

# **Inquiry on Abortion on the Grounds of Foetal Abnormality in England and Wales**

**Oral Evidence**

**18 March 2013**

**Witnesses:**

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## Preface

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This document constitutes a report drawn up in order to support and supplement oral evidence presented by Nicky Priaux and John Horan at the Parliamentary inquiry on *Abortion and Disability* held in March 2013. The Report was submitted in advance of the Inquiry to present the Commission of Inquiry with an opportunity to engage with a broader range of literature and opinions than the timing for Oral Evidence could permit.

The Inquiry was set up to collect evidence from “parents, medical practitioners, academia, support groups, disability groups, lawyers and individuals with an interest regarding the current theory, practice and implications of the approach to abortion on the grounds of disability in the UK”. The Terms of Reference for the Inquiry were detailed as seeking to:

- Establish and assess the intention behind the law governing abortion on the grounds of disability.
- Establish how the law works in practice and is interpreted by medical practitioners.
- Determine the impact of the current law on disabled people and assess the views of groups representing their interests.
- Assess the effectiveness of the information and guidance provided to families following the diagnosis of a disability and the impact that has on outcomes.
- Examine how the law, guidance and support for practitioners and families can be developed going forward.

The Inquiry, Chaired by Fiona Bruce MP, was held across four sessions and transcripts are available for the first three. Transcripts for the fourth and final session in which John Horan and Nicky Priaux gave Oral Evidence have not as yet been included, although the full report detailing the recommendations of the All Party Parliamentary Groups concerned has been released. Further details as to the Inquiry, including the peers and MPs who led this Inquiry, can be found at: <http://www.abortionanddisability.org/>.

**17 August 2013**

## INTRODUCTION

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Our evidence is set out in four broad sections, each of which seeks to centralise what we see as being key issues of law, and then to draw in broader literature and ideas which come from a broad range of fields, including medical ethics and law, sociology, disability rights, feminism and clinical practice. Though we do hold views in respect of the existing legal provision, our aim is to illustrate a broad map of issues which interconnect and relate to the questions being asked by the Inquiry, as well as providing sources from a diverse range of fields which could prove useful for further analysis. The sections as laid out refer to the following issues:-

1. **PART I: Is paragraph (d) of the 1967 Act discriminatory?** Ascertainable from the literature there are two alternative invocations of concept of “discrimination” in this context: *legal* and *social*. Discrimination in a general social sense can refer to drawing distinctions between things in ways that are seen as morally or practically justified or not (or indeed it can refer to distinctions which are totally innocuous and have little social or moral import). In the absence of a case of discrimination in strict legal terms, some can legitimately form the view that the kinds of distinctions being drawn should become the subject-matter of law as illustrated by the development of various pieces of equality legislation in respect of gender, sexuality and disability. These two ideas of social and legal discrimination very clearly arise in the literature. In the first section of the note we explore the question of discrimination in a strict de jure sense as it applies to the 1967 Act, and then look at the more complex question as to whether paragraph (d) of the 1967 Act has discriminatory aspects to it. The extent to which paragraph (d) and reproductive practices may be symptoms of a broader discriminatory structure needs careful analysis. We note a number of things relating to this. We place heavy emphasis upon the link between the problematic distinction raised between normality and abnormality and the pervasiveness of that distinction within a disabling environment; here we highlight concerns around the lack of support for and acceptance within society of *existing* people with disabilities and those charged with caring for individuals with disabilities from the beginning of life to its end stages. We provide a discussion which draws in some of the leading commentators in respect of the provision now under analysis by the Inquiry, as well as broader literature from fields of disability studies, also including reference to the kinds of recommendations that theorists, scholars and activists have made. We seek to critically appraise these in Part I, but we also return to these themes later on in this note.
2. **PART II: Discrimination, women and disability:** While the Inquiry is shaped by concern with whether this specific aspect of the Abortion Act 1967 discriminates against people with disabilities, it is also critical to note that the rights of women are clearly central to this question. The provision of safe and legal access to contraception and abortion services has been a key part of the women’s rights movement and regarded as critical for women’s equality in society. Insofar as it remains the case that the role of child-rearing continues to fall predominantly upon women, a socio-economic analysis of the impact of caring for any child, including those with disabilities, is demanded. As such, a concern with equality and the elimination of discriminatory practices raises a

broad range of highly complex and seemingly competing issues. It is not evident that revisions to the existing abortion regime will constitute anything more than a rhetorical victory for disability equality in the context of a disabling society; furthermore, while the distinctions drawn within the Abortion Act may well seem suspect and smack of social discrimination, restricting women's ability to terminate (though accepting the possibility some women may terminate for such reasons) is tantamount to forcing women to raise an unwanted disabled child and to experience corresponding limitations in her own life, and the life of her child. We do not, however, think that that is a satisfactory state for our society but it is a reality for the women in question. As such, we prefer to place a stronger emphasis upon creating an enabling society, to exploring how individuals' choices are shaped, and to making the choice for women as to whether to continue a pregnancy or not, far more real and informed than it would seem to be.

3. **PART III: Paragraph (d) in its broader medico-legal context:** As we note later in this section, and as will become apparent throughout this note, the question of discrimination in the context of section 1(1)(d) of the Abortion Act 1967 raises a broad range of concerns which extend beyond the provision of abortion. The distinction drawn between disability and normality is highly pervasive and underpins much of reproductive practice as a whole, from genetic counselling, prenatal scanning and screening, to a range of practices relating to the provision of *in vitro* fertilisation (e.g. pre-implantation genetic diagnosis). There has been a heavy drive towards making the provision of antenatal screening for conditions such as Down syndrome. These practices/distinctions are also legally reinforced in other ways, for example, through wrongful birth negligence suits where a claim is brought for compensation based upon the wrongful birth of a disabled child owing to alleged negligence in the provision of counselling and treatment provision designed to detect foetal anomaly; the claim is explicitly underpinned by reference to the deprivation of the opportunity to terminate that pregnancy under paragraph (d).<sup>1</sup> In this respect we draw attention to existing regulatory aspects which relate to medical practice, from those directly pertaining to paragraph (d) of the 1967 Act, to questions around informed consent to litigation.
4. **PART IV: Human Rights and International Perspectives:** Here we engage with some aspects of law in a European context in order to assess whether it could be said that there is a "European perspective" on abortion law, and if so, what guidance and jurisprudence is available in the context of being a Signatory Member to the European Convention on Human Rights (ECHR) and a Member State of the European Union (EU). We also highlight a range of different legal approaches in respect of various European states as this relates to foetal abnormality to assess key similarities/differences. The object of this latter section is to provide a non-exhaustive, but indicative insight into legal regimes which will need to address the very same concerns that form the basis of paragraph (d) of the Abortion Act 1967.

## PART I: DISCRIMINATION

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### Formal Discrimination (*de jure* – in law)

5. The provision of abortion on the grounds of foetal abnormality clearly distinguishes between presumed normal foetuses and presumed disabled foetuses. Critical to the question of whether this distinction can be said to be discriminatory in a *de jure* sense (i.e. captured by existing discrimination legislation) in respect of the *foetus* is the issue of legal personhood. This is thought to be a matter of well-settled law, since English law affords the embryo and foetus no legal personality or independent rights until birth (*Paton v BPAS* [1979] QB 276. In addition, attempts to claim that a foetus has a right to life under Article 2 of the ECHR have failed; in *Vo v France* (2005) 40 E.H.R.R. 259, the European Court of Human Rights declined to recognise a foetus as a person under the Convention, stating that this question was one for individual signatory states.<sup>2</sup> The claim that the Abortion Act 1967 discriminates against disabled persons has been met specifically by reference to the standing of the foetus in English law; “if one accepts that a foetus does not have legal personality, rules that prohibit discrimination cannot apply *in utero*’ (Jackson, *Regulating Reproduction*, 2001, p. 481). A similar point is made by Ann Furedi who notes that, “the idea that abortion for abnormality represents discrimination against the disabled... elides the difference between foetal life and our respect for persons” (Furedi, 1991, p. 17).
6. Nevertheless, insofar as this is dispositive of the matter of formal discrimination as the law is presently structured, the Inquiry will receive written evidence which nevertheless compels an analysis as to what justifies this practice. It is in this sense that the foetus is not the specific concern, but rather that practices to eliminate foetal life *with* disability can be linked to discriminatory attitudes against *existing* persons with disabilities in a more general sense. As such, the question of formal discrimination is arguably irrelevant. While it cannot be said that the law (or indeed the practices permitted by it) discriminates against (disabled) foetuses, it is nevertheless arguable that it does serve to draw pernicious distinctions about disabled individuals given that the policy of the law is shaped by *ex-utero* considerations. Often such arguments are attended by the language of ‘discrimination’, in the sense that disability rights proponents are drawing attention to practices which treat persons with disabilities as second-class citizens. Moreover, for some authors, the distinctive treatment of disabled foetuses which underpins termination of pregnancy under paragraph (d) and broader reproductive practices seem resonant of eugenic practices of the past. We specifically return to the issue of eugenics later.

### Disability Rights and Social Discrimination

7. Here we raise a series of considerations around the question of whether, in a social sense, the foetal abnormality clause can be seen as discriminatory (or indeed, ‘eugenic’). This does not point to one single perspective or conclusion, but is raised to illustrate some different issues and views which congregate around paragraph (d) of the 1967 Act. Our aim is to flesh out in

more detail a complex of views around the idea that the policy of the law as discerned from paragraph (d) is based upon discriminatory attitudes towards disabled people.

8. The disability rights movement has fought (and continues to fight) hard to promote disability equality and the inclusion of disabled people in society. An important aspect of that fight has been to illustrate that disability to a very significant extent is created by society, rather than through impairment. Slogans such as “disabled by society, not by our bodies” encapsulate powerfully how attitudes and indeed, architecture – social choices – can *disable* (so a decision to build stairs, rather than a lift, for example, can disable an individual with mobility issues; as such, it draws attention to the kinds of social choices that can make an impairment, disabling). This theory, and political conception, is often referred to as the “Social Model of Disability”, which is often raised in opposition to a quite different paradigm – the “Medical Model of Disability”, which posits impairment as inherently disabling/tragic/something to be cured or eliminated, and ignores the importance of the social environment in constructing disability.
9. There is no doubt that, based on a preliminary view of the social model of disability, that paragraph (d) of the Abortion Act 1967 looks immediately problematic and pernicious. The assumption that termination of potentially disabled life is something desirable and acceptable as forming the basis of *general* legal policy seems to smack of the medical model of disability. We return to think about how abortion policy plays out specifically, but at this level, there is no doubt that this particular aspect of abortion policy needs justification. In terms of how these ideas feed directly to abortion policy, various commentators including disability rights activists have focused on the question of whether it can be said to be discriminatory in this social sense. We attempt to capture some of this commentary, also having reference to some leading bioethical, legal and disability rights commentary.
10. The UK Disability Rights Commission (DRC), which was set up in 2000 (replaced in 2007 by the Equality and Human Rights Commission) with the remit of advising how to combat discrimination against the disabled singled out paragraph (d) for concern. The DRC stated of section 1(1)(d) that it is: “offensive to many people; it reinforces negative stereotypes of disability and there is substantial support for the view that to permit terminations at any point during a pregnancy on the ground of risk of disability, while time limits apply to other grounds set out in the Abortion Act, is incompatible with valuing disability and non-disability equality.” In the same statement, the DRC stated that “in common with a wide range of disability and other organisations” it believed “the context in which parents choose whether to have a child should be one in which disability and non-disability are valued equally” (Disability Rights Commission, 2004). Critically, the DRC did not make any proposal to repeal any part of the 1967 Act, but was concerned with the information and advice women received from the medical profession.
11. Some of the literature engages the concept of ‘eugenics’ in reference to abortion policy as it relates to this hard distinction between ‘normality’ and

'disability'. The concept of what is 'eugenic' and how a eugenic system operates creates sharp disagreement between different authors. Sally Sheldon remarks in her analysis of Parliamentary debates leading up to the enactment of the 1967 Act that the original 'foetal abnormality' clause (s.1(1)(b)) prior to the amendment by section 37 of the Human Fertilisation and Embryology Act 1990 (which removed the time-limit in respect of foetal abnormality) clearly displayed eugenicist considerations, however, it can also be interpreted with regard to the welfare of the woman: "in part on the grounds that to force a woman to carry an abnormal child to term will discourage her from future pregnancy" (Sheldon S. , 1997). However, over two decades have passed since that revision. Ann Furedi also notes that while 1967 Act in its original form may have been "initially motivated by eugenic considerations", she comments that "today, it is very definitely the case that abortion is not seen by doctors, policy-makers or women themselves as within that tradition of social engineering" (Furedi, 1991, p. 16). Rather the contemporary context for abortion is one where "its provision meets the request of a woman who no longer wants to be pregnant". Lee and Morgan by contrast, note how paragraph (d) was "most clearly favoured ground for abortion" and suggest that Britain has actually embraced a "much more explicitly based eugenic abortion policy than before 1990" (cited in Bailey, 1996, p. 160).

12. Amongst these engagements sit very different views as to what 'eugenics' means; the most thoughtful and perhaps reflective engagement with the concept of eugenics is provided by Tom Shakespeare, a leading disability rights commentator; he draws a distinction between hard and weak eugenics. Strong eugenics he argues can be defined as "population-level improvement by control of reproduction via state intervention, such as happened in the 1930s. It is motivated by the social judgement that disabled people's lives are unworthy of life, and/or that society should not have to bear the financial costs of supporting its non-productive members". By contrast, weak eugenics "could be defined as promoting technologies of reproductive selection via non-coercive individual choices" (Shakespeare, 1998, p. 669). Based on this definition, and particularly focusing on prenatal screening, he comments that "current British genetic practices are weakly, but not strongly, eugenic. There is strong rhetorical commitment to individual choice and to the avoidance of suffering" (Shakespeare, 1998, p. 669). As Shakespeare's broader engagement with questions around prenatal screening and abortion on the grounds of disability illustrate, it is not necessarily helpful to describe these practices as straightforwardly eugenic, although clinical practice and the 'context in which reproductive decisions are made, undermines the capacity for free choice and promotes eugenic outcomes' (Shakespeare, 1998, p. 666). We return to Shakespeare's analysis of abortion on the grounds of foetal abnormality and the practices which surround it shortly, as well as examine his recommendations for potential reform.

13. But a preliminary observation at this point is to note that it may not be helpful to refer to paragraph (d) as (strongly or weakly) eugenic, insofar as it may be better seen as an expression or symptom of highly pervasive norms in society which continues to be structured by reference to ideas which draw strong distinctions between health and abnormality; insofar as some of these can be

assessed as deeply problematic, others cannot. There are also practical and understandable reasons for drawing such distinctions which we do all the time – concerns with road safety, health and safety in the workplace, alcohol and drug consumption, obesity, the spread of HIV/STIs and a range of range of diseases and conditions which we actively try to avoid – are all directed towards combating social factors which can abbreviate life or make it harder. Insofar as these are all based upon a distinction drawn between normality and abnormality, the normative aspiration is not based upon a pernicious distinction, but rather one that is directed at making our lives as full and healthy as they can be. An assumption that to draw a distinction between health and abnormality is necessarily eugenic would result in a quite perverse claim that most public policy interventions were harmful and should cease.

### **Sheldon and Wilkinson's Analysis of Paragraph (d)**

14. Sally Sheldon (academic lawyer) and Steve Wilkinson's (bioethicist) (2001) analysis of paragraph (d) of the 1967 Act is one of the most sophisticated in considering the ethical justifications (and whether they succeed) for that provision. Their work provides a leading reference point in the literature. They do not rule out the possibility that at least in terms of some aspects of its operation, that it may appear discriminatory but this follows a careful and well considered critique. They highlight a number of possibilities as to how that provision has been typically regarded as justified, the most convincing of which are the 'foetal interests' argument and the 'parental interests' argument.
15. The 'foetal interests' argument: abortion for foetal abnormality would be justified if it were possible to say that if born, the child would quite literally be better off dead. As Sheldon and Wilkinson note, such a reading would be wholly out of line with abortion practice, given that the vast majority of abortions are performed for conditions such as Down syndrome, where a person need not suffer at all. As such, as a justification for paragraph (d), the 'foetal interest' argument fails.
16. The most convincing justification for paragraph (d), Sheldon and Wilkinson argue, is the 'parental interest' argument. This idea is based on the effects on the mother resulting from the birth of a disabled child. As academic lawyer Gillian Douglas notes, considerations of impact on the parents 'seem[ed] to have qualified the compelling nature of the arguments that a handicapped child's right to life is as valid as that of any other' (Douglas, 1991, p. 93). The effect in question is commonly related to the emotional, financial and caring burden which results from the birth of a disabled child and is well elucidated by Barnes et al,

"The justification offered is that a disabled child places an excessive burden on the woman/family/society – both in terms of additional time needed to support the child as well as the financial and emotional resources that must be devoted to its well-being – with a consequent deterioration in the quality of family life and relationships" (Barnes, Mercer, & Shakespeare, 2003, p. 222).

Sheldon and Wilkinson note, quite critically, that there are “serious problems with the Parental Interests Argument, even if one accepts for the sake of argument (as we do here) its empirical premise that caring for a child with a disability is typically more difficult and costly than caring for a child without a disability” (Sheldon & Wilkinson, 2001). In this respect they identify a number of issues:

17. *Paragraph (d) is not simply about Parental Interests:* Here Sheldon and Wilkinson look at the issue of the intentions of Parliament. If paragraph (d) relates to Parental Interests then it is superfluous and unnecessarily repeats the provision contained in paragraph (a) of the 1967 Act which permits termination when continuing with the pregnancy would be likely to threaten the woman’s mental or physical health. This combined with section 1(2) (the social ground) which permits practitioners to take account of the woman’s “actual or reasonably foreseeable environment” has been interpreted as permitting terminations where there is evidence that continuing a pregnancy would place the woman under unnecessary strain. When interpreting Parliament’s intention, it surely must not have sought to reiterate paragraph (a); and indeed the removal of the time limit in respect of paragraph (d) also adds to this view.
18. *The Disability Rights Objection:* The second objection to paragraph (d) is what Sheldon and Wilkinson refer to as the Disability Rights Objection (DDO) which has been levelled by individuals from the disability rights movement. The thrust of the DDO claim is that paragraph (d) fails to take into account that many of the problems confronted by parents of children with disabilities are the result of discrimination rather than impairment per se. A parallel, Sheldon and Wilkinson note, often made by disability rights commentators is to that of gender and ethnicity where it would seem outrageous to suggest that abortions could be permitted on grounds of race or gender by reference to the additional strain that parents would be subject to. Sheldon and Wilkinson note, that if disability were on a par with gender and ethnicity that the ‘Parental Interest’ Argument would also fail (because the DDO would be completely made out). As Sheldon and Wilkinson note, if the social model of disability holds, in the sense that it can be said that it is only society that ‘disables’, then abortion on the grounds of disability would appear to amount to “colluding with (and perhaps also encouraging) discrimination against people with disabilities”.

### **Impairment *per se* can be disabling**

19. Sheldon and Wilkinson argue that the social model of disability ‘ignores the obvious fact that some of the disadvantages associated with disability are not caused by society, but are intrinsic parts of the impairment itself’. Here they note that:

“Disabilities can involve pain, or reduced life-span, or important inabilities of various kinds: such as the loss of a sense modality or reduced mobility. Where present, these things are intrinsic ‘evils’: harms which are not caused by society and which, arguably, no

amount of social intervention, short of removing the impairment, can take away. So while, clearly, many people with disabilities are the victims of harmful (and wrongful) social discrimination and exclusion, these social factors are not the whole story.”

20. As such, Sheldon and Wilkinson argue that disability is not, in this sense, like gender or ethnicity. Disability also involves impairment, whilst gender and ethnicity do not. While it is plausible to think that while virtually all of the problems experienced by women are the product of social discrimination, in the context of disability, some of these are caused by the impairment itself. On this basis the parallel drawn between disability and gender, is (at least partially) flawed. As such, the authors note that the ‘disadvantages associated with disability (unlike, say, those associated with being female) are not *entirely* a matter of social discrimination, but are at least partly caused directly by impairment.’
21. The problems that Sheldon and Wilkinson highlight with the Social Model of Disability, in the sense that too much emphasis is placed upon *society as disabling* without much attention to the impact of impairment, are also highlighted by others. Tom Shakespeare (Shakespeare, 2006) for example, notes that the social model began as the definitions “which underpinned a set of practical political positions”. It was intended to be a political intervention, not a social theory. Noting that the social model has been an important means to the goals of the disability movement in promoting disability equality and the inclusion of disabled people in society, he notes that the social model now needs rethinking where it has become outdated. Shakespeare’s analysis is sophisticated and extends beyond what can be encapsulated here (though is germane to any policy-directed enquiry as to how to promote equality) but it does point to the difficulty in disentangling the complex relationship between impairment and disability, and the social from the biological.
22. In particular, however, he notes how the Social Model has defined disability in terms of oppression and barriers, and breaks the link between disability and impairment. This has led to the “common criticism that social model approaches have neglected the role of impairment” (Shakespeare, 2006, p. 36). Here the thrust of such criticisms is not that impairment is an explanation for disadvantage, but impairment is nevertheless an important aspect of disabled people’s lives; for some the personal experience of pain and limitation can often be a part of impairment. As Shakespeare notes, ‘there is a danger of ignoring the problematic reality of biological limitation’. While impairment affects people in different ways, and can also bring opportunities, some are,

‘comparatively unaffected by impairment, or else the main consequences of impairment arise from other people’s attitudes. For others, impairment limits the experiences and opportunities they can experience. In some cases, impairment causes progressive degeneration and premature death. These features of impairment cause distress to many disabled people, and any adequate account

of disability has to give space to the difficulties which many impairments cause' (Shakespeare, 2006, pp. 42-3).

Shakespeare notes that everyone, even the supposedly able-bodied experience limitations; but for many 'impairment is not neutral, because it involves intrinsic disadvantage. Disabling barriers make impairment more difficult, but even in the absence of barriers impairment can be problematic' (Shakespeare, 2006, p. 43). This analysis, which has only been very broadly summarised here, leads Shakespeare to comment:

"The social model of disability makes a distinction between impairment and disability; claims that disability can be removed by social change; and downplays the role of impairment in the lives of disabled people. ... My claim is that, even in the most accessible world there will always be residual disadvantage attached to many impairments. If people have fatigue, there is a limited amount that can be done to help: motorised scooters and other aids may help increase range and scope of activities, but ultimately the individual will be disadvantaged when compared to others. An accessible environment minimises the inconvenience of impairment but does not equalise disabled people with non-disabled people" (Shakespeare, Disability Rights and Wrongs, 2006, p. 50).

#### **Paragraph (d): Social Discrimination**

23. Shakespeare's work, which is worth reading in full, neatly intersects with the concerns raised by Sheldon and Wilkinson. In considering the complex relationship between impairment and *disability as social discrimination*, and its application to paragraph (d) of the Abortion Act 1967, Sheldon and Wilkinson note that in certainly one key respect, the Disability Discrimination Objection partially succeeds:

"For *one* of the reasons why selectively terminating disabled fetuses is judged to be in parents' interests is social discrimination, one aspect of which is a lack of support services for the parents of disabled children or prejudice against those children".

Here they raise the concern as to problems relating to the provision of welfare services, financial benefits to parents of disabled children, in order to make it easier for parents to choose to decide to continue with such a pregnancy. As they note in this respect,

"If parents would feel able to care for a disabled child with greater social assistance and in the absence of prejudice and discrimination, then legally to endorse termination because prejudice exists and assistance will not be forthcoming is worrying. Whilst any society will have to make a choice about where resources are to be allocated, in this instance the availability of abortion may conceal the pressure placed on potential parents by the lack of availability of financial and

other support. A more honest and open evaluation of the rationale for s.1(1)(d), should at least contribute to public debate of this issue” (Sheldon & Wilkinson, 2001).

24. Sheelagh McGuinness, an academic lawyer and bioethicist, notes in similar force to Shakespeare, Sheldon and Wilkinson that ‘In the context of reproductive choice, there are good reasons to be concerned about potential disease, illness or disability in future children and further good reasons to take steps to ameliorate these where possible. If this were not the case, then why endorse policies of pregnant women taking folic acid or avoiding smoking?’ However, she also notes that ‘the problem with the current operation of s.1(1)(d) is that it fails to distinguish between cases where we have reason to be concerned and cases where we do not.’ Rather, in McGuinness’s view, it is time that the law relating to reproductive choice reflects a more nuanced and subtle understanding of ‘disability’ than the Abortion Act 1967 currently encapsulates (McGuinness, 2013, p. 29).

### **Seeking a more ‘nuanced’ understanding of disability in the 1967 Act**

25. Authors such as McGuinness, Sheldon and Wilkinson, Shakespeare (and others not encapsulated here) illustrate the presence of the view that even if it cannot be said that the entire operation of s.1(1)(d) relates to issues of social discrimination given that impairment can also be inherently disabling, certainly one aspect of its operation can be said to coincide with discrimination. From a practical perspective this raises serious issues which are somewhat messy to untangle;

- a. first about the extent to which one can separate out and draw up medical criteria which distinguishes from impairments which are inherently disabling from those which are the product of social discrimination;
- b. second, even if that might be thought possible, there is also the question of whether we should. This latter issue raises issues of whose interests are at stake here, as well as the implications for prospective parents who will nevertheless in the absence of serious work on the part of society and the government in creating an enabling environment, be confronted directly with the hard reality of an absence of such resources/support. This raises a serious question about the extent to which those individuals themselves will become the victims of social discrimination.

### **Distinguishing Inherently Disabling Conditions from the Disabling Impact of Social Discrimination**

26. In terms of a practical operation of this in terms of abortion law, drawing such distinctions presents a problem. As Sheldon and Wilkinson note, the solution would seem to point to a law that permits abortion which is only directed towards the harms caused directly by impairment. Nevertheless they note that this might mean “making rather finer-grained distinctions between, on the one hand, disabilities which involve relatively minor impairments and where most

of the 'evils' are social and, on the other, disabilities which have more substantial impairment elements and would be seriously harmful even in the absence of social discrimination" (Sheldon & Wilkinson, 2001). And indeed, as Shakespeare's extended and sophisticated analysis on the complex interrelationship between society and impairment illustrates, 'it is hard to separate impairment from disability in the everyday lives of disabled people' (Shakespeare, Disability Rights and Wrongs, 2006, p. 36).

27. As such, an analysis of this broader literature as to the extent that existing abortion policy as based upon paragraph (d) colludes with social discrimination, presents a complex picture. Some terminations will be directed towards impairment, the most obvious example being where the foetal abnormality is lethal or where the outcome for the foetus following birth is so bleak, as cases of Tay Sachs, where even with the best care, most children will have died of this condition by the age of four. Though little discussion attends McGuinnesses' proposal for a more nuanced definition of disability under paragraph (d), she seems to intimate that we should reject the language of 'handicap' in favour of focusing instead on 'concepts like suffering as we have in other areas' (McGuinness, 2013, p. 30). Here McGuinness would seem to have in mind those cases involving severely disabled neonates and the operation of the kinds of medico-legal guidelines that apply in cases involving the proposed withdrawal of life sustaining treatment to severely disabled neonates. This would, it seems, serve to reduce the scope of permissible terminations to those which are adjudged as fitting the 'Foetal Interests' Argument – where it can be said that it would be better (or indeed, in the 'best interest' of the foetus) to not exist. Nevertheless, an analysis of the variety of approaches used in addressing even that question in the context of a live neonate, illustrate the problems of defining and determining when life is no longer worth supporting (Morris A. , 2009).
28. There are three particular objections to reducing paragraph (d) to a restrictive definition of 'suffering'. The first relates to the extent that this can be identified *in utero* and the reliability of medical science and available technologies to objectively identify conditions which 'fit' the Foetal Interests Argument and ideas of "intolerable suffering", "no chance", "no purpose" or "unbearable" if any such concepts were to be applied. What conditions are productive of suffering depends on the particular prognoses in question, and these can often be highly complex and probabilistic. It may, however, be easier determining which conditions *do not* involve inherent suffering (e.g. conditions which are remediable), though it is also to be expected that this information will be readily put to prospective parents. We return to this issue in Part III where we look at these concerns as they operate in medical practice.
29. The second issue relates to the question of whether 'suffering' should be assessed *purely* on the basis of medical determinations. Even if it were reasonable to suppose that 'suffering' could form the basis for a revised understanding paragraph (d), it would be hard, if not superficial, to restrict it to foetal health alone. In terms of the current interpretation of the Abortion Act 1967, paragraph (d) can be rationalised as speaking to parental interests. In the case of *Jepson*, the applicant in an action for judicial review sought judicial

clarification of particular aspects of paragraph (d), and claimed that the practice of clinicians consulting with and taking into account the views of parents was unlawful. Though this issue was never judicially considered, it is noteworthy that while the 1967 Act is silent on the matter, and affords no specific 'right' to decide other than to doctors who must determine in good faith whether a woman meets relevant grounds of the 1967 Act. Yet case law has consistently placed women at the heart of such decision-making,<sup>3</sup> in a way that aligns with and supports contemporary consultative medical practice (Royal College of Obstetricians and Gynaecologists, 2010). Once one takes women and the familial environment into account, the reproductive interests of individuals, their ability to manage, as well as broader equality concerns relating to women who typically continue to be the main caretakers of children, the question of whose interests are at stake in respect of paragraph (d) of the 1967 Act, and the issue of when and how 'suffering' is assessed is tough. Even if one were to seek to stipulate that suffering should become the central tenet for that provision, it is difficult to restrict that to a medical prospect of foetal suffering in the abstract. Rather the interests and welfare of potential children are inextricably intertwined with the interests and welfare of prospective parents; suffering in respect of a condition cannot be assessed in a vacuum. Even in a more enabling society which provides more in the way of support for caretakers of seriously disabled children, it is realistic to think that the kinds of adaptations required for and needs of providing a meaningful life for a seriously disabled child including hands-on care may impact upon a woman's life and employment prospects in a way that also raises serious equality concerns. Reducing a woman's ability to terminate a pregnancy in respect of this is tantamount to compelling her to continue a pregnancy and raise a child with potentially a very significant impact upon her life as well as the life of the child. We return to this issue in Part II under the heading of women, reproduction and equality.

30. The third issue relates to the point above, but is firmly situated in the society in which we live; disentangling the relationship between social discrimination and impairment is far harder to do. There may be the presence of particular conditions which in themselves have a very significant disabling effect but not entail intolerable suffering, yet when combined with a society that is not enabling, that this leads to suffering. This does uncomfortably raise the issue of social discrimination and/or the fact that society needs to place a great deal of investment and time into creating an enabling environment which meets the multifarious and sometimes very complex needs of parents and their children, but it is nevertheless the society in which we, and indeed prospective parents of disabled children do live.
31. To a large degree, we confront a dilemma here; few can deny that "considerable personal and financial sacrifice may be involved in raising a child with disability and this will be exacerbated by lack of appropriate support." (McGuinness, 2013, p. 29). How we might respond to this really depends on the extent to how we identify the problem. McGuinness notes, that social discrimination exists and makes raising children with disabilities harder "does not justify or make section 1(1)(d) any more acceptable"; in her view, we should reject this ground, but critically alongside this, that "work

should be done on changing social institutions so that there is better support in place” (McGuinness, 2013, p. 29). For the present writers, given that Disability Discrimination legislation has now been in existence for nearly two decades, the idea that rejecting this ground and suggesting that ‘work should be done’ is a rather academic and problematic conclusion. As we suggest later here, we do not accept that the 1967 Act should be reformed at this point in time, but that there is absolutely no doubt that an enormous governmental and social effort needs to be made in changing social institutions so that there is better support in place. Not only will this help prospective parents to feel that they have the resources and support to continue with any pregnancy, but from a population wide perspective, working upon creating an enabling environment is vastly in the interests of us all. Most of us are likely, whether through road accidents, or illness or simply old age, to suffer restrictions in mobility and function, and as such, most of us should be able to identify that creating an enabling environment will enhance all of our lives. To reject aspects of paragraph (d) of the Abortion Act 1967, is actually a lazy option and a non-solution to a problem which is far more pervasive and problematic insofar as it cuts through every aspect of our daily lives.

### **Scholars’ Recommendations in respect of Paragraph (d)**

32. A variety of positions can be found in respect of how, if at all, the Abortion Act 1967 might be revised in line with a finding that aspects of the operation of paragraph (d) might be said to send out – as many have suggested – negative signals about the lives and value of existing individuals with disability. Commentators in the field admit of three slightly different positions:

- a. restricting terminations for disability to a specification of very serious conditions as assessed clinically;
- b. the creation of a common time limit irrespective of health or abnormality;
- c. leaving the 1967 Act undisturbed.

In respect of (b), few are prepared to pin down where precisely that common time limit should sit, but in our view it cannot be considered in the absence of (a) *unless one is prepared to compel women to continue pregnancies to term irrespective of the fact that they may be carrying a foetus with a lethal abnormality or grave defect*. We would note the utility of exploring the kinds of conditions for which termination is typically performed under paragraph (d) after 24 weeks, and the numbers of abortions involved (see further paragraphs [34 – 39] of this document).

### **Stipulating what amounts to serious disability**

33. As we saw above, Sheelagh McGuinness recommended the possibility of centralising ‘suffering’ as the central criterion in assessing when termination of pregnancy for foetal abnormality might be permissible. We noted some of the difficulties of the view that one should only focus on foetal health, when in our view the question of suffering and welfare can be seen as part of a familial

equation and in a social environment. Such questions cannot be addressed in the abstract. Nevertheless, even on clinical grounds alone there are concerns. McGuinness' approach seems to take inspiration from other clinical contexts, in particular the determination of when clinicians would be justified in withdrawing life sustaining treatment from severely disabled neonates. However, an application of this criterion to *in utero* situations would present, other than in the very clearest cases such as anencephaly or the presence of other certain fatal defects, a serious definitional and practical problem for medical professionals using diagnostic tools which can rarely provide certainties. Those diagnostic issues are also amplified when one considers obvious definitional problems and the legal environment in which medical decision making takes place. The manner by which the Abortion Act 1967 presents a series of defences to what are otherwise criminal offences also needs considering; the slippery nature of 'suffering' coupled with the chilling effect of the criminal law, alongside doctors sense of responsibility to parents and wanting to do the right thing by foetal life and parents, will create stark and difficult choices for clinicians who believe, probabilistically, that a foetus if born may well "suffer" or have "no chance". In some circumstances, clinicians may feel that these are likely outcomes, but not certainties; as such there is an opposite danger of clinicians erring on the side of 'legal safety' and bringing into existence children who will lead short lives and suffer. We need to be guided by medical opinion carefully in adjudging the ramifications of setting down criteria which has proved difficult to apply in cases of live neonates as well as clarifying the extent to which criteria of this sort already is operationalized in the context of prenatal testing and counselling.

34. As was made explicit in the *Jepson* action, the applicant for judicial review wanted an analysis of what constituted a 'serious handicap'. This approach would appear to complement that of McGuinness, as well as the position of other authors who have suggested that paragraph (d) should be understood as relating to the "seriousness of the condition which the prospective child might have" (Scott, 2005, p. 303). *Jepson* argued that paragraph (d) has to be understood by reference to whether the condition was remediable or not. As medical professionals have impressed upon us, health care teams take serious steps to address with parents, through a care journey including referral to relevant practitioners including paediatric consultants, where remediability of a condition is a possibility. Insofar as cleft palate can be indicative of a range of other, and far more serious chromosomal problems it is not sufficient to assume that the clinicians who were the subject of the *Jepson* case, had authorised an abortion simply for cleft palate. Rather an initial investigation of the case by the West Mercia police found that medical professionals had adjudged the case in good faith, and the Crown Prosecution Service on analysis of a broader range of evidence, including medical evidence, arrived at the same conclusion. This raises the question as to whether there is any evidence supporting that the medical profession is really providing terminations of pregnancy for anything less than serious disability; our discussions with clinicians suggested that while there used to be a practice of terminating for trivial conditions this is far less prevalent and that in respect of cleft palate alone (along with twisted ankle/club foot), the view was expressed "we wouldn't terminate for just those".<sup>4</sup> We do not assume that

the clinicians to whom we have spoken present a unified position that is typical of obstetric practice, but raise the question in terms of whether it is. A broader analysis of the conditions for which terminations under Ground E are performed after 24 weeks, however, provides some substance to the idea that 'seriousness' does constitute a medical threshold in practice (see further, paragraph [37] of this document in particular). In the face of a widespread and routine practice of antenatal screening, with a total of 716,060 maternities (Office for National Statistics, 2012), coupled with the complexity of assessing the results which emerge (there will be few 'perfect pregnancies'), the number of abortions performed under paragraph (d) (Ground E) would appear to be fairly modest at just over 1 per cent of all terminations performed (Department of Health, May 2012). A second strand of the *Jepson* case would seem to suggest that what constitutes a 'serious handicap' should be defined by law. The difficulties we allude to above highlight difficulties in achieving such a definitive list, and this approach has also been rejected by the RCOG (Royal College of Obstetricians and Gynaecologists, 2010). We discuss the definition of 'substantial risk' and 'serious handicap' in Part III in respect of the medico-legal environment.

## **Common Time Limit**

### ***Common Time Limit: At 24 weeks***

35. A fairly significant number of authors argue that while the distinction between presumed 'normal' and presumed 'disabled' foetal life does appear, in some respects, to send out negative signals in respect of the equal value of all human beings, the simplest and most obvious solution would be to create a common time limit in respect of any abortion. This would remove, at least in the letter of the law, the problematic dichotomy between normal and abnormal, and the differences between gestational points at which a foetus can be destroyed. Tom Shakespeare for example argues that "the law should not discriminate between impaired and non-impaired fetuses: a common time limit should be adopted for all pregnancies" (Shakespeare, 1998, p. 671). The more difficult question is where that 'common time limit' should sit.
36. The point of viability accepted by medical professionals as standing at 24 weeks is a useful starting point for analysis. It is difficult to identify anyone who has suggested that that common time limit should stand at 24 weeks, the point of foetal viability, though there are, very practical and important reasons shaping why that point would be impossible and impractical in respect of all pregnancies.
37. A critical point to make is that while in 2011, in England and Wales a total of 2,307 of abortions (constituting just over 1 per cent of all abortions performed, 196,082) were performed under Ground E/Paragraph (d), a total of 146 terminations were performed after 24 weeks (Department of Health, May 2012, para 2.14). An analysis of the statistics and information made available states that 2 of those 146 terminations were performed under Grounds other than E, and that of those performed under Ground E, that these reveal that

the underlying conditions include Congenital abnormalities relating to the nervous system (Anencephaly (3), encephalocele (1), microcephaly (1), hydrocephalus (3), other malformations of the brain (24), spina bifida (9), with other nervous system abnormalities (13), the cardiovascular system (17), the respiratory system (7), the urinary system (7), the musculoskeletal system (7); other conditions such as Down's syndrome (17), Edwards' syndrome (2), Patau's syndrome (1); with other conditions being referenced by a range of factors including exposure to communicable disease, fetal disorders related to gestation and growth, and the fetus affected by maternal factors. Quite critically, an analysis of the disorders in question suggests that grave conditions do lie at the heart of most if not all abortions performed under paragraph (d) after 24 weeks. And importantly, no abortions were recorded as being performed under any ground, at any time for cleft lip and cleft palate (Department of Health, May 2012, p. 23).

38. This analysis (paragraph 37) helps to contextualise what we are talking about and what the repercussions of creating a common time limit to 24 weeks would entail. On the statistics of 2011, this would impact upon around 144<sup>5</sup> terminations, which do seem to admit of extremely serious conditions. As such, valid questions can be asked about the viability of those foetuses, and where the conditions in question could be said to admit of such serious impairments which are disabling in themselves, the extent to which we can say that terminations performed after 24 weeks really serve to collude with social discrimination (even if the manner by which law is drawn up, in terms of what it appears to permit, sounds discriminatory). An analysis of medical practice problematizes the idea that paragraph (d) as it operates as a special ground beyond 24 weeks, *in practice* is either eugenic or discriminatory.
39. The absence of a limit for abortions performed under paragraph (d) can be seen as being shaped by the state of technology where society and medical practice has well-established means of detecting foetal abnormality. As has been impressed upon us through discussions with general practitioners and consultant gynaecologists, while initial scans occur at 10-12 weeks, the second scan that all women (within Wales) receive typically occur between 19-20 weeks. As was impressed upon us, around 80 per cent of abnormalities can be detected between 16-18 weeks, cardiac abnormalities between 19-22 weeks alongside a range of other conditions. 2 per cent of women may present for a variety of reasons as late as 22 weeks and typically these women come from backgrounds which are predisposed to presenting with high risk of foetal abnormality. Some scans might suggest the presence of Down syndrome in which case amniocentesis is offered. Some cardiac problems are detected as late as 30-32 weeks, and later scans can flag up problems in respect of foetal growth. In the midst of this, medical professionals in the context of a broad team will also need to explain to patients what the problem is, how it will affect the foetus and to provide information. Patients in turn need time to think over that information, to consult with other professionals to whom they are referred in respect of advice concerning post-delivery treatment (e.g. cardiac abnormalities) and ultimately make an informed decision about what to do. A time limit of 24 weeks across the board in respect of the state of the foetus would have the impact of

denying many women the opportunity to terminate a pregnancy of a seriously disabled foetus or potentially, resulting in a rushed decision based on a paucity of information (where more reliable information is available later in respect of foetal growth). More accurate information concerning serious disability typically can only be made available in some cases after 24 weeks following further testing and investigation.

***Common Time Limit: Removal of Time Limit in Respect of All Terminations***

40. An alternative approach is to remove the gestational time limit entirely. This approach is favoured by Julian Salvaescu and is implicit in the approach of Sheldon and Wilkinson. As Salvaescu argues, by reference to the fact that maternal interests are necessarily implicated by the question of abortion and paragraph (d) and that the foetus lacks full moral personhood and lacks legal personhood entirely, “We should liberalise our approach to [late termination of pregnancy] and eschew considerations of foetal abnormality as a ground for [late termination of pregnancy]. If we are to give any weight to maternal interests, this should be the sole ground for justifying [terminations of pregnancy], early or late” (Salvaescu, 2001, p. 169). It may be thought that for some, that the removal of the upper time limit for abortion will prove an unpalatable choice. For objectors, this will be extending an open invitation for terminations to occur at any point during gestation in a ways that is totally divorced from issues of foetal viability which many see as clinically and morally significant. But it is an approach that merits examination. In practice, as a variety of commentators have pointed out (Jackson, *Regulating Reproduction*, 2001; Furedi, 1991) late abortion is not an easy choice for women and in practice, most seek terminations as soon as possible; very few abortions, beyond cases where foetal abnormality is detected at a late stage, take place after 24 weeks. Rather the vast majority (91 per cent) occur between 10-13 weeks with a ‘continuing increase in the proportion of abortions that are performed under 10 weeks since 2002’ (Department of Health, May 2012, p. 9). As such there is no reason for thinking that a change in the gestational time limit would actually change existing practice; rather women’s behaviour in seeking professional help as early as possible is being met with a corresponding ability of clinicians to facilitate that. And clinical norms and the medical systems work hard towards ensuring that abortions can be provided at the very earliest point and making it earlier.
41. While the analysis of Sheldon and Wilkinson highlights that some abortions performed under paragraph (d) may be shaped by social discrimination (for example the lack of support and services), they note that their own position is “that no woman should be forced to carry to term a disabled, or any other, foetus. In other words, termination should be legally justified by the mere fact that a woman does not wish to continue with a pregnancy.” Agreeing with the recommendation that Tom Shakespeare makes, notably that the same principles should apply to all abortions, regardless of any foetal disability, Sheldon and Wilkinson note that “such principles should be very liberal” (Sheldon & Wilkinson, 2001).

## **Retain paragraph (d) in its existing form**

42. There are some, who have raised the possibility that maintaining foetal abnormality as a separate ground might actually prove desirable 'in order to allow for the tiny number of abortions carried out in the third trimester of pregnancy following the discovery of a grave fetal abnormality' (Jackson, *Medical Law*, 2010, p. 682). We find that this is worthy of serious consideration. An analysis of the operation of paragraph (d) in practice as it relates to terminations performed after 24 weeks suggests that clinicians would appear to already factor in issues of 'suffering', 'seriousness' and take seriously the issue of 'remediability'. This would seem to reveal that the vast majority of the (tiny number) of abortions performed under paragraph (d), and indeed, the minute number performed after 24 weeks, are performed on the basis of some kind of 'seriousness' criteria. It may be on analysis, that all are; in respect of conditions which some commentators note, such as Down Syndrome, are not incompatible with the living of a happy and fulfilled life, even this condition can be accompanied by a range of other problems. Individuals with Down syndrome are at higher risk of other conditions given that the consequences of additional genetic material are variable and can affect the functioning of any organ or bodily process, including blood defects including leukemia, and immune system problems. As such, it is not sufficient to assume that clinicians permitting women to terminate on the basis of Down syndrome are doing so in respect of discriminatory attitudes or assumptions about the worthwhileness of life. By way of an example, with a woman presenting at 35 years,

[O]nly 57 per cent of Down syndrome foetues diagnosed at 13 weeks gestation would result in a live birth (the others miscarry or are stillborn) (Morris & Alberman, 2009).

43. Nevertheless, we would not recommend, for broader reasons that we highlight later in this opinion, that abortions under paragraph (d) are restricted to "grave foetal abnormality", and that there is a need to factor in broader considerations into a matter which speaks to one of the most intimate episodes of our lives. In particular in the next section we point to the equality of woman as a critically important issue for examination in any Inquiry which holds a concern with equality and the elimination of 'discrimination' at its heart. Insofar as it is possible that some abortions may be influenced by reference to the woman's view of her ability to manage a child with a serious disability and of the environment which makes this harder to manage, we also raise questions as to the complex interplay of social discrimination with the lives of women who care for children with severe disabilities, and the impact that any revision to the Abortion Act 1967 would have upon these individuals.

**Continued.../(Part II: Women, Reproductivity and Equality)**

## PART II: WOMEN, REPRODUCTION AND EQUALITY

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### Women and the Abortion Act 1967

44. There is a risk that the question as to whether elements of the 1967 Act are discriminatory in respect of disability might overshadow a broader but very important issue: the equality of and respect for women. Anna Grear in a comment about the *Jepson* litigation noted that 'it is likely that any reductive medicalization of the abortion question will result in an incipient denigration of the rights of *both* women and the unborn' (Grear, 2004, p. 4). As we noted above, women are central to the Abortion Act 1967, and indeed to the evaluation of paragraph (d). Very serious equality considerations need to be taken into account before disturbing this.
45. The Abortion Act 1967 emerged largely as a response to the horror of backstreet abortions but nevertheless constituted a major victory for the women's rights movement who sought to secure access to safe and lawful contraception and termination. As the women's liberation movement emphasised, gaining the freedom to decide whether or not to bear and nurture children is not merely important for women gaining control of their reproductive lives, but ultimately for gaining an identity untied to reproduction. Moreover, for women upon whom the burden of childrearing more often than not continues to fall, the decision of whether to become a mother or not is crucial to women's personal well-being "definitive of her social persona, and predictive of her economic horizons" (Meyers, 2001, p. 735).
46. Insofar as a foetus does not have legal personhood, a woman clearly does; a key principle of English law is respect for the autonomy of the patient. The Court of Appeal in *St George's Healthcare NHS Trust v S; R v Collins and others, ex parte S* [1998] 3 All ER 673<sup>6</sup> determined that a pregnant woman cannot be forced to undergo unwanted medical treatment even if that would result in harm to her, or result in the death of a viable foetus. As the Court of Appeal commented, "In our judgment while pregnancy increases the personal responsibilities of a woman it does not diminish her entitlement to decide whether or not to undergo medical treatment. Although human, and protected by the law an unborn child is not a separate person from its mother. Its need for medical assistance does not prevail over her rights. She is entitled not to be forced to submit to an invasion of her body against her will, whether her own life or that of her unborn child depends on it. Her right is not reduced or diminished merely because her decision to exercise it may appear morally repugnant' (at 692).
47. While the distinctive treatment of presumed normal and disabled fetuses may seem highly problematic, and in a juxtaposed way, deeply offend our sense of the value of all individuals in society, removing women's ability to terminate in respect of disability is tantamount to *compelling* women to continue with a pregnancy and give birth to a disabled child that she will need to care for. This would appear to run against the grain of ideas of reproductive autonomy, and would appear to make women the martyrs of a political correctness model which has not been implemented in a society which

remains largely disabling and harder for women to exercise free choice over whether to continue with a pregnancy or not.

48. Insofar as domestic Courts have resisted attempts by putative fathers to force a woman to continue a pregnancy (*Paton v. B.P.A.S.* [1979] Q.B. 276) by reference to the literal terms of the Abortion Act 1967, the (formerly termed) European Commission considered that the woman's Article 8 Right to Private and Family life must prevail over that of the putative father's. Although in a very different context, the pillar of consent is central to reproductive ideals in the context of the provision of assisted reproduction (it can be withdrawn at any point up to the point of implantation of embryos, see further *Evans v. Amicus Healthcare Ltd and Others* [2004] E.W.C.A. Civ. 727; *Evans v UK* (Application 6339/05, ECtHR Grand Chamber, decided 10 April 2007).
49. Making women central to deliberations around the current structure of the law is critical. At present the Act permits termination for women who meet paragraph (a) up to 24 weeks irrespective of the condition of foetus, taking into account her social environment and circumstances. Some women in these circumstances may feel, for a range of valid reasons that they are not ready to take on the responsibilities of parenthood, whether by virtue of age, employment and financial circumstances, by virtue of health, or in respect of the particular relationship that that individual is in as well as the presence or absence of social support and family networks. In respect of the prospect of a child with a disability, where information surrounding the risk of foetal abnormality can occur very late, remarkably similar considerations apply. Though one can expect that many women do choose to proceed with a pregnancy even in the face of diagnosis of a serious foetal disability, not all women will feel capable or ready to take on the challenges entailed with such an outcome. The prospect of caring for a child with a serious disability can have a serious financial impact, and impose very significant caring and emotional costs upon its carer in a way that leads to an impoverished life for the woman concerned, as well as the child she cares for.
50. While in a more enabling environment women (and where applicable their partners) would feel better supported in caring for children with serious disabilities, as well as feeling content that society will support that child in later life, with better educational, social and employment prospects, so as to be better able to feel that continuation of pregnancy is a far more open choice, this is not the society in which we yet live. Research to date highlights extraordinary problems in respect of poverty, standard of housing, social deprivation and vulnerability to living with debt in respect of families with one disabled child, and very poor standards of living, and prospects for qualifications and employment by individuals with disabilities when compared to their non-disabled counterparts.<sup>7</sup> In the context of even medical provision, and community care in respect of children with complex health needs, there is a strong realisation that it is far from all it could be; the shift from areas like paediatrics moving from a curative paradigm to an emphasis upon care of children with long term disability is a relatively recent one (Simkiss, 2011, p. 193). As such there is much to do in achieving the delivery of an integrated service, with joined up working practices that provide for treatment, care and

support that matches a child's needs, between the NHS and other agencies, which helps children and "their families live as ordinary lives as possible" (Simkiss, 2011). Yet such themes cut across every aspect of social life, illustrating a profound disparity between the lives of families with a disabled member, and those who do not. As Read et al note in respect of families supporting a disabled child,

When all groups in the UK are taken together, the median equivalised income for a household with a disabled child is around 13 % lower than those with non-disabled children. They are more vulnerable to living with debt, social deprivation and in poor housing. Consequently, in addition to the exclusion and discrimination associated with living with impairment, many disabled children are likely to live in circumstances that have been shown negatively to affect children's development and educational achievement and to place them at risk of poor health and social exclusion (Read, Blackburn, & Spencer, 2012).

51. As such, very serious attention needs to be paid to the strong correlation between families raising a child (or children) with disabilities, poverty and its perpetuation. It may well be the case that a great many of the limitations and barriers that carers and their disabled children experience are largely the product of a society which is structured so as to ignore their needs, however, forcing women through pregnancies in a way that will immerse them into a society that does not cater for their needs on the basis of 'abortion' colluding with social discrimination is quite another matter. Insofar as paragraph (d) of the Abortion Act resting in its existing form may be seen to collude with social discrimination, it remains the case that for individuals contemplating their reproductive futures and the prospects of having a child with a serious disability, the impact of a wide potential range of sources of social discrimination upon many aspects of their lives will be very real.
52. The assumption that making changes to paragraph (d) of the Abortion Act 1967 would result in a corresponding reduction in terminations on the grounds of foetal abnormality is to ignore a broader European and global context in which some individuals go to great lengths in order to facilitate their reproductive needs. In countries where access to abortion has been severely restricted, there is strong evidence pointing to a corresponding growth of clandestine terminations (see further discussion of the European Court of Human Rights in *Tysiqc v. Poland* Application no. 5410/03 [2007] 1 F.C.R. 666) and of reproductive tourism (in respect of such reproductive tourism from states such as Ireland and Northern Ireland, see further IPPF European Network, May 2012, p.41; Fegan & Rebouche, 2003). As such, instances of restrictive regulation start to look like doorstep regulation. In Part IV of this document where we point to legal abortion regimes in other countries, there is a significant variation in the manner by which different jurisdictions regulate access to abortion on the grounds of foetal abnormality; a deeper analysis of the provision of abortion as it goes beyond the letter of law illustrates profound differences in practice.

53. There is a risk of stereotyping women that do access termination of pregnancy for foetal abnormality and presenting this as a typical or easy choice. The statistics on the numbers of abortions performed under Ground E every year, particularly in light of routine antenatal testing do not suggest that most women presented with negative information about foetal health do decide to terminate.. Some women do continue with pregnancies in the face of test results which point to a high risk of serious disability, and by no means do all women accept amniocentesis.
54. In this latter respect, amniocentesis refusal can be shaped by a variety of reasons, from a personal objection to abortion to a willingness to accept a child irrespective of what conditions it may have. Indeed, it may be useful to explore through semi-structured interviews in the UK context, more stories of these kinds, as well as why women take up the option of amniocentesis when it is offered.<sup>8</sup> Nevertheless, this information also needs to be taken into consideration alongside issues that we have raised above. Here we seek to highlight a concern with the practices which may influence termination on the grounds of foetal abnormality at any stage and for presenting women with a fuller choice, and indeed for shaping an environment which gives women a real choice.
55. Even if one assumes that discriminatory attitudes help to shape the choices that individuals make, and that particular conditions ought not to form the subject of a termination of pregnancy, this is still not the whole story. There are objectively some conditions where it would not only be pointless but harmful for a woman to continue with a pregnancy owing to the presence of a fatal anomaly (such as anencephaly where the foetus may not have a head, some diaphragmatic abnormalities where the foetus will die or severe untreatable cardiac conditions). Insofar as continuing with a pregnancy in itself presents risks to the woman, with no prospect of a live child upon birth, on clinical grounds a termination of pregnancy would seem highly appropriate.

**Continued.../(Part III: Abortion, Medical Practice and the Law)**

### **PART III: ABORTION, MEDICAL PRACTICE AND THE LAW**

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56. There are a number of legal issues at stake in respect of the clinical provision of services and treatment leading up to decisions to either terminate or not, under paragraph (d). The Inquiry will be presented with a great deal more practical information from clinicians that we hope will supplement and indeed refine what we say here. Our comment in this respect flags up the issues around the definition of paragraph (d) within law, the issue of informed consent and litigation against clinical professionals. It also turns to broader issues which may extend far beyond what law requires.

#### **Meaning of “Substantial Risk” and “Serious Handicap”**

57. There is no legal definition of either “substantial risk” or “serious handicap” in the 1967 Act. Wicks *et al* suggest that the legislation has been left ‘deliberately vague’ in an effort to avoid fettering the discretion of the two certifying doctors’ (Wick, 2004). As McGuinness comments, the reluctance to consider explicitly the implications of section 1(1)(d) and to defer to the discretion of the medical profession, ‘is not surprising given the historically medicalised approach to abortion’ (McGuinness, 2013, p. 13).

58. This issue of defining ‘serious disability’ was central to the case of *Jepson v The Chief Constable of West Mercia Police Constabulary* [2003] EWHC 3318 (Admin),<sup>9</sup> in which it was alleged that clinicians had performed an abortion on a woman at 28 weeks gestation because of a diagnosis of bilateral cleft palate. Jepson, who sought judicial review of the failure of the West Mercia Police to prosecute the doctors, claimed that this termination of pregnancy was not consistent with the terms of the 1967 Act. Her action failed to result in a prosecution, the Crown Prosecution Service having reopened the case and considered a wide range of evidence pertaining to the circumstances of the case.

59. As the Royal College of Obstetricians and Gynaecologists Working Party (Royal College of Obstetricians and Gynaecologists, 2010) have stated ‘whether a risk will be a matter of substance may vary with the seriousness and consequences of the likely disability’. In respect of “serious handicap”, the RCOG Working Party notes, “nor is it clear whether the disability has to be present at birth or will qualify if it is something that will afflict the child later in life”. As such the RCOG Working Party recommends that: “The Working Party sees little reason to change the current law regarding the definition of serious abnormality and concludes that it would be unrealistic to produce a definitive list of conditions that constitute serious handicap. An assessment of the seriousness of a fetal abnormality should be considered on a case-by-case appraisal, taking into account all available clinical information.” (Royal College of Obstetricians and Gynaecologists, 2010, p. 10). The Royal College of Obstetricians and Gynaecology has stated that a strict definition of “serious handicap” is ‘impractical by virtue of the absence of sufficiently advanced diagnostic techniques to detect malformations accurately all the time and it is not always possible to predict the ‘seriousness’ of the outcome (in terms of the

long-term physical, intellectual or social disability on the child and the effects on the family).’ Instead, they recommend that its interpretation should be ‘based upon individual discussion agreed between the parents and the mother’s doctor.’<sup>10</sup>

60. Later in this document we allude to different legal regimes in Europe that appear to endeavour to draw distinctions, sometimes providing a ‘tiered’ framework for addressing different potential outcomes in respect of the severity and impact of the disability. We do note, however, that a focus on foetal abnormality as the central issue for structuring termination of pregnancy, is tantamount to ignoring issues that we highlighted earlier in respect of equality concerns of women, the potential weaknesses of probabilistic data at different stages to detect very grave disabilities, how ‘suffering’ is a social and not just a medical issue, as well as the broader concerns relating to social discrimination.

### **Informed consent**

61. In the context of medical procedures, it is well established law that a clinician owes a duty of care to a patient to warn him or her in general terms of the possible serious risks involved in that procedure (*Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] AC 871). The concept of informed consent in earlier law placed a significant emphasis upon the clinical view in determining what information/risks were detailed, much assisted by the way that negligence was determined, whether the practices of the defendant could be said to be in accordance with one body of medical opinion skilled in the particular field (*Bolam v Friern Hospital Management Committee* [1957] WLR 582). More recent cases have moved towards a more patient-centred perspective; in *Chester v Afshar* [2004] UKHL 41, Lord Steyn noted that ‘in modern law medical paternalism no longer rules and a patient has a prima facie right to be informed by a surgeon of a small, but well established risk of serious injury as a result of surgery’. This shift is also discernible from the High Court determination of *Birch v UCL Hospital NHS Foundation Trust* [2008] EWHC 2237 (QB) where the patient had been warned that there was a 1 per cent risk of stroke associated with catheter angiography, but the patient was not informed that there was an alternative albeit slightly less exact diagnostic technique (an MRI scan) which carried no risk of stroke. Mrs Birch suffered a stroke and claimed that the doctor had breached his duty of care by failing to inform her of the comparative risks of angiography versus MRI. While the defendant’s expert witness claimed that the doctor’s duty consisted of merely informing the patient of the risks associated with the catheter angiogram (which he had indeed done) Cranston J agreed with Mrs Birch that this approach was not logically supportable.

62. An analysis of practices in respect of the care of pregnant women and information provision up to the point of termination raises interesting questions in respect of informed consent; there are two issues which arise in respect of the provision of services around suspected foetal abnormality and the option of termination for foetal abnormality; the first is in relation to risk disclosure around the variety of tests which are provided as part of antenatal care, for

which many will not provide 'certainties', but rather more probabilistic 'information', and the extent to which patients confronting that data understand the nature and purpose of those tests and their ramifications. The second concerns a more contextualised assessment of what choices are open to a woman/couple in such situations, both in respect of whether it is clear that such tests can be refused at any time, and that when confronted with data that suggests availability of termination, that alternatives are explored such as information around the implications of continuing with a pregnancy and the prospect of caring for a disabled child with the particular condition(s) highlighted.

63. In respect of "understanding" risk disclosure in order to assist a patient in making a decision, the General Medical Council (General Medical Council, 2008) provides guidance which highlights for doctors that they should bear in mind that some barriers to understanding may not be obvious, and as such, clinicians should make sure where practical, that arrangements are made to give patients any necessary support. In addition it advises that clinicians should use simple, clear and consistent language about risk given that patients may understand concepts of risk differently to clinicians. A broader sociological literature highlights this as a particular concern and the problems of creating a bridge between medical concepts of risk and the interpretation of medical data, and lay conceptions. Paul Atkinson's (Atkinson & Parsons, 1992) study, for example, which looks at the genetic hereditary condition Duchenne Muscular Dystrophy, found very fundamental differences between medical and lay understandings of statistical issues involved and suggested that these "discrepancies may have important consequences for the women's reproductive behaviour". Such work is amplified by an analysis of work exploring the communication of risk in the context of reproductive medicine (Karpin & Savell, 2012). Moreover, in the context of NP's discussions with clinicians, she posed the question directly in terms of how individuals understand probabilistic risk, and she was told that "Some don't understand what 'high risk' of Down Syndrome means" but that clinicians would take the time to explain.

64. Nevertheless, what is clear, is that in the context of "understanding" existing law does not (and cannot) impose a detailed and high standard upon medical professionals that requires them to 'force patients' to understand. A relatively low level of understanding is needed to ensure the provision of valid consent so that no claim in battery would lie, in the sense that providing the patient agreed to a procedure which was in fact carried out, their consent will be effective and no action in battery will lie. As Bristow J held in *Chatterson v Gerson* [1981] QB 432 consent will be real as long as the patient had been informed in "broad terms" about the nature of the procedure. In the context of negligence, where the level of information then turns to the issue of more specific risk disclosure, and will require far more information so that a patient can make decisions about his or her body in determining whether to go ahead with a treatment or not, *understanding* would not seem to be the focus of the negligence tort. In *Al Hamwi v Johnston* [2005] EWHC 206 (QB) it was argued by the claimant that the clinician's duty of care incorporated a duty to ensure that the information given to the patient had been understood. In this case,

while the patient had received standard information about the risks of amniocentesis, which include a one per cent risk of miscarriage, Mrs Al-Hamwi claimed to have understood the risk to be about 75 per cent. Simon J held that to place the doctors under a duty to ensure that the patient has, in fact, understood the information would be to “place too onerous an obligation on the clinician”.

65. The question of informed consent also raises other issues in respect of highlighting alternatives. In respect of decisions to terminate, authors such as Shakespeare for example have noted the desirability of providing individuals with information that balances the issue of termination; as he notes, “disability equality resources could be balancing the ‘medical tragedy’ information with more realistic accounts of living with a disabled child and, indeed, living as a disabled adult” (Shakespeare, 1998, p. 678). While we take this seriously as a live concern in the context of an ethical obligation for informed consent, it will likely go so much further than any legal standard. The emphasis in *Birch* upon the need for clinicians to counsel in respect of alternatives, goes further than previous authorities (and it is a High Court judgment with limited authority) but even if thought to form a desirable or compulsory aspect of medical practice, it would seem to be limited (and reasonably so) to medical practitioners exploring *medical* alternatives i.e. existing services and treatments which are routinely accepted within medical practice.

66. In terms of whether clinicians are currently meeting a medico-legal standard of informed consent for women in the context of prenatal testing and abortion, it is not clear, at least on the basis of RCOG guidance, coupled with insights from obstetricians in the field, that clinical personnel are falling short of what is required by law. Nor is it clear that clinicians see themselves as actively promoting termination of pregnancy and ignoring the presence of clinical alternatives where these are present. As such, it seems likely that clinical practice in this area would seem to conform to the legal standard expected of them in respect of existing law, in promoting informed consent and counselling of options. It may be that a range of things conspire collectively to promote termination, however this needs analysis and extends beyond an analysis of abortion to the provision of reproductive services as a whole. The existence of tests for foetal abnormality, which is part and parcel of reproductive clinical practice, presents in itself a need to make sense of that information with individuals; in turn, other factors, like the existence of wrongful birth suits (essentially claims in negligence) help to confirm that offering tests, information, and indeed making clear the availability of abortion, are regarded as part of good medical practice which conforms with law. On the basis of NP’s informal discussions with two clinicians in Wales, and on preliminary view of the review undertaken by the RCOG Working Party (Royal College of Obstetricians and Gynaecologists, 2010) it would appear that there are clearly defined care pathways, which include a practice of speedy referral to other clinicians, such as paediatric cardiologists and other persons to discuss with patients the outlook for the foetus, and to discuss treatment options post-delivery, which speak directly to issues of remediability. These pathways and broader sources of information seem to form a critical part of what is needed for clinicians to discharge within a medico-legal paradigm their

duty towards achieving informed consent. Nevertheless, the Inquiry might form a view that prospective parents contemplating the issue of test results, or the prospect of continuing a pregnancy irrespective of a diagnosis of foetal abnormality, need broader support. There are questions as to who might be best positioned to provide this.

67. In respect of this broader support, we consider here an ethical standard of informed consent that would very probably exceed the abilities and expertise of medical professionals, and indeed may not suitably be provided within a clinical context even if it would be useful for clinicians to endorse and recommend the approach (given patient deference to clinical/medical views). We are aware from our local discussions with Welsh clinicians, that there is a great emphasis on equipping clinicians with broader information which is germane to their patients, such as receiving lectures from people who look after children with various conditions such as Spina Bifida, or Down syndrome. Indeed talks by the Down Syndrome Society provide some insights from parents about how difficult/easy such children are to care for. As such, clinicians are being exposed to broader information and learning from people's experience in a way that is clearly valuable. We would recommend that this kind of information transfer process becomes the norm if it is not already, insofar as this creates an enabling environment for prospective parents to feel comfortable with declining tests or indeed the option of termination when presented to them by clinical professionals.

68. In respect of this broader support, which would appear to at least form an important part of clinicians discharging their responsibility to provide informed consent, we might hope for a greater emphasis upon broader information to be provided. In this respect, three issues loom hard for us.

- a. Firstly, the extent to which women and their partners understand the reasons that particular tests are offered to them, and that these tests are optional; as Karpin et al note (Karpin & Savell, 2012, p. 7), there is a strong concern that 'prenatal testing is presented as something they have a responsibility to undergo'. They further note that,

“although the literature provided to pregnant women about prenatal testing is at pains to present as *genuine* the choice confronting women about whether to (a) accept the offer of testing and (b) to have an abortion for an abnormality if identified (or in the case of PGD to select against disability), in fact it sometimes creates an environment in which pressure is placed on women to make particular decisions to reproduce “responsibly” (Karpin & Savell, 2012, p. 7).

We believe that there is a compelling need for society to consider in far greater depth why precisely we do provide these tests, when we do and with what aspirations in mind; as Shakespeare notes “the very existence of a test for foetal abnormality can create pressures to use the technology” (Shakespeare, 1998, p. 675). In addition it would be useful to gain a stronger insight into why individuals do accept these

tests; it may be that individual women expect 'reassurance' which an understanding of the nature of these tests and the way that information is typically presented, might suggest is unlikely to be forthcoming for many with more sophisticated forms of testing provided later in pregnancy. As Karpin et al note, prospective parents may undertake testing in ignorance of its potential implications or because they expect the testing will provide reassurance. There may even be an expectation of a "perfect" pregnancy" (Karpin & Savell, 2012, pp. 13-14).

"For most parents, the news that an abnormality has been identified in their unborn baby is completely unexpected. A problem of abnormality identified in the developing baby generally comes as a shock... In the light of the technologies available to monitor pregnancy, more and more abnormalities are also being identified through "routine" examinations such as ultrasound. Often the parents of babies identified in this way have never given consideration to the possibility that such a routine test would find something wrong with their unborn baby" (cited in Karpin & Savell, 2012, p. 13).

Importantly, in terms of law, these subtle issues will be missed but themes of genuine choice in a deeper and critical sense are raised,

"I don't think the test for disability in the unborn child is presented as a choice, when I said I didn't want tested the doctor was shocked and she tried to talk me into it because it's an easy test, everybody gets it done nowadays, it's simple. But I don't think there is a choice, I think that we're pressured into taking as many of these tests as are available" (cited in Shakespeare, Choices and Rights: Eugenics, genetics and disability equality, 1998, p. 675).

Alongside this are a panoply of concerns, ranging from the 'rollercoaster' journey which women are upon in the context of these obstetric procedures, to broader issues relating to how much trust is placed upon clinical professionals (Shakespeare, 1998, p. 675) in relation to decisions which essentially have far wide social import; it may be that here there is a mismatch between how clinicians view the information that they give (respecting that ideally prospective parents will search elsewhere for broader information) and how prospective parents centralise medical information.

- b. Second, and intersecting with the above, there is also need for some analysis around the understanding of risk in the context of information around the diagnosis of, and prognosis of a suspected disability. As we note above, there is a literature which illustrates the problems of gaining patient understanding of risks, for very understandable reasons. There is a rich psychological literature that suggests that depending on the way that information is framed, risks can be understood in very different ways with greater significance being placed on potentially a less likely but serious outcome (e.g. 75 per cent chance of survival versus 25 per cent risk of death).

- c. Third, we think that it is important to focus on the provision of information which is given that helps prospective (or non-prospective) parents to contextualise (a) and (b) and to explore openly and without hindrance the option of continuation of pregnancy, as a genuine option. This would potentially include exploration of what it would be like to raise a child with a condition of the type that tests have illustrated might result; as well as information from existing parents of children about their experiences of testing and differential outcomes. We do not think that it would necessarily be appropriate for medical practitioners to take the lead (though certainly a supportive one) in facilitating this aspect of informed consent given that the medical encounter is a rather value-laden one and indeed is time-limited with ever increasing pressure upon services. But importantly, it is also expertise-limited (to what extent does medical training involve insights into parenting children with disabilities?) so that one can doubt whether clinicians are well-positioned to provide information of this nature. We highlight here resources which are at this stage experimental but designed to assist decision-making around amniocentesis in a way that goes beyond existing medical practice and what the law requires for informed consent: <http://www.amniodex.com/>.<sup>11</sup>

69. A final issue, though still non-exhaustive, concerns other legal and practical pressures which 'harden' up the way that "good" medical practice is shaped and understood in respect of reproductive care. In addition, it also helps to redefine the way that abortion on the grounds of paragraph (d) is understood. As we would wish to note, obstetric and gynaecological practice is heavily encumbered by litigation, and in respect of the provision of antenatal services, from counselling, to testing to information provision, clinicians are susceptible to a range of negligence suits. In particular, suits known as wrongful conception and wrongful birth suits can be brought in respect of parenthood which is claimed to be unwanted. The latter, the wrongful birth suit is brought in respect (typically) of the birth of a seriously disabled child where it is claimed that but for negligence in the provision of counselling, diagnosis or information where there has been a failure to detect foetal abnormality, that the woman would have terminated her pregnancy under paragraph (d) of the Abortion Act 1967. Such claims can be, particularly in that they relate to the costs of raising a seriously disabled child (typically the costs of raising a 'normal child' are deducted where the parents sought a healthy child) very significant in financial terms.

**Continued.../(Part IV: Human Rights and International Perspectives)**

## PART IV: HUMAN RIGHTS AND INTERNATIONAL PERSPECTIVES

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70. As Gevers notes in the European context, there is an absence of binding international standards on abortion; as such 'it is up to the national legislator to make laws on the scope for and the limits to abortion' (Gevers, 2006).
71. In the context of the European Court of Human Rights, this position has been confirmed in *Vo v France* (2005) ECHR 12 the ECtHR stating that the question of when a right to life accrued fell within the margin of appreciation of Signatory States. In the case of *Tysiqc v. Poland* Application no. 5410/03 [2007] 1 F.C.R. 666, which concerned the applicant being denied access to a therapeutic abortion, the ECtHR demonstrated a preparedness to address questions relating to abortion only where these concerned procedural failures on the part of a Signatory State in facilitating services which are provided for by law. While the ECtHR found that Poland had failed to comply with their positive obligations to safeguard Ms. Tysiqc's right to effective respect for her private life under Article 8, this was in respect of failing to provide sufficient safeguards by which to properly determine access to termination of pregnancy on therapeutic grounds as determined by Polish Law. Poland has become the subject of extended analysis in respect of its seemingly haphazard abortion provision in *P and S v Poland* 57375/08 HEJUD [2012] ECHR 1853 (30 October 2012) where it was found that the Polish State had violated Article 8 in respect of the determination of lawful access to abortion. In this case a young teenager of fourteen years of age became pregnant after being raped was found to have faced pressures, harassment and obstructiveness from public hospitals, the police force and the Catholic Church in order not to terminate that pregnancy. The emphasis on the "determination" here is important given that the ECtHR noted that neither the Convention nor Article 8 determined a right to abortion as such (only that States provided access to abortion in accordance with their own laws). Note that the *Tysiqc* case does raise interesting questions about the transparency of the law in respect of provision of termination, as well as safeguards and appeal mechanisms (though in the context of that case, the absence of these had the effect of denying the applicant an abortion). Similar considerations attend the recent case of *A, B and C v Ireland* [2010] ECHR 2032.<sup>12</sup>
72. The UK has recently become a signatory to the Charter of Fundamental Rights of the European Union, which is binding on all EU law, and has a vertical effect. In particular we point to Articles 1 and 3;
- a. Article 1 states that "human dignity is inviolable. It must be respected and protected."
  - b. Article 3 refers to the "Right to integrity of the person". Here Article 3 which determines the importance of "free and informed consent of the person concerned" where this applies to the fields of medicine and biology, also notes in the same context "the prohibition of eugenic practices, in particular those aiming at the selection of persons".

It is not clear what 'eugenic' in this context means, nor indeed what "the selection of *persons*" means. This could mean existing persons, or *potential persons*. In the case of the former, which is the least problematic definition,

areas like euthanasia would be appropriate for analysis, as well as other practices which have been condemned as eugenic, such as compulsory sterilisation of individuals with intellectual disabilities. Such practices continue to be performed in specific cases although the English courts now take a far more cautious attitude in adjudging whether a sterilisation would be in the 'best interests' of the individual in question (see the Court of Appeal's management of *SL (Adult Patient) (Medical Treatment)* [2000] 2 FCR 452). In the case of *potential persons*, however, this would not seem to be compatible with most Member States' domestic law, including that of England and Wales where a foetus is not afforded legal personhood. As such, the foetus is not seen as a 'person' and rights which pertain to existing persons are not extendable to the foetus. Nevertheless, the emphasis upon the question of 'eugenics' and 'the selection of persons' should compel us to analyse practices which do have these aspects in mind at the beginning and end of life. And as we have stated throughout this note there is a very strong correspondence, irrespective of the question of whether abortion is eugenic or discriminatory, between the kinds of practices which are widespread in reproductive medicine, and a society that continues to construct barriers to the attainment of equality between all existing persons.

73. Insofar as there would appear to be nothing that *compels* a domestic revision of existing abortion legislation our focus is firmly upon the broader issues our study has revealed. An analysis of the extent to which society which on one hand purports to respect the inherent dignity of all persons yet on the other provides little in the way of support for *existing* women and for families with disabled children and for disabled people themselves presents a story of lack of human rights in respect of a very specific categories of individuals in society: *existing* women as the individuals that bear and care for *existing* children (whether disabled or not) and *existing* disabled people. Women also take the lion's share of performing caring work for not only children, but for elderly parents who also may suffer from a range of conditions which prove limiting in a range of ways (Milne, Brigden, Palmer, & Konta, 2012). The extent to which abortion law might be felt to sit out of kilter with our purported equal respect for all human beings, and our value of all individuals, is a *tiny* part of a far more troubling picture. Here enormous questions can be posed as to the extent to which the UK is genuinely committed to promoting the human rights of disabled people and fostering networks and services which create not only an enabling and caring environment, but one filled with equal opportunities in the workplace and in broader social life. In this sense, the focus on abortion may be not only a distraction, but risks paying lip service to what is an incredibly serious issue. Indeed the connection between abortion and far broader trends, illustrates the extent to which disablism remains troublingly prevalent within society.

### **European abortion regimes**

74. We briefly highlight here research undertaken from the International Planned Parenthood Federation European Network which provides a report detailing abortion legislation across Europe (IPPF European Network, May 2012). This provides an opportunity for gaining an insight into the manner by which

different legal regimes provide for abortion on the grounds of foetal abnormality. We do not attempt to summarise this, even with respect to the issue of foetal anomaly but rather we try to identify where it would seem to be the case that other jurisdictions manage paragraph (d) considerations in similar (but often with subtle differences) or very distinctive ways at least in the 'letter of the law'. We felt that this could offer the panel a further route for exploring questions around the management of abortion on the grounds of foetal abnormality.

75. We would offer three further cautionary notes: differential approaches on foetal abnormality does not tell us much in itself and would need to be read alongside the development of abortion law as a whole to understand it (e.g. in respect of countries where further safeguards are provided in respect of foetal abnormality, this can also be attended by a far more liberal regime in respect of abortions performed before 12 weeks); secondly, there will be broader cultural, technological, practical, moral and social conditions that shape differing approaches. So a fuller appreciation of these is needed, alongside an insight into how the system functions, to identify whether any revisions might be transferable in the UK context. Finally, as a number of recent ECtHR cases have illustrated, there can be a profound difference between what the law says, and what actually happens in practice. As such, a literal reading of the abortion regimes of different countries tells us remarkably little of the effectiveness and operation of abortion in those jurisdictions (e.g. *Tysiqc v. Poland* Application no. 5410/03 [2007] 1 F.C.R. 666).

**a. Akin to 67 Act where no time limit in respect of foetal abnormality:  
Examples –**

- i. Albania - for an abortion on medical grounds (no limit) a health commission consisting of three physicians has to decide on the procedure after examination and consultation). Note that *no limit* in respect of a "Severe (incurable) malformation of the foetus".
- ii. Belgium - no gestational limit in respect of a serious threat to the woman's life or in the case of "Extremely serious and incurable disease' of the foetus". The opinion of a second doctor is required in both of these cases. The IPPF note that abortion legislation is interpreted liberally in practice (note that for abortions up to 12 weeks, these are permitted in cases where the pregnancy causes a 'state of distress' for the woman).
- iii. France – up to 12 weeks for 'normal' terminations, and no limit in cases of serious risk to life of woman, and in respect of foetal abnormality: "If a strong probability exists that the expected child will suffer from a particularly severe illness recognized as incurable".
- iv. Germany – normal abortions permissible on request up to 12 weeks following mandatory counselling, or where pregnancy the result of a sexual crime, no limit where this is intended:
  1. To avert danger to the life of woman

2. To avert the danger of a grave impairment of the physical or emotional state of health of the pregnant woman (This mental health risks for the woman include the ones caused by foetal malformation, and general health risks caused by adverse socio-economic conditions.)
- v. Kazakhstan: on request up to 12 weeks; social grounds operate from 12 weeks to 22 weeks; no time limit akin to 1967 Act in respect of danger to woman's life or health, and "foetal malformation". There are concerns in terms of the implementation of abortion law and access to abortion in practice: *Abortion is available all over the country but illegal abortions still exist and contribute to the maternal mortality ratio.*

**b. Up to 22 weeks in respect of foetal abnormality:**

- i. In Armenia, abortions are permitted up to 22 weeks in respect of indications relating to the foetus (e.g. Indications related to the foetus: intrauterine foetal death, congenital abnormality incompatible with life, repeated cases of infants born with congenital deformities/malformations or chromosomal diseases and sex-linked hereditary diseases in the family). Note also that Armenia constitutes an interesting case in respect of reproductive norms - Ultrasound examination is not mandatory for the provision of early abortion, but is recommended in the following cases: previous history of, or suspected ectopic pregnancy; suspected significant abnormality of the uterus, tubes or ovaries; obesity that may preclude accurate clinical dating; suspected multiple or molar pregnancy. Note also broader concerns, where IPPF reports that: Many women want to avoid legal abortion services and try to self-induce abortion at home using Cytotec (Misoprostol) based on a physician's advice or the experience of other women. Cytotec is generally used to treat ulcers and can be purchased in pharmacies without prescription.

**c. Second trimester abortions permitted (between 13-27/8 weeks):**

- i. Austria: Second trimester terminations are permitted in respect of grounds similar to those in the 1967 Act, including for serious foetal abnormality; however, there are concerns raised in relation to problems of accessing abortions generally in respect of conscientious objection. The IPPF note that after the 18<sup>th</sup> week it is virtually impossible to get an abortion in Austria, and that women travel to the Netherlands to get a late second trimester abortion.
- ii. Czech Republic: Abortions typically permitted up to 12 weeks on request; abortions are permitted after 12 weeks on grounds of serious foetal malformation or if the foetus is incapable of life. Terminations are permitted up to the beginning of the 24<sup>th</sup> week if there are genetic grounds for the abortion.
- iii. Denmark: the wording of Danish law is particularly interesting; abortions are permitted on request up to 12 weeks; in respect of

other contraindications, second trimester termination grounds are:

1. Risk to life of woman
  2. Risk of 'severe deterioration of woman's physical or mental health'
  3. If pregnancy, childbirth or care of the child entails a risk of deterioration of the woman's health on account of an existing or potential physical or mental illness or as a consequence of other conditions
  4. Danger that the child will be affected by a serious physical or mental disorder
  5. When the woman is incapable of giving proper care to a child due to a physical or a mental disability
  6. If the woman is for the time being incapable of giving proper care to a child on account of the woman's youth or immaturity
  7. If it can be assumed that pregnancy, childbirth or care of a child constitutes a serious burden to the woman which cannot otherwise be averted
  8. When pregnancy resulted from a criminal act
- iv. In Sweden, while abortion is on request (permitted for any reason whatsoever) up to the 18<sup>th</sup> week; abortions cannot be refused up to the 18<sup>th</sup> week. After that point the woman needs permission from the National Board of Health and Welfare (*Socialstyrelsen*). Abortion is not generally permitted after the point of viability, which is generally treated as 22 weeks, except in extreme circumstances.
- v. Portugal; on request up to 10 weeks; up to 12 weeks to avoid irreversible damage to health of woman; up to 16 weeks in case of rape or other sexual crime; up to 24 weeks "if there are substantial grounds for believing that the foetus has serious or incurable malformations"; no time limit if abortion only way to avert risk of death to pregnant woman.
- vi. Tajikistan: up to 12 weeks on request; broad range of grounds for up to 22 weeks (including existing disabled member of family); no limit in case of serious risk to woman's life or health. Note that where abortion regulations in England and Wales require that the opinion of two doctors are required in respect of determining whether a woman meets any of the grounds under the 1967 Act, in *Tajikistan in the case of foetal malformation, assurance of three doctors (obstetricians/gynaecologists) is needed stating that the child if born may suffer from serious physical or mental defects.*

**d. 'Tiered' regimes drawing distinctions between foetal abnormalities and other grounds in terms of 'seriousness':**

- i. Finland has a fairly 'staged' or 'tiered' approach to termination; this provides a wide range of grounds for terminations up to 12

weeks (If continuation of the pregnancy or delivery would endanger the life or health of the woman on account of a disease, physical defect or weakness in the woman. If the delivery or taking care of the child would be a substantial burden. The burden can be of any kind. If a disease, mental disturbance or other comparable cause, affecting one or both parents, seriously limits their capacity to care for the child. Risk to mental health of woman The pregnancy is a result of rape or another sexual crime; If the woman is aged under 17 or above 40; If the woman already had four children; Risk of malformation), up to 20 weeks (Risk to physical health of woman; If the woman is younger than 17; or any other reason accepted by the National Board of Medico-legal Affairs) and terminations up to 24 weeks in the cases where “a major foetal malformation has been detected using reliable methods). There is no time limit whatsoever in cases where there is a risk to the woman’s life.

- ii. Greece: up to 12 weeks on request; up to 19 weeks in respect of pregnancy being the result of sexual crime;
  - 1. up to 24 weeks in case “If signs of severe foetal abnormality induced abnormal infant birth”;
  - 2. No limit in respect of: “In case of demonstrated severe foetal dysfunction; If there is an inevitable risk to the life of the pregnant woman or a serious and lasting damage to physical or mental health, affirmed by the relevant doctor.”
- iii. Hungary: up to 12 weeks on request for a number of grounds including “If the risk of a major genetic problem of the foetus is higher than 10 per cent”, up to 18 weeks for other grounds; up to 20 weeks “If the risk of a major genetic problem of the foetus is higher than 50 per cent and up to 24 weeks in case of delayed diagnostic procedure”; No limit in cases where designed “To save the life or to protect the health of the woman from grave permanent injury; or if there is a substantial risk that the child will be seriously disabled or if the foetus is unable for extra-uterine life”.
- iv. See also Iceland which provides a staged access depending on seriousness of grounds (so foetal anomaly is one of many grounds for terminations up to 16 weeks), but terminations can be provided beyond 16 weeks in cases where life and health of woman endangered and where “the risk of malformation, hereditary defects or damage to the foetus is high”.
- v. Spain – up to 14 weeks on request; up to 22 weeks in respect of risk to woman’s life and health or in case of serious foetal abnormalities; after 22 weeks, “If foetal malformation is deemed incompatible with life or if the foetus is diagnosed with an extremely or incurable disease”.

- e. No Gestational Limit specified in law in respect of any ground (common time limit):**
- i. Cyprus: Not that there is a lack of data and research around the provision of abortion; the Cyprus Family Planning Association is considering recommending gestational limits, introduction of family planning services in hospitals, and a national survey on abortion.
  - ii. Israel: no time limit in respect of any of the grounds under abortion law, of which “the child is likely to have a physical or mental defect” is one. Note that Israel requires that for all abortions sought for after 24 weeks (where foetal status changes) permission is required from the relevant Committee.

**Continued.../(Conclusions)**

## CONCLUSIONS

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76. At present, we would recommend no change in existing provisions of the Abortion Act 1967. While we note that the foetus does not have personhood, this is potentially one of the most mundane (though critical) conclusions that can be drawn in respect of the 1967 Act, in the sense that there are far greater considerations to take into account in arriving at the view that no revision of the 1967 Act should occur. That the law does not afford foetuses personality is a starting point for analysis, not its conclusion. As such, in analysing the question of social discrimination against disabled people, there are nevertheless many considerations beyond the status of the foetus that demand exploration. It is with this aspiration in mind that we have sought to provide a wide-ranging analysis of a multi-faceted problem to assist the Inquiry.
77. We do not suggest that the distinction between presumed healthy and disabled foetuses is unproblematic. Rather the distinction as drawn in strict law appears invidious and does smack of discriminatory attitudes towards persons with disability in a way that we should strive to eliminate. This view is shared by many others in the field of medical law and ethics. Importantly, however, this *does not* point to any need (rather, all that we say above points to the opposite) to revise existing abortion law. An analysis of how abortion is provided in practice, suggests that the 'discriminatory' aspect of terminations performed under paragraph (d) may be largely rhetorical, and based on a strict reading of a piece of legislation which though sounding discriminatory in nature, operationalizes in contemporary practice in a very different way. The kinds of conditions for which termination of pregnancy is performed under paragraph (d) beyond 24 weeks (which is the "distinction" that sits at the heart of commentaries which claim paragraph (d) to be discriminatory) reveals that a tiny number of terminations take place at that point, and that these would seem to present examples of very grave conditions. As such, an assumption that paragraph (d) as it operates in practice is in fact discriminatory (rather than based on conditions which are in themselves impairments that are disabling *per se*) would seem to be largely a fiction. Nevertheless we do find that there are problems in the operation of the broader system which leads up to the decision to terminate, which itself may admit of 'disablism', and we focus heavily upon these as a means of identifying a more fruitful problem-based approach.
78. There are, of course, some who have made strong recommendations in respect of how paragraph (d) might be redefined or revised. Yet an analysis of literature from a range of fields illustrates a lack of genuine interdisciplinary effort in thinking through problem-based solutions even where it is possible to identify some areas of broad agreement by authors. There are also issues in respect of the comprehensiveness and expertise of authors who are bold enough to make normative recommendations as to how abortion law might change in respect of a finding that it is, at least in some respects, colluding with social discrimination. Some might suggest that a common time limit at 24 weeks should be set; yet this is to ignore the medical reality that of the few

terminations performed after that point, grave serious disabilities can be diagnosed very close to that point, and after it. Others who have not recommended any change in the gestational period have, for example claimed that it would be important to make “suffering” (foetal) central to paragraph (d); insofar as we find that it seems likely that in practice suffering may constitute a key marker for medical professionals, to legally mandate this raises other serious issues. To legally mandate ‘suffering’ or ‘seriousness’ is to ignore other issues such as the ability of medical science to determine whether a particular condition meets this threshold, as well as the question for us, in terms of whether suffering or seriousness should be determined by reference to foetal health alone. In this respect, we have also pointed to broader factors relating to the real contexts and lives of those that live with severe disabilities, or indeed the lives of those that care for them. These issues tend to be missed where the focus is upon foetal condition *in utero*. If equality is the concern, there is often a suspicious absence of concern around women, and lack of analysis of the reality of caring for existing children with disabilities in literature, so that claims that ‘suffering’ or ‘seriousness’ of a foetus should be the guiding principle appear to be based upon romanticised assumptions about the reality of impairment and idealised images of an equal and enabling society which does not yet exist. A change in existing law, which restricts termination of pregnancy on grounds of disability, would be ignore to our peril, the equality and dignity of existing women, women who care for individuals with disabilities, and the lives of disabled people themselves. A wide range of factors, from a woman/family’s social and economic circumstances, their ability to cope, as well as the impact upon a woman’s life, employment circumstances, responsibilities towards other individuals, such as existing children or elderly parents need to be taken into account. None of these are trivial issues. Beyond this there is also a failure to account for how the distinction drawn between health and abnormality serve to underpin most of reproductive practice and shape many of our social institutions – sometimes in highly practical and important ways, and sometimes in invidious and clearly discriminatory ways. There is, in addressing the question of abortion on the grounds of foetal abnormality a need to unpack what is a highly complex series of questions and a problem which is polygenetic (stemming from multiple sources) in nature.

79. The factors that we have highlighted here combined with the broader information that the Inquiry will be party to should strongly suggest that while promoting equality is critical, that any revision to the Abortion Act 1967 would result in a short-lived rhetorical victory for equality, and arguably counterproductive outcomes for society. Our view is that given the lack of state support and facilities for individuals with disabilities and for their carers alongside the very real impact upon women typically charged with the care of a disabled child, and indeed the prospects for that child itself, that decisions to terminate a disabled foetus in what is a disabling environment and society, do not look *unreasonable*. This is not to suppose that this does constitute the basis for termination decisions, but rather that if it were, this is less to do with abortion on the grounds of paragraph (d) being in itself discriminatory; rather it stands as a nasty symptom of a broader discriminatory structure and society which surrounds it.

80. There are, however, issues that we have flagged up that we feel need analysis. We would like more analysis of the kind of information that is presented to individuals, and the way that information is presented, so that women and their partners confronting the clinical issues at stake in prenatal care feel supported in making an open decision concerning their reproductive futures. In some cases this may present some with the opportunity to freely express that testing is not necessarily important (that this is their choice), to feel comfortable with refusing tests, and to feel that a decision to continue a pregnancy even where a known disability has been highlighted is reasonable. We also recommend that further enquiry be made of the provision of screening and specific tests such as amniocentesis, throughout every stage of a potentially wanted pregnancy, and to ask the question of *why* these tests are offered in the sense that the information would already seem to be shaped by unarticulated ideas about the intrinsic good of 'information'. It would be worth analysing why particular women accept or refuse the opportunity to avail themselves of this information in specific cases. In addition further research on the attitudes of individual women and men to the prospect of having a child with varying levels of disability would be useful, alongside an analysis of how people understand probabilistic information about the risk of disability. As such, what we highlight here are the complex interactions which take place well before the question of abortion. In this sense, abortion practice in respect of paragraph (d) is interconnected with a wide range of practices and analysis of abortion in isolation is insufficient; in this sense, it opens up not only every area of reproductive practice for scrutiny, but raises far more reaching questions that cut across our society and relate to virtually every aspect of our social lives.
81. Based on a broader picture of the existing treatment of those charged with the care of seriously disabled children, and the financial and hands on support offered to them, as well as the opportunities for people with disabilities in society, the overall picture is very gloomy indeed – illustrating a wide range of factors which coalesce to structure a disabling society. It is the presence of a disabling society which will make a decision to terminate a pregnancy for foetal abnormality a sadly not so unreasonable one for some individuals to make. An emphasis on a fuller operationalization of the spirit and aims of the Equality Act 2010 is demanded here. This means mobilising greater political and social support in respect of creating an enabling society in a way that makes the lives of existing disabled people (throughout the life course) and the people that care for disabled persons (where this care is needed) acceptable and normal. The Equality Act 2010 will need far more in the way of a political commitment to be placed behind it, for ultimately the focus upon existing persons with disabilities, and improving every aspect of society in the context of employment, social mobility, access to services and so on, seems to be the only genuine way of shaping an equal and enabling society.
82. We are concerned that at a time when public services are being cut and where welfare benefits will be, in real terms relative to inflation, likely to reduce over time as a means of tackling the national deficit that those caring for individuals with disability or indeed disabled individuals themselves are

likely to be heavily and deleteriously impacted by these measures. Moreover, insofar as this presents a rather frightening picture, we are also concerned that the kind of effort required for creating the kind of enabling environment critical for allowing individuals a genuinely informed choice about continuing pregnancy, requires a very considerable investment on the part of society. To be clear, insofar as the emphasis here is upon structuring society in such a way as to facilitate freedom of choice and supporting decisions to continue pregnancy in a way that illustrates respect for all individuals in society, current governmental policy would seem to point in the opposite direction in creating ever greater obstacles and barriers for the very individuals it should support. In summary, the starting point for an analysis about discrimination should not be on the isolated issue of abortion, but upon a society that industriously pays lip service to the equality and dignity of existing individuals with disability. It is in this latter respect, that society must change.

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## NOTES

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<sup>1</sup> See further, (Priault, 2007).

<sup>2</sup> The case arose from an incident involving a French doctor who mistakenly ruptured a pregnant woman's amniotic sac when he mistook her for another patient who was not pregnant. The Court considered that the issue of when the right to life begins was a question to be decided at national level: firstly, because the issue had not been decided within the majority of the States which had ratified the Convention, in particular in France, where the issue has been the subject of public debate; and, secondly, because there was no European consensus on the scientific and legal definition of the beginning of life. Having regard to this, and the stance currently adopted in France, the European Court determined that "the issue of when the right to life begins was a question to be decided at

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national level: firstly, because the issue had not been decided within the majority of the States which had ratified the Convention, in particular in France, where the issue has been the subject of public debate; and, secondly, because there was no European consensus on the scientific and legal definition of the beginning of life.”

<sup>3</sup> In the case of *Paton v. B.P.A.S.* [1979] Q.B. 276 where a putative father sought an injunction to restrain the defendants from terminating his estranged wife’s pregnancy, George Baker P stated, “The Abortion Act 1967 gives no right to a father to be consulted in respect of a termination of pregnancy. True it gives no right to the mother either, but obviously the mother is going to be right at the heart of the matter consulting with the doctors if they are to arrive at a decision in good faith. . .” Furthermore, we have made various references to the presence of ‘wrongful birth’ suits, which are brought in respect of alleged negligence in the provision of counselling and treatment resulting in the birth of a disabled child. These would, as one scholar has suggested, appear to have converted paragraph (d) into a ‘right’ on the part of women (Scott, 2005); certainly in its practical application, where women complain that “but for” the negligence they would have sought a termination under paragraph (d), seems to suggest that at least in most cases, an abortion would have been provided. To the authors’ knowledge, where this latter tenet is scrutinised it tends to be based on whether a woman would really have accessed a termination of pregnancy, rather than the practical issue of whether clinicians would have denied such an abortion.

<sup>4</sup> Telephone interview with a consultant gynaecologist in South Wales, March 2013.

<sup>5</sup> Insofar as 2 abortions were performed on other grounds.

<sup>6</sup> S was a 28 year old veterinary nurse who, at 36 weeks of gestation, sought to register as a new patient with a GP. She was diagnosed with pre-eclampsia severe enough to require hospital admission and an induction of labour. S was advised as to the potentially life threatening risks to her and her baby. It was accepted that she understood the risks but she rejected the advice because she wished nature to take its course, without intervention. She was compulsorily detained for assessment under s.2 of the Mental Health Act 1983 (justified by reference to a previous diagnosis of moderate depression). An *ex parte* declaration that a non-consensual caesarean would be lawful was granted, a caesarean was performed and the baby safely delivered. At no point during her detention was S treated for any mental disorder. In the Court of Appeal, S was declared competent, and confirmed that it was the right of the individual to decide whether to accept or refuse treatment, and as such treating a patient in the face of their refusal constituted trespass. It also determined that it was well established principle that the foetus had no independent existence or legal recognition as a person.

<sup>7</sup> See in particular information available at the Office for Disability Issues whose 2012 fact sheet (Office for Disability Issues, 2013) makes particularly depressing reading of which we allude here to only a part (the fact sheet as a whole highlights statistics concerning living standards, employment, education, independent living, discrimination, leisure and social activities, transportation, communications, the justice system and housing). As this fact sheet notes, while 16 per cent of children in families with no disabled member are in poverty, this percentage increases to 22 per cent in families with one disabled member. While the gap in non-decent accommodation has closed over recent years, one in three households with a disabled person still live in non-decent accommodation. One in five disabled people requiring adaptations to their home believe that their accommodation is not suitable. Although improvements have been made in respect of disabled persons gaining employment over the last decade, it remains the case that disabled people remain far less likely to be in employment. In 2012, 46.3 per cent of disabled people are in employment compared to 76.2 per cent of non-disabled people. Disabled people are around twice as likely not to hold any qualifications compared to non-disabled. 20 per cent of working age disabled people do not hold any formal qualification (compared with 7 per cent of non-disabled equivalent); over a quarter of disabled people say that they do not frequently have choice and control over their daily lives; disabled people remain significantly less likely to engage in cultural, leisure and sporting activities than non-disabled people. In the context of access to the internet, in 2010, 58 per cent of disabled people lived in households with internet access, compared to 84 per cent of non-disabled people. Disabled people are significantly more likely to be victims of crime than non-disabled people.

<sup>8</sup> An extremely interesting paper (Markens, Browner, & Mabel Preloran, 2010) based on research undertaken in California, United States explores through interviews why women accept or refuse

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amniocentesis which highlights issues of what women in different situations read into the offer of particular tests (ranging from not wanting to disappoint physicians, feeling that it must be worthwhile because it has been recommended by clinicians to a woman who believed that the test was compulsory following a positive result on an earlier blood screen) which may be offered merely for the objective of knowing more, about avoiding shock at birth and allowing time to prepare for the resulting child.

<sup>9</sup> In this case, Reverend Joanna Jepson successfully sought leave to apply for judicial review of the decision by the West Mercia Police not to prosecute clinicians who it was alleged conducted an abortion on a woman at 28 weeks gestation, because of a bilateral cleft palate. Jepson considered that this constituted an example of an abortion which fell short of the criterion of “serious handicap” under paragraph (d). The CPS reopened an investigation of this case (which the West Mercia Police had earlier determined there was no case to prosecute and that the doctors had made their decision in good faith meeting the standards of the 1967 Act) but concluded that following a review of the evidence of various kinds, it would not prosecute the doctors in question.

<sup>10</sup> <http://www.rcog.org.uk/what-we-do/campaigning-and-opinions/briefings-and-qas-/human-fertilisation-and-embryology-bill/abort>.

<sup>11</sup> Professor Glyn Elwyn, who also leads Cardiff University’s Decision Laboratory research group, said: “With existing information and support provided to women who are offered an amniocentesis widely considered to be insufficient, amnioDex has been developed to facilitate decision making by providing decisional support and unbiased information. amnioDex has been carefully designed to offer women decisional support and unbiased information, and to assist them in a difficult decision made at a time of strong emotional upheaval. We are thrilled to receive these awards which recognise our commitment to developing and evaluating high-standard decision support interventions” (Cardiff University, 2009).

<sup>12</sup> The essence of *A, B and C v Ireland*, is essentially the same as that found in the case of Poland. Finding that Ireland had violated Article 8 in respect of one of the applicants (C), the ECtHR stated: “...the authorities failed to comply with their positive obligation to secure to the third applicant effective respect for her private life by reason of the absence of any implementing legislative or regulatory regime providing an accessible and effective procedure by which C could have established whether she qualified for a lawful abortion in Ireland in accordance with Article 40.3.3° of the Constitution”. For a fuller analysis of this case see further Kalt (2010).