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INVITED REVIEW

# Who benefits from diagnostic labels for developmental disorders?

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The number of diagnoses of developmental disorders is on the rise and the use of labels for developmental disorders, such as attention-deficit/hyperactivity disorder and autism spectrum disorder, is widening. Diagnostic labels can play an important role in helping those who display atypical behaviour and their caregivers to cope with associated challenges and, possibly, to get treatment. But these labels are increasingly contested and associated with a variety of harmful effects. In this paper, we analyze the role diagnostic labels can play in four different contexts (scientific, therapeutic, social, and administrative) and identify what various stakeholders stand to gain or lose with continued, expanded, or abolished use of those labels. Our analysis reveals labels serve different purposes in each of these contexts, benefitting different stakeholders. Any overall evaluation, critique, or defence of labels needs to consider the interests of all stakeholders in these contexts.

The classification of mental disorders found in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5)[1] has been widely criticized for its lack of scientific merit. The classifications and their criteria are repeatedly criticized for their heterogeneity, over- and underinclusiveness, poor interrater reliability, low predictive validity, and insufficient basis in neurobiology.[2–4] Many, therefore, believe that on scientific grounds, DSM categories should be revised, replaced in favour of a different diagnostic system, such as the Research Domain Criteria of the US National Institute of Mental Health initiative, or be abolished altogether.[5,6]

It might be thought that scientific status is the sole basis for determining whether diagnosticlabels have any merit at all, but this would ignore the influential roles they play outside of scientific contexts, with a variety of positive and negative effects. The term 'labels' is used here in a non-pejorative sense to refer to terms used in psychiatric classification (or categories of mental disorders). By using labels we do not want to suggest any negative appraisal or outlook.

In clinical settings, labels play a role in facilitating patients' self-understanding and in shaping treatment plans. In social contexts, labels help to communicate information about special needs, but can also contribute to the stigmatization of atypical behaviour. On an administrative level, labels determine who can and cannot lay claim to care provisions and special accommodation. The stakes are, therefore, high in determining the precise criteria of a diagnostic category (see Kapp and Ne'eman[7] for a report on how the Autistic Self Advocacy Network influenced the revision of the DSM-5 description of autism spectrum disorder [ASD]). Any overall evaluation, critique, or defence of diagnostic labels needs to consider the role of labels in these contexts as well. In this review, we provide a concise overview of the role of labels in these contexts and survey the positive and negative effects for different stakeholders. We focus exclusively on labels for neurodevelopmental disorders, in

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**Abbreviations:** ADHD, Attention-deficit/hyperactivity disorder; ASD, Autism spectrum disorder.

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particular attention-deficit/hyperactivity disorder (ADHD) [*] and ASD[**]. Many of the issues raised in this analysis also apply to other DSM categories, but a parallel analysis may yield different results for other categories. We focus on these classifications not only because they play a central role in the public debate, but also because the potential harmful effects of labels are particularly important to recognize when they occur in children.

We distinguish four contexts in which the labels ADHD and ASD play a significant role: scientific, clinical, social, and administrative. For each of these contexts, we outline the functional role of labels and analyse the benefits and harms for the stakeholders involved. We use these four contexts to help identify the function of the diagnostic labels ADHD and ASD, including their advantages and disadvantages. It is important to point out that certain functions may occur in multiple contexts, and that we should guard against double counting (easy communication is helpful in therapeutic, social, and administrative contexts, for instance, but should not count triple in an overall evaluation) or that some functions go beyond any of the distinguished contexts (self-understanding is not limited to therapeutic contexts). We use these contexts of use merely to identify the various roles of labels and to make some progress with an evaluation of the pros and cons of labels.

This analysis shows that currently there are insufficient grounds for settling on one superior policy for the future use of the labels ADHD and ASD. There are too many conflicting values involved for different stakeholders. Regarding proposed revisions and policies, we should ask: Who would benefit and at whose expense?

**What this paper adds**

- Criticism and defence of diagnostic labels must be contextualized if we are to avoid misunderstandings and talking at cross-purposes.
- Diagnostic labels serve important practical purposes outside of their scientific use.
- Scientific validity is not the only criterion by which to judge the value of diagnostic labels and their continued use.
- An alternative to diagnostic labels is needed to determine who deserves help and support.

## LABELS IN SCIENTIFIC CONTEXTS

The original purpose of the DSM categories was to introduce a shared language to describe and investigate mental disorders. While the categories listed in the first versions of the DSM were heavily influenced by assumptions about aetiology, since the DSM-III the categories are intended as ‘descriptive’ and ‘neutral’ with respect to their underlying causes.[8] This means that labels group people together with similar behavioural patterns, enabling researchers to investigate the real causes of these patterns, their typical course of development, relationships with other features exclusive to this group, and the outcome of therapeutic interventions.

In a scientific and psychometric context, however, the benefits of a classificatory system depend crucially on its ability to support explanation and prediction.[9] Judged by this standard, however, the DSM classifications have repeatedly been shown to fall short on both counts. The categories do not *explain* the behavioural patterns because they do not pick out the same underlying structures or mechanisms. Both ADHD and ASD have been proven to possess a familial genetic component and correlate with various abnormalities in brain functioning.[10,11] But for neither category (or their subcategories) has the link between genetics and environmental factors been properly understood, nor have the same neurological differences been found in children similarly classified. Because of causal heterogeneity, the categories cannot be said to explain the behavioural patterns.[12–15] It should be noted that this observation is compatible with the fact that for those receiving the diagnosis, the label can be insightful and explanatory. By reducing a multitude of problems and difficulties into one or two traits – a concentration deficit, or hyperreactivity to sensory stimulation – labels can help them more easily grasp the challenges they face (see Hens and Langenberg[16] for insightful illustrations). This may be true, even though the causal roots of these traits and behavioural patterns remain heterogeneous.

Scientific classification also serves to support generalization. Here, the taxonomic goal is to divide up conditions in such a way that we can predict other features of people in the same category. The DSM categories, including ADHD and ASD, score notoriously low in predictive value. To know someone’s classification is to know relatively little beyond that they meet the inclusion criteria, and what naturally follows from those criteria. Of course, children who are easily distracted will perform better in situations with fewer distractions. Children with an impaired ability to understand non-verbal communication do better with explicit communication. But these are direct consequences of the inclusion criteria and not the sort of features that lend the classification predictive validity. For

* (The category ADHD (together with attention deficit disorder) was introduced to the DSM-III in 1980. In DSM-5, the category describes individuals who show signs of inattention (e.g. easily distracted, forgetful, unable to start or finish a task) and/or with hyperactivity-impulsivity (e.g. excessive talking, unable to stay seated, fidgeting). These patterns must be present before the age of 12 years for at least 6 months, occur in multiple settings (such as school and at home), be inappropriate for the person’s stage of development, and interfere with school, work, or social functioning.[1])

** (autism was first seen as a species of childhood schizophrenia but was introduced as a separate category in the DSM-III. In the latest edition, DSM-5, subcategories such as Asperger syndrome have been grouped together under ASD. This category is descriptive of children who exhibit, in multiple contexts, persistent deficits in communication and interaction, such as reciprocity, non-verbal communication, having relationships, and/or restricted, repetitive patterns of behaviour such as insistence on sameness, fixated interests, and hyper/hyporeactivity to sensory input.[1])

example, we know that the central characteristics of ADHD diminish until the age of 30 years and that for about 65% of those diagnosed with childhood with ADHD, functional impairment continues into adulthood.[17] It has also been established that pharmaceutical treatment tends to be effective in the first 2 years after the diagnosis, while cognitive behavioural therapy has relatively little effect.[17] But the overall predictive value of the label remains low.

In a scientific context it would, therefore, be best to discard the current diagnostic categories in favour of a more fine-grained, causally informed, and predictively powerful taxonomic system.[12,15,18,19] Such a new taxonomy might distinguish different types of ADHD, depending on the different underlying neurological pathways,[20,21] or different types of ASD, depending on which genetic, environmental, or neurological factors are causally or constitutively involved.[22] There are serious feasibility concerns about this sort of 'neurotyping', given the complexity found at causal levels. Spitzer (the main author of DSM-III and first editor of DSM-IV) writes:

> Despite the considerable advances in psychiatric research, disappointingly, little progress has been made toward understanding the pathophysiological processes and aetiology of mental disorders. If anything, the research has shown that the situation is even more complex than initially imagined, and we believe that not enough is known to structure the classification of psychiatric disorders according to aetiology.[23]

But if it were possible, the newly created classifications would have sufficient explanatory and predictive value to meet the standards of scientific validity. If such categories could not be constructed, labels for disorders would prove scientifically inadequate and redundant.

It is clear that from a purely scientific point of view, these transformations of classificatory schemes would count as major improvements. But would they also benefit stakeholders, such as clinicians, children with a developmental problem, and their caregivers? The answer is less obvious than some suggest,[12,18] and will depend on whether fine-grained classification or transdiagnostic approaches will result in better options for prevention and treatment. If that is not the case, other stakeholders will stand to gain relatively little and, as we will see below, may even be harmed when the current labels are revised in this manner.

## LABELS IN THERAPEUTIC AND PEDAGOGICAL CONTEXTS

Whereas explanation and prediction are the guiding values in scientific contexts, the central value in therapeutic and pedagogical contexts is the well-being of individuals (including the neuro-psycho-social development of children). As one service user said: 'I'm not all that interested in the cause of my autism. What I mostly need are practical tools to cope with it in the best way'.[21]

People experiencing difficulties seek the help of a psychologist or psychiatrist to understand their difficulties and to get practical help and advice. Which role do diagnostic labels have in this context, and what is their effect?

The first therapeutically beneficial role of labels is that they help to explain the multiplicity of experiences and difficulties by reducing them to central behavioural traits, summarized in a diagnostic label. This sense-making effect of labels can be hugely helpful to children and their caregivers, and often brings a strong sense of relief, even liberation.[16] Diagnostic labels turn complex and context-bound behavioural problems into 'a thing'. This can help children and caregivers see why they experience the challenges and struggles that they do (even if the labels do not offer a deeper scientific explanation). It also helps to understand why simply trying harder will not work, or why normal pedagogical strategies do not always have their expected effect. The label indicates that there is some causal structure in the child that cannot be influenced merely by will or effort, even if the precise causal structure differs in children with the same label.

A direct effect of this form of explanation is to exculpate those with a diagnosis (and their caregivers) and to diminish inappropriate self-blame. Children with ADHD are easily regarded to be wilfully disruptive, lazy, or disinterested; children with ASD are sometimes viewed as intentionally egoistic, cold, or unruly. These interpretations can result in frustration and anger in caregivers and teachers. The diagnostic label signals that it is neither the child's fault (they cannot help it), nor a shortcoming of the parent (not caused by a lack of love or good parenting). As a result, labels make it easier for parents and children to accept that certain features belong to the child . Interviews with service users reveal that labels help with accepting themselves and their limitations. Some say they have become 'gentler' towards themselves after getting the diagnosis or that they no longer feel the need to 'pretend' or 'try to fit in'.[16]

Even so, one might wonder whether we really need labels to free people – children in particular – from unwarranted forms of guilt and self-blame. The root problem may well lie elsewhere: would there be as much need for labels if our society were less demanding and unforgiving? Addressing these patterns in society could also have the advantage of benefitting a wider range of stakeholders, including those who do not receive the label (owing to lack of access to health services, misdiagnosis, or compounding intersectional effects related to cultural, ethnic, and sexual bias, etc.). That said, in society as we know it today, a label conveys a clear message that some characteristics must be accepted as part of who that person is, periodically or permanently.

A third role of diagnostic labels is that they provide guidance regarding therapeutic interventions and suitable pedagogical strategies. According to some critics, the categories are clinically useless because of their heterogeneity and overall low predictive validity.[24] However, although

DSM categories may have low predictive value, almost everything that is currently known about effective treatment is based on them. Some practical instructions follow directly from the inclusion criteria: a diagnosis based on being easily distracted already makes clear that the person would do better in low-distraction environments, just as someone whose diagnosis is based on difficulties interpreting non-verbal communication would benefit from explicit, literal forms of communication. But the labels ADHD and ASD also suggest several further treatment options and strategies that can be explored and put into practice together with a psychologist or coach. Finally, diagnostic labels can help orient caregivers in their search for information, support networks, suitable schools, or tailored social activities.

Despite these four beneficial functions of labels, there are also significant downsides to their use in therapeutic contexts. First, labels can be overly reductionistic, to the point that people feel they are viewed as nothing other than a label.[25] The danger is that every aspect of life is interpreted through the lens of the label. Second, some people misuse their label to avoid legitimate and constructive criticism, either in a self-serving way or by reconfiguring opportunities for improvement into threats to their identity. A third and closely related point of concern involves the way labels shape identity, especially in children and adolescents. As we discuss below, identification with a label can promote healthy acceptance of traits that lie beyond the individual's control and can help to fight off self-blame. Identification with a label may also result in 'self-ambiguity' as it may no longer be clear what results from the individual and what is the effect of their disorder.[26,27] But it can also maintain and intensify the defining characteristics of the disorder; in such cases, labels function as self-fulfilling prophesies and can, thereby, constitute a form of harm. Clinicians cite this concern as one of the main reasons for caution in using labels in clinical practice, particularly with young children.[28] To our knowledge, there has been no systematic research into the self-fulfilling effects of diagnostic labels for developmental disorders. Current research and clinical experience suggest the following principle: in cases where traits or limitations are chronic and relatively immune to influence, as with various (severe) forms of ASD, there are fewer concerns about the self-fulfilling effects of labels and thwarting effective coping strategies. By contrast, in cases where there is more room for transformation of traits and behavioural patterns, identification may indeed cause stagnation, undermining possibilities for improvement, again by representing change as a threat to the person's identity.

There are two further downsides to labels that apply to the currently used labels ADHD and ASD, concerns that a scientifically valid taxonomy would not be susceptible to. Given the coarse-grained nature of current classifications, it is expected that many people diagnosed in terms of these labels do not recognize themselves in parts of the description. In such cases, the explanatory and liberating effects discussed above are replaced by doubt and confusion. Finally, however much labels such as ADHD or ASD give people the sense of finally understanding the difficulties they face, the suggestion that the causes behind the behavioural patterns are thereby known, is most often illusory. Once this becomes clear, the initial sense of relief may quickly make way for disappointment.

For specific therapeutic and practical purposes (explaining the source of difficulties, relieving misplaced self-blame, directing therapy, and guiding the search for information and networks), diagnostic labels can be invaluable. It is not clear how these practical purposes can be realized effectively without diagnostic labels. A better, scientifically more adequate taxonomy, however, might equally be able to serve these ends, and potentially, be more suitable for explanation of and directing therapeutic interventions.

## LABELS IN SOCIAL CONTEXTS

Diagnostic labels also play a role in society at large. One easily overlooked benefit of diagnostic labels is their ability to facilitate efficient communication about atypical behaviour and needs. An individual mentioning they have ADHD can ensure that they can work in a quieter place with less distractions. Similarly, the term 'autism' can help adjust expectations and elicit more detailed and structured communication. Moreover, labels allow people to avoid having to explain their condition repeatedly and at length, shifting to others the responsibility for finding out the relevant information.[16] Of course, this works only when people in society have a shared and accurate background knowledge about the labels. Where labels are contested or dismissed, their usefulness is undermined.

In a social context, diagnostic terms can also be stigmatizing. Stigma occurs when a property – in this case a form of behaviour – is taken as a social identity and viewed as negative or inferior.[29] Stigma comprises at least three dimensions: stereotypes, prejudice, and discrimination.[30] Stereotypes refer to collective assumptions about a certain social identity, for instance that 'autistic people are good at maths', or that 'the mentally ill are dangerous'. When people agree with and believe in such false generalizations, the result is prejudice. When prejudice is acted upon, for instance by not hiring someone purely based on a label, this amounts to discrimination. When stereotypes, prejudice, and discrimination get internalized, we may speak of 'self-stigmatization'.[30]

Labels are instrumental in the creation and perpetuation of stigma. This results in extensive harm (including therapy avoidance, low self-esteem, underestimation of capabilities) and injustice (unwarranted exclusion and differential treatment). On the other hand, labels can also have a role in fighting off stigma. It has been shown that in some cases a negative response to a child's behaviour gets revised when people learn the child has been diagnosed with ADHD, though similar studies have found that the label ADHD can also have adverse effects.[31,32] Generally, it appears that the stigmatizing effects of labels differ greatly per label,[33,34] and

the way people understand the label .[35] Nevertheless, efforts to combat stigma also require the use of the label. Refraining from using the term ADHD will not help in destigmatizing people who behave in corresponding ways. Fighting off stigma requires exposing false stereotypes and informing the general public about the meaning of the label and the differences that may exist between the people to whom it applies. Like anti-racist movements that affirm Black and Brown identities rather than advocating 'colour-blindness', and feminist efforts to employ sex classifications to monitor patterns of inequity,[36] the unabashed appropriation of labels represents one key strategy for destigmatizing mental health issues.

This final point about the socio-political benefits of labels becomes most apparent in the neurodiversity movement.[37] The effort to recognize ASD and ADHD as socially acceptable forms of human diversity – perhaps even benefiting humanity at large[38] – is initially possible only with the use of such labels. Once social acceptance and accommodation has been achieved, the labels (like all labels for social identities) may outlive their usefulness in this role; but currently, the availability of well-recognized developmental labels has concrete benefits for those engaged in the ongoing struggle for recognition and inclusion.

## LABELS IN ADMINISTRATIVE CONTEXTS

A final context in which diagnostic labels play a key role is in the allocation of resources. In most Western health care systems, psychiatric and psychotherapeutic treatment is only available (or covered by insurance schemes) for people who fall under one or more DSM category. Other social provisions, such as extra financial support or educational services, also often depend on the use of diagnostic labels. The advantages of using labels for these ends are clear: we need a system to distribute resources in a society that takes fair distribution and equality of opportunity seriously. A society with a (semi-)social health care system needs some way to determine who can make a rightful claim to health services and special accommodations, and who cannot.

The downsides are also clear. Making social services and other special accommodations conditional on having a diagnostic label places enormous burdens on those in need of services (and their caregivers) to overcome administrative hurdles, on clinicians to meet growing demands for diagnostic testing, and society at large to bear the costs. Such a system also creates incentives to seek a diagnosis of ADHD or ASD. In the context of the Dutch health care system, for instance, the number of diagnoses of ADHD rose drastically when labels were required for extra provisions at school, but dropped when schools were given a lump sum to spend on children they considered in need of extra support.[39,40] Perhaps most troublingly, these administrative systems can put pressure on clinicians, educators, and others to use diagnostic labels in circumstances when it is not in the individual's best interest, for example because of the acute risks of stigma or therapeutic concerns about the adverse effects of identification with a label.

When labels are required for receiving health care and other forms of support, those who do not meet the criteria but are in genuine need of support suffer the consequences. There are a variety of reasons why this underdiagnosis may occur: overburdened health services may cause delays; someone may not quite meet the criteria but still require support and extra attention; they (or their advocates) may also be subject to biases related to sex, age, and ethnicity; and caregivers may not know how to navigate the health care system well enough. When a label is required for receiving the relevant care and social provisions, the risk of harm and injustice is significant.

## CONCLUSIONS

In this paper, we have highlighted how diagnostic labels play different roles in different contexts, each with positive and adverse effects for stakeholders. The DSM categories may have never been intended for most of these roles. But given the role and functions labels have now acquired, any overall evaluation, critique, or defence of labels needs to take these roles into account (as well as the availability of alternatives). What the analysis shows is that, first, neither science nor people with the diagnosis hold a monopoly over the use of language. Scientific research is just one context in which labels serve a specific purpose. If scientific progress requires abandoning the currently recognized categories of developmental disorder, this should not come at the expense of those now helped by labels in treatment, self-understanding, and assistance. Equally, if a label for a developmental disorder turns out to be harmful in therapeutic settings, resisting its use should not come at the expense of the scientific search for valid categories of disorder and research into causal factors. Our analysis also reveals that criticism and defence of labels must be contextualized if we are to avoid misunderstandings and talking at cross-purposes. Finally, the contextual analysis developed here highlights the need to think about an alternative way to determine who deserves help and support, and in this regard, the use of labels in administrative contexts appeared most problematic. In general, everyone involved in evaluating the use of diagnostic labels should ask of each proposed policy and future direction: who would benefit? We hope to have offered some tools for answering that question.

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No empirical data has been used for this manuscript.

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