

Summary of Comments on Revised Outline of the International Declaration on Human Genetic Data

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Author: Default

Date: 3/17/03 9:12:08 AM

Type: Note

The term person is still not defined. see <http://www.bioethicsanddisability.org/Personhood.html> for some definitions which can outdefine many human beings from being persons

Sequence number: 2

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Date: 3/17/03 9:20:48 AM

Type: Note

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.

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Author: Default

Date: 3/17/03 9:21:42 AM

Type: Note

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

Sequence number: 4

Author: Default

Date: 3/17/03 9:23:17 AM

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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.

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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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Date: 3/17/03 9:25:12 AM
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what is mend with behavioural genetic studies?

Sequence number: 3
Author: Default
Date: 3/17/03 9:42:32 AM
Type: Note

handicapped is not a term used in english anymore. Furthermore the term person has to be defined somewhere

Sequence number: 4
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Type: Note

so if genetic counseling is not mandatory in all cases what does that mean? in what cases is it not mandatory? How does the parents get help with the results thrown at them. If it is not mandatory that also leads to the question whether genetic counselling is paid for by insurance companies. And another question arises namely whether alternative procedures will be available..

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very problematic!!. As the term 'significance for medical and other scientific research or public health purposes' is so broad that in essence the taking of a sample against the consent and will of the person can be justified all the time. Also it does not say whether research includes comercial scientific research.

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what if the donor of the material demands different benefits?