

## **Report IASSIDD - DSiN Webinar New Eugenics & Covid-19**

On June 25 2020 almost 100 people from over 20 countries gathered virtually to attend the DSiN/IASSIDD webinar on new eugenics and Covid-19. Four presentations were weaved together by Dr. Alice Schippers and Dr. Jennifer Zarcone, with technical support by Irene van Helden, and adorned with musical interludes by United By Music (<https://www.unitedbymusic.nl/>), who played live from the gym hall in Sliedrecht. The first presentation was held by keynote speaker Prof.dr. Hans Reinders, emeritus professor at the Free University of Amsterdam, and chair of IASSIDD's SIRG (Special Interest Research Group) for Ethics. The following three presentations were given by cospeakers Jacqueline Kool, Fionn and Jonathan Angus, and Tim Stainton, in response to Hans Reinders. Some time after the presentations was reserved for a short reflection by professor Fiona Kumari Campbell and a discussion between the speakers to answer questions and express some final thoughts.

### **Prof. dr. Hans Reinders: Eugenics 'Old' and 'New' - Reflections on Recasting a Debate**

After the SIRG for Ethics' publication of "The Quiet Progress of the New Eugenics" following IASSIDD's 16th World Congress in Glasgow in 2019, some readers expressed concerns about using a term as abhorrent as eugenics to describe medical practices affecting the lives of people with IDD. In this presentation, Reinders addresses the differences and similarities between 'old' and 'new' eugenics in response to those concerns.

Reinders first emphasizes the importance of the distinction "between what happened at the centre-stage of history, and the cultural undercurrents of what was going on behind the scenes". He argues that while the act of eugenics may take different forms in different times (as nothing is comparable in scale nor method to the practices of the Nazi regime), "what enabled the rise of the eugenic movement since the late 19th century has been with us, and never faded until the present day". **These undercurrents consist of deeply rooted ableism and the "compelling force of normalcy with regard to expectations of cognitive ability"**. In order to connect 'old' and 'new' eugenics, Reinders turns to Herbert H. Goddard, known as "one of the most outspoken 'eugenicists' of the early 20th century". In his book "The Kallikak Family" from 1912, Goddard took a scientific approach to 'feeble-mindedness' and argued that his research proved his theory on the genetic origin of human intelligence. Goddard's goal was not to argue that people with IDD should not exist (he "governed an institution where people with IDD lived and used his study to plea for increased funding"), but rather to keep them segregated and "outside the circle of human reproduction". Reinders connects the similarities between Goddard's eugenics and present day medical practices targeting IDD to liberalism's natural theology, to which Goddard adhered and which lives on in "the cult of normalcy in our time".

Relating these undercurrents to the COVID19 pandemic, Reinders points out that "far reaching lock down measures" to protect "the most vulnerable in society" provided relative freedom for the general population, whereas "people in nursing homes were forced to stay inside" and "institutionalized persons with IDD also saw their activity centres and workplaces closed". This disconnect between theory and practice furthermore manifested itself in the priorities of medical

triage: **the concern for vulnerable people's safety "came second, after the goal of providing specialized care in ICUs for the general population was secured"**.

Reinders concludes with an analogy "with the rising debate on systemic racism that also points to cultural continuities rooted in the past": "The analogy regards the cult of normalcy that reproduces ableism as the cultural norm in response to which the prevention of disability is justified as a matter of individual choice".

*Comments from the webinar chat:*

Prof. Fiona Kumari Campbell: "Glad you mention ableism which underpins eugenics."

### **Jacqueline Kool**

Jacqueline Kool, author and researcher on belonging and representation of people with disabilities, follows Reinders with a moving talk on whether preventing disability actually prevents suffering. She points out the tension between the medical and social models of disability, the first of which argues for prevention and cures through technical possibilities for 'human enhancement', and the latter of which looks at "disability and the right of living a good life in society". Again there seems to be a disconnect between theory and practice, as Kool argues that there exists a tension "between valuing life of disabled people as all nations say and at the same time putting in costs and efforts in wiping disability". She refers to Bas Heijne's television series "The Perfect Human" (2015, VPRO), criticizing him for stating that "of course no one can object to preventing disability and illness". Such statements add to the narrative of disability and illness as revolving around suffering, which ignores the real life experience of people with a disability or illness who say that they don't value their lives as less, and that "the suffering that comes with living with a disability is often more located in an inaccessible society". This leads Kool to pose the following question: "Would eugenics prevent a societal or mankind level of suffering?" Adding to Dr. Reinders' argument, Kool points out that "we are called the vulnerable in this crisis who should be protected, but our rights have been taken away and the death rate was the highest of all". Neither on a personal or family level, nor on a societal level, was suffering prevented.

Kool states that "**the train of eugenics is going and it won't be stopped**". The ethical question is: "Who decides which people are there to be in the future and what is to be erased?" Such decisions may "take away freedom from future generations to make their choices".

Counternarratives are needed to "make people aware of what lived experience of disability looks like", so that people can make well-informed choices that are not based on "abstract fears of disability". Kool calls for a **Disabled Lives Matter hashtag**, "because all lives matter but often disabled lives don't. We should value and love our own and other's disabled bodies". Kool ends with the following passage from poet Kenny Fries' "The History of my Shoes and the Evolution of Darwin's Theory" from 2007: "*Feeling the strong pulse of spraying water run over me, I close my eyes, and it is as if the water's heat slowly dissolves the skin of my limbs. Then my bones. Until I am one of those armless legless Greek statues, all torso. Something akin to a male Venus the Milo who, despite having no arms or hands, the stump of her upper right arm extending just above her breast, despite her scarred face and severed left foot, despite having the big toe cut at her right foot and missing her left nipple, not being real, is considered one of the most beautiful figures in the world.*"

### **Fionn and Jonathan Angus**

Determined to show that living life with a disability can be rich and fulfilling, Fionn Angus and his father Jonathan joined forces in their social enterprise *Fionnathan* (<https://www.fionnathan.com/>). Fionn has Down's syndrome, and together with his father has shown many people that Down's is not and should not be a hindrance to achieve dreams. Fionn firmly establishes this fact by opening with the unequivocal statement that **he has a great life**. This is the first of three points he and his father want to make in response and addition to Prof. Reinders' presentation. To emphasize this point they list several of Fionn's achievements (see the Fionnathan website). Many of these, as Jonathan says, could have been achieved without Down Syndrome, "but in many cases, Down Syndrome has led to their happening". With this acknowledgement, Fionn and his father challenge the widespread idea that when people with disabilities are successful it is *despite* of their disability.

Their second point is about the importance of treating individuals as equal while at the same time understanding that "each person has their own requirements to support them in achieving a good life" (Jonathan). "**People are equal, but each person is unique**", Fionn says. While some support has been easy to win, such as the Wage Subsidy Scheme that pays employers for hiring someone with a disability, they have had to work hard to receive other types of support, such as an educational assistant for Fionn's private school and supported independent living. Their final thoughts on support are that "**community is crucial**" because "that's where most of the support we need for life organically grows" (Jonathan), and that "**everyone of us is disabled when we don't have appropriate support. When we have the love and support we need, disability disappears**" (Fionn).

Their third point circles back to the webinar's overall topic. "**Ableism is the final frontier of -isms**", says Fionn. First, Jonathan expresses their support and enthusiasm for the Black Lives Matter movement, because it can both address the worldwide problem of racism, and "open people's minds to the other social justice issues", which includes all discriminatory -isms, such as racism, sexism and ageism. Ableism is the final frontier of those -isms, argues Jonathan, because "**to question ableism is to question meritocracy**", a system that rewards people with wealth and status "based on their ability to perform under a certain set of constraints and measurements", instead of on their needs. This system "is at the root of eugenics, and it's time for a new way to look at our human societies." Fionn and Angus end their presentation by referring to a new discovery that has expanded the history of Down syndrome by 4,000 years and that proves old societies cared for people who were vulnerable (this can be read about here: <https://www.peoriapublicradio.org/post/ancient-bones-offer-clues-how-long-ago-humans-cared-vulnerable#stream/0>), and with the following statement: "**When you consider 499 out of 500 babies suffer from lack of Down syndrome, my parents are incredibly lucky**".

### **Prof. dr. Tim Stainton**

Prof. Tim Stainton, professor at the School of Social Work, and director of the Canadian Institute for Inclusion and Citizenship at the University of British Columbia, begins his presentation by addressing the different forms old and new eugenics have taken, to reflect on and add to Reinders' comments: "old eugenics was a very explicit program" that "provided an explicit target", whereas "the current eugenics is much more subtle" and is becoming normalized, which also means that, to an extent, it is invisible. Because new eugenics is deeply embedded in ableism and medical practices, "**our task is to confront this and to make the invisible visible**". Unpacking some

aspects of the Covid19-crisis that are related to disability and eugenics, Stainton uses the triage protocols in Ontario to demonstrate “the levels of vulnerability someone with a disability would face in the healthcare system”. Triage protocols were set up to “get the greatest incremental benefit”. However, “what constitutes benefit is highly subjective” and in this case subject to the normalization problem. Stainton highlights three criteria that clinicians use to make treatment decisions. The first two include severe baseline cognitive impairments, progressive illnesses, and advanced irreversible neurodegenerative diseases. **The third criterium excludes people from care who have a clinical frailty score greater than seven, which as Stainton points out “covers a significant part of the disabled population”.**

Another one of the biggest Covid-related issues, says Prof. Stainton, has been the lockdown on visitors in hospitals and long-term care facilities. Providers of essential and communication support for vulnerable people and people with IDD are being denied access to hospitals, which is in contravention with the Canadian Charter of Rights and Freedoms. Even after a statement by the ministry of health saying that “visitors who are required to provide support should be allowed in the hospital”, provoked after a month of advocacy, people were still being denied access. This meant that many people with IDD were terrified and alone, all because of the alleged aim to “protect the vulnerable”. One woman died alone and without support. These events lead. Stainton too, to point out the stark differences between theory and practice: “the policies may all *look fine*, but the embedded attitude and the strength of the medical model, and the normalization in the medical profession create a very dangerous mix that allows for eugenics practices to carry on”. Additionally there seems to be, especially in the United States, a “willingness to let the vulnerable die in favour of economic opening up”. Stainton concludes by stating that in response to these policies and attitudes, **“a strong equality rights focus is a really good starting point”.**

*Comments from the webinar chat:*

EJ Bakker: “In the ID research group in Rotterdam, the Netherlands, they constructed a validated frailty score for people with ID which rather differs from the clinical frailty scale (CFS) used in the general population. The good news is that the federation of Dutch medical specialists is aware of this other frailty scale that should be used in case of people with ID.”

### **Reflection and discussion**

Professor of Disability and Ableism Studies Fiona Kumari Campbell starts the discussion by reflecting on one of the biggest concerns people with disabilities have in the UK: the disability registration measure that ‘shields’ people so that they can have access to supermarkets and food deliveries at home, if they are not allowed to go outside. There is a fear of data matching which. Campbell relates to the dangers of DNR criteria, and to historical memory: “once we’re on a database, how could this potentially be misused in the form of biopolitics like social measures and social policy?” Picking up on Reinders’ comments on cultural undercurrents, Campbell argues that saying Nazi practices couldn’t happen again, is naive. She furthermore states that **“you can’t have racism without ableism”**, because they’re both about hierarchies and about which people are the most perfect and who is to be discarded. Similar to the cospeakers’ arguments, she believes eugenics to have continued since the 1930s, just in a different expression. She ends with the following question: “What are the dangers and benefits of naming what’s going on as another eugenics movement?”

*(See prof. Campbell’s “Precision Ableism”, 2019).*



Prof. Reinders shares Campbell's concerns and adds that a registration system and data matching is a complicated issue because if such a system is not used it also means "to forgo benefits it *could* have for people with disabilities".

Dr. Jennifer Zarcone points out the intersections between the concerns about data matching and the Covid-crisis: if data is misused and people are for instance labeled as having had Covid, or as having a disability, where will that lead? Is it still possible that the path that is taken in triage protocols ("you are frail and therefore at a lower level of care"), will change?

Prof. Stainton answers this question by clarifying that **"most people aren't aware that you don't need to give permission for a DNR, that's a medical decision. I suspect that most families, when they check their [family member's] charts, would find one if they had a significant disability. It's part of this unmasking the invisibility of eugenics and I would encourage everybody's families to do that."** In a self-proclaimed cynical mindset he states that, although we need to keep fighting, "the ship sailed a long time ago". Covid is being used as an excuse to do "what's best for the general population", which he argues is code for "we have to do what's right for the privileged white folks".

*Comments from the chat:*

Rhonda Faragher: "I think we can make a difference if we draw the attention of the population who have no idea about these things. In Australia we have just succeeded in having NIPT kept off the public health scheme (you can still pay privately for it)."

Picking up on the aspect of family, Fionn and Jonathan Angus emphasize the importance of having people in your life you can rely on and who take an interest in you. Jonathan points out that, while it is in principle unfair that parents need to "pick up the slack" of being caregivers and advocates, it is necessary because **"society isn't ready to support people like Fionn to the degree that people should be supported"**.

Jacqueline Kool adds to this that 'personal problems' and 'societal problems' are connected: while Kool shares Stainton's cynicism, as she already stated that the train of eugenics is going, she also argues that **"we must be able to raise our voices to at least tackle the arguments that the person is embedded in social structures and judgments and these structures are enveloped in the overall view on humanity and what is right and wrong"**. This is why there is a need for social model thinking and to provide people with disabilities with "support and the freedom to be cobuilders of society". Ultimately Kool hopes that the people who are dealing with rest effects from Covid will join these discussions.

Prof. Reinders ends the discussion by commenting on cynicism: "I understand the temptation, but try to resist it." He is hopeful for change, especially because of the many young people from different cultures engaging in the anti-racist movement. **"The possibility will be that if representations are questioned and moods change, more people will discover that the train is not going anywhere"**.

**Short film from the SIRGS:**

[https://www.youtube.com/watch?v=geVJO0OeBhQ&feature=emb\\_logo](https://www.youtube.com/watch?v=geVJO0OeBhQ&feature=emb_logo)

**Credits and thanks to whisper interpreter Eva Haverkort & closed captions writer Theo Tomassen.**

**Report by Lesley Verbeek, July 2020**