

NYC talk

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Hi everybody,

First let me thank the organizers for inviting me and I want to thank Erich for his comments on my earlier attempts of this talk. Although the event is about autism prevention as a possible goal indicated by certain language in the 2030 document “Transforming our world: the 2030 Agenda for Sustainable Development”[1]my talk will try to go beyond as I think the sentence in question of the 2030 document can be applied to various ability differences and as such the concern you have should be shared by other disability rights groups and other justice groups.

The language of the 2030 document

The 2030 document contains quite a bit of language that allows for the improvement of the social situation of disabled people such as the premise of the 2030 agenda to respect, protect and promote human rights and fundamental freedoms for all, without distinction of any kind, that People who are vulnerable must be empowered the goal “”empower and promote the social, economic and political inclusion of all,

However there is also wording that seems to go against the very sentiment of what I stated so far and which raises various questions

- We are committed to the prevention and treatment of non-communicable diseases, including behavioural, developmental and neurological disorders, which constitute a major challenge for sustainable development.

Alistair spoke about the issue of autism where of course a battle is underway as to whether it’s a disease/disorder or not? Developmental which would include Down Syndrome for example the situation is similar with two narrative one questioning the disease narrative around Down Syndrome and the prevention focus around it. As written it also raises questions from the point of the psychiatric survivor movement.

Given that “Cardiovascular diseases cancers respiratory diseases and diabetes account for 82% of all NCD deaths and that the main risk factors for NCD are Tobacco use, physical inactivity, the harmful use of alcohol and unhealthy diets they could have mentioned that here if they wanted to make a case for the impact of NCD on SD. <http://www.who.int/mediacentre/factsheets/fs355/en/>

The impact of imagery

As is we have two flavors of how to deal with disabled people in the document. One flavor is in sync with the CRPD goal of bettering the social situation of disabled people. However the other flavor is about prevention and treatment whereby its not clear what the scope of prevention/treatment is as most ‘disabled people’ could also be classified as impaired as having a disorder.

Given the constantly changing and diverging idea of what entails a disease it seems adamant that a general discussion has to take place as to what is a disease, a disorder an impairment, what should be prevented and treated, who is the one having the power to make that decision and what type of preventions/treatment are within the scope of the 2030 agenda (does it include genetic elimination, somatic gene interventions, germline genetic interventions, changing peoples lifestyles, environmental degradation?).

The use of “prevention and treatment of non-communicable diseases, including behavioural, developmental and neurological disorders” without any qualifier suggests certain form of ableism (the negative treatment of biological entities not fulfilling ability expectations) exhibited by the originator of this language. We need the ability to behave in certain ways, we have to have certain cognitive abilities and neuro-abilities. It leaves the 2030 agenda wide open to a form of ableism that perpetuates a negative view and negative treatment of ability differences something which disempowers disabled people including autistic people and anyone else not fitting ability expectations, which make all of them more vulnerable and seems to counter the goal of promoting the social, economic and political inclusion of all,

In the discussion forum *disability and the Post 2015 development goal agenda* [2] which took place in 2013 many questioned the prevailing medical model of disability which was seen as detrimental to being included in development and other processes [2] cited in [3]. These imageries are detrimental to disabled people including autistic people taking part in SD discourses as ‘normal’ citizens.

The impact of the imagery of disabled people including autistic people and the presence of the two flavors of how to deal with disabled people will play itself out in many areas of the 2030 agenda. One such area is the agenda setting, vision of utility, priority of projects and governance of science, technology and innovation.

Science and Technology governance

Words starting with tech (e.g. technology, technologies) are mentioned 57 times; words starting with scien (e.g. scientific, science,) are mentioned 27 times and words starting with Inno (e.g. innovation, innovative) are mentioned n=22 times in *Transforming our world: the 2030 Agenda for Sustainable Development* [1]. The solution summit was described as “a catalytic gathering that took place on Sunday, 27 September 2015 at UN Headquarters in New York to turn attention toward breakthrough solutions for achieving the new Sustainable Development Goals” and as marking “the beginning of a longer-term grassroots effort to lift-up exceptional innovators – technologists, engineers, scientists, who are developing solutions that address one or more of the 17 sustainable development goals” [4]. 838 submissions were received from more than 100

countries: bit.ly/solutions-summit-responses[5]. Words starting with *disab* were mentioned 121 times. However, many of the submissions exhibited problematic aspects for disabled people around language and focus and assumptions.

The technology facilitation mechanism to support the sustainable development goals is said to be “based on a multi-stakeholder collaboration between Member States, civil society, the private sector, the scientific community, United Nations entities and other stakeholders” [6]. Question is how strong groups are present that question the negative imagery of disabled people?

Given that agenda setting, vision of utility, priority of projects and governance of science, technology and innovation is so much impacted by how we view disabled people, what is there influence on the agenda setting, vision of utility, priority of projects and governance of science, technology and innovation in relation to the 2030 agenda in general? Which flavor of disability has an influence?

What is needed is a questioning of who has the power to set ability expectations, the oppression linked to various ability expectations, and what is needed is the development of an ability expectation narrative that allows for the 2030 agenda to succeed without exhibiting ability expectation discrimination towards groups such as autistic people and other disabled people to the detriment of their well-being.

1. United Nation. Transforming our world: The 2030 agenda for sustainable development. <https://sustainabledevelopment.un.org/post2015/transformingourworld>
2. Participants of the UN Department of Economic and Social Affairs (UNDESA) and UNICEF organized Online Consultation - 8 March - 5 April Disability inclusive development agenda towards 2015 & beyond. Disability inclusive development agenda towards 2015 & beyond,. <http://www.worldwewant2015.org/node/314874>
3. Wolbring, G.; Mackay, R.; Rybchinski, T.; Noga, J. Disabled people and the post-2015 development goal agenda through a disability studies lens *Sustainability* **2013**, *5*, 4152-4182.
4. Summit, S. Solution summit. <http://www.solutions-summit.org/>
5. Summit, S. Solution summit responses. <http://bit.ly/solutions-summit-responses>
6. United Nations. Outcome document of the third international conference on financing for development: Addis ababa action agenda. http://www.un.org/ga/search/view_doc.asp?symbol=A/CONF.227/L.1&Lang=E