## LETTER TO THE EDITOR

# Inaccurate prevalence estimates impacts autism policy: A letter to the editor in relation to "Global prevalence of autism: A systematic review update" by Zeidan et al. (2022)

Autism prevalence has at times been a controversial question, as was discussed in a cornerstone 2012 autism prevalence paper (Elsabbagh et al., 2012), that sought to establish the body of evidence in regards to global autism prevalence, and that has been updated in a recent article (Zeidan et al., 2022) published in your journal. The original paper made an important contribution to the field and is one of the most referenced autism epidemiology papers to date. This follow-up paper aimed to update the evidence since 2012, and expands on important issues in its analysis, such as the role of services in different autism prevalence rates, the role of different prevalence by ethnic groups, and differences by sex. We are concerned by the omission of our recent article (Roman-Urrestarazu et al., 2021) since the search timeframes suggests that the authors should have included our study in this follow up paper. As described in the methods, a first search was conducted in December 2020 with a final search in November 2021 (although rather confusingly in Table 1 of their search strategy suggests inclusion of studies right up to 2022). It is very surprising the authors did not capture our article in their analysis as it had been published the 3rd of March 2021. Our paper provided novel findings in the largest prevalence study in Europe (and among the largest in the world) to date with a sample size of n = 7,047,238 with 119,821 autistic pupils, of whom 21,660 (18.08%) also had learning difficulties. Not only does our study provide the largest European sample size overall, but also presents the largest sample of autistic children included in any prevalence study and is almost 4 times higher than the next largest study (Jariwala-Parikh et al., 2019). The latter used MEDICAID claims and has a total of autistic participants of n = 29,745 for a slightly larger total sample size of n = 8,129,270 participants, being the largest prevalence study carried on in the United States. Our work used routinely collected school data, similar to other articles referenced in the update paper (Diallo et al., 2018; Pinborough-Zimmerman et al., 2012), but it includes all children in state schools in England which represent 93% of English children who attend the state school system

(Roman-Urrestarazu et al., 2021). Another important topic that we present in our paper is that we give the first autism prevalence estimate for Europe's largest ethnic minority, namely the Roma/Irish traveler community, and reported higher prevalence estimates across other ethnic groups such as Black and Asian communities, discussing our findings in relation to the impact social deprivation might have in obtaining a diagnosis. Although health inequalities are pervasive in all health systems, the British National Health System remains free at the point of service; therefore differences in access might be less acute than, for instance, the USA where prevalence differences seem to follow racial and socioeconomic disparities (Zeidan et al., 2022). The evidence we present in relation to differential prevalence by ethnicity could also be seen aligned to other neurodevelopmental conditions such as psychosis and schizophrenia (Brandt et al., 2019), where it also took time to fully grasp the role of immigration in psychosis risk, and the increased incidence in certain ethnic minorities. These conditions also align closely to autism genetically (Carroll & Owen, 2009; Kushima et al., 2018; Tick et al., 2016), and these findings have also been supported in autism by other population studies in countries with socialized medicine (Keen et al., 2010; Magnusson et al., 2012), making the role of the health system financing and access an important issue the authors of this paper could have discussed and added as a variable of interest.

To evaluate the impact that the exclusion of our article poses, we have listed the prevalence estimates reported by Zeiden et al. (2022) if our study is not included on Table 1. As you can observe by not including our study, the sample size range for Europe has an upper limit of 2,431,649 and not the n = 7,047,238 it would have with our study. The impact of the n = 119,821 autistic pupils, of whom 21,660 also had learning difficulties is also important since the total included autistic population for the whole of Europe in all prevalence studies is n = 75,183 which is only 62.7% of our sample size.

**TABLE 1** Extract of European autism prevalence data from 'Global prevalence of autism: A systematic review update' by Zeidan et al. (2022)

| Region | # Estimates | Sample size | | | ASD prevalence (/10,000) | | | Gender ratio | | | Proportion of cases with ID (%) | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| | | IQR | Range | Median | IQR | Range | Median | IQR | Range | Median | IQR | Range | Median |
| Europe | 31 | 454,113.5 | 1796–2,431,649 | 32,342 | 63.5 | 24–268 | 100 | 1.3 | 0.8–5.4 | 4.1 | 28.7 | 0–47.5 | 20.9 |

We are certain that including our work will impact the reported IQR, gender ratio, autism prevalence/10,000 estimate and their proportion of cases with ID not only in Europe but perhaps also globally. These differences are not trivial. We would therefore kindly suggest the authors that the estimates provided are corrected for this omission if they are to accurately reflect the current evidence base and because government policy and the planning of services delivered to autistic people are usually based on this type of data and this is included routinely in the costing and planning of services. Therefore, the best evidence available is needed to address the likelihood that using the estimates provided carries significant gaps for those who are disadvantaged in our societies. The authors may therefore reflect on how to correct this, including the possibility of correcting their paper's estimates which as currently framed is likely to be used widely.

## DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available in Autism Research at https://doi.org/10.1002/aur.2696. These data were derived from the following resources available in the public domain: Paper published in this journal, https://doi.org/10.1002/aur.2696.

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