



## **A DISABLED PERSON'S PERSPECTIVE ON EUGENIC ABORTION**

### **The law and statistics**

Abortion performed on the grounds that the baby has a disability is usually regarded as being one of the most publicly acceptable reasons for abortion. Some polls suggest that as many as 75% of British people think abortion should be allowed for disability.<sup>1</sup>

“Ground E” of the British Abortion Act (as amended by the Human Fertilisation and Embryology Act 1990) states that abortion is permissible if there is “substantial risk of the child being born seriously handicapped.” In 2001, the latest full year for which figures are available, in England & Wales there were 1,641 abortions done under Ground E alone with a further 81 being Ground E combined with another ground. Of this number 127 were for spina bifida (the disability I have), and 347 for Down’s syndrome, six of these abortions being done after 24 weeks.<sup>2</sup>

In addition to these figures, there were 15 cases of “selective reduction” in which one of more disabled babies in a multiple pregnancy are killed by injecting poison into their hearts, while the other babies in the pregnancy are left to continue their lives and eventually be born. Some pregnancies were “reduced” by one baby, some by two and one by three.<sup>3</sup>

Under Ground E abortion is allowed with no time limit i.e. up to the moment of birth.

The discriminatory factor in these abortions is made clear by simple statistics. About 20% of all pregnancies are aborted, but about 90% of babies with spina bifida are aborted,<sup>4</sup> as are 92% of babies with Down’s syndrome.<sup>5</sup> This is, of course, in addition to the babies who are aborted for “social” reasons without their disability being detected.

These deaths are sometimes dismissed as “only” 2% of the total. “Only” implies a value judgment that these lives are somehow less important because of their smaller absolute numbers, but the vastly greater discrimination is clear in the statistics.

### **Pressure to have pre-natal testing leading to eugenic abortion**

These eugenic abortions cannot be dismissed simply as women freely “choosing” to abort, just as the diagnosis of a disability does not just “happen.”

Dr. Josephine Venn-Treloar wrote in the British Medical Journal of being given Nuchal Translucency ultrasound test without her knowledge or consent. This test measures the amount

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<sup>1</sup> “Britain and the Unborn Child” The Sunday Telegraph 26 October 1997

<sup>2</sup> Office of National Statistics – Abortion Statistics 2001, published 2002

<sup>3</sup> ONS Abortion Statistics 2001 Ibid

<sup>4</sup> LINK September-October 2002

<sup>5</sup> BMJ – “Trends in pre-natal screening for Down’s syndrome in England and Wales 1989-1997. 3 October 1998



of fluid at the back of the unborn baby's neck, and can indicate Down's syndrome. The test was simply presented as "the first trimester scan" with no indication of its true purpose.<sup>6</sup>

An Editorial in the BMJ admitted that "When first trimester scanning does detect an abnormality, there may be pressure for the decision to terminate to be made quickly to facilitate a suction termination." No mention was made of the possibility that the woman might decide *not* to abort.

In a survey<sup>7</sup> by the University of Leeds, only 32% of obstetricians reported counselling pregnant women non-directively, and two researchers recently concluded that all pre-natal counselling is, in reality, directive. A father of a baby aborted on grounds of disability said "Our consultant guided us through the decision making process ... she made it easier to say yes (to the abortion) knowing it was the only way.

The Association for Improvements in Maternity Services reported<sup>8</sup> having "a stream of complaints" from women who tried to refuse pre-natal tests and were "bullied or treated like pariahs." They noted that this had the effect of some women choosing not to have any pre-natal care until 24 weeks to avoid pressure to be screened and to abort if a disability was detected.

The Dept of Health Advisory Committee on Genetic Testing issued a report in April 2000 suggesting that pregnant women considered "at risk" of having a disabled baby should be "encouraged" to notify their GP of their pregnancy as soon as possible, so that pre-natal screening could be organised. (Note here the use of the term "risk" rather than "chance" of a baby being disabled. Risk implies a bad outcome. Does anyone ever speak of the "risk" of something nice happening?) No mention was made of the fact that such women might well prefer not to have these tests. The report went on to say that "counselling about an abortion should be given as a matter of course if the fetus is found to be abnormal"

The report also called abortion "prevention of disability" and mentioned it as the first possibility after an "abnormal" test result. There was much mention of the need for "adequate support" for women who aborted their disabled baby, but NO mention of support for those who decided to keep their baby. The report went on to say that two photos should be taken of an aborted baby – one for the post-mortem, and one for the family to keep "as a memento"<sup>9</sup> How sad that a photograph will be treasured, but the baby him or herself was rejected as "not up to standard."

Sometimes, women are accused of being "selfish" if they refuse to be screened or to abort. For instance Caroline Armstrong-Jones, whose daughter India has Down's syndrome was told by her doctor "you must do everything in your power to ensure you do not give birth to

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<sup>6</sup> BMJ – "Nuchal translucency – screening without consent" by Dr. Josephine Venn-Treloar 38 March 1998

<sup>7</sup> "Antenatal screening for Down's syndrome" by Helen Statham and Wendy Solomou. The Lancet 5 December 1998

<sup>8</sup> Independent – "Voluntary HIV Tests" Letter by Beverley A. Lawrence Beech (Hon. Chair) and Jean Robinson (Hon. Research Officer) AIMS 16 August 1999



another Down's child.<sup>10</sup> Fortunately she resisted all the pressure, and did not have her baby tested. The baby did not have Down's syndrome.

Another doctor was reported as saying to a woman who had a child with Down's syndrome "So, you'll be having the tests, seeing you have a handicapped child already." She refused, and "he looked up in horror and said 'But of course you must! You can't have two handicapped children'"<sup>11</sup>

Pressure to abort a disabled child is particularly apparent when the mother also has a disability.<sup>12</sup>

### **Diagnosis and Information about Disabling Conditions**

In addition to the question of whether consent is obtained to pre-natal screening, the question must be posed whether women actually know about the disabilities which might be detected. In other words they may be making supposedly "informed decisions" about conditions they know little or nothing about.

In a survey, 60 women were asked to rate how much they knew about Down's syndrome on a scale of 1 (very little) to 10 (a lot). 39% out of 62 women rated their knowledge of Down's syndrome at 3 or less. 70% said they felt they had not had adequate preparation for a nuchal translucency test.<sup>13</sup> Similarly I once had a phone call from a woman who had been told her unborn baby had spina bifida and had been advised to abort. She said "no one will tell me what spina bifida is."

Sadly this ignorance of the facts about disability is not just on the part of parents. Dr. Theresa Marteau, Professor of Health Psychology at Guy's & St. Thomas' Medical School, London has described a study of 84 consultations with parents prior to pre-natal testing for Down's syndrome.<sup>14</sup> Only two of the consultations included any information at all about Down's syndrome, and both of those were inaccurate! It is clear that parents are sometimes given "grossly inadequate or frankly misleading" information about their child's disabling condition.<sup>15</sup> Some parents are not even given details of support groups which could give accurate information.

Doctors are notorious for giving negative judgments about the lives of disabled people. Just to mention a few of many examples Peter, who has spina bifida and hydrocephalus and uses a wheelchair full-time, is now 46 years old. At his birth his mother was told to "leave him in the hospital, go home and have another baby" as he would not live beyond three months.

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<sup>10</sup> "India enriches the lives of those around her...." By Olga Craig. The Sunday Telegraph 5 March 2000

<sup>11</sup> "The baby dilemma that won't go away" by Julia Llewellyn Smith. The Times 30/1/96

<sup>12</sup> "Down's but not out" by Tom Shakespeare. The Guardian 5 November 1998

<sup>13</sup> BMJ "Counselling should be considered an integral part of screening programmes by Dr. Johanna Layng 12 September 1998

<sup>14</sup> "Considered Choices" conference organised by the Norah Fry Research Centre in Bristol June 1997 reported in "Speak Out" July 1997

<sup>15</sup> "Prenatal diagnoses of sex chromosome conditions" by Barbara Biesecker. BMJ 24 February 2001



Sarah Thomas, whose son Luke is now 13 years old, was told when Luke was unborn and diagnosed as having spina bifida and hydrocephalus, that he had “a head like a banana” and “part of the brain missing.” Doctors said he would be unable to do anything much for himself if he survived, which was considered unlikely. When she refused to abort she was called “awkward” and “unrealistic.” The hospital even started phoning her up to see if she had changed her mind and would now “do the sensible thing.” Luke uses a wheelchair, is very bright, and enjoys going to a mainstream school. His head looks remarkably ordinary, and Sarah says his two able bodied brothers are far more trouble than Luke.

Agnes Marshall, who would never have considered an abortion, was told her daughter Rachel would not live to see her first birthday. Rachel will be 10 years old on 27<sup>th</sup> July 2003. She is one of only 50 children in the world who have Hydranencephaly, a condition in which most of the brain is missing. Rachel’s contribution to the world is simply her existence, which elicits so much love from all who meet her. Children like her are, however, in the forefront of those who many people think “should be aborted.” Agnes has other ideas, saying

She’s so loving the way she looks at me. I wouldn’t want to change her in any way. In fact I’d have 10 of her<sup>16</sup>

Much of the difficulty in giving parents information about disability in their unborn child stems from the fact that doctors are trying to describe a disability without mentioning the person who has that condition. It is rather like trying to describe a short-sighted person by stating the prescription for his glasses. Spina bifida is what I have, not what I am, but still many doctors refer to me as being “a spina bifida.” In similar vein, parents are being asked to make life or death decisions about a person about whom they know nothing except that they have particular conditions.

### **Deaths of non-disabled babies a direct result of attempts to eliminate the disabled**

It has been reported that if 25,000 women a year have amniocentesis after a positive screening test result, at least 245 “healthy” babies are miscarried.<sup>17</sup> This statistic is quoted in an article praising a new “integrated” test using maternal serum screening plus nuchal translucency, which would prevent the deaths of the non-disabled babies. The article makes the common assumption that losing a “healthy” baby is a tragedy, while the equal, and deliberate, tragedy of the deaths of disabled babies are regarded as somehow more justified.

Often the main argument used against pre-natal testing aimed at aborting disabled babies is that as a result of it, non-disabled babies may be lost, either by miscarriage, or by being aborted in error. This only serves to confirm the common view that aborting a non-disabled baby is very much worse, and that abortion is justified in direct proportion to the severity of a baby’s disability. It would be more correct to say that the deaths, in error, of non-disabled babies compound the deliberate deaths by abortion of disabled babies, which are the aim of pre-natal testing programmes.

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<sup>16</sup> “My baby was born without a brain” by Maria Croce. Daily Record 20 May 2000

<sup>17</sup> “Testing times” by Angela Dowden. The Sunday Times Magazine 28 November 2001



The views of people like Anya Souza, who is 40 years old and has Down's syndrome, need to be heard. She says:

I want to change the way people view Down's syndrome...it should feel good to have a Down's syndrome baby, and see how much it can achieve in the world.<sup>18</sup>

Anya has also said:

I think getting rid of a baby because it has Down's syndrome is wrong. It's something you just don't do to children.<sup>19</sup>

While so much money is being spent on eliminating disabled people, little is spent on true prevention of disability (for instance giving pregnant women folic acid supplements which can protect the baby against developing spina bifida) and treatments for those who have disabling conditions, for instance the assessment service for Down's syndrome babies at the Lejeune Clinic in London. This is perhaps inevitable. It is impossible for society to have a truly positive, non-discriminatory attitude towards a group of people whose deliberate destruction by abortion it is simultaneously condoning.<sup>20</sup>

### **Economics of pre-natal testing and eugenic abortion**

It has been estimated that the economic cost of a positive maternal serum testing, a diagnostic amniocentesis test and an abortion is £38,000 compared with an estimated cost of £120,000 for supporting a child with Down's syndrome.<sup>21</sup> The implication is clear that pre-natal testing and abortion are a bargain compared with the perceived burden of caring for a disabled child.

Joyce Arthur of the "Pro-Choice Action Network" claims that "the issue of abortion for genetic reasons is not about eugenics or discrimination against disabled people" but goes on to say that care of the disabled "consumes substantial time and resources on the part of the caregiver."<sup>22</sup> She notes that most parents do not feel able to give their child up for adoption, using that as an argument for killing the child by abortion! She says

even if others raise the child, this just shifts the burden, it doesn't justify it. Why should taxpayers foot the bill for the institutionalized care of a disabled child if the parents don't want the responsibility themselves?

She also says "The planned birth of a disabled child could even be considered a form of child abuse" as disability "tends to impose a poor quality of life on people." She argues that disabled babies, far from having a right to life, have a "right not to be born." The presumption of "low quality of life" and a right only to be killed is quite breathtaking.

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<sup>18</sup> "I have a demanding job and run my home" by Anya Souza. Daily Mail 6 June 2000

<sup>19</sup> "Disabled children will be a 'sin' says scientist" by Lois Rogers. Sunday Times 7 July 1999

<sup>20</sup> "Doctor's diary" by Dr. James Le Fanu. Daily Telegraph 25 May 1999

<sup>21</sup> "Hidden cost of testing for Down's" by Dr. Kieran Sweeney. The Times 5 April 1994

<sup>22</sup> "Debate Statement: Abortions should be permitted for the avoidance of severe genetic illness" by Joyce Arthur. The Pro Choice Press Summer 2002



It is perhaps useful to note here that in 1998 it was estimated that the 2,500 youths in custody had cost the taxpayer £200 million, an average of £75,000 each. The cost of detaining each young offender was up to £2,167 per month.<sup>23</sup> No doubt many of them have a “poor quality of life” but no one suggests (one hopes!) that they are too expensive to keep alive and should be eliminated. Why the difference?

It is too easy to dismiss disabled people as nothing but “burdens.” This is what Kate Powell, who has Down’s syndrome and is 20 years old has to say:

I worry about my mum and dad. Thinking about them dying makes me unhappy. I don’t even want to talk about it because I want them to look after me always. And when they can’t look after me, I’ll look after them. Simple, isn’t it?<sup>24</sup>

If only our Government, and society in general, could see the devastating simplicity and logic of Kate’s argument.

### **Implications of pro eugenic abortion policies**

The Government claims “discrimination on the grounds of disability in our health services is unacceptable.”<sup>25</sup> Nevertheless when abortion time limits were debated in 1990, every MP member of the Labour cabinet voted at least once for abortion up to birth for disabled babies, and Tony Blair, currently the British Prime Minister, voted for it three times.<sup>26</sup>

Peter Singer, now Professor of Bioethics at the Centre for Human Values, Princeton University, is a known advocate of abortion for disabled babies, and of pushing them into death after birth, saying “killing a disabled infant is not morally equivalent to killing a person. Very often it is not wrong at all.” He is, however, opposed to killing animals. In his 1993 book *Practical Ethics* he argued in favour of killing newborn babies with spina bifida and Down’s syndrome up to 28 days old. However, he has recently said he simply thinks the killing should be done “as soon as possible after birth.” He says:

When the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed. The loss of the happy life for the first infant is outweighed by the gain of a happier life for the second. Therefore, if the killing of the haemophiliac infant has no adverse effect on others, it would be right to kill him.<sup>27</sup>

Note he doesn’t say “it would not be wrong to kill him” but that it would be positively *right* to do so.

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<sup>23</sup> “Detained youths cost taxpayer £75,000 a head” by Richard For, Home Correspondent. *The Times* 14 December 1998

<sup>24</sup> “Relative Values” by Caroline Scott. *Sunday Times Magazine* 30 May 1999

<sup>25</sup> Hansard – “Down’s syndrome” debate Column 13WH; speech by Yvette Cooper, Parliamentary Under-Secretary of State for Health 7 July 2000

<sup>26</sup> SPUC Branches Briefing August 1997

<sup>27</sup> “The New Grim Reapers” by Wesley J. Smith. *San Francisco Chronicle* 9 June 2002



John Harris, Professor of Bioethics at Manchester University has said that in the interests of producing “a happier world” screening and eugenic abortion should be available, saying

When it is an embryo or a fetus, before it has a conscious life, the calculation to be made is which action causes the least suffering, and I think termination is the answer to that question<sup>28</sup>

Similarly Prof. Michael Tooley, now of the University of Colorado, has said that those who have no “sense of continuing self” have no right to life and may be killed.<sup>29</sup> This would of course include vast numbers of people, arguably including the unborn, the newborn, infants, elderly people with dementia and people with profound disabilities of all ages.

Dr. Robert Edwards, who worked with Prof. Patrick Steptoe on the world’s first IVF baby, Louise Brown, who was born in 1978, has said it will soon be “a sin” for parents to give birth to a disabled child. He says “We are entering a world where we have to consider the quality of our children.”<sup>30</sup>

Acceptance of eugenic abortion also has implication for those who escape being killed before birth. There have been many reported cases of *newborn* babies being “pushed” into death by doctors, usually because they were not dying, but had a disability or a high chance of acquiring a disability. In 1997 The Royal College of Paediatrics & Child Health issued a report identifying situations “where it may be right to stop active treatment.”<sup>31</sup> It should be noted that, since the judgement in the case of Tony Bland, who was in a Persistent Non-Responsive State, and whose death by starvation and dehydration was sanctioned by the Courts, “medical treatment” is taken to include tube delivered food and fluids.<sup>32</sup>

In several countries, including France, the USA, Australia and Canada, so called “Wrongful Birth” cases have been brought on behalf of disabled children. In these cases, the parents say they would have had an abortion, had they known of the disability before the child’s birth, and thus claim the child is entitled to “compensation” for the supposed “damage” of existing.

In January 2002 the French parliament presented a Bill to “stop wrongful birth cases” after a ruling to allow compensation to a 17 year old young man with rubella disabilities. However, in fact French parents would still have a statutory right to compensation if they were “denied the chance to abort” a disabled child due to “negligence” by the doctor.

This means that French parents can get money for having a disabled child, but only if they say they would have aborted him or her. And for the first time French doctors can be condemned

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<sup>28</sup> “Ethical Aspects of Prenatal Diagnosis. By John Harris in *Antenatal Diagnosis of Fetal Abnormalities* (Edited by JO Drife, D. Donnai) Springer-Verlag Ltd. London 1991 279-96

<sup>29</sup> “Abortion and Infanticide” by M. Tooley. Oxford: Clarendon Press, 1983

<sup>30</sup> “We don’t need perfect kids” by Allison Pearson. London Evening Standard 7 July 1999

<sup>31</sup> “Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice” Royal College of Paediatrics & Child Health September 1997

<sup>32</sup> “Withholding or Withdrawing Life-prolonging Medical Treatment: Guidance for decision making” by the British Medical Association. BMJ Books 1999



for NOT killing. The French State is thus actively encouraging eugenic abortion, and parents have a vested interest in their disabled child failing to do well.

In the UK it has been reported that following a ruling affecting cases where compensation was given for a child born after a failed sterilisation operation, “compensation payable to parents for a disabled child not detected pre-natally will now be substantially less.”<sup>33</sup> This suggests that while not being strictly speaking “Wrongful Birth” rulings, decision very like “Wrongful Birth” rulings *are* being made in this country.

Such developments are probably inevitable once it has been decided that killing the unborn is an acceptable “solution” to the challenges of disability. Once this killing has been established, it becomes easy to extend the killing to those who somehow slipped through the net.

### **Possible positive moves**

However, the draft Charter of Fundamental Rights of the European Union<sup>34</sup> presents an interesting challenge to the received wisdom that killing disabled babies is simply a matter of “choice.” The draft contains four principles including “the prohibition of eugenic practices.” This provision could possibly give an opportunity to claim that eugenic abortions are illegal under EU law.

The Disability Rights Commission, set up by the Government in 2000 to combat discrimination against disabled people has also labelled the eugenic abortion provision in the law as discriminatory, saying it “reinforces negative stereotypes.”<sup>35</sup> The objections were mainly on the discriminatory time limit inherent in the law (24 weeks for “social” abortions, no time limit for eugenic abortions), but they did say that “disability and non-disability (should be) valued equally. The only just solution, however, would be a law to protect ALL unborn children, disabled or not, from the fatal injustice of abortion.

Whether or not these developments turn out to be paper tigers remains to be seen. But it would take a huge change to overcome the monolith that is now the killing industry aimed at the destruction of people like me.

ALISON DAVIS, Coordinator of No Less Human, a group within SPUC, March 2003

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<sup>33</sup> “A lawyer writes...” With Mari Rosser of Edwards Geldard. South Wales Echo September 2000

<sup>34</sup> Charter of Fundamental Rights of the European Union, as signed and proclaimed by the Presidents of the European Parliament, the Council and the Commissioners at the European Council meeting in Nice on 7<sup>th</sup> December 2000

<sup>35</sup> “Abortion Act Discriminatory” BBC News: Health 21 August 2001