

Ability Expectation and Ableism Studies (short Ability Studies): An innovative approach to catalyze a new community of practice to monitor, evaluate and address Synbio linked ability expectation challenges to how society functions: The Issue of Ability Expectation Governance

Gregor Wolbring, University of Calgary, Dept. of Community Health Sciences

First let me thank my students who do such an amazing job (more about them at http://www.crd.s.org/research/faculty/Gregor_Wolbring.shtml); their logo

Background

Ability Studies [1-3] investigates how ability expectation (want stage) and ableism (need stage) hierarchies and preferences come to pass and the impact of such hierarchies and preferences on multiple subject formations, social relationships and lived experiences based on diverse ability expectations and the actions linked to such expectations. Every individual, household, community, group, sector, region, and country cherishes and promotes numerous abilities and finds others non-essential. For example some individuals regard the ability to buy a given product as essential, while others do not; some perceive living in an equitable society as important, others do not; countries compare each other on whether one has certain abilities (e.g., provision of good education or high employment to its citizens) [1-2]. Furthermore negative treatments of others are often justified by a narrative where one powerful group decides that a certain ability is essential and that another group lacks the ‘essential’ ability[2]. The way humans interact with nature is also characterized by ability expectations with for example anthropocentrism and bio/eco-centrism exhibiting different ability expectations of what nature is to do for humans [3-4]. What abilities do we want to sustain? What new ability expectations are emerging? Who has the ability power to push their ability expectation agenda? How these questions are answered in the synthetic biology discourse will influence the cultural, social, economic and environmental impact of synthetic biology disrupting existing ability expectations. As such anticipatory governance of ability expectations [5-6] is a needed facet of anticipatory governance of technology in general and anticipatory governance of synthetic biology in particular. The Ability Studies framework allows for a new community of practice bringing together people and ideas in an innovative way, generating knowledge that will assist to advance a vision that enables maximum positive impact from the governance of synthetic biology. Ability expectations are linked to value, labeling, conflict, choice, identity, motivational, achievement, goal, self-determination, neo-institutional, body and social constructivism theories. Ability expectations are linked to the cultural reality of disablism experienced by entities labelled as lacking ‘essential’ abilities, as not fulfilling ability expectations of the ones setting the ability expectation agenda. As such ability expectation adds to the labeling theory discourse which focuses on the linguistic tendency of majorities to label negatively minorities or those seen as deviant from norms. Value theory records what people do value and attempts to understand why they value certain things. Ability expectation is about valuing certain abilities. Expectancy-value theory of achievement motivation (the ability desired) is used to analyze dynamics of various discourses. Ability desires are evident in the synthetic biology discourse. Conflict theory emphasizes possible conflict between social groups. Groups of people with different ability expectations are often in conflict with each other. Ability expectations influence and are shaped by the pillars and carriers of institutions and mechanisms and processes by which institutions persist or change identified by Scott[7]. Ability expectations are a factor in many of the

components of the discourse-institutionalist framework developed by Genus [8]. Finally one chooses between different abilities which can be classified as a ‘social choice’ problem [9]. The ability expectations we choose, whether as individuals or as another social entity impact and are impacted by the synthetic biology discourse. The abilities one favors within and outside of the synthetic biology discourse impact human-human, human-animal and human-nature relationships and how one defines ecological problems and identifies solutions to the problem. It also shapes which Ability privileges are accepted. Ability privilege is “the advantages enjoyed by those who exhibit certain abilities and the unwillingness of these individuals to relinquish the advantage linked to the abilities especially with the reason that these are earned or birth given (natural) abilities” (whereby down the road it will be interesting to see whether, and if yes how, synthetic biology will change the meaning of natural or the importance of natural as a qualifier) [4]. Ability privilege can play itself out between traditionally defined social groups (e.g. race, gender, class); for example if we look at the history of the Suffragette’s fight for women’s right to vote in USA the men constructed a narrative that valued rationality as an ability and men claimed that women were irrational and as such women were labelled as unfit to vote. This is an example of an ability privilege supporting male privilege. The claim that women are irrational beings is still used [10-14]. Irrationality is used as a tool to discredit one’s opponents in many discourses (see for example [15-16]). There continues to be constant formations of social groups that are defined by certain abilities and the privileges that come with it; for example people that are seen as productive versus non-productive or countries that are seen as competitive versus non-competitive. 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 ([see the movie Fixed the science/fiction of human enhancement that covers certain ability expectation dynamics](#)).

Short analysis of 17 sources

If one looks at the 17 reports for some keywords of importance if one looks at various aspects of Ability Expectation governance the following hits are obtained: ability 290; able 1152; challenge 406; choice; compet* 73; democra* 54; DIY 193; disab* 5; health 371; well-being/wellbeing 41; energy 237; ethic 671; expectation 18; govern 453; governance 128; igem 76; impact 163; independen* 51; issue 696; opportunity 240; option 135; patient 29; productive* 39; rational 37; regain 6; risk 892; stakeholder 106; gender 6; women 11; industry 273; NGO 60. To interpret some of the numbers, whose ability expectations are covered in the sources is mostly unclear as the sources often use the boiler plate term, “stakeholder” without identifying who they mean. In the case that groups are mentioned there are visibility differences between groups (industry versus other groups such as women, disab*). Democratizing science and technology is discussed for a long time. When democratization of synbio is covered (source 1, 9, 11 and 17) source 1 does link it to the DIY of synbio. Sources 9, 11 and 17 talk about Democratic deliberation and active participation of citizens but do not cover the abilities required by an individual or social group in order to participate in such deliberation. Indeed, there are assumptions as to the abilities that individuals and social groups have that are envisioned to participate in the discourse around democratizing technology (my Master student, Lucy Diep will be presenting on that topic at the CNS UCSB Democratizing Technologies Conference). When the sources talk about products linked to individuals the individual is mentioned within a

medical framework (patient, medical use of the term disabled, or health mostly with the meaning of medical health not social health) indicating the sales pitch for body linked interventions (including genomes) and the ability expectation discourse to come. As to abilities, to just mention sustainability (due to space restriction), sustainability is mentioned concretely around product sustainability (source 3), good health, reduction in Greenhouse gas as an example of a sustainability indicator (source 4) and natural resources/climate change (source 15) but for example social sustainability is not mentioned. As to applications energy is mentioned in all sources with the exception of source 6 and 8 but it is interesting to note that many ability expectations of synbio are not mentioned such as human enhancement which is only mentioned briefly in source 12 and 17 and the linkage between synbio and biological diversity (source 8) such as the proposal to generate biological diversity through synbio. **Proposal:** I suggest that an ability expectation taxonomy (e.g. which ability expectations are mentioned by whom, for whom, for which problems) including ability expectation synergy and conflict maps and ability expectation related decision trees and impact assessment are some concrete outputs the Ability Studies field can generate that would benefit the synbio discourse in general and the synbio governance discourse in particular. Ability Studies can be a catalyst for inter-, trans- and intra-disciplinarily innovation to practice and the emergence of a community of practice bringing together people and ideas in an innovative way filling the gaps evident so far in the synbio discourse.

The list of documents:

- 1) Next steps for European synthetic biology: a strategic vision from ERASynBio
<http://www.agence-nationale-recherche.fr/fileadmin/aap/2014/aap-erasynbio-2014-StrategicVision.pdf>
- 2) Seven Myths & Realities about Do-It-Yourself Biology;
<http://www.wilsoncenter.org/publication/seven-myths-and-realities-about-do-it-yourself-biology-0>
- 3) Symposium on Opportunities and Challenges in the Emerging Field of Synthetic Biology
 OECD Royal Society 2010; <http://www.oecd.org/science/biotech/45144066.pdf>
- 4) Emerging Policy issues in synthetic biology OECD 2014 http://www.oecd-ilibrary.org/science-and-technology/emerging-policy-issues-in-synthetic-biology_9789264208421-en
- 5) Perceptions of Synthetic Biology and Neural Engineering Key Findings from Qualitative Research April 18, 2014; <http://www.synbioproject.org/publications/6684/>
- 6) Synthetic Biology Report to Congress July 2013 Dept. of Energy
http://synberc.org/sites/default/files/DOE%20Synthetic%20Biology%20Report%20to%20Congress_Fnl.pdf
- 7) Synthetic Biology and the US Biotechnology regulation system: Challenges and Options
 Craig Venter Institute May 2014
<http://www.jcvi.org/cms/fileadmin/site/research/projects/synthetic-biology-and-the-us-regulatory-system/full-report.pdf>
- 8) The Nagoya Protocol and Synthetic Biology research: A Look at the Potential Impacts
 2013
http://scholarship.law.duke.edu/cgi/viewcontent.cgi?article=5916&context=faculty_scholarship

- 9) New directions The Ethics of Synthetic Biology and Emerging Technologies Presidential Commission for the Study of Bioethical Issues Dec 2010 <http://bioethics.gov/synthetic-biology-report>
- 10) Comments Submitted by the Synthetic Biology Engineering Research Center (Synberc) to the National Academy of Sciences Forum on Synthetic Biology October 21, 2013 <http://synberc.org/sites/default/files/SynbercNASSynbioForumRemarksOctober2013.pdf>
- 11) Creating a research Agenda for the ecological implications of synthetic biology May 2014 http://web.mit.edu/cis/Publications/SYNBIO_res_agenda.pdf
- 12) Trends in American and European Press Coverage of Synthetic Biology: published 2008 http://www.synbiosafe.eu/uploads///pdf/synbio_perception.pdf
- 13) Trends in American and European Press Coverage of Synthetic Biology: 2008 – 2011 http://www.wilsoncenter.org/sites/default/files/synbio_press_final.pdf
- 14) Ethical Aspects of Synthetic Biology 2009 http://ec.europa.eu/bepa/european-group-ethics/docs/publications/round_table_ethical_aspects_of_synthetic_biology_en.pdf
- 15) Ethical Issues in Synthetic Biology 2008 <http://www.wilsoncenter.org/publication/ethical-issues-synthetic-biology>
- 16) Awareness & Impressions of Synthetic Biology 2013 Hart Research Associate 2013 <http://www.synbioproject.org/site/assets/files/1289/synbiosurvey2013.pdf>
- 17) Synthetic Biology Roadmap for the UK 2012 <http://www.rcuk.ac.uk/RCUK-prod/assets/documents/publications/SyntheticBiologyRoadmap.pdf>

Reference List

1. Wolbring, G., Expanding Ableism: Taking down the Ghettoization of Impact of Disability Studies Scholars. *Societies* 2012, 2 (3), 75-83.
2. Wolbring, G., Why NBIC? Why Human Performance Enhancement? *Innovation; The European Journal of Social Science Research* 2008, 21 (1), 25-40.
3. Wolbring, G., Ecohealth through an ability studies and disability studies lens In *Ecological Health: Society, Ecology and Health*, Gislason, M. K., Ed. Emerald: London, UK, 2013; Vol. 15, pp 91-107.
4. Wolbring, G., Ability Privilege: A needed addition to privilege studies. *Journal for Critical Animal Studies* 2014, 12 (2), 118-141.
5. Wolbring, G.; Diep, L., Engaging with technology governance in social work education: An essential for preparing future social work(ers) *Journal of Continuing Social Work Education* 2014, coming in the fall.
6. Diep, L.; Cabibihan, J.-J.; Wolbring, G., Social robotics through an anticipatory governance lens. *LNAI* 2014 (forthcoming), 8755, 116-125.
7. Scott, W. W. R., *Institutions and organizations: Ideas, interests, and identities*. 3rd ed.; Sage Publications: Thousand Oaks, Ca, USA, 2008.
8. Genus, A., Governing sustainability: A discourse-institutional approach. *Sustainability* 2014, 6 (1), 283-305.
9. Sen, A., The Ends and Means of Sustainability. *Journal of Human Development and Capabilities* 2013, 14 (1), 6-20.
10. Cornia, R. D., Current use of battered woman syndrome: Institutionalization of negative stereotypes about women. *UCLA Women's L.J.* 1997, 8 (1), 99-123.

11. Goldberg, P., Are women prejudiced against women? *Society* 1968, 5 (5), 28-30.
12. Oakley, A.; Roberts, H., Interviewing women: A contradiction in terms. In *Qualitative Research*, Bryman, A.; Burgess, R., B., Eds. SAGE: London, UK, 1981; Vol. 4, pp 30-62.
13. Toffel, H., Crazy Women, Unharmed Men, and Evil Children: Confronting the Myths About Battered People Who Kill Their Abusers, and the Argument for Extending Battering Syndrome Self-Defenses to All Victims of Domestic Violence. *S. Cal. L. Rev.* 1996, 70, 337-344.
14. Daily Star, Japanese Women Boycott Sex With Any Man Who Votes For Tokyo's "Menstruating Women Are Irrational" Governor. *Daily Star* February 7, 2014, p online.
15. van Montagu, M. The Irrational Fear of GM Food. Available online: <http://online.wsj.com/news/articles/SB100014240527023036804045791417413999663> 28 (19th September, 2013),
16. Osborne, H. James Delingpole Leads Climate Change Sceptics in Trashing IPCC's 'Sexed-up' Report. Available online: <http://www.ibtimes.co.uk/ipcc-climate-change-report-skeptics-royal-society-509664> (19th September, 2013),