Autism as a Dynamic Construct: Potential Implications for the Future of Life with Autism

Pedro Vital[1]

[1] University of Greater Manchester, Bolton, United Kingdom

P.Vital@greatermanchester.ac.uk

Abstract.
A consequence of the increase in the prevalence of Autism during the last decades is that it became a focus for political and legal debates. Of relevance in terms of fueling a debate around the condition is the fact that the increase in diagnoses has been described as an 'epidemic', an idea with scientific, medical, legal, and political implications. This presentation will focus on findings suggesting that rather than being a consequence of environmental factors, as implicitly suggested by the notion of an epidemic, the increase in prevalence reflects a transformation in how Autism is conceptualized. More specifically, the increased prevalence is mainly rooted in a shift in diagnostic criteria that presided to the identification of individuals with milder manifestations of the condition, the recognition of less typical presentations, such as the 'female autistic phenotype', and increased awareness among the general population. These factors have contributed to the diagnosis of individuals who would previously not have been diagnosed. Although this evidence offers an explanation for the increased prevalence rates, it still suggests that the present meaning of 'being autistic' is distinct from that associated with previous iterations of the diagnostic criteria. Additionally, it offers theoretical and empirical grounds from which to reimagine the debate around the medical, societal, and political ramifications of this phenomenon can be contextualized. Finally, this evidence must be considered in terms of future societal and policy directions that will shape the lives and lived experiences of Autistic individuals, in a more inclusive and life-affirming future.

Keywords: Autism, ASD, dynamic construct, diagnostic criteria, female Autism phenotype, prevalence, life with Autism, neurodiversity, policy, education, disability rights.

1 Introduction: A New Understanding of Being Autistic

The present paper is based on the ideas that informed a presentation on the conference 'The Future of Life: Legal, Scientific, and Geopolitical Challenges'. More specifically, it addressed ethical, identity, and policy challenges associated with the recent changes around the concept of 'being autistic' and their potential impact on the future of life for individuals with a diagnosis of the condition. The presentation was based on a conceptual and theoretical interdisciplinary narrative review of the evidence on the topic.

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As a consequence of the exponential increase in research into Autism during the past four decades, the conceptualization of this condition has undergone significant changes [1], [2]. This resulted in a new understanding of Autism, with the ensuing reshaping of the views regarding what it means to be autistic. In this context, rather than being simply a broader version of previous conceptualisations, the contemporary meaning of 'being autistic' is a new entity with distinct ethical, social, educational, legal, and policy implications [3],[4] that need to be considered.

Critical to the changes that presided to the current understanding of Autism was the gradual broadening of its clinical nosology, which represented a pivotal shift from Kanner's [5] view of a syndrome with very clear boundaries, towards a wider definition of the condition [6], [7]. The relevance of this event was that it crystalised the recognition of Autism as a heterogeneous spectrum of experiences, instead of a discrete condition characterised by an almost stereotypical profile. An important consequence of this re-conceptualisation was that it legitimised the diagnosis of individuals without, or with only mild, cognitive disability or language delay, and with later symptom onset, leading to Autism being understood not merely as a disorder but also as a distinct neurodevelopmental variation [8].

A further significant implication of the re-conceptualisation of Autism as a heterogeneous spectrum with somewhat fluid boundaries was the identification of a wide range of phenotypic variation. This was based on the identification of phenotypic subtypes of Autism linked to genetic and molecular differences [9], [10] and the suggestion of 'multiple spectrums' [11] clearly supporting the notion that heterogeneity is a hallmark of the condition. Evidence contributing to a less airtight view of Autism also included reports that rather than being simply one condition, in which a set of symptoms co-occur, the core traits seem to be somewhat independent at the genetic, neural, and cognitive levels, leading to the suggestion of a 'fractionated triad' [12].

Research findings have also contributed to the identification of specific phenotypes, mainly based on the evidence that the core Autism symptoms present in a qualitatively distinct manner in different demographic groups. Most significantly, this is the case for autistic females, who display a cognitive and behavioural profile that is distinct from that of their male counterparts, a phenomenon referred to as the 'female autistic phenotype' [13]. This development was critical to the increase in the identification and diagnosis of girls and women in recent years [14].

In similar lines, evidence supporting distinct developmental trajectories, with symptoms becoming more apparent only during adulthood [15], potentially also reflecting increasing social demands [16], suggests that the profile in adults might be distinct from that in children. The potential phenotypic variation in adults is further supported by evidence of diagnostic overshadowing [17], which was only addressed by the latest version of the DSM in 2013 when it became more likely to have a diagnosis of Autism alongside the presence of other conditions, suggesting that the presentation in adults might be distinct from a 'pure' form of the symptoms 2. This blurring of autistic traits by the presence of co-morbid conditions has also contributed to a more adequate understanding of the condition, mainly by allowing the identification of underlying Autism among adult psychiatric populations [18].

This broader understanding of Autism endorsed by the prevailing diagnostic manuals has been reflected in the development of standardised retrospective screening and observational diagnostic tools, such as the Autism Diagnostic Interview [19] and the Autism Diagnostic Observation Scale [20]. The high sensitivity and relative lower specificity of these instruments [21] have been critical in the diagnosis of individuals with less prototypical presentations [22], without cognitive and language difficulties [23], [24], as well as those with milder phenotypes [25]. This has also been a contributing factor in the changing meaning of being autistic.

A final factor that contributed to a new autistic identity has been the growing public awareness of the condition during the last four decades [26]. This has been based on a combination of institutional policies [27], autistic self-advocacy, and the neurodiversity movement [28]. The main result of these factors has been a shift from a deficit-focused model towards a neuro-affirmative framework that embraces neurodiversity which asserts that Autism is a valid way of being [29]. This shift must be taken into account as it has significant implications for societal attitudes, educational practices, and the development of support systems.

Together, these efforts to disseminate information about Autism have played a key role in shifting perceptions towards a strengths-based view, and a more positive autistic identity, mainly by means of advocating for autonomy and the value of being autistic [30]. The reduction of stigma associated with a more positive understanding of the condition has encouraged families and individuals to seek for a diagnosis [29].

The combined effect of the aforementioned factors has been a marked increase in Autism prevalence estimates during the last few decades [26], [31]. Illustrative of these trends, it is estimated that the prevalence rate increased between 20- to 40-fold during the last 3 decades [22], [32], with Russell and co-workers 24 reporting an increase of 787% between 1998 and 2018 in the United Kingdom. This trend mostly reflects the diagnosis of individuals that did not meet previous iterations of the diagnostic criteria, such as those with milder manifestations of the symptoms, without cognitive or language difficulties, those with a less typical profile such as females and adults, and those with an historically reduced access to health care and diagnostic services, like ethnic minority groups [26].

The presentation on which this paper is based aims to contribute to the conceptual debate about the meaning of ‘being autistic, mainly by providing clarity to the reasons behind the recent increase in prevalence estimates of the condition, and to inform future policies that potentially impact the lived experience of autistic individuals.

2 The Impact of the ‘Autism Epidemic’ Narrative

The consistently reported increase in the prevalence estimates of Autism has led to the use of the expression ‘Autism epidemic’ [33], [34]. Although in some occasions the term is simply used to illustrate to marked increase in diagnoses [33], in others the

expression is loaded with the implication that it reflects the role of putative environmental, social, or biological factors [34]. This is problematic in a number of ways as it negatively impacts the life of autistic individuals.

Firstly, by largely ignoring the robust evidence suggesting that the heightened prevalence estimates are based on the factors previously mentioned (i.e., the broadening of the nosological concept, more sensitive diagnostic tools, etc.), it creates a context within which the public discussion about Autism becomes vulnerable to myths and conspiracies fuelled by 'misinterpreted scientific observations and charismatic scientists, whether misguided or charlatan' [35].

This is illustrated, for example, by the misinterpretation of evidence suggesting an association between the use of Paracetamol during pregnancy and Autism [36] as being causal. Evidence based on more robust methodology that controlled shared genetic and environmental factors within families [37] does not support a link between Paracetamol use during pregnancy and an increased risk of Autism.

A further example, that is behind a number of misinterpretations of the causal factors of Autism, is the association between the development of the condition and vaccinations. Stemming from a now retracted paper linking Autism to the MMR vaccine [38], the view of a causal relationship between thimerosal and Autism has been consensually rejected among the scientific community [39], [40].

In similar lines, the fact that the notion of an Autism epidemic suggests a central role for putative environmental factor, for example an 'environmental toxin' (as suggested by the US Health and Human Services Secretary on the 16/04/202541), reinforces an understanding of the condition's aetiology that does not adequately reflect the scientific evidence. More specifically, despite evidence suggesting that environmental (e.g., infectious), and social (e.g., parental age) factors may increase the risk of Autism [42], the Autism epidemic narrative does not involve a consideration of the condition's multifactorial aetiology, with a large genetic contribution, as evidenced by heritability rates [43] and potential for complex gene-environment interaction effects [44].

A further way in which the Autism epidemic narrative has a negative impact on individuals and families living with the condition, is the potential it has to evoke negative emotions, such as fear, based on the misconceptions that it is a contagious or dangerous condition. This may exacerbate stigma against autistic individuals, as evidence suggests that the main cause of this type of discrimination is reduced knowledge of the condition [45], [46], [47], often based on outdated and erroneous beliefs around the causes of Autism [35].

Adding to the relevance of the former, is evidence linking the experience of stigma with negative mental and physical health outcomes, reduced social connectedness, and lower quality of life [48]. This is especially relevant as evidence suggests that only 7% of autistic adults feel accepted as an autistic person by society [49]. Given the prevalence of mental health co-morbid conditions in Autism [50], the potential for the notion of an Autism epidemic to increase the stigma experienced by this population exponentially increases its impact on the lives of autistic individuals.

One example of how stigma may have an impact on the mental health outcomes of autistic individuals is by adding to the pressure to conform to the norms of the neurotypical social world. More specifically, by fuelling a greater need to camouflage their

Autism traits, a common strategy used by autistic individuals to hide Autism traits and facilitate fitting in socially [51], but also associated with detrimental outcomes [52], increased stigma can play an obvious detrimental role.
Additionally, the suggestion of an epidemic may reinforce negative stereotypes about autistic individuals, framing them as a burden on society rather than as part of a neurodiverse community. This raises very pertinent issues that are relevant for the way in which Autism is understood, and the value of autistic individuals as members of society.
In practical terms, the notion of an 'Autism epidemic' has significant implications to a wide range of domains, including public health, policy, and societal attitudes. These implications may profoundly impact on the lives of autistic individuals.

3 The Future of Life with Autism

3.1 Implications regarding autistic identity

Even if it does not involve speculations regarding the potential role of putative environmental factors, the description of the increased prevalence rates as an 'Autism epidemic', by contributing to shaping public and self-perceptions of the condition, has deep implications for society in general, but mainly for those with a diagnosis. The most obvious of these stems from the framing of the increase in prevalence as a crisis, which may lead to a retrocession in the public understanding of the condition and foster negative views of the conditions. Crucially problematic is that this view implies a problem that need to be addressed, which might encourage the pursuit of a 'cure', or 'normalisation' of autistic individuals, which not only fails to recognise the value of autistic lives, but also denies an autistic existence [53]. By potentially eroding individuals' autistic identity, this entails an ethical issue that cannot be overlooked.
A further potential consequence of this negative framing of Autism is that it might counteract the gradual dissipation of myths and stigma surrounding the condition that has characterised the last decades [54], thus undermining the advances of the neuroaffirmative approach and leading to a reduced quality of life among autistic individuals 48. This may lead to a return to a view of Autism that emphasises difficulties rather than strengths and sees the condition as a disability rather than a 'way of being'. Additionally, by being biased towards difficulties and largely ignoring the strengths associated with the Autism phenotype [55], such a view would represent an inaccurate reflection of the scientific evidence, having the potential for a public perception that ignores the potential for Autism to contribute to society, and thus overlook an essential aspect of autistic identity.

Ethical considerations. Only two levels of headings should be numbered. Lower level headings remain unnumbered; they are formatted as run-in headings. These issues are

amplified by the re-conceptualisation of Autism as a broader spectrum of phenotypic variation that includes milder manifestations of the core symptoms, in some cases very distinct from a prototypical profile, as this heterogeneity entails issues regarding the ontological category to which Autism belongs. The fact that Autism is both a psychiatric diagnosis and a neurocognitive reality suggests a fluid interpretation of the phenomena that define it, meaning that it might be seen, in some cases, as a social construction [56], [57]. Given that these issues have potential implications in terms of developments in nosology and diagnosis practices, which might result in a narrowing of the clinical definition of Autism, they imply ethical questions regarding the rights of individuals with milder difficulties who may, in the future, no longer be receive a clinical diagnosis.

The potential diagnostic exclusion of individuals falling outside a categorical definition of Autism defined by significant need for support would result in preventing the continued increase in prevalence of what is portrayed as an ever-expanding syndrome. This would imply a significant change to the lives and identity of those with mild atypical differences mainly associated with difficulties fitting in their social environments, as they would no longer be diagnosed. In practical terms, the legal context of these individuals would also change, meaning that they would no longer have the right to adjustments at work, or eligibility to public support services [58]. In this case, rather than experiencing reduced barriers and stigma, the life of those with milder phenotypes would suffer a retrocession in terms of access to services and support. On the other hand, by narrowing the clinical spectrum, there would be a possibility that those with greater support needs would be cared for more effectively. Whichever the outcome, a potentially narrowing of the concept, likely to be biased towards the disorder end of the spectrum, will imply a marked change to the present notion of autistic identity. Given the implications associated with the latter, mainly in terms of societal and policy responses that might impact the lives of autistic individuals, the views of those with a diagnosis of Autism, their families, professionals involved in the screening, diagnosis and support of the condition should be considered in the debate around policy developments. In order to ensure that this process is not contaminated by lay and misguided views of Autism, the scientific evidence, as well as medical and legal implications, should inform the development of policies. The moral obligations of governments to protect and support those with vulnerabilities and difficulties must not be diluted by political debates that are not based on scientific evidence. A guiding principle in this process should be the objective of developing more inclusive and affirming outcomes, that grant autistic individuals full access to what society has to offer.

Policy risks. As any changes to policies involving the allocation of public resources to support autistic individuals to achieve their potential might have significant implications to the lives of those with a diagnosis of Autism, these are critical aspects that must be carefully considered. Although the notion of an ‘Autism epidemic’ may lead to increased funding to research and support initiatives, it may also lead to the misallocation of resources focused on ‘curing’ rather than supporting the development of societal policies that facilitate the social functioning of autistic individuals. Changes to the existing rights of those with a diagnosis have obvious legal consequences to what it means

to be autistic, such as the consideration of the role that a distinct cognitive style might play in criminal contexts [59], which would result in potentially inadequate court procedures.

The increased prevalence and the fluid boundaries of the condition that have been behind a drive for the development of public health strategies associated with earlier screening and diagnosis, might have the undesired effect of curtailing this effort. As it is already the case in the countries characterised by a more marked increase in prevalence estimates, this creates additional pressure on healthcare systems, which may lead to longer waiting reduced quality of care, and increased competition for resources among families. As such, the expanding syndrome and ensuing prevalence increase might drive a re-conceptualisation that will reduce the focus to those with greater support needs. As such, there is the possibility that the spectrum nature of Autism may be overshadowed by a focus on those with greater support needs. All of these potential changes have implications on the meaning of 'being autistic' and the identity of those who will no longer qualify for a diagnosis or support.

A further potential ethical implication associated with the notion of an 'Autism epidemic', the inclusion of those with a milder phenotype, and scientific developments is that in the future diagnosis might become associated with genetic testing, rather than based on behaviour observation. This has implications for the lives of autistic individuals as it would mean that private personal information would become public by means of a diagnosis. This would raise complex ethical questions about the nature of informed consent, privacy of individuals and their families, potential discrimination, among others [60], that would potentially change the value associated with an autistic identity.

In societal terms, the idea of an epidemic clearly conflicts with the neurodiversity movement, which advocates for acceptance and understanding of autism as a natural variation rather than a disorder to be eradicated. Given the potential of this narrative to shape broader societal attitudes towards disability and difference, by means of influencing how various neurodiverse conditions are perceived and treated, feeding into a wider debate about the nature of Human differences, it is essential that scientific evidence is at the centre of any significant change that might impact the lived experience of Autism.

4 Conclusion

As societal perceptions evolve, it is crucial to consider the potential implications of the conceptual changes around Autism that took place during the last four decades as these may have an influence on the lived experiences of autistic individuals. This follows from the fact that this new understanding, the ensuing increase in diagnosed cases, and the public and political reaction to the latter, have the potential for redefining what it means to be autistic in contemporary society. The potential for a detrimental impact on identity and self-perception among autistic individuals associated with reactions to the

present conceptualization of Autism must be taken into account when developing social, legal, medical, and educational policies.

While discussions around an autism epidemic can draw attention to the importance of understanding and supporting autistic individuals, it is crucial to approach this topic with sensitivity, recognizing the obvious potential for stigma and misunderstanding, and the ethical implications that it poses to the boundaries within which autistic lives are experienced. In order to prevent a reduction of the gains in inclusiveness that have characterised the last decades, largely fuelled by self-advocacy and the neurodiversity movement, which were essential to valuing autistic lives as valid expressions of Human experience, the potential risks associated with a misinterpretation of scientific data must be adequately considered.

Regarding recommendations for concrete policies, the observation of principles that take into consideration the ethical and identity issues addressed in this paper will make these more actionable. Within this framework, it is recommended that an effort is made to conduct the debate on the meaning of 'being autistic' that avoids the stigmatisation of those with a diagnosis, and that the public discourse on Autism is aware of the potential to increase the experience of stigma among this population. This can be addressed by evidence-based policies that reflect un understanding of the factors behind the challenges associated with Autism. Policies should also take into account the need to preserve the rights of those with a diagnosis in a background of increasing diagnoses and a public view that a considerable number of these might be false positives. A legal protection associated with a diagnosis must be strengthened in order to avoid a loss of support and access to social participation. Finally, an effort must be made, mainly at a conceptual level, in terms of clarifying what it means to be autistic so that diagnostic inclusivity is understood by the wider public. An effort to provide a more nuanced view of Autism, that is based on less pronounced manifestations rather than on emphasising stereotypical views, likely to be associated with sharing of lived-experiences by autistic individuals has the potential to address these issues.

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