

Summary of Comments on Draft Report on Pre-implantation Genetic Diagnosis and Germ-line Intervention

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Sequence number: 1

Author: Owner

Date: 12/8/02 12:53:26 PM

Type: Note

biased, directive, able-ist, disabilityphobic language. Where ever you see this comment it also indicates that the term used are not objective but terms used within a societal prejudiced framework often not reflecting the views of the 'affected high risk... people

Sequence number: 2

Author: Owner

Date: 12/8/02 12:17:48 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

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Sequence number: 1

Author: Owner

Date: 12/8/02 1:05:57 PM

Type: Note

there is for sure no general agreements on the use of prenatal testing in general. for sre disaled people are not part of this general agreement. and what are major indications. According to 67 there are no ways to distinguish between severity therefore there ca not be 'major indications'.

Sequence number: 2

Author: Owner

Date: 12/8/02 1:06:42 PM

Type: Note

Sequence number: 3

Author: Owner

Date: 12/8/02 1:07:47 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 4

Author: Owner

Date: 12/8/02 1:07:55 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 5

Author: Owner

Date: 12/8/02 1:07:59 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 6

Author: Owner

Date: 12/8/02 1:09:18 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 7
Author: Owner
Date: 12/8/02 1:11:05 PM
Type: Note

smoke screen. implies that the framework of use is limited to 'severe' but as 67 says 'severe' is not definable

Sequence number: 8
Author: Owner
Date: 12/8/02 1:11:22 PM
Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 9
Author: Owner
Date: 12/8/02 1:11:47 PM
Type: Note

smoke screen. implies that the framework of use is limited to 'severe' but as 67 says 'severe' is not definable

Sequence number: 10
Author: Owner
Date: 12/8/02 1:12:03 PM
Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 11
Author: Owner
Date: 12/8/02 1:16:46 PM
Type: Note

wrong. as the conceit of health disease defect anomaly... is by itself a societal construct elimination of it is a social reason just the same. With other words conventional form of prenatal diagnosis has a social character just the same

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Sequence number: 1
Author: Owner
Date: 12/8/02 12:19:08 PM
Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 2
Author: Owner
Date: 12/8/02 12:19:15 PM
Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 3
Author: Owner
Date: 12/8/02 12:30:28 PM
Type: Note

tells you that parents have no choice. THAT fits nicely with research done by Dorothy Wertz which showed that if you ask people involved in giving and counselling mothers about predictive test that the majority in 24 countries believed it is unfair to the child to be born with a disability. 40% agreed in USA, Canada and Chile. 36% in Finland and UK; 33% in Switzerland and the Netherlands; 29% in Argentina, 27% in Australia 25% in Sweden and 18% in Japan. (Wertz DC (1998) Science in Context 11, 3-4 pp 493-510 (p501))

Furthermore they believed that

"It is socially irresponsible knowingly to bring an infant with a serious [no legal document defines what is serious] genetic disorder into the world in an era of prenatal diagnosis." More than 50% agreed in South Africa, Belgium, Greece, Portugal, Czech Republic, Hungary, Poland, Russia, Israel, Turkey, China, India, Thailand, Brazil, Columbia, Cuba, Mexico, Peru and Venezuela. 26% of US geneticists, 55% of US primary care physicians and 44% of US patients agreed. (Wertz DC (1998) Science in Context 11, 3-4 pp 493-510 (p501)). This mindset of course also leads to the situation where parents have to give their children any genetic /non genetic enhancement available (see

Sequence number: 4
Author: Owner

Date: 12/8/02 12:31:21 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 5

Author: Owner

Date: 12/8/02 12:31:28 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 6

Author: Owner

Date: 12/8/02 12:31:40 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 7

Author: Owner

Date: 12/8/02 12:31:52 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 8

Author: Owner

Date: 12/8/02 12:31:59 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 9

Author: Owner

Date: 12/8/02 12:32:19 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 10

Author: Owner

Date: 12/8/02 12:32:25 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 11

Author: Owner

Date: 12/8/02 12:32:33 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 12

Author: Owner

Date: 12/8/02 12:32:53 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 13

Author: Owner

Date: 12/8/02 12:33:03 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

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Sequence number: 1

Author: Owner

Date: 12/8/02 12:33:50 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 2
Author: Owner
Date: 12/8/02 12:33:57 PM
Type: Note
biased, directive, able-ist, disabilityphobic language

Sequence number: 3
Author: Owner
Date: 12/8/02 12:34:07 PM
Type: Note
biased, directive, able-ist, disabilityphobic language

Sequence number: 4
Author: Owner
Date: 12/8/02 12:34:24 PM
Type: Note
biased, directive, able-ist, disabilityphobic language

Sequence number: 5
Author: Owner
Date: 12/8/02 1:19:22 PM
Type: Note
this leaves the impression as if sex selection is special as the selection is based on social reasons but as the concept of health disease defect anomaly... is by itself a societal construct elimination of it is a social reason just the same. With other words conventional form of prenatal diagnosis has a social character just the same

Sequence number: 6
Author: Owner
Date: 12/8/02 1:20:05 PM
Type: Note
as the concept of health disease defect anomaly... is by itself a societal construct elimination of it is a social reason just the same. With other words conventional form of prenatal diagnosis has a social character just the same

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Sequence number: 1
Author: Owner
Date: 12/8/02 12:35:32 PM
Type: Note
biased, directive, able-ist, disabilityphobic language

Sequence number: 2
Author: Owner
Date: 12/8/02 12:35:48 PM
Type: Note
biased, directive, able-ist, disabilityphobic language

Sequence number: 3
Author: Owner
Date: 12/8/02 12:55:15 PM
Type: Note
smoke screen. implies that the framework of use is limited to 'severe' but as 67 says 'severe' is not definable

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Sequence number: 1
Author: Owner
Date: 12/8/02 12:36:22 PM
Type: Note
biased, directive, able-ist, disabilityphobic language

Sequence number: 2

Author: Owner
Date: 12/8/02 12:37:15 PM
Type: Note
biased, directive, able-ist, disabilityphobic language

Sequence number: 3
Author: Owner
Date: 12/8/02 12:37:25 PM
Type: Note
biased, directive, able-ist, disabilityphobic language

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Sequence number: 1
Author: Owner
Date: 12/8/02 1:45:46 PM
Type: Note
even that is not so clear. As we allow termination of pregnancy related to the mental health of the mother the choice described here could easily be seen under that concept and would become a medical reason. The only difference is that the medical reason related to the mother not the child to be

Sequence number: 2
Author: Owner
Date: 12/8/02 1:48:46 PM
Type: Note
if we look at the term medical reason as relating to the child often that term medical reason covers up societal prejudice and really is a social reason. In reality the term health and medicine increasingly becomes a social construct.

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Sequence number: 1
Author: Owner
Date: 12/8/02 1:38:27 PM
Type: Note
A high percentage of genetic counselors feel that societies will never provide enough support for people with disabilities. The percentage of agreement for the statement ranges from 18% as a lowest to 80% in the UK. Germany is in the middle with 57%. The USA has a number of 65%. (Wertz, 1998 Science in Context 11, 3-4 pp 493-510). Furthermore the claim that there was never as much attention and care of the handicapped is wrong. Reality is that in many countries the support for disabled people dropped within the last 10 years. Furthermore the employment rate for disabled people in e.g. USA dropped whereas the employment for non disabled increased US Bureau of Census Employment, Earnings and Disabilities, 2000, page 9
<http://www.cache.census.gov/hhes/www/disable/cps/cps300.html>
48,2% of disabled people are food stamp recipients US Census Bureau, Oct 2001
<http://www.census.gov/population/www/pop-profile/disabil.html> and 70% are unemployed National Council on Disability USA, 2000, Executive Summary <http://www.ncd.gov/newsroom/publications/policy98-99.html#3>
For many expects see

Sequence number: 2
Author: Owner
Date: 12/8/02 12:40:00 PM
Type: Note
what entails the term healthy?

Sequence number: 3
Author: Owner
Date: 12/8/02 12:39:27 PM
Type: Note
biased, directive, able-ist, disabilityphobic language

Sequence number: 4
Author: Owner
Date: 12/8/02 12:41:23 PM
Type: Note

if that is true why would we have to prohibit 'sex selection for non-medical reasons'

Sequence number: 5

Author: Owner

Date: 12/8/02 12:43:23 PM

Type: Note

the whole draft shows a climate and bias that would suggest that proper genetic counselling is related to the promotion of use of the technology to eliminate the 'unhealthy,abnormal...)

Sequence number: 6

Author: Owner

Date: 12/8/02 12:43:42 PM

Type: Note

there is no such thing as informed consent

Sequence number: 7

Author: Owner

Date: 12/8/02 12:44:24 PM

Type: Note

that by itself is not enough information. the decision of the parent is not a technical one but a societal one

Sequence number: 8

Author: Owner

Date: 12/8/02 12:56:38 PM

Type: Note

smoke screen. implies that the framework of use is limited to 'severe' but as 67 says 'severe' is not definableb

Sequence number: 9

Author: Owner

Date: 12/8/02 1:39:03 PM

Type: Note

care ? very patronizing medical view of disabled people

Sequence number: 10

Author: Owner

Date: 12/8/02 1:40:07 PM

Type: Note

it is questionabl whether there is increased reproductive choice (see attached notes to 25)

Sequence number: 11

Author: Owner

Date: 12/8/02 1:40:42 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

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Sequence number: 1

Author: Owner

Date: 12/8/02 12:45:00 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 2

Author: Owner

Date: 12/8/02 12:45:14 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 3

Author: Owner

Date: 12/8/02 1:49:49 PM

Type: Note

what is a burden? couldn't it be a burden that the parent does not accept their child? If we promote a culture where a parent can have the child fitting their expectations the scenario of 73 is only a natural extension It doesn't make it unethical because the majority . It only makes it unethical if the concept as a whole is denounced therefore closing the door on the right of the parent or

society to have children as they want them. The use of sperm and egg banks prenatal testing PID... to have kids with desired (non disability related) characteristics is as unethical as the case described in 73

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Sequence number: 1

Author: Owner

Date: 12/8/02 12:57:35 PM

Type: Note

smoke screen. implies that the framework of use is limited to 'severe' but as 67 says 'severe' is not definable

Sequence number: 2

Author: Owner

Date: 12/8/02 1:55:29 PM

Type: Note

fits with 67

Sequence number: 3

Author: Owner

Date: 12/8/02 1:53:31 PM

Type: Note

if we look at the term medical reason as relating to the child often that term medical reason covers up societal prejudice and really is a social reason. In reality the term health and medicine increasingly becomes a social construct.

Sequence number: 4

Author: Owner

Date: 12/8/02 1:54:26 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 5

Author: Owner

Date: 12/8/02 1:54:48 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 6

Author: Owner

Date: 12/8/02 1:55:10 PM

Type: Note

smoke screen. implies that the framework of use is limited to 'severe' but as 67 says 'severe' is not definable

Sequence number: 7

Author: Owner

Date: 12/8/02 1:56:33 PM

Type: Note

open future for the adult? so disabled children destroy the future of parents? Very biased statement which by the way is academically proven as wrong (see

Sequence number: 8

Author: Owner

Date: 12/8/02 1:58:14 PM

Type: Note

if we look at the term medical reason as relating to the child often that term medical reason covers up societal prejudice and really is a social reason. In reality the term health and medicine increasingly becomes a social construct.

Sequence number: 9

Author: Owner

Date: 12/8/02 1:59:50 PM

Type: Note

seems to prepare for an argument that we can't prohibit genetic enhancement as lines can't be drawn readily. In essence you only have to say it's for medical purposes it will be ok

Sequence number: 1

Author: Owner

Date: 12/8/02 12:59:02 PM

Type: Note

smoke screen. implies that the framework of use is limited to 'severe' but as 67 says 'severe' is not definable

Sequence number: 2

Author: Owner

Date: 12/8/02 1:00:26 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 3

Author: Owner

Date: 12/8/02 1:00:39 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 4

Author: Owner

Date: 12/8/02 2:00:44 PM

Type: Note

since when is obesity normal? It is seen as a medical condition

Sequence number: 5

Author: Owner

Date: 12/8/02 2:03:51 PM

Type: Note

if we do not have the right to predetermine characteristics of future generations that should also than lead to prohibition pf PID and PD. And that should not relate to whether we arbitrarily define something as a medical or social reason.

Sequence number: 6

Author: Owner

Date: 12/8/02 2:01:49 PM

Type: FreeText

Sequence number: 7

Author: Owner

Date: 12/8/02 2:05:25 PM

Type: Note

that should also than lead to prohibition pf PID and PD. And that should not relate to whether we arbitrarily define something as a medical or social reason. Because good is the social reason and bad is the medical reason

Sequence number: 8

Author: Owner

Date: 12/8/02 2:09:07 PM

Type: Note

that should also than lead to prohibition of PID and PD as it will lead to the discrimination and discrimination against people living with a 'medical characteristic' deemed accetable for elimination for medical reasons with PID /PD...
If that argument is true than this does not just relate to normal and raits because what is a trait is a social construct as well.

Sequence number: 9

Author: Owner

Date: 12/8/02 2:09:33 PM

Type: Note

that should also than lead to prohibition of PID and PD as it will lead to the discrimination and discrimination against people living with a 'medical characteristic' deemed accetable for elimination for medical reasons with PID /PD...
If that argument is true than this does not just relate to normal and raits because what is a trait is a social construct as well.

Sequence number: 10

Author: Owner

Date: 12/8/02 2:09:42 PM

Type: Note

that should also than lead to prohibition of PID and PD as it will lead to the discrimination and discrimination against people living with a 'medical characteristic' deemed accetable for elimination for medical reasons with PID /PD...
If that argument is true than this does not just relate to normal and raits because what is a trait is a social construct as well.

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Sequence number: 1

Author: Owner

Date: 12/8/02 12:59:47 PM

Type: Note

smoke screen. implies that the framework of use is limited to 'severe' but as 67 says 'severe' is not definable

Sequence number: 2

Author: Owner

Date: 12/8/02 1:01:15 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 3

Author: Owner

Date: 12/8/02 1:01:23 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 4

Author: Owner

Date: 12/8/02 1:01:42 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 5

Author: Owner

Date: 12/8/02 1:01:57 PM

Type: Note

biased, directive, able-ist, disabilityphobic language

Sequence number: 6

Author: Owner

Date: 12/8/02 1:02:09 PM

Type: Note

smoke screen. implies that the framework of use is limited to 'severe' but as 67 says 'severe' is not definable

Sequence number: 7

Author: Owner

Date: 12/8/02 2:11:02 PM

Type: Note

if that would be true we woudn't have to prohibite sex selection for 'non medical reasons'

Sequence number: 8

Author: Owner

Date: 12/8/02 2:18:36 PM

Type: Note

a note before showed that the choice actualle decreases see also statement below in this paragrap that we have to increase efforts to preventthe birth of severely handicapped people

Sequence number: 9

Author: Owner

Date: 12/8/02 2:13:32 PM

Type: Note

this draft obviously did not look at the impact on disabled people and the claim that there was never as much support for disabled people was questioned and rejected in note to 64

Sequence number: 10

Author: Owner

Date: 12/8/02 2:17:07 PM

Type: Note

this statement is another indication that choice as claimed in the paragraph earlier does not exist. And it's biased and will never lead to respect for disabled people if we follow arguments from 102

Sequence number: 11

Author: Owner

Date: 12/8/02 2:18:50 PM

Type: Note

why people not person?