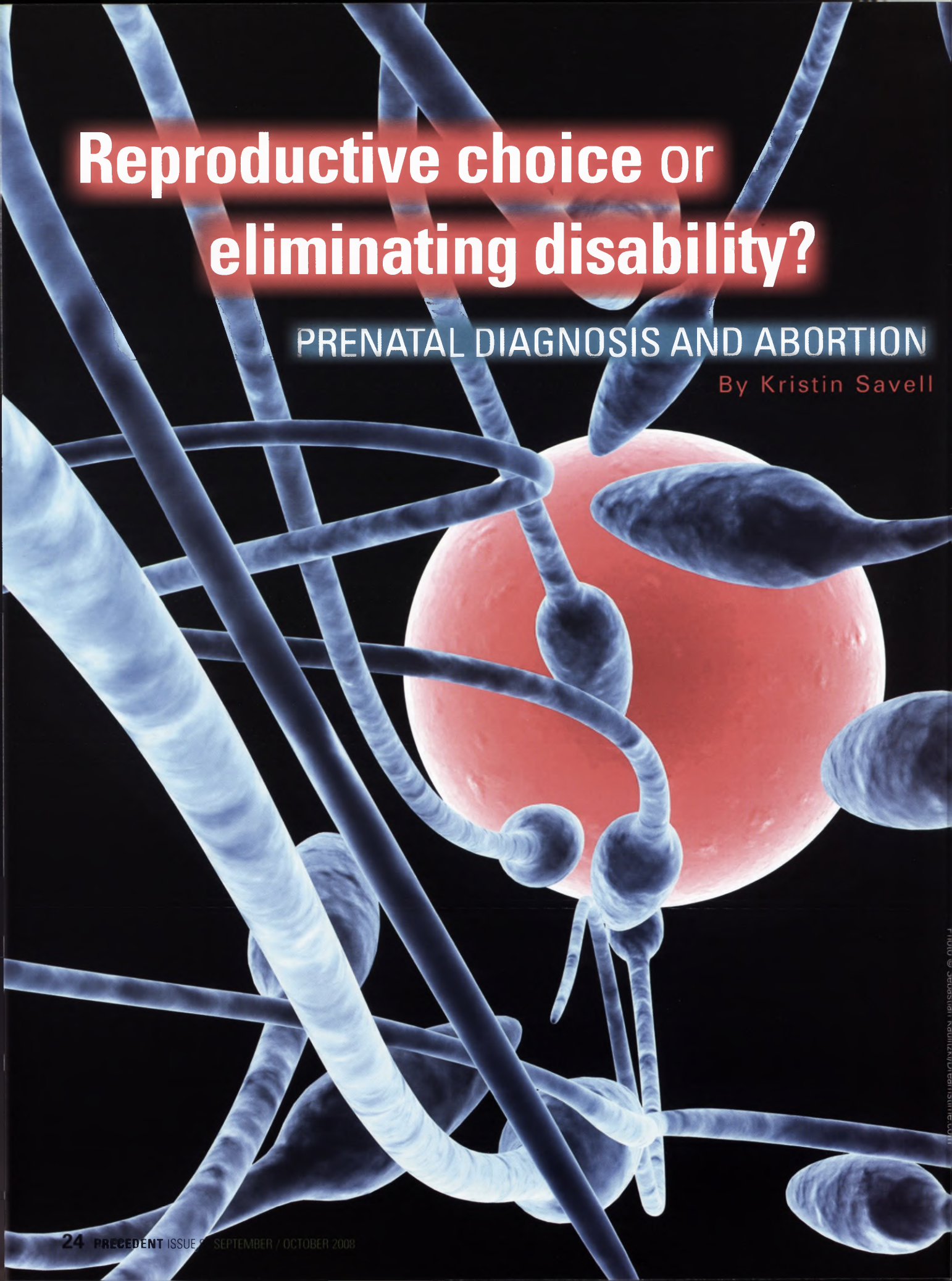
Reproductive choice or eliminating disability?

PRENATAL DIAGNOSIS AND ABORTION

By Kristin Savell



Prenatal testing has become a routine aspect of prenatal healthcare and has been embraced by many Australian women. Testing is now available for chromosomal abnormalities (such as Down Syndrome and other trisomies[1]), and structural abnormalities (such as congenital heart, brain and renal defects, club foot, cleft palate, extra or missing digits). Notwithstanding the availability of these tests, there is some legal uncertainty about the practice of late abortion following such a diagnosis.

In recent years, public attention has been drawn to this issue as a result of some highly publicised cases of late abortion involving disability, both here and abroad. In Victoria, the termination of a pregnancy at 32 weeks' gestation following a diagnosis of achondroplasia (dwarfism) was widely reported and commented upon in the media[2] and federal parliament.[3] In England, a third-trimester abortion for bilateral cleft lip and palate became the subject of an application for judicial review and parliamentary debate about whether such a condition met the legal criteria for abortion on the grounds of 'serious handicap'.[4] Even more recently, a nationwide debate has erupted in India, following the High Court of Mumbai's refusal to exempt a proposed termination for serious congenital heart defect from the prohibition on abortion after 20 weeks' gestation.[5]

Although the debate about abortion for foetal disability intersects with, and remains influenced by, debates about the moral status of the foetus and the pre-eminence of reproductive choice, it also moves beyond these debates into new terrain. The moral and legal contest no longer coalesces around absolutist positions: is abortion right or wrong, legal or not? The questions have been re-framed along different axes: is it responsible to bring a disabled child into the world? Does the differentiation between 'disabled' and 'non-disabled' foetuses, in either law or medical practice, imply a devaluation of the lives of people already living with the disability? In what sense is it meaningful to speak of autonomous prenatal decision-making in a social and economic environment that is hostile to disability?

MAPPING THE DEBATE

This set of questions poses significant challenges for women and their doctors, who face these decisions with greater frequency as the frontiers of prenatal diagnostic technologies expand. Lawmakers are also confronted by these questions, both from an increasingly vocal disability rights movement who worry that distinguishing disabled foetuses for legal purposes perpetuates a culture that is hostile to disabled people and, on the other hand, from those who criticise the lack of clarity of Australian abortion law as a threat to women seeking terminations[6] and to doctors who are vulnerable to prosecution and/or reputational damage.[7] To make sense of these claims, and assess the adequacy of current responses to these issues, we must look first to the existing legal frameworks with respect to abortion for foetal abnormality and, second, to the parameters of this debate.

THE LEGAL POSITION IN AUSTRALIA

Some Australian jurisdictions specifically address the issue of abortion for foetal abnormality, while others do not. Of those that do, approaches differ. The South Australian legislation is based on the UK model, which permits an abortion at any stage until birth if 'there is a substantial risk that, if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped'.[8] However, the SA provision differs from the UK model in two respects. First, it limits abortions for 'serious handicap' to foetuses that are not capable of being born alive (there is a presumption that this occurs at 28 weeks' gestation); and second, this 'upper' time-limit applies equally to abortions on other grounds (except where necessary to preserve the life of the woman, for which there is no limit).[9]

The Northern Territory legislation makes special provision for abortion on the grounds of 'serious handicap', although >>

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its scope is more limited than the South Australian provision. Abortions on this ground are permissible until 14 weeks into the pregnancy.[10] In Western Australia, abortions are permissible up to 20 weeks' gestation if the woman has given informed consent to the procedure.[11] However, an abortion may be performed after 20 weeks' gestation if two or more members of a ministerially appointed panel agree that the mother or the unborn child 'has a *severe medical condition* that . . . justifies the procedure'[12] and the procedure is carried out in a facility approved by the minister for the purposes of the section. In this sense, the WA approach mirrors the UK model by designating a lower time-limit for abortions carried out on the grounds of maternal preference than for foetal abnormality. Significantly, all of the legislative regimes that specifically acknowledge foetal abnormality (that is, UK, SA, NT and WA) leave open the question of which conditions or disabilities fall within the meaning of 'serious handicap' or 'severe medical condition'.

In the remaining jurisdictions (except the ACT),[13] no specific legislative provisions exist for abortion on the grounds of foetal abnormality. Among these jurisdictions, once again, approaches differ. NSW, Victoria, Queensland and Tasmania all have offences concerning unlawful abortion[14] and, with the exception of NSW, offences relating to 'killing an unborn child'.[15] Nonetheless, medical termination of pregnancy is lawful in certain circumstances in each of these jurisdictions.[16] In Victoria and Queensland, abortion is not unlawful if the doctor holds an honest belief, based on reasonable grounds, that the abortion was necessary to avert the risk of serious danger to the woman's life or physical or mental health, beyond the normal dangers of pregnancy and childbirth, and that abortion was a proportionate response to the danger. In these jurisdictions, the defence has been interpreted to cover dangers arising during the course of the pregnancy. NSW also recognises a defence of necessity to a charge of unlawful abortion. This has been interpreted more broadly to include social and economic as well as medical grounds as possible bases for an opinion that the pregnancy might present a serious danger to a pregnant woman's physical or mental health.[17] These grounds may exist at the time of the decision, at some stage during the pregnancy[18] or, on Kirby P's interpretation in *CES v Superclinics*, after the birth of the child.[19]

Although these jurisdictions do not specify foetal abnormality as a distinct justification for abortion, it is no doubt the case that diagnoses of serious foetal abnormality may be considered relevant to the question of whether the pregnancy poses a danger to the woman's physical or mental health. If passed, the Abortion Law Reform Bill 2008 (Vic), currently before parliament, will permit terminations up to 24 weeks' gestation by a medical practitioner for any reason, and after 24 weeks' gestation if at least two doctors reasonably believe that an abortion is appropriate in all the circumstances.[20] The explanatory memorandum notes that 'the reference to all relevant medical circumstances is intended to ensure that the medical condition of the foetus and the woman are taken into account'.

As this brief survey demonstrates, the laws regulating abortion vary immensely across the states and territories, both in content and approach, and it is fair to say that there are areas of legal uncertainty that may pose unacceptable risks to medical practitioners and women alike.[21] On the specific issue of late terminations for foetal abnormality, there is little evidence of a consistent, principled or uniform legislative approach across states and territories. This situation has been criticised on the grounds that that is 'unfair and discriminatory'.[22] For example, De Crespigny and Savulescu claim that 'access to prenatal testing and termination of pregnancy depends not on maternal or foetal considerations, but on where a woman happened to receive her care, her personal resources and the values and attitudes of the doctor, institution or ethics committee into whose hands she happens to fall'.[23] Others have criticised current approaches to prenatal testing and abortion as discriminatory, too, but for rather different reasons. For example, Lippman argues that public funding of prenatal screening programs, 'which necessarily reflects state-sponsored use of some genetic variation alone to value one group more than another', raises issues of eugenics and calls into question the extent to which women are allowed to 'make genuine choices about child-bearing'.[24]

ARGUMENTS IN FAVOUR OF TREATING LATE ABORTION FOR DISABILITY AS A SPECIAL CASE

Some of the arguments in favour of a permissive attitude toward abortion for foetal abnormality apply to abortion at any stage of pregnancy. However, in general terms, these arguments attempt to strengthen the case for treating 'late abortion' for foetal abnormality as a special case, as, for example, has occurred with the model adopted in the UK.

If the foetus is not viable, it is cruel to insist that the mother should continue the pregnancy to term

This argument is sometimes referred to as the 'lethal abnormality' justification. Its thrust is simply that it is illogical to compel a pregnant woman to continue with a pregnancy that will result in the birth of a dying child. As Savulescu and de Crespigny observe, 'the uterus is indeed the best intensive care unit; foetuses with the most terrible abnormalities usually do not die before birth. Denying abortion may only delay the inevitable and extend the suffering of the family.'[25] This argument was persuasive in the reform undertaken in the UK in 1990 that amended the >>

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Abortion Act 1967 to allow abortion for 'serious handicap' at any time until birth.[26] The House of Lords Select Committee Report on the *Infant (Life Preservation) Act* 1929, upon which the reforms were partly based, concluded that:

> 'If … an unborn child were diagnosed as grossly abnormal and unable to lead any meaningful life, there is … no logic in requiring the mother to carry her unborn child to full term merely because the diagnosis was too late to enable an operation for abortion to be carried out before the 28th completed week.'[27]

If there is any difficulty with this argument, it is that it appears to be limited to foetuses that are not viable. It is not clear whether it covers the case of a termination for a disability that falls short of the lethal abnormality. Yet, as the British Medical Association points out, the objectives of prenatal testing include the detection of anomalies that are incompatible with life, as well as anomalies associated with high morbidity and long-term disability.[28] Thus, if a provision allowing termination of foetal abnormality is to encompass both lethal disabilities and disabilities which, though not lethal, will likely lead to long-term disability, then this raises questions about where the line will be drawn (and by whom) between acceptable and unacceptable impairments.

By removing time pressure from the decision to terminate, women will enjoy the benefit of reflection and further opportunities to gain diagnostic confirmation

This argument rests on the presumption that gestational time restrictions impose a further burden on women and doctors in their attempts to clarify the diagnosis and reach a decision about termination. As many foetal abnormalities are not detected until the 18 to 20-week scan, difficult decisions are likely to be rushed if women feel threatened that they will lose the option to terminate should they delay their decision. In the Victorian context, Savulescu and de Crespigny suggest that medical uncertainty about the legality of abortion after 20 weeks leads to two unwelcome results: ultrasound scans are performed too early, producing potentially inaccurate results; and women are having terminations in the face of uncertain diagnoses because they cannot risk losing the option to terminate if they wait for confirmation or, potentially, resolution of the problem.[29] On this argument, preserving the option of late termination will remove some of the pressure from the difficult decision faced by the woman, and may even save some foetuses in situations where the early diagnosis later turns out to be wrong.[30]

Restricting prenatal testing and late abortion for disability is an unreasonable intrusion on a woman's right to reproductive choice

The argument that the law should not intrude on a woman's right to control her bodily integrity and reproductive future, some argue, has even stronger than usual force where a foetal abnormality is diagnosed. Compelling a woman to continue with a pregnancy and give birth to a disabled child risks harming her psychological health, and imposes unreasonable social and economic burdens on her and her family. In the UK context, Lee observes that 'the law recognises that there is a difference between becoming a parent to a child with a disability and becoming a parent to a child without a disability. And a good thing this is, too.'[31] She goes on to defend a woman's right to end a pregnancy on the grounds of foetal abnormality 'because it is the woman's pregnancy, her future and her family that will be affected by the choice she makes. She will live with the consequences of what she decides to do; and she must have the right to make a choice that others disagree with.'[32] Savulescu also supports an unrestricted 'maternal interests' criterion for abortion[33] and warns of the consequences of limiting the choices of women who do not wish to continue with pregnancies following a diagnosis of disability. De Crespigny and Savulescu claim that 'women are less likely to choose to have a child, or more children, if they are not confident that access is available to both appropriate testing and abortion if a major abnormality is found'.[34]

ARGUMENTS AGAINST TREATING LATE ABORTION FOR DISABILITY AS A SPECIAL CASE

Arguments that seek to rely on reproductive choice have been criticised for being unduly simplistic about the impact of social conditions on reproductive decision-making. For example, Lippman wonders whether women feel able to refuse prenatal testing when it is offered to them, and doubts whether they feel 'that there will be support, acceptance, and appreciation for the child predicted to have some disability if that child is brought into the world'.[35] She draws attention to the awareness that many women have of the 'obstacles placed in the way of those with disability' and wonders whether in this context, it makes sense to speak of 'choosing' prenatal testing and termination.[36] Thus, the arguments that caution against an uncritical acceptance of prenatal testing and abortion are more likely to consider the broader social implications of these practices.

Permitting late abortion for disability expresses a negative attitude toward the lives of already born disabled people

The view that the social practice of prenatal testing and abortion 'expresses a discriminatory or negative attitude towards people with disability'[37] is sometimes referred to as the 'expressivist objection'. Edwards observes that 'many people with disabilities hold the view that selective termination of pregnancy does convey a message or otherwise imply that it would have been better had they not been born'.[38] As the decision to terminate a previously

wanted pregnancy following prenatal diagnosis connotes a choice between a world with the prospective child in it, and a world without, Holm argues that this 'must, in some cases at least, entail that they value (the particular) disability so negatively that they think the world without the disabled child is preferable simply because it does not contain the child'.[39]

The expressivist argument rests on the idea that, for many disabled people, their disability is partly constitutive of their identity, with the result that a screening program designed to prevent the births of 'people like them' is a social practice that is both threatening and offensive to them. Holm observes that the mere fact that a disabled person knows that people view their disability negatively will affect their identity and social standing, even if the negative evaluation does not lead to any actual discrimination.[40] Examples of the negativity and discrimination complained of by disabled people are occasionally reported in the press. For example, a clinical geneticist practising in Victoria told journalists that he had received numerous calls from distressed short-statured patients following the publication of a study which found that 78 per cent of practitioners of obstetric ultrasound supported termination of pregnancy for dwarfism at 13 weeks.[41] Many of his patients confided to him that 'they were afraid or ashamed to go outside because they felt that society didn't want them around'. As one patient walked down the street, a man yelled from a car: 'you should have been aborted'.[42]

Although the practice of prenatal testing need not *necessarily* express a negative attitude towards disabled people, Holm suggests that, in the context of current conditions where the 'social and healthcare needs of disabled people are not being met', prenatal testing and abortion does actually express a negative attitude towards the disabled.[43] But the question of how to reconcile this undesirable social effect with reproductive choice remains. For example, Edwards has argued that even if we accept that prenatal testing does imply that many people would not want to have children with disabilities, it is not clear that the offence or hurt caused to disabled people by this state of affairs should necessarily trump the right to reproductive self-determination.[44]

Permitting late abortion for disability is discriminatory in that it confers a greater level of protection on non-disabled compared with disabled foetuses

Closely related to the expressivist argument is the view that allowing the abortion of a disabled foetus in circumstances where it would not be permitted if the foetus were not disabled, confers a greater level of legal protection on non-disabled foetuses and is, therefore, discriminatory. The UK Disability Rights Commission has issued a statement indicating concern about the implications of s1(1)(d) of the *Abortion Act* 1967:

> 'The section 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 equally.'[45]

This argument rests on the assumption that either all foetuses – or, at least, later-term foetuses – have significant moral standing that should be reflected in the level of legal protection accorded to them. For those who do not accept this, the argument does not seem to add anything to the expressivist argument described above.

Serious disability is notoriously difficult to define

This argument contends that the line between 'serious' and 'non-serious' impairments is unstable and, thus, leaves open the possibility that even minor or correctable disabilities might eventually come to fall within the scope of any special exception. This argument has been the subject of extensive debate in the UK as a result of the third trimester cleft lip and palate abortion referred to above. In this case, the Reverend Joanna Jepson, having failed in her quest to have prosecutorial authorities lay charges against the doctors who performed the abortion, turned to the courts to seek judicial review of the decision. In assessing the application for review, the High Court held that the question of whether 'serious disability' should be assessed against the remediability of the condition raised 'serious issues of law and issues of public importance'.[46] In the >>

press, Jepson stated her purpose as seeking a clarification of the law 'so that abortions do not take place for trivial reasons and so that discrimination against the disabled does not become widely accepted'.[47] The House of Lords subsequently debated the meaning of 'serious disability' for the purposes of the UK abortion legislation, but the debate served only to highlight the instability of the concept. There was no agreement as to whether a serious disability was one in which the affected person would be 'unable to lead a meaningful life', whether it might extend to 'irremediable conditions' or whether, even where a condition was remediable, it might still be regarded as a serious disability if the treatment was prolonged or painful.[48]

CLARIFYING THE LEGAL ISSUES

As this brief mapping of the debate about foetal abnormality shows, there are tensions between an approach that focuses on individual reproductive autonomy and one that seeks to contextualise prenatal testing and abortion as social practices with broader impact. The question is whether and, if so, how the law should negotiate these tensions. Thus far, the debate has raised a number of important questions for law, including: Should the law permit abortion without restriction as to time or reason, provided that the woman consents and the procedure is performed by a doctor? If more restrictive regulation is deemed appropriate, should the law recognise foetal abnormality as a distinct ground for abortion? If so, should legislation stipulate a later time limit for this reason than other reasons? Moreover, should the law provide some guidance on the scope and meaning of 'serious handicap'? As the Victorian Law Reform Commission recently pointed out, 'as a community we have probably not yet directly confronted the full social ramifications of the increased use of foetal testing'.[49] It is important that we try to grapple with these difficult issues and, in so doing, formulate a principled and consistent approach to them. ■

Notes: **1** Chromosomal abnormality characterised by the presence of an extra chromosome. **2** M Shaw & D Gray, 'Doctors Suspended over Late Abortion', *The Age*, 3 July 2000. **3** Australia, *Parliamentary Debates*, Commonwealth Senate, 29 November 2000, 20106 (Julian McGauran) and Australia, *Parliamentary Debates*, Commonwealth Senate, 13 March 2002, 638 (Julian McGauran). **4** *Jepson v The Chief Constable of West Mercia Police Constabulary* [2003] EWHC 3318 (Admin). **5** BBC Online, *Abortion-ban Indian Baby Dies*, 14 August 2008, accessed at http://news.bbc.co.uk/2/hi/south_asia/7560321.stm on 19 August 2008. **6** De Crespigny and Savulescu, 'Pregnant Women with Foetal Abnormalities: The Forgotten People in the Abortion Debate' (2008), 188 *Medical Journal of Australia* 100 (hereafter *The Forgotten People*). **7** L de Crespigny & J Savulescu, 'Abortion: Time to Clarify Australia's Confusing Laws' (2004), 181 *Medical Journal of Australia* 201. **8** *Abortion Act* 1967 (UK), s1(1)(d). **9** *Criminal Law Consolidation Act* 1935 (SA) s82A. Under the *Abortion Act* 1967 (UK), abortion for maternal health reasons (excluding serious risk to life or grave permanent injury to physical or psychological health, for which there is no limit) is limited to the first 24 weeks of pregnancy, and abortion on the grounds of 'serious handicap' is permissible at any stage until birth. **10** Section 11, *Medical Services Act* (NT). **11** Section 334(3), *Health Act* 1911 (WA) **12** Section 334(7)(a), *Health Act* 1911 (WA). **13** In this jurisdiction, abortion is permitted where performed by a doctor in an approved facility (*Health Act* 1993 (ACT), ss80-83). **14** See ss82-84 *Crimes Act* 1900 (NSW), s208B-C *Criminal Code Act* 1983 (NT); ss224-226 *Criminal Code* 1899 (Qld); s199 *Criminal Code Act* 1913 (WA); ss134-135 *Criminal Code Act* 1924 (Tas); ss65-66 *Crimes Act* 1958 (Vic); and 81-82 *Criminal Law Consolidation Act* 1935 (SA). Note that the Abortion Law Reform Bill 2008 (Vic) is currently before parliament and, if passed, will permit terminations up until 24 weeks' gestation by a medical practitioner for any reason. **15** Jurisdictions other than NSW and SA have separate offences relating to 'killing an unborn child', 'causing the death of a child before birth' or 'child destruction': see s42 *Crimes Act* 1900 (ACT); s170 *Criminal Code Act* 1983 (NT); s313 *Criminal Code* 1899 (Qld); s290 *Criminal Code Act 1913* (WA); s165 *Criminal Code Act* 1924 (Tas); s10 *Crimes Act* 1958 (Vic). It is not entirely clear whether these offences set 'upper limits' on the medical termination of pregnancy in each of the jurisdictions to which they apply. This uncertainty may soon be resolved in Victoria as the Abortion Law Reform Bill 2008 (Vic), if passed, will repeal s10 of the *Crimes Act* 1958 (Vic). **16** See *R v Wald* (1971) 3 DCR (NSW) 25; *R v Davidson* [1969] VR 667; *R v Bayliss and Cullen* (1986) 9 *Qld Lawyer Reps* 8; s164 *Criminal Code* 1924 (Tas). **17** *R v Wald* (1971) 3 DCR (NSW) 25. **18** *Ibid.* **19** *CES v Superclinics (Australia) Pty Ltd* (1995) 38 NSWLR 47 at 60. **20** See cl 5 Abortion Law Reform Bill 2008 (Vic) **21** *The Forgotten People* (see n6 above). **22** *Ibid*,103. **23** *Ibid.* **24** A Lippman, 'Eugenics and Public Health' (2003), 93 *American Journal of Public Health*,11. **25** Above n6, 102. **26** The *Human Fertilisation and Embryology Act* 1990 (UK) amended the *Abortion Act* 1967 (UK) to remove the upper time-limit on abortions for foetal abnormality (s1(1)(d), and to lower the time-limit for most other abortions to 24 weeks' gestation (s1(1)(a)) (exceptions remain where the pregnancy poses a risk to the woman's life (s1(1)(c)) or of grave permanent damage to her physical or psychological health (s1(1)(b)). **27** Cited by Sir David Steel in UK, *Parliamentary Debates*, House of Commons, 21 June 1990, column 1184 (Sir David Steel). **28** British Medical Association, *Abortion Time Limits – A Briefing Paper by the BMA* (2005), http://www.bma.org.uk/ap.nsf/Content/AbortionTimeLimits~Factors~Diagnosing [accessed on 25 September 2008]. **29** Above n7, 103. **30** *Ibid.* **31** E Lee, 'Who's Afraid of Choice?' (2003), http://www.prochoiceforum.org.uk/ocrabortdis3.asp accessed on 18 August 2008. **32** *Ibid.* **33** J Savulescu, 'Is Current Practice around Late Termination of Pregnancy Eugenic and Discriminatory? Maternal Interests and Abortion' (2001), 27 *Journal of Medical Ethics*165. **34** *The Forgotten People*, above n6 at 103. **35** Above n3. **36** *Ibid.* **37** S Holm, 'The Expressivist Objection to Prenatal Diagnosis: Can It Be Laid to Rest?' (2008), 34 *Journal of Medical Ethics* 24, 24. **38** SD Edwards, 'Disability, Identity and the "Expressivist Objection"' (2004), 30 *Journal of Medical Ethics* 418, 418. **39** Above n6, 24. **40** *Ibid.* **41** This is a reference to the survey published in Savulescu, see n32. Savulescu found that around 70% of the practitioners of obstetric ultrasound surveyed thought that abortion should be offered after a diagnosis of dwarfism at 24 weeks. **42** M Toy & C Milburn, 'Whose Life Is it Anyway?', *The Age*, 8 July 2000, 3. **43** Above n36, 25. **44** Above, n37. **45** Disability Rights Commission, Statement on s1(1)(d) of the *Abortion Act*, 5 July 2003, http://www.drc-gb.org/library/policy/health_and_independent_living/drc_statement_on_section_11.aspx accessed on 5 May 2007. **46** *Jepson v The Chief Constable of West Mercia Police Constabulary* [2003] EWHC 3318 (Admin). **47** BBC News, Curate Takes Action over Abortion', Wednesday, 19 November 2003, accessed at http://news.bbc.co.uk/1/hi/england/hereford/worcs/3285601.stm on 27 September 2008. **48** For a critical discussion of these parliamentary debates, see K Savell, 'Turning Mothers into Bioethicists: Late Abortion and Disability' in Carney, Bennett and Karpin (eds), The Brave New World of Health, Federation Press, 2008) pp93-111. **49** Victorian Law Reform Commission, *Law of Abortion – Final Report* (2008), 45.

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