

'Policy Options for Canada' Comments from Europe

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Europe:

- World's smallest continent;
- 6.8 % of world's land area;
- 50 countries;
- Uncountable languages;
- (EU: 23 official lang.)



Europe:

European countries have **different legal traditions / approaches**, also with respect to:

- Regulating the employment/insurance sector;
- Non-discrimination;
- Privacy;
- Genetics.

Some approximation of laws by:

- Council of Europe;
- European Union.



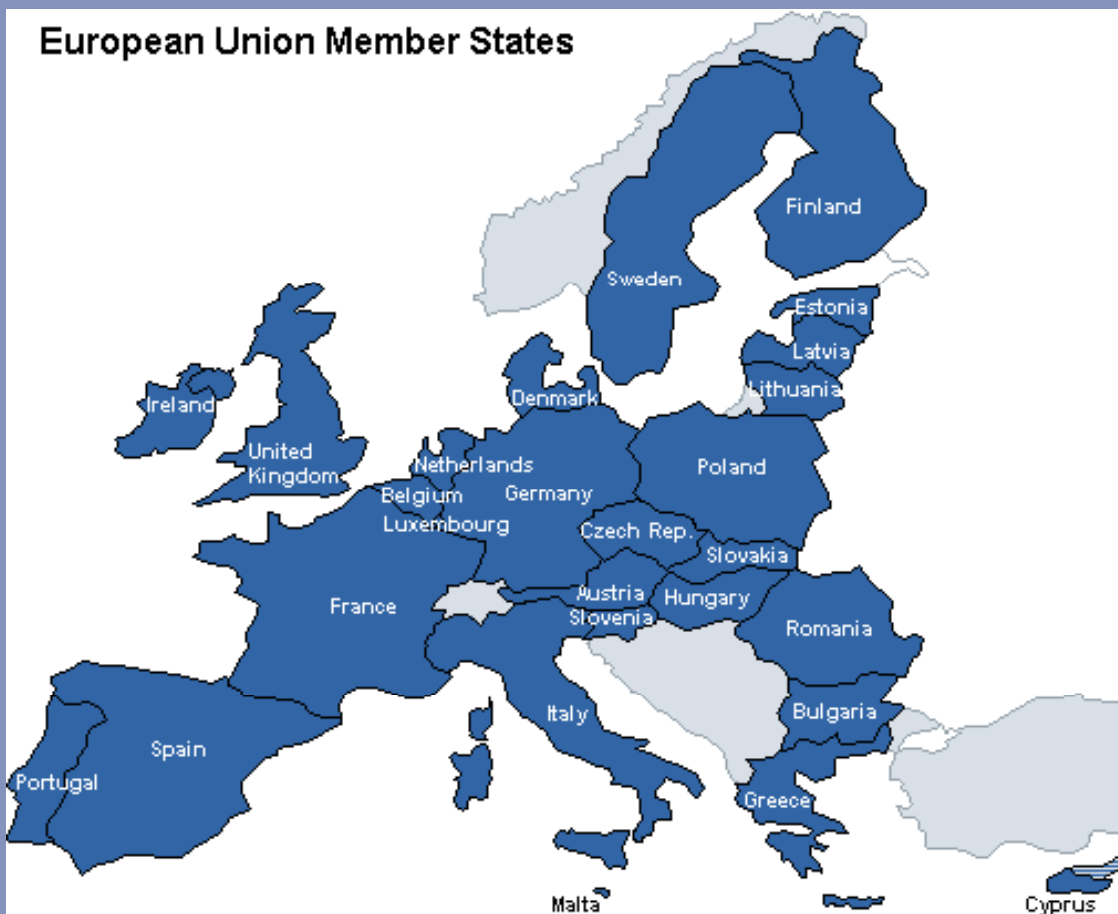
More European integration / regulation is contested



Aim presentation:

- Short **overview** (standards) Council of Europe and European Union;
- **Comments** on Discussion paper, based on work / experiences Council, EU and individual countries.

European Union (27)



European Union (1)

- Founded in 1957 – 6 Members (EC);
- In 1957: 6 Members / now: 27;
- **Supranational** organisation – but limited powers;
- Aim: **economic** integration;
- Free movement persons, goods, services and capital & free competition;
- Throughout years: aims broader / more power.

European Union (2)

- Limited powers to regulate employment sector
 - Exceptions: discrimination and occupational health.
- More powers to regulate insurance sector (= service) > free competition;

European Union (3)

- No mandate protection of **privacy**
 - Privacy directives aimed at proper functioning of freedom of services;
- Limited powers to prohibit **discrimination**
 - Exhaustive list of protected grounds (NOT genetics, INCL disability);
 - Incl. 'perceived ground' and 'by association'
 - No transparency? > assumption discrimination.

European Union (4)

- No mandate to protect **privacy**
 - Privacy directives aimed at proper functioning of freedom of services;
- Limited powers to prohibit **discrimination**
 - Exhaustive list of protected grounds (NOT genetics)

European Union (5)

- Since 1992 – limited powers in the field of public health ('strengthen cooperation')
- Since 2009 – Charter of Fundamental Rights:
 - Prohibition of discrimination on basis of **genetic features**

Council of Europe (47)



Council of Europe (1)

- Founded in 1949 – 10 Members; now 47 Members, 5 observers (incl. **Canada**);
- **Intergovernmental** organisation;
- Aim: greater unity; safeguarding and realising common ideals and principles (democracy, rule of law and human rights)

Council of Europe (2)

European Convention of Human Rights (1950):

- Respect for private life (Art. 8)
 - Health and genetic information extra protection (S. & Marper v. UK, 2008)
- Non-discrimination (Art. 14)
 - Only in conjunction with other rights;
 - No reference to genetics (but disability covered, Glor v. Switzerland, 2009)
 - Interpretation of 'discrimination' inconsistent.

Council of Europe (3)

European Social Charter (1961, revised 1996):

- Rights with respect to employment
 - Non-discrimination > 'health'

Biomedicine / Oviedo Convention (1997)

- Right to private life (Art. 10)
- Non-discrimination genetic heritage (Art. 11)
- Predictive genetic tests for health (Art. 12)

Council of Europe (4)

Additional Protocol Biomedicine
Convention on genetic testing
for health purposes (2008):

- Can be of relevance to
employment sector, not
insurance sector.

Comments (1)

Meaning of 'genetic information' in unclear:

- Results of DNA-test (*source-based*);
- Information about heritable features (*contents based*).

Comments (2)

Assumption:

- Genetic information is **medical information** (race, gender etc.);
- Genetic information is **personal** (relatives)
- Heritable features can be distinguished from environmental factors.

Comments (3)

Assumption:

Employers can only obtain genetic information by way of questions, questionnaires or medical exams
< > duty to disclose.

But what if the information is on internet or otherwise available?

Comments (4)

Assumption:

Privacy, non-discrimination and duty to disclose information have the same meaning for the employment and the private insurance sector.

- Employment: is person *now* qualified;
- Employment: health protection may be relevant;
- Insurance: (only) *future* risks.

Comments (5)

Assumption:

Protecting genetic discrimination through disability discrimination laws requires amendment of term

disability:

Court of Justice EU:

- Actually or perceived;
- Also 'associated with'
- Difference 'because of' and 'on grounds of'.

Comments (6)

Meaning of discrimination not clear:

Does it cover both direct / disparate impact discrimination and indirect / adverse effect discrimination?

What should be the burden of proof?

Comments (7)

What is the problem????

- 'Processing' genetic information or
- Using genetic information prior to employment and/or insurance?

Comments (8)

As long as we do not know where to draw the line between justified differentiation and discrimination, introducing specific non-discrimination legislation does not make sense.

Comments (9)

To the extent that protection against discrimination is felt necessary, why not cover under the ground disability?

Be aware of an inflation of non-discrimination grounds.

Comments (10)

Why should we have genetic specific enforcement bodies (and legislation)?

In Europe: more single ground bodies and integration of non-discrimination laws.

Comments (11)

Sector specific options ('self regulation') require a legal framework:

- to facilitate enforcement,
- to prevent parties from not abiding by them and
- to counter the effects of the international market.

Comments (12)

As long as we do not know where to draw the line between justified differentiation and discrimination, introducing specific non-discrimination legislation does not make sense.

Privacy legislation is less problematic. There is no justification for genetic exceptionalism.

