A Commentary from Disability Studies in Germany

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The results of the authors' research show a rather distinctive difference between the two countries in the political and the activist discourse on disability and prenatal diagnosis. Even though the research sample is quite small, it can be stated that the German discourse on disability, and especially activists' attitudes, are still very much influenced by "the long shadow of history". Here, this refers to the eugenic programmes of the National Socialists, which led to the forced sterilisation of 300.000 disabled and mentally ill persons. Denigrated as "ballast existences", "useless eaters" and "life unworthy of life", the Nazi regime planned and carried out the murder – euphemistically dubbed "euthanasia" (Greek for "good death") – of about another 300.000 disabled persons. Research has shown (cf. Friedlander 1995) that the "euthanasia" programme was the first of the Nazi killing programmes that aimed to "purge" the race of all "spoiling" influences. After the "euthanasia" programme was discontinued, the staff and the equipment were sent on to the killing camps to employ their expertise there. These facts have broadly been ignored in the Holocaust discourse. In Germany, the societal discourse about the crimes committed against disabled people started only in the early 1980s.

After the Second World War eugenics was largely discredited because of the National Socialist practices, but re-emerged as a new discipline of human genetics in 1965. The ancestry of this "new" science went unchallenged for a long time, and its founding fathers who had been active in promoting and teaching "racial hygiene" (the term in Nazi Germany for eugenics) continued to propagate their ideas about controlling the quality of German offspring, although now the target was not the health of the *Volkskörper* but the prevention of individual health conditions through genetic counselling. Here the aim was to identify the precise risk of particular couples to produce disabled children, and to counsel them to avoid having children of their own when the calculated risk was deemed too high. Shortly afterwards, prenatal genetic testing became possible and available. Though officially introduced to support reproductive self-determination, the offer still had the eugenic goal of avoiding the birth of "defective" children. Cost-benefit analysis also played an important role in the process of establishing prenatal testing – how much money could be saved by preventing the birth of disabled children, especially children with Down syndrome, which was relatively easy to detect?

It took a long time for post-war German politics and society to recognise disabled people as victims of Nazi persecution. It was only in 2007, 62 years after the end of the war, that the German parliament declared the Law for the Prevention of Offspring with Hereditary Diseases (*Gesetz zur Verhütung erbkranken Nachwuchses*) of 14 July 1933 to be a Nazi injustice, but the victims of this injustice were not officially recognised as victims of Nazi persecution and are not entitled to any compensation. The central Memorial and Information Point for the Victims of National Socialist "Euthanasia" Killings in Berlin was not opened until 2 September 2014, the last of the four memorials to the victims of the Nazis' racial and extermination policies (Jews, Sinti and Roma, homosexuals, and disabled people) in the German capital.

One of the main achievements of the disability movement and disability studies has been to break the established traditional link of the medical model of disability between disability and suffering through the development of the social model of disability, which was named and formulated first in the United Kingdom. Disability rights movements in other countries, like Germany, developed similar perceptions of disability without calling it a social model. In a medical model disability is perceived as a tragic, individual problem that is equated with suffering, that needs to be cured or must be endured. In this view lack of social participation, education or general access are inevitable consequences of the personal condition. This perception was revolutionised with the advent of social model thinking: here, disability is no longer a personal problem but a social one, and the task for society is to provide conditions that allow people with all kinds of impairments to participate in it equally. In a social model view, disability is not individual suffering, but something that is imposed by society on top of individual impairments (UPIAS 1976) – and can thus be altered. This perception of disability has been reinforced immensely by the UN Convention on the Rights of Persons with Disabilities (CRPD 2006), a major success of the international disability movements. The first article of the CRPD states: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." In Germany, this definition of disability has become the official political stance on disability and can be found in several laws concerning disabled people. On the other hand, scientific and social discourses on prenatal testing in combination with selective abortion, as well as discourses on medically assisted suicide, often argue that these interventions help to avoid individual suffering. This argumentation re-emphasises the link between disability and suffering, thus supporting the medical model of disability.

The German disability movement, as well as German disability studies, which emerged from the movement, has always taken a critical stance towards eugenics. We could even say that it is one of the defining traits of the German disability movement. Every method and technology that may possibly lead to the devaluation of disabled lives is under this scrutiny. A distinctive part of the public and political discourse on prenatal testing and selective abortion is also influenced by the historical experience of Nazi eugenics and in consequence is critical towards the selective potential of new testing technologies. But this is only one side of the coin. On the other we find widespread acceptance for ever finer methods of detecting "defects" in the unborn, mostly in the name of reproductive autonomy and responsible parenthood as well as the prevention of pain and suffering.

Against the backdrop of German history, the disability movement was and still is very vigilant against eugenic practices in any guise – be it prenatal testing, the allocation of medical services according to quality adjusted life years (QALYs), discussions about medically assisted suicide in which "the suffering" of disabled persons is (ab)used, and ethics that divides humankind into persons and non-persons and denies non-persons the right to life, as the Australian ethicist Peter Singer does. The most recent critical debates occurred in the COVID-19 related discussions about triage decisions which were supposed to be "objective" while based on an evaluation system that rated the value lives of people who needed support and assistance in daily life distinctly lower than that of people who lived without this support.

These recent developments have shown that vigilance on the movement's part towards life-denying developments for disabled people is still necessary. We live in times where disabled people paradoxically have more legal rights than ever before, but simultaneously the results of genetic research, discussions about the "just" distribution of healthcare and the discourse on the right to a self-determined death threaten the very existence of disabled people. In public discourse, "inclusion" is the dominant topic, but society's view of disability is still very much informed by ableism, which leads to negative, neo-eugenic attitudes.

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