



RESEARCH ARTICLE

# Naming and Describing Disability in Law and Medicine

Heloise Robinson  and Jonathan Herring 

Exeter College, University of Oxford, Oxford, UK

**Corresponding author:** Heloise Robinson; Email: [heloise.robinson@exeter.ox.ac.uk](mailto:heloise.robinson@exeter.ox.ac.uk)

## Abstract

This article explores the effects of naming and describing disability in law and medicine. Instead of focusing on substantive issues like medical treatment or legal rights, it will address questions which arise in relation to the use of language itself. When a label which is attached to a disability is associated with a negative meaning, this can have a profound effect on the individual concerned and can create stigma. Overly negative descriptions of disabilities can be misleading, not only for the individual, but also more broadly in society, if there are inaccurate perceptions about disability in the social context. This article will examine some relevant examples of terminology, where these issues arise. It will also suggest that the role of medicine and the law in naming and describing disability is particularly important because in these areas there is, perhaps more than anywhere else, a recognized source of authority for the choice of terminology. Labels and descriptions used in the medical and legal contexts can not only perpetuate existing stigmatization of disabled people, but can also contribute to creating stigma at its source, given that the words used in these contexts can constitute an exercise of power.

**Keywords:** disability; stigma; terminology; language; naming

## Introduction

It might be thought to matter very little to a patient whether their condition is called X or Y. The name of a medical condition, or its description, might not seem to be that significant. Patients will be more concerned with obtaining the right diagnosis, or the right treatment.

Similarly, where the law addresses medical conditions, it might seem that what matters most are the rights at issue, or the legal decision, and not the precise terminology which is used, so long as the terminology can sufficiently identify the matter at hand. We think it is important if a person faces discrimination because of their condition, but we do not necessarily think much about the particular label or description used within a statute, or within a judgment, unless it has direct legal consequences.

However, there are many reasons to think about the importance of the particular name and description used. In medicine labels can be the first introduction to another of the condition and can strongly impact the way it is understood, and indeed, the very fact the condition has a medical label is an indication that the patient has something recognized as a disease or abnormality. The name attached to it will impact on the perception the person has about their condition. It will also have significance when the individual comes to tell friends and family members what they have, and the name may be the initial indicator of how the condition is to be thought of. The terminology used can convey negative (or positive) connotations. It may provide a person with reassurance that they can now put a label onto the array of symptoms they have identified and indicate fellowship with others with the same condition or gene. The particular terminology used, in both the medical and the legal contexts, can also reveal implicit views that relate to the condition.

In this article, we would like to explore more the effects of naming and describing disability in law and medicine. While substantive issues such as medical treatment and legal rights are of course important, there is also a need to examine language itself. Medical conditions may or may not be disabilities, but a focus on disability is important because this can potentially have a strong effect on someone's identity. Furthermore, while there are issues to examine in relation to the words used about disability more widely in the general social discourse, there are particularly strong reasons to be concerned with the way that disability is named and described in contexts which have more authority and power over terminology. In medicine, the medical establishment can provide an official name for a condition, and an authoritative description of symptoms or traits. The first source of people's perceptions about a condition can come from the medical terminology and information provided. While people can adopt different approaches to speaking about disability, and while disabled people themselves can have their own preferences about the way they describe themselves or their condition, in medicine precision in terminology will be important. In the legal context, although many people might not always be aware of legal phrasing, the legal terms might seem particularly authoritative, and as reflecting the view of the state.

The concerns about the use of terminology here are twofold. First, it may be that the name creates a negative attitude, such as shame or stigma in the individual concerned, or that the individual may face such an attitude from their friends and family due to associations with the name. Second, the label may be misleading the patient or others about the condition. The information provided might simply be inaccurate. This not only creates risks for the patient, but can have broader social repercussions if the inaccuracy perpetuates misguided perceptions about disability.

These issues are not easy to address. In the first case, the risk of stigmatization goes beyond the particular choice of label, as certain negative connotations can be associated with it, and socially supported. In the second case, there might not be a way of describing disability in an entirely value-neutral manner, and again the social context will be influential. While improving terminology will not be sufficient on its own to address all social influences and stigmatization, we would like to suggest some reasons why the role of medicine and the law in naming and describing disability is particularly significant, because in these contexts there is, perhaps more than anywhere else, an exercise of power.

### Naming and stigma: What's in a name?

Having the authority to impose a label on others is an exercise of power. Just like the power to give one's name to a child is an important form of power, as it leads to identification and categorization,<sup>1</sup> the power of the medical establishment to determine the official name of a condition is significant when such a label closely attaches itself to the disabled person's sense of identity, affects their feelings of self-confidence, and influences the way that this person is perceived by others. Even other terms used by medical professionals, other than the official name for a condition, can reflect power because the professional will be seen as having a greater authority over the choice of appropriate terminology. Likewise, the power of the state to label disability in the law can reflect significant authority. Furthermore, whether or not people like to use certain labels, there will be circumstances where precision is required, and the particular medical or legal term must be used. The precise reference to a name might be a particular concern, for example, in the case of conditions that are potentially more stigmatized, such as in the case of intellectual disability, or for some mental health conditions. The medical and legal terminology will sometimes be unavoidable.

While a name need not be negative, any label can have a powerful effect. In the context of disability, Tom Shakespeare describes the possibility of "identity spread," which arises where "the person's individuality—both their personality, but also other aspects of their identity such as gender, sexuality and ethnicity—can be ignored, as the impairment label becomes the most prominent and relevant feature of their lives, dominating interactions."<sup>2</sup> Although sometimes disability can contribute in a positive way to someone's self-perception, even then a person might not wish to be primarily associated with a label, or might not want one trait to suppress other elements of a person's identity or individuality. In the context of prenatal testing, Adrienne Asch has referred to the risk that the future child can be

judged entirely based on only a trait, and that the test would suggest that there is no need to find out any other information about the person.<sup>3</sup> Thus, the parents and medical professionals might form a view about the child based on a diagnosis of spina bifida, or of a cleft lip. While this is more of a risk in prenatal testing, when perhaps we know of no other traits of the fetus at that point, there is also a risk that this same trait can continue to dominate the judgments that people will make of the person. A similar process can also occur outside of the context of prenatal testing, if one trait dominates all others.

The effect of the name, in the context of disability, will come not only from its particular dictionary definition, or from the fact that it might dominate over other labels, but also from the way it is perceived in the social context. If understandings of disability, or of a particular condition, are negative in society, this can mean that a label will attract stigma. Further, whereas terminology surrounding disability can be associated with a number of negative connotations, including prejudice, the concept of stigma might best be understood as requiring societal support and social power.

One important example of the name of a condition which is linked to power is Down syndrome, which was named after John Langdon Down, who described people with the condition as “Mongols” through the use of a racist form of categorization. This meant that the name of the condition not only stigmatized people with Down syndrome through its association with a racist misunderstanding, but that it could also offend people from Mongolia.<sup>4</sup>

In his seminal analysis of stigma, Erving Goffman explains how for the Greeks the term stigma referred to actual physical signs, such as ones that were cut or burnt into the body, and that would be intended to signify that the affected individual was “blemished” or “polluted,” and to be avoided.<sup>5</sup> This could apply to a slave, a criminal, or a traitor, and the stigmatization was a sign of wrongness, or of the person’s lower moral status.<sup>6</sup> This meaning of stigmatization emphasizes the importance of the visibility of stigma, and the public reaction. Rosemarie Garland-Thomson also explains how the most important factor in stigmatization is that the negative social judgments are collective, which is “part of a communal acculturation process.”<sup>7</sup> Similarly, Crocker et al<sup>8</sup> explain that “stigmatized individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular social context.”

In their influential article on the definition of stigma, Bruce Link and Jo Phelan<sup>9</sup> propose that stigma exists when different interrelated components converge:

In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics—to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them.” In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination.

Therefore, for Link and Phelan, stigma arises where a powerful group imposes a label on a less powerful group. Importantly, for them stigmatization *starts* with labeling, but it is the further negative meaning associated with the labeling, and the perpetuation of this meaning through social forces, that leads to stigmatization.

The above understanding is also similar to that provided by Iyiola Solanke, who has argued that “stigmatisation is characterised as a process that is contingent on access to social, economic and political power” and that stigma “is the consequence of a continuum of disempowerment.”<sup>10</sup>

Elsewhere, she explains as well that stigmas “are by definition contextual: they are socially determined and maintained, and to focus on them is to prioritize social meanings.”<sup>11</sup> This is a crucial point because if stigmas are social creations, then there is a societal obligation to combat them and most certainly not to perpetuate them. It is important too because it reminds us that if stigmas are created by society, they can be destroyed by society as well. Just as categories and definitions can be used to uphold or express stigma, they can also have a place as tools to dismantle stigma. Furthermore, if the stigma is associated with

power, this means that we have particular reasons to ask questions about the exercise of power in determining the names of conditions. While the names can be repeated thereafter, targeting the initial labeling will more directly go to the source of power.

To illustrate these issues, we highlight here four examples.

### *Disease versus condition*

The distinction between a disease and a condition is important, but one that is often overlooked. A condition is a neutral term that indicates that a person is healthy, but there is something about them which may indicate a provision of healthcare is needed. By contrast, a disease is a medical state for which medical intervention is required to rectify the situation, and to remove, if possible, the symptoms and return to the patient to good health.

Take pregnancy, for example: this is clearly not a “disease” in that it is not something that we seek medical intervention to cure. While there are many health risks associated with pregnancy, and many associated ill effects, normally pregnancy would be something to celebrate and welcome, which is not something that would normally be said about a disease. We can separate out preeclampsia and gestational diabetes from pregnancy itself.

Another example is Down syndrome. This is a condition that is not itself a health issue in the conventional sense, although people with Down syndrome can have associated health problems.<sup>12</sup> Chris Kaposy, for example, suggests that Down syndrome can be seen as a trait “within the realm of normal human variation, rather than as an illness, pathology or stigmatized identity.”<sup>13</sup>

In the legal context, a good example of potentially misleading references to health can be found in two significant cases involving failed sterilization procedures. In *McFarlane v. Tayside Health Board*,<sup>14</sup> there were numerous references throughout to the fact that the child born following the father’s vasectomy operation was “healthy,” in the context of a refusal to award the full costs of raising the child. Subsequently, in *Parkinson v. St James and Seacroft University Hospital NHS Trust*,<sup>15</sup> a disabled child was born following the failed sterilization procedure, but the court here took a different approach to that affecting a “healthy” child, and decided that the additional costs associated with raising a disabled child could be recoverable. This would appear to suggest that the disabled child is a harm, or “actionable damage.” Indeed, Hale LJ (as she then was) said that in many cases, it is much less likely that a disabled child will bring as much pleasure and as many advantages as would bring a “healthy” child, and that the “additional stresses and strains can have seriously adverse effects upon the whole family, and not infrequently lead (...) to the break-up of the parents’ relationship and detriment to the other children.”<sup>16</sup> However, she also attempted to avoid negative stereotyping by saying that a disabled child has the same worth as a nondisabled child, and it is simply that the costs of raising a disabled child are higher.<sup>17</sup> In this legal context, it would be helpful to separate out disability as a condition on the one hand, and health problems on the other.

In some jurisdictions, there are practical considerations that can impact on the use of language. For example, insurance-based models of funding healthcare may only cover “medical diseases.”<sup>18</sup> Even state-based healthcare systems distinguish between “healthcare” and “social care.”<sup>19</sup> Such practical consequences can lead to patients wanting to accept stigmatic labels as the best way of securing access to healthcare.

### *“Abnormality”*

While “normality” is commonly used in medical discourse, it is certainly a troubling term. A leading recent analysis of the concept explains, after an extensive review of the literature, that “[n]ormality has no consensual definition in medical literature. Not only the meaning varies, but also does the way it is conceptualized.”<sup>20</sup>

As the authors indicate there is a major division of views as to whether the term is normative or whether it is simply a statistical observation, independent of any value judgment. This makes the

widespread use of the term problematic for patients. They may understand the assessment that a medical test is “abnormal,” and that it is targeting something bad, while the medical professional might, or might not, simply mean that the patient’s situation is not average, but that this not anything of concern.

Although there are different ways of understanding references to normality, the labeling of a condition, or especially of a person, as abnormal certainly also has the potential of being stigmatizing. This means that there are particular reasons to be concerned about the way that this terminology is used.

One example of the use of this term in the law is in the Abortion Act 1967, which provides that abortion can be lawfully obtained, among other reasons, if “there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.”<sup>21</sup> In a recent legal case pertaining to this ground, there was a reference to a witness statement from a person working with Mencap, a charity for people with a learning disability, who criticized the reference to abnormalities, as well as the terms “handicap,” “risk”, and “suffer.”<sup>22</sup> These words were considered by her to perpetuate negative stereotypes against disabled people, and, in Mencap’s opinion, the provision “stands out as an offensive anachronistic anomaly in the legislative landscape” which “conveys the powerful message that a life with a disability is a lesser life, even a life not worth living”, and that it “should have no place in a modern and inclusive society that values all people.”<sup>23</sup>

In more recent regulations in Northern Ireland, different terminology is used while providing a similar ground for abortion. Instead of “handicap” it uses the expression “seriously disabled,” and instead of “abnormalities,” it refers to “physical or mental impairment.”<sup>24</sup> Nonetheless, the provision still refers to a “risk” that the child will “suffer” from impairment, which are words that still imply a negative judgment.

### ASD, and the importance of a spectrum

A good example of how a label can educate or mislead is autism. The shift in terminology from “autism” to autism spectrum acknowledges that there is not a single condition of autism, but it covers a wide range of conditions. As NHS Scotland explains,

Autism is highly variable—the word ‘spectrum’ refers to how autism is experienced differently by different people. Autism is considered a spectrum because it’s different for every autistic person—some autistic people might need more support than others to live the lives they want to lead.<sup>25</sup>

This is a welcome and important development. Simply because a person knows one person on ASD does not mean that every person with that diagnosis will be the same. As Timothy Beck writes

It is, as such, not always enough for researchers and mental health professionals to simply describe the symptoms of those diagnosed with autism in ways that can be packaged and circulated according to a biomedical framework. There is an unavoidable ethical imperative to consider, moreover, how any representations they circulate could create unpredictable social effects—and new affects—around those who become labelled or disordered as such.<sup>26</sup>

Even the reference to a “spectrum,” however, can be seen as a problem, as it can position and rank persons according to a low to high functioning scale. Melissa Anderson-Chavarria, for example, proposes a “predicament model,” which moves beyond a spectrum approach and reframes autism so that it can reflect the individuality of each person’s experience, without any reference to a standard of “normal.”<sup>27</sup>

Sadly despite the growing understanding of the ASD, the courts have been slow to catch up. In *Khan v. Meadows*, the Supreme Court in 2022 stated in their summary of the facts that “[i]n December 2015 Adejuwon was diagnosed as also suffering from autism.”<sup>28</sup> In paragraph 41, they acknowledged that there is a spectrum between advice and information, a nuance they failed to pick up in relation to ASD itself. It is also worth noting that the judgment refers to ASD as a “disability” with no explanation for why they so describe it. There are fierce debates as to whether ASD should be regarded as a disability<sup>29</sup> (which

we do not enter here) save to note that it is surprising the courts were not sensitive to the issues of the labels around ASD in this case.

### *Retardation and intellectual disability*

Perhaps the most compelling example of stigmatizing language used in the medical context is the term “retardation,” which is widely regarded as highly offensive.<sup>30</sup> In a BBC survey that examined which terms were found most offensive by people with disabilities, “retard” came out at the top.<sup>31</sup> An international campaign has been running for many years, supported by the Special Olympics, to stop the use of the terms “retard” and “retarded.” In 2013, The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) changed the terminology “mental retardation” to “intellectual disability.”<sup>32</sup> A House of Commons committee has accepted the term “retard” being “as offensive as the worst terms of racist abuse.”<sup>33</sup>

Despite this wide recognition of the highly negative associations with the term and the distress it causes, it is still used extensively. A Google Scholar Search of the term “retardation” found over 5000 returns for articles written in the first forty days of 2023. In 2022, a Guardian Report highlighted the offense caused by the use of the term by the WHO and the NHS.<sup>34</sup> At the time of writing Harringey CHAMS inform young people they are eligible to access their services if they have moderate severe or “profound mental retardation.”<sup>35</sup> The impact of such terminology on young people whose mental health they are meant to be promoting does not bear thinking about.

In the legal context, in the United States, we have an example where changes were made to change the language used. Modifications to federal law (because of Rosa’s law) were made such that “mental retardation” should be referred to as “intellectual disability” for all legal purposes.<sup>36</sup>

In case law, there are also other examples of some highly stigmatizing language used in the context of intellectual disability. In the 1981 case of *Re B*,<sup>37</sup> which was concerned with a child with Down syndrome, the condition was mentioned twice, but there were far more frequent references to the condition by reference to the “mongol” or “mongoloid” child. There was even a comparison made between people with severe intellectual disabilities and a vegetable, with Templeman LJ saying that it was likely that the child at issue in this case “will not be a cabbage as it is called when people’s faculties are entirely destroyed.”

While more recently, such language is usually avoided, cases continue to refer to people in a “vegetative” state. The landmark case of *Airedale NHS Trust v Bland*, from 1993,<sup>38</sup> uses the expression “persistent vegetative state,” and recent cases also continue to use terminology referencing a “vegetative” state, although it is true that this also reflects the medical terminology.<sup>39</sup> The use of the word “vegetative” does not seem to attract the same condemnation as the word “retardation”; perhaps, because those in an unconscious state cannot themselves feel offended by the terminology. Nevertheless, their family members might feel this way, and it seems hard to explain how references to human beings as vegetative persists despite the particularly insulting nature of the language, which is so obviously, and quite literally, dehumanizing.

### *Describing disability: “Balanced” information and neutrality*

While the above four examples show how labels can be stigmatizing, some of the examples illustrate how the terminology used can also be simply inaccurate, or misleading. This is the case, for example, and as mentioned above, with the use of the word disease in cases where there are no adverse health effects associated with a condition. Whether or not there is a reference to a spectrum with autism can also affect whether autism is better understood.

Descriptions of disability can stigmatize in a similar way to the labeling of disability, but it might be thought that one way to address this risk is to present information in an entirely value-neutral, factual manner. Instead of making a judgment that a condition is necessarily “bad,” a description could simply list any associated symptoms or traits.



One problem with this objective is that it is very difficult to provide any description of disability which is entirely separate from any value judgments. Inevitably, a choice will often be made to reflect more positive or negative traits, or an overall judgment. On the whole, the literature on disability suggests that there is a serious divide between the views of many disabled people, and those of nondisabled people. This is often termed the “disability paradox”: that many people with serious disabilities report that they have a good or excellent quality of life, whereas many external observers, who are not disabled, believe that they live an undesirable existence.<sup>40</sup>

When thinking of the right approach to naming and describing disability, it might be thought that the most desirable objective would be to take a neutral approach. Anita Silvers, for example, proposes a neutral conception of disability that seeks to bridge the divide between the common bioethical perspective and the usual approach within the disability literature,<sup>41</sup> which reflects the divide mentioned above on the perceptions about disability, and according to which bioethicists tend to view disability more negatively. She suggests that a neutral approach to valuing disability would mean that “the conversation must take a neutral stance in regard to the intrinsic value of being disabled.”<sup>42</sup> Thus, she says, for example, that bioethicists will “have to give up assuming that disability is intrinsically bad”, and disability advocates will need to “not preemptively reject bioethicists’ beliefs about the contingent harms of being disabled.”<sup>43</sup> While Silvers’ analysis centers on a philosophical understanding of disability, it might be thought that it could translate into a more balanced approach to describing disability as well in medical and legal contexts.

Silvers’ proposal, however, seems to be more of a call for dialogue, rather than one that can finally determine how we understand disability. It might be that, in conversations about disability, including in the context of medical information and advice, or of legal descriptions and analysis, it is important to keep in mind that there are different views. While no definition or description might be fully neutral, perhaps it is desirable to present “balanced” information about disability: to draw attention to both positive and negative features of a condition. At least, if information is provided in an overly negative manner, and in a way that does not represent the views of most disabled people themselves, this will not seem balanced or neutral. However, finding a balance that is uncontested might prove difficult.

Instead of searching for neutrality, or an overarching conception of disability, another option would be to take a more targeted approach to address particular concerns. Jonas-Sébastien Beaudry, for example, suggests that instead of settling the debate on the overarching definition of disability, we can address specific ethical issues.<sup>44</sup> Again, this proposal takes place in the context of philosophical questions about the meaning of disability itself, but we might again think that more specific information about particular symptoms or traits, for example, might be done in the absence of a value judgment. For example, although pain might well not be entirely bad in all cases, it is more usually accepted that this will be seen as negative. However, other symptoms or traits might not as obviously be negative, and could be seen as simply variants. Indeed, it might be that Silvers’ proposal is not so much about theorizing a conception of disability which is truly neutral, but about calling for attention to specific concerns, like pain, loss of options, or oppression.<sup>45</sup>

One area where discussions of balance repeatedly arise is in relation to the information provided to prospective parents in the context of prenatal testing for disability. Perhaps the use of a particular description is especially a concern here because a decision might be made based on an evaluation of the meaning of the condition the child could have, rather than a decision about, for example, treatment options to target specific health problems associated with a condition. Indeed, in this context the description might sometimes be more important than the name of the condition, as the parents might not have heard of the particular named condition, or know much of what it means. Providing accurate information in this context is often also considered to be important to support reproductive autonomy. While this might mean that it is necessary to describe some negative features that are associated with a condition, there is a recurrent criticism that the approach of health professionals is overly pessimistic about disability, and that they may only discuss the negative sides of raising a disabled child, and only rarely the joys as well.<sup>46</sup> For example, according to a recent empirical study based on the experiences of parents of children with Down syndrome, a majority of parents reported that obstetric medical providers were most likely to provide information about medical issues and reproductive options, while a minority

reported that the providers discussed psychosocial options, supports, and services.<sup>47</sup> In this study, a parent response referred to “the power of words and how [they] often set the course of what the journey can feel like for a parent—one of despair or hope” and this response emphasized that “[W]ords are powerful.”<sup>48</sup> As the authors of this study say, the “moment prenatal screening results are delivered represents the first point in the life course for parents of children with [Down syndrome] as a forever-remembered, ‘flash-bulb memory’” and this “initial experience can have a lasting impact for the family.”<sup>49</sup>

It may in this regard be helpful to distinguish cases where the condition can be cured, and where the condition is lifelong. It is understandable that where a condition has a cure that medical descriptions will set out the impact of the condition and the effect of any treatment. That is all the more so where the treatment has unpleasant side effects and the patient needs encouragement to consent to the recommended treatment. Where, however, no treatment is available, it becomes all the more important to ensure a description of the condition which emphasizes both the positive and challenging aspects of the condition. It is almost cruel in such circumstances to define lifelong conditions in entirely negative terms.<sup>50</sup> This is all the more so in the many cases where a lifelong condition, such as Down syndrome, may become tied to the identity of the individual. There a negative description of the condition easily becomes a negative description of the person.

The provision of good quality information might be thought to be a matter of “balance.” While some negative traits and health effects might need to be raised, good-quality provision of information would also require mention of positive traits. We highlight here two recent examples which relate to prenatal testing, and where we can identify certain types of descriptions: one in relation to the information provided in the medical context, and the other which is a description of Down syndrome in a legal case concerning the law on abortion on the grounds of disability. In these two examples, it seems that there is an attempt made to provide “balanced” information, but these examples also illustrate the difficulties in achieving this.

### *NHS guidance on prenatal testing*

A recent example of an attempt to provide more balanced information in the context of Down syndrome is in NHS guidance about prenatal screening. This guidance refers, for example, to a “chance” that a baby is born with a particular condition,<sup>51</sup> rather than a “risk,” which is a word with a more pejorative meaning, as mentioned above.<sup>52</sup> Indeed, the word “risk” is so ubiquitous in the context of prenatal screening, or in the context of diagnosing disability more generally, that the use of the word “chance” can be quite powerful.

The guidance also describes Down syndrome while listing both positive and negative characteristics: It says that children with this condition will have a learning disability and will be more likely to have certain health problems, but it also mentions that they can have a good quality of life and attend school.<sup>53</sup>

While it is certainly welcome that the booklet does not only mention negative features, it should be noted that there is a strong critique that the screening process itself, and the availability of abortion on the grounds of disability, sends the message that it is undesirable to have a child with the condition for which there is testing.<sup>54</sup> Interestingly, on the NHS site that describes Down syndrome for new parents (as opposed to prospective parents considering screening), the description of the condition appears to be more positive. This site says, for example, that babies with Down syndrome “are like any newborn babies,” that they will be “eating, sleeping, crying and needing love and cuddles just like all babies,” and that there is “support available for whatever you or your baby needs.”<sup>55</sup>

### *Description of Down syndrome in Crowter*

Another example where there is perhaps an attempt at a balanced description is in a recent legal case, *R (Crowter) v. Secretary of State for Health and Social Care*, which concerned the law on abortion on the grounds of disability.<sup>56</sup> The appellants in this case have Down syndrome, and made arguments that the



law sends a negative message about the value of the lives of people with their condition, and other disabled people.

In this case, the following description of Down syndrome was included:

The extent and seriousness of the disabilities suffered by people with Down's syndrome who reach adulthood varies considerably. Many may suffer from very serious disabilities and be vulnerable to various severe health problems. The lifelong care of someone with Down's is likely to require more, and often far more, from parents and other family members than in the case of a child without a disability. In very many cases that additional level of responsibility is very willingly undertaken, but in other cases parents and family find it extremely difficult to cope.<sup>57</sup>

This paints a very negative picture of Down syndrome. Many people with this condition can find it offensive to be considered to be a burden. We note, however, that the judge did seem to separate out disabilities and health problems from the condition itself, Down's syndrome.

In this case there was also, it seems, some attempt at providing some balanced information:

On the other hand, it is clear from the evidence that notwithstanding those risks many people with Down's syndrome are able to lead happy and fulfilled lives, bringing joy to their families and others, and that their prospects of doing so have been much enhanced by improvements in both clinical care and societal attitudes in recent decades. Many people with Down's have a substantial degree of independence and can work and live on their own...<sup>58</sup>

While this description of positive features might seem more "balanced," it should be noted that once again the overall message might still be thought to be negative. The features described here are in fact ones that would generally apply to most people: we usually think that people can lead fulfilling lives, can bring joy to others, and can work and live on their own. The passages thus suggest that the best case scenario is that a person with Down's syndrome will be able to do many things that most everyone can do, but not everything. This does not suggest that overall, it is desirable to have a child with this condition. It suggests, rather, that the most one can hope for is that the child will be "normal" in some ways, but not in all, and that often the reality will be worse. Furthermore, the judgment does not mention some of the specific benefits of the condition itself.

Having said this, the reality is that it might never be possible to describe disability in a way that is entirely balanced, or neutral. This is especially as many conditions will have a range of presentations, making it difficult to capture the diversity of experience. As we discussed earlier, it is possible to provide both positive and negative information, but the resulting effect is not in fact truly "neutral." One difficulty as well is that any descriptions given will inevitably be provided in a particular social context, where widespread prejudice about disability will also inform perceptions. This is a reason why a concern with stigma might be the most important.

## Conclusion

Our objective in this article was not to provide a full solution to the problems in naming and describing disability in medicine and the law, but to raise some issues to consider, and to draw attention to the particular power which exists in these contexts and that creates a risk of stigmatization, and of misleading and inaccurate information. An insult in the playground is hurtful, but this form of offense is magnified when the label or description used is supported by those in positions of authority, or, worse still, created by them. Labels and descriptions used in medicine and the law will not only perpetuate existing stigmatization, but can contribute to creating it at its source, because of the power associated with this terminology.

If stigma is understood as requiring social support, and is linked to power, it is true that removing one instance of offensive terminology will not entirely eliminate stigma at its source. Sometimes it is not the

word itself, in its inherent meaning, which is offensive, but rather the connotations attached to it. It is also possible that if an offensive word is no longer used, a new word will eventually attract a stigmatizing connotation instead. This shows that changes in terminology are not enough on their own. Efforts to address stigmatizing language can in themselves contribute to reducing stigma in society, but if stigma is deeply socially entrenched, the reality is that targeting stigma might be not only the most important objective, but also the most difficult.

Nevertheless, some cases of stigmatizing language, addressed above, might seem fairly straightforward to address. As Shakespeare says, a label need not at all be stigmatizing, at least, in theory.<sup>59</sup> Words that are highly stigmatizing and offensive could simply be avoided. Of course, this is easier said than done, but we can at least imagine that efforts can be made to no longer use the most offensive words. Taking this approach does not eliminate altogether the risk that naming and describing disability can sometimes be associated with certain negative associations, from the social context, but it can avoid a more direct perpetuation of stigma. Furthermore, since medicine and the law are areas where there is an exercise of power, combatting stigma can be particularly effective if there is an effort to target terminology used in these contexts.

As mentioned at the beginning of this article, we are concerned here only with terminology, although of course we recognize that there are other sources of stigmatization. We have not addressed this here, but in particular the influence of the law itself, in substance rather than through terminology, is particularly important due to the law's exercise of power. Indeed, the law and the state more broadly might also have the primary responsibility for combatting stigma. Nevertheless, we emphasize again that we think there is value in isolating particular instances of inaccurate, misleading and stigmatizing terminology, distinctly from any analysis of its legal effect. The words themselves have power.

As relational beings,<sup>60</sup> we construct our identities through our relationships with others. While those relationships can enable flourishing lives, they can also be used to undermine well-being. Stigma is one powerful way in which a person is constructed by the labels that are attached to them, particularly where those labels carry with them some negative connotation. In providing authoritative labels and descriptions for disabilities, medicine and the law have a powerful role to play in setting the scene for the subsequent social interactions and relationships that will shape identities.

**Competing interest.** The authors declare none.

## Notes

1. Herring J. The power of naming: Surnames, children and spouses. In: Freeman M, Smith F, eds. *Law and Language* Oxford: OUP; 2013:310–27.
2. Shakespeare T. *Disability Rights and Wrongs Revisited*. 2nd ed. New York: Routledge; 2014, at 95.
3. See discussion of this point in: Parens E, Asch A. The disability rights critique of prenatal genetic testing: Reflections and recommendations. *The Hastings Centre Report* 1999; 29(5):S1–S22, at S2.
4. A good narrative account of an interplay between these different sources of prejudice is found in this story of a Mongolian woman's experience after her son was diagnosed with Down syndrome: Ramsey U. *Mongol*. Salford: Saraband; 2014.
5. Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin Classics; 2022, at 1.
6. See note 5, Goffman 2022.
7. Garland-Thomson R. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press; 1997, at 31.
8. Crocker J, Major B, Steele C. Social stigma. In: Gilbert DT, Fiske ST, eds. *The Handbook of Social Psychology*. Boston, MA: McGraw-Hill; 1998: 2, at 504–53, 505.
9. Link B, Phelan J. Conceptualizing stigma. *Annual Review of Sociology* 2001;27:363–85.
10. Solanke I. *Discrimination as Stigma: A Theory of Anti-discrimination Law*. Oxford: Hart Publishing; 2017.

11. Solanke I. The anti-stigma principle and legal protection from fattism. *Fat Studies* 2021;10(2):125–43.
12. Lloyd C, Corcoran E, Murray L. Public health England and co-production with the fetal anomaly screening programme. *The New Bioethics* 2023;29(3):216–25.
13. Kaposy C. Prospects for limiting access to prenatal genetic information about Down syndrome in light of the expansion of prenatal genomics. *The New Bioethics* 2023;29(3):226–46.
14. *McFarlane v. Tayside Health Board* [2000] 2 AC 59.
15. *Parkinson v. St James and Seacroft University Hospital NHS Trust* [2002] QB 266 (CA).
16. See note 15, *Parkinson*, [90].
17. See note 15, *Parkinson*, [90].
18. Daniels N. Justice, health and health care. *American Journal of Bioethics* 2001;1(2):2–16.
19. Glasby J, Littlechild R. *The Health and Social Care Divide: The Experiences of Older People*. 2nd ed. Bristol: Policy Press; 2004.
20. Catita M, Águas A, Morgado P. Normality in medicine: A critical review. *Philosophy, Ethics, and Humanities in Medicine* 2020;15(1):3.
21. Abortion Act 1967, section 1(1)(d).
22. *R (Crowter) v. Secretary of State for Health and Social Care* [2022] EWCA Civ 1559, [54].
23. See note 22, *Crowter*, [54].
24. The Abortion (Northern Ireland) Regulations 2020, section 7.
25. NHS inform. Autism spectrum disorder (ASD); available at <https://www.nhsinform.scot/illnesses-and-conditions/brain-nerves-and-spinal-cord/autism-spectrum-disorder-asd> (last accessed 19 Oct 2023).
26. Beck TJ. Tracing disorder across Theories of autism, empathy, and mental health care. *Disability & Society* 2018;33(8):1303–26.
27. Anderson-Chavarria M. The autism predicament: models of autism and their impact on autistic identity. *Disability & Society* 2022;37(8):1321–41.
28. *Khan v. Meadows* [2021] UKSC 21, [8].
29. See note 27, Anderson-Chavarria 2022.
30. Herring J, Johnson K, Richstein JJ. Use of “Retardation” in FRAXA, FMRP, FMR1 and Other Designations. *Cells* 2022;11(6):1044.
31. Ouch! (BBC Website); available at <https://web.archive.org/web/20070320214418/http://www.bbc.co.uk/ouch/yourspace/worstwords/> (last accessed 19 Oct 2023).
32. Regier DA, Kuhl EA, Kupfer DJ. The DSM-5: Classification and criteria changes. *World Psychiatry* 2013;12(2):92–8.
33. House of Commons, Petitions Committee. Online abuse and the experience of disabled people 2019, at para 34; available at <https://publications.parliament.uk/pa/cm201719/cmselect/cmpetitions/759/759.pdf> (last accessed 19 Oct 2023).
34. Thomas T. ‘Insulting’: Shock as NHS uses offensive term for people with learning disability. *The Guardian* (18 October 2022); available at <https://www.theguardian.com/society/2022/oct/18/insulting-shock-as-nhs-uses-offensive-term-for-people-with-learning-disability> (last accessed 19 Oct 2023).
35. Haringey London. Haringey CAMHS – Learning Difficulties; available at <https://www.haringey.gov.uk/children-and-families/local-offer/health-services/children-and-adolescent-mental-health-service-camhs/haringey-camhs-learning-difficulties> (last accessed 19 Oct 2023).
36. Public Law 111–256, U.S. Congress.
37. *in Re B. (A Minor) (Wardship: Medical Treatment)* [1981] 1 W.L.R. 1421 (decided on 7 August 1981). For a discussion of this case and its significance, see: Herring J. *Re B (A Minor) (Wardship: Medical Treatment)* [1981]: ‘The child must live’: Disability, parents and the law. In: Herring J, Wall J, eds. *Landmark Cases in Medical Law*. Oxford: Hart Publishing; 2015:63–82.
38. *Airedale NHS Trust v. Bland* [1993] AC 789.
39. See for example on the NHS website: NHS. Disorders of Consciousness; available at: <https://www.nhs.uk/conditions/disorders-of-consciousness/> (last accessed 19 Oct 2023). For a criticism of the use of the term vegetative, see for example: Laureys S, Celesia GG, Cohadon F, Lrvijisen J, León-Carrión J,

- Sannita WG, et al. Unresponsive wakefulness syndrome: A new name for the vegetative state or apallic syndrome. *BMC Medicine* 2010;**8**(1):68.
40. Albrecht GL, Devlieger PJ. The disability paradox: High quality of life against all odds. *Social Science & Medicine* 1999;**48**(8):7–88 Amundson R. Quality of life, disability, and hedonic psychology. *Journal for the Theory of Social Behaviour* 2010;**40**(4):374–92
  41. Silvers A. On the possibility and desirability of constructing a neutral conception of disability. *Theoretical Medicine and Bioethics* 2003;**24**(6):471–87
  42. See note 41, Silvers 2003, at 475 and 477.
  43. See note 41, Silvers 2003, at 475–6.
  44. Beaudry J-S. Beyond (models of) disability? *Journal of Medicine and Philosophy* 2016;**41**(2):210–28.
  45. See note 44, Beaudry 2016, at 218–9.
  46. Robinson H. Abortion on the basis of a risk of disability: The parents' interests and shared interests. In: Phillips AM, de Campos TC, Herring J, eds. *Philosophical Foundations of Medical Law*. Oxford: Oxford University Press; 2019:214–27; Bruce F. Parliamentary Inquiry into Abortion on the Grounds of Disability (House of Commons) 2013; at 30; available at <https://dontscreenusout.org/wp-content/uploads/2016/02/Abortion-and-Disability-Report-17-7-13.pdf> (last accessed 19 Oct 2023).
  47. Meredith S, Weiss S, Kleinert HL, Tyrrell CA. The impact of implicit and explicit bias about disabilities on parent experiences and information provided during prenatal screening and testing. *Disability and Health Journal* 2023. doi:10.1016/j.dhjo.2023.101514.
  48. See note 47, Meredith et al. 2023.
  49. See note 47, Meredith et al. 2023. On the receipt of a diagnosis as a flash-bulb memory, see also: Skotko B. Mothers of children with Down syndrome reflect on their postnatal support. *Pediatrics* 2005;**115**(1):64–77, at 76; May CP, Dein A, Ford J. New insights into the formation and duration of flashbulb memories: Evidence from medical diagnosis memories. *Applied Cognitive Psychology* 2020;**34**(5):1154–65.
  50. Of course, there may be a few conditions where there is nothing positive that can be said about them.
  51. Public Health England. Screening tests for you and your baby (last updated 4 Aug 2022); available at <https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-description-in-brief> (last accessed 12 Jan 2023).
  52. See for example: Shakespeare T. “Losing the plot”? Medical and activist discourses of contemporary genetics and disability. *Sociology of Health & Illness* 1999;**21**(5):669–88, at 673.
  53. See note 51, Public Health England 2022.
  54. See note 3, Parens, Asch 1999.
  55. NHS. Advice for new parents: Down's syndrome; available at <https://www.nhs.uk/conditions/downs-syndrome/advice-for-new-parents/> (last accessed 19 Oct 2023).
  56. See note 22, Crowter.
  57. See note 22, Crowter, [18]. The Down Syndrome Association explains that the terminology Down Syndrome or Down's Syndrome is acceptable: Down's syndrome association; available at <https://www.downs-syndrome.org.uk/about-downs-syndrome/> (last accessed 19 Oct 2023).
  58. See note 22, Crowter, [19].
  59. See note 2, Shakespeare 2014, at 95.
  60. Herring J. *Law and the Relational Self*. Cambridge: Cambridge University Press; 2020.