

## **Prenatal screening, ethics and Down's syndrome**

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### **Abstract**

Universal prenatal screening services for Down's syndrome are growing fast and have important ethical dimensions. The medical and midwifery press scarcely consider these but concentrate on how to make screening more sensitive and specific, cost-effective, and open to prospective parents' choices. Emphases in mainstream bioethics on cost-benefit analysis, respect for the rational autonomous person, on freedom of choice, and non-maleficence, which now includes the notion of preventing a wrongful life, can all be used to condone screening for Down's syndrome. Mainstream bioethics is compared with more critical approaches. Professional and mainstream bioethics concerns can divert attention from two prior questions considered in this paper: Why screen for Down's syndrome? And on what evidence and logic are the arguments which support screening based?

### **Key words**

prenatal screening, ethics, Down's syndrome, disability, learning difficulty, mental retardation

### **Introduction**

Over the past three decades, prenatal screening and bioethics have both expanded rapidly. They now affect Western prenatal care generally, in terms of how professional time, expertise and resources are organised and rationalised, in relationships between pregnant women and prenatal staff, and in professionals' efforts to prevent litigation and to offer informed choice. This paper reviews the symbiosis between screening technologies and mainstream bioethics, taking Down's syndrome as a case study. Rather than offering independent and critical analyses of prenatal practices, mainstream bioethics tends to reinforce the liberal assumptions underlying clinical policies.

### **Prenatal tests over three decades**

There is an increasing trend towards universal prenatal testing for Down's syndrome (Reid, 1990). The first antenatal diagnosis of Down's syndrome by amniocentesis was made in 1968 (Wald *et al.*, 1997). Since the 1980s, chorionic villus sampling has also been widely used. These invasive diagnostic tests are now usually preceded by maternal serum screening and/or ultrasound scanning to select pregnancies at higher risk of having Down's syndrome. Serum screening is routinely offered to pregnancy women or administered not necessarily with their knowledge or consent (Green and Statham, 1996; Marteau *et al.*, 1988). During the 1990s, screening for Down's syndrome, through ultrasound scanning for a nuchal fold in the fetal neck, became more universally applied (Nicolaidis *et al.*, 19992).

### **Birth rates and Down's syndrome**

In England, the rate of Down's syndrome per 100,000 total births fell steadily from 8.6 in 1982 to 5.7 in 1992 when 371 babies were born (OPCS, 1994) despite the rise in average maternal age. In 1996, 319 babies with Down's syndrome were born (Mutton *et al.*, 1998), although the birth rates may be under-estimated by about one half (Huang *et al.*, 1997) and Olsen *et al.* (1996) and Saridogan *et al.* (1996) found that screening has not reduced the live birth prevalence significantly. Wyllie *et al.* (1997) reported that of 412 pregnancies with Down's syndrome, 78 per cent resulted in a live birth.

## **Policies**

It is uncertain how many cases were "missed" by screening, or how many women chose more or less deliberately to continue their pregnancy, and why, or how much the general public is concerned to reduce the birth rate of babies with Down's syndrome.

The main drive towards introducing screening appears to come from medical agencies (Reid, 1991), not from lay people through public or parliamentary debate. In Britain, no laws regulate screening. Policies are formulated by expert (mainly medical and health economics) advisory committees, which issue guidance. Economics influences screening policies through three main aims: to reduce the "life time costs of care" for people with Down's syndrome; to avoid costly litigation for "wrongful birth" of undiagnosed cases; and to develop comparatively cheaper although also profitable technologies. The estimated costs of £38,000 worth of screening "for each Down's syndrome birth avoided" were compared with £120,000 for the "lifetime care" of an individual with Down's syndrome (Wald *et al.*, 1992). This assumes a high rate of terminations after diagnosis, and further assumes that people with Down's syndrome cannot contribute to society, and need expensive support, without providing any supporting evidence. Current screening costs appear to be too low, given the evidence of inadequately informed counselling (Smith *et al.*, 1994), and the need to train under-informed staff (Sadler, 1997). Close links between national policy making and commercial concerns are illustrated by the NHS Report which advocates universal antenatal screening for Down's syndrome; the lead author is a director of the company which markets the necessary soft-ware (Wald *et al.*, 1998).

Screening is complicated by high false positive and false negative rates. Some clinicians calculate a net gain to society, because of the severity of Down's syndrome, of screening 100,000 pregnancies, involving 3,000 amniocentesis (2,960 with negative results) incurring the inadvertent miscarriage of 30 (one per cent) of unaffected fetuses, in order to reduce the incidence of Down's syndrome from 100 to 60 live births. Two per cent of terminations are found to be unaffected (Painton, 1997). Others are less certain of the benefits. Fletcher *et al.* (1995) compared different screening policies for Down's syndrome using "a decision tree that combined data from local sources and the medical literature to predict the likely frequency of several outcomes. Sensitivity analyses were used to test the robustness of the conclusions drawn.... Each option for screening for Down's syndrome that we considered had significant drawbacks. In Oxfordshire, offering serum testing to women of all ages would prevent the birth of approximately one more baby with Down's syndrome per year than would a policy of screening for women aged 30 years or more. The cost of preventing this one extra Down's birth would be one or two normal babies lost after amniocentesis, 4500

blood tests for young women (with the associated anxiety and counselling), approximately 200 false positive serum test results and amniocentesis (with the associated anxiety and distress), and £90,000 for the extra tests, counselling, and amniocentesis. Opinions are divided as to which policy is the better option for the population.” The authors advised focussing “debate and decision making on outcomes of care, which in turn makes it clear that the choice of screening programme for Down's syndrome depends on the relative importance ascribed to the different outcomes. If individuals' values vary widely it may be impossible to find one screening policy that meets the needs of all pregnant women.”

By 1998, universal maternal serum screening was officially proposed in the UK (Wald, *et al.*, 1998). In an unusual step, the Netherlands Screening Act (1996) prohibited routine use of the serum test, and required that it be an opt-in test by request only.

The mass media tend to welcome new medical technologies including screening as signs of progress towards better health for all. Detailed cost-benefit considerations, such as those given by Fletcher *et al.* (1995) are not discussed in the public media. However, personal stories by parents about how highly they value their child who has Down's syndrome occasionally appear in newspapers, midwifery and women's magazines (Alderson, 1997). Yet these individual accounts are in marked contrast to the general media trend to stress the benefits of screening. The next sections give examples of related discussion in the British medical and midwifery literature.

### **The medical literature**

This section reviews how the medical literature tends to assume negative views of Down's syndrome as “the most common form of severe mental retardation” linked to “precocious dementia of Alzheimer type” (Takashima 1997). Abortion is seen as the only “effective remedy” and to some authors, prenatally, ethics becomes a matter of providing screening services which are “quantified and predictable” (Wald *et al.*, 1998:5).

Numerous papers report research, through fetal imaging, for more precise anatomical indicators of Down's syndrome, such as relative chest size (Petrikovsky, *et al.*, 1996) and “cardiac abnormalities, duodenal atresia, femur length, humerus length, pyelectasis, and hyperechogenic bowel” (Wald *et al.* 1997). In explaining the practical value of the research findings, Heuther *et al.*, (1996) and others combine the contradictory aims of encouraging personal choice versus conducting public health programmes designed for the “continued reduction in incidence prevalence rates for Down's syndrome through prenatal diagnosis and elective abortion,” a distinction which the geneticists Harper and Clarke (1997) repeatedly stress should be observed.

Medical journals also publish many items on how to refine prenatal tests and calculate their cost effectiveness (as found in a review of all copies of the *British Medical Journal*, 1994-1999, and on Medline). Serra-Pratt *et al.* (1998) define “major trade-offs” for certain screening programmes in terms of detection rates, false-positive results, lower inadvertent fetal loss and costs. Methods of screening are also “validated” by evidence that they are cheaper than another type (for example, Vintzileos *et al.*, 1998).

Another wide-spread concern is how to clarify decision making rules for pregnant women and staff. Cuckle *et al.* (1996) advise using “graphical information in

nomograms when counselling women considering whether or have maternal serum screening, using a statistical modelling of the frequency distribution of estimated Down's syndrome risk for four marker combinations: maternal age, detection and false-positive rates, and the proportion of pregnancies with different estimated risks." They conclude that "when screening is offered, clinicians need to have information readily available on test accuracy and the likely result, which is specific to the individual." Thornton (1994) uses diagrams of doorways to make "stark simple choices", showing how choosing one option closes off others, in his efforts to speed and clarify decision-making.

Paediatric text books tend to describe Down's syndrome negatively as *not treatable* (Goodman and Scott, 1997), or mention it only in reference to prenatal screening, (Cade *et al.*, 1995). The journals also emphasise childhood pathology. Brookes and Albermarle (1996) followed up 100 children with Down's syndrome to five years after birth, and found high mortality and morbidity rates. They concluded that "this negative information as well as that regarding the more positive aspects of Down's syndrome, should be made available to those counselling parents [prenatally]". Records for nearly one third of the sample were not traced and, typically, the medical authors do not explain what the "more positive aspects". In contrast, a study of 280 cases of Down's syndrome, identified prenatally and followed up to one year after birth, attributed the poor health rates to lack of "necessary care" by parents and health professionals, and commented that the "influence of prenatal diagnosis of chromosome disorders as a determining factor of the social acceptance of Down's syndrome is still questionable" and may partly account for sub-standard health care of affected children (Julian-Reynier *et al.*, 1995).

One in six children with Down's syndrome has a heart defect. However, Abu-Harb *et al.*, (1995) concluded that "screening for Down's syndrome is likely to have only a small effect on the requirements for paediatric cardiology services", after reviewing 1347 infants with heart disease in one region, and should not be a reason to attempt to economise on cardiac costs by terminating affected pregnancies. Despite the high incidence of heart defects, no one with Down's syndrome, so far in Britain, has had a heart transplant. During publicity about Katie Atkinson aged 9 who has Down's syndrome, when doctors refused to consider her for a transplant, the Department of Health stated in news bulletins on 26 July 1999 "there is certainly no ban on people with Down's syndrome receiving organ transplants." Clinicians cite the shorter life expectancy of people with Down's syndrome as an obstacle, but less than half the heart transplantation cases survive for more than ten years (Heart 1999 82:47-51), an expected survival time well within the lifetime of teenagers with Down's syndrome. To deny treatment to children because of shorter life expectancy, and thereby to contribute to reducing their life span, becomes a circular argument.

Unpublished professional case reports, including medical statements of special educational need, often emphasise difficulty, inability and need, for the useful purpose of seeking to obtain more resources and services for the child. Many parents and *self-help* organisations similarly (over)emphasise the frequency and severity of the problems, believing that this will benefit affected people by increasing professional support and public funding. All such reports serve specific purposes, but may be mistaken for stating general comprehensive truths about the condition.

Children with Down's syndrome may be considered less worthy of costly care because of their average lower intelligence. Yet their IQ ranges from 10 up to 92 or almost normal (Lorenz 1984), and their educational achievements and expectations are rising considerably (Alderson and Goodey, 1998). Prenatal prognoses are complicated, not only by uncertainty about the severity of each case, but also by the immensely wide-ranging and unpredictable effects of future life style, social changes and opportunities for people with Down's syndrome. Equally crucial are the attitudes of all concerned, for instance in seeing problems as insuperable barriers or as challenging opportunities. The medical literature mainly sees "mental retardation" as biological and immutable. In contrast, the disability literature sees "learning difficulties" as partly socially constructed (Morris, 1998; Ward 1997). As shown later, the two approaches encourage different ethical viewpoints.

Some notable exceptions in the medical literature are more cautious about prenatal screening and take greater account of social perspectives. Santalahti (1998) records women's distress about screening and terminations, and Clarke (1997: 123) accepts that children "with Down's syndrome often do not suffer physically. Because the promotion of prenatal screening for Down's syndrome may actually promote the stigmatization and intolerance that is a major cause of the suffering experienced by many affected individuals and their families, it is not at all clear that such screening is helpful."

Psychological surveys also tend to qualify the benefits of prenatal screening by measuring women's anxiety and exploring ways of reducing this (for example, Green and Statham, 1996; Marteau and Coyle, 1998). For example, Kornman *et al.* (1997) reported that three quarters of the Dutch women they questioned would prefer first trimester testing because of the easier termination of pregnancy and/or the earlier reassurance provided.

### **The midwifery literature**

This literature emphasises the utilitarian ethics of providing efficient screening services, rather than questioning their overall value and justice, purpose and social effects. This observation is based on a review of articles on the computerised lists at the Royal College of Nursing and Royal College of Midwives libraries, and a hand search review of *MIDIRS* journal). Jokey titles like "It could be you" (Rogers, 1997), the slogan of the British lottery, suggest that "positive" test results are hardly seen as raising profound ethical problems. A rare reference to women's distress attributes this to fear of the syndrome; "the prospect of having a child whose prognosis [with Down's syndrome] is deemed very bleak by conventional medical opinion" (Grayson 1996).

Most midwives support universal prenatal screening for Down's syndrome (Fairgrieve *et al.*, 1997; xSandall). Authors such as Ockenden (1997) report only the advantages of "informed choice", and not possible drawbacks, that not all the choices may be informed or welcomed. The Royal College of Midwives guide to pregnancy and childbirth (RCM and Boots, 1997) features smiling women with pretty babies featured among many other commodities in the glossy advertisements. The style is light and the explanations brief. With Down's syndrome (p 17) "People with Down's syndrome usually need care and support for the whole of their lives." So does everyone to some extent, and it is not clear how much more care people with Down's syndrome receive or actually require.

A few articles take more positive approaches towards Down's syndrome, such as one qualitative evaluation of support for ten mothers who chose to continue their

pregnancy after diagnosis of Down's syndrome (Helm and Miranda, 1998). These articles are cautious. It is assumed that women need much extra support, and Atherton, (1996) warns, "Of course, the life of a child with a learning disability cannot be guaranteed to be trouble free", although no one's life can be so guaranteed.

A main change for midwives is their increasingly technical and scientific prenatal role, in explaining the range of tests and their statistically complex results, rather than concentrating, as in former decades, on physical and emotional care. A woman may be told for example, "You have a raised serum level of over 1 in 250", possibly with mention of alphafetoprotein and human chorionic gonadotrophin. "There's a higher chance you might have a handicapped baby. Do you want to have an amnio, to make sure?" The "handicap" may not be precisely explained, but if they are warned that "trisomy 13 is also a possibility, when the baby may die after a few weeks", women may opt for a test hoping to resolve fears of more severe conditions than Down's syndrome. There may be quite detailed explanations of Mendelian inheritance patterns, although these are irrelevant to the chromosomal and neutral tube disorders which maternal serum screening searches for. Some nurses welcome this new stage of nursing as raising the profession's scientific status and authority (Sigmon *et al.*, 1997). Yet evaluations suggest that practitioners tend not to understand or explain screening test results clearly (Smith, Shaw and Marteau, 1994), thus raising ethical questions about the benefits of midwives' increasing involvement in screening, which the literature does not clearly address.

### **Mainstream bioethics and Down's syndrome**

This section considers dominant and here called "mainstream" influences of bioethics on prenatal screening which both share a concern for non-directive methods of decision making, and also share influential underlying values. In the *Journal of Medical Ethics* (April 1999, 35,2) several articles interpret principles of social justice and personal autonomy to advocate increased medical authority over activities such as prenatal screening, informing families about their gene pool, preimplantation diagnosis, embryo selection and cloning. Other papers in this issue challenge what are identified as a eugenic and anti-disability stance in the former articles. The special issue illustrates the diversity and lively debates in bioethics, and also the way some influential bioethics authors overtly or implicitly apply bioethics principles in ways described later in this section.

It is crucial to emphasise that bioethics is often subtly and densely argued. However, mainstream bioethics principles (for example, Beauchamp and Childress, 1983; Gillon, 1994; and as applied in Glover and Glover, 1996) are open to varying interpretations. Like any complex, influential philosophy, bioethics is inevitably liable to be widely understood and applied to specific practices in rather simplified ways. The main impact of sophisticated bioethics on health services policy and practice is mediated through the way busy practitioners apply the theories. So, in many clinical meetings I have observed, reference to ethics tends to be a check list of the main principles. This section shows how simplified principles can be interpreted in ways that raise problems for people with Down's syndrome. The following section will review more complex bioethics analyses.

*Respect for autonomy* emphasises vital regard for the rational person's body and mind, property and privacy, for protection from unwanted medical interventions, and for treating persons as ends in themselves and respecting their informed, voluntary

consent (Kant, 1948). Yet such respect can set an all-or-nothing standard, which offers no respect or protection to anyone deemed non-rational, such as people with Down's syndrome, or not fully a person such as a fetus. The higher the respect for rational persons, the greater their potential power to treat nonpersons as property (Mendus, 1987; Brazier, 1996), especially if conflicting interests are framed, for example, as maternal rights versus child or fetal rights (Bromham *et al.*, 1990). When the intellect is highly prized in definitions of human identity, and in bioethics decision making, this can further disadvantage people with the lesser or different kinds of understanding considered later.

*Cost-effective justice* in bioethics is the proper distribution of resources by merit or need. The frequent emphasis on cost-effectiveness leans towards limiting and rationing public resources in order to respect the rights of tax payers, to promote self-help and discourage dependence. These policies can pose problems for people with Down's syndrome who need extra support. The implicit individualism in mainstream bioethics concepts of justice, similar to the individualised biological medical model of disability mentioned earlier, can ignore structural changes in society towards greater inclusion, which benefit people with Down's syndrome.

*Nonmaleficence* rightly avoids unwanted and ineffective medical interventions. Yet harm is also defined as untreated or untreatable "disease" when Down's syndrome is confused with physical or mental illness; as "wrongful life" when health professionals do not prevent the birth of a child with Down's syndrome which is assumed to be a life not worth living; as the "suffering" which life with Down's syndrome is believed to involve for the individual or the family. Harris (1990:172), referring to Down's syndrome, speaks expansively of "suffering as shorthand for a whole range of disadvantageous conditions. I do not literally mean being in pain or being in discomfort". Lilford (1990) describes women who "clearly regard a baby with Down's syndrome as an infinitely worse outcome than losing a normal baby from a prenatal diagnostic procedure". Tooley (1983), Kuhse and Singer (1985), and Harris (1985) advocate infanticide as well as feticide of impaired infants; they argue that, as non-persons unable to be conscious of consciousness or to value their life, these infants cannot be harmed. Nonmaleficence can cover the harm of withholding medical information, which thereby disrespects patients' autonomy, decision making and potential to avoid the harm of having a child with Down's syndrome.

*Beneficence* can mean to identify, treat, cure, palliate or prevent disease and to promote physical and mental health. Down's syndrome, when seen as a set of untreatable and severe anomalies (Goodman and Scott, 1997) which could be taken as hopelessly unsusceptible to any medical beneficence except prevention through termination. When beneficence as caring or deciding for others appears to conflict with respect for autonomy, beneficence is criticised as the harm of paternalism. Health staff therefore aim to give non-directive information to enable competent people to make their own decisions.

*All these principles* help to promote patients' interests and high standards of care although, as shown, they can be interpreted positively or negatively.

### **Critical ethics**

The term "critical ethics" here covers bioethics and other literature which takes less clear cut, less popularised approaches, with greater account of the surrounding

social and political context, and of inner feelings and relationships than mainstream ethics tends to take. Critical texts raise important questions and reservations; they show how mainstream ethics, rather than being neutral, tends to be based subliminally against pregnancy, childbirth and disabled people. A few of the critical approaches are summarised here, on risk management, autonomy, xetc

*Protecting women from risk paradoxically expose them to medical power* Many feminists, like mainstream ethicists, promote women's autonomy and independence, but they show how women are disadvantaged by inequalities of gender, income, education and control over power and resources (Ramazanoglu, 1989; Sherwin, 1992), and how childbearing and child care hold women in subordinate positions and make them sick (Doyal, 1995). This can repeat the mother-child conflicts in mainstream ethics discussed above, and can paradoxically make women more vulnerable. The more the fetus's future is seen as provisional and potentially hostile to the woman's interests, as the threat or enemy within, open to clinical inspection ostensibly to offer women choice, the more licensed invasive prenatal care becomes. Efforts to protect women from risk, partly paradoxically, make them more vulnerable to intrusive services. Feminists criticise debates about *in vitro* (in glass) fertilisation which ignore women, but prenatal ultrasound literally renders the woman, and potentially her own autonomy, invisible.

*Autonomy through relationships instead of isolation* Opportunity for choice helps women who unequivocally want an abortion. It does not necessarily help women during a longed-for pregnancy, those who are uncertain about accepting a disabled child, cases when the severity of the fetal condition is unknown, women who would rather accept fate than take on responsibility through choice, those who identify parenthood with unconditional acceptance of the child, or who want to enjoy a fulfilling rather than a tentative (Rothman, 1994) pregnancy. Setting the assumed interests of these women potentially against the fetus can deny them autonomy, while aiming to safeguard it.

Ross (1995) and Adams (1995) review contradictions about motherhood when medicine and psychology tend to denigrate yet also to fear it, and when women and children struggle with the contradictions of motherhood as very fulfilling yet constraining. They review how problematic masculine concepts of autonomy and justice are for women. The morality of motherhood tends to be analysed crudely, as fitting neither public, masculinist principles of disinterested duty to the abstract unknown other, not intimate relationships, which Kant (1948) did not count as moral because they are "instinctive" and mutually rewarding not sacrificially altruistic (Seidler, 1986; Benhabib and Cornell, 1987). Yet this ignores how very demanding parenting can be.

Kantian extremes of isolated autonomy, never being another person's means, are incompatible with pregnancy and motherhood: women are the means for their future children's existence, and children inevitably invade their parents' liberty and use their property. Human autonomy, when defined in intellectual terms (to be conscious of consciousness) excludes children and people with learning difficulties (if they are assumed to be unselfconscious). When Kantian autonomy is assumed to be neutral, factual and universal, rather than a quite recent Western theory about male humanity, it can covertly bias prenatal consultations and policies, and endorse hostility towards the fetus, more so to an impaired fetus, as a threat to the woman's autonomy. A child with Down's syndrome is seen as making far above average



demands on the parents, being exceptionally dependent, and giving far less satisfaction. Prenatal decision-making and the related literature, including this paper, are intellectualised, drawing on philosophy, science and statistics. Yet human relationships are perhaps far more to do with doing and feeling ways forward through experience. A sociology of prenatal decision making and ethics could helpfully ground these events in the everyday experiences from which they are partly artificially lifted by new technologies.

Mainstream bioethics often slips over the crucial public/private distinction by treating “respect for autonomy” as if it applies equally to all relationships, including mother and child ones, or else as if, without full equal autonomy, a relationship is not a fully human, ethical one. When ethicists deny that the fetus “exists” as a person or potential person, this can dismiss abortion as a non-event, as if there is no form of life to end.

The mother-child psycho-biological relationship is stretched into a model for all social-economic relationships, and burdened into being a source and symbol of healthy or unhealthy societies (such as when crime is blamed on poor mothering). So traditionally, men were seen as guaranteeing order as “gatekeeper(s) between public and private spheres, while women and especially mothers represent the disorderly matter that must be sorted out” (Adams, 1995:416). These subliminal psychological and political fears help to explain why modern policy makers promote technologies to regulate reproduction, despite scarce prenatal resources and staffing. Pfeffer (1993) shows why there is little public debate about these funding decisions, because governments are loathe to be openly associated with potentially eugenic services. They eschew “front door” public programmes, and use “backdoor” approaches of offering women individual choices (Paul, 1992), although the net effect is the same in the reduction of birth rates of certain conditions. The acceptance of very high costs per Down’s syndrome birth prevented, mentioned earlier, may be explained partly by general masculine fears of unregulated fertility.

Referring to research such as Oakley’s (1993), Adams (1995:427) comments that some feminists see that mothers function “often against great adversity” to balance “both emotional/biological and social/economic levels [thereby] mothers have brought about profound social and economic changes that outstrip the interpretative power of representations of motherhood”. Detailed studies of women’s ambivalence, for example after learning their fetus has Down’s syndrome (Santalahti *et al.*, 1998) or their conflicting feelings about their disabled child (Larson, 1998) show the contrast between the relative clarity of mainstream ethics and the complex realities. “In the embrace of paradox mothers created a positive bias and regained a sense of control that fuelled their optimism in maternal work” (Larson, 1998).

Noting similar ambiguities in lay people's views on the new genetics Cunningham-Burley *et al.* (1998) believe that "rather than being a reason to discount lay views, we suggest that ambivalence should be a resource for critical discussion of the new genetics". Jallinoja (1998) and Jallinoja *et al.* (1998) agree that "contradictory attitudes towards genetic testing should be given greater significance" in research and in clinical practice. Gilligan's (1982) research, showing how men tend to fear intimacy and women to be reassured by it, helps to explain gender differences between isolationist mainstream ethics and "critical ethics", mainly by women, that takes greater account of relationships and feelings. Feminists tend to see autonomy as realised and enriched through relationships, in which people are fulfilled rather than diminished. These and other research propose different concepts through which to research pregnant women's responses to screening and disability.

*Paradoxes of fear and reassurance* Screening is presented as benignly intended "to reassure that the baby is all right". Yet in contrast with requested opt-in *testing* for a specific familial condition, the *screening* of large asymptomatic groups is complicated. Screening can never tell if the baby is "all right" - free from any potential anomaly. Fears raised in previously unaware women have to be soothed by screening staff, and the stronger the reassurance, the more this implies that women are rightly very afraid of having a disabled child, without outswimming how informed or realistic their responses are. Midwives may feel that sadness at terminating a pregnancy is not as bad as the grief, shock, anger and denial parents are supposed to feel after the birth a disabled child. Yet the few studies of women's reactions after termination for fetal abnormality suggest that it does not prevent distress (Marteau, 1995), and a study of parents of children with Down's syndrome reported that the parents felt that the maternity staff expressed shock and grief which they, the parent did not particularly share (Goodey, 1991).

*The fabric of morality* Grimshaw (1986) discusses how mainstream philosophers dismiss living experiences as "household rubbish" to be cleared away in order to examine the universal abstract principles they illustrate. But she argues that moral dilemmas are actually constituted from their social and political context and from personal experiences. Gilligan (1982), advocating a more socially contextual and compassionate "ethic of care" to complement the mainstream ethic of justice, illustrates how women take account of practical small and large influences when trying to resolve conflicting obligations to their self and to others, in dilemmas about abortion. (Alderson, 1990). Care can complement and express respect rather than inevitably compromising or conflicting with autonomy. Everyone is realistically recognised as being interdependent, neither simply non-autonomously dependent nor autonomously isolated.

Debates about maternal versus fetal rights look less conflictual when set in their political context. Women are most pressed to consider abortion when they lack support and resources, so in many ways the mother and potential child *share* disadvantages which often require political solutions (Callahan and Knight, 1992) - reasonable support, income and appropriate employment for parents who wish to spend time with their children.

*Redistributive justice* Rationing and cost cutting in public spending have dire effects on children across the world (O'Neill, 1996), and it is a heavy responsibility to have any child, still more a disabled one. However, disabled researchers have moved on from concepts of justice as equal treatment for all, to the importance of

equal opportunity to assist equal outcomes and, from there, also to respect for difference, rather than futile, oppressive attempts to standardise people (Philpot and Ward, 1995; Oliver, 1996). Respect for diversity involves working to change the status quo which mainstream ethics tends to support, by redistributing resources more fairly, and changing unjust laws and segregational systems in education and employment, transport and housing, systems which follow medically guided patterns of discrimination (Oliver, 1996).

Mainstream bioethics tends to reinforce rather than question masculine values that dominate the prenatal services, which primarily control women (Stacey, 1992). These values include covert patriarchal assumptions about property rights and inheritance through worthy heirs. Notions of intellectual disability originated in legal disputes about proof that an heir was competent and not a “fool” whose estate could pass to the monarchy, and in the physician John Locke’s linking of concepts of mental competence to rights, democracy, autonomy and consent (Goodey, 1996). Rather than assuming a solid philosophical base here, it could be useful to unravel the assumptions and their implicit influences.

*Risk management calculations* can look just and rational when reduced to mathematical terms. For example, tests are justified when the “risk from the investigations is no greater than the risk of having an affected fetus”. Then, a one per cent risk of abortion after amnio is justified ethically if there is at least a one per cent chance that the fetus will have Down’s syndrome. Yet the reasoning is not logical, when it measures only the *probability* of a result and not its *severity*. Parents might be offered amnio with a one per cent risk of miscarriage against a 50 per cent risk that the child will have unwanted brown eyes instead of blue. On risk *incidence*, the amnio would be entirely justified, but on risk *severity*, few people would accept the choice as ethical. How closely does Down’s syndrome become an aesthetic choice like eye colouring? Harris (1990) argues for parents’ rights to choose characteristics like eye colour or (in an interestingly racist example) a lighter skin colour, as part of the accepted morality of furthering the child’s interests and potential. He ignores the frustrations that ensue when parents treat children as their property, make unrealistic demands, and give only highly qualified competitive approval instead of unconditional love. Brazier (1996) illustrates how technologies which treat sperm and ova as commodities affect attitudes towards children and their legal rights. Harris’s view gives ethical respectability to values which feminists criticise, of treating potential children as “consumer objects subject to quality control [and assumes that] certain fetal conditions are intrinsically not bearable” (Lippman, 1991).

## **Conclusion**

Oakley (1984:292-3), quoting Fritjof Capra, warned of destructive splits in prenatal policies between reason over intuition, science over religion, competition over cooperation, and exploitation of natural resources over conservation, of broadly masculine over feminine values. The increase since then in terminations of “wanted but impaired” pregnancies further illustrates (OPCS 1994) the contrast which Ruddick (1990) points out between the desire to control, intervene, correct or destroy, versus “maternal” responses of holding, observing, negotiating and adapting. In the controlling model, risk and failure are feared when personal

responsibility is paramount. In the holding model, with less aim to be in control, risks may be opportunities that bring unexpected supports as well as difficulties.

Paradoxically, public screening programmes invade what were the most private areas of family life, yet are also among the trends moving child care away from being a shared public responsibility towards a private responsibility for parenthood (O'Neill, 1994), partly by presenting prenatal decisions as personal choices, and concealing the political pressures. The valuable principle of autonomous choice can be oppressive when it obscures social injustices when women individually have to bear so much responsibility for caring for the next generation. This can make a decision to "do nothing" (have the baby) seem a selfish extravagance, wasting resources on a life that it is kinder to prevent.

In summary, the concerns in mainstream bioethics about potentially harmful loss of control and the threat of intimacy also powerfully influence values, policies, practices and research in prenatal screening. A vital part of social research about screening, as in this review, is to clarify these often covert values in the light of alternative ones. Stacey (1996:332) discusses the power which technologies like screening put into the hands of the few, and the way this goes unrecognised and unaddressed. She argues not for obstructing new technologies but for bringing new understanding to them, more widely and systematically, about their social context, in order to reduce avoidable suffering.

While a direct influence of bioethics on medical policies cannot be proved, it is indicated by, for example, the popularity among health practitioners and policy makers of bioethics courses and conferences, and the numbers of doctors and nurses writing about ethics and references to bioethics in policy reports. Certainly, the alternative range of feminist, disability and social science literature, here termed "critical ethics", appears to have little impact on prenatal health policies and counselling, even if it influences nursing ethics.

Choice either way loads women with responsibility and potential for guilt and blame. To refuse the tests may appear to be casual, even callous, to accept the birth of an impaired child, expected or not, can look like selfish extravagance and can become a lonely burden. Critical analysis of prenatal choices is restricted by sharp divisions of viewpoints into either pro-life or pro-choice faction and attempts to look at the complex middle ground of abortion for a longer-for but impaired baby tend to be dismissed by each side as siding with the opposing faction.

Feminists, including disabled ones, particularly defend women's right to abortion, as a vital practical and symbolic key to respect for women's physical and mental autonomy. As a disabled woman, Degener (1990) tries to reconcile feminist and disability rights by saying that at least women contemplating abortion of an impaired but wanted fetus should "know" what they are doing, but that is as far as she goes. Arguably, to know but not to change what you do is no gain, although the more people know about prenatal screening, the less likely they are to use it (Marteau and Coyle, 1998).

This paper has taken Degener's point further, of "knowing" what prenatal decisions involve. It has shown how, far from being neutral, screening and bioethics can be used to support policies which are negative towards motherhood in general, and also to disability and learning difficulties. A companion paper examines knowing in terms of evidence about living with Down's syndrome based on interviews with adults with Down's syndrome (Alderson, forthcoming). Can a life with Down's

syndrome worth living? In an era of evidence based medicine, evidence about the value and quality of life with Down's syndrome is urgently needed. Equally vital is greater understanding of the underlying bioethics assumptions which influence our attitudes towards prenatal choice and learning difficulty and which this paper has attempted to clarify.

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Note 1. Screening incurs false positive rates of about 60 cases to every one proven case, and false negative rates miss about 40 per cent of affected cases.

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Note 2. A survey of ultrasonographers' views about informing pregnant women confirmed their explicit opposition to giving "alarming though realistic information" (Oliver *et al.*, 1996) and this potentially misleading caution and vagueness is implicit through many midwifery texts and leaflets which do not help midwives and patients to share informed decision making.

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