

**NOT DEAD YET'S WRITTEN EVIDENCE
SUBMISSION TO THE HUMAN TISSUE AND
EMBRYOS (DRAFT) BILL SELECT COMMITTEE**



This submission has been prepared by Simone Aspis who is a member of the Not Dead Yet Network and reviewed by other members of the Network. Simone has spoken extensively on equal right to life of disabled babies. She has been interviewed extensively for national news programmes and Newspapers on bioethics issues including those concerning embryo selection. She has been awarded a MA in Ethics and Law in Healthcare Practice at Middlesex University.

Not Dead Yet (NDY) is a national network of disabled people who are campaigning against any attempt to undermine disabled people's equal right to life. NDY was established in 2006 initially to resist any attempt to legalise assisted dying. Whilst end of life issues are important,, disabled people are increasingly concerned with the beginning of life issues such as the testing and selecting out of babies who are likely to be born disabled. With advances in technology and testing techniques, there is growing concern at the implications for disabled people who are living today, disabled children growing up in the 21st century and the diversity of a society where every individual's contribution is equally valued and everyone can receive in equal measure from what society has to offer. NDY is well placed to submit evidence on the Human Tissue and Embryos Draft Bill which the Government has just published. As the only such national network of disabled people we would value the opportunity to give oral evidence.

Context of understanding disability

Despite each of us having a unique genetic profile with a wide range of genetic difference, there is a myth that there is a 'normal' human being. There is a belief that there is a predetermined fixed range of genetic characteristics that 'normal' human beings should have. This is a myth. For instance the genetic characteristics that are considered as a health condition have evolved and changed over time. Not so long ago, homosexuality¹ and running away from slavery² were considered mental disorders. And human beings who did not follow society's rules for social interaction used to be considered as little eccentric, This has now been replaced with a diagnosis of Aspergers Syndrome which, if a test can be developed for it, may be screened out. So therefore, impairment is socially constructed - which personal characteristics influenced by genetic make-up are considered as "disability" evolves as society determines what kind of human beings are needed in order to keep itself, for instance the economy going.

¹ Pilgrim Peter and Rogers Ann "A Sociology of Mental Health and Illness", Open University, 1993

² "Medical Nemesis : Limits of Medicine". Marion Boyars 200p 118

Background behind the Prenatal Testing

NDY are not against prenatal testing if it is used to safeguard the baby's or the mother's life. But too often the motives behind testing are to screen out disabled babies because of the prejudice and fear surrounding disabled people and their potential quality of life. Evidence shows that 90% babies are aborted if the prenatal test shows either of the impairments Downs Syndrome or Spina Bifida.³ And what constitutes a "serious disability" under the 1967 Abortion Act when deciding whether an abortion can take place up to birth has included cleft palate⁴. NDY has witnessed the fear that will intensify as more tests are developed to screen out embryos which will develop into a disabled human being. The HFEA started off by giving parents the permission to screen out embryos which may develop into life threatening or life limiting conditions⁵. Then the goal posts moved to the screening out of embryos that may develop into disabled babies with profound / severe impairments or health conditions and now to disabled babies who may be born with an Autistic Spectrum Disorder⁶ and even a squint⁷. Testing for such conditions, even ones that can be accommodated with perhaps prescribed glasses, intensifies the fear of giving birth to any disabled baby regardless of the nature or severity of an impairment or health condition. The consequence will be the narrowing of desired genetic / biological characteristics which are seen as "normal" for a human being. NDY believes eugenics is already being brought in through the back door, and the consequences of this Bill will be that there will be an expectation to screen out embryos like with foetuses that may be born disabled.

Quality of Life

One of the common reasons for not wishing to give birth to a disabled baby is the quality of life she or he will have. Disabled people do not see the quality of life as being determined by whether their bodies or brains work in the same ways as those who are not disabled.

³ Harmon Amy Prenatal Tests Puts Downs Syndrome In Hard Focus **New York Times** May 9th 2007

⁴ Mansfield C, Hopfer S, Marteau T (1989), Termination rates after prenatal diagnosis of Downs Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes : A Systematic literature review *Prenat 19 : 810*

⁵ Templeton S, HEFA is Expected To Look Favourably On The Application ", *Sunday Times* February 2nd 2007

⁶ Wheldon J, Ethical Row Erupts Over Designer Babies Breakthrough, *Daily Mail* 19th June 2006

⁷ Templeton S Doctors Screen Embryos To Avoid Babies With Squint *Sunday Times* 6th May 2007

"I am an autistic adult and a valid member of society. No one can tell how an autistic child will fare later in life, what they will grow to be. I am an example of a successful adult (I will be studying for a degree in Autism next year), there are many others like me. In fairness not every autistic person will end up at University anymore than every "neurotypical" child but even the severity of Autism during childhood is no indicator of how the child will grow into an adult and unlike some conditions, autism is not an invitation to an early grave. No one can tell before birth which child will be a future Prime Minister, or Wayne Rooney, or which will die in a car accident or from a drugs overdose during a life of Crime. Every child has equal value whatever their future station in life." Larry Arnold⁸

Quality of life is determined by what inclusive education, independent living support and so on is out there and how accepting others are of disabled people in their communities.

"I am an autistic...I see autism as a natural part of human diversity, a part that has giving great benefits to man kind. Many of the great scientists of the past and present had/have autistic traits or are autistic them selves. There are others that live, work and contribute to society and have families just like every one else. There are others that do struggle. I am not saying I or anyone else on the spectrum has an easy life, but what minority does? To try and wipe out this part of diversity is short sighted and wrong. Different ways of seeing the world should be celebrated not dehumanized and "weeded out"". Jonathan, Croydon⁹

There is no guarantee that a baby with high IQ genes will enjoy a better quality of life than someone with a low IQ who is considered to be a disabled person. Someone with a high IQ may end up entering into a pressured job with no time to pursue their interests and this may potentially reduce quality of life. Another problem with assessing quality of life is that no one really knows what our potential will be, as many of the factors are external, governed by society, legislation, policies and how resources are distributed and used.

"...Life as a disabled person is for me, very painful and restricting and I would wish that for no one. The services, support and access for disabled people is appalling. So let all these people who are against embryo

⁸http://www.dailymail.co.uk/pages/live/articles/news/news.html?in_article_id=391264&in_page_id=1770&in_page_id=1770&ct=5&expand=true#StartComments

⁹http://www.dailymail.co.uk/pages/live/articles/news/news.html?in_article_id=391264&in_page_id=1770&in_page_id=1770&ct=5&expand=true#StartComments

screening get the services, support, access and financial upkeep for disabled people sorted." M. Beattie, Plymouth, Devon¹⁰

Human Tissue and Embryos (Draft) Bill

NDY feels there is a need to update legislation governing the testing and selection of embryos as the current position is completely unsatisfactory. NDY believes the Human Fertilization and Embryology Authority has taken it upon itself to decide if and when embryos can be tested and screened out for potential impairments and health conditions without any agreed guidelines. However, NDY feels that the Bill's guidance on permitting testing and screening out impairments and health conditions will introduce a greater level of eugenics. Evidence of this is already coming from formal applications to screen out embryos with squints (that can easily be corrected by glasses) or forms of autism (that can be corrected by society's acceptance of individuals who may interact in different ways from themselves). This is because it will be unlawful to deliberately place the embryos after being tested as having an impairment or health condition into the woman's womb.

Clause 18 Schedule 2 section (3) Embryo selection and sex selection

NDY does not support sex selection. Such techniques may be used to select out impairments and health conditions which may be highly represented in one sex, e.g. Muscular Dystrophy and Autistic Spectrum Disorders in boys. We think this is wrong because we do not accept any form of screening unless it is to do with identifying and planning for treatment that the baby may need before or after birth.

Schedule 2 section 3(1)(z) of the draft Bill states that the RATE must be satisfied that there is a significant risk that a person with abnormality will have or develop a serious physical or mental disability, a serious illness or other serious medical condition. In addition RATE must have regard to:

- To what extent is treatment available for the disability, illness or medical condition.
- The likely onset of disability (e.g. Huntington's disease may strike at the age of 40)
- Disability, illness or medical condition is a progressive disorder, the likely rate of degeneration.

¹⁰http://www.dailymail.co.uk/pages/live/articles/news/news.html?in_article_id=391264&in_page_id=1770&in_page_id=1770&ct=5&expand=true#StartComments

- The proportion of those having the 'abnormality' in question who are likely to be affected
- The reliability of the test.

NDY considers this schedule being unacceptable because

- Decisions should never be made on whether the state can afford to treat a disabled baby. This is discriminatory and is likely to lead to embryos being screened out simply because it will cost too much to provide their healthcare. Nor should decisions be made on available treatment. None of us really knows whether there is going to be available treatment for us when we become ill or have been involved in a serious accident.
- None of us ever know how long we are going to live. Many NDY members had been told that they would not live beyond their early years and now they are adults living very useful lives. Decisions should never be made simply on someone's prediction of how long a human being will live after birth, because we just do not know.
- It does not matter how many disabled people with the specific impairment or health condition will be affected - selecting out humans that may have particular characteristics must not be allowed.
- The reliability of tests is irrelevant because selecting out humans which may have particular characteristics must not be allowed.

Clause 21 Conditions of Licences for treatment

Clause 21 (4) states that it is unlawful for a licensed authority to prefer to select embryos with 'abnormalities' over those which do not have any. NDY believes this implies that that licensed authorities who can select embryos must give preference to embryos which are likely to be born non disabled, (without 'abnormalities'). The consequence of these clauses read together can not be overestimated - that it will be unlawful for an embryo with 'abnormalities' to be allowed to grow into a disabled baby. Parents will only be allowed to carry embryos without 'abnormalities'. We fear the repercussions can not be under estimated, with the state able to control who is or who is not to be born. This goes further than the 1967 Abortion Act where technically speaking doctors can not force a woman to have an

abortion if she **chooses** to give birth to a disabled baby after having her test results. Clause 21(4) should be removed as the consequence will be that women are forced to give up their disabled babies if they choose to undergo the screening in hope of safeguarding the baby's life when developing in the womb or after birth.

Not Dead Yet are deeply concerned that the Human Tissue and Embryos Draft Bill will introduce provisions which are eugenic in nature, that being the state will deliberately prevent the birth of disabled babies if "would be" parents undergo the screening process. This goes further than the 1967 Abortion Act where at least in theory the state can not force women to have an abortion, even when she fully knows she will give a birth to a disabled baby.

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