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# RESOURCE ALLOCATION AND THE BEGINNING OF LIFE

*Belinda Bennett\**

Like many other countries, Australia is increasingly being forced to face the spiralling costs of health care. Population increases, an aging population, and the high cost of many items of modern medical equipment and of medical care generally, have all contributed to the pressure on health care resources. Within this climate of resource scarcity, more and more questions are being asked about the prioritization of items of health expenditure. The aim of this article is to consider the claim of reproductive technology, prenatal care, and prenatal diagnosis on health care resources and to evaluate the balance between treatments and preventative measures.

## I. THE RISING COSTS OF MEDICAL CARE

Many countries clearly spend considerable resources on the provision of health care. From 1970 to 1990, Australia's total health care expenditure averaged at 7.1% of gross domestic product; compared to 9.5% in the United States, 7.8% in Canada, and 5.5% in the United Kingdom.<sup>1</sup> From 1982-83 to 1990-91, real total health expenditure in Australia (expressed in 1990-91 prices) increased from \$A22,401 million to \$A30,923 million, or by 72.4%.<sup>2</sup> During the same period, the average annual growth rate in total health expenditure in Australia was 4.1%.<sup>3</sup>

The impact of the aging of the population on health care is also significant. It is estimated that by the year 2010, 12.8% of Australia's population will be aged 65 years or over (an increase from 8.1% in 1950 and 10.9% in 1990), and that by 2025 the proportion will have increased to 17.5%.<sup>4</sup> Similar in-

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1. AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE, AUSTRALIA'S HEALTH 1992: THE THIRD BIENNIAL REPORT OF THE AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE 347 (1992) [hereinafter AUSTRALIA'S HEALTH 1992].

2. *Id.* at 339.

3. *Id.*

4. *Id.* at 299.

creases are expected in other countries. In the United States, an estimated 13.6% of the population will be 65 or over by 2010 (up from 8.1% in 1950 and 12.6% in 1990), and will increase to 19.8% by 2025.<sup>5</sup> In the United Kingdom, 15.7% will be 65 or over in 2010, rising to 19.4% in 2025, compared with 10.7% in 1950 and 15.4% in 1990.<sup>6</sup>

The elderly use a "disproportionate" share of health care resources.<sup>7</sup> More than 30% of actual hospital admissions in Australia are of persons aged 60 years or over, representing over 50% of bed-days in hospital.<sup>8</sup> The aging of the population in Australia and other comparable countries, and the shift from acute to chronic diseases as the cause of death,<sup>9</sup> will continue to place increased burdens on health care resources.

Advances in medical technology have also placed additional burdens on health care resources with the development of more expensive items of medical equipment or forms of medical treatment. Artificial life-support mechanisms, kidney dialysis, organ transplants such as of the heart or liver, and the new reproductive technologies are just some of the advances contributing to the squeeze on resources. Developments in diagnostic technologies have also had an impact. For example, computerized tomography (CT) scanners may cost up to \$A1.5 million.<sup>10</sup> Their use has become widespread. In 1985, Australia had 8.6 scanners for every one million people, compared with 14.7 for every one million people in the United States.<sup>11</sup> Magnetic resonance imaging (MRI) is also expensive. It has been suggested that in Australia, the use of MRI may have overall costs of \$A500-600 per examination.<sup>12</sup>

Because the cost of health care has risen, and appears likely to continue to rise, we are faced with the increased possibility that it may be necessary to ration health care resources. In short, allocation decisions may have to be made that will cause some people to miss out as the health care cake is

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5. *Id.*

6. *Id.*

7. As the Australian Institute of Health and Welfare notes: "For example, in Australia, it is estimated that 38 per cent of health expenditure in 1988-89 was for those aged 65 years and older. In June 1988, this group comprised 10.9 per cent of the population." *Id.* at 97. My use of the term "disproportionate" in the text here is used in a statistical rather than a normative sense and is not intended to imply that the elderly do not deserve these health resources.

8. *Id.* at 127-28.

9. NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL [AUSTRALIA], DISCUSSION PAPER ON ETHICS AND RESOURCE ALLOCATION IN HEALTH CARE 2 [hereinafter NH& MRC 1990 DISCUSSION PAPER].

10. AUSTRALIAN INSTITUTE OF HEALTH, AUSTRALIA'S HEALTH 1990: THE SECOND BIENNIAL REPORT OF THE AUSTRALIAN INSTITUTE OF HEALTH 173 (1990) [hereinafter AUSTRALIA'S HEALTH 1990].

11. *Id.* at 173-74.

12. These figures exclude interest and assume a public hospital setting. *Id.* at 184.

divided.<sup>13</sup>

In one sense, there is nothing new about the need to ration health care resources. Health care resources are never infinite. Rationing decisions are constantly being made at levels of both macro- and micro-allocation:<sup>14</sup> At the macro level, decisions must be made about the location of health services such as new hospitals and the location and even general availability of specialist services such as new and expensive forms of diagnostic technology.<sup>15</sup> As Justice Kirby has argued:

*[M]acro* decisions have their ripple effect. Ultimately, they affect the lives of ordinary people. For such people, either the tumor will be discovered early or it will not. Either the dialysis will be made available or it will not. Either the CT scan will be used or it will not. Either the *in vitro* fertilization program will be available or it will be denied. Either the heart or liver transplant will be ventured or it will not.<sup>16</sup>

The making of macro-allocation decisions involves certain opportunity costs as some services or treatments are not made available.<sup>17</sup>

At the micro-allocation level, physicians have been the traditional “gatekeepers” of medical resources.<sup>18</sup> Physicians have always been gatekeepers in some sense as they recommend “what tests, treatments, medications, operations, consultations, periods of hospitalization, or nursing homes the patient needs.”<sup>19</sup> This form of gatekeeping is exercised in the patient’s interests and involves no ethical conflict for the physician.<sup>20</sup>

In addition, health professionals have often had to make allocation deci-

13. Maxwell J. Mehlman, *Rationing Expensive Lifesaving Medical Treatments*, 1985 Wis. L. REV. 239, 241 (1985).

14. Beauchamp and Childress explain this distinction in the following terms:

[I]n general, macro-allocation decisions determine how much should be expended and what kinds of goods will be made available in society, as well as how it is to be distributed. These decisions are made by Congress, state legislatures, health organizations, private foundations, and health insurance companies. Micro-allocation decisions determine who will obtain available resources.

TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 283 (1989).

15. Michael D. Kirby, *Bioethical Decisions and Opportunity Costs*, 2 J. CONTEMP. HEALTH L. & POL’Y 7, 13 (1986).

16. *Id.*

17. *Id.* at 17.

18. Edmund D. Pellegrino, *Rationing Health Care: The Ethics of Medical Gatekeeping*, 2 J. CONTEMP. HEALTH L. & POL’Y 23, 23 (1986).

19. *Id.* at 26.

20. For a discussion of some forms of gatekeeping that may involve ethical conflicts, see, Pellegrino, *supra* note 18, at 27-29. On the issue of ethical conflicts and resource allocation see, Robert M. Veatch, *Physicians and Cost Containment: The Ethical Conflict*, 30 JURIMETRICS J. 461 (1990).

sions deciding how best to allocate limited time or medicine among a number of needy patients. Triage is one example of the rationing of health care resources. Although it developed on the battlefield, triage, "the practice of sorting patients according to the urgency of their needs under emergency conditions in which such needs are likely to be urgent and medical resources scarce,"<sup>21</sup> is regularly applied in the health care context as patients' medical needs are classified as "immediate," "urgent," or "nonurgent."<sup>22</sup>

Although there is nothing new about the rationing of health care resources per se, the spiralling cost of health care, the aging population, and population changes have all placed increased burdens on health care budgets and focused increased attention on the rationale for decisionmaking in this area. Indeed the bases upon which these allocation decisions are to be made, at the levels of both macro- and micro-allocation, have been and remain the focus of considerable attention from governmental and other bodies,<sup>23</sup> philosophers,<sup>24</sup> and in legal and health care<sup>25</sup> circles. Resource allocation in health care is becoming one of the issues in bioethical and medico-legal debates.

## II. THE IMPACT OF THE NEW REPRODUCTIVE TECHNOLOGIES

Like many recent developments in medical technology, the new reproductive technologies readily capture public attention. The success of "test-tube baby" technology appears to confirm the image of modern medicine as capable of achieving almost anything. Yet, like many other recent developments in medical technology, the new reproductive technologies have presented us with dilemmas over allocation decisions about resources against the backdrop of spiralling health care costs. Having been confronted with the fact that it is possible to assist human reproduction artificially, we must now ask ourselves whether we are prepared to meet the financial costs of providing reproductive technologies to the infertile.

### *Treatment of Infertility*

Four procedures are generally grouped under the umbrella term "new re-

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21. James F. Childress, *Triage in Neonatal Intensive Care: The Limitations of a Metaphor*, 69 VA. L. REV. 547, 548 (1983).

22. *Id.* at 550.

23. See e.g., NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL, AUSTRALIA DISCUSSION PAPER ON THE ETHICS OF LIMITING LIFE-SUSTAINING TREATMENT (1988).

24. See e.g., J. GLOVER, CAUSING DEATH AND SAVING LIVES at ch.16 (1977); BEAUCHAMP & CHILDRESS, *supra* note 14, at 283-306.

25. See, e.g., *Symposium, Rationing Health Care: Social, Political and Legal Perspectives*, 18 AM. J.L. & MED. 1 (1992); *Symposium, The Law and Policy of Health Care Rationing: Models & Accountability* (1992) 140 U. PA. L. REV. 1505 (1992).

productive technologies:" donor insemination (DI), in-vitro fertilization (IVF), embryo transfer (ET), and gamete intrafallopian transfer (GIFT). Although other technological developments such as sex selection, ectogenesis, or genetic engineering may also be considered by some to be reproductive technologies, they will not be so considered for the purposes of this discussion.

Donor insemination may be achieved in one of several ways. Donated gametes (sperm) may be introduced into either the cervical canal or the uterus of the recipient woman in the procedure known as artificial insemination, or artificial insemination by donor.<sup>26</sup>

With IVF, the actual fertilization of the human egg takes place outside the human body. In this procedure, eggs (oocytes) are collected from the body of a woman either with the assistance of laparoscopy or with the use of ultrasound. Once removed, the eggs are then mixed with sperm in order to achieve fertilization. If normal cell division and early development follows, the embryos will be placed in the woman's uterus in a procedure known as embryo transfer.<sup>27</sup>

GIFT uses the same techniques for collection of sperm and eggs as for IVF. Unlike IVF, however, GIFT fertilization does not take place outside the woman's body. Rather the sperm and eggs are introduced into the woman's fallopian tubes in order to allow fertilization to occur naturally.<sup>28</sup>

#### *The Success and Cost of Treatment*

Although accurate determinations of rates of infertility are difficult to establish, it is generally estimated that 10% of couples are infertile.<sup>29</sup> In 1990, in Australia and New Zealand, of 7153 IVF treatment cycles, 10.1% resulted in live births; of 2783 GIFT treatment cycles a live birth rate of 20.8% resulted.<sup>30</sup> An estimated 5000-6000 donor inseminations are performed annually in Australia. An estimated 6-10% per cycle result in a live birth.<sup>31</sup>

In 1987, the estimated cost of IVF for 5000 infertile couples in Australia was \$A30 million: \$A17 million paid by the Federal Government, \$A6 mil-

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26. NATIONAL BIOETHICS CONSULTATIVE COMMITTEE, ACCESS TO REPRODUCTIVE TECHNOLOGY: FINAL REPORT FOR THE AUSTRALIAN HEALTH MINISTERS' CONFERENCE 10 (March 1991) [hereinafter ACCESS TO REPRODUCTIVE TECHNOLOGY] (background paper for Australia Health Ethics Committee).

27. *Id.*

28. *Id.*

29. *Id.* at 7-8.

30. AIHW NATIONAL PERINATAL STATISTICS UNIT, ASSISTED CONCEPTION: AUSTRALIA AND NEW ZEALAND 1990 4, 6 (1992).

31. ACCESS TO REPRODUCTIVE TECHNOLOGY, *supra* note 26, at 14.

lion by patients, and \$A7 million by health insurance funds.<sup>32</sup> The cost of each IVF baby was put at about \$A40 THOUSAND.<sup>33</sup> In the United States, the cost of IVF has been put at \$3500-5000 per attempt.<sup>34</sup>

Clearly, IVF is an expensive form of medical treatment with what some may claim are relatively low success rates. Yet, the use of IVF as a means of alleviating infertility appears to have met with community acceptance. In the words of the Australian Federal Minister for Community Services and Health: "While these technologies are still developing, they are no longer purely experimental but are accepted medical procedures for the alleviation of infertility."<sup>35</sup> Even with such community acceptance, however, reproductive technology is not immune from the broader debates over resource allocation taking place in health care, which demand that the rationale of allocation decisionmaking be made explicit. Even if we accept at a general level that IVF and related techniques are worth providing, it will be necessary to consider the bases upon which access will be granted and the best possible means of ensuring that justice will be achieved.<sup>36</sup>

#### *Value for Money?*

Given the expense of the treatment, its apparently low success rate,<sup>37</sup> and the climate of resource scarcity, it is necessary to ask whether the new reproductive technologies give value for the money. Of course, the answer depends upon our criteria for measuring success,<sup>38</sup> but, for many infertile people, some chance of having a baby may be much better than no chance at all.<sup>39</sup> The issue of whether IVF gives value for the money has been framed by some writers in terms of a comparison between funding of research into reproductive technology and research into the causes of infertility and/or preventative health care measures:

In 1988, of the \$[A]37 million dispensed by the Medical Research Endowment Fund of the National Health and Medical Research Council, \$[A]1.84 million went to genetic engineering and geneti-

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32. MAX CHARLESWORTH, *DISTRIBUTING HEALTH CARE RESOURCES: ETHICAL ASSUMPTIONS* 40 (Background Paper For Australian Health Ethics Committee Seminar) [hereinafter *DISTRIBUTING HEALTH CARE RESOURCES*].

33. *Id.*

34. Laurie Nsiah-Jefferson, *Reproductive Laws, Women of Color, and Low-Income Women*, in *REPRODUCTIVE LAWS FOR THE 1990s*.

35. *ACCESS TO REPRODUCTIVE TECHNOLOGY*, *supra* note 26, at 1; *DISTRIBUTING HEALTH CARE RESOURCES*, *supra* note 32, at 40.

36. *See ACCESS TO REPRODUCTIVE TECHNOLOGY*, *supra* note 26, for a discussion of these issues.

37. *See supra* note 30 and accompanying text for IVF and GIFT success rates.

38. *DISTRIBUTING HEALTH CARE RESOURCES*, *supra* note 32, at 39.

39. *Id.*

cally related research; community health research was allocated about \$[A]160,805. IVF-related research received \$[A]433,659 while no money was given to research into the prevention of infertility. Breast cancer, the single biggest cause of death in Australian women, received \$[A]42,923 in research funds and cervical cancer \$[A]232,131.<sup>40</sup>

That "prevention is better than cure" is just as true for infertility as for other areas of health care. In the long run, preventative measures will undoubtedly be more cost-effective than treatment. Yet it does not necessarily follow that funding should be directed towards research on preventing infertility, to the exclusion of IVF-and related research. It is important for funds to be spent on both infertility research and infertility treatments (such as IVF), for only when both are funded will the health needs of society be met. As the authors of *Tomorrow's Child* argue, preventative measures will not assist those who are already infertile.

. . . [H]owever much was spent on prevention, there would still be some people who would seek infertility treatment. We do not feel it would be appropriate to offer them nothing. We therefore think that there should be some provision of infertility treatment, including reproductive technologies. It is also important that some research continues in these areas, because they may have spin-offs which can help far more people.<sup>41</sup>

Some feminists have been critical of the new reproductive technologies, claiming pronatalist social pressures leave infertile women little choice but to use the technologies;<sup>42</sup> that the women are exploited and depersonalized through the use of the technologies,<sup>43</sup> their bodies fragmented into a variety of reproductive components;<sup>44</sup> and that the technologies pose a real threat to

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40. ROBYN ROWLAND, *LIVING LABORATORIES: WOMAN AND REPRODUCTIVE TECHNOLOGIES* 225 (1992). See also L. HEPBURN, *OVA-DOSE? AUSTRALIAN WOMEN AND THE NEW REPRODUCTIVE TECHNOLOGY* 108-10 (further detailing the funding of women's health issues in Australia).

41. LYNDA BIRKE ET AL., *TOMORROW'S CHILD: REPRODUCTIVE TECHNOLOGIES IN THE 90s* 303 (1990).

42. Robyn Rowland argues:

In reproductive technology the 'choice' presented to infertile women is either to live the life of the infertile with all the social stigma and negativity which is currently attached to that, OR to undergo abusive, violent and dangerous procedures in the attempt to have a child.

ROWLAND, *supra* note 40, at 279.

43. Deborah L. Steinberg, *The Depersonalization of Women Through the Administration of 'In Vitro Fertilization*, in *THE NEW REPRODUCTIVE TECHNOLOGIES* 74 (Maureen McNeil, et al. eds., 1990).

44. *Id.* See also the collection of essays in *MAN-MADE WOMEN: HOW NEW REPRODUCTIVE TECHNOLOGIES AFFECT WOMEN* (Gena Corea et al. eds., 1985) [hereinafter *MAN-MADE WOMEN*]; *TEST-TUBE WOMEN: WHAT FUTURE FOR MOTHERHOOD?* (Rita Arditti, et al. eds.,

the continued role of women in the reproductive process.<sup>45</sup>

Although it is important for us to be aware of the impact of the new reproductive technologies on all women, and to endeavor to minimize any adverse consequences, the provision of reproductive technology as an infertility treatment also responds to the needs of women: infertile women. The validity of reproductive technology's claim to a share of health resources should, therefore, be recognized. In Australia, this was recognized by the former National Bioethics Consultative Committee when it concluded "that infertility is a serious disability and that the alleviation of its effects by the various forms of reproductive technology should be supported by public health care resources in the same way as other medical (surgical, hormonal[,] etc.) treatment for infertility."<sup>46</sup> In short, the issue is not whether funding should be directed to preventative measures or to reproductive technology. Both deserve funding and, given that prevention should be regarded as at least as important as treatment, they should be regarded as equally important in terms of funding priorities.

### III. PRENATAL CARE

There is no doubt that funding of prenatal care must always be a priority in the funding of health care. There is ample evidence to show that good prenatal care is an important element in good neonatal outcomes.<sup>47</sup> Lack of prenatal care and delivery services may lead to low birth weight and an increased risk of death in the child's first year.<sup>48</sup> Women of color and of low income appear to suffer disproportionately from inadequate prenatal care.<sup>49</sup> Financial and other barriers may hinder access to prenatal services.<sup>50</sup> The provision of prenatal care and other services is important to resource allocation for it allows for more efficient targeting of expensive treatments.

A change in focus from end-stage high-tech procedures aimed at individuals to broadly aimed basic prenatal care programs will make existing resources go further. When good prenatal care and

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1984) [hereinafter TEST-TUBE WOMEN] for feminist critiques of the new reproductive technologies.

45. Renate Klein, *What's 'new' about the 'new' reproductive technologies*, in MAN-MADE WOMEN, *supra* note 44, at 64, 70.

46. ACCESS TO REPRODUCTIVE TECHNOLOGY, *supra* note 26, at 40.

47. McNulty, *Pregnancy Police: The Health Policy and Legal Implications of Punishing Pregnant Women for Harm to Their Fetuses*, 16 N.Y.U. REV. L. & SOC. CHANGE 277, 293-94 (1987-88).

48. *Id.*

49. Dorothy E. Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality and the Right of Privacy*, 104 HARV. L. REV. 1419, 1446-47 (1991).

50. McNulty, *supra* note 47, at 298.

other health and social interventions are not available, the results are more difficult deliveries and more low-birth-weight babies needing expensive technologies. With fewer pregnancy complications, it should be easier to arrange for all those who need high-tech services to get them.<sup>51</sup>

Of course, it may be necessary to formulate prenatal services with particular groups in mind, such as pregnant drug addicts whose situation demands affordable and accessible prenatal care and treatment designed for their needs.<sup>52</sup> The provision of such services and programs will probably be expensive. However, as Wendy Chavkin points out, "they will be far less costly than hospital-based treatment of obstetric and neonatal complications of perinatal drug use, and hospital or foster-based custodial care of the children."<sup>53</sup>

#### IV. PRENATAL DIAGNOSIS

Many pregnant women will undergo some form of prenatal diagnosis during their pregnancy. For most, the testing may be no more than an ultrasound to confirm gestational age or detect multiple births. For women at risk of giving birth to a child with congenital or genetic disabilities, the availability of prenatal diagnosis takes on a much greater significance. Those at risk include women of "advanced" maternal age (generally regarded to be 35 years or over), women who have had a previous pregnancy resulting in the birth of a child with a chromosomal abnormality (for example, Down's syndrome) or neural tube defects, or women who have a family history of chromosomal or genetic disorders.<sup>54</sup> There is a marked correlation between maternal age and the risk of giving birth to a child with a chromosomal disorder. At age 20, the risk of giving birth to a child with Down's syndrome is 1:1,667; by age 35 the risk has increased to 1:385; and by age 45 the risk is as high as 1:30. Similarly, the total risk of giving birth to a child with chromosomal disorder increases dramatically with maternal age. At age 20 the risk is 1:526; at age 35 it is 1:192; by age 45 is 1:21.<sup>55</sup>

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51. Nsiah-Jefferson, *supra* note 34, at 40.

52. Wendy Chavkin, *Drug Addiction and Pregnancy: Policy Crossroads*, 80 AM. J. PUB. HEALTH 483, 486 (1990); McNulty, *supra* note 47, at 301-02; Michelle Oberman, *Sex, Drugs, Pregnancy, and the Law: Rethinking the Problems of Pregnancy Women Who Use Drugs*, 43 HASTINGS L.J. 505, 511-12, 546-47 (1992).

53. Chavkin, *supra* note 5, at 486.

54. NEW SOUTH WALES GENETICS SERVICE EDUCATION PROGRAM, PRENATAL DIAGNOSIS: SPECIAL TESTS FOR YOUR BABY DURING PREGNANCY - CHORIONIC VILLUS SAMPLING (CVS) AND SPECIAL TESTS 8 (1991) [hereinafter SPECIAL TESTS].

55. SHERMAN ELIAS & GEORGE J. ANNAS, REPRODUCTIVE GENETICS AND THE LAW 85 (1987).

A number of procedures are available that enable prenatal diagnosis of a large number of genetic, metabolic, or congenital conditions. The available procedures include ultrasound, amniocentesis, chorionic villi sampling (CVS), fetoscopy, and alpha-fetoprotein testing.<sup>56</sup>

Ultrasound is a visual diagnostic tool, often used in conjunction with other tests. The reflection of ultrasound waves from the fetal body enables an image of the fetus to be projected onto a monitor, either as a static image or in "real time," which permits fetal movement to be observed.<sup>57</sup> Ultrasound imaging may be used to confirm gestational age, detect multiple pregnancies, and to detect certain conditions including neural tube defects and cleft palate. Ultrasound may also permit fetal sex identification.<sup>58</sup>

Amniocentesis is usually performed at fourteen to eighteen weeks' gestation. The test involves removal of a small amount of amniotic fluid from the amniotic sac surrounding the fetus through a hollow needle inserted through the woman's abdomen. It is generally three to four weeks before the test results are available, as the fetal cells contained in the fluid must be cultivated prior to testing. Amniocentesis is usually accompanied by ultrasound imaging, which enables accurate location of the placenta, fetus and amniotic fluid.<sup>59</sup> The risk of serious maternal complications or fetal injury associated with amniocentesis is very low.<sup>60</sup> The risk of miscarriage associated with amniocentesis is approximately 0.5%.<sup>61</sup>

One major difficulty associated with amniocentesis is that it cannot be performed before fourteen weeks gestation. Allowing three to four weeks for the availability of test results, a woman who wishes to have an abortion following prenatal diagnosis of future disability must have her abortion during a relatively advanced stage of her pregnancy. In contrast, chorionic villus sampling (CVS) can be performed between nine and twelve weeks' gestation, thus allowing the possibility of a first-trimester abortion if a disability is detected.<sup>62</sup> CVS involves testing of the chorionic villi, or placental tissue, which have the same genetic information as the fetus. The removal of the villi may be achieved through one or two means: either the insertion of a hollow tube through the vagina and cervix into the uterus, or by means of a hollow tube through the abdominal wall. In both cases ultrasound is used as

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56. Bernard Dickens, *Abortion, Amniocentesis and the Law*, 34 AM. J. COM. L. 249 (1986).

57. *Id.* at 251.

58. Abby Lippman, *Access to Prenatal Screening Services: Who Decides?*, 1 CANADIAN J. WOMEN & L. 434, 436 (1986).

59. ELIAS & ANNAS, *supra* note 55, at 122; SPECIAL TESTS, *supra* note, 54 at 9.

60. ELIAS & ANNAS, *supra* note 55, at 129.

61. SPECIAL TESTS, *supra* note 54, at 11.

62. Lippman, *supra* note 58, at 436.

a means of guidance.<sup>63</sup> The miscarriage rate associated with CVS is approximately 2%<sup>64</sup> and as such is much higher than that of amniocentesis.

Fetoscopy, like ultrasound, is a visual diagnostic tool. However, unlike ultrasound, which presents a picture of the fetus from outside the womb, the image presented by fetoscopy is from inside the womb. Fetoscopy involves the insertion of an endoscope, a hollow needle with a viewing device on the end, into the amniotic sac. By allowing the fetus to be seen in utero, fetoscopy permits diagnosis of observable disabilities such as cleft lip.<sup>65</sup> In addition, biopsies of fetal skin or fetal blood testing may be performed, permitting further testing. The procedure may be of limited use since it has a miscarriage rate of 3 to 5%.<sup>66</sup> Finally, screening of maternal blood for alpha-fetoprotein (AFP) enables identification of women whose fetuses are more likely to suffer neural tube defects. Affected women may then undergo further testing in order to determine whether the fetus is affected.

The availability and use of prenatal diagnostic technologies provides women with technologies of both reassurance and prevention:<sup>67</sup> they are reassured that their pregnancy is proceeding normally and that there are no signs of disability in the developing fetus or, if there are indications of disability, they may consider terminating the pregnancy.<sup>68</sup> Lippman argues that prenatal testing is justified in terms of women's needs and that it is important for us to assess the manner in which those needs are socially constructed: through the allocation of responsibility for the health of the child to the pregnant woman;<sup>69</sup> by the fact that the technology provides "external verification" that everything is alright;<sup>70</sup> by labelling women of a certain age group as being "at risk" of having a child with disabilities;<sup>71</sup> by the fact that as prenatal diagnosis becomes increasingly routine for "older" women, the disabilities it seeks to diagnose appear more threatening;<sup>72</sup> and prenatal diagnosis answers the "public health 'need' to reduce unacceptably high levels of

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63. SPECIAL TESTS, *supra* note 54, at 3-5.

64. *Id.* at 6.

65. Dickens, *supra* note 56, at 252.

66. ELIAS & ANNAS, *supra* note 55, at 140.

67. Abby Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 17 AM. J. L. & MED. 15, 22 (1991). Lippman argues that there are two models of prenatal diagnosis is presented as a way to reduce the frequency of selected birth defects. "In the other, . . . the 'reproductive autonomy' model, prenatal diagnosis is presented as a means of giving women information to expand their reproductive choices." *Id.* (footnote omitted).

68. *Id.*

69. *Id.* at 27-28.

70. *Id.* at 29.

71. *Id.* at 29-30.

72. *Id.* at 30-31.

perinatal mortality and morbidity associated with perceived increases in 'genetic' disorders."<sup>73</sup>

So, where does prenatal diagnosis fit into the debate over resource allocation? Even accepting that perceived needs for prenatal diagnosis may be socially constructed as Lippman argues, and acknowledging the disquiet that some have expressed over the implications of prenatal diagnosis for people with disabilities,<sup>74</sup> it seems clear that prenatal diagnostic services should be available.<sup>75</sup> However, it is vital to ensure that adequate funds are available to publicize the existence and availability of the services so that women know they exist.<sup>76</sup> It is also vital to provide comprehensive counselling on genetics and disabilities in order to ensure that prospective parents, faced with a diagnosis of a future disability, will have sufficient, accurate information upon which to base their decisions.<sup>77</sup>

Effective counselling can assist prospective parents faced with a positive prenatal diagnosis to come to terms with both the medical and the social implications of the particular disability. Public understandings of disability are imperfect. In part, the lack of understanding about disability is due to a lack of comprehension about its lived realities. It is extremely difficult, if not impossible, for able-bodied individuals to comprehend life with a disability. Walking around with one's eyes closed cannot even begin to approximate the realities of blindness because the person with sight always retains the ability to open his/her eyes in the event of danger (e.g. the risk of falling), if he/she wishes to read the newspaper, or if the "game" simply becomes boring. Similarly, spending a day in a wheelchair does not mirror the experience of paralysis because the able-bodied individual always retains the ability to stand up. In general, those without disabilities cannot accurately imagine the reality of life with a disability, in either its highs or its lows.

The difficulty of comprehension is not the only barrier to understanding. Many able-bodied individuals may not wish to confront disability even at the level of attempting to imagine a life with a disability. They may feel a sense

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73. *Id.* at 31.

74. Adrienne Asch, *Reproductive Technology and Disability*, in *REPRODUCTIVE LAWS FOR THE 1990s*, *supra* note 34, at 69; Anne Finger, *Claiming All of Our Bodies: Reproductive Rights and Disability*, in *TEST-TUBE WOMEN*, *supra* note 44, at 281; Saxton, *Born and Unborn: The Implications of Reproductive Technologies for People With Disabilities*, in *TEST-TUBE WOMEN*, *supra* note 44, at 298.

75. As the authors of *Tomorrow's Child* argue: "If prenatal diagnosis were to be banned altogether, then some women, who might have chosen not to, will be dedicating their lives to the care of their handicapped children and some children, who might otherwise not have been born, will lead short and painful lives." BIRKE, *supra* note 41, at 291.

76. Nsiah-Jefferson, *supra* note 34, at 33.

77. See Asch, *supra* note 74, at 90; BIRKE, *supra* note 41, at 292-93.

of uneasiness, fear, or even aversion when confronted with disability.<sup>78</sup> There may be a fear of those who look different, or a fear of the disability itself.<sup>79</sup> Able-bodied people may feel distinctly uncomfortable around those with disabilities due to the fear of being similarly disabled.<sup>80</sup> In addition, people with disabilities may make limiting assumptions about disability, such as the assumption that it is the individual's physical impairment rather than socially and environmentally imposed constraints that create difficulties;<sup>81</sup> the construction of the person with disabilities as a victim;<sup>82</sup> the assumption that the individual defines himself or herself primarily in terms of their disability rather than in terms of other factors such as occupation, race, gender, or class;<sup>83</sup> and finally, the assumption that those with disabilities are helpless or incompetent and in need of social services and support.<sup>84</sup> These assumptions form an image of a limited life of an individual who is helpless and a victim of his or her disabilities. It is an image that may be vastly at odds with the self-image of those with disabilities. Some or all of these assumptions may affect the perceptions of prospective parents concerning the quality of life of a future child with a disability.

Effective counselling can therefore provide prospective parents with sufficient, accurate information about the particular disability so they can make informed choices and decisions. Yet in order to be really effective, such counselling must be non-judgmental and sensitive to cultural beliefs.<sup>85</sup> In addition, it is essential that counselling be available in community languages so that women of non-English speaking backgrounds can avail themselves of the services.<sup>86</sup>

## V. CONCLUSION

As the pressures over resource allocation in health care become more acute, the need to consider the rationale upon which rationing decisions are made becomes more pressing. As we seek to ensure that rationing decisions

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78. Harlan Hahn, *The Politics of Physical Differences: Disability and discrimination*, 44 J. SOC. ISSUES 39, 40-41 (1988).

79. *Id.* at 42.

80. *Id.* at 42-43. Hahn argues that "the threat of a permanent and debilitating disability, with its resulting problems, can even outrank the fear of death, which is, after all, inevitable." *Id.* at 43.

81. Michelle Fine & Adrienne Asch, *Disability Beyond Stigma: Social Interaction, Discrimination, and Activism* 44 J. SOC. ISSUES 3, 9 (1988).

82. *Id.* at 10-11.

83. *Id.* at 12.

84. *Id.* at 12-13.

85. Nsiah-Jefferson, *supra* note 34, at 34.

86. *Id.* at 32-33.

are just it will be important to consider general social inequalities and the relevance of these inequalities to the construction of health needs. The balance between preventative measures and treatment; the implications of poverty, disability and cultural difference; and the rights and needs of particular social groups, as they perceive and advocate them must all be included in the formulation of allocation rationale. Unless these factors are taken into account, allocation decisionmaking, whether it be through legislative measures, governmental bodies, or through more informal means, will simply reproduce rather than remedy existing health inequalities.