



Workshop 8:

Science, technology and innovation governance for the 2030 agenda



Responsible Innovation and the intersection between technology and disabled people

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Responsible innovation (RI) is a governance framework and emerging academic field concerned with emerging science, technology, and innovation (STI). According to Owen, Macnaughten and Stilgoe, the field emerged from an “increasing awareness of the global (and intergenerational) impacts of complex innovations in modern society” (1). Pioneers of the field of RI aim to integrate social, ethical and legal considerations into the process of innovation (1), and in the last ten years a number of scholars began engaging in a discussion on how to do just that. RI has 8 performance indicators

1. Governance	2. Open access/open science
3. Public engagement	4. Ethics
5. Gender equality	6. Sustainability
7. Science education	8. Social justice/inclusion

All of these are important for disabled people. However. Disabled people are not visible in RI yet

For example, in 2014, Taylor Francis publishing company formed the Journal of Responsible Innovation (JRI), further solidifying the field of RI in the academic sphere. Since that time, a total of 69 articles have been published in the JRI, in a total of four issues and two journals.

When I searched these articles for the code “disab*” (which would encompass the terms “disability”, “disable”, “disabled”, “disabilities”), I found a total of 55 mentions coming from 5 of the 69 articles, which is only 7.2% of the total. Furthermore, only 3 articles (4.3%) discuss disabled people concretely (2-4). The first of the two non-concrete articles is an editorial that simply describes another article (5). The second is found in the references section of an article titled “Justice and Innovation – towards principles for creating a fair space for innovation”, which could arguably benefit from mentioning the importance of the inclusion of traditionally and systematically marginalized groups (such as disabled individuals) in STI governance discussion (6).

One article reviews the film *FIXED: The Science Fiction of Human Enhancement* explores the effect of technology on ablism as well as the concept of extra-ablism, where human enhancement of technology normalizes and those who do not possess the enhancement become ‘disabled’ in relation to individuals who possess the enhancement (2). This is an example of the kinds of discussions that bring to light the disparities felt by a number of disabled people today by allowing species-typical

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individuals to imagine a world where they become marginalized by human enhancement (2). This effect is reiterated in Eggleston & Berry's article, in which they show the film to doctoral students and principle investigators in biological computer science (3). The aftereffect of watching the film showed that individuals began to view how we as a society evaluates others in a negative light, showing evidence of the deconstruction of the assumptions we make about how one values others as a result of their abilities.

In the article reviewing the film, de Saille concludes with a comment about how the film leaves the viewer to decide their own position on the relation between technology and humans, which reflects of the way that the RI literature seems to leave the discussion on the intersection (2). Due to the personal nature of medicine and treatment, it is easy to see why RI scholars might be reluctant to set boundaries for a population with a high degree of variation in needs. However difficult, though, the discussion about the intersection between disabled people and STI is important, and the RI literature is currently a grossly under-utilized space that could be used to build the theoretical foundations for continued academic discourse.

1. Owen R, Macnaghten P, Stilgoe J. Responsible research and innovation: From science in society to science for society, with society. *Science and Public Policy*. 2012;39(6):751-60.
2. de Saille S. Fixed: the science/fiction of human enhancement. *Journal of Responsible Innovation*. 2014;1(1):142-5.
3. Eggleston K, Berry S. Macroethics exploration with impact: technological innovators reconsider profound personal and societal questions after viewing the film FIXED: The Science/Fiction of *Journal of Responsible Innovation*. 2015.
4. Sadowski J. Exoskeletons in a disabilities context: the need for social and ethical research. *Journal of Responsible Innovation*. 2014;1(2):214-9.
5. Guston D. Responsible innovation: a going concern. *Journal of Responsible Innovation*. 2014;1(2):147-50.
6. Ziegler R. Justice and innovation—towards principles for creating a fair space for innovation. *Journal of Responsible Innovation*. 2015.