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# The More Things Change, The More They Stay The Same: Criminal Law, Down Syndrome, and a Life Worth Living

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**THE MORE THINGS CHANGE, THE MORE  
THEY STAY THE SAME:  
CRIMINAL LAW, DOWN SYNDROME,  
AND A LIFE WORTH LIVING**

*Fran Wright*<sup>1</sup>

**Abstract**

This article considers changes in how legal rules reflect attitudes towards children with Down Syndrome between the early 1980s and the present day. In the early 1980s children with Down Syndrome did not have the same access to medical treatment and education as other children, and were not fully included in their local communities. Some children and adults lived in state-run institutions. As a result of case-law and legislative changes, children with Down Syndrome are now unlikely to be denied medical treatment and they are included in mainstream education. Most children live with their own parents and there is support for adults who wish to live independently. Both adults and children with Down Syndrome are visible members of the community. However, despite changes in the law and in public attitudes towards disability generally and Down Syndrome in particular, the majority of parents who receive a pre-natal diagnosis of Down Syndrome terminate the pregnancy. This reflects concerns about the child's quality of life and also the effect that bringing up a child with a disability would have on the quality of life of other family members. These concerns are legitimated by the government policy of supporting and extending pre-natal testing, with the explicit goal of detecting serious disability. Further legitimation is provided by abortion legislation which permits termination on the ground of serious disability at any stage in pregnancy. The article concludes that although there have been many changes in the lives of those with Down Syndrome since the early 1980s, there are still socially constructed barriers to their full participation in society and their lives are considered less worth living than those of normally developing children.

**Keywords:** law relating to disabilities; life worth living, right to life, medical treatment, medical responsibility, parental rights, Down Syndrome;

**Introduction**

This article considers changes in how legal rules have reflected attitudes towards children with disabilities between the early 1980s and the present day. Although much of what is said applies to all children with disabilities, there is a specific focus on Down Syndrome.<sup>2</sup>

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<sup>2</sup> The term 'Down Syndrome' will be used in this article rather than the equally common 'Down's Syndrome'. This is preferred because the possessive in 'Down's' suggested that the syndrome was something that Down suffered from, rather than something that he identified.

In the early 1980s, the view that a life with Down Syndrome was not a life worth living was not uncommon. Babies and children with Down Syndrome did not receive the same access to medical treatment as other babies and children. Medical conditions that were treated in 'normal' children were less likely to be treated where the baby or child had Down Syndrome. Even where treatment was on offer, when parents refused consent for that treatment, doctors were likely to accept the parents' decision even if that meant that the child died. The lives of children with Down Syndrome were very different from those of other children. Where parents rejected or could not support a baby or child with Down Syndrome, the result was likely to be institutionalization. Children with Down Syndrome were usually schooled separately from other children and, as adults, were unlikely to have the opportunity to live independently or take paid work.

In the last 20-30 years, much has changed. In 1949 life expectancy for children born with Down Syndrome was 12 years: in developed countries, it is now 60 years.<sup>3</sup> Most children with Down Syndrome live with their parents, although a few live with adoptive families. Children with Down Syndrome and other intellectual disabilities are often educated in mainstream schools, and adults with Down Syndrome leave the parental home and work in paid employment.<sup>4</sup>

There is judicial and legislative recognition of the rights of people with disabilities. In *Re A (conjoined twins, surgical separation)*, decided in 2000, the Court of Appeal insisted 'it is impermissible to deny that every life has an equal inherent value. Life is worthwhile in itself whatever the diminution in one's capacity to enjoy it and however impaired some of one's vital functions of speech, deliberation and choice may be.'<sup>5</sup> The 'official' story is that the lives of people with Down Syndrome are worth living and worth protecting. The question that will be posed is whether there has been real improvement in the lives of people with Down Syndrome or whether old attitudes persist, but simply take effect in different ways.

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Some older resources on Down Syndrome use the term 'Mongol' or 'Mongoloid'. This is no longer accepted terminology but it has been left in quoted material for the purpose of historical accuracy. The term 'intellectual disability' will be used instead of 'mental disability' or 'learning disability'. Again, the terminology in quoted material has been left unchanged.

<sup>3</sup> Frank and Sue Buckley, 'Wrongful deaths and rightful lives: screening for Down Syndrome' (2008) 12(2) *Down Syndrome Research and Practice* 79.

<sup>4</sup> For further detail see text footnote 66 and following.

<sup>5</sup> *Re A (conjoined twins: surgical separation)* [2000] 4 All ER 961 at 1001 per Ward LJ.

Why focus on Down Syndrome? When attitudes towards disability are explored without distinguishing between the various types of disability, significant differences between those disabilities can be obscured. Some of the changes discussed in this article relate to specific types of disability rather than disability in general. For instance, physical and intellectual disabilities produce different responses, as do congenital and after-acquired disability. Some issues arise specifically to disabilities that can be detected through prenatal testing and therefore avoided if the diagnosis is made early enough to enable termination of pregnancy.

Down Syndrome has been chosen as the focus of this article in part because it is one of the most common causes of intellectual disability.<sup>6</sup> The condition has both intellectual and physical effects, and can be diagnosed prenatally. Where there is no prenatal diagnosis, the diagnosis is generally made at birth. The physical signs of the condition are easy to detect and the diagnosis can be confirmed through genetic testing. These features of Down Syndrome are relevant to the discussion that follows. Another reason for this focus is that the two major legal cases that are discussed in the article both involve babies who were diagnosed with Down Syndrome at birth. Some writers have asserted the outcome of those cases would not be the same today. Down Syndrome is therefore a useful disability to highlight the changes that have occurred in the last 20-30 years.

The genetic condition Down Syndrome was first described by Dr John Langdon Down in 1866. Langdon Down was the medical superintendent and proprietor of Normansfield, a private residential home for children and adults with what we would now call intellectual or learning disabilities, and were at the time known as 'idiots' or 'feeble-minded'. He noticed that a number of patients with congenital intellectual disabilities had facial similarities to each other and also looked somewhat Asian or 'Mongolian'.<sup>7</sup> Typically, they had hair 'of a brownish colour, straight and scanty. The face is flat and broad, and destitute of prominence. The cheeks are roundish, and extended laterally... The lips are large and thick with transverse fissures. The tongue is long, thick, and is much roughened. The nose is small.'<sup>8</sup> Langdon Down's theory was that 'Mongols' were an example of racial degeneration, caused by the mother's

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<sup>6</sup> The birthrate is currently 1/1100 live births: [www.library.nhs.co.uk/geneticcondition/viewresource.aspx?resID=88948](http://www.library.nhs.co.uk/geneticcondition/viewresource.aspx?resID=88948), last accessed 15 January 2011.

<sup>7</sup> John Langdon Down, 'Observations on an ethnic classification of idiots' *London Hospital Reports*, 3 (1866) 259-262. This is available at <http://www.neonatology.org/classics/down.html>.

<sup>8</sup> Langdon Down, 'Observations'.

tuberculosis.<sup>9</sup> Her disease supposedly broke down the racial divisions between Caucasian and Mongoloid, and leading to 'retrogression, or at all events, of departure from one type and the assumption of the characteristics of another'.<sup>10</sup>

The real cause of the condition described by Langdon Down was discovered by Jerome Lejeune and Patricia Jacobs in 1959 - the trisomy or triplication of the twenty-first chromosome.<sup>11</sup> Because the trisomy can be detected through genetic testing, it has become possible to diagnose Down Syndrome in a foetus; this technology was in its infancy in the 1980s but is now routinely used. In addition to a range of learning, communication and physical difficulties, people with Down Syndrome often have heart defects, bowel defects, are more likely to suffer from childhood leukaemia, a particular type of epilepsy, and autism, and also to develop Alzheimer's disease at a young age.<sup>12</sup>

My discussion starts with a study of the trial of Dr Leonard Arthur in 1981 for the attempted murder of John Pearson, a newborn baby with Down Syndrome and the civil case of 'Baby Alexandra' whose parents refused consent for life-saving surgery.<sup>13</sup> I then turn to contemporary law and practice, in order to contrast 'then' with 'now'. I will argue that although there are now improved life-chances for children with Down Syndrome and children with disabilities more generally, this is only part of the story. Although attitudes have changed, parents who receive a diagnosis of Down Syndrome during pregnancy may still regard the prospect of bringing up their child as a burden, possibly an intolerable burden, and that may affect their decision-making about the pregnancy. Although people with disabilities are no longer seen as potential criminals and a moral threat to society, as they were at the height of the eugenics movement in the early twentieth century, those who are unable to be self-supporting are still not accorded full membership of society.

## **1 The Crime That Never Was: the Trial of Dr Arthur**

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<sup>9</sup> In the mid-nineteenth century, there was considerable interest in the link between race and intelligence, and a number of writers proposed a hierarchy of races, with 'Caucasians' at the top and 'Negroes' at the bottom. The term 'Mongolian' or 'Mongoloid' referred to the inhabitants of East and North Asia.

<sup>10</sup> A similar theory is proposed by Dr F.G. Crookshank in *The Mongol In Our Midst, A Study of Man and His Three Faces* (Kegan Paul, Trench, Trubner & Co Ltd, London, 1925).

<sup>11</sup> Instead of two copies of chromosome 21, the fertilized egg has three. Chromosome 21 holds 200 to 250 genes and so the trisomy has a wide range of effects.

<sup>12</sup> E. Marder and J. Dennis, 'Medical management of children with Down's syndrome' (2001) 11 *Current Paediatrics* 57-63.

<sup>13</sup> *R v Arthur* [1985] Crim LR 705, *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421.

One of the two cases that can be used to demonstrate changing attitudes towards Down Syndrome is that of Dr Leonard Arthur, a consultant paediatrician who was tried for attempted murder in 1981 after the death of a newborn baby with Down Syndrome. He was acquitted. The case received a lot of press and academic attention at the time and is therefore an interesting indicator of how the lives of those with Down Syndrome were understood in the early 1980s.

John Pearson was born on Saturday, June 28, 1980 at 7.55 am<sup>14</sup> At about 9 am, the obstetric house officer informed his mother, Molly Pearson, aged 31, that her baby had Down Syndrome. According to the doctor, Mrs Pearson 'sobbed and turned away' when the midwife offered her the baby.<sup>15</sup> The midwife said that she left the baby in a cot by Mrs Pearson's bed for about 20 minutes: 'if a bond between mother and son was to have formed, it would have been made at that early stage.'<sup>16</sup> Other reports of Mrs Pearson's early reactions to the baby indicate that she said, 'I don't want it.'<sup>17</sup> At 11.30 am the consultant paediatrician, Dr Arthur, spoke with Molly Pearson and her husband Malcolm. He wrote in his notes, 'Parents do not wish it to survive. Nursing care only.'<sup>18</sup>

Dr Arthur prescribed 5mg of the sedative drug DF118 (dihydrocodeine) to be given to the baby every four hours. This drug is related to morphine, and the purpose of administering the drug was to ensure the baby did not suffer pain, and possibly also to prevent him from seeking food. After receiving the first dose of the drug, it was noted that John was going grey and becoming increasingly ill. A doctor had visited the ward during the evening, and was informed about John's worsening condition but did not examine him. He died, seemingly of broncho-pneumonia, at 5.10 am on the Tuesday morning.

The matter came to the attention of the police when a hospital employee contacted the anti-abortion pressure group SPUC to say that the baby had been left in a side-ward to starve to death, and SPUC contacted the police.<sup>19</sup> A post-mortem was

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<sup>14</sup> This name was given to the baby when he was christened by the hospital chaplain.

<sup>15</sup> It is unclear whether Mr Pearson was present at this time.

<sup>16</sup> 'Mother of Down's baby sobbed and turned away' *The Times* October 15 1981.

<sup>17</sup> Oliver Gillie, 'How the 69-hour life of John Pearson put a doctor in the dock' *The Sunday Times* 18 October 1981, reprinted in Tony Booth *Eradicating Handicap: Special Needs in Education* (1982, Milton Keynes, Open University).

<sup>18</sup> Diana and Malcolm Brahams, 'The Arthur case – a proposal for legislation' (1983) 9 *Journal of Medical Ethics* 12-15, p.12.

<sup>19</sup> It is not clear from accounts of the trial whether the complaint was made immediately after the baby's death.

carried out and on 2 February 1981, Dr Arthur was charged with murder. The trial started on 17 October 1981. After 10 days of evidence, the charge was amended to attempted murder, because a second post-mortem carried out on behalf of the defence had discovered that John Pearson had a number of serious medical problems, and these were the likely cause of his death.<sup>20</sup>

In order for Dr Arthur to be convicted of attempted murder, the prosecution needed to prove that there was an unlawful act or omission by Dr Arthur (or steps towards such an act or omission that were more than merely preparatory) *and* that Dr Arthur intended the baby to die.<sup>21</sup> There were two omissions that the prosecution could rely upon, either singly or together: the failure to give the baby food or water, and the failure to provide medical treatment once he became ill. The alternative approach was based on the positive act of giving the baby DF118, which was thought to have resulted in lung damage.<sup>22</sup> If the case was based on an omission to treat rather than on any positive act by the doctor, it was also necessary to show that Dr Arthur was under a duty to treat the baby. There were two ways in which the required intent could be established. One was to prove that it was Dr Arthur's purpose to end the child's life and that he foresaw that his actions would have that result (direct intent). Alternatively, this could be a case of indirect or oblique intent. In 1983, the applicable test was the one set out in *Hyam v DPP*.<sup>23</sup> This held that a person who foresaw death was a highly probable consequence of his action could be assumed to intend death even if he had no desire that death should result.

The basis of the defence argument was that Dr Arthur was simply following normal medical practice and he was under no duty to provide John with medical care. The trial judge emphasised to the jury that 'it was lawful to treat a baby with a sedating drug and offer no further care by way of food or drugs or surgery if certain criteria were met.'<sup>24</sup> Those criteria were that the child was irreversibly disabled and that it had been rejected by its parents. Sedation and failure to nurture were characterised as omitting to keep the baby alive, which was lawful where a positive act of giving drugs to kill the baby would not be. Without this instruction, it seems likely that Dr Arthur would have been convicted, since it is difficult to deny that he had the foresight that his actions would lead to John Pearson's death.

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<sup>20</sup> Brahams and Brahams, 'The Arthur Case', p.12.

<sup>21</sup> For a murder charge, it is sufficient to show the intent to cause grievous bodily harm.

<sup>22</sup> Brahams and Brahams, 'The Arthur Case', p.12.

<sup>23</sup> *DPP v Hyam* [1974] 2 WLR 607.

<sup>24</sup> Ian Kennedy, *Treat Me Right: Essays in Medical Ethics* (Clarendon Press, 1988) p.155.

Legal responses were mixed. In a 1985 article, Gunn and Smith suggested *Arthur* established that the duty owed by parents and doctors to preserve the life of a disabled child is 'different from and of a lower order than that owed to a normal child'<sup>25</sup> and that 'a joint decision by both parents and doctor that the child shall die is not unlawful.'<sup>26</sup> Not all commentators thought the decision had such far-reaching implications. Diana Brahams argued that a 'handicapped baby, who does not fall into an "exceptional" category...has...the same right to medical care and treatment as a normal baby' but that John's medical condition meant he was in the exceptional category.<sup>27</sup> This can only be a retrospective justification for what happened to John Pearson, though, since the evidence of his serious problems did not emerge until after his death. She did not consider Arthur's case to have any real significance as a legal precedent, though she acknowledged it suggested that 'no sensible jury would be willing to convict a doctor of murder for 'allowing a handicapped child to die' with the parents' consent.'<sup>28</sup>

Dr Arthur's acquittal received a lot of press coverage. *The Times* front page headline was 'Women cry "Thank God" as Dr Arthur is cleared'. The paper reported that

when Mr Malcolm Pearson, the dead baby's father, heard of the acquittal, he said: "Justice has been done. My wife and I have been worried stiff by the case. We are sure that everything that Dr Arthur did was the best for our child and our family. He really tried his best."<sup>29</sup>

There were also several inside items, including an editorial and an opinion piece by Professor A.J. Ayer entitled, 'Why the Doctor Arthur verdict is right'.<sup>30</sup> Although the headline story was sympathetic in tone, the editorial expressed concern that the expert medical evidence had been one-sided, with 'all who offered evidence... broadly of one mind' and that there had been excessive deference to parental wishes.<sup>31</sup> The *Sun* and the *Mirror's* coverage included interviews with parents of children with Down Syndrome, but did not examine the ethical issues in any detail. The general response of the press seems to have been sympathetic to Dr Arthur.<sup>32</sup> Both the BBC and ITV ran programmes on the case, and the BBC show *Panorama*

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<sup>25</sup> MJ Gunn and JC Smith, 'Arthur's case and the right to life of a Down's Syndrome child' (1985) *Criminal Law Review* 705-715, p.708.

<sup>26</sup> *Ibid* p.714.

<sup>27</sup> Diana Brahams, 'Putting Arthur's Case in Perspective' (1986) *Criminal Law Review* 387-389.

<sup>28</sup> *Ibid*.

<sup>29</sup> 'Women cry "Thank God" as Dr Arthur is cleared' *The Times*, 6 November 1981

<sup>30</sup> *The Times*, 6 November 1981.

<sup>31</sup> 'When a child is born' *The Times*, 6 November 1981.

<sup>32</sup> For a useful summary of the press coverage, see Richard Smith, 'Medicine and the media' (1981) 283 *British Medical Journal* 1327.



revealed the results of an opinion poll: three quarters of paediatricians and paediatric surgeons surveyed said that 'if parents did not wish a baby to survive and there were severe handicaps then they would ensure that the infant died.'<sup>33</sup>

The acquittal was also discussed in the House of Lords. Lord Vernon demanded information about how much the case had cost, adding that 'very many people throughout the country deplore the fact that this prosecution... was ever brought in the first place'. He suggested that 'in these admittedly very delicate and difficult cases it is better to leave the decision to the discretion of the medical profession, who have over the years exercised that discretion with both humanity and good sense'.<sup>34</sup> In the same debate, Lord Wilson of Langside, asked the Lord Chancellor if he thought it

conceivable that any sensible English jury properly directed... could have returned a verdict of guilty of murder or guilty of attempted murder against the doctor in question? If he thinks that is conceivable, would he agree that perhaps there is something wrong with the English law pertaining to murder? If, on the other hand, he thinks it inconceivable... does he agree that some public recognition should be given to the doctor concerned that the person who made the decision to prosecute was guilty of a serious error of judgment?'<sup>35</sup>

A 1980 editorial in the *British Medical Journal* which welcomed the acquittal suggests that Dr Arthur's views were consistent with common medical practice. It suggested:

an infant with physical or mental handicaps that are not immediately life-threatening should not, we believe, be allowed to die by default. If the parents reject an otherwise healthy baby with Down's syndrome the proper course for the paediatrician is to ask the local authority to take the child into care.'<sup>36</sup>

However, it would be reasonable to withhold treatment if the baby had congenital defects of the heart or other organs and there had been parental rejection. If the parents wanted the baby to be treated, that should generally override other considerations. On balance, though:

our society has no right to insist on maximum medical efforts to preserve the lives of unwanted handicapped babies when it provides them with such a bleak future. For most such babies unwanted by their families the present reality is a miserable lifetime in an NHS institution...'<sup>37</sup>

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<sup>33</sup> Ibid.

<sup>34</sup> Lord Vernon, HL Deb 10 December 1981 Hansard vol 425, 1435.

<sup>35</sup> Ibid 1435-1436.

<sup>36</sup> Editorial, 'Paediatricians and the law' (1981) 283 *British Medical Journal* 1280-1281.

<sup>37</sup> 'Paediatricians and the law' 1280.

Correspondence in a later issue of the journal was split between approval of this statement and disapproval, with some correspondents pointing out that John Pearson's heart defect was not discovered until after his death and therefore could not justify the withholding of nursing care.<sup>38</sup> M.J. Absolom commented in a letter that

for parents one of the most distressing results of recent events has been the resurrection of the myth that Down's syndrome children are monstrous vegetables who, if rejected, will be consigned to grim institutions.<sup>39</sup>

Some correspondents also showed awareness that institutionalization was less likely than it had been in the past.<sup>40</sup> However, although Dr Arthur's response to parental rejection was presented in his trial as consistent with normal medical practice, another case involving a newborn baby with Down Syndrome reveals that opinion was divided. The baby in this case, dubbed 'Baby Alexandra', was born on 28 July 1981. Virtually nothing is known about her background: the courts were keen to ensure no information 'leaked out'.<sup>41</sup>

In addition to having Down Syndrome, Alexandra had an intestinal blockage and needed urgent surgery to save her life. Her parents refused consent for the surgery because they thought it would be better for her to be allowed to die. Not all the doctors concerned agreed with this decision and therefore the hospital informed the local authority and Alexandra was made a ward of court. According to the Director of Social Services responsible for making this decision, 'the baby was an independent person and had a right to life... It was our legal responsibility as a social services authority to intervene... She was a *child* first and had Down's syndrome second.'<sup>42</sup>

Eventually, the case was heard by the Court of Appeal. The argument on behalf of Alexandra's parents was that 'nature has made its own arrangements to terminate a life which would not be fruitful and nature should not be interfered with'. The court

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<sup>38</sup> Letters from R.B. Zachary and M. Blackwell, (1981) 283 *British Medical Journal* 1463.

<sup>39</sup> Letter from M.J. Absolom, *ibid* 1463.

<sup>40</sup> Letters from M.J. Absolom and J. Campbell Murdoch, *ibid* 1463.

<sup>41</sup> *Re B (A Minor)(Wardship: Medical Treatment)* [1981] 1 WLR 1421. According to one report, Alexandra was the second baby of a married couple living in Chester. Their first child had health problems and the mother, who was in her 30s, had undergone repeated amniocentesis tests as she did not wish to have a child with Down Syndrome, but the results had been inconclusive. Another account, this time by Dame Elizabeth Butler Sloss, described the parents as 'elderly first time parents'. These two descriptions are obviously inconsistent, which makes it impossible to draw any useful conclusions from them. 'Down's syndrome baby's mother had six tests' *The Times*, 11 August 1981 and Rt Hon Dame Elizabeth Butler Sloss GBE 'Legal aspects of medical ethics' (2006) 2 *Web Journal of Current Legal Issues*.

<sup>42</sup> Personal interview with David Plank, quoted in Janet Read and Luke Clements, 'Demonstratively awful: the right to life and the selective non-treatment of disabled babies and young children' in Luke Clements and Janet Read (eds) *Disabled People and the Right to Life: The protection and violation of disabled people's most basic human rights* (Routledge, 2008) p.163.

was not prepared to leave decisions about whether the baby should live or die solely to the parents. Templeman LJ asked 'whether the life of this child is demonstrably to be so awful that in effect the child must be condemned to die, or whether the life of this child is so imponderable that it would be wrong for her to be condemned to die'.<sup>43</sup> He concluded that Alexandra would certainly die if she was not treated but if she was treated she 'may live the normal span of a mongoloid child with the handicaps and defects of a mongoloid child.'<sup>44</sup> Her future was imponderable: while she would certainly be severely handicapped, her life was not destined to be so awful that she should be allowed to die. The court ordered that the surgery should go ahead.

It is not known whether *Re B* was considered by those involved in *Arthur's* case, nor is it clear whether the result in *Re B* meant that if John Pearson had been made a ward of court after his parents rejected him, the hospital would have been required to provide him with medical treatment. Smith and Gunn argue that the two cases can be reconciled with each other. The outcome of *Arthur* was that failure to treat John Pearson was within the bounds of acceptable medical practice, and this is not inconsistent with *Re B* even though the eventual decision was a different one. The two cases, read together, indicate that there is discretion as to whether to treat and *Re B* sets out the test to be applied should the court have to decide whether treatment is provided. The test set out in *Re B* does not say that medical treatment must be provided for all disabled newborns or all newborns with Down Syndrome. Nor is there any suggestion in *Re B* that criminal liability would have arisen if everyone involved was in agreement and Alexandra left untreated. The court in *Re B* showed no great hope that Alexandra would have a happy life, and the comments about Down Syndrome are negative. 'No-one can expect she will have anything like a normal existence... good adoption arrangements could be made and... in so far as any mongol child can be provided with a happy life then such a happy life can be provided.'<sup>45</sup>

Further evidence about societal attitudes in the 1980s and before can be found by looking at autobiographical accounts by, and interviews with, parents of children with disabilities. Some mothers interviewed for a 1983 study admitted that they would

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<sup>43</sup> *Re B*, 1423-1424.

<sup>44</sup> *Re B*, 1424.

<sup>45</sup> *Re B*, 1423.

have prevented the child's birth or survival if they had known of the disability. One mother said:

The more handicapped children I see, the more I'm inclined to think that it would be best to let nature take its course because once you'd had them, you love them but really there's nothing much you can do except keep them reasonably happy, but they are never going to be like the other kids and they're never going to have a chance in life ... If you've not had them you don't miss them, not really.<sup>46</sup>

Anne Crosby's biography of her son Matthew explains how when she recognised at birth that Matthew had Down Syndrome she begged for him to be allowed to die. She was treated as though she was deluded and dangerous. When Matthew was two weeks old, a paediatrician confirmed the diagnosis of Down Syndrome, and Anne received what could be construed as an apology - 'Your responses to your son's condition now appear rational.'<sup>47</sup>

Regardless of whether Dr Arthur was in the majority or the minority in acceding to the parents' request to let their baby die, it is clear in the early 1980s, there was nothing particularly unusual or controversial about the view that babies with serious disabilities should be allowed to die and Down Syndrome was regarded as a serious disability. However, attitudes towards the children with disabilities who did survive were clearly changing and the nature of those changes will now be explored.

## **2 Becoming Part of Society**

One possible reason why a disability such as Down Syndrome was viewed as incompatible with a life worth living by some mothers as late as the 1970s and 1980s was the policy that began in the later part of the nineteenth century policy of hiding children and adults with disabilities away in institutions. The mass institutionalization of the disabled has multiple origins: the opportunities offered by the nineteenth century Poor Law, the medicalization of disability, and then the influence of the eugenics movement on policy makers in the early twentieth century. Initially, institutions were for those who could afford the fees or were funded by charity, but by the early twentieth century, institutionalization was a matter of state policy. By the interwar period in the twentieth century the 'normality' was that not only did few people come across the intellectually and physically disabled in their everyday lives,

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<sup>46</sup> Caroline Glendinning, *Unshared Care: Parents and their Disabled Children* (Routledge & Kegan Paul, 1983) p.39.

<sup>47</sup> Anne Crosby, *Matthew: A Memoir* (Paul Dry Books inc, 2006) p.35.

but the regimes the disabled were subjected to were harsh and punitive. It was a life, but a grudgingly offered one.

Historically, responsibility for providing support for those unable to support themselves lay with the parish where they were settled, and there was a legal right to that support.<sup>48</sup> The Poor Law Amendment Act 1834 sought to reduce the cost of this 'outdoor relief', that is, the nineteenth century equivalent of care in the community. Under the new system, the 'undeserving poor' were housed in workhouses rather than in the community, and were required to work as a condition of receiving support. The workhouses tended to cater for both the able-bodied and the disabled, and punitive regimes designed to discourage the able-bodied from seeking relief applied to most if not all inmates.

Although the original purpose of the workhouses was to provide financial support as cheaply as possible, a new reason for separating the 'feeble minded' from the rest of society was developing, that of social protection. Eugenics became popular because of a combination of interest in the implications of Darwin's natural selection and concern about the falling British birth rate, especially among the upper and middle classes.<sup>49</sup> It was not only the working classes whose reproductive habits concerned the eugenicists. The mentally retarded or disabled were thought to have prolific sexuality and to breed more rapidly and in greater number than the 'normal' population. Female imbeciles were particularly dangerous: they were thought likely to become sexual offenders, to spread sexually transmittable diseases and their children were also likely to be either neglected, disabled themselves or criminals.<sup>50</sup> In 1908 the report of a Royal Commission set up to investigate the problem of the expanding population of 'feeble-minded' recommended compulsory detention of the mentally inadequate and sterilisation of the unfit.<sup>51</sup> The Mental Deficiency Act 1913 did not include any positive eugenic measures, but it did construct a system for the indefinite detention of the mentally and intellectually disabled, categorised as either idiots, imbeciles, the feeble-minded and moral defectives.<sup>52</sup> From 1907 there were

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<sup>48</sup> Lorie Charlesworth, *Welfare's Forgotten Past A Socio-Legal history of the Poor Law* (Routledge, 2009).

<sup>49</sup> Richard Soloway, *Demography and Degeneration: Eugenics and the Declining Birthrate in Twentieth-Century Britain* (Chapel Hill, 1995) p.4.

<sup>50</sup> Sharon L. Snyder and David T. Mitchell, *Cultural Locations of Disability* (The University of Chicago Press, 2006) pp.84-91.

<sup>51</sup> Royal Commission on the Care and Control of the Feeble-Minded (1904-1908) *The Radnor Report* (HMSO, Cmnd 4202, London).

<sup>52</sup> The categorisation of different types of mental deficiency was based on the effect of the disability rather than its cause.

compulsory medical examinations of schoolchildren to determine whether they had an intellectual or physical disability, and this might result in them being sent to a specialist institution.

It was not unusual for children with physical disabilities to be placed in hospitals for the mentally handicapped. There was a common belief that physical defects were evidence of mental defects.<sup>53</sup> Children with physical disabilities might also be misdiagnosed because they failed intelligence tests. This might be because they had been excluded from formal education or it might be the direct result of their disability. Evelyn King was admitted to a mental handicap hospital in the North of England in 1951, when she was five. Her medical statement stated that 'she fails to name common objects, to indicate objects by their use and to copy a circle. She has a mental age of 3 years...'<sup>54</sup> When interviewed for Humphries and Gordon's study *Out of Sight: The Experience of Disability 1900-1950*, Evelyn commented that at the time she could not walk and could not talk: it is hardly surprising that she 'failed' the intelligence test. The medical report notes that Evelyn is in poor health and suffers from cerebral dysplasia with a history of epilepsy' but nonetheless went on to classify her as an 'imbecile'.<sup>55</sup>

The institutions that were built were designed to be as self-sufficient as possible, with the less disabled inmates working on site, performing duties such as gardening, cleaning, and laundry. The majority of children admitted to institutions were working class. Borsay suggests that a request for a place in an asylum or hospital was often a response to changing circumstances, and a pragmatic response to economic need.<sup>56</sup> For those children who did live at home, little or no assistance was available to their parents, even after the introduction of the National Health Service. The original system of social security benefits did not provide specialist payments for the disabled.<sup>57</sup> There was now an entrenched belief that children with disabilities were better off in specialist institutions.<sup>58</sup>

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<sup>53</sup> Steve Humphries and Pamela Gordon, *Out of Sight: The Experience of Disability 1900-1950* (Northcote House, 1992) p.89.

<sup>54</sup> *Ibid* p.89.

<sup>55</sup> *Ibid* pp.88-89.

<sup>56</sup> Anne Borsay, *Disability and Social Policy* (Palgrave MacMillan, 2005) p.177.

<sup>57</sup> *Ibid* pp.160-167.

<sup>58</sup> In 1963 there were 64,622 people resident in hospitals for the mentally subnormal, including children: this fell to 59,918 by 1970. Borsay, *Disability and Social Policy* p.87.

The homes were harsh and regimented. Another of the former child inmates of institutions interviewed for the study *Out of Sight* was Mary Baker. She had a dislocated hip and walked with a limp. In 1935, when she was 12, her mother died and the local authority decided that her father was unable to bring up Mary and her three brothers. The boys were sent to a workhouse and Mary was sent to the Halliwick Home for Crippled Children. She described her first night at Halliwick:

When I first arrived at Halliwick the nurse took me into this bathroom and she stripped me off completely. She cut my hair short, right above the ears, And then I was deloused with powder of some description. Then they put me in a bath and scrubbed me down with carbolic soap.<sup>59</sup>

Former residents also tell stories of punishments such as caning blind children on the hands (so that they could not sign), and punishment for bedwetting even where there was a medical reason for incontinence. Food was poor and many children complained there was not enough of it.<sup>60</sup> Male and female residents were strictly segregated.<sup>61</sup> Although separate education of boys and girls was common at the time, institutions for the disabled were particularly concerned about the dangers of promiscuity, especially among girls with intellectual disabilities. 'The main strategy to curb the fertility of the "unfit" was sex segregation. It was pursued with extraordinary vigour in almost all institutions where disabled people lived.'<sup>62</sup>

Eugenics policies were discredited by the extreme form adopted by Nazi Germany, but this does not mean that the disabled were thereafter treated as valuable members of society. The emphasis on a healthy body and healthy mind continued, and the focus in the post-war period was on cure. This had an economic justification: 'the expenditure of money on their treatment is not merely an act of merit but a sound investment. It means that thousands of children who would otherwise grow up to be a burden on their relatives and the community will become useful, self-supporting citizens.'<sup>63</sup> Well into the second half of the twentieth century, institutionalization was a common response to childhood disability, and children were also educated (if at all)

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<sup>59</sup> Humphries and Gordon, *Out of Sight*, p.68.

<sup>60</sup> *Ibid* pp.90-93.

<sup>61</sup> Not all institutions were like this, of course. At Normansfield, the home set up by John Langdon Down, residents wore their own clothes, ate good food, had holidays at the seaside, and returned to their families for short stays. For some examples of the Normansfield experience, see Andy Merriman, *Tales of Normansfield: the Langdon Down Legacy* (Down's Syndrome Association, 2007) pp.11-25.

<sup>62</sup> Humphries and Gordon, *Out of Sight*, p.101.

<sup>63</sup> J Herbert Lewis of the Board of Education, addressing a conference organised by the Central Council and the Invalid Children's Aid Association, 1920, quoted in Borsay, *Disability and Social Policy* p.55.

separately from their peers. Various events coincided to force the end of the era of institutionalization.

From the late 1960s, disabled people themselves started to challenge both explanations of disability as an individual and medical issue and their incarceration in institutions. The then-prevailing view was of disability as a kind of tragedy for those involved:

this encompasses an individual and largely medicalized approach: first, disability is regarded as a problem at the individual (body-mind) level; second, it is equated with individual functional limitations or other 'defects'; and third, medical knowledge and practice determines treatment options.<sup>64</sup>

If a person with paraplegia could not physically enter a building that was approached by steps, that was because of their medical condition. If a person who was partially sighted could not obtain employment, it was because of their medical condition. The social approach to disability challenged this. The problem was the physical barrier of the steps or the failure to provide adaptive technology, not the paraplegia or visual impairment. This approach to disability framed the disabled as oppressed by society, not by their disability.<sup>65</sup> The social approach to disability has been more influential in policy relating to access to buildings and employment than in social welfare, education and health-care, and it is more convincing when applied to physical and mental rather than intellectual disabilities, but it is another aspect of the changing environment in the latter part of the twentieth century.

The 1971 White Paper *Better Services for the Mentally Handicapped* started the process of closing institutions, setting a target of reducing the number of long-stay hospital places for adults and children, and increasing the number of residential care and day places in the community.<sup>66</sup> At the same time, changes to social welfare law increased the help available to those with disabilities and their families. Invalidity pensions and the Attendance allowance were introduced in 1971<sup>67</sup> and the first carers allowance in 1976.<sup>68</sup> The process took a long time, but there are now no resident children in long-stay hospitals. It has been estimated that of the 7% of children in the UK who have a disability or long-term condition, more than 98% live at

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<sup>64</sup> Colin Barnes and Geof Mercer, *Disability* (Polity, 2003) p.2.

<sup>65</sup> *Ibid* p.19.

<sup>66</sup> *Valuing People: A new strategy for learning disability for the 21<sup>st</sup> century* (2001, Cmnd 5086) 17.

<sup>67</sup> Borsay, *Disability and Social Policy* p.165.

<sup>68</sup> *Ibid* pp.165-166.



home with their parents – this includes some who are dependent on complex technology such as ventilators.<sup>69</sup>

A series of scandals about abuse and poor care in large institutions also hastened the process of deinstitutionalization. One of those scandals arose at Normansfield, the hospital opened by John Langdon Down. When Dr Terence Lawlor obtained the position of medical superintendant in 1970 the hospital was already in poor condition and it continued to deteriorate. During the 1970s, there were several critical reports from the Hospital Advisory Service and the Community Health Council. One report commented that ‘there was no therapy, patients were expected to sit for hours on end, the lockers held no personal possessions and... there was a total lack of stimulation.’<sup>70</sup> Dr Lawlor was a poor manager and unwilling to work with parents or voluntary organisations. Eventually, in May 1975, there was a strike by nursing staff. As a result, Lawlor was removed and an enquiry was set up into staff morale and patient care at the hospital.

The report found that, although there had not been cruelty or ill-treatment, low standards of nursing care were evident and the patients had suffered:

The roof of the building let in water for many years ... Patients were sometimes soaked as they slept. The standards of hygiene were often appalling and patients and staff alike suffered from demarcation disputes between nursing and domestic staff. Faeces and urine were frequently left unattended for days on end.<sup>71</sup>

Introducing the report in Parliament, the Right Honourable David Ennals M.P., Secretary of State for Social Services, indicated a new policy direction for intellectual disability: ‘The Government’s aim is to enable as many mentally handicapped people to live in the community, but hospital care will be required for many of these patients for a long time to come.’<sup>72</sup> The negative publicity on the conditions in a series of hospitals had contributed to a growing sense that a better approach to care for the

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<sup>69</sup> Joint briefing from Scope, Treehouse and Working Families, *Achieving a work/life balance with a disabled child* (2007)

<sup>70</sup> Merriman, *Tales of Normansfield* p.189, quoting Mr R.J. Wix.

<sup>71</sup> *Ibid* p. 201, quoting Report of the Committee of Inquiry into Normansfield Hospital.

<sup>72</sup> HC Deb 21 November 1978 vol 958, 1095. Unfortunately, conditions at Normansfield were not vastly better in 1983 when it was visited by Susannah Seyman of the Down’s Syndrome Association. A number of patients in a ward for those with challenging behaviour were naked. She was told to step over a naked woman who was lying on the floor, blocking her path. Cuddly toys given to patients had been taped to the ceiling, where patients could look but not touch. There was no privacy in the bedrooms and she was taken into a bathroom where a man was in the bath; the nurse did not apologise. ‘There was a sense of being in a kind of underworld where rules and expectations were a million miles away from what was acceptable ... It was Hogarthian.’ Merriman, *Tales of Normansfield* p.9.

disabled was required but at the same time, press images of the institutions and of those living in them would not have been reassuring to new parents.

Education was another area where change was occurring. When attendance at school had become mandatory between the ages of 5 and 10 in 1880, there had been no specific mention of disabled children. Initially, they had either attended with other children or had been excused attendance. In 1889, a Royal Commission had recommended schooling for the 'blind, deaf and dumb, and the educable class of imbeciles' in order to prevent them being a burden on the state.<sup>73</sup> Special schools were set up for the blind and deaf, but there was no requirement for Local Education Authorities to provide schools for the intellectually disabled until the Elementary Education (Defective and Epileptic Children) Act 1899. Schooling for disabled children became mandatory under the Education Act 1918. Secondary education became compulsory in 1944, and all but the 'ineducable' came under the control of the education rather than the health system. The system of special schools expanded, and along with this came a narrower curriculum than provided in the secondary modern or grammar schools. Expectations were low.

Just as deinstitutionalization placed disabled children back in their local communities, the major change in education was the move towards educating disabled children with their non-disabled peers. The Warnock Report in 1978 recommended that most children with special needs should be supported in normal ('mainstream') schools, with special schools catering only for the most disabled. The Education Act 1981 went further than this, stating that children with special needs should be educated in normal schools where possible, and setting up the 'statementing' system whereby resources were allocated to particular children based on their needs rather than allocated to specialist schools. Schools are now required to provide appropriate support for children with disabilities. Today, at least at the primary education stage, the majority of children with Down Syndrome attend mainstream schools.

There have been significant changes in access to health care and the effectiveness of treatment. There have been allegations of hospitals steering parents of children with Down Syndrome away from surgery<sup>74</sup> and also of unequal access to transplants,

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<sup>73</sup> Borsay, *Disability and Social Policy* p.108.

<sup>74</sup> See Debashis Singh, 'Doctors accused of discriminating against Down's syndrome patients' (2004) 329 *British Medical Journal* 591; Zosia Kmiotowicz, 'Down's children received "less favourable" hospital treatment' (2001) 322 *British Medical Journal* 815.

but the situation is nonetheless vastly different from that when John Pearson was born. The changes in the way the courts treat disputes about whether medical treatment should be given contrary to the parents' view or contrary to the doctors' view are subtle. Cases that come to court are usually concerned with much more severe disabilities than Down Syndrome - these are children who would have had little or no chance of survival in 1980. References to a life worth living have been replaced with the notion of a balancing act and the best interests of the particular patient. The presumption should be in favour of prolonging life, but the court is also required to consider the pain and suffering of the patient, and the quality of their life if they require prolonged treatment.<sup>75</sup> In practice, although this test is intended to consider emotional and welfare issues and not merely medical opinion, judges tend to defer to medical opinion.<sup>76</sup> Morris' survey of case-law suggests that 'intellectual impairments are seen as especially burdensome'.<sup>77</sup>

The other important change to note is the introduction of legislation dealing with discrimination on the basis of disability. The first discrimination legislation was passed in the 1960s and 1970s and was concerned with discrimination on the basis of sex and race. Disability discrimination began to be prohibited in the 1990s, and in the UK, the Disability Discrimination Act (DDA) came into force in 1996. The Act made it unlawful to discriminate against those with a disability when providing services, and also applied to most employers. A person with a 'disability' was defined as someone with a physical or mental impairment which has a substantial and long-term adverse effect on his/her ability to carry out normal day-to-day activities. This was, notably, an attempt to incorporate the social model of disability into the legislation. The DDA has now been incorporated in the Equality Act 2010, which further restricts discrimination against people who are associated with a person who has a disability.

It would not be unreasonable to say that in the 30 years since *R v Arthur* and *Re B* were decided there have been improvements in the way society responds to a person with an intellectual disability such as Down Syndrome, and that is reflected in changes to the law. While the level of support provided may not be ideal, and the benefits paid to carers are meagre, the outcome for children who remain with their

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<sup>75</sup> *Re J* [1992] 3 WLR 507.

<sup>76</sup> Anne Morris, 'Selective treatment of irreversibly impaired infants: decision-making at the threshold'

(2009) 17 *Medical Law Review* 347-376, p.358.

<sup>77</sup> *Ibid* p.359.

parents and who receive the benefits of proper healthcare and education is significantly better than might have been expected before the 1980s. These progressive changes were presumably what Jo Bridgeman had in mind when she wrote:

Current medical and social understanding would demand the conclusion that life with Down's Syndrome is not 'so intolerable' that consent should be withheld for ordinary treatment... Neither would good medical practice support the provision of 'nursing care only' and the administration of sedatives to a baby born with Down's Syndrome as in *R v Arthur*.<sup>78</sup>

However, the provision of treatment for newborn babies or better opportunities for children with Down Syndrome do not necessarily indicate a change in public attitudes towards Down Syndrome and other disabilities as decisions at other stages in a person's life-cycle must also be considered.

### **3 A Bundle of Joy or a Lifelong Burden? The Changing Locus of Decision-Making**

The reason why a focus on issues around the beginning of life can be misleading is the ability we now have to detect Down Syndrome before birth. Women who might once have rejected a disabled baby or asked a doctor to allow it to die would now be offered the chance to find out in advance about Down Syndrome, and would also have the option to terminate the pregnancy following a positive diagnosis. In order to determine whether things have really changed since 1983, therefore, it is necessary also to consider the law and practice relating to abortion. This is an important aspect of the legal and cultural context of disability. Rules about when and why abortions can be carried out lawfully provide further information about the legitimate responses to disability.

Under section 1(1)(a) Abortion Act 1967 Act, a pregnancy of less than 24 weeks can be terminated where 'the continuation of the pregnancy would involve risk, greater than if the pregnancy were terminated, of injury to the physical or mental health of the pregnant woman or any existing children of her family.' Under section 1(1)(d) an abortion is lawful where there is 'a *substantial risk* that if the child were born it would suffer from such physical or mental abnormalities as to be *seriously*

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<sup>78</sup> Jo Bridgeman, 'Caring for Children with Severe Disabilities: Boundaried and Relational Rights' (2005) 13 *International Journal of Children's Rights* 199-120, p.101. See also Anne Morris, 'Selective treatment', p.349.

*handicapped* (emphasis added). There is no time limit for abortions under the handicap ground.

A very high percentage of mothers who have a prenatal diagnosis of Down Syndrome choose to terminate the pregnancy. The following statistics do not indicate which ground of abortion was relied upon, or when the Down Syndrome diagnosis was made, but it would appear that the overwhelming majority of positive diagnoses were followed by termination.<sup>79</sup> Between 1992 and 1996, there were a total of 5,922 diagnoses of Down Syndrome in the UK. Of those, 3,004 were prenatal diagnoses (51% of the total). There were 3,015 live births, 149 miscarriages and 2,758 terminations. In the 1997-2001 period, the number of diagnoses was 6747, and the rate of prenatal diagnosis increased to 56% (3,979 cases). During this period, there were 3,488 terminations. For the final period under review, 2002-2006, 60% of cases were diagnosed prenatally, numbering 4,986. The number of terminations was 4,518.<sup>80</sup> This suggests that the majority of women with a prenatal diagnosis responded by requesting termination of pregnancy - the percentage ranges from 90 to 92%. There are similarly high termination rates for other disabilities that can be diagnosed prenatally, including spina bifida, Turner syndrome and Klinefelter syndrome.<sup>81</sup>

The main themes in first-hand accounts by women who have terminated pregnancy are their concern that the child will have a poor quality of life and is likely to suffer pain and discrimination, and concern about the impact on the family of bringing up a child with a disability. Julia Langdon wrote:

For me, the decision - and it was mine and mine alone - was not about the rights and wrongs of abortion. It wasn't about whether the child would have been loved, as she would have been.

And when it came down to it, nor was it about whether I could cope, because somehow or other I would have managed.

It was only about not wishing to bring a disabled child into the world, a child whose life would be more difficult. I was given the choice. I made it. I do not regret it.<sup>82</sup>

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<sup>79</sup> It is, however, unlikely that Down Syndrome would be detected after termination as there would be no reason to look for it in the foetus.

<sup>80</sup> Buckley and Buckley, 'Wrongful deaths and rightful lives', p.82.

<sup>81</sup> Caroline Mansfield, Suellen Hopfer and Theresa M. Marteau, 'Termination rates after prenatal diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A systematic literature review' 19 (1999) *Prenatal Diagnosis* 808-812.

<sup>82</sup> Julia Langdon and Shelley Thoupou, 'Would you abort a baby with Down's syndrome' *The Daily Mail* 29 October 2009, available at <http://www.dailymail.co.uk/femail/article-1223439/Would-abort-baby-Downs-Syndrome.html#ixzz14Ed7GCjy> (last accessed 18 January 2011).

An anonymous contributor to an online discussion wrote:

The fact is that children with Downs are considerably more likely to have congenital heart defects, serious bowel impairment and hearing problems from birth... Maybe some people are thinking about the suffering endured by these babies rather than their own ends.<sup>83</sup>

Another focussed on the burden that such a birth would place on the mother:

I only knew two DS children whilst growing up. In both cases, their mothers left successful jobs to care for them, pretty much full-time. I must say, frankly, that to me, that would feel like a jail sentence. If I had a child born with DS, I'd do it, of course: I'm sure I'd love them and would make any sacrifice for them. But it would be a lifelong regret, I think...<sup>84</sup>

Clearly, not all prospective parents of a child with Down Syndrome feel this way, since some do choose to continue a pregnancy despite the diagnosis. One American study found that most women who rejected termination were motivated by their religious beliefs and opposition to abortion, so it is not necessarily possible to say that these women rejected the negative view of Down Syndrome found in the termination accounts.<sup>85</sup>

One thing that is clear is that decisions about termination are made on the basis of a medical diagnosis that can only predict how 'disabled' the child is likely to be. The progress that the disability activists made in developing the social theory of disability has not extended to decision making about prenatal diagnoses. Many of the worries that are reported are not about the intrinsic effect of disability, they are about social responses to disability. These worries are rational: regardless of rhetoric about equality and ending discrimination, there are many ways in which a life with a disability, and especially an intellectual disability, is treated as being less valuable.

Although the choice whether to end a pregnancy is a personal choice, there is a policy element to the provision of the information required in order to make that decision. Prenatal testing and the termination itself are funded by the National Health Service. Government policy is to enable that choice by making screening available to

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<sup>83</sup> Reader comments on article by Tom Shakespeare 'The human cost of screening for Down's', *The Guardian* 28 October 2009, available at <http://www.guardian.co.uk/commentisfree/2009/oct/28/downs-syndrome-screening> (last accessed 18 January 2011).

<sup>84</sup> Reader comments on 'The human cost of screening for Down's'.

<sup>85</sup> One American survey suggested this was the most common reason given for continuing pregnancy, although cultural differences may not permit this to be generalised to the UK: Brian Slotko, 'Prenatally diagnosed Down syndrome: mothers who continued their pregnancies evaluate their health care providers' (2005) 192 *American Journal of Obstetrics and Gynaecology*, 670-677.

all pregnant women.<sup>86</sup> The assumption is that further testing will follow if the screening suggests a possibility of Down Syndrome. The UK National Screening Committee recently made recommendations for increased accuracy of screening and also emphasised the need for early diagnosis. Timing is only relevant if a termination is to be carried out, so the emphasis on early diagnosis is therefore one consistent with an assumption that termination will be the result.

### **Conclusion: Disability as Deviance?**

Article 4(1) UN Convention on the Rights and Dignities of Persons with Disabilities requires signatories to 'undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.' Article 7(1) requires states that are party to the Convention to 'take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.' The UK was one of the first countries to sign the Convention, on 30 March 2007. It ought to be possible to say that things have improved for children born with disabilities in the UK today. This article has suggested that some of the improvements are very real, others are illusory, and that many people still regard disability as a personal misfortune, and something to be avoided if at all possible.

There is not sufficient space here to enter any complex discussion about whether encouragement of prenatal testing and legislation permitting termination of pregnancy with no time limit in the case of disability sends the message that the lives of the disabled are less valuable than those of other citizens. There are opposing arguments on both sides about this, but at least some will perceive the message in this way.<sup>87</sup> If this was the only policy or legal arena in which there was a contradiction between the equality rhetoric and actual rules, it might be possible to say that this was an area of law where the choice of the parent took precedence over equality. It is at least arguable that this is appropriate, as giving birth and bringing up a child is a very personal business. However, there are other areas where disability and law

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<sup>86</sup> Department of Health, *Our Inheritance, Our Future: Realising the potential of genetics in the NHS* (2003, Cmnd 5791-II). The screening process involves initial screening through a blood test/and or nuchal transparency scan, and if this initial screening detects a high risk of the foetus having Down Syndrome, a definitive test is offered, either amniocentesis or CVS (chorionic villus sampling).

<sup>87</sup> For the argument that prenatal testing and a preference for children without disabilities is ethical and does not indicate prejudice against those born children with disability see Jonathan Glover, *Choosing Children: Genes, Disability, and Design* (Clarendon Press, 2006).

brush against each other, and the same message of disability as misfortune for both child and parent is received. Two will be mentioned briefly here.

One problematic area is where a parent of a disabled child or adult kills that child, and raises as their defence to a charge of murder the intolerable burden of caring for the child, or their fear for the child's future. Homicide cases of this type have arisen in many jurisdictions, including the UK, Canada, Australia and New Zealand. The outcomes and how they are reached are various: in the UK and Australia, the defence of diminished responsibility has had some success.<sup>88</sup> That defence is not available in New Zealand, but provocation has been successfully argued.<sup>89</sup> An attempt to argue that killing was necessary, being the lesser evil, failed in Canada.<sup>90</sup> However, what all these cases have in common is the presentation to the court of a life of unremitting misery. Phillip French and Rosemary Kayess comment that there seems to be a 'latent belief that the "burden" and "suffering" caused by a child with disability *ipso facto* diminishes the culpability of parents for that child's murder.'<sup>91</sup>

At the same time, current approaches to the idea of citizenship emphasise the obligations as well as the rights of citizenship. The labels vary - the Blair Labour government spoke of 'active citizens' and used the language of communitarianism, the Conservative/Liberal Democrat coalition government speaks of 'the big society' and uses the language of classic liberalism - but the basic concepts are similar. The emphasis is on 'the obligations that must be fulfilled in order to assure the health and stability of local communities and the wider society.'<sup>92</sup> David Blunkett, a Minister in the Blair government and himself disabled, wrote:

A citizen cannot truly be an equal member of the community if he or she is reduced to a state of permanent dependency on the support of others. If a person is simply reliant on income transfers, he is not genuinely free and enabled to participate.<sup>93</sup>

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<sup>88</sup> In cases of diminished responsibility, guilty pleas are routinely accepted and therefore cases of this type do not appear in the Law Reports unless there is an appeal about sentencing or the prosecution refuse to accept the plea. Reported cases include *R v Daniella Dawes* [2004] NSWCCA 363 and *R v Raymond Douglas Sutton; R v Margaret E. Sutton* [2007] NSWSC 295. Newspaper reports include Elizabeth Grice 'What could have driven Yvonne Freaney to murder her son?' *The Telegraph* 19 May 2010.

<sup>89</sup> *R v Albury-Thomson* (1998) 16 CRNZ 79.

<sup>90</sup> *R v Latimer* [2001] 1 SCR 3.

<sup>91</sup> Phillip French and Rosemary Kayess, 'Deadly currents beneath calm waters: Persons with disability and the right to life in Australia' in Luke Clements and Janet Read (eds) *Disabled People and the Right to Life: The protection and violation of disabled people's most basic human rights* (Routledge, 2008) 57-98, p.67.

<sup>92</sup> Jenny Morris, *Citizenship and disabled people* (Disability Rights Commission, 2005) p.2.

<sup>93</sup> David Blunkett, *Active Citizens, Strong Communities* (Home Office, 2003) 16, quoted by Morris, *Citizenship*, p.26.



There are some people with disabilities who are not able to support themselves financially, and others face significant barriers to doing so: the attitude of Blunkett and others who emphasise the conditionality of state support implies that they are therefore something less than a citizen. This is not far removed from the classification of the dependent as deviant, especially in a political climate where the assumption is that recipients of state benefits are likely to be fraudsters or 'scroungers'.<sup>94</sup>

It is this emphasis on economic contribution that still influences attitudes towards disability, probably combined with occasional reactions of disgust at the disabled body. Barnes and Mercer comment,

Disabled people are viewed as 'unfortunate' because they are unable to enjoy the social and material benefits of contemporary society. These include the opportunity for marriage, parenthood and everyday social interaction. The few exceptions are lauded for their "exceptional courage", but this simply confirms the 'tragic' plight of the vast majority.<sup>95</sup>

The perception of disabled people as 'useless' flows from their lack of engagement in mainstream economic activities. As a consequence of their failure to conform to 'normality', whether in appearance or in control over their minds and bodies, they are set apart as 'different'. That difference is still a major factor in decision making about whether to become a parent of a child with a disability such as Down Syndrome. The decision can now be made before the child is born, but many of those making this choice base it on the perception that a life with Down Syndrome is unlikely to be a valuable or fulfilling life, or on the perception that the sacrifice required from the family bringing the child up is too great. The more things change, the more they stay the same.

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<sup>94</sup> See, for instance, the campaign in *The Sun* newspaper: 'Help us to beat cheats' *The Sun* 13 August 2010, <http://www.thesun.co.uk/sol/homepage/features/3093818/Stop-the-benefits-scroungers-Day-2-Readers-flood-hotline.html> (last accessed 18 January 2011).

<sup>95</sup> Barnes and Mercer, *Disability* p.9.