Disability and a Good Life

UNSW AUSTRALIA

GLOSSARY

Ableism and Ability

Ableism captures the idea that able-bodiedness is considered 'normal' and most valued in society. An ableist approach to thinking helps explain why and how some people whose bodies are different from this norm are excluded. Ideas of ableism and its link to the ordering of ability and disability emerged in North America, in particular, from disability activists in thinking through their everyday experiences of exclusion. Fiona Kumari Campbell (2009) helped to articulate ableism in her book, *Contours of Ableism: the Production of Disability and Ableness,* which conceptualized, defined and described everyday forms of disability exclusion due to processes of ableism. In particular, ableism denotes the ways in which particular abilities such as independence, competence and productivity are hyper-valued by society which, in turn, results in the devaluation of individuals who are assumed not to have these abilities. While this does include other groups, it is particularly salient to disabled people's experiences of everyday forms of exclusion and discrimination.

Access and Accessibility

Access and accessibility are about the experience of equality – equality of opportunity, equality of experience and equality of participation and inclusion. If your local library's only entrance is via stairs, then as a wheelchair user you are unable to get access to the books, supports and resources available within the library. The consequences are certainly grave. If the building is fully accessible then you will have access to the books, DVDs, and learning activities that will enable you to learn, develop and flourish. Therefore, accessibility to the physical environment is critical to ensure that you can access the resources, knowledge and opportunities that are inside the building. Moreover, if you are someone who is blind or has a vision impairment, you may be able to access the building, but not the resources and books if they are not available in braille, large print or alternative formats. If you are a person with a cognitive disability, the way that information is presented may mean that it uses concept that are too complex to be understood clearly. In these cases, the built environment is fully accessible, but you are denied access to the resources, knowledge and hence, opportunities that are inside the building. Thus, access and accessibility are not only about environmental conditions such as buildings, pavements and public transport, but also about the ways things are designed and produced.

Affirmative Model of Disability

https://detrich.wordpress.com/tag/affirmative-model-of-disability/

The affirmative model of disability emerged from the ideas of people with disabilities who want to positively recognize that they have an impairment and that this impairment is an important part of their lives. Unlike the medical model, people with disabilities who use the affirmative model view their impairment positively. Having an impairment is not the problem, the problem lies with the social barriers that impede their development, participation and flourishing. Thus, the affirmative model is strongly connected to the social model of disability as it aims to reaffirm the person with a disability as a valuable human being who can contribute to society.

Ageing

Ageing is something that we do throughout our lives. As a social concept 'ageing' is particularly associated with growing old, and the physical, social and cultural processes and practices associated with this. Ageing is significant in relation to disability in two ways. Firstly, as people age, they are more likely to acquire an impairment which will have a significant impact on their lives. Usually this will require more support and in many countries can mean moving into supported accommodation. There is also significant stigma attached to age, which in itself can have a disabling effect – ableism also applies to the aging body. Secondly, we are among the first generations to experience people with certain impairments growing old. This means that ageing is rarely considered in relation to life-long impairment.

Bodies

We often take for granted what we mean by the word 'bodies', but how we understand bodies (and minds) is socially and culturally constructed. Western thought continues to be influenced by the 17th century philosopher Descartes' idea that the mind and body were distinct, split and different from one another. While the mind was considered the site of humanity and individuality, the body was seen as more corporeal or animal. Descartes' thinking on the body valued independence, and in the Enlightenment period bodies were increasingly judged for their capability to work independently (Cameron, 2014). Descartes' ideas influenced medical science's approach to impairment as something that was wrong with the body which required treatment or cure.

This approach located 'problems' within the body of a person with an impairment, rather in the ways this body is made different and excluded.

Care

When most people think of the word 'care' they think of it as a positive thing offered through love. But 'care' has a very different history in the lives of many people with disabilities and in disability studies. Caring for and about people with disabilities is tightly bound to histories of oppression. Care has been associated with unequal power relations, where 'looking after' people with disabilities can occur in ways which justify other people managing and controlling their lives. Some people with disabilities argue that while they might need support, they don't need care. In some contexts, this has lead to a change in the language from 'care' to 'support'. But other people with disabilities and their allies have argued that the devaluation of the process of care, caring and care relationships is a social problem. Writers like Eva Kittay (2011) have argued that society needs an 'ethics of care,' where everyone is understood to require caring relationships and where humans are recognised as inter-dependent.

Charity

http://disabilitynow.org.uk/blog/bandaid-30-and-lessons-disability;

One of the campaigns central to the disability rights movement has been to contest disability charity and the behaviours, attitudes and practices that it generates towards people with disability. A key concern has been the ways charitable organisations perpetuate the myth of disability, inability and deficit to raise funds to support disabled people, who are seen as passive and dependent on the benevolence of these organizations and the public at large. Too often the work of large disability charities are not driven by disabled people but by professionals whose livelihoods and professional identities are tied to disabled people as recipients of charity, rather than holders of equal human rights.

Citizenship

The origins and definition of citizenship are contentious. Often used is Marshall's (1950) definition as the 'status bestowed on those who are full members of a community', and all who have this status have equal rights and duties (p. 28). Human rights, then, are the cornerstone of citizenship debates. People with disabilities have historically been absent from these debates (Meekosha and Dowse, 1997). Morris (2005) argues that when talking about citizenship in terms of disability we need to discuss: self-determination (exercising choice and autonomy), participation (e.g. in community) and contribution (economic and social life of one's society). There are significant barriers to people with disabilities accessing these three forms of citizenship;

such as being represented, included and actively participating in decision making about their lives, their communities and their nations.

Colonisation

Colonisation is the forming of a settlement or colony by a group of people from a different place, who then claim the place they have settled as their own. Implicit in colonisation is the sense of superiority and power of one group of people over another. Disability Studies examines how colonisation and disability are tied together, in particular in the ways that violence and dispossession create impairment. However processes of colonisation have far-reaching consequences which go beyond the impact for one generation. Rather it has long term and ongoing effects which create and compound impairment often through loss of land and culture, social dis-enfranchisement and poverty.

Crip

http://dsq-sds.org/article/view/60/60

Crip is the shortened word for Cripple. Cripple has had strong negative connotations and people with disabilities have rejected it as a highly disparaging and disrespectful term. However, the term 'crip' has emerged as a way for some disabled people to take back power by giving new meanings to demeaning words - using it instead as a term of disability pride. It has become a way for some people with disabilities to differentiate their physical differences from non-disabled people. In particular, it is often used as a way to describe how many people with disabilities will do things differently, but achieve the same results as non-disabled people.

Disablism

http://www.raggededgemagazine.com/departments/closerlook/000947.html

The term 'disablism' emerged from the disability rights movement as a way to capture the forms and processes of exclusion and discrimination that disabled people experience. The word builds on the idea of sexism and racism but in this case the types of discrimination and segregation are specific to being a person with a disability. Everyday forms of overt disablism include things such as only having stairs to gain access and entry into a building when there could be a ramp or lift. Disability scholars have also pointed out that these structural forms of disablism also have consequences for disabled people that are more hidden. Psycho-emotional disablism refers to the impacts of a disabling society on the psycho-emotional well-being of people with impairments. (Reeve 2012). Thus, disablism as an idea captures both the structural barriers to disabled people's inclusion and participation as well as impact that experiencing these on a daily basis has on the lives and wellbeing of disabled people.

Disability Studies
http://disstud.blogspot.com.au

Disability Studies or Critical Disability Studies is not the study of impairments or conditions (Cameron and Moore, 2014). Disability Studies emerged in the UK and the USA as a result of disabled people working to critically think through the historical, cultural, social and economic forces that have lead to disabled people's exclusion, segregation and marginalization. It is now a rich academic field of inquiry and many scholars, researchers and academics are undertaking research that illustrates the ways in which societies have developed and organised over time to exclude disabled people.

Disability inclusion
http://disabilitymediamatters.me

The principle of inclusion fits within the social model of disability and suggests that it is the responsibility of society to think through ways that allow everyone to participate. Inclusion is contrasted to integration which implies that people with disabilities should be 'more like' non-disabled people so that they can participate in mainstream society (Cameron, 2014, p.79).

Disabled People's Movement
http://disability-studies.leeds.ac.uk/files/library/BCODP-workbook4.pdf

The Disabled People's Movement and the formal and informal advocacy and activism of disabled people globally have created significant change in the social, cultural, political and legal understandings of disability. Since the 1890s, groups of people with disabilities have campaigned against their shared oppression, and for equal rights and recognition. In the 1960s and 1970s the Disabled People's Movement followed other social movements (particularly in the UK and North America) to campaign against exclusion, marginalization and stigmatization.

Discrimination

At its most basic, discrimination is about identifying and responding to difference. We all discriminate daily, when we choose between one thing or another based on our preference. So in and of itself, discrimination is not necessarily harmful and is even necessary. The difficulties arise when the identification of difference or discrimination becomes the basis for oppressing a group of people and responding to the group identified as not just 'different' but unequal. There are multiple forms of discrimination, including personal, institutional and systemic discrimination.

Education

Schooling and education is a useful place to examine institutional approaches to disability. It is important to note the difference between 'special education' and 'inclusive education.' 'Special education' reinforces the idea that children with disabilities have 'special' needs that are beyond and outside of mainstream education, justifying their segregation into different institutions. 'Inclusive education' recognises that all students are entitled to an education and that children with disabilities are entitled to an education on the same basis as that of their non-disabled peers. Importantly, in this definition, supports are provided to disabled children in a way that makes education inclusive of all.

Eugenics

Eugenics is a set of theories and beliefs that civilisation would be more successful if only the 'best' human stock were able to reproduce. Clearly, at the basis of the eugenics movement is a value judgement around what is good human stock – what appearance, abilities and characteristics are most highly valued and therefore should be passed on to future generations and those which should be eradicated. The German Nazi regime supported eugenics through forced sterilization and 'euthanasia'. Some argue that eugenics continues today through practices like pre-natal testing.

Human rights

http://www.un.org/en/universal-declaration-human-rights/

Human rights are principles which should be afforded to every human so that they can flourish. The Universal Declaration of Human Rights was drafted after the atrocities of WWII as a way of protecting the dignity of, and ensuring justice and equality for all humans.

Impairment

Disabled People's International (DPI) defines impairment as 'the functional limitation with the individual caused by physical, mental or sensory impairment.' (DPI, 1982 in Goodley, 2011, p. 8). This definition is in line with the social model of disability, which recognises impairment as distinct from disability. While impairment is a physical, sensory, cognitive or psychological difference, disability encompasses the negative ways in which this difference is understood and responded to. This has caused considerable debate in disability studies. Feminist disability scholars such as Carol Thomas (1999) have emphasised that impairment must be acknowledged. Thomas argues that impairments have 'impairment effects' – that is, restrictions that are directly related to the impairment. Cameron (2014) notes that people with different impairments experience different aspects of disability.

Intersectionality

Intersectionality explores how social categorizations, such as race, class, gender and disability, are interconnected. This can potentially create overlapping and interdependent systems of discrimination or disadvantage. The term intersectionality was first used by Crenshaw (1989) to explain minority women's experiences of discrimination. This is a rather new area of investigation in disability studies, which, until recently, focussed on an assumption that experiences of disablement are both common to and similar for all disabled people.

Misfit, misfitting

A misfit is a person whose behaviour or attitude sets them apart from others in uncomfortable and conspicuous ways. When Sara Ahmed (2010) talks about misfitting though, she takes this difference, this 'misfitting,' as a political action – someone who pushes against what is expected of them or against the shape they should take.

Medical Model of Disability

The medical model of disability has long been the dominant way of thinking about disability. It has its roots in medical science and the idea that an impairment is a problem, something that is wrong or 'broken' with a person, something that needs to be treated and cured. Under the medical model impairment is understood as an individual's problem, and medical and associated psychological and therapeutic professionals are seen as a central part of the solution. People with impairments usually find the medical model problematic.

Needs

People with impairments are often thought about as having special needs or additional needs. Larry Arnold (2014) asks a great question in his chapter on 'Need' in *Disability Studies: A Student Guide*. He says, 'Are these needs conditioned by an impaired person's experience of embodiment, or by some psychological and cognitive difference that predisposes one to engage the negotiation of 'need' from a different perspective?' (2014, p. 104). Arnold suggests that everyone has needs, but most often they are not called or labelled as needs. In other words, it is the failure to acknowledge human diversity which results in the 'needs' of people with impairments being constructed as different or additional.

Neoliberalism

http://www.onlineopinion.com.au/view.asp?article=11647

Neoliberalism refers to the monetary and trade policies which privilege the privatised free market economy that has dominated economic and global politics since the 1980s. Neoliberalism involves the state removing itself from economic control and investment in public services and social welfare, and shifting its responsibility for provision of these on to the private sector (privatisation).

Normal, normalcy and the normate

http://whoneedsnormalcy.blogspot.com.au/2014/05/dont-let-them-be-autistic.html

These three words are strongly linked together as they attempt to describe how disabled people are valued and judged against dominant assumptions of what is 'normal' in terms of behaviour, skills and competencies, and who is able to be considered as a normal person based upon these dominant assumptions. Thus, if someone is 'normal', they experience the world and behave in 'normally' expected ways, they are called 'the normate'. Thus, these three words are used to describe the ways in which social norms shape how we define disabled people and justify their exclusion, by reifying the 'normal as normal'.

Oppression

Put simply, oppression involves one group having more power than another, which in turn creates inequality. Oppression can operate in very different ways. There are structural forms of oppression, for example, when people with certain impairments are not able to participate due to lack of provision for their access needs. But there are also more subtle forms of oppression, for example, pitying a disabled person or seeing their navigation of daily life as "inspiring".

Passing

http://www.raggededgemagazine.com/0903/0903ft2.html

Passing is a term that is often used to explain how some people with a disability may act to hide their disability so that they can appear like a 'normal' person. Passing is a term that is rich in sociological inquiry. The idea is that if someone 'passes' they are recognised as conforming to the social norm, rather than as a minority. The term 'passing' is often used to refer to sexuality and gender (she can pass as straight, she can pass as a woman). In the context of disability, passing refers to being recognised as able-bodied (either deliberately or unintentionally), which can mean avoiding stigma, barriers to opportunity, inclusion and participation often confronted by disabled people.

Personalisation

Personalisation in relation to disability refers to the broad number of ways in which a disability policy has focussed on more self-determined or self-directed approaches to support. Personalisation has been conceived as a way of enabling people with disabilities to enact choice and control around service provision and social supports. It could take the form of individualised funding, person-centred planning, or direct payments. This person driven approach emerged out of the UNCRPD and the Disabled People's Movement.

Policy

Policy is any act, statement or plan used to direct a particular set of outcomes or achieve a particular end. In this way, a policy is a way of collectively organising and analysing around a particular problem and outcome. Policy is also dynamic. It moves through stages of development which involve processes of negotiation. In disability policy, we see how global policy (such as the *UN Convention on the Rights of Persons with Disability*) has had a significant impact on local policy and vice versa (Soldatic, 2010).

Sexuality

http://www.theguardian.com/commentisfree/2014/feb/21/sex-and-disability-yes-the-two-can-and-should-go-together

Sexuality does not just refer to the practices of sex or sexual orientation, it also refers to intimacy, emotions and general flourishing (Shildrick, 2014). People with disabilities have historically been excluded from thinking around sexuality. Thus, people with disabilities have been excluded from sexual citizenship and from the diverse expressions of human sexuality.

Social Model of Disability

http://www.pwd.org.au/student-section/the-social-model-of-disability.html

The social model of disability emerged in response to the medical model of disability, which saw disability as an individual tragedy or problem. Under the social model, disability was reconceptualised as a social issue in the way that impairments are problematically recognised and responded to in society. This change was driven by the Disabled People's Movement, with a strong focus on people with a diverse range of impairments joining together in a common understanding of a shared oppression or disablement.

Statistics

http://www.unescap.org/sites/default/files/Chapter1-Disability-Statistics-E.pdf

Statistics are the collections of large amounts of numerical data. It might interest you to notice that the word 'state' is the base of the word statistics, reflecting how statistics developed to better understand how the state or country worked.

Stereotypes

http://www.disabilitymuseum.org/dhm/edu/essay.html?id=24

Stereotypes involve reducing people to a set of (usually negative) characteristics that reflect a person's apparent membership of a certain group. It is usually powerful social entities that propagate stereotypes, in particular the media, which makes it very difficult to counteract stereotypes with other narratives. There are many stereotypes about people with disabilities, including the tragic victim, the supercrip, the childlike, and the dependent.

Sterilisation

http://www.pwd.org.au/documents/temp/FS_Sterilization.pdf

Sterilisation has been forced on women who have disabilities, since at least the beginning of the 20th Century. Forced sterilisation is a procedure which women do not consent to and which makes them unable to bear children. Forced sterilisation was justified by theories of eugenics that claimed disability was hereditary and that it was important to stop women from passing impairments on to the next generation. Forced sterilisation was used in Nazi Germany, but was also legalised in the US, where from the 1930s to the 1970s women with intellectual and mental disabilities were legally sterilised. Sterilisation still happens today; some parents and support workers seek it out as a form of menstrual management and contraception.

Stigma

Goffman's work in 1963 is the basis of much thinking around stigma today. He argued that stigma involves reducing a person to a discounted characteristic, an undesired or 'abnormal' characteristic, rendering the person disqualified from social acceptance.

Support

The word 'support' is used extensively in disability studies and policy to talk about a broad range of practices and processes which are provided to enable people with disabilities to live the lives they want to. Support has become central to the idea of people with disabilities exercising their rights. Support can mean anything that enables someone to live their life their way. It can involve resources, equipment, training, personal assistants or interpreters.

Vulnerability

People with disabilities are sometimes described as 'vulnerable'. Someone who is vulnerable is more likely to be at risk of harm than other people in society. Children are often thought of as vulnerable. Vulnerability suggests a certain level of powerlessness, which many people with impairments will not identify with.

Welfare

Some people suggest that disability is created by public policy (Scott, 2014, p. 157). Changes in public policy (the statements governments make around how they view and act on certain issues) change who is categorised as disabled, who receives support and what kinds of support they receive. Welfare is one form of support that people with disabilities receive, usually recognised as certain forms of 'benefits' which can be payments, allowances or subsidies.

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