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Expanding Ableism: Taking down the Ghettoization of Impact of Disability Studies Scholars

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Abstract: This paper highlights the utility of an expanded ableism concept beyond how it is used in disability studies; expanding the concept of ableism so it connects with all aspects of societies and making ableism applicable to many academic fields. It introduces this expanded form of ableism as a new angle of cultural research and suggests it to be one possible venue for disability studies scholars to escape the ghettoization of their impact.

Keywords: ableism; ability studies; disability studies; society

1. Introduction

The concept of impact is all around us and influences many discourses [1–3]. We live in an impact assessment society with culturally constructed hierarchies of impact importance. Academics are expected to have an impact [4] for example through their publications [5]. The impact of their research is evaluated constantly [6]. Knowledge translation is a buzzword to describe another expected impact of academic work [7,8]. Universities are seen to have to change their priorities and cultures “as a result of the recognition by governments that they are at the heart of their efforts to build competitive knowledge economies” [9]. As academics, we seem to live in a culture of impact. In this paper, I will submit impact considerations that an academic disability studies researcher might have to take into account.

The field of disability studies and disabled people activists were the first to look at cultural dynamics and the cultural impact of ability preferences, coining the term ableism [10] as a cultural concept in the process. I showcase in this paper the utility of an extended form of ableism which I submit can become a seed for new discourses, perspectives and paradigms that focus on ability

favouritism as a basis for analysing existing and future cultural dynamics. I see ableism as a concept essential for being able to deal with ability expectation challenges for societies and individuals to come, especially for those linked to advances in science and technologies [11]. I submit that the extended form of ableism is a possible way for disability studies scholars to escape among other things the ghettoization of their impact.

2. Disability Studies Scholars and their Impact

Disability studies scholars face numerous impact challenges such as: (1) who to serve (academia, or disabled people, or both); (2) which field of academics to impact; (3) which problems to tackle; (4) which space to influence; and (5) the ghettoization of the disability studies field and its impact.

2.1. Challenge 1

The first challenge is whether disability studies scholars want to serve their own academic field, or whether they want to serve disabled people, or both? In order to serve academia scholars have to fulfil their impact expectations which are, among others, about publishing in high impact journals whereby impact factors are not generated by the amount of people reading an article but by how often one article is cited by other academics [12]. If scholars want to serve disabled people, the question is whether they can do so by not interacting with disabled people. Indeed many disability studies scholars are also activists [13], which goes against the “detached objectivity” [13], an expectation in many research fields. It also leads to a reorientation of where one tries to publish. Publication in high impact academic journals would only make sense if they are: (a) open access allowing a broad group of disabled people to have access to the writings, and (b) the time from submission to notice of decision (whether the decision is positive or negative) is reasonable (e.g., less than 3 month) and the time from notice of acceptance to publication in an open access format is shortly thereafter (e.g., less than 4 weeks). Fulfilling these two characteristics ensures one’s impact is as timely and as broad as possible. Furthermore, to serve disabled people as a scholar, the publication strategy would also have to include other venues of publication such as blogs and social networking sites in a more non-academic language given that the level of education of disabled people varies so much. In the end, the disability studies scholar will have to be a hybrid, trying to serve academia and disabled people. However, this is not an easy undertaking as the often-present conflict between disability studies scholars and non-academic disabled people [13] shows.

The impact dilemma does not stop here.

2.2. Challenge 2

In order to have impact as an academic one needs money to do research. This leads to the question for disability studies scholars which granting agency to apply to and how to phrase the research question. Non-medical research topics pertaining to disabled people can be a hard sell (e.g., ongoing discussions in Canada [14]). As the medical field has a strong influence on how disabled people are perceived and treated, a disability studies scholar has to engage with the medical and rehabilitation field and understand the existing dynamics. This might be fundable by health research related granting

agencies. At the same time, a disability studies scholar also has to impact other cultural researchers, sociologists, economists and so forth given that the life of disabled people can be improved through the works of academics from many fields. Here we have another hybrid model of impact. As a disability studies scholar, I submit that one has to be able to engage with academics of various fields, including the medical and rehabilitation ones, and enable them to engage with the disability studies analysis of a given issue.

2.3. Challenge 3

Another hybrid of impact originates from the timeline of the problem. One can cover historical problems, current problems and one can perform so-called foresight analysis—identifying problems to come and their impact in order to give disabled people and their organizations knowledge they can use to prepare themselves, to develop resistance, resilience and adaptation strategies. As a disability studies scholar one may have to strive in one's grant proposals to cover historical, current, and future issues, often collaborating with and including multiple timeline event experts to their team. However, one only has this luxury if one applies for certain grants, which comes with certain rules and a certain amount of money. At the moment I would submit that the foresight is under-developed.

2.4. Challenge 4

Then there is the challenge of glocalization [15], the reality that the local can influence the global and *vice versa*. This means that a disability studies scholar in a particular geographical and cultural space should keep in mind how their work might influence other geographical and cultural spaces and how developments elsewhere might impact their work. This means that one has to be a scholar with both a local and global outlook.

However, even if a disability studies scholar is able to deal with the challenges outlined so far there is the issue of ghettoization of the disability studies field and its impact.

2.5. Challenge 5

How much good can one's work do if disabled people, disability studies scholars and people linked to them access and use one's work but is ignored by other academics, policy makers and individuals? There are various disability studies journals in various countries of which publications are open access. On the one hand, as a disability studies scholar, one may want to publish in these journals but depending on who accesses these journals one might have a bigger impact academically and on the living situation of disabled people if one publishes in a non-disability studies journal. Then again, disability studies based reasoning or topics may be rejected in many of these journals. How much one's academic work is read outside the disability area and how much of one's arguments are seen to have a broader applicability beyond the social group of disabled people influences one's ability to produce positive change for disabled people. Impact often depends on other social groups and their academic and non-academic members. Thus, a disability studies scholar may have to strive for positive change not only for disabled people but for society as a whole. Indeed analytical work done in disability studies has the ability to change the lives of 'non-disabled' people for the better as well.

However, for this type of impact to happen one's work has to be recognized as being useful for tackling problems that society as a whole and other social groups face. Disability studies scholars face a huge challenge in the ghettoization of their impact. How can they convince others, not directly related to their area, of the utility their work has for 'others'? Disability studies-based research, especially the work around the concept of ableism, has strong utility outside disability studies, but so far, it is rarely applied outside of the disability studies realm.

3. Broadening the Ableism Concept

According to the award winning *Encyclopedia of Disability* edited by disability studies scholar Gary Albrecht, the term ableism evolved from the disabled people rights movements in the United States and Britain during the 1960s and 1970s [10] and it is used by various disability studies scholars [16]. Ableism "describes prejudicial attitudes and discriminatory behaviors toward persons with a disability. Definitions of ableism hinge on one's understanding of normal ability and the rights and benefits afforded to persons deemed "normal" [10]. Handicapism is a term with similar meaning than ableism; it was coined by Biklen and Bogdan in 1977 [17,18]. Handicapism is defined "as a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences" [17]. Both terms highlight the negative treatment [19] disabled people experience because their body abilities do not fit the cultural preference for species-typical normative ability functioning and who therefore are labelled as 'impaired', as not able enough, as not able in the right way [20–22]. Sometimes ableism is used to only highlight the species-typical ability preference whereby the negative treatment of a person labelled as impaired due to their sub species-typical perceived body-related abilities (physical, mental, neuronal, behavioural or cognitive) is covered by the term disablism [19].

So far, the discourse around ableism leaves the impression that it is about species-typical versus sub species-typical body-related (physical, mental, neuronal, cognitive or behavioral) abilities and that ableism is a dynamic that plays itself out between people who adhere to normative species-typical body-related abilities and people labelled as not having these normative abilities. Still, ableism is not employed as an analytical tool to investigate other 'isms' such as racism and sexism or in the context of non-body related abilities. I submit that ableism can be understood in a broader and more pervasive way than its original meaning and application [23,24]. Ableism is not limited to the discourse around abilities of the body and abilities of disabled people. Every person cherishes certain abilities and finds others non-essential. Some people cherish the ability to buy a car, some the ability to mountain climb, some the ability to perform academic work and others manual work [25]. Some societies are structured around GDP-ism (the ability to produce a GDP), efficiency, productivity and consumerism (the ability to consume) [23,24], others could be organized around equity and empathy or any set of abilities [26]. The list of abilities one can cherish is endless with new and different abilities appearing all the time. The cherishing of abilities happens on the level of individuals as well as the level of households, communities, groups, sectors, regions, countries and cultures. There is a frequent trade-off between numerous abilities [25]. Furthermore ableism as such does not have to be negative—as it is used within the discourse around disabled people rights and disability studies—it just highlights that one favours certain abilities and sees them as essential. However ableisms can also be used to support negative

actions and 'isms' such as sexism and racism [23,24]. During the fight for voting rights in the beginning of the 20th century women in various Western countries were for example told that (a) rationality is an important ability, and (b) that women do not possess rationality [21,22]. This was used to deny women the right to vote. Racism is often linked to cognitive ability narratives whereby it is claimed that groups of certain racial or ethnic backgrounds are less cognitively able than others [21,22]. Ableism used in a negative way often leads to disablism [19] which linked to the broader sense of ableism means the lack of accommodation for the needs of people and other biological structures who are seen to not have certain abilities; the unwillingness to adapt to the needs of others. What abilities are seen as essential and positive or which abilities or lack thereof are seen as negative are negotiated. Ableism in its general form leads to an ability based and ability justified understanding of oneself, one's body, one's relationship with others within one's species, other species and one's environment [27]. Let's give a few examples. To stay first with the body; we see an increase in narratives that push for the modification of the human body beyond the species-typical boundary. The social movement of transhumanism is all about enhancing the human body beyond the species-typical. According to Humanity+ formerly the World Transhumanist Association, transhumanism is, "The intellectual and cultural movement that affirms the possibility and desirability of fundamentally improving the human condition through applied reason, especially by developing and making widely available technologies to eliminate aging and to greatly enhance human intellectual, physical, and psychological capacities" [28].

This leads to a transhumanization of ableism where species-typical and so called sub species-typical exhibition of body-related abilities are seen as problematic, as less desirable [11]. The transhumanization of ableism and ability expectations might impact what we perceive as healthy bodies leading to the transhumanization of the meaning of health [29]. It might lead to the scenario where only certain beyond species-typical body abilities are seen as healthy [29]. Changes to the understanding of the term health bring forth a change in how we define various health related terms such as burden of disease [29]. We might also transhumanize various health related instruments; disability adjusted life years could morph to mean years lost due to not being enhanced [29]. The purpose of health insurances could change in such a way that it's not used anymore to ensure access to restorative medical treatments towards the species-typical but to ensure access to enhancement medicine, to ensure that people have money for a body upgrade beyond the species-typical [29]. This scenario fits with the dynamic that enhancements get better and better and that one does not want to be obsolete [29,30]. The transhumanization of ableism will also impact non-health related ability expectations, like when a person is seen as productive enough, competitive enough or efficient enough. We know that body consumerism is on the rise [30]. It is a form of ableism that expects beyond species-typical abilities that might add to this consumerism given that one might feel in ill health or simply as unprepared for given ability expectations (work, education) without body upgrades. Expanding ableism to include beyond-species typical ability expectation dynamics gives all kind of disciplines such as sociology, various forms of ecology or sport an angle to discuss the impact of changing ability expectations linked to science and technology advancements.

The relationship between humans and nature can also be investigated through an ableism and ability expectation lens. For example the anthropocentric view of the relationship between humans and nature has different ability expectations (nature is there to fulfil desires of humans) than the bio-centric view

(where humans are to live in harmony with nature) [27]. I submit that eco-ableism is a conceptual framework for analysing enabling and disabling human ability desires, a class of desires that shape the relationship between humans and their environment. One can also investigate different ecological movements from eco-feminism to shallow or deep ecology movement for their ability expectations which in turn gives one a new handle on how different movements might complement each other or not. Analyzing various environmental treaties through an ability expectation lens gives one a new angle to evaluate the usefulness of treaties for various social groups.

Which abilities one cherishes impacts also one's perception of energy security and what actions one wants to pursue to gain or retain energy security [27]. Ability expectation differences between various social groups play themselves out around energy and climate change policies [27].

Ability expectations are also at the root of how one perceives waste. A vegetarian very likely perceives the use of 19,000 litres of water to generate 1 kilogram of beef as waste, whereas one who has the ability expectation of consuming meat might not perceive the water used as waste [31].

Two more examples of 'isms' influenced by ability expectations are ageism where one treats the elderly badly as one expects the abilities of youth and youthism of a non-youth [32].

Broadening ableism allows for the general realization of possible problems and opportunities of ability based judgements and problems with disablements and disablism linked to a negative use of ableism. One could make an argument that an agreement in negotiations such as the climate summits is impossible if the ability expectations of different players are irreconcilable [27]. Broadening ableism allows disability studies scholars, other scholars and non-academics to investigate nearly every facet of social actions as they all have ability expectation components. Furthermore it allows us to not just look at what is wrong, as one often does in disability studies, but to be part of ability studies which is the study of how we, as individuals or social structures, come to favour certain abilities and how we make trade-offs between different abilities [23,24]. This opens up a whole new area of impact for everyone. The impact is not so much rectifying negative actions but foresight oriented. It allows for the generation of knowledge around and impact assessment of ability preference decisions that might prevent negative actions from the start. A broader conventionalization of ableism allows for an appreciation of cultures based on ability preferences in general and the cultural wars between entities adhering to different ability preferences. The broader conventionalization of ableism allows disabled people and others to see commonalities as to how ableisms impact them and to learn from each other and support each other.

4. Conclusions

Culture is a "way of life shared by members of a group" and "includes common beliefs, rules of behaviour, traditions, and customs" and "is learned and passed down to children" [33]. Ability expectations and preferences are one dynamic through which members of a group judge others and themselves and their lives. Ability preferences and judgments are at the root of many rules of behaviours and customs. I submit that the cultural concept of ableism and the dynamic of ability expectations is a gift from the disabled people rights movement and disability studies to the rest of the world, academic or otherwise [25]. I submit that broadening the focus of ableism is a means to break down the ghettoization of impact of the field of disability studies and disabled people. It allows the

wisdom around ableism-driven disablement, generated within disability studies and the disabled people rights movement, to be applied to problems the ‘non-disabled’ face. Every disability studies scholar is, among others, an ability-cultural researcher. I submit that many academics outside the realm of disability studies might find it fruitful to be an ability-cultural researcher, to investigate cultural aspects of ability preferences, the culture of ability preferences and the impact of ability preferences on society.

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