**Using the innovative emerging framework of Ability Studies to bridge HTA and PTA**

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First let me thank Maria for her leadership in organizing this panel an for finding ways for me to contribute although I can not join you in person. Also I would like to thank my students who do such an amazing job (more about them at http://www.crds.org/research/faculty/Gregor_Wolbring.shtml); their logo 

Short decription of them here http://www.crds.org/research/faculty/wolbpackfeb2015.pdf

Background

This presentation is part of the Session Panel: Complementarity between Health Technology Assessment (HTA) and Parliamentary Technology Assessment (PTA). We state in the CFP that more inter and trans-disciplinarity between HTA and PTA is warranted". However, in many places that is not enough, for example in Canada where I am based no PTA really exists. Furthermore I submit we need a scope of assessment of health technologies that includes the focus of HTA and PTA but also of health impact assessment, health needs assessment and participatory technology assessment whereby participatory technology assessment around health technologies has to go beyond patient engagement[1]. I contribute to the panel the framework of ability studies an innovative approach that can be used in inter-, trans- and intra- disciplinarily ways to perform system analysis, inform policies and advance knowledge. It allows for a new community of practice that can be a bridge between the different assessment fields mentioned as all of them are impacted by the influence ability expectation dynamics have on the meaning of health, the scope of healthcare and how to achieve and maintain medical and social health.

This talk has three parts.

In the first part I introduce the audience to the field of ability studies and the concepts of ability expectations and ableism.

In the second part I use the dynamic around the North American birth of the term learning disability to link non- health system based ability expectations to the shifting meaning of health and the emergence of health technologies.

In part 3, I use the example of the emerging field of ecohealth as an example how the ability expectation premise of a given field might influence the very meaning of what constitutes a health technology.

Part 1: Ability Studies

Ability Studies is an academic field [2] conceptualized to investigate how all kind of ability expectation (want stage) and ableism (need stage) hierarchies and preferences come to pass and the impact of such hierarchies and preferences on human-human, human-animal and human-nature relationships [2-5] and on multiple subject formations, social relationships and lived experiences based on diverse ability expectations and the actions linked to such expectations.

The term ableism was coined by the disabled people's rights movement in the UK and North America to indicate the cultural preference for species-typical physical, mental, neuro and cognitive abilities which was/is often followed by the disablement/disablism of people who are judged as lacking these required abilities. However there is more to ableism. Every individual, household, community, group, sector, region, and country cherishes and promotes numerous abilities and finds others non-essential for example some individuals see the ability to buy a given product as essential, others don't; some perceive the ability of living in an equitable society as important, while others don't. The list is endless but to give one health example, Canadians expect their health systems to have the ability to be sustainable, equitable, inclusive, accessible, innovative and responsive.

Exhibition of ability expectations or ableism's can have positive (enablement/enablism) and negative (disablement/disablism) consequences.

Sustainable development [6] was put forward as an alternative positive ability expectation of how humans are to engage with their natural environment to reign in the as negative perceived ability expectation of uncontrolled consumption of natural resources. Proponents of the capability approach developed lists of abilities they think have positive consequences if implemented [7]. Sustaining a democracy is seen in need of certain abilities exhibited by citizens[8-9].

Having certain abilities is having power. A 1853 NYT article [2] thematized that power comes with the ability to obtain knowledge. Having power allows one also to influence what abilities are seen as essential and how to treat and label people who do not have the 'essential' abilities[10]. This power to influence what abilities are seen as essential is often used to disable the less powerful. Disabled people coined the term ableism to highlight the disablement they experience because they are seen as not fulfilling certain ability expectations. The ability expectation of rationality is another example. Male decided that rationality is important and decided at the same time that women were not rational leading to the disablement of women (see e.g. Suffragette's fight for women's right to vote) [2]. The claim that women are irrational beings is still used [11-15]. The claim that 'others' are not rational is used as a tool to discredit one's opponents in many discourses (see for example [16-17]). A gendered discussion around ability stereotypes exists [18-20]. Racism is often justified by claiming that a certain level of cognition is essential and that one ethnic group is less cognitive able than another [2]. People fighting racism question all kind of stereotypes linked to the oppressed groups including ability linked stereotypes [21].

Having abilities is also the portal to access privileges such as income, political influence and employment [5] and being able to obtain certain abilities is a privilege by itself (see acess to education). Technologies are one factor generating ability privileges; having the ability to access and to master certain technologies gives one access to better education and better paying jobs. Finally one new ability privilege on the horizon is linked to techno/genetic modifications of the body we perceive today as normal. These enhanced bodies will have abilities that will give them an edge such as in employment which, given today's dynamics, will lead to the enhanced bodies having ability privileges.

Part 2 Ability expectation and the meaning of health: The case of learning disability (LD) (mostly from Wolbring and Yumakulov, 2015 accepted out in June at http://www.inklusion-online.net/index.php/inklusion-online

Cognitive abilities are one group of abilities that are cherished for a long time. The book, The Bell Curve,[22] is an example of using IQ, a cognitive ability expectation, to justify disabling racist tendencies and racism[2]. The feeble minded were one of the main groups targeted for eugenic practices (http://eugenicsarchive.ca/).

In general numerous cognitive ability expectations are used to label people as lacking and to disable them [23]. Cognitive ability expectations are often linked to other ability expectations such as being competitive. To give one example for this linkage; Christine Sleeter's 1987 book chapter, *Why is there learning disabilities? A critical analysis of the birth of the field in its social context* outlined her interpretation of the early history and the coming to be of the term LD [24]. The author classifies LD as a constructed category [24-26] generated in respond to certain political and social goals such as raising standards in schools for the purpose of the USA staying competitive against the Soviet Union after the Soviet Union launch the Sputnik [24-25]. The idea here is that the political Anti- Communism establishment in the USA found in unacceptable that the USA was beaten in putting a satellite into space by the Soviet Union. It was felt that there has to be a problem in the education system, as to what is expected from students in schools. Accordingly expectations were raised which led to the situation that students who were before seen as 'normal' all by a sudden found themselves as not fitting ability expectations anymore. As these students did not had a label before a new medical label was coined in North America in 1963 namely the term "LD" and during the discourse of coining LD the special education system was also birthed. LD is one example of changing the meaning of healthy based on a change in ability expectations. Before LD these children were seen as healthy. After the ability expectation shift in schools these children were seen as impaired. And with this label came health technologies to diagnose LD. Not surprisingly LD is also covered by the DSM-V. Indeed the history of the DSM is a case study in the constant generation of new disease labels.

Now, a creeping ableism/ableism creep is under way that increasingly expects people to move beyond species-typical abilities through cognitive, neuro, mental and physical enhancements [1, 10, 27] .What does this mean for the label of LD? Every student without enhancement measures related to learning could be classified as LD and as such justifying the use of enhancement procedures for students. Of course people could reject the broadening of today's LD definition but that would not solve their problem. Other labels competing with LD would be generated that would allow that new group to ask for support. Our accommodation system for students that are

seen to not fulfill ability expectations is based on the student's ability to link their difference to a medical diagnostic. The dynamic of the medicalization of the healthy [1, 3, 28-29] that allows body ability enhancement interventions to be classified as a health care intervention with access to health dollars - copies over to the area of education. One medicalizes missing abilities so that that new groups can benefit from the special education funding.

Part 3 Ecohealth and the re-envisioning health technologies (mostly from[4-5])

The linkages between humans, animals and nature within and outside the health arena have been discussed for some time as has been the importance of developing an integrated approach to health research and practice. Two recent notable developments within the health discourse are the 'One Health' framework, which focuses on the impact of the human-animal relationships on animal and human health [30-32] and the emergence of the Ecohealth field [33-34] which engages in active debates around important environment and health issues facing the world today [35]. A defining mandate of the Ecohealth field is that any intervention must improve the health and wellbeing of people, animals and ecosystems.
The abilities one favours and the ableist frameworks one subscribes to contour not only how people approach human-human, human-animal and human-nature relationships [36] but also inform how people define ecological problems, imagine solutions to these problems and, therefore, whom they invite to the table as stakeholders and knowledge producers [37]. Anthropocentric and biocentric views not only differ in how humans are perceived as causing the ill health of nature and what to do about it, but also in how to use nature to improve the health of humans.
Lets look at techno-tools such as geoengineering and human engineering.
In principle, geoengineering [38-42] could be defined as a health technology enabling an increase in the medical and social health of humans due to decreasing climate change seen to impact medical and social health. Geo-engineerintg could also be seen as a health technology given that ecohealth is about the health of humans, animals and the environment and geo-engineering could be seen to heal nature or prevent worsening of the ill health of nature. Of course at the same time Geo-engineering could be seen to be geo-toxic and as such contributing to the ill health of the environment making it an undesirable technology.

In adaptation scenarios, human survival is sometimes premised upon the ability to modify the human body to cope with harsh or disruptive climates. [43] making enhancement also a health technology.

Conclusion

People of different cultures and countries have different expectations of their health systems, the scope of healthcare and how to achieve and maintain medical and social health. Canadians expect in the moment their health systems to have the ability to be sustainable, equitable, inclusive, accessible, innovative and responsive. Achieving and maintaining this vision depends on many factors, including the constant monitoring and evaluation of ability expectations developing within and outside of health system discourses; e.g. sustainability, ecohealth, healthcare and homecare technologies such as sensors, social robotics and bionics, human enhancement, aging well, health consumerism, quantified-self, personalized medicine and

anticipatory governance discourses have developed ability expectations that impact expectations Canadians have of their health systems, the scope of healthcare, the meaning of health and how to achieve and maintain medical and social health.

The Ability Studies framework allows for a new community of practice bringing together people and ideas in an innovative way generating knowledge that will allow to deal with the ever changing societal challenges of ability expectations such as ability expectation oppressions experienced by various social groups and to tackle the issue of ability expectation governance (the need to control ability expectation dynamics and prevent negative consequences) and ability power. Ability Studies can be used as a bridge between the different assessment fields mentioned as all of them are impacted by ability expectation dynamics


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