

Disability Language and Diversity

A guide for the perplexed

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The term 'disability language' refers to the language we use when talking to or about an individual with either a cognitive or a physical condition¹ and for whom social, environmental, or attitudinal barriers disable them in some way. This includes people with physical disabilities such as those who use a wheelchair or, for example, an individual with a learning disability. Any language pertaining to what it means to be human affects us all. How do we describe what it means to be a human being? Language is the primary social expression of identity. Our name, our culture, the colour of our eyes, the relationship we have to our family and the role we have in our communities is all articulated and owned in the use of language. Language can be used to assert power or diminish, or it can affirm equal access and participation in the community.

'Disabled' does not refer to a defined group of people. There is no such group as 'the disabled'. Each person is different, and we are all only temporarily non-disabled anyway. This is demonstrative of the systemic problem of defining people by what they are not rather than who they are. Furthermore, language is always evolving, especially when it is used to describe groups that have been historically marginalized or discriminated against. Disability language was developed in comparison with ability or what is considered 'normal'. It should be noted however, that the term disability was not widely used before the mid-nineteenth century, nor was the term normal² and only in the 1960's did 'Disabled' become a collective identity.

However, for many years 'the disabled' were seen in the context of charity. In modern parlance the word is tainted because of its use of power and its use of pity to describe relationships with disabled people. It is one of the flaws of this approach that, well-meaning though it might be, it sees disabled people as being the object of its actions. Disabled people are having something done *to* them, rather than *with* them. The loss of partnership in such an approach can be replaced by pity for the 'plight' of disabled people, rather than acknowledging their equal status in society or the degree to which their gifts would immeasurably enhance society, if only the barriers to participation which hinder them were removed.

1 Medical model

To better understand disability language and how it shapes identity, it is helpful to understand how perceptions of disability have changed over time and how language has changed. There are two dominant models of (or ways of perceiving) disability: the medical model and the social model. The medical model is a more traditional approach in which disability focuses on the body and the condition a person lives with. It dates back to the eighteenth century and has been articulated most clearly by the 20th century philosopher Michel Foucault who pointed out that the industrial capitalist society viewed disability as a 'problem' with the body. It is a deficiency. The problem here is that it doesn't take much

¹ Throughout this paper we have used the word 'condition' or 'disabling condition' instead of the word 'impairment' which is traditional when disability is about the nature of the body. We are uncomfortable with the word impairment because of its negative connotations. We have retained it when the context shows that it is used negatively or placed it in quotation marks.

² For more reading on the invention of normal see Davis, Lennard J. *Enforcing Normalcy: Disability, Deafness, and the Body*. Nota, 2016

to infer that it is the person, themselves, who is deficient, and the history of disability is replete with examples of the ways in which disabled people have been denied their human rights on this basis.

Foucault wrote specifically about the growth of asylums in the eighteenth and nineteenth century and within this new model or paradigm of understanding disability, around three hundred thousand people were committed to asylums between 1800 and 1914. This included people with both physical and cognitive conditions. During that same time the number of people with psychological ‘impairments’ increased almost sevenfold from 14,300 to 967,000.

While the medical model refers to much more than is described by the approach of medical institutions to people who are disabled. These approaches often give good examples of how this model operates and its shortcomings. For example, placing a label on somebody, (the bloke in the wheelchair) can reduce a person’s sense of self, making them feel that they are merely part of a system. It is also easy to see how power can be exercised by professionals who, in treating a patient, can ignore someone’s own story about living as a disabled person. In the same way, professionals may use specialist language that is not understood by people with disabilities to describe their condition. It may also be assumed that it is disabled people who must adjust to a society that is designed around non-disabled people, rather than that society having to adjust to provide them with access to every area of its life as a matter of justice and fairness.

However, one strength of this model is that it does take the body seriously. People are disabled by their condition as well as by the environment they live in and the barriers to participation they face in society. While it is true that people can be treated as passive recipients of medical attention or social care having little say in what is said or done to them, it is also true that the quality of many peoples’ lives has been enhanced by progress in medical treatment, rehabilitation, early intervention, and social care. There can be benefit in the naming of a condition to aid in understanding our own person, as well as the people around us and can also point to treatment or adjustments that enable a person to more fully participate in their community. For example, someone who experiences depression in a disabling way can choose to take medication to mitigate the effects of their condition.

Taking the needs of the body seriously cannot be ignored. All too often this approach is described stereotypically and negatively because it appears to avoid discussing issues related to social justice and rights. However, within the day-to-day experience of people with disabilities, the interventions and support they receive from medicine and therapy are often extremely important. Whatever the weaknesses of the approach, restricting such an approach to the word ‘impairment’ (a word which is rarely used in conversation) rather than including it as an essential element and legitimate response to disability, inevitably reduces the impact of the lived experience of what it means to be disabled. In many senses it is a misnomer to attribute the word ‘medical’ to this approach since the essential element of it is that it focuses on the body. For instance, many attempts to ‘heal’ somebody in a religious context, (or indeed any other context) focus on changing the (‘impaired’) body by prayer or other practices and by doing so bring it into line with some functional norm, which is preferable. However, changing the social context in which the person lives, as they are, may be just as transformative for them.

2 Social model

In contrast, the social model focuses on external factors and asserts that it is society that disables an individual. An essential part of what it means to be human is our social nature; we are social animals.

Just as our bodies express something of our human identity, so the environment in which we live and the attitudes we face every day are also a part of who we are. The social model sees this element as being more dominant in the definition of disability. People with a disabling condition live in a disabling society. Since the society is organized around people perceived as non-disabled, anybody who does not share those characteristics struggles, yet again, to find a way of being a worker, citizen or even family member in such a world. The social model does not deny that a person with a disabling condition has their day-to-day activities affected by it, but within the social model, the emphasis is elsewhere. It is a fundamental objective of human rights to challenge and eliminate the barriers that keep disabled people from fully participating in society and exercising their freedom.

Such barriers to participation can be environmental, for example, steps to buildings to which a wheelchair user needs access, narrow doorways that cannot accommodate assistive devices such as wheelchairs, or lack of access to transport systems. Disabled churchgoers will be familiar with buildings to which they have no access or are proudly shown to an accessible toilet in which they cannot turn round in a wheelchair, which has obviously been designed without any advice from disabled users

But barriers can also be attitudinal. One mother with autistic children spoke of how she is frequently shouted at in the street in abusive terms and told to get out of the community. Hate crime is also experienced by disabled people. Abusive language is also prevalent on social media. Many people still think of disabled people negatively and as having less to contribute to society, or even being a burden on society.

The Equality Act 2010 was designed to end all forms of discrimination which can be directed at disabled people. That discrimination can be found in access to employment, housing or simply being a low priority in having access to resources. During the pandemic, disabled people suffered more from loneliness and isolation than did non-disabled people. They were also six times more likely to die as a result of contracting Covid-19 which led to high rates of anxiety for many. In terms of employment, there are many stories of disabled people not getting an interview for a job when they said that they were disabled on the application form but getting one when they did not. The social model sees these barriers and attitudes as matters of human rights and that the best way to deal with such a disabling society is to protest and campaign, seeking to overturn such behaviour by changing the law, challenging oppressive behaviour and educating the community. The idea is also that if you improve society for disabled people you improve it for all people.

Critics of the social model, however, suggest that it omits factors such as class, age, gender, and ethnicity which might also contribute to a person's experience of society alongside their disability. It also overlooks the personal implications of a person's experience such as pain, depression and internal oppression. It implies that a disabled person's identity and experience is wholly defined by the external society and is a consequence of it. Some argue that as a result, people with disabilities, resigned to the stereotypes and labels placed on them, do not have the power to overturn existing policy, language or any other disabling barriers embedded in society.

Some feminist writers have commented that the social model does not take the distinctiveness of women's bodies seriously enough. Others state that those who advocate in favour of social change and disability rights have as little legitimacy in speaking for other disabled people as non-disabled people, because they do not know what it means to live with the disabling conditions of others. People with learning disabilities are frequently cited as often being unable to advocate for themselves and needing

others who know them and may live with them to advocate for them. These people may well be non-disabled but represent the voice of somebody who may otherwise be voiceless.

Another prominent and active debate surrounding disability language is whether to use 'person-first' or 'identity-first' language. The intention in this short paper is to set out what is helpful in each approach but also to show that each has weaknesses.

3 Person-first language

Person-first language was brought to the fore in the 1960s by an American psychologist named Beatrice Wright, who studied the social-psychological effects on people with physical disabilities. This language is widely used in North America. It emphasizes that someone is a person or a citizen first and that disability is one aspect of a person, but not all of them. It emphasizes that the disability community is primarily a community of people. It also confirms the right for people with disabilities to define themselves. For example, a person can identify themselves as a person who uses a cane, or a person with MS. Both are true, but one is more explicit than the other. Person-first language has gained considerable acceptance among people with disabilities and organizations representing them throughout North America and many other countries around the world. It is used by the United Nations, most visibly, on its annual day for 'Persons with Disabilities' and in the UN Convention on the Rights of Persons with Disabilities. The primary legislation on disability in the US, the Americans with Disabilities Act (1990), uses person-first language throughout and the Accessible Canada Act (2019) also uses person-first language throughout.

There are specific conditions where person-first language is preferable. With conditions such as epilepsy or diabetes it is more respectful to say, 'person with epilepsy' or 'woman with diabetes' rather than 'epileptic' or 'diabetic'. Similarly, with reference to obesity as a disease state, person-first language is more respectful. A 'man with obesity' is preferred to 'obese man'. In the case of people with mental health challenges it is usually best to use person-first language. 'A man with schizophrenia' (not a schizophrenic) or 'a woman with a bipolar disorder' (not a bipolar woman) is preferable. Some would use the words 'living with', so person-first language might describe somebody as 'a person living with epilepsy' or 'a woman living with MS'. One can also see why certain forms of language have become insults and unacceptable. To say 'he is retarded' or 'she is a moron' might have been used in previous times but the emphasis now is on the personhood and dignity of every human being, their inherent rights and full participation in the community; these terms are now considered derogatory and very hurtful.

When combined with the social model of disability, person-first language was meant to shift the focus away from the 'impairment' to the social barriers that impede full participation in the community.

4 Identity-first language

However, some people feel that person-first language does not represent identity accurately. Advocates of identity-first language prefer the term, 'disabled person'. This approach states that disability is a diverse human experience and an essential identifier in what it means to be human. It is often the preferred language of the disability movement. Disability activists will nearly always express a strong preference for the term 'disabled person' and will contest any other way of describing them. Some would say that they found it a moment of liberation when they identified with their disability. From this

perspective, disability is not an 'add-on' to the otherwise, common experience of humanity. It is central to how a person sees themselves. It is about diversity not deficiency, and by identifying themselves as a 'disabled person' they are simply acknowledging that they belong to a specific cultural group. So, for instance, at times there has been a strong reaction to placing the word 'person' before the word 'blind' since it appears to be defensive, conveying the impression that to be blind is a matter of shame. The UK legislation, enshrined in the Equality Act (2010), uses identity-first language throughout.

The Deaf community prefers identity-first language. There is a preference for 'a Deaf person' and an upper-case 'D' is used. Deaf people regard themselves as members of a cultural or linguistic community who use sign language to communicate. Where 'd' is used in lower case it refers to people who are hard of hearing. Sometimes these are combined, and 'D/d' is used to show that deafness is being addressed in its broadest sense. Many Deaf people will reject 'hearing impaired' as they do not perceive an inability to hear as a deficit. Being 'Deaf' is therefore not an experience of disability but of belonging to a different cultural and linguistic group. It is essential to the way in which the person sees the world. So, for identity-first advocates, the language of person-first does not sum up the extent to which disability is an essential part of a person's identity. Only the phrase 'disabled person' will do. Of course, advocates of person-first language would say that one of the intentions of that approach was precisely to enable people to be free to describe themselves as they wish to be known. Since they are a person first, they have choices.

There are exceptions to these generalizations, however. In the US and Canada especially, there is a movement to use identity-first language when referring to autism. The preferred term is Autistic person (with an upper case 'A') rather than a 'person with autism' whilst in the UK, people with Down's syndrome prefer 'person with Down's syndrome' as opposed to Down's person.

The etiquette that applies to this is to ask the person how they wish to be addressed. If that is not possible, to use person-first language as it confers on them a recognition of their humanity over their disability. It also gives them the freedom to state their preference for identity-first language and to be called a disabled person.

5 The debate

The debate as to which language to use can be quite heated and it is not readily apparent to those who are not a part of the disability community as to why this should be the case. Surely the phrases are merely different in emphasis and not mutually exclusive?

Sometimes the reason is that somebody feels that others are trying to define who they are in a way that is unwarranted. This is especially true when a non-disabled person assumes that they know how a disabled person (or a person with a disability) wishes to be addressed. This issue is not just confined to personal relationships. There is, within the disability movement, a phrase which says, 'nothing about us without us'. It means that non-disabled people do not have the right to speak about disability because they have not experienced it. Nothing should be written about disabled people unless it can be owned by them. In many senses this commitment has been a powerhouse of the disability movement and the legislation which has attempted to change the way society views disability would not have come about had it not been for this unifying sense of purpose. But can somebody who is Deaf speak on behalf of someone who is a wheelchair user? Of course, their worlds will overlap to a certain extent due to their experience of disability. For instance, someone who is Deaf and in a wheelchair could presumably speak

on behalf of someone who is not Deaf and in a wheelchair around issues of wheelchair access. However, there are boundaries between these lived experiences which need to be observed.

The experience of disability, however, is not confined to people who live with a disabling condition. Families, neighbours, friends and various professional groups all have their own experience of what it means to live with, or relate to, people with disabilities. They can relate their own life story and the way in which disability has affected their own lives. In the spirit of being inclusive, one can also argue that our communities are made up of both disabled and non-disabled individuals, therefore both should be part of the conversation. A phrase used in community development that encompasses this idea is, 'for us, by us.'

The idea that somebody only has 'lived experience of disability' because they live with a disabling condition and also experience attitudinal and other barriers to participation does not go far enough. Siblings who have a brother or sister with a disabling condition such as uncontrolled epilepsy or cystic fibrosis will be deeply affected by it and will have their own story to tell. Parents who have battled with the education system because it fails to recognize the specific needs of their child will certainly have experienced barriers to participation. However, such people cannot speak as if they are a disabled person. A non-disabled person who says to a disabled person, 'I know just what you are going through', is likely to get a firm response! They can therefore speak as somebody with lived experience of disability *but not as a disabled person*.

Also, people can fail to appreciate the extent to which a person has moved from seeing their disability as a negative constraint to seeing it as an expression of diversity. Instead of reducing their impact on the world and their ability to contribute to society, their disability is the means by which that can be achieved. Disabled people protest when stereotypical images are used to imply tragedy, weakness, or attempt to evoke pity from the audience. Rather, there needs to be awareness around the resilience of disabled people and their ability to participate equally in society as well as challenging the social, environmental, and attitudinal barriers that prevent this.

When one looks at disability within a global perspective there is much to do. One billion people in the world today are disabled, according to the World Health Organization. In countries where there is extensive poverty and little medical infrastructure, let alone equality legislation, disabled people are facing seemingly insurmountable odds. It is here that we can see that the social model is a very Western idea. You need to have a democratic system and access to a good health and welfare system before it can be considered. A model which is culturally bound is a problem when considering disability in a global context.

As mentioned, language is always evolving especially as it pertains to identity. The aims of disability language are no different than that of any other language of a collective – to deny that they are 'other' and affirm identity. As humans, we are all worthy of dignity, freedom, respect and the right to fully express our humanity through participation without barriers in our communities.

6 A Theological Reflection

Any discussion about what it means to be a person who is perceived to be different in some way must begin by asking the question, 'what does it mean to be human?' If there is some divinely sanctioned

norm then, of course, anybody who does not conform to that will be seen to be less than fully human. Whether we are considering ethnicity, sexual orientation, gender, education, or ability it is difficult to find one's way in a society which is constantly reinforcing norms that suppress the desire of those who do not conform to those norms to find their own identity. It is particularly painful when the Church adds to the difficulties they face rather than providing a theology which is a source of liberation and a foundation for participation in society.

It is not possible to sum up the contribution of theology to the debate about disability in a few paragraphs. However, there are some themes which are useful to highlight. The starting point for any theological approach to humanness is the nature of God and particularly God in creation. The creativity of God and the declaration that creation is 'good' is an essential insight into what it means to be human. God says, 'let us make humanity in our own image'. (Gen. 1:26) We reflect something of who God is. Being made in the image of God is part of what it means to be human, and people deserve dignity and respect because of that. But this is not just something which is about the individual. In the creation account at the beginning of Genesis, it was only when the woman was made that humanity became 'persons in relationship'. The first person, portrayed as made of dust, who was on their own, was judged as 'not good'. This was not just because of loneliness, but because God is Trinity, and an individual could not represent a God who is love because love flows between the three persons of the Trinity. So, with the creation of the woman, humanity became, not a collection of individuals but 'persons in relationship'. The image of God is personal, in that we reflect something of who God is, but it is also between us.

So, human relationships are blighted when others are not treated with dignity and respect. We are called, not just to make statements about being made in the image of God but, in relationship, to look for that image in others and celebrate it. Whether we are with someone living with dementia or a person with severe learning disabilities, we celebrate our common humanity and respect the differences between us. We look beyond social convenience and popular stereotypes to something which unites us deeply: the image of God reflected in us all, whether religious or not, disabled or non-disabled.

A theology which wants to counter the tendency of societies to become utilitarian as they become modern will always want to focus on the person. As abortion rates of unborn children with disabling conditions increase, and DNR notices (Do Not Resuscitate) are placed on the files of the frail elderly and people with learning disabilities, (a scandal during the pandemic) there is a need to place the onus on the fact that vulnerable people are worthy of dignity, respect, and protection. Many will want to use person-first language in a utilitarian society to emphasize how important personhood is and how important it is to honour the lives of those who may be most powerless. Nevertheless, the desire to use identity-first language and by doing so to draw attention to one's belief that disability is about diversity and not deficiency, can be seen as a radical stance which confronts society, biased in favour of ability rather than disability, with a different way of seeing the world.

Both have their place. Both are attempting to convey different truths. What the theological insights show us is that mutual respect is important because it is through conveying that respect that the image of God is between us.

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