

Letter to the editor: Dillenburger on Kupferstein: applied behaviour analysis, autism, and post-traumatic stress symptoms

Nicholas Paul Chown

We write in reply to Karola Dillenburger's response to the recently published *Expression of Concern* issued by the journal in relation to research undertaken by Henny Kupferstein (2018, 2020), which suggested the possibility of a link between post-traumatic stress symptoms (PTSS) in autistic people who had undergone applied behaviour analysis-based interventions.

Nicholas Paul Chown is
Independent Scholar at
Ann Arbor, Michigan, USA.

The journal has alerted its readers as follows: "that concerns have been raised that the research, and therefore article, may contain a possible error in research standards. An investigation is ongoing and is currently unresolved. Further information will be provided by *Advances in Autism* as it becomes available". Dillenburger adds that any reference to Kupferstein's paper should be viewed "with extreme caution". We disagree with most of Dillenburger's comments and contribute the following thoughts to the investigation.

For the record, the author responded to earlier criticism of Kupferstein's work by Leaf *et al.* (2018) writing that "her findings appear to us to justify the expression of concern about a possible link between ABA and PTSD" and concluding "Unless and until there is clear scientific evidence against Kupferstein's preliminary finding of a link between ABA and PTSD, we think she and this finding should be taken seriously" (Chown *et al.*, 2019, p. 318). We felt that the methodological criticism by members of an organisation funded via a major charity was unfair to a sole, unfunded researcher undertaking academic work in her spare time.

Some seven years after Kupferstein published her original paper suggesting a link between PTSS in autistic individuals who had been in receipt of ABA-based interventions, Kupferstein's work has been attacked again. Before responding to the methodological issues Dillenburger raises, we want to focus on the matter which takes up about one-third of her letter, namely the category error made by Kupferstein in referring to people who "received ABA". We agree that this is a category error but regard it as a trivial error. To write of "receiving ABA" is common parlance, indeed a search of the literature shows that about 1,200 items use this incorrect form of words. Kupferstein uses a correct form of words (e.g. received ABA-based interventions) elsewhere in her work. Why Dillenburger chooses to make so much of a trivial error only she knows. But what concerns us most in this regard is that she uses Harold Shipman – arguably the worst serial killer in British history – in an example of a similar category error. Whilst she does not make a direct comparison between Kupferstein and Shipman, there is a risk of readers associating the two. At best this indicates a lack of empathy on the part of Dillenburger.

Dillenburger goes on to stress "that behaviour analysts are highly skilled certified or licenced professionals [...] who have undertaken masters or doctoral-level training at

Table 1

<i>Dillenburger's critique</i>	<i>Our response</i>
Kupferstein (2018, 2020) argued that autistic adults who experience posttraumatic stress disorder (PTSD) do so because they had received applied behaviour analysis when they were young children	There was no causal argument in the Kupferstein study. The study investigated scoreable stress symptoms in participants who received any autism early childhood intervention (implying autism diagnosis). The data reporting indicates a significant correlation between the ABA-exposed group and the severity of their reported stress symptoms. Correlation is not causation
Kupferstein did not ask respondents to verify their clinical autism diagnosis	This was not a clinical study so clinical data was not relevant to the survey, and clinical diagnostics were not determined based on the data collected from participants. What evidence do they have that autism research conducted without clinical records would be invalid? This is an industry standard, much like surveying queer people, and indigenous people, and not asking them for proof of their queerness or indigenous status. Given the financial and clinical barriers in getting an autism diagnosis (Ardeleanu <i>et al.</i> , 2024), the enabling of self-identification is essential
Nor did her analysis differentiate between those who were clinically diagnosed and those who self-identified as autistic	Conducting a study exclusive to clinically diagnosed people would seriously restrict the generalisability of the findings beyond those privileged to be able to access diagnosis. It is highly unlikely that individuals would self-identify as autistic unless they felt they were autistic and the nature of autism is such that most will have undertaken extensive research into the characteristics of autism. Results of research with self-identified autistic adults have been found to be "very similar to the results of adults with a formal diagnosis of autism" (Overton <i>et al.</i> , 2024, p. 689)
Autistic adults as well as parents of autistic children appear to have been asked to respond to exactly the same 26-question survey	The survey was identical but with contextual modifications. For example, adults were asked if they believe they met their therapy goals, while caregivers were asked whether they believe their child met the therapy goals
It is also unclear whether the responses from non-autistic parents were related to their own stress symptoms or those of their children	The questions were carefully worded to avoid any risk of parents reporting their own stress symptoms
Conclusions drawn from her survey appear to be based on responses from seven participants	The conclusions were drawn from responses from 460 participants.
Kupferstein did not evidence that her participants had a formal clinical diagnosis of PTSD. Instead, she merely asked participants about some stress symptoms and then asserted that they had this very serious clinical mental health disorder	The purpose of this study was to determine if early childhood intervention recipients who reported severe stress symptoms on a survey would likely be diagnosable with PTSD in a clinical screening, as the survey used the same questions a clinician would use. There was no assertion of a "serious clinical mental health disorder" to any of the survey participants
There was no formal assessment of any traumatic life events that may have taken place after any early childhood intervention	Kupferstein used an industry standard instrument. We recommend development of a specific instrument for future research into the risk of ABA-based interventions for autistic people causing trauma to minimise any issues around the adequacy of instrumentation

(continued)

Table 1*Dillenburger's critique**Our response*

Since Kupferstein neither requested clinical evidence nor elucidate the level of training of service providers who may have provided early intervention (NB, most of her participants were not diagnosed/self-identified until they were at least in their mid-20s), we cannot say for sure that what may have been provided would have been in line with ABA as described by Baer and others since then

We agree that one cannot be sure whether the interventions would have been in line with ABA as described by [Baer et al. \(1968, 1987\)](#) and others. However, it does not appear to be standard practice for behavioural researchers to confirm compliance with the Baer, Wolf and Risley principles so in this regard Kupferstein's study is no different from the behaviourist academic literature

accredited universities, extensive supervised pre-qualifying practice and continuous post-qualifying education". What she does not mention is that the large majority of ABA practitioners have not received training in autism. The first author has undertaken training to qualify as a Registered Behaviour Technician (to better understand ABA, not to practice). The 40-hour course involved did not include *any* content on autism even though the organisation involved only works with autistic people. We argue that no one should work with autistic people without a thorough understanding of autism. It has been written that "none of the As in ABA stand for autism" ([Dillenburger and Keenan, 2009](#), p. 193): as so many practitioners of ABA-based interventions work with autistic people it is high time that they understood the missing A for autism. This principle must apply to *all* autism interventions of course, not just those based on ABA.

We now respond to the methodological points raised by Dillenburger after corresponding with Kupferstein regarding her methodological practice, which Dillenburger did not do.

In conclusion, we remain of the view that "Unless and until there is clear scientific evidence against Kupferstein's preliminary finding of a link between ABA and PTSD, we think she and this finding should be taken seriously". We hope that in future researchers will seek to prove one way or the other whether ABA-based interventions may cause harm to autistic people rather than continue to criticise a major achievement for a sole, unfunded researcher working in her spare time. We hope that the criticism of Kupferstein is not an example of anti-autism bias.

The author is involved in a dialogue with ABA academics at a major US university. We have shown that critical autism studies scholars and behaviourist scholars can sit at the same table. But is cooperation between these disciplines on the trauma issue too much to hope for?

Nicholas Paul Chown, FIRM, PG Cert Asperger Syndrome, MA Autism, PhD

References

- Ardeleanu, K., Steinberg, H., Garfield, T., Voltaire, S., Shea, L., Brown, M., . . . and Tan, C.D. (2024), "Self-identification of autism: why some autistic adults lack a clinical diagnosis and why this matters for inclusion", *Autism*, p. 13623613241297222.
- Baer, D.M., Wolf, M.M. and Risley, T.R. (1968), "Some current dimensions of applied behavior analysis", *Journal of Applied Behavior Analysis*, Vol. 1 No. 1, p. 1310980.
- Baer, D.M., Wolf, M.M. and Risley, T.R. (1987), "Some still-current dimensions of applied behavior analysis", *Journal of Applied Behavior Analysis*, Vol. 20 No. 4, pp. 313-327.

- Chown, N., Hughes, E., Leatherland, J. and Davison, S. (2019), "Response to Leaf et al.'s critique of Kupferstein's finding of a possible link between applied behaviour analysis and post-traumatic stress disorder", *Advances in Autism*, Vol. 5 No. 4, pp. 318-319.
- Dillenburger, K. and Keenan, M. (2009), "None of the As in ABA stand for autism: dispelling the myths", *Journal of Intellectual & Developmental Disability*, Vol. 34 No. 2, pp. 193-195.
- Kupferstein, H. (2018), "Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis", *Advances in Autism*, Vol. 4 No. 1, pp. 19-29.
- Kupferstein, H. (2020), "Why caregivers discontinue applied behavior analysis (ABA) and choose communication-based autism interventions", *Advances in Autism*, Vol. 6 No. 1, pp. 72-80.
- Leaf, J.B., Ross, R.K., Cihon, J.H. and Weiss, M.J. (2018), "Evaluating Kupferstein's claims of the relationship of behavioral intervention to PTSS for individuals with autism", *Advances in Autism*, Vol. 4 No. 3, pp. 19-29.
- Overton, G.L., Marsa-Sambola, F., Martin, R. and Cavenagh, P. (2024), "Understanding the self-identification of autism in adults: a scoping review", *Review Journal of Autism and Developmental Disorders*, Vol. 11 No. 4, pp. 682-702.