA and the role of BCBAs. 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', 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 (BPS, 2018).

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 (Keenan, 2004), was so appalled by the BPS's handling of the situation that he returned his Equality of Opportunity Award.

533

534 Clearly, when the propaganda machine has run out of methods to discredit the
535 message, ways are found to humiliate or otherwise try to harm the reputation of the
536 messenger.

537

538 **Conclusion**

539 The problems that arise when public policy is guided by misinformation and the
540 consequences of fake news described in this paper do not only apply to Northern
541 Ireland or the UK. All over Europe, parents of children with autism, professionals
542 who want to deliver ABA-based services, and academics who teach the science, have
543 similar experiences.

544

545 To offset the lack of support for ABA in public policy, parents have taken control.
546 They set up their own initiatives to ensure that they can avail of ABA-based
547 interventions for their children. For example, in Portugal, parents set up the parent-
548 led charity MyKidUp (www.mykidup.com), in Germany, parents started the
549 Münster Early Intervention in Autism initiative (MIA; Dillenburger, Röttgers et al.,
550 2014), and in the Czech Republic parents set up the Czech Society for Behaviour

551 Analysis (Gandalovicova, 2016). In Northern Ireland, parents established a charity in
552 1997 called Parents' Education as Autism Therapists (PEAT) (www.peatni.org; Derry
553 Now, 2017). PEAT's mission is to train parents in ABA with the ultimate goal of
554 ensuring that statutory authorities assume responsibility for this work. Against all
555 the odds, PEAT has generated significant achievements. They published the first
556 book in Europe on ABA for parents (Keenan, Dillenburger, & Kerr, 2000) and were
557 made the 'Family Support Organization of the Year' by NI4Kids in 2016.

558
559 Importantly, parents, professionals and academics are coming together in Europe to
560 educate others about the science of Applied Behaviour Analysis. With a grant from
561 the Big Lottery and extensive European funding from the Leonardo Lifelong
562 Learning Programme, PEAT produced the first online multimedia ABA training
563 program in Europe for parents (www.simplestepsautism.com). This platform offers
564 training in practical solutions for teaching children with autism. The SimpleSteps
565 platform has been translated and adapted and translated into 10 European cultural
566 and linguistic contexts. Most of the development of this platform was funded
567 through European Union funding, though the most recent adaptation in Portugal
568 was led by MyKidUp and the Czech adaptation was resourced from the largest
569 Czech Health Insurance company.

570
571 While government sponsored projects focus mainly on autism awareness and
572 remain reluctant to engage in evidence-based practices, SimpleSteps provides
573 practical solutions to problems faced by parents when rearing a child with autism.
574 For example, it teaches parents how to increase functional speech, how to manage
575 food acceptance, how to improve social interaction with peers, how to reduce severe
576 challenging, self-stimulatory, or anxiety related behaviours. Most importantly,
577 SimpleSteps makes this information available in 10 local adaptations, to ensure that
578 parents have easy access to accurate and scientifically validated information.

579
580 Policy on social, educational, and health interventions should always be fully
581 informed by scientific evidence. Unfortunately, as outlined in this paper, across
582 Europe there is evidence that institutional discrimination and anti-ABA propaganda
583 has resulted in public policy decisions that are based on alternative facts and fake
584 news (Peregrine, 2017). This is not to say that the science of behaviour analysis does
585 not value legitimate criticisms (Foxy & Mulick, 2015; Kelly et al, 2018). However,
586 parents are increasingly coming to the conclusion that self-help (ABAA4all, 2017)
587 and legal action (Byrne & Byrne, 2000; *The Irish Times*, 2000; 2005; *WalesOnline*,
588 2005) is their only hope of regaining control from people who use propaganda
589 strategies when bringing politics into science instead of using science to inform
590 public policy.

591
592
593

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