HEBA Symposium March 2022 – Disability, Friendship and Inclusion Session 1 – What is Disability?

In this first session I'm going to start by exploring the language of disability. The inappropriate use of language is one of the ways in which disabled people experience exclusion from society and church communities. We also need to be aware of some of the less obvious barriers that language creates.

I will then outline three ways of understanding disability and who disabled people are. I will note that other models exist. The session will end with an opportunity to discuss these in breakout groups, before a brief Q&A.

At the end I can post my PowerPoint and notes, with bibliography, in the chat if that is helpful.

Language of Disability (No PP)

The language of disability can feel like a minefield. There are two ways in which language shapes our understanding of disability, firstly through descriptive language and secondly through metaphoric language.

Descriptive language such as 'handicap', 'cripple' etc. is now frowned upon and should be avoided. The frequently used phrase 'the disabled' is problematic in two ways: it emphasises disability rather than personhood; it assumes that disabled people are alike when we are a very diverse group of people.

In the US people tend to use 'person first language', i.e. "a person with a physical/intellectual/learning Disability". I'm a little uncomfortable with that is as it can infer that a person 'owns' their disability. It sounds too much like "a person who has XYZ disability [with an internal characteristic]" rather than "a person who is disabled [by something external]".

UK tends towards opposite approach – 'Disabled Person' or 'Disabled People'. However, when being specific about a particular disabled individual then person first language can be helpful, i.e. a person with learning disabilities, or person with a physical disability. Phrases like 'a Downs person' should be avoided as this puts the emphasis on the medical condition of Downs Syndrome. I was once referred to as 'a wheelchair', as in 'There's a wheelchair coming up to the platform', when asking for assistance boarding a train.

There are subtle differences between the language of 'a wheelchair user', 'Person who *uses* a wheelchair' and 'person *confined* to a wheelchair'. This can depend on perspective of either congenital disability or acquired disability. I am freed by my wheelchair not confined by it. Even among people with acquired disability that perspective differs.

The terminology of 'able-bodied' is understood by some disabled people, including myself, to be problematic. It sets up a dualism between dis-abled and able-bodied which is unhelpful. I tend to use disabled and non-disabled to differentiate the two very broad and diverse groups. Some people use the phrase 'temporarily able-bodied', though this is a bit cumbersome.

Sometime a very small change to the language we use can have a significant effect. For instance, saying 'Please stand if you are able to,' before we sing in church is much more inclusive than 'Please stand.' Similarly asking people to stand in response to something God may be doing in a congregation excludes a response from those who cannot stand.

Much of the language we use when talking about God and our faith is metaphoric. At their most basic, metaphors can be thought of as speaking about one thing, that is relatively poorly understood, in terms of another, which is relatively well understood. This is sometimes referred to as the 'like and unlike' or 'similarity and dissimilarity' of metaphors. This can be unhelpful if disability is used as a metaphor for something else. For instance, blindness is often used as a metaphor for lack of understanding.

Some metaphors can be described as emotive, producing an emotional response. One example would be the 'fight/battle' metaphors often used regarding the experience of having cancer. Disabled people are sometimes described as 'overcoming' or 'battling' the challenge of disability.

It has been argued by Sally McFague, Brian Wren and others that metaphors form dominant groups, which in turn create models and paradigms that not only reflect but shape our understanding of concepts such as disability. For example, the group of metaphors that describe God as King-God-Almighty-Father-Protector, that Wren refers to as KINGAFAP¹ links issues of gender and power, shaping our understanding of church and society such that gender roles are distinct and related to issues of power over others. The underlying assumption that the 'norm' is male and non-disabled, infers that to be female or disabled is to lack power.

We will examine metaphors of 'walking with' and 'watching over' in the third section as they are a significant aspect of Baptist covenant theology.

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¹ (Wren, 1989, p. 123f)

Models of Disability (PP)

Without most of us realising it we tend to understand disability/disabled in one of two ways: either as a characteristic of a person/individual, as we do with sex/gender or ethnicity; or as an attitude of society known as ableism, as we do with racism and sexism. These are reflected in two dominant models of disability, with a third one often use in US text books which are influential here.

Medical/Individual Model

Firstly, there is a medical or individual model of disability. The following three terms and definitions were only formally stated in the mid to late twentieth century. They describe the dominant understanding of disability, and therefore which people were identified as disabled, which has its roots in the late seventeenth and early eighteenth centuries, with the Enlightenment, the beginnings of modern medicine, and the Industrial revolution. Unfortunately, this understanding often persists today.

Impairment – Any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability – Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap – A disadvantage for an individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex, social and cultural factors) for that individual.²

This understanding locates the so-called 'problem of disability' with the individual in isolation from society. The solution is understood to be curing or healing someone of their impairment so that they can fit in with so-called 'normal society'. If this is not possible then the impact of the impairment needs to be reduced by provision of aids, like a wheelchair.

According to this model of disability, my inability to walk is identified as an impairment. My disability is the restriction my impairment places on my ability to move independently and carry out tasks that a non-disabled person would do, which in turn produces the disadvantage described as handicap. This leads to my handicap being understood as the disadvantage I experience due to my

² (Barnes & Mercer, 2010, p. 20) Quoting from (WHO, 1980, pp. 27-29).

disability and impairment. Within this model, the attitudes and actions of other people and society as a whole are not taken into account.

We should acknowledge that churches had been a significant, if not dominant, source of support for disabled people during the 18th and 19th centuries. This was, however, often in the form of charity, both to those in the community but often through institutions. While this is to be commended it tended to isolate disabled people and reinforce the asymmetric relationships they experienced with non-disabled people. The rise of modern medicine was often a negative experience for disabled people, with power located with doctors rather than disabled people. However, the defining of disabled people within this model also identified those who might receive support and assistance.

Social Model of Disability

Secondly, in the UK the Social Model of disability was developed in the 1980's by sociologists and disability campaigners as a reaction against the Medical/Individual model. Many of the proponents of this model were and are disabled people, both academic sociologists and activist campaigners. This model has only two terms.

Impairment – Lacking part or all of a limb, or having a defective limb, organ or mechanism in the body.

Disability – The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have a physical impairment and thus excludes them from participation in the mainstream of social activities.³

This understanding locates the so-called 'problem of disability' in society rather than the individual. It explicitly breaks the link between a person's impairment and the disability resulting from attitudes and actions of society. The solution is to change the attitudes and actions of society, rather than the individual, often through legislation such as the Disability Discrimination Act (1995) and the subsequent Equalities Act (2010). These seek to remove barriers that exclude and discriminate against disabled people.

³ (Barnes & Mercer, 2010, p. 30; Johnstone, 2001, p. 14; Oliver, 1990, p. 30) both quoting (UPIAS, 1976, p. 14). (Goodley, 2017, p. 9) references the definition in (Disabled Peoples' International, 1982) which has slightly different wording. (Owens, 2015, p. 386f) provides a history of the various Social Models.

Unfortunately, both pieces of legislation define whether you are disabled in terms of individual impairments, rather than arising from social attitudes, stating that:

You're disabled ... if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.⁴

It might be better to say that you have an impairment... which leads to experiencing disability... arising from the attitudes and actions of others.

According to the Social model my impairment, not being able to walk and therefore my use of a wheelchair, is **not** connected to my experience of being disabled. My experience of disability arises from societal attitudes and actions towards me as a wheelchair user, excluding me from participating fully in society.

One of the key criticisms of the Social Model of Disability is that it either ignores or significantly downplays the real impact of impairments. We cannot escape the reality that disability, while very much to do with the attitudes and actions of others, is embodied in a person. Even if all social, economic, political and physical barriers are removed, the impact of some impairments will prevent a number of disabled people from participating in some aspects of society. For instance, as a wheelchair user I would never have been able to pursue a career in the front line of the police, fire or ambulance services. By tending to ignore the impact of impairments, this model risks homogenising disabled people, since there is a failure to take into account the diversity of impairment and experience among disabled people. In order to take into account diversity of impairment, the model would have to identify a fragmented series of minority groups.

⁴ Both acts use the same definition: Disability Discrimination Act (2005) definition http://www.legislation.gov.uk/ukpga/1995/50 Accessed 18/8/2019 and Equality Act (2010) definition https://www.gov.uk/definition-of-disability-under-equality-act-2010 Accessed 18/8/2019

⁵ (Hughes & Paterson, 1997; Thomas, 2014, pp. 13-15)

⁶ (Johnstone, 2001, p. 21)

⁷ (Shakespeare, 2013, pp. 80-81) There is a need, however, to be careful about developing a hierarchy of disability. Reinders is concerned about this regarding physically disabled people and people with learning disabilities (Reinders, 2008, pp. 24-26). See also (Marks, 1999, pp. 115-136) for a discussion regarding the diversity of impairments among disabled people. On the other hand, Block suggests all disabled people 'have equal standing within the disability rights movement.' (Block, 2002, p. 54)

⁸ Such as may occur for people who have Down Syndrome with an act of Parliament (The Down Syndrome Act 2022) focusing on their medical condition that is currently progressing through parliament.

The model is also at risk of ignoring the differences between disabled people on grounds of race, gender, or sexuality, very much in the same way as writers in other fields are at risk of ignoring disability, or using it in a negative way. In addition, there are dangers of reducing disability to macro-social phenomena, which both disembodies and dislocates disabled people from their life experiences. Ultimately, this dislocation of impairment and disability can sustain an unhelpful dichotomy of the two, by focusing on the latter to the exclusion of the former. For example, although I may experience the same discriminatory social attitudes as other wheelchair users, how I respond is shaped by my particular limits, family and social context. When I was living in a hostel for disabled people, I was aware that other wheelchair users with similar impairments responded to social attitudes in very different ways, partly shaped by their family and school experiences.

Minority Group Model

Thirdly, there is a different approach in the USA. This model understands disabled people to be members of a minority group which is oppressed, excluded and marginalised by the majority group of non-disabled or 'ablebodied' people. The underlying minority group model was developed in the 1960s with the civil rights movement addressing discrimination against women and ethnic minority groups. It was adopted by disability rights groups seeking better treatment of disabled Vietnam veterans in the early 1970s.

A definition is given by Nancy Eiesland, which is a bit cumbersome but is the best I've come across. Disabled people seen as a minority group are understood to be:

... a group of people who, because of their physical characteristics, are singled out from the others in the society in which they live for differential and unequal treatment, and who therefore regard themselves as objects of collective discrimination.¹²

If you read some of the literature on disability, both in sociology and theology, we find that the minority group model is sometimes equated to the social model but it is in reality a different model.

⁹ (Marks, 1999, pp. 89-94)

¹⁰ (Gleeson, 1999, pp. 19-22) argues that the Social Model has a tendency to ignore history. He also critiques the underpinning philosophies of the Social Models, raising concerns about structuralist, humanist, idealist and normalisation approaches.

¹¹ (Shakespeare & Watson, 2002, pp. 8, 10, 15-19)

¹² (Eiesland, 1994, p. 63)

Other models

Other models exist, attempting to account for the very complex interactions between individuals and society that give rise to discrimination and exclusion of disabled people. These are known as 'critical realist' approaches. For instance, Tom Shakespeare defines disability as

... the outcome of the interaction between individual and contextual factors, which includes impairment, personality, individual attitudes, environment, policy and culture.¹³

Worldwide poverty and related health issues are the biggest causes of worldwide disability. In the developed world the aging population is a significant factor in the increase in the number of disabled people. In the UK the estimate of the number of disabled people is in the range of 10-20% of the population, depending on how the statistics are interpreted. This means that churches will face some these issues even if no obviously disabled people are part of the congregation.

We are going to look at the advantages and disadvantages of each model in the next session, once you've had an opportunity to talk about these models in a breakout group.

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Breakout Group Questions

- What might be the strengths and weaknesses of each model of disability?
- 2. How might each model exclude or include disabled people in society and churches?
- 3. Why might some people see disability as a 'problem'?
- 4. How might these models have some sort of theological implication?

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¹³ (Shakespeare, 2013, p. 77)

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