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When autism researchers disregard harms: A commentary

Michelle Dawson[1] and Sue Fletcher-Watson[2]

Like medications, nondrug interventions carry potential harms as well as potential benefits. What we know about the balance of benefits versus harms for any intervention depends on how well researchers assess, interpret, and report adverse events in trials (Junqueira et al., 2021). It also depends on long-term studies to document harms overlooked or not fully evident in the short term. When researchers fail to adequately monitor adverse outcomes or even consider them a possibility, harms of any kind are unlikely to be detected and reported as such, even when they are both prevalent and important (Zorzela et al., 2016).

The literature on nonpharmacological early autism interventions has profoundly influenced how autistics are regarded and treated. It underlies the widespread promotion of early interventions as having large and lasting effects on the lives of autistic people. But do these effects include short- and long-term harms? Bottema-Beutel et al. (2020a) investigated this rarely asked question by examining 150 early autism intervention group designs. Attention to adverse outcomes was absent in almost all studies and inadequate in the remaining few: 139 (93%) did not even mention or allude to this possibility, 11 (7%) had cursory statements, and none indicated that adverse events were monitored, much less how. Scrutiny of the poorly reported reasons for participant withdrawal and of effect sizes for reported outcomes yielded evidence that harms had occurred, yet were never interpreted as such.[1]

Bottema-Beutel et al. follow Rodgers et al. (2020), whose systematic review of early intensive applied behavior analysis (ABA)–based autism interventions also found a pervasive failure to consider harms. Nowhere in this highly influential literature was there any reported effort to monitor or collect data on adverse outcomes. Study protocols, where plans to assess adverse events should prospectively be specified, were unavailable. Reported long-term outcomes, crucial for understanding harms, were lacking for early autism interventions claimed to have lifelong effects. What harms there may have been across any timescale thus could not be determined. Instead, Rodgers et al. found poor quality studies at high risk of bias, leaving ignored *ergo* unknown harms balanced against uncertain and inconclusive evidence for benefits. Such "preventable uninformativeness" due to poor standards in intervention research has been flagged as a violation of research ethics, entailing de facto harms for study participants and the studied population (Zarin et al., 2019). In this way, the widespread promotion of early intensive autism interventions, based on the biased deployment of a literature uninformative about their benefits versus harms, has been and continues to be inherently harmful to autistics.

In nonautism areas, a growing literature exposes and challenges inadequate attention to harms from nonpharmacological interventions (e.g. Britton et al., 2021; Papaioannou et al., 2021). Autism research, meanwhile, remains unfortunately distinct. Low standards have persisted unchallenged, as has disregard of harms, as has the magnitude of plausibly harmful practices routinely applied to autistics. Negligent reporting, also unchallenged, serves to obscure the actual procedures used and at what intensity they may be applied for how much of an autistic's life. These distinctive failures plausibly underlie extreme practices, such as the use of skin shock, which, like other forms of physical punishment, is not a thing of the past for autistics (Yadollahikhales et al., 2021). Unacknowledged harms from an uninformative but influential autism intervention literature thus combine with the routine use and negligent reporting of plausibly harmful practices that accumulate and multiply, and lead to unethical extremes.

Within a short commentary, we can only briefly mention a few examples of common plausibly harmful intervention practices that persist in autism research. One example is the use of functional analyses unnecessarily subjecting autistics to repeated contrived provocations until harms ensue. Another is the use of junk food reinforcers and related practices requiring junk food consumption

[1]University of Montreal, Canada
[2]University of Edinburgh, UK

Corresponding author:
Sue Fletcher-Watson, Salvesen Mindroom Research Centre, Centre for Clinical Brain Sciences, University of Edinburgh, Kennedy Tower, Royal Edinburgh Hospital, Edinburgh EH10 5HF, UK.
Email: sue.fletcher-watson@ed.ac.uk

(e.g. preference assessments). Another is the imposition of impoverished environments depriving autistics of information they need (Mottron, 2017). Another is the targeting of anything autistics show (distress, pain, fear, sadness, excitement, amusement, concentration, perseverance, curiosity, resourcefulness, etc.) as noncompliant "problem" or "challenging" behavior (Bearss et al., 2015). Another is the punishment (response blocking, response cost, etc.) of autistics for being autistic (flapping their hands, discussing their interests, etc.).

Wider harms may derive from interventions displacing important activities and opportunities (Jachyra et al., 2020) and from the ubiquitous use of early developmental measures that underestimate autistics' potential starting early in life (Courchesne et al., 2019). There are methods and goals common across major early interventions that impose rigid views of learning, development, and behavior (Mottron, 2017). Because these interventions aim to reduce or remove any sign of autism, the loss of autistic interests, adaptive behaviors, and strengths is intended, and interpreted as beneficial rather than harmful. In this way, the accurate assessment of harms in early autism intervention research has not only been disregarded but actively undermined by the selection and measurement of intervention targets.

Failures in addressing harms have proliferated across autism research, Bottema-Beutel et al. suggest, for reasons such as the embrace of low standard by journals, and the omnipresence of unchecked conflicts of interest (Bottema-Beutel et al., 2020b). Disregard of harms has in turn wrongly been interpreted as evidence of no harms, with consequences rippling out to other areas (e.g. early detection and screening), distorting research and practice. Despite a large literature spanning decades, accumulated knowledge about potential or actual harms to autistics from interventions that may occupy many of their waking hours, for years, is negligible. The foundations for adequate systems or methods for monitoring harms beyond the scope of intervention studies are thus lacking. Indeed, conflicts of interest entangled with low standards in research and practice would undermine future efforts to accurately capture harms via routinely collected data. Nothing justifies these multiple failures on the part of autism researchers.

We welcome the attention to harms shown by Bottema-Beutel et al. and Rodgers et al., as well as by Benevides et al. (2020), who include, among their top 5 autism research priorities, a question about the harms of behavioral and other interventions. But this attention is as rare as it is terribly overdue. We are left with an influential literature lacking fair tests of the benefits versus harms of autism interventions that have been widely implemented for decades. Autism researchers should be deeply troubled by this comprehensive failure to apply fundamental standards. We must recognize, understand, take responsibility for, and reduce the unacceptable biases that have led to autistics being considered unharmable, such that anything can be done to them.

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Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: M.D. declares she has no conflicts of interest; S.F.-W. declares the following conflicts of interest: involvement in development of a commercially sold iPad app for autistic children—while no royalty payments were ever paid and the app is no longer on sale, she has received consultancy/speaker fees for delivering talks and workshops on the topic of technology-based autism support; currently, she is the Co-I on a clinical trial of the Managing Repetitive Behaviours Intervention though with no commercial stake in its delivery.

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ORCID iDs

Michelle Dawson https://orcid.org/0000-0003-1090-7995
Sue Fletcher-Watson https://orcid.org/0000-0003-2688-1734

Note

1. Note that one such paper, reported on in the review as including evidence of harms not identified as such by the original authors, was by an author of this commentary: Fletcher-Watson et al. (2016). This commentary is intended to take responsibility for, rather than gloss over, this fact.

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