

Thank you for inviting us to participate in this conversation. The Commission deals with discrimination in many forms, and through three programs -- cases, knowledge development and research, and discrimination prevention initiatives. I will take a pragmatic lens to the issues raised in the policy brief.

INFLUENCING THOUGHTS/Commission Philosophy

A key framing philosophy which informs our work, exposes my bias, and influences my comments today:

- Human Rights protections are not the sole responsibility of Commissions, Tribunals, and Courts. High-level policy instruments such as legislation can provide the framework for human rights protections, but if these are to be meaningful, they need to be built into organizational systems and integrated into daily practice. Especially in emerging and fast-developing scientific and health-related fields where genetic information is used, industry regulations, policies, standards, codes of conduct, and internal redress mechanisms are important tools, both to ensure prevention of discrimination and to provide timely responses to human rights issues. *(this point was shortened in Ms. Mosher's verbal remarks)*

The Current Context:

- LaForest Panel reviewed the Canadian Human Rights Act in 1999 and reported that genetic discrimination may be the human rights issue of the future. It recommended that the CHRA include “the predisposition of a disability” in the ground of disability. In the intervening ten years, the CHRC has not acted on this recommendation, but had a radio silence.

Complementary current priorities

- CHRC has made disability issues a priority. Not sufficient to deal with individual cases – need to address the systemic issues that inhibit full social and economic integration.
- This is especially true now that Canada has ratified the Convention on the Rights of Persons with Disabilities, which challenges us to perceive disability differently. Disability is not simply the result of an individual's impairment, but is rather the result of the attitudes, policies, laws, and barriers that exclude people rather than include them.
- Ultimately, the success of this ratification will be measured by how the Convention rights are being enjoyed on the ground, not how they appear on the page. This document is available on the table in the foyer.

This concludes our CHRC plug/public service announcement. I will now turn to the business at hand, and the options in the policy brief regarding strengthening the existing HR regime.

1. OPTION TO ADD A NEW GROUND (MP Judy Wasylycia-Leis Private Members bill)

- While we have not taken a formal position on the draft bill, it is simple and comprehensive – at least at the federal level. It would provide visibility, clarity, and parliamentary direction. It would align Canada with other countries and international instruments that already protect against genetic discrimination. Insurance companies and employers would be required to justify any discrimination under human rights scrutiny, just as with any other ground.
- Not a change the CHRC would pursue independently. We believe that the primary public concern – genetic discrimination based on a propensity for a disability – is already sufficiently covered by the “perceived disability” interpretation of the Supreme Court in *Boisbriand*.
- Neither we nor provincial commissions are receiving significant numbers of inquiries on genetic discrimination. This should not be the sole indicator, but this information is helpful to influence the public and policy agenda: is there a compelling rationale for legislative priority? We have not found an overshadowing effect from complaint activity as of yet. And when we have such a compelling rationale---such as the repeal of section 67 of our Act---it has still taken two reports to Parliament and over 20 years of work to extend the human rights protections enjoyed by all Canadians, to First Nations.
- We recognize that some systemic issues, such as genetic profiling, are a serious concern, but they remain emergent and have not yet crystallized into either a complaint or a policy context.

2. OPTION TO AMEND CHRA DEFINITION OF DISABILITY

- Carries the same legislative burden. In addition, amending the definition of disability while ignoring possible links to other grounds (such as race, ethnic origin, or family status) has two risks.
- First, genetic discrimination based on race, ethnic origin, family status, religion, or pardoned criminal conviction, for example, would remain invisible. This disparity in recognition could reduce, rather than increase, clarity about coverage of the issue.
- Second, and more substantively, the singular attachment to disability might be interpreted as an intended limitation, reducing protection of genetic discrimination based on other grounds. With such a rapidly developing technology that might have unpredictable and wide-ranging impacts, it might be a good idea to leave these threads uncut.

3. OPTION TO DEVELOP REGULATIONS AND GUIDELINES:

- While the *Canadian Human Rights Act* allows the creation of regulations and guidelines, in fact, we don't do this often (if ever in recent memory). The development process takes significant time and resources, and they are not the time or energy savers they appear to be. Given the complex technical expertise required, the turbulence in the developing field, the shared insurance jurisdiction with the provinces, and the current commitments of the CHRC, it is unlikely that we will undertake regulatory development in the near future.
- This is not just shuffling off, but reflects our conviction that comparable impacts can be accomplished through other initiatives

Are there are other options to attain the worthwhile goals of visibility, recognition and clarity around this issue?

OTHER OPTIONS AVAILABLE

“Model Policy” to encourage Industry Implementation:

- Developing a written policy at the working level offers great flexibility and high visibility for less effort. Similar consistent policies can be proposed across Commissions with greater ease, through our all-commission network. This serves an educative and awareness-raising purpose, and can develop common understandings of some of the complex issues at play. The CHRC normally works with employers and interest groups in creating instruments such as these. Although these are not binding instruments, nor determinative in complaints, they can provide guidance and illuminate boundaries in relation to the duty to accommodate, BFORs, and undue hardship. We have some similar experience in issuing documents on the issue of drug and alcohol testing, and accommodating mental health issues in the workplace. Undertaking this kind of activity would depend on stakeholder interest and engagement, including employers and industry representatives.

Strategic Litigation Strategy

- Using the CHRC's Litigation strategy as a vehicle, we can identify and expedite cases that raise a significant public interest or novel legal issues such as genetic discrimination. We can also promote international human rights principles and treaty obligations as we litigate these cases. This approach provides high visibility and encourages the development of a reliable body of case law.

Other Initiatives:

- I mentioned that we do not have many inquiries on this matter, but neither do we have a good system to collect this data. We are taking advantage of a re-tooling

of our internal information system to ensure we can more clearly tabulate the number of inquiries we receive about genetic discrimination, in the future.

- In addition, we hope to raise awareness by sharing these conference results with our network of Commissions, where we have regular discussions about issues of common interest. We will also suggest the topic of genetic discrimination as a workshop for our 2011 Annual Conference, which is open to the public.

CLOSING

We are seeking direction regarding the future work and collaboration we might have on this issue, and we look forward to discussion, questions, and identification of other concrete measures we can take to enhance understanding and awareness of this complex issue. Thanks for the opportunity to learn and share.