Childhood: a suitable case for treatment?

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We examine the contemporary debate on attention deficit hyperactivity disorder, in which concerns about medicalisation and overuse of drug treatments are paramount. We show medicalisation in attention deficit hyperactivity disorder to be a complex issue that requires systematic research to be properly understood. In particular, we suggest that the debate on this disorder might be more productive and less divisive if longitudinal, evidence-based understanding of the harms and benefits of psychiatric diagnosis and misdiagnosis existed, as well as better access to effective, non-drug treatments. If articulation of the values that should guide clinical practice in child psychiatry is encouraged, this might create greater trust and less division.

Lancet Psychiatry 2015; 2: 661–66

http://dx.doi.org/10.1016/S2215-0366(15)00106-6

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> "As children, we need time to wander, to be outside, to nibble on icicles and watch ants, to build with dirt and sticks in a hollow of the earth, to lie back and contemplate clouds and chickadees. These simple acts forge the connections that define a land of one's own..."[1]
>
> *Stephen Trimble, naturalist*

What do today's children need to flourish? Bookshelves groan with a collective lament against the loss of childhood innocence in a frenetic, wired world. Harvard ethicists worry about the trend of hyperparenting that throws parents into a frenzied drive to mould and manage their children's academic careers.[2] In low-resource settings, children are viewed as victims of toxic environments, in which parents need to be taught to talk and read to their children in the name of nurturing their cognitive potential, their mental capital for the public good.[3,4] And finally, around the world, paediatricians and child psychiatrists describe a medical condition, attention deficit hyperactivity disorder (ADHD), and marshal increasingly sophisticated genetic and neuroscientific evidence to argue that it represents a valid diagnosis with a specific drug treatment, namely stimulant medication. It can look like a sterile, unimaginative, overmanaged, overdiagnosed, and overdrugged world. At its centre sits the so-called bible of mental illness, the DSM, handed down by successive committees of the American Psychiatric Association.[5] DSM's vision of child flourishing does not include icicles and ants, dirt and sticks, clouds and chickadees. In the DSM, development is a determined, linear, milestone-oriented process, and not the circular, broody, curious time of a more idyllic childhood.

As an argument against psychiatric diagnosis, childhood has a powerful moral force: innocence is shattered by the civilising forces of modernity. But why does this naturalised, moralised account of childhood have such enduring and powerful force in debates about psychiatric diagnosis in children? One way of answering this question is to see psychiatry as an essentially vulnerable science, poised as it is on the boundaries of medicine, mind, and society. On this contested ground, psychiatry has only imprecise methods to provide proof that its medical description of what is going on with a child is the right description. In this sense, psychiatry is continuously battling diagnostic uncertainty.[6,7] In many other disease categories, but in by no means all, validated biological markers—biomarkers—can inform diagnosis and authorise the medical account of disease. These biomarkers can also be problematic—there are false positives in cancer and shifting thresholds in heart disease. But ideally, biomarkers in these specialties provide some account of what is going on under the skin, enabling better predictive algorithms and treatment strategies.

Psychiatry has yet to discover, let alone use, well established biomarkers in diagnosis and treatment—or when it does, as for example in the case of neurosyphilis, the problem suddenly ceases to be psychiatric. This is why Thomas Insel, director of the National Institutes of Mental Health (NIMH, USA) recently announced that biomarker discovery would be the mainstay of NIMH research.[8] The aspiration is for biomarker information to help improve psychiatric classification and to increase diagnostic accuracy (by informing complex biosocial diagnostic algorithms) and treatment efficacy. Many putative biomarkers have been identified for ADHD, but thus far, no biomarker or set of biomarkers is deemed clinically useful.[9,10] Moreover, diagnosis and treatment decision making based on biomarkers risks missing an important point of the psychiatric assessment: to understand a child's strengths and weaknesses, and thereby to chart the best course of intervention.[11] Although biomarkers are likely to take on greater importance in the diagnosis and treatment of ADHD, they need to be integrated with clinical experience and a child-centred approach to treatment.

It is also worth considering that biomarkers do not resolve the ethical concern about the diagnosis of ADHD as a violation of childhood: should this particular set of childhood behaviours or capacities be labelled a medical disorder requiring observation or intervention? This aspect of the problem of diagnostic uncertainty in ADHD is not about whether or not the diagnosis is correct; it is more fundamentally about whether or not medical diagnosis is the right thing to do. From this perspective, biomarker evidence might contribute to better (that is, more accurate) diagnosis of ADHD, but clinicians might also get better at doing the wrong thing.

The rise in children acquiring labels such as autism and ADHD is often cited with concerns about the medicalisation of childhood, particularly when an

For more on **medicalisation of childhood** see https://www.bps.org.uk/events/division-educational-child-psychology-one-day-event-medicalisation-childhood-time-paradigm-sh increasing number of children seem to be diagnosed with disorders that cause few or no impairments in their lives. Medicalisation is defined as a process in which non-medical conditions or behaviours come to be viewed as medical.[12] The philosopher Erik Parens distinguishes between "good" and "bad medicalisation".[13] For example, homosexuality is not a disease and ended up in the DSM because of societal intolerance, with terrible consequences for alleged patients and their families. But, "good medicalisation" has more positive consequences:[13] recognition, diagnosis, and treatment of mental illness have kept many children and adults from a lifetime of social alienation and abuse, locked up in institutions or living on the street. Erroneous theories about the causal role of the family in autism once added greatly to the distress of parents struggling to cope with the challenges of bringing up differently-abled children. Today, concepts like the so-called refrigerator mother have largely lost their influence. Core characteristics of autism and its biological correlates are now more widely accepted, although, as with ADHD, disagreement persists over how autism should be managed and treated.[14]

Medicalisation provides an important critical perspective on biomedical advances in psychiatry; it is a reminder that in an age of biomarker development, we should continuously scrutinise the social conditions that mediate concepts and classifications of disorder, as well as diagnostic and treatment practices. But medicalisation makes for a poor evaluative method in individual cases of diagnosis of ADHD. When is it clear that a child has been medicalised in a bad way? What is the right threshold for impairment in the diagnosis of ADHD, and whose narrative of impairment has authority? To illustrate these difficulties, we present the composite anonymised case of John, a participant in the VOICES study of children's experiences with a diagnosis of ADHD and treatments with stimulant medications.

For more on the **VOICES study** see www.adhdvoices.com

> John was diagnosed with ADHD when he was 9 years old. Now 11 years old, he takes Concerta, a long-acting form of Ritalin every day. His mother watches his diet carefully to make sure that he is not eating too much sugar, which she thinks makes him more hyperactive. She is also trying a new food supplement that is meant to improve memory and focus. John's mother rates him highly on most hyperactive factors on a child behaviour checklist, and also on impulsivity and inattention—even with his medication. His teachers disagree, viewing him as an average learner with some difficulties that should not amount to diagnosis. Acknowledging the uncertainty, the child psychiatrist offered a short-term trial of medication, which was then continued.
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> John says: "I'm just taking two tablets now. I don't know what they're called, but I think one is to give me more memory. I forget things a lot and I have trouble focusing and being mature. That means it's like, I'm not doing my work like I'm supposed to. I want to keep doing better. I want to have a good life when I grow up.
>
> My teachers are ok. I can walk around the class sometimes when my legs, like, need me to be walking around. It's hard to just sit there and listen and work like other kids do. Sometimes I talk to other kids when the teacher is talking and she tells me to sit down. It makes me feel stupid. The other kids find sitting still hard too probably but they can stop easier.
>
> During the school day we have lunch for an hour. We don't have a field but we play football. We don't go out that much in the winter. If it's raining or really wet, we stay inside. If I get in trouble, I have to stay inside.
>
> When I get home I do my homework and then sometimes I go around to my mate's house. I don't play in the road or go exploring. Kids don't do that really; that's just a story."

Responses to this case presentation are likely to mirror the differences of opinion found among John's caregivers. Some might argue that John's childhood represents a life of containment: across different institutional contexts, John's behaviour is carefully managed, allowing few opportunities for the kind of liberal self-fashioning imagined by Trimble. The sociologist Erving Goffman called this process the "bureaucratisation of the spirit".[15] Others will point out that adult guidance and management are essential to child flourishing; indeed, these form part of society's obligations of care for a child. Some of this care involves inculcation into social norms through institutions erected for this purpose. From this perspective, it is good that John himself wants to "keep doing better", and diagnosis and medication arguably support these efforts.

Such arguments, which have been the mainstay of the debate over the diagnosis and treatment of ADHD, are unlikely to unlock the stalemate of disagreement. The challenges need to be viewed from a different perspective. If a child's spirit and freedom are potentially at stake, then we should care about evidence that children such as John are routinely misdiagnosed (that is, diagnosed with non-existent disorders), and we should ask what evidence exists about the consequences of misdiagnosis. So, what are the chances that John has been misdiagnosed?

It is possible to piece together a response to this question on the basis of the extensive epidemiological research into diagnosis of ADHD. In the USA, where the proliferation of diagnosis and treatment of ADHD regularly makes international headlines, estimates suggest that about 11% of school children have been diagnosed with ADHD at some point.[16] But as Polancyzk and Jensen have shown in a substantive review,[17] these figures are not the world's highest; for example, one study[18] found that 20·4% of school-age children in Colombia qualified for a diagnosis of ADHD. As also indicated in their review, prevalence of ADHD in Europe is estimated to be lower (generally 2–5% of school-age children) than in the USA. This prevalence is likely to remain that way because of several factors, including application of higher diagnostic standards and thresholds, less pharmaceutical industry influence in government and on consumers, parenting and educational differences, and less social acceptance of psychiatric diagnosis and treatments in Europe than in the USA.[19–21]

However, diagnoses of ADHD and use of stimulant drug treatments have been rising in Europe, especially in the Netherlands, Norway, and Sweden.[22,23] The UN Narcotics Control Board, which tracks the annual worldwide consumption of methylphenidate, shows the US proportion of worldwide methylphenidate consumption to be steadily shrinking, from 83% in 2007, to 66% in 2011.[24]

The trend towards globalisation of diagnosis of ADHD and stimulant drug treatment has been attributed to social and economic factors, including pharmaceutical company activities, ADHD group advocacy, psychiatric manuals, and the growth of biological psychiatry.[25] Whether these factors contribute to (bad) medicalisation of children's behaviour or support a welcome corrective to a problem of underdiagnosis is disputed. The calculation of a worldwide prevalence of childhood ADHD at 5% is widely cited as a means of estimating the problem of overdiagnosis and underdiagnosis.[26] Similar to other estimates of the global burden of mental health, this calculation has economic, clinical, and ethical utility. But it is also notable that this estimate obscures the interpretive differences that exist cross-nationally in observation, management, and treatment of problematic child behaviour.[27,28]

One response to these cross-national differences has been to nationalise the problem of diagnosis of ADHD (ie, ADHD is seen primarily as an American disorder).[29] This response oversimplifies the contributions of culture and context to the diagnosis and treatment of ADHD. For example, most people would agree that in the USA, use of medications to treat ADHD in children is excessive.[20,30,31] Fewer people know that the USA has problems of both overdiagnosis and underdiagnosis of ADHD.[19] Geographical variation, child age, poverty, gender, and race or ethnic origin mediate overdiagnosis and underdiagnosis, with overdiagnosis and overuse of stimulant medications more prominent in affluent white communities. Children in the USA from low-income families and children from some ethnic minority groups, however, are more likely to meet criteria for diagnosis of ADHD but are less likely to receive adequate treatments, including stimulant drugs, than are children from affluent white families.[32] As ADHD diagnosis spreads worldwide, this local variation is importantly instructive: we need a better understanding of the systemic ways in which microlevel and macrolevel factors interact and intersect to produce the processes that enable diagnosis and misdiagnosis of ADHD.

We also need to know more about the consequences of misdiagnosis of ADHD. Let us say that John is an American middle-class white adolescent, who attends an academically high-ranking school in which children with a diagnosis of ADHD are provided excellent educational and learning support.[33] On this basis, John represents a demographic in which higher rates of ADHD diagnosis exist and, consequently, more suspected cases of bad medicalisation. Of course, to reject the possibility that ADHD diagnosis for John might be both valid and beneficial would be a mistake. But if John has been misdiagnosed (that is, diagnosed with a disorder when no disorder exists), then what can we anticipate for him?

To answer this question, we need a programmatic approach to understanding the prevalence, causes, and consequences of misdiagnosis of ADHD. This was the approach taken in a famous study of children's hearts, undertaken in 1967.[34] At the time, children were frequently diagnosed with innocent heart murmurs—that is, murmurs that were expected to go away or to have no impact on child development. The authors termed such diagnoses cardiac nondisease,[34] in contrast to murmurs that indicated either congenital or acquired cardiac disease, the latter often the result of either definite or presumed acute rheumatic fever. The authors investigated the prevalence of actual organic heart disease in a large population of children, and then looked at the group that did not have heart disease—the innocent murmurs or the misdiagnosed rheumatic fevers—and what happened to them. The results are astonishing: the cumulative negative consequences of diagnosis were significantly greater for children with so-called cardiac nondisease than for children with organic heart disease. The most decisive factor in determining one measure of the consequence of diagnosis—restricted activity in childhood—was the advice of the physician at the time of diagnosis. Children who had been diagnosed with a disorder they did not have, and those who had been wrongly advised to restrict their activity, did worse than children with proven organic disease.

The heart study supports the intuition: diagnosis matters. Get it wrong—either by failing to diagnose a disorder for which treatment and support exist, or by incorrectly labelling a child—and the results can be serious. Errors of commission and omission are both accompanied by adverse consequences, and such errors are certainly not restricted to childhood disorders.[35] No research base yet exists to address the adverse consequences of ADHD nondisease diagnosis. The design of such a study would be a challenge, in view of the ambiguity surrounding ADHD diagnosis. However, this same ambiguity makes it reasonable to infer consequences of ADHD nondisease diagnosis on the basis of what we know about the consequences of diagnosis of ADHD and psychiatric disorders more generally.

Two consequences immediately present themselves. A diagnosis of ADHD in a child can mean treatment with stimulant drugs. Indeed, assuming that the diagnosis is correct, stimulant drugs are a well researched and validated treatment option for ADHD.[36] Medications are not the culprit here; psychotropic drugs make an important difference to many people with mental illness, and some children themselves report that they experience the benefits of stimulant drug treatment.[37] The problem is with the way that psychotropic drugs can be used in child psychiatry; moreover, few validated alternatives exist to psychotropic drug treatment.[38,39] In the UK, the National Institute for Health and Care Excellence recommends parent training as the first line of treatment for mild to moderate ADHD.[36] But adherence to and accessibility of parent training and similar interventions can be poor, particularly among families who need the support most.[36] Research and resources should be made available to offer a range of accessible non-drug, evidence-based interventions for children with behavioural and emotional difficulties. These resources should be combined with a system of diagnosis that recognises these difficulties as dimensional, not categorical.[40] The result will probably be that ambiguous cases such as John's will result in a different process of evaluation and intervention. Moreover, the risks associated with nondisease diagnosis of ADHD would arguably be reduced, at least in terms of the burdens associated with drug treatment.

A second known consequence of psychiatric diagnosis is stigma associated with the label of mental illness. Such labels are thought to be oppressive because they are seen to impose social norms and to mark individuals as different.[41] The stigma of ADHD and other psychiatric diagnoses certainly affects the everyday lives of children and families.[42,43] At the same time, burdens of this stigma might have been overgeneralised in the medicalisation debate: some children with a diagnosis of ADHD show resilience to ADHD stigma and labelling, and they do not associate their emerging sense of self with an oppressive ADHD identity.[44] Developmental resilience in ADHD has received very little research attention, perhaps partly because the debate over the diagnosis requires both sides to frame children as victims, of biology on the one hand, and of social influences on the other. The children's heart study suggests that valid diagnosis and early clinical communications might have an important role in children's developmental resilience. As research into ADHD begins to address the challenge of intervention at a preclinical stage in high-risk young children,[45] the issues of labelling, clinician communication, and child resilience are highly resonant. Early intervention trials offer an important opportunity to prospectively investigate the effects of early labelling (and, potentially, of nondisease diagnosis), while highlighting individual, social, and clinical factors that mediate and moderate outcomes in children.

A further consideration in the stigma experience of ADHD, at least in some western countries, is a gradual shift in public perception of mental illness as psychiatric diagnoses are integrated into the social fabric of everyday life. Advertising, films, television, books, and music increasingly link disorder not to madness, but to productivity and creativity: Olympic gold medallists and successful corporate executives have ADHD.[46,47] We, the public, devour these angles on mental disorder, thereby participating in a socialising process that creates social capital around diagnosis. Rhetorically, these processes oppose stigma. The message for some children is that psychiatric diagnosis is not a devastating detour on the road to success.

As the psychiatrist Peter Kramer showed in a widely discussed book, *Listening to Prozac*, the positive socialisation of psychiatric diagnosis and drug treatments is a double-edged sword that raises more medical, ethical, and social concerns than it resolves.[48] It almost certainly contributes to psychiatric nondisease diagnosis in some affluent groups in which a diagnosis has become almost trendy. This positive socialisation of diagnosis might put children such as John at increased risk of ADHD nondisease diagnosis. Yet for other children and families, the positive socialisation of ADHD might contribute to a greater willingness to seek and accept services. This is especially important in populations that have been historically underserved or badly treated by psychiatry.[49,50] Without systematic study of ADHD diagnosis and misdiagnosis across different contexts, speculation about the risks of diagnosis associated with ADHD will prevail, and responses to the problem of ADHD or medicalisation are more likely to be shaped by individual and collective biases. This situation undoubtedly makes decisions about ADHD diagnosis and treatment more difficult for clinicians, parents, and children.

We are asking for a more reasoned, less emotional approach to the problem of ADHD diagnosis and medicalisation. To properly investigate the consequences of psychiatric diagnosis and nondisease diagnosis, the impetus to immediately drive a moral stake in the ground must be restrained, to allow intuitions to be weighed against evidence. But we would not want our argument to be taken to mean that intuitions do not matter in this case. The sense that childhood is a special time of innocence, curiosity, and creativity might be a product of history and of culture, but it is also important.[51] Indeed, this intuition has led many countries to erect protections for children that are informed by ethical commitments to concepts such as childhood. We acknowledge and value the ethical dimensions of the ADHD debate, and we sympathise with some of its concerns. But the diverse commitments entailed in the broader debate over diagnosis and treatment of this disorder have perpetuated reductive arguments and have scattered energy unproductively. If the goal is to answer the difficult questions that surround ADHD with evidence rather than with speculation, then a more collaborative agenda of research and public engagement is needed.

Child development will always be a scientific, social, and moral concern. No matter how much the science improves, and it will improve, boundary problems will persist. The behaviours that make up disorders such as ADHD are common, and a part of normal childhood—in the way that coughing up blood or having complex delusions are not. The days when doctors were the sole arbiters of the boundary between normal and pathological states have long disappeared, if those days ever existed at all. In the present situation, substantive public discourse about the values that should guide clinical practise is needed, and these discussions should be integrated with systematic investigation into the causes and consequences of diagnosis and nondisease diagnosis of ADHD across different contexts. Availability of and access to validated, non-drug interventions for children exhibiting difficult or problematic behaviours must be improved. Until these needs are met, parents, doctors, and children will continue to oscillate between the Scylla of medicalisation—bringing extra support, understanding, treatment, and resources—and the Charybdis of labelling, bringing stigma and social alienation and, perhaps, a life with restricted opportunities for wandering, dreaming, and building with dirt and sticks.

Contributors

IS wrote the initial draft and led revisions of subsequent drafts. SW contributed to all drafts of the Personal View.

Declaration of interests

SW is the President of the Royal College of Psychiatrists. IS declares no competing interests.

Acknowledgments

The VOICES study was funded by an award from the Wellcome Trust to IS (Grant #08029). The Wellcome Trust had no role in the research or in the writing of this Personal View, and the corresponding author has full access to all the data in the study. The VOICES study received National Health Services research ethics approval in the UK, and Institutional Review Board approvals at relevant universities in the USA. All children and parents in the study consented and assented to subsequent use and publication of interviews. Interview data was collected as part of the VOICES study, funded by the Wellcome Trust between 2008–2011. See www.adhdvoices.com for publications.

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