

Summary of Comments on Outline of the international instrument on human genetic data

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Author: Owner

Date: 12/8/02 10:04:01 AM

Type: Note

A qualification of the term 'person' is needed in the light of the fact that the bioethics debate shows that not everyone is defining 'personhood' in the same way.

Sequence number: 2

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The knowledge of genetic sequences does not have lifelong relevance per se. It only has the relevance till symptoms associated with the sequence appear after that the symptoms themselves lead to the judgment. Often genetic sequence has no higher accuracy than prediction based on family history.

Sequence number: 3

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It should better read "The collection...shall not take place without the individual and where applicable societal approval

Sequence number: 4

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The term independent, multidisciplinary and pluralist ethics committee should be read in accordance with the relevant paragraphs of the UNESCO World Conference on Sciences Declaration (25) and the UNESCO World Conference on Sciences Framework for Action (79,91) and it should ensure that disabled people are NOT equated with patients.

Sequence number: 5

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This article has two weaknesses. A) it assumes that we can stigmatize and discriminate against a person, family or group only if the human data is taken from humans who are born. But reality is we can also stigmatize and discriminate against a family or group if the target tested is the fetus or cell because the decision execute by the family, the parent might stigmatize them or stigmatize the group living with the same characteristic. It is said in article 67 of the PID working paper that setting up a hierarchy of severity will lead to stigmatization of the condition selected. If that is true the same is true if we select based on one characteristic period. One of the arguments against sex selection is that it stigmatizes the group containing the same characteristic as the targeted characteristic for deselection.

b) Genetic discrimination describes in many legal proposals the differential treatment of individuals or their relatives based on their actual or presumed genetic differences (social reason) as distinguished from discrimination based on having symptoms of a genetic-based 'disease' (medical reason) (Geller, L.N., Alper, J.S., Billings, P.R., Barash, C.I., Beckwith, J. & Natowicz, M.R. (1996). Therefore stigmatization and discrimination takes also place if the protection is terminated as soon as symptoms related to the genetic data appears. Genetic discrimination describes the differential treatment of individuals or their relatives based on their actual or presumed genetic differences as distinguished from discrimination based on having symptoms of a genetic-based disease (Geller, L.N., Alper, J.S., Billings, P.R., Barash, C.I., Beckwith, J. & Natowicz, M.R. (1996) (the same criticism is true for article 14).

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Who defines the benefits and the mode of sharing?

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How is public health defined? And health in general? Does it follow the Jakarta Declaration of Health?..