

The Right to Dignity or Disorder? The Case for Attention Deficit Hyperactivity Diversity

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Abstract

Different medically based constructions of Attention Deficit Hyperactivity Disorder (ADHD) have been around since ‘mental restlessness’ in 1798, evolved through the 20th century with ‘minimal brain dysfunction’ and distinctions between Attention Deficit Disorder (ADD) and ADHD (DSM-III), to current presentations of ADHD (DSM5). As new insights and knowledge have become available, the meaning and labels attached to ADHD have changed, and so they are malleable. This piece will explore two different labels (or frameworks for meaning) for the cluster of behaviours and difficulties associated with the phenomenon known as ADHD; that is, the disorder label and the diversity label. These labels will be explored in terms of accuracy and consequences, particularly their impact on human dignity. Problems inherent in the disorder label will be critically considered, particularly how accurate it is given that psychobiological differences should not be viewed as disorder, may not ‘cause’ functional deficits, and may be understood as strengths. These problems call the disorder label into question, and suggest that ADHD-type behaviours could be understood as traits. This piece will also call into question taken-for-granted social structures that could contribute to or be responsible for the difficulties associated with ADHD, in particular, the stigmatisation of the ADHD label and socio-cultural norms and expectations around ADHD-type behaviours. An alternative diversity label, the neurodiversity framework (or Attention Deficit Hyperactivity Diversity) will be explored, in terms of whether it applies to ADHD and the opportunities it offers for empowerment of people and the protection of their fundamental human dignity. In essence, this piece is a socio-political debate about identity; about the labels that can inadvertently harm human dignity and prevent other human rights. It is also about people’s right to choice and autonomy in their identity and ways of being in this world. These are human rights issues, because identity is about one’s inherent worth and dignity, and human dignity is the basis for human rights.

Key words: ADHD, labelling, children’s rights, human rights, neurodiversity

Introduction

The notion that every person, by virtue of their inherent dignity and humanity, is entitled to certain rights is a relatively new concept. While it has roots in earlier traditions, it was propelled onto the global agenda following World War II especially with the UN Universal Declaration

of Human Rights (UDHR) and the European Convention on Human Rights. In more recent decades, it has evolved to include movements, such as those involving race, gender and disability, which have led to greater recognition that cultural semiotics belies unhelpful and often taken-for-granted structures of an oppressive system.

Structural inequalities exist and affect a range of minority groups. These inequalities are often maintained (possibly unwittingly) by a powerful majority, which systematically exclude and deny rights to minority groups. As a result, there is a need to critically consider, challenge and change these structures. This piece focuses on one form of systemic oppression and abuse of human rights on the basis of the tarnishing of, or a lack of recognition and respect for human dignity, through the use of pejorative, closed, stigmatising labels. This oppression or exclusion is the structural disablism experienced by people whose behaviour is different, often currently referred to as disordered. Structural disablism refers to ways in which systems of policies, practices, representation and other norms work in ways to reinforce and perpetuate group inequality.

This piece will critically explore the current framework for meaning attached to the ADHD label and ADHD-type behaviours, which is the ‘disorder’ label, in terms of its usefulness in nonclinical contexts and its impact on people (especially children) labelled as such, with particular consideration for consequences on human dignity. An alternative framework, the ‘neurodiversity’ label (or Attention Deficit Hyperactivity Diversity), will also be considered in terms of its usefulness and its benefits, especially from the perspective of human dignity.

This piece explores socio-cultural norms around behaviours and the impact of the medical model’s supremacy, its construction of difference and especially questions the use of medicalised labels outside clinical contexts. ADHD will be used as a case example, due to the controversy and stigma surrounding it, but these points can be applied to many other disorder labels. Disorder labels affect children’s self-image and inherent dignity, and so prevent their participation in an array of social arenas (e.g., education and community). It is about the right to live with dignity and respect, free from the wholly negative, stigmatising and pejorative term ‘disorder’. To be clear, this is not an argument against all forms of medicalisation, nor does this piece advocate a deconstruction of all knowledge associated with ADHD. Indeed, people should have the right to access support and to identify as disordered if they so choose. As individuals and as a society we need to critically consider the meanings attached to the ADHD label and ADHD-type behaviour, so as not to negatively affect peoples’ dignity, especially children who may be even less involved in decisions around diagnosis and labels.

Human Rights and Human Dignity

Human rights are intimately related to the notion of human dignity; indeed, one cannot be understood without the other – they are inextricable. Human rights are promoted, at least implicitly, due to a recognition for, and in order to protect, human dignity.

The preamble to both the Universal Declaration of Human Rights (UDHR, 1948)¹ and the United Nations Convention on the Rights of the Child (UNCRC, 1992)² contain references to human dignity two and three times respectively. Both preambles begin by stating that, ‘...

¹ United Nations, *Universal Declaration of Human Rights* (United Nations, 1948).

² United Nations, *Convention on the Rights of the Child* (United Nations, 1992).

recognition of the inherent dignity and of the equality and inalienable rights of the human family is the foundation of freedom, justice, and peace in the world ...'. The UDHR affirms that all humans are born free and equal in dignity and rights (Article 1) and uses dignity as a basis for social rights and decent living conditions in Article 23. Similarly, the UNCRC uses human dignity as the basis for children with any disability living a decent life, being self-reliant and being active participants in their community and its opportunities (Article 23).

Human rights activists often use dignity to justify their claims when they advocate for the right to live without discrimination, torture and inhumane treatment. Human dignity is also used as the basis for making legal decisions about human rights issues³. Thus, human dignity is inextricable from human rights and, indeed, can be understood as the basis for human rights.

In order to explore the impact that labels could have upon dignity it is important to consider the notion of human dignity. Human dignity is often understood non-secularly using Kantian 'Categorical Imperative' which states that every person must be treated with respect. This idea maintains that everything has either a price or a dignity. Things have a price, in that they have value as long as someone likes them, desires them or regards them as valuable. So, they are relatively good; their value and worth is conditional and subjective. In contrast, human beings have intrinsic and objective worth – each person is recognised as unique and irreplaceable, that is, they have dignity. Accordingly, a person must be valued as an ends, and never a means to an end, because they possess dignity by which they extract 'respect'; and it is by the virtue of this dignity they are equal and free (3).

The basis for all human rights rests upon a recognition for the intrinsic worth, value and individuality of each human being. This is distinct from and can be harmed by labels and the language we use; stigmatising and pejorative labels can tarnish the person in the eyes of themselves and the eyes of others. The role of language in constructing realities and the social world has long been recognised, as Wittgenstein⁴ said, 'The limits of my language . . . mean the limits of my world' (5.6). The 'disorder' label's ability to tarnish a person's dignity is already well established. For example, in practice, person-first terminology is used in recognition that people shouldn't be identified as disordered first; thus, we say child with ADHD rather than ADHD child, so as to emphasise their individuality and dignity as a human first and foremost. This piece goes a step further and asks whether we should be using the 'disorder' label at all.

ADHD and the Disorder Label

This section will explore the question of whether ADHD can and should be understood using the 'disorder' label to explore critically the current dominant framework for meaning associated with ADHD. In the next section, the problems inherent within the 'disorder' label, and its impact on human dignity, will be explored as structural disablism.

For something to be 'disordered' is not a good thing, that is, it is a pejorative. In general, its meaning refers to confusion or a disruption in functioning. Undeniably, children with ADHD experience functional deficits across most, if not all, areas of life. For example, children with ADHD experience a range of social relationship difficulties; they have poorer social skills,

³ Willy Moka-Mubelo, *Reconciling Law and Morality in Human Rights Discourse* (Springer, 2017), 89–125.

⁴ Ludwig Wittgenstein, *Tractatus Logico-Philosophicus*, trans. D. F. Pears and B. F. McGuinness (London: Routledge & Kegan Paul, 1961), 5.6.

fewer friends and experience rejection from an early age⁵; at home, ADHD is associated with increased familial stress and dysfunction⁶. Most children with ADHD experience some degree of academic dysfunction, including failure and exclusion, and are more likely to drop out of school than their non-ADHD peers^{7 8}. They are also less likely to attend university, and as adults, they are more likely to earn less, be unemployed and get fired or ‘job hop’⁹. In contrast to current trends around ‘living your best life’, people with ADHD are often struggling to cope. They experience higher levels of stress, poorer quality of life, and a range of socio-emotional and behavioural difficulties and psychiatric comorbidities, such as anxiety, depression and low self-esteem^{10 11}. However, we have to question what causes these functional deficits, and whether social structures are involved – preventing the participation of people with ADHD. We also need to consider how useful and accurate the ‘disorder’ label is, and what the consequences of its use are for people labelled as such.

A mental disorder, according to the Diagnostic and Statistical Manual (DSM5)¹², is defined as ‘a behavioural or psychological syndrome or pattern that occurs in an individual that reflects an underlying psychobiological dysfunction’ which causes ‘clinically significant distress’, ‘impairments in functioning’ and ‘social deviance or conflict with society’. Therefore, to identify someone as disordered means that there is something (often presumed inherently) ‘wrong’ with them, which means they cannot function in school, make friends in their community or cope with the demands of employment or intimate relationships. Thus, for ADHD to be a mental disorder, the cause must be neurobiological.

Look anywhere for a definition of ADHD and you are automatically propelled into a medical arena. Even in non-medical texts you will find ADHD is defined as a neurodevelopmental disorder that spans cognitive, behavioural and affective domains of attentional processing, executive functioning, response inhibition and/or increased levels of activity. The very label ‘neurodevelopment’ presupposes that the ‘fault’ lies in neurobiology. There is cumulative evidence, spanning decades, which suggests neurobiological differences in people with ADHD (for a review see Curatolo, E. D’Agati, and R. Moavero¹³ and M. D. R. G. Corral and P. S. Hernández¹⁴). A number of neuroimaging, neuropsychology and neurochemical studies implicate the frontostriatal network (particularly the lateral prefrontal cortex). Genetics also appear to be involved, with twin, family and adoption studies indicating

⁵ P.M. Wehmeier et al., “Social and Emotional Impairment in Children and Adolescents with ADHD and the Impact on Quality of Life,” *Journal of Adolescent Health* 46 no. 3 (2010): 209–17.

⁶ Kate Carr-Fanning, “There’s Nothing So Wrong with You that What’s Right with You Couldn’t Fix: A study of stress, emotion, and coping in children with ADHD” (PhD diss., Trinity College Dublin, 2015).

⁷ Russell Barkley, *Attention-Deficit/Hyperactivity Disorder: A Handbook for Diagnosis and Treatment*, 4th ed. (New York: Guilford Press, 2013).

⁸ J. Breslau et al., “Childhood and Adolescent Onset Psychiatric Disorders, Substance Use, and Failure to Graduate High School on Time,” *Journal of Psychiatric Research* 45 no. 3 (2011), 295–301.

⁹ A.B. Kuriyan et al., “Young Adult Educational and Vocational Outcomes of Children Diagnosed with ADHD,” *Journal of Abnormal Child Psychology* 41 no. 1 (2013): 27–41.

¹⁰ E. de Schipper et al., “A Comprehensive Scoping Review of Ability and Disability in ADHD using the International Classification of Functioning, Disability and Health-Children and Youth Version (ICF-CY),” *European Child & Adolescent Psychiatry* 24, no. 8 (2015): 859–72.

¹¹ P.M. Wehmeier et al. “Social and Emotional Impairment in Children and Adolescents with ADHD and the Impact on Quality of Life,” *Journal of Adolescent Health* 46, no. 3 (2010): 209–17.

¹² American Psychiatric Association, *Diagnostic and Statistical Manual*, 5th ed. (American Psychiatric Association, 2014), 20.

¹³ P. Curatolo, E. D’Agati, and R. Moavero, “The Neurobiological Basis of ADHD,” *Italian Journal of Pediatrics* 36, no. 1 (2010): 79.

¹⁴ M. D. R. G. Corral and P. S. Hernández, “ADHD: neurobiological Basis and Social Aspects,” *Edita IeS*. 17, no. 21 (2018): 81–90.

strong genetic contribution to ADHD with heritability ranging from 60 to 90%, making ADHD potentially more heritable than height and weight. However, all of this remains controversial in that the underlying mechanisms are not understood.

The lack of clarity does not end there; you would be hard pushed to find a more controversial diagnosis. ADHD lacks a singular diagnostic entity, and aetiology is complex. For example, symptom presentation and functional deficits vary across ages (e.g., child vs adult), and different genders show distinct profiles¹⁵. Indeed, many have even questioned its validity as a diagnosis, with controversies surrounding over-diagnosis, the medication of children using stimulants and the role of big pharma¹⁶. This piece is not about questioning the validity of the ADHD diagnosis and to claim, as others have, that ADHD is entirely socially constructed. There is clearly something ‘different’ about people who are labelled ADHD. Indeed, without some individual difference, there would be no social reaction to it. However, different does not and should not mean ‘disordered’ or ‘disabled’. There appears to be different psychobiological workings involved in temperament and personality traits, but we do not label these differences or personal traits as ‘disorder’. Moreover, we may be tarnishing people’s intrinsic worth by claiming that psychobiological difference is disorder, subjectively valuing these behaviours as undesirable.

Indeed, differences can often mean strengths. In spite of the wholly negative associations with the term disorder, the ADHD community boasts many famous and talented people among its ranks, from entrepreneurs and inventors, to musicians and actors. If certain traits or ADHD-type behaviours can be understood in some or all contexts as strengths, then it calls into question whether the ‘disorder’ label (a wholly pejorative term) is appropriate. A survey of ADHD which included 174 experts across 11 disciplines and 45 countries identified a range of positive attributes, such as creativity, energetic, fun to be around, the ability to be flexible and multi-task, along with resilience and risk taking¹⁷. Another study found that university students with greater ADHD-type behaviours were more likely to have entrepreneurial intentions¹⁸. Indeed, while risk taking might be associated with concerns in adolescence (e.g., substance misuse or sexual behaviour), it is generally true that you have to be willing to take risks if you want to set up on your own. David Neeleman, founder of JetBlue, might have struggled with his ADHD in childhood, but credits his success in part to his willingness to take risks and think outside the box.

There are a number of issues with the ‘disorder’ label when it comes to ADHD. Just because people have psychobiological differences should not mean that they are disordered. By labelling these behaviours as undesirable, we may be undermining people’s inherent worth and dignity. Furthermore, the recent inclusion of a strengths-based perspective on ADHD calls into question the ‘disorder’ label, given its pejorative nature. In addition, it suggests that ADHD-type behaviours can be (in the right contexts) advantages, and so do not ‘cause’ dysfunction. Indeed, ADHD, like all ‘disorder’ labels, cannot be understood free from context, because these psychobiological traits have to be the cause of functional deficits, like an inability

¹⁵ Aja Louise Murray et al., “Sex Differences in ADHD Trajectories across Childhood and Adolescence,” *Developmental Science*, 22, no. 1 (2019), e12721.

¹⁶ Iina Singh, “Biology in Context: Social and Cultural Perspectives on ADHD,” *Children & Society* 16, no. 5 (2002): 360–67.

¹⁷ E. de Schipper et al., “A Comprehensive Scoping Review of Ability and Disability in ADHD using the International Classification of Functioning, Disability and Health-Children and Youth Version (ICF-CY),” *European Child & Adolescent Psychiatry* 24, no. 8 (2015): 859–72.

¹⁸ I. Verheul et al., “ADHD-like Behavior and Entrepreneurial Intentions,” *Small Business Economics* 45, no. 1 (2015): 85–101.

to make or keep friends, to live in harmony in a family system, to engage with educational opportunities or hold down a job. Therefore, we have to consider whether it is the context and its social structures that is the ‘cause’ of the dysfunction experienced by people with ADHD. In essence, if the fault lies within the context it is essentially a human rights issue because social structures would be denying children with ADHD the right to participate fully within their community (e.g., education). Given that human dignity is the basis for this participation, then a lack of recognition and respect for human dignity could be responsible for this exclusion.

Structural Disablism and the ADHD Disorder Label

An alternative way we can understand the dysfunction linked to ADHD is as a disorder of society or as structural disablism. Instead of the medical view of disorder as something psychobiological in need of treatment and ‘cure’, so the person can fit in with existing structures, we shift the focus to problematic structures and the impact of the environment. This perspective, based within the social model of disability and embedded within rights-based discourse, would advocate an acceptance of diversity, the provision of social support and adapting the environment through reasonable accommodations.

Who gets to say what’s normal?

One of the preeminent and prolific authors in this area, Thomas Szasz¹⁹, argued that mental disorders were not caused by psychobiological diseases, but rather were deviations from behavioural norms. Based on his work with people with schizophrenia, he developed the ‘ideology of normalisation’, or the idea that what is normal is a relativistic values judgement tied to contextual rules for behaviour. He observed that when people with schizophrenia interacted with each other they developed their own norms and rules, and so ‘symptoms’ (or interactional preferences / differences) no longer caused dysfunction. Szasz did not think people labelled as disordered didn’t experience dysfunction; he just saw these difficulties as ‘problems of living’ as the challenge of being different and trying to live up to social expectations. He simultaneously acknowledged the role of medical professionals in supporting individuals overcoming these problems and questioned the position of power and control they have over these people. For that reason, he advocated for the rights of people to choose their own supports and direct their own lives. So, in essence, Szasz was recognising and trying to promote the dignity of people labelled disordered.

Szasz’s perspective would argue that the ‘disorder’ label is about power and control; it would claim that labelling is about the power held by the majority to define someone as ‘disordered’ and then ‘treat’, ‘fix’ or ‘help’ them in an attempt to normalize people to realities that may be oppressive or non-existent²⁰. In this way, we can view treatment as a form of punishment or correction, a way of trying to control socially undesirable behaviour²¹, in the same way that we punish children in school for speaking out of turn or a social group rejects an adolescent for not fitting in with group norms.

There are plenty of examples to support the notion that behavioural norms have an impact on diagnosis, symptom presentation and functional deficits. For example, in a

¹⁹ Thomas Szasz, “The Myth of Mental Illness,” *American Psychologist* 15 (1960): 113–18.

²⁰ A. Lock and T. Strong, “Social Constructionism: Sources and Stirrings in Theory and Practice (Cambridge: Cambridge University Press, 2010).

²¹ Michel Foucault, *History of Madness*, trans. J. Khalfa (New York: Routledge, 2016).

systematic review of the literature in the United States, Liang, Matheson and Douglas²² explored the role of race/ethnicity in misdiagnosis of children. The researchers reported that there may be cross-cultural variations in terms of what is considered normal and abnormal behaviours. For example, when compared with white parents, minority parents may be more likely to identify their child's behavioural problems as non-mental health related, not identify them as a problem at all or believe they will improve on their own with time. The review suggested that this may be because white parents have a lower threshold for 'problem' behaviours, are more aware or better educated about mental health or their views of pathology is more aligned with Western notions of mental health. Clinical judgement (and so bias) may also influence diagnosis. White children were reported as more likely to be diagnosed with ADHD, whereas ethnic minorities were said to be more likely to receive a diagnosis of disruptive behavioural disorders.

Diagnosis and the disorder label requires functional deficits, and so cannot be extricated from socio-environmental context. Anecdotal evidence suggests that the COVID-19 lockdown highlighted some of the issues people with different interactional preferences experience trying to function in a world not designed to include them. When lockdown happened, many neurotypical people struggled with their mental health and wellbeing, whereas, for some people, such as introverts²³ or adults with ADHD²⁴, life improved. For example, introverts could focus on their work, control their environment and not expend energy talking to people, which they may find more tiring than extroverts. Similarly, adults with ADHD found it easier to pay attention without a distracting work environment full of co-workers. So, their ADHD symptoms were reduced, disappeared or at least did not cause functional impairments. As a result of changes in their environment, their 'disorder' was not a disorder any longer, because perhaps their 'disorder' is just a problem in living in this world.

We can understand many of the 'difficulties' associated with ADHD in a similar way. According to Russell Barkley²⁵, children with ADHD have differences in executive functioning (higher-order cognitions). As a result, among other traits, they may perceive and manage time in a different way than 'typical' children. Due to this different perception of time they may struggle to manage time on long-term projects or to navigate the structure of a school day (e.g., getting to class on time). However, if we make time external, such as using visual timetables, alarms, stop watches or egg timers, they can function well. Similarly, if a child is very active and they are encouraged to move or sit on a ball, rather than sit still for prolonged periods, they do not experience problems in living. The environment accommodates their way of being in this world. Indeed, small adaptations to a classroom (e.g., reducing stimuli, providing opportunities for movement and breaking up lessons) and the workplace (e.g., providing opportunities for movement breaks, working from home options and adapting supervision methods) can create an environment that works for someone with ADHD.

²² June Liang, Brittany E. Matheson, and Jennifer M. Douglas, "Mental Health Diagnostic Considerations in Racial/Ethnic Minority Youth," *Journal of Child & Family Studies* 25 (2016), 1926–40.

²³ Katie Russell, "Why Introverts could Thrive in the Work-from-home Revolution," *The Telegraph*, 3 September 2020, <https://www.telegraph.co.uk/education-and-careers/2020/08/03/introverts-could-thrive-work-home-revolution>.

²⁴ "Summary of ADHD Ireland Survey: Coping with COVID-19 and ADHD," *ADHD Ireland*, accessed 3 September 2020, <https://adhdireland.ie/summary-of-adhd-ireland-survey-coping-with-covid-19-and-adhd/>

²⁵ Russell A. Barkley, *Managing ADHD in School: The Best Evidence-Based Methods for Teachers* (USA: PESI, 2016).

The Stigmatisation of ADHD

Perhaps one of the most problematic factors associated with the disorder label, from the perspective of human dignity, is the stigmatisation associated with ADHD labels and ADHD-type behaviours. Labels are not inherently negative; they are functional. We would struggle to navigate the world without the use of labels and schemas. However, the meaning behind the labels, particularly the disorder label, can contribute to stigma and oppression, robbing people of their human dignity.

Stigma refers to any attribute or behaviour that causes a person to be labelled as unacceptably different from the norm. Differences are not universally stigmatised. For example, Mozart's ability to play the piano and compose is and was an accepted, valued and respected difference. It is the 'unacceptable' difference or 'deviance' that causes stigmatisation. The effects of stigma may be significant, as Howard Becker²⁶ asserted; the deviant label has consequences not only for self-image, but also for all future social participation. The view people have of themselves impacts upon the decisions they make; for example, if a child sees themselves as unintelligent, they may be less likely to try hard in school. If particular behaviours are viewed as unacceptable, then the social group will continue to reject people who demonstrate them on the playground or in the office. So, a deviant label can affect all aspects of a person's life and opportunities, meaning things like friendships, school, university and employment can all be affected. Indeed, even the person's full humanity is called into question because people who are ascribed the deviate label become devalued or spoilt as people in their own eyes and the eyes of others. Therefore, they are not respected and valued for their humanity, and so their human dignity is not protected: it is spoilt. As Becker notes, this tarnishing of human dignity can also prevent participation in other areas of life, and in doing so deny other human rights, such as the right to education.

ADHD is perhaps one of the most stigmatised diagnostic categories. Overwhelmingly, qualitative research with children with ADHD indicates the negative stigmatising consequences of ADHD on self-identity and social participation: with children reporting feeling 'different' and chronically disempowered, misunderstood and rejected, describing themselves as 'mad', 'bad', 'crazy', 'wako', 'broken' and 'stupid'^{27 28 29 30 31 32 33 34 35}.

²⁶ Howard S. Becker, *Outsiders: Studies in the Sociology of Deviance* (New York: Macmillan, 1963).

²⁷ T. Arora and L. Mackay, "Talking and Listening to Children Diagnosed with ADHD and Taking Psycho Stimulants," in *Children at the Margins: Supporting Children, Supporting Schools*, eds. T. Billington and M. Pomerantz (London: Trentham Books, 2004).

²⁸ Geraldine Brady, "ADHD Diagnosis and Identity: A Sociological Exploration," *Clinical Psychology* 40, (2004): 42–44.

²⁹ Paul Cooper and Thomas Shea, "ADHD from the Inside: An Empirical Study of Young People's Perceptions of the Experience of ADHD" in *ADHD: Research, Practice and Opinion* eds. Paul Cooper and K. Bilton (London: Whurr, 1999): 223–45.

³⁰ D. J. Gallichan and C. Curle, "Fitting Square Pegs into Round Holes: The Challenge of Coping with Attention-Deficit Hyperactivity Disorder," *Clinical Child Psychology and Psychiatry* 13, no. 3 (2008), 343–63.

³¹ J. Kendall, D. Hatton, A. Beckett and M. Leo, "Children's Accounts of Attention-Deficit/Hyperactivity Disorder," *Advances in Nursing Science* 26, no. 2 (2003): 114–30.

³² S. Kildea, J. Wright, and J. Davies, "Making Sense of ADHD in Practice: A Stakeholder Review," *Clinical Child Psychology and Psychiatry* 16, no. 4 (2011): 599–619.

³³ M. Kruger and J. Kendall, "Descriptions of Self: An Exploratory Study of Adolescents with ADHD," *Journal of Child and Adolescent Psychiatric Nursing* 14, no. 2 (2001): 61–72.

³⁴ Ilna Singh, "A Disorder of Anger and Aggression: Children's Perspectives on Attention Deficit/Hyperactivity Disorder in the UK," *Social Science & Medicine* 73 (2011): 889–96.

³⁵ C. L. Travell, "Attention Deficit Hyperactivity Disorder (ADHD): Experiences and Perspectives of Young People and their Parents" (PhD diss., University of Birmingham, 2005).

In the UK, Cooper and Shea³⁶ interviewed children with ADHD (11–16 years old) about their perceptions and experiences of ADHD-type behaviours and the ADHD label. For some, who believed they ‘had’ ADHD they perceived themselves ‘broken’, whereas others found the label a useful way to explain the problems they had, decreasing guilt and shame. Therefore, perhaps it is not about getting rid of the label, but rather changing the meaning of the label.

The meaning of the label is malleable across time and context. Indeed, since the first medical paper written in 1779, through its various medical iterations in the past 100 years and currently across different diagnostic texts, the ADHD label and ADHD-type behaviours have changed significantly. It also varies across cultures. For example, Iliina Singh³⁷ explored the voices of 151 children with and without ADHD in the US and UK and found that the meaning of ADHD, and so children’s perceptions of themselves and of ADHD, varied based on socio-cultural norms. In the US, ADHD was experienced as a disorder of learning, whereas in the UK, where socio-emotional regulation is more emphasised, the children view ADHD and themselves in terms of anger and aggression.

Indeed, the meaning can vary within cultures, across people and contexts, such as different homes or schools. In Ireland, a study of the voices of 20 children (7–18 years), their parents and teachers, found that most children reported negative self-perceptions and negative attributes associated with ADHD; however, some reported positive and empowering ones too. These reports (both positive and negative) were reflected in the meaning of ADHD reported by their parents and teachers. Thus, we can conclude that the meanings of ADHD held by others, communicated directly and indirectly to children, can have a significant impact on how children view themselves and their difficulties.

Furthermore, the meaning of behaviour may also need to be challenged. The ADHD label may not be required for stigmatisation. For example, Iranian teachers were found to have negative attitudes towards ADHD-type behaviours: the label was irrelevant³⁸. Some children report preferring the ADHD label, because ‘street labels’ were worse³⁹. Thus, clearly, there is a need to rethink behavioural norms and expectations which could be the source of social oppression. Indeed, we could ask the question: is it the internalising of or the reaction to social oppression which is responsible for some or all of the difficulties associated with ADHD? For example, one US study reported that children with ADHD (aged 8–12 years) felt chronically sad, helpless and angry because they felt their social world was uncaring and antagonistic, and so they responded dysfunctionally (e.g., with aggression)⁴⁰. These social responses may be the so-called ‘problems in living’ to which Szasz was referring. The researchers concluded that these and other ‘problem’ behaviours may be the result of exclusionary and oppressive practices.

³⁶ Paul Cooper and Thomas Shea, “ADHD from the Inside: An Empirical Study of Young People’s Perceptions of the Experience of ADHD” in *ADHD: Research, Practice and Opinion* eds. Paul Cooper and K. Bilton (London: Whurr, 1999): 223–45.

³⁷ Iliina Singh, *VOICES Study: Final Report* (London, UK, 2012).

³⁸ Ahmad Ghanizadeh, M. Fallahi, and Shahin Akhondzadeh, “Disclosure of Attention Deficit Hyperactivity Disorder and its Effect on Rejection of Students by Teachers,” *Iran Journal of Medicine Sciences* 34, no. 4 (2009): 1–6.

³⁹ Paul Cooper and Thomas Shea, “ADHD from the Inside: An Empirical Study of Young People’s Perceptions of the Experience of ADHD,” 223–45.

⁴⁰ R. R. McKinnon, “An Exploratory Study of the Perceptions and Associated Coping Skills of Children with Attention-deficit Hyperactivity Disorder” (PhD diss., Philadelphia College of Osteopathic Medicine, 2009).

Clearly, there are significant and longstanding consequences for people who do not fit in with normative rules for development and behaviour. As a result, one might question whether we should be labelling children at all, which is summed up well in Brahm Norwich's *Dilemmas of Difference*⁴¹. On the one hand, identification can often mean access to resources. Along with the ADHD label children and their families receive social supports, treatment options, educational accommodations in school, an explanation for their difficulties and access to knowledge and understanding. For children with ADHD, intervention may be essential to provide support and avoid negative outcomes⁴². However, on the other hand, labelling may result in social oppression and exclusionary practices, which can harm the child's dignity, and in so doing prevent their participation in things like school and future employment.

However, there is no dilemma about 'if' people should recognise difference. Recognition is inevitable; people will inevitably construct stories to cope with difference. The 'meaning of difference' is and has been subject to change, as has the meaning of ADHD across context, culture and time. Furthermore, labels are never inherently 'true', nor are they 'bad'; they can only be understood as more or less useful⁴³. In a clinical context medicalised labels serve a function, in that they aid identification and understanding of difficulties and direct treatment. The problem is that medicalised labels are used in all areas of life and practice, where their utility is questionable at best and detrimental at worst. However, if we reject labels entirely, then practice may become reliant on people's implicit beliefs, which are potentially more detrimental and less subject to change. Structural disablism could be attributed to the stigmatisation of both the ADHD label and ADHD-type behaviours. Stigma fails to recognise and respect the person's human dignity, contributing to oppression and marginalisation of people labelled as deviants.

If we understand disorders as structural disablism, that is, it is society which is disabling children and adults with ADHD, then it is up to society (and both the individuals and institutions within it) to confront expectations about behavioural norms, in addition to the structures and practices that are based upon these expectations and norms. When it comes to challenging norms it takes collective dialogue and individual responsibility because people and groups are responsible for the maintenance of social structures. This approach, located within critical social theory, would advocate a need to deconstruct and question the ideological underpinnings of structural inequalities⁴⁴. In practice, other human rights movements, such as Black Lives Matter (BLM), have done this. BLM demonstrated the need for and the consequences when all people within society engage in collective critical dialogue and critical self-reflection about themselves and their institutions. BLM advocates that to confront structural racism we should be confronting the uncomfortable. Following their example, and applying it to structural disablism, we could ask ourselves questions such as:

- In what way have I been advantaged due to my behaviours fitting in with the norm? Was / is it easier to participate in my school or my workplace?

⁴¹ Brahm Norwich, *Dilemmas of Difference, Inclusion and Disability* (London: Routledge, 2007).

⁴² Edward G. Feil et al., "Early intervention for preschoolers at risk for attention-deficit/hyperactivity disorder: Preschool first step to success," *Behavioral Disorders* 41, no. 2 (2016): 95–106.

⁴³ Kate Carr-Fanning, Conor Mc Guckin, and Michael Shevlin, "Using student voice to escape the spider's web: A methodological approach to de-victimising students with ADHD," *Trinity Education Papers* 2 (2013): 85–112.

⁴⁴ G. Thomas, "An Epistemology for Inclusion" in *Psychology for Inclusive Education*, eds. P. Hick, R. Kershner, and P. T. Farrell (New York: Routledge, 2009), 13–23.

- In what ways are people who are different oppressed and excluded? How do I contribute to this? How do the structures in different institutions, including the ones I am a part of (e.g., education, healthcare, workplaces) contribute to this?
- What are my assumptions about and reactions to people who behave ‘abnormally’ (e.g., do I laugh, do I feel awkward, do I look away)?
- How many of my friends and colleagues are different? Why do I associate with people who are the same as me? Who do I think of as normal?

In essence, we must question the taken-for-granted ways of being in this world and their relation to the social structures that exist. This must include a questioning of the labels we use about people who are different, because many of these are pejorative, and result in stigmatisation and marginalisation.

ADHD and the Diversity Label

An alternative label which is more respectful of human dignity is the neurodiversity label. The framework of neurodiversity offers a meaning for both ADHD-type behaviours and the ADHD label, with a slight adjustment to the label – Attention Deficit Hyperactivity ‘Diversity’ – while keeping the existing acronym. This framework is more about respecting, accepting and valuing difference, rather than the label of disorder which is wholly negative and stigmatising, and may have limited use outside a clinical context.

The term ‘neurodiversity’ has for most of its short history been strongly associated with the autism community; it was coined by Harvey Blume, an Australian social scientist with autism and popularised Steve Silberman’s book *NeuroTribes*⁴⁵. The idea of neurodiversity was put forward in response to oppression and stigmatisation, with advocates championing the rights of people who were different to be respected and accepted with dignity, rather than pathologised. Neurodiversity is premised on the assertion that a ‘normal’ brain does not exist, although the term ‘neurotypical’ is used to refer to people with the majority brain. It further argues that differences in behaviour or interactional styles should be understood as examples of diversity, one type of brain or way of being among the many possible brains and ways of being, none of which are ‘normal’ and all are just a little different.

Accordingly, neurodiversity requires the same respect for the dignity of people with ADHD and other presupposed ‘disorders’ as is afforded to other aspects of diversity (e.g., race, gender or religion)⁴⁶. For example, left-handers are a neurodiverse group, living in a majority right-hand world; they do not have to be pathologised and cured. In a similar way, a neurodiversity framework would argue that children with ADHD-type behaviours should not be pathologised, and so would need to be accepted for their emotional nature or their level of activity, rather than have these behaviours treated and normalised to fit in with the neurotypical world, that is, their uniqueness and worth as human beings should be respected. Alternatively, minor adjustments are made to the environment, such as how we organise classrooms or the ways we work, to enable people with ADHD to function well. As such, their dignity is protected and their inclusion within the community is promoted by ending the structural disablism that is excluding them.

⁴⁵ Simon Baron-Cohen, "Editorial Perspective: Neurodiversity—a revolutionary concept for autism and psychiatry," *Journal of Child Psychology and Psychiatry* 58, no. 6 (2017): 744–47.

⁴⁶ T. Armstrong, *Neurodiversity: Discovering the Extraordinary Gifts of Autism, ADHD, Dyslexia, and other Brain Differences* (Massachusetts: DaCapo Press, 2013).

As discussed earlier, because people have innate human dignity, they are free and have autonomy. An advantage of the neurodiversity perspective is that it affords freedoms and autonomy in the construction of one's identity; thus, adults may wish to identify as 'having' or 'being' ADHD. This freedom would not require them to believe that all aspects of ADHD were in need of cure, and so they may choose to identify as diverse or disordered. In line with this, one would not need to have a diagnosis or an underlying psychobiological difference to identify as ADHD. Many parents already self-identify as ADHD without a diagnosis, often following the diagnosis of their child, and should be free to do so, if it provides them a way to understand their strengths and/or difficulties.

We live in an age where we recognise gender fluidity, where people can identify as a gender which is not the one assigned at birth or different to their chromosomes. Persons are allowed to change their names and have their birth certificates changed. In a similar manner, accommodation can be made for different personal traits and behavioural patterns as well. The freedom to choose does not negate treatment. For example, a person may have naturally brown hair, but dye it blond; they will not be excluded if they do not do so, but they are free to make an informed choice about the way they want to be in this world. Similarly, a parent may chose early intervention for their child (before or after a diagnosis) or a person may have a different level of attention than another and so chose to take Ritalin, because they want to, not because they have no other choice. Thus, we can identify and label difference, and people can still access the resources, if they choose, without the same oppression, because 'diversity' is not automatically a pejorative word nor does it have to be stigmatised. The UNCRC⁴⁷ advocates both the protection of dignity and the promotion of participation (Article 23), while also insisting that children have access to appropriate services (e.g., healthcare: Article 24), and places them at the centre of such decision-making, with their voice and opinion being given due consideration (Article 12).

While notions of disorder are wholly negative, neurodiversity also provides people, parents and practitioners other frameworks through which to consider potential strengths associated with that diversity. That is, it does not only focus on the pathology and what someone cannot do, but also what they can do. Thus, we can praise a child with ADHD for showing leadership qualities, rather than being 'bossy' or 'domineering', and tell the adolescent that their willingness to take risks is an asset and encourage them to think about setting up their own business. Accordingly, we can nurture their talent and protect their dignity, and in doing so support them towards a more fulfilling life. As a result, their intrinsic worth, value and dignity is not only respected, it is celebrated.

The neurodiversity label has been criticised for several reasons⁴⁸. For example, for rejecting notions that people have a disorder or the severity of the dysfunction it causes. Undeniably, some children will experience disorders which are medical (e.g., epilepsy or diabetes), and we recognise these as disorders that require treatment. They do require treatment and access to appropriate services, and while there may be consequences to their dignity as a result of medical labelling, these types of difficulties are also distinct from ADHD. For example, if you do not treat diabetes you may be limiting life, whereas, if we changed our norms around behaviour, it may not limit the life of a child with ADHD and may provide that life greater opportunity and equality. Similarly, there are many conditions where disorder is

⁴⁷ United Nations, *Convention on the Rights of the Child* (United Nations, 1992).

⁴⁸ Simon Baron-Cohen, "Editorial Perspective: Neurodiversity—a revolutionary concept for autism and psychiatry," 744–47.

not questioned, such as severe anxiety, depression, psychosis, etc. For these individuals they cannot function in any culture or environment. In contrast, in the case of ADHD we can create environments where they can function, which accommodate differences, and in so doing remove the dysfunction and the need for the disorder label and its cure. This, however, is hard, because this means changing social structures, which comparably is much more challenging to do.

Summary and Conclusion

This piece raised the question of how we label people (especially children), exploring the question of labels, and in particular, the shift from pejorative closed labels to positive open labels. This piece explored the role of labelling, using ADHD as a case example, with regards to the ‘disorder’ label versus the ‘diversity’ label. However, many of these points can be applied to other socio-political discussions around labels and identity, such as race / ethnicity (e.g., Irish travellers identifying as a distinct ethnic group), sexuality and gender (e.g., gender identity). These are human rights issues because identity is about one’s inherent worth and dignity, and human dignity is the basis for human rights.

Currently, the ‘disorder’ label, a medicalised, pejorative and stigmatising construction, can dominate the lives of people labelled as ADHD. However, there are several problems inherent in the disorder label. Labelling of certain behaviours or traits as disorder is subjectively based on norms (constructed and maintained by the majority within society), valuing certain types of people and their behaviours above others. Also, if some / all behaviours can be understood as strengths in some contexts, then this raises questions about accuracy of the ‘disorder’ label and whether the context is to blame for creating dysfunction. Exiting social structures, which give rise to the need for the disorder label, can be understood as structural disablism. Structural disablism can negatively affect self-image, which impacts all other social participation; in the tarnishing of human dignity it may contribute to other forms of exclusion.

The alternative ‘diversity’ label or Attention Deficit Hyperactivity Diversity provides a more empowering, open and positive framework. The ‘diversity’ label recognises the person as different, but not unacceptably so or less than anyone else. This label requires acceptance of, and respect for, difference, and so recognises the intrinsic worth of the human being involved and in doing so allows strengths to be identified and nurtured. It also affords people freedoms to direct their own lives, making decisions about how they want to be in the world and how they want to identify. As a result, neurodiversity is respectful and provides people with ADHD the autonomy to choose. People with ADHD may seek support or treatment and adapt their behaviour, and/or they may choose to make changes to the environment to enhance life opportunities. In providing these opportunities, afforded by a positive and open label, it protects and promotes not only human dignity, but other human rights.

This approach, moving away from pejorative closed labels to positive open labels, has implications across all sectors and the broader society in terms of promoting equality of opportunity resulting in greater acceptance and success in social groups.

For policymakers, there is a need to emphasise the removal of barriers within a range of settings, including healthcare, education and employment. For example, one-size-fits-all approaches do not create space for diversity, and so can create that subjective normal-abnormal value judgement. Policy can also further emphasise the need for people and children to be

central to the decision-making process, particularly within diagnosis and treatment, and to question current practices around labels and identity. For example, should a child have to identify as disordered in order to get educational accommodations? Can an adult decide that they want to identify as diverse (rather than disordered) and continue to seek treatment? So much of our social services and disability support systems are based upon that disorder label, so to change its meaning, we have to change the structures that maintain it.

Educationalists and employers can take responsibility for the environments they create – critically reflecting on how people with differences are included and what social structures prevent participation, and where needed, make adjustments to accommodate differences. If this is done, it could reduce the requirement for treatment, making service use a choice because without services people with ADHD would still be valued for their inherent worth and uniqueness. The present more closed system often requires people to view their behaviours as deficits and get treatment so that they can fit in with existing structures. Educationalist and employers can change their policies and practices so as to enable accommodation by empowering (and educating) their staff to work inclusively, and providing support for anyone identifying as neurodiverse. For example, can a young adult access supports in university or access schemes to university without a diagnostic label?

Children and adults with ADHD can be provided with opportunities to critically consider different labels and make decisions about how they want to identify. In childhood, parents can support this by constructing useful frameworks for meaning with their child to aid the development of a positive self-image. Clinicians may be central to this, and they can critically consider the ways in which they discuss ADHD labels with parents and children, as well as the adults they work with. The diagnostic label, and the stigma that goes with it, can sometimes mean people avoid referring for diagnosis or engaging in the diagnostic process, meaning supports and other advantages are not accessible.

The implications of this approach extend broadly, including the need for the general public to deconstruct behavioural norms and expectations because people are responsible for the construction and maintenance of these norms. Thus, all people may need to critically consider how they view and react to behaviours they view as ‘abnormal’.

Critically considering, challenging and changing terminology and labels is a useful exercise. However, it needs to be accompanied by individual and collective responsibility to challenge and change the social structures that underlie these labels. Otherwise, we could just be changing the wallpaper while the foundations of the house are rotten.

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