

**“Revisiting Genetic Discrimination Issues in 2010: Policy Options for Canada” by Trudo Lemmens, □ Daryl Pullmant and Rebecca Rodal‡
Commentary by**

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webpage: <http://www.bioethicsanddisability.org/>
Ableism and Ability Ethics and Governance blog: <http://ableism.wordpress.com>
column The Choice is Yours:
http://www.innovationwatch.com/commentary_choiceisyours.htm
Nano Bio Info Cogno Synbio Blog: <http://wolbring.wordpress.com/>
What Sorts of People blog: <http://whatsortsofpeople.wordpress.com/>

Who am I

- PhD in Biochemistry 1992; Research Scientist Biochemistry 1992-2008 Last 12 years on mechanism of thalidomide and its derivatives
- Assistant Professor, University of Calgary, Faculty of Medicine, Dept. of Community Health Sciences 2008-
- Part Time Professor, Faculty of Law, University of Ottawa, Canada 2007-
- Founding Member and Distinguished Scholar, Center for Nanotechnology in Society at Arizona State University, USA 2005-
- Adjunct Faculty Critical Disability Studies York University Canada 2008-
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Ongoing Research Projects

- Genome Canada grant Metagenomics for Greener Production and Extraction of Hydrocarbon Energy: overall PI Gerrit Voordouw UofC; Team leader: ethical, environmental, economic, legal and social issues (E3LS) of Climate change, energy security, water security, metagenomics, oil and gas
- SSHRC grant with Ian Kerr UofO Therapeutic enhancements and performance enhancements
 - impact on professional identity such as health and rehab profession
- SSHRC/CURA grant: Lead PI Rob Wilson UofA History of Eugenics in Western Canada/Newgenics

Ongoing Research Projects

- Synthetic Biology
- Ableism: a term developed within the disability rights movement in the 70's to highlight the discrimination based on expected species-typical body abilities/body structure and functioning
- However ableism is much broader and is a general dynamic where one sees certain abilities in oneself or others as essential (e.g. Productivity, competitiveness, ability to consume....). Ableism leads to an ability based and ability justified understanding of oneself, one's body, ones desires and one's relationship with others of one's species, other species and one's environment.
- Science and technology discourses and marginalized group
- Tele-health
- Ubiquitous cities and privacy

Issues with the Discourse around Genetic Discrimination

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Issue of Scope of Genetic Discrimination Discourse

- This Policy Brief focuses on the employment and insurance sectors
 - Disability, health, and life insurance genetic discriminations. (ref in PPT note)
 - Prebirth genetic discrimination
 - Does it include genetic enhancement related discrimination ?

Issue of Scope of Genetic Discrimination Discourse

- Initiatives that single out genetic discrimination as somehow unique and worthy of free standing legislation would face challenges from those who see other types of information as equally sensitive in nature, or from other vulnerable groups who might claim the need for greater protection .
- Indeed
 - Sex selection No impairment deselection Yes
- There is a problem with the reality of inconsistent legislation around genetic discriminations

Issue of Language

- “more detailed genetic risk information .
- Employers could also use genetic information to exclude those at higher risk of disease in order to avoid higher disability insurance costs probability
 - If Risk is the preferred use over a neutral term one invites discriminations

Legal approaches

- the definition of ‘disability’ in human rights acts could be amended, for example, by stating that the term ‘disability’ includes ‘the perception or belief that the person will have a disability in the future’. This has the advantage of clearly including future disability or illness associated with genetic mutations in an existing prohibited ground of discrimination, while avoiding criticism that genetics is singled out for special protection.
 - the disability rights commission in the United Kingdom asked that asymptomatic disability be added to the definition of disability within the British laws prohibiting disability discrimination to protect them from genetic discrimination (DRC)
 - The Americans with Disabilities Act: an anti-disability discrimination law, which has been interpreted by the Equal Employment Opportunity Commission (EEOC) to prohibit some forms of genetic discrimination. (EEOC)
 - However despite the ADA the Health Insurance Portability and Accountability Act (HIPAA) and Title VII of the Civil Rights Act of 1964:the US opted for a specific AGD law which by itself raises the question whether the ADA is not seen as strong enough.

Legal approaches

- Fourth, a new prohibited ground of discrimination could be added to the CHRA and PHRAs that focuses on genetic information. This is what the current Private Members Bill by Judy Wasylycia-Leis proposes for the CHRA. This option has the advantage of explicitly capturing genetic information. Prohibited grounds reflect a societal recognition of historical or contemporary experience of discrimination and stigmatization. Including a specific ground conveys an expressive meaning and reflects societal concern and condemnation of the inappropriate use of this trait.
 - Will it cover all forms of genetic discrimination?
 - And does it include symptomatic (continue next slide)

Legal approaches

AGD laws could prohibit genetic discrimination against, for example, people who *have the gene for xxx*, whether or not they exhibit symptoms related to xxx.

Or these laws could prohibit discrimination against people who have the gene for xxx *until they develop the symptoms related to xxx*

This means that it would be legal to discriminate against someone with the gene for xxx as soon as that person exhibits the symptoms related to xxx.

In other words, one is protected from discrimination as long as one is viewed as asymptomatic (in the framework of the ADA, this would be an 'asymptomatic disabled') but as soon as one is viewed as symptomatic (a symptomatic disabled), one is not protected anymore.

Legal approaches

- The German Federal Parliament approved in 2009 a Draft Human Genetic Examination Act, which includes a review process and the establishment of a Genetic Diagnostic Commission Yes however this law
 - § 2(1) This Act applies to genetic examinations and genetic analyses conducted within the framework of genetic examinations involving born natural persons as well as embryos and fetuses during pregnancy and the handling of genetic data and genetic samples gained thereby **for medical purposes, for purposes of determining descent as well as in the insurance and employment sectors.**
 - § 15 (2) Any prenatal genetic examination aimed at determining genetic characteristics of the embryo or foetus in relation to an illness may not be conducted if, according to the generally accepted status of science and technology, such illness only breaks out after the age of eighteen.
 - (I assume this is like a sort of no to testing for predisposition)
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Legal and Governance Issue

- A comprehensive framework could be developed through stand-alone legislation, which would introduce comprehensive review and establish a specialized regulatory body. ... It could further identify the need for genetic counseling and set information standards, which are concerns even outside the health care context
 - For whom the person who wants to discriminate?

Future Research Question

- Judy Wasylycia-Leis's motion, M-444, reads:

“That, in the opinion of the House, the government should develop and implement anti-discrimination protections with respect to genetic information, including, but not limited to, information gathered through genetic testing and family history, that include:

 - A. effective enforcement mechanisms;
 - B. a standing body mandated to document cases, evaluate the effectiveness of anti-discrimination protections, and make recommendations to the government about the uses of genetic information and direct-to-consumer testing;
 - C. a public awareness campaign to focus attention on the issue of genetic discrimination and its link to genetic testing and research.”



Future Research Question

- Investigate ableism the underlying issue of why we discriminate.
- Look into Ableism Ethics, governance and studies
- How is the argument around genetic discrimination pre and after birth impact discourse around genetic and other enhancements
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Thank You

- Any Questions