Screening Networks: Shared Agendas in Feminist and Disability Movement Challenges to Antenatal Screening and Abortion.

> By Dr Janice McLaughlin Lecturer

Word Count: 6900

School of Geography, Politics and Sociology University of Newcastle Newcastle upon Tyne NE1 7RU Email: Janice.Mclaughlin@newcastle.ac.uk Tel: 0191 222 7511

Screening Networks: Shared Agendas in Feminist and Disability Movement Challenges to Antenatal Screening and Abortion.

Abstract

This paper identifies common ground in feminist and disability movement concerns with the social and ethical implications of antenatal screening and abortion. By examining the frameworks used by particular authors within each area, I argue that they both can and do have a shared agenda, which is focused on the social values that are embedded in antenatal screening and promote abortion as the obvious choice to the diagnosis of a congenital condition. It is important to develop some kind of shared agenda in order to construct theoretical and methodological approaches, which pay equal attention to pregnant women (disabled and non-disabled) and disabled people. To aid the development of such an agenda I draw on Actor Network Theory (ANT), which focuses on analysing the role of sociotechnical networks in securing particular social values and moral worlds. The issue for both disability studies and feminism is what kind of screening networks produce moral worlds that promote abortion, shape women's choices and express discrimination against disabled people?

Screening Networks: Shared Agendas in Feminist and Disability Movement Challenges to Antenatal Screening and Abortion.

Introduction

In various debates and issues non-disabled feminists have been rightly criticised for advocating ideas that are problematic for disabled people and counter to the principles of the disability movement. For example, Morris (1993) criticises feminists who analyse the 'plight' of women as carers, but show much less concern for women and others who require material and social support, which is just about all of us at one point or another. While feminists working within disability studies (Fawcett, 2000; Thomas, 1999) have developed greater dialogue between feminist frameworks and disability studies, reproductive rights remain an important point of contention between the two approaches. Sheldon (1999) argues that non-disabled feminists fail to recognise that reproductive rights mean different things for different groups. For some non-disabled women it is the right not to be mothers through the use of contraceptives that is the demand, while for many disabled women it is the right to be mothers and not be sterilised without their consent (Kallianes & Rubenfeld, 1997). Feminists campaigning for abortion rights use the fetus diagnosed with a congenital condition as the worse case scenario (along with rape), which proves the legitimacy of women's right to choose. This argument shows an apparent lack of concern for the conflict that this might suggest between women's right to choose and disabled people's right to life. At the very least the argument exploits people with impairments to serve someone else's agenda.

In a recent article in <u>Disability and Society</u> Sharp and Earle (2002) argue that the different positions within feminism and the disability movement on antenatal

screening and abortion create an insurmountable gulf between them. For feminists the base line in all abortion debates is that women have the individual right to choose. For the disability movement screening and aborting a fetus diagnosed with a condition such as Down's syndrome is a major component of the forms of discrimination that create disability. According to Sharp and Earle the logical outcome of the disability movement critique is to demand limitations on women's right to abortion, as unrestricted rights are discriminatory against disabled people. They conclude that this demand cannot be reconciled with the feminist position. This paper argues that claiming incompatibility between the disability movement and feminism does little to capture the complex dilemmas and political processes involved in screening practices and feminist and disability movement responses to them.

The paper begins by exploring the disability movement critique of both antenatal screening and its liberal defenders. I argue that this critique does not necessarily lead to the demand that there should be an absolute ban on aborting fetuses diagnosed with a congenital condition. I next move on to detail feminist concerns with screening and individual choice, to indicate the significant and central common ground between feminist and disability movement arguments. The next section considers the use of Actor Network Theory (ANT) as a framework able to aid the feminist and disability movement agenda of querying the social values and beliefs embedded in particular forms of antenatal screening. The paper concludes by arguing that analyses of screening should not prioritise the rights and wrongs of terminating a fetus, but instead examine and challenge the social values and structural inequalities that promote the choice, express discrimination towards disabled people and incorporate pregnant women into that expression.

Disability Movement Critique of Antenatal Screening

An important aim of the disability movement critique of screening has been to challenge the liberal bioethical framework used to defend it; that is that screening is legitimate where it allows the individual to make an informed choice (Bewley & Ward, 1994). It is the form of this critique that Sharp and Earle argue necessitates a significant gulf between the frameworks of the disability movement and feminism. The disability movement challenge to liberal (feminist or bioethical) defences of screening is based on a core set of issues:

- People do not reject the offer of a screening test because they are unaware of its purpose;
- People choose to have an abortion when they receive a 'positive' diagnosis due to a lack of real knowledge about the lives and experiences of disabled people;
- People falsely assume that raising a disabled child will only bring burden and heartache;
- 4. Disability is a product of discrimination and structures in society;
- 5. Antenatal testing and selective abortion expresses prejudice against living and future disabled people (Asch, 2000).

Liberal feminists and bioethicists reject the argument that antenatal screening expresses prejudice towards disability (Baily, 2000). In particular, they argue that it is wrong to read desires and intent into the actions of individual women. Feminist studies of why women abort after a 'positive' prenatal diagnosis indicate the complex and varied reasons why they make such a choice (Brookes, 2001). But acknowledging this point does not invalidate the expressive argument. There is an important distinction in the level of inquiry between liberal theorists and disability writers. For those working within a liberal approach it is the individual and the protection of their rights that lies at the core of their judgement about the legitimacy of screening. Disability writers draw out from the individual to consider the social structures that provide the context within which individuals make their choices.

Disability activists challenge presenting the issue as resolvable by exploring the values and interests of abstract individuals. This narrow focus is critiqued because it presents an 'illusion of freedom' (Jennings, 2000: 130). To discuss screening in an abstract context makes no sense, instead it 'can only be evaluated in the world the way it is, and on that basis they [screening programmes] have been and will be used in ways that devalue people with disabilities' (Saxton, 2000: 151). When making decisions people are influenced by the world around them, moral and ethical frameworks are embedded with social values and meanings. In a context where it is morally acceptable, even encouraged, to abort a fetus with a congenital condition, the more likely it is that this will be the result. Antenatal testing is expressive of societal rather than individual dis-valuing of disabled people (Asch, 1999). Working with the social model, activists argue that the 'burden' people seek to avoid when they decide to abort is the burden caused by social structures of inequality and discrimination. Brookes (2001) argues that some of the women she interviewed chose abortion because of their awareness of the discrimination disabled people face in society. In a way the women are working with a social model of disability, but from that position they see abortion as their only avenue.

Shakespeare (1998) argues that the individual rights defence of screening can be thought of as a form of 'weak eugenics', which does not involve state enforcement. Instead it operates through 'promoting technologies of reproductive selection via noncoercive individual choices' (ibid: 669). Shakespeare argues that the medical model of disability (burden, pain, and personal tragedy) informs the choices people make. This model of disability has an engrained powerful position in society and is able to shape the outcomes of screening in a way that challenges the claim that women are faced with a genuine free choice. Evidence of shaping can be found amongst obstetricians who believe that women should only have an amniocentesis test if they agree beforehand that they will terminate if the diagnosis turns out to be 'positive' (Brookes, 2001; Green, 1995). It can also be seen in the directive quality of the counselling women receive, particularly from obstetricians (Marteau *et.al.*, 1994). The issue is whether disputing the rights argument places the disability movement in direct conflict with feminism. Shakespeare is prominent amongst disability activists who argue it does not.

The Sharp and Earle piece argues that the disability movement and feminism cannot come to a unified position on antenatal screening and abortion because acknowledgement of the disability movement critique must result in a condition being placed on women's right to an abortion. Feminists would and do argue that denying women the right to abortion is as unjust as compelling them to participate in screening. However, it is not necessary that the disability movement critique outlined above does lead to the demand to place strict conditions on abortion, apart from in one area of current abortion provision. The disability movement case does not support

diagnosis of a fetal congenital as grounds for allowing an abortion to happen later in pregnancy than allowed for other declared reasons. I will suggest later that feminists can acknowledge this position as fair.

A ban on abortion would not tackle the structures of discrimination and inequality that produce disability. If the response is to target women it retains the problems of the individual framework viewed as inadequate by the social model; that women must act as the moral guardians of society by being compelled to have or not have babies with particular conditions. It removes the abortion from the processes that generated its offer. If we acknowledge the difficult choices women are faced with due to the structures and positions from which choices must be made, we can think of their individual actions as contributory to the cycle of oppression, without seeing them as individually to blame for that cycle. Mourning the choice the woman is compelled to make is not the same as saying she is wrong or an active participant in discrimination. Instead it points to the ways in which she too is a victim of the contexts that demand that she choose.

We can argue that we would prefer women not to abort on diagnosis of a congenital condition, provide alternative information to counter the medical model of disability and develop alternative methods and forms of counselling. However, it is unjust to argue that they cannot abort when the problem lies not with their individual choice, but with the contexts that present and demand both the choice and the outcome. This is not to say that there are no selfish or prejudiced women who abort simply because they do not like Down's syndrome or view it as ill fitting with their

lifestyle. However, to deny the right to abortion because of these motives is problematic and costly on three grounds:

- It does little to tackle the other reasons why women have abortions after a 'positive' diagnosis, such as poverty and lack of sufficient social and state support;
- It can be (and is) adopted to support anti-abortion arguments by groups such as the Society for the Protection of the Unborn Child (SPUC), placing the disability movement in the same problematic right wing company radical feminists found themselves aligning with in anti-porn campaigns;
- 3. Research on women's decisions to abort indicate that few do it easily or happily, instead for many it is based in regret and pain (Brookes, 2001; Rapp, 1999).

It is for these kinds of reasons that Shakespeare argues that the absolute denial of abortion is not the only possible demand produced by the disability movement critique. A viable alternative is for the disability movement to look beyond the actions of individual women to challenge the individual rights framework and examine the influence of the medical model in shaping their choices. This kind of response considerably reduces the gulf between the disability movement and feminist arguments.

Feminist Approaches to Screening

The gulf is further reduced by acknowledging that for two important reasons, it is not reasonable to argue that for all feminists, particularly those working outside a liberal

framework, women's absolute right to abortion in any circumstances cannot be questioned. The first is the theoretical debate within feminism about the limitations of an abstract individual rights model. The second is that feminists have problematised the supposed choices and rights given to women by antenatal screening in ways influenced by and similar to the arguments by disability activists outlined above. This work has a closer affinity to social model arguments than an oppositional account allows for.

The theoretical debate about the values and limitations of working with a liberal rights framework is complex and I do not have the space to fully develop it here. What a brief summary can indicate is two things. First, that feminists can agree that it is wrong for diagnosis of a congenital condition to be treated as a special case in terms of abortion. Second, that there is a shared agenda for feminism and the disability movement to challenge the processes and values embedded in antenatal screening. Feminists have become uneasy with the liberal individual rights model, because it presumes a model of the human condition that is inadequate to reflect the variety of human experience, interaction and relationship. Phillips argues that a fixation on the rights of the individual in the abstract sense is a 'powerful impediment' (1993: 115) to responding to the inequalities and dilemmas faced by many women. Brown (1992) argues that it is 'gratuitous' to talk of the rights women have, without acknowledging the inequalities that make those rights illusionary.

Significantly, a sole concentration on rights is increasingly seen as blocking full recognition of the interdependencies and differences amongst people. Rudy (1999) argues that abstract rights fail to capture the role of communities and

interdependencies in shaping our sense of self and values (good and bad). The benefit of individual rights is their universal character, but recognition of differences amongst people challenges the notion that universality is achievable. What are proposed instead are frameworks and processes that allow space for the acknowledgement of differences and inequalities embedded in the structures of society (Young, 1990). If we work with this kind of approach, then it is feasible for feminists to acknowledge that the special right women have to abort a fetus later in their pregnancy because it has a congenital condition is unfair. This is because the right is a product of discrimination and is harmful to disabled women and men.

It is this kind of argument that is being explored by feminists who examine the realities and complexities of women's reproductive rights. Rights contain hierarchies where social position and cultural values influence whether one has the same access to the entitlements that are supposed to come with those rights (Rapp, 1998; Schott & Henley, 1996). Within reproductive issues there are numerous hierarchies around rights, including the lesbian denied the right to artificial conception services; the disabled woman 'encouraged' to have a sterilisation procedure; and the non-disabled woman offered abortion for a fetus diagnosed with a congenital condition but not for a baby of the 'wrong' sex.

The issue is whether arguing that the hierarchies should be removed and all have an equal right to different entitlements is a useful response to the problem. For a growing number of feminists participating in reproductive rights debates and in other areas the answer on its own is no. In debates about abortion, there is acknowledgement that the right to abortion while necessary is not sufficient to ensure

the issue is resolved. The complex social and material processes that lie behind many women's 'choice' to have an abortion, indicate it is a needed, but painful right. In such contexts to advocate the right, without tackling the underlying structures and inequalities that produce the need is unethical.

Contemporary feminist approaches to antenatal screening have acknowledged that a focus only on the rights of the individual does not capture the complex processes women experience, which implicates them in worldviews not necessarily of their making:

Ending a pregnancy to which one is already committed because of a particular diagnosed disability forces each woman to act as a moral philosopher of the limits, adjudicating the standards guarding entry into the human communities for which she serves as normalizing gatekeeper. (Rapp, 1999: 131)

Issues of screening, while involving the individual, cannot be narrowed to being thought of as 'personal troubles'. The greater the ability of technology to identify potential conditions, the greater pressure there is on women to eradicate such conditions from existence. The danger is that wanting and having a child with an impairment becomes seen as an increasingly irrational, abnormal, even selfish act, when the avenues for avoiding such an outcome increase. Hubbard argues that women who choose not to abort could be reproached for 'having so to speak "caused" that human being's physical pain' (1997: 196).

Leaving choice to the individual is an inadequate response to the implications of screening, because it is unable to respond to the social and individual pressures that both frame and deny choice for individuals and social groups. Indeed it can operate to disguise the complex inequalities built into screening. The shared ground for the disability movement and feminism is the concern with the contexts that lead to the right to abortion being exercised. Below one way to explore these contexts is discussed.

Actor Network Theory

Actor Network Theory (ANT) is closely associated with French writers Bruno Latour (1996) and Michel Callon (1986) and is an offshoot of social studies of technology. It seeks to explore how social and political priorities and meanings are embedded into the design, implementation and use of technologies (Bijker & Law, 1992; Law, 1991). It considers the relations and interactions between different actors and technologies as forming networks. Stable uses for technology are the product of the successful and enduring enrolment of actors into networks. ANT examines the work 'heterogeneous engineers' (Law, 1987) must do to build a socio-technical network around a technology in order for it to become acceptable and successful (McLaughlin *et al.*, 1999).

ANT seeks, from a position influenced by post-structuralism and Michel Foucault, to find a way to treat the non-human and human in a symmetrical way; that is it makes no a priori judgement about the identity or significance of either. Both achieve meaning and identity through the networks they are part of. It is important to

give technologies heightened focus, because they help provide the durability that sustains and allows for the reproduction of social relations. Durability is achieved through chains that connect humans and technical artefacts together. The object at the heart of a network is embedded with meanings and social ideas that are under negotiation between different actors. These negotiations can be thought of as translations, where different interpretations are turned into a stable set of meanings for the network and its components. ANT theorists argue that network actors use various repertoires - rhetorical devises - to enrol people into support of the network, and to exclude others from joining and changing it. Actors form a set of practices, shared language and common meanings for each other; the technical components of the network help keep it together. Woolgar (1991) argues that networks thus maintain particular 'moral orders'. Technologies, through the networks within which they gain meaning and the human relations that occur through them, help generate and reproduce influential moral outlooks and identities.

Below I use this kind of ANT framework to produce both a feminist and disability studies agenda for examining antenatal screening.

Screening Networks

ANT approaches antenatal screening as a collection of networks and actors varied by national and local context. The kinds of actors likely to be part of particular screening networks include:

✤ Government bodies who make policy recommendations;

- Healthcare insurance companies who approve payment for treatments;
- The equipment and procedures used to carry out the screening test;
- Different medical personnel, including radiographers, midwives, consultants; laboratory technicians and counsellors;
- ♦ Women who have the tests, along with partners in some cases, family and friends.

ANT offers a useful way to consider what kinds of moral orders emerge from the interactions of these varied actors in different settings. What kind of screening network maintains a moral order that aligns people around a narrative claim that abortion is the logical outcome of a 'positive' diagnosis? If both the screening test and the abortion find their meaning within screening networks, then this is where the priority of analysis should lie. The arguments of disability writers and feminists can be used to indicate the types of network relation and interactions that construct moral orders, which implicate disabled people and pregnant disabled and non-disabled women in choices not of their making in particular screening practices. From this perspective tackling the issues on screening through an abstract concern with the offer of an abortion misses the expressive quality of the networks within which the abortion takes on meaning.

An ANT approach can also aid the critique of the individual rights framework, by conceptualising it as an aligning tool that pulls disparate actors together within screening networks. The language of rights is an important repertoire in screening networks, operating as a narrative shared by different actors, which pulls together the different processes under one agreed statement: screening allows for informed choice (Press, 2000). Individual rights rhetoric is useful because it foregrounds choice 'while

backgrounding the social matrix of a technoscientific marketplace to whose requisites individual choices are increasingly enrolled' (Rapp, 1999: 38). The privileging of individual rights excludes the level of social analysis demanded by disability activists and allows the problematic delegation of responsibility to pregnant women. Those who abide by and re-articulate the values and criteria of screening do the labour that is involved in maintaining the network. Women are incorporated into a role of policing themselves and the 'quality' of the population, justified in a repertoire of empowerment and free choice (Shildrick, 1997).

To be fully developed this kind of ANT approach requires analyses of the intricacies of different screening networks, at the national and local level. In the UK the NHS is committed to the development of an **Antenatal Screening Infrastructure** (ASI). The ASI is being introduced to reduce the wide variation in screening practice found throughout the UK (Harris *et al.*, 1999; Lane *et al.*, 2001; Reynolds, 2001). The National Screening Committee (NSC) is the central organisation in the planning and implementation of the ASI. A number of processes have begun and policy recommendations have been made as part of its development. These include:

- Regional co-ordinators and local screening contacts set up across England and Wales;
- 2. Recommendation that second trimester serum testing for Down's syndrome be offered to all pregnant women during their second trimester by 2004;
- 3. Recommendation that new borns are screened for cystic fibrosis by 2004.

The NSC stresses that its aim is to allow for informed consent and choice for those involved. Its Information Sheet on Down's syndrome argues that the introduction of the national programme is 'not intended to increase discrimination against disabled people but to promote choice for families'.

ANT can provide the theoretical grounds and empirical agenda for examining the ASI. The concern is whether the ASI will make durable the expressive social disvaluing of disabled people and women's role as delegates of that expression. To answer that one needs to look at the moral order generated by the network, the interactions of actors and discourses within that network and its relation to other socio-technical networks in society. The ASI will be the product of the interrelationships between various networks with their own moral orders, translated into the one set of shared meanings, moving between worlds through the policy guidelines. As the ASI is implemented and the network aims to incorporate other groups and actors into its moral order, the processes of enrolment will become more complicated. The regional co-ordinators and local screening contacts will play an important role in enrolling local services into the national network. It is here that pregnant women are incorporated into the network.

Part of the moral order being generated by the ASI already can be seen in the introduction of second trimester serum screening for Down's syndrome. The new test means that wider communities of women will be introduced to screening processes earlier in their pregnancy. Women will have the option of opting out of being screened for Down's syndrome. By being an opt-out rather than opt-in element of antenatal care, the procedure is presented as unproblematic rather than something to

consider carefully. Screening for fetal conditions is translated from being a contentious ethical dilemma into a routine, everyday aspect of antenatal care, alongside the other everyday aspects of care and support. The form in which the test is offered, rather than the test itself expresses values that can be thought of as dangerous by both feminists and disability activists. It is at this level of questioning that the ASI must be examined and probed in order to consider whether it expresses the kind of discrimination disability activists' fear in screening.

Taking an ANT perspective on screening and the ASI in particular requires some adaptation of the approach. Feminists and others (Winner, 1993) have highlighted a number of weaknesses in the original articulation. In particular three important aspects of the ANT framework as outlined by Callon and Latour have been refuted by feminists. The first is its proposed neutrality about the processes that shape networks. Callon and Latour both argue that they seek to describe the processes they find rather than look for particular dynamics such as gender or class. Feminists consider this to be a form of conservative positivism (Saetnan, 1997; Silva, 2000). It presumes that the analyst can describe what is there, without their own position influencing what they see. Lohan (2000) points out that feminist theorising has long made us aware that if you do not look for certain things, have an eye for certain processes, then you are unlikely to see their emergence. In the same way disability studies' exploration of the social model has made visible patterns and structures of oppression against people with impairments, which existing social divisions literature had not identified. The second aspect rejected is the sole concentration on local relations and negotiations in the production of meaning within networks. This is rejected because it appears to relinquish a concern with the contexts within which networks operate (Wajcman, 2000). This is closely related to a third aspect that feminists challenge. ANT writers remain 'agnostic' about power; power relations are internal to the operation of the network and cannot be predicted or determined. For feminists interested in taking ANT forward this level of local power relations is not enough to explain how alliances form and reform, and how some rather than others become the significant 'heterogeneous engineers' (Harding, 1991). Considering power as an effect or consequence of the workings of the network is not sufficient an explanation for consistent patterns of dominance and exploitation (Faulkner, 2000). Why is it that 'some networks are remarkably enduring' (Gill & Grint, 1995; 21)?

To resolve these weaknesses, various feminists have adapted the ANT conceptual framework to allow for greater recognition of the political significance of particular forms of network relation. Feminists explore the enduring nature of some networks by highlighting the role of existing networks and their moral orders in securing and guiding the path of new networks (Berg 1994). Akrich (1992) argues that the process of disparate actors coming together to agree shared meanings is aided by pre-existing scripts from other networks. Ormrod (1995) discusses the ways in which existing gender or class relations and identities aid network formation through the narratives they provide to be repeated in new network relations. Star (1991) reorients ANT by concentrating on what is excluded and marginalised from networks in order to secure their operation. She argues that the significance of the stability that networks bring to certain values and technological practices is that they can

standardise life and socio-technical relations. The standardising activities of networks create a form of loss, where the ambiguous is not allowed. This loss includes 'a destruction of the world of the non-enrolled' (ibid: 49).

Taking on board the issues introduced by feminists increases the scope of ANT analysis of screening and the ASI. It shifts the focus to the existing networks and relations that may frame the possible future direction of screening generally and the ASI in particular. For example, the medical discourse can be thought of as a powerful rhetoric able to draw other actors and interests into a particular approach and rationale to screening. In particular, the privileging of the medical rhetoric helps validate and maintain the burden argument in support of abortion. An important issue to examine with the ASI is whether the existing repertoires of personal tragedy and burden, which the discourses of already established and establishment actors and networks promote, will play a significant role in shaping its objectives, policies and practices.

Drawing on the arguments of Star we can consider the moral order expressed in the statement 'that abortion is the logical outcome of 'positive' diagnosis' as dangerous because it promotes standardising forms of life. The screening network that troubles disability activists and feminists is the one that seeks 'to narrow the boundaries of the normal' (Willis, 1998: 178). In this network the boundaries of the normal are secured by marginalising those deemed unable to be accommodated within its cultural and political values and notions of the good life. This form of network and moral order can be thought of as a component of 'regulatory and disciplinary regimes' that 'maintain normative standards of bodily and mental well-being' (Shildrick, 1997:

60). Such screening networks are significant because they 'take their place in the field of forces that constitute the construction/(re)production of identity' (ibid: 197). It is reasonable to suggest that in both medical and government practices in the UK and elsewhere and in liberal feminist and bioethical defences of antenatal screening this kind of network and moral order has been developed and continues to stabilise.

In addition, this kind of network analysis generates particular agendas for challenging the ASI. Resistance involves encouraging instability in the networks of relations embedded in the uses made of screening technologies. This work includes refusing to screen out the work of the delegated, making visible the 'illusion of freedom' maintained in the repertoires of free choice and individual rights. Those marginalised are those who can give testimony to the processes of disqualification that follow through the dominant moral order. This suggests a possible shared agenda for feminist and disability activists. This agenda includes challenging the choices that lie behind the priorities of screening polices and the connected lack of adequate ante and postnatal care available to a whole range of groups in society (Kallianes & Rubenfeld, 1997).

In less abstract terms ANT pushes for the inclusion of different kinds of disruptive actors and arguments into the screening process and debates to make visible, critique and provide alternatives to the moral order being developed. In particular, challenging the dominant moral order present in existing screening networks requires providing alternative accounts to the personal tragedy and burden narratives provided by the medical model. It also implies being more explicit about the purpose of screening with women, and the use of opt-in rather than opt-out

mechanisms within screening policy and practice. This work can prioritise and publicise the processes of surveillance and social control, which may operate within the methods used to offer screening and inform women of the issues involved.

ANT also broadens the concern from not just screening but to issues revolving around other networks, such as welfare, which generate the 'burden' women may seek to avoid through abortion. A focus on the networks also triggers crucial questions about funding priorities within modern healthcare and scientific study. The majority of illnesses and impairments are not congenital. Many of our current health care problems derive from poverty and health inequalities, and simply being a human organism that 'shall be born and die' (Stacey quoted in (Shakespeare, 1998: 678)). In the choice to fund the ASI a decision is also made not to fund other areas of healthcare and social welfare, which could support these other aspects of human life.

Conclusion

Theoretically and politically debating whether in abstract terms women should have the right to abort a fetus diagnosed with a congenital condition is neither valid nor useful for the following reasons:

- 1. Abstracts judgements are formed by the contexts within which they emerge;
- 2. Rights claims are contingent and relational;
- It is not sufficient to encompass the social values and worldviews maintained in screening.

Claiming that individual choice is the best ethical response is inadequate to the social and political processes that lie behind medical and government support and advocacy of screening. So to is arguing that screening and abortion should never take place. The disability movement and feminists must and do find other grounds to explore what is at stake with screening and how to challenge practices and values within it, which are expressive of discrimination.

The issue is how to interrogate the implications of screening without working with a framework that hides social processes, by debating about what women should or should not do. The ethics of abortion can be queried on bases other than the values of individual women. Instead it points to challenging the repertoire of choice by a focus on the social contexts in which women make 'choices' and that shape the options that appear available. Antenatal screening policy in the UK has the potential to further a dangerous moral order in the network of decisions, actors and technology it represents and keeps together. Screening is part of a series of networks that construct disability as removable and marginal, and the categories of the non-disabled as central. Incorporating disabled actors, as well as non disabled women from a variety of locations, can be the trigger to a series of new and unsettling questions. The concentration of effort cannot be with the technology or the choices it brings for individuals in abstract terms, but with the social and political priorities embedded in it and made real and stable in the networks operating around it. A focus on the networks can change the 'social world' of the screening network and introduce uncertainty and challenge to its standardising potential.

REFERENCES

- Akrich, M. (1992) The de-scription of technical objects, in: W.E. Bijker & J. Law (Eds) Shaping Technology/Building Society: Studies in Sociotechnical Change, (Cambridge, Mass, MIT Press).
- Asch, A. (1999) Prenatal diagnosis and selective abortion: A challenge to practice and policy, *American Journal of Public Health*, 89, pp. 1649-1657.
- (2000) Why I haven't changed my mind about prenatal testing: reflections and refinements, in: E. Parens & A. Asch (Eds) *Prenatal Testing and Disability Rights*, (Washington, D.C., Georgetown University Press).
- Baily, M.A. (2000) Why I had amniocentesis, in: E. Parens & A. Asch (Eds) Prenatal Testing and Disability Rights, (Washington, D.C., Georgetown University Press).
- Ber, A-J. (1994) Technological flexibility: bringing gender into technology or was it the other way around? In: C. Cockburn & R. Fürst-Dilic (Eds) *Bringing Technology Home: Gender and Technology in a Changing Europe*, (Buckingham, Open University Press).
- Bewley, S. & Ward, R.H., (Eds) (1994) *Ethics in Obstetrics and Gynaecology*, (London, RCOG Press).
- Bijker, W.E. & Law, J. (Eds) (1992) *Shaping Technology/Building Society: Studies in Sociotechnical Change*, (Cambridge, Mass, MIT Press).
- Brookes, A. (2001) Women's voices: prenatal diagnosis and care for the disabled, *Health Care Analysis*, 9, pp. 133-150.
- Brown, W. (1992) Finding the man in the state, Feminist Studies, 18, pp. 7-13.
- Callon, M. (1986) The sociology of an actor-network: The case of the electric vehicle, in: M. Callon, J. Law, & H. Rip (Eds) *Mapping the Dynamics of Science and Technology: Sociology of Science in the Real World*, (Basingstoke, Macmillan).
- Faulkner, W. (2000) The power and the pleasure? A research agenda for "making gender stick" to engineers, *Science Technology & Human Values*, 25, pp 87-119.
- Fawcett, B. (2000) Feminist Perspectives on Disability, (Harlow, Prentice Hall).
- Gill, R. & Grint, K. (1995) The gender-technology relation: contemporary theory and research, in: K. Grint & R. Gill (Eds) *The Gender-Technology Relation*, (London, Taylor and Francis).
- Green, J. (1995) Obstetricians views on prenatal diagnosis and termination of pregnancy: 1980 compared with 1993, *British Medical Journal*, 309, pp. 769-772.
- Harding, S. (1991) *Whose Science? Whose Knowledge*? (Buckingham, Open University Press).
- Harris, R. et al. (1999) National confidential enquiry into counselling for genetic disorders by non-geneticists: general recommendations and specific standards for improving care, *British Journal of Obstetricians and Gynaecologists*, 106, pp. 658-663.
- Hubbard, R. (1997) Abortion and disability: who should and who should not inhabit the world? in: L.J. Davis (Ed.) *The Disability Studies Reader*, (London, Routledge).
- Jennings, B. (2000) Technology and the genetic imaginary, in: E. Parens & A. Asch (Eds) *Prenatal Testing and Disability Rights*, (Washington, D.C., Georgetown University Press).

- Kallianes, V. & Rubenfeld, P. (1997) Disabled women and reproductive rights. *Disability & Society*, 12, pp. 203 – 221.
- Lane, B., et al. (2001) Existence and quality of written antenatal screening policies in the United Kingdom: postal survey. *British Medical Journal*, 322.
- Latour, B. (1996) *Aramis, or the Love of Technology*, (Cambridge, Mass., Harvard University Press).
- Law, J. (1987) Technology and heterogeneous engineering: the case of Portuguese expansion, in: W.E. Bijker, T.P. Hughes & T. Pinch (Eds) *The Social Construction of Technological Systems: New Directions in the Sociology and History of Technology*, (Cambridge, Mass, MIT Press).
 (Ed.) (1991) *Sociology of Monsters*, (London, Routledge).
- Lohan, M. (2000) Constructive tensions in feminist technology studies, *Social Studies* of Science, 30, pp. 895-916.
- Marteau, T.M., et al. (1994) Counselling following diagnosis of a fetal abnormality: the differing approaches of obstetricians, clinical geneticists and genetic nurses, *Journal of Medical Genetics*, 31, pp. 864-867.
- McLaughlin, J. et al. (1999) Valuing Technology: Organisations, Culture and Change, (London, Routledge).
- Morris, J. (1993) Feminism and disability, Feminist Review, 43, pp. 57-70.
- Ormrod, S. (1995) Feminist sociology and methodology: Leaky black boxes in gender/technology relations, in: K. Grint & R. Gill (Eds) *The Gender-Technology Relation*, (London, Taylor and Francis).
- Phillips, A. (1993) Democracy and Difference, (Cambridge, Polity Press).
- Press, N. (2000) Assessing the expressive character of prenatal testing: the choices made or the choices made available? In: E. Parens & A. Asch (Eds) *Prenatal Testing and Disability Rights*, (Washington, D.C., Georgetown University Press).
- Rapp, R. (1998) Refusing prenatal diagnosis: the meanings of bioscience in a multicultural world, *Science, Technology and Human Values*, 23, pp. 45 70.
 (1999) Testing Women, Testing the Fetus: the Social Impact of Amniocentesis in America, (London, Routledge).
- Reynolds, T.M. (2001) Down's Syndrome, *Journal of Clinical Pathology*, 53, pp. 893-898.
- Rudy, K. (1999) Liberal theory and feminist politics, *Women and Politics*, 20, pp. 33-57.
- Saetnan, A.R. (1997) Standing one's ground requires finding some ground to stand on, in: B. Berner (Ed.) Gendered Practices: Feminist Studies of Technology and Society, (Linkoping, Sweden, Department of Technology and Social Change, Linkoping University).
- Saxton, M. (2000) Messages and meanings of prenatal genetic testing, in: E. Parens & A. Asch (Eds) *Prenatal Testing and Disability Rights*, (Washington, D.C., Georgetown University Press).
- Schott, J. & Henley, A. (1996) Antenatal screening and diagnosis in a multiracial society, *British Journal of Midwifery*, 4, pp. 346 349.
- Shakespeare, T. (1998) Choices and rights: eugenics, genetics and disability equality, *Disability & Society*, 13, pp. 665-681.
- Sharp, K. & Earle, S. (2002) Feminism, abortion and disability: irreconcilable differences, *Disability & Society*, 17, pp. 137-145.
- Sheldon, A. (1999) Personal and perplexing: feminist disability politics evaluated. *Disability & Society*, 14, pp. 643 - 658

Shildrick, M. (1997) Leaky Bodies and Boundaries, (London, Routledge).

- Silva, E.B. (2000) The cook, the cooker and the gendering of the kitchen, *Sociological Review*, 48, pp. 612-28.
- Star, S.L. (1991) Power, technologies and the phenomenology of conventions: on being allergic to onions, in: J. Law (Ed.) A Sociology of Monsters, (London, Routledge).

Thomas, C. (1999) *Female Forms: Experiencing & Understanding Disability*, (Buckingham, Open University Press).

- Wajcman, J. (2000) Reflections on gender and technology studies: in what state is the art? *Social Studies of Science*, 30, pp. 447-464.
- Willis, E. (1998) The 'new' genetics and the sociology of medical technology, *Journal* of Sociology, 34, pp. 170 183.
- Winner, L. (1993) Upon opening the black box and finding it empty: social constructivism and the philosophy of technology, *Science, Technology and Human Values*, 18, pp. 362-378.
- Woolgar, S. (1991) Configuring the user: the case of usability trials, in: J. Law (Ed.) *A Sociology of Monsters*, (London, Routledge).
- Young, I.M. (1990) *Justice and the Politics of Difference*, (Princeton, Princeton University Press).

Biographical Details

Dr Janice McLaughlin is a Lecturer in the School of Geography, Politics and Sociology at the University of Newcastle. Her work examines various social issues around health technologies and professions. In addition she writes on feminist social theory. *Feminist Social and Political Theory* will be published by Palgrave in 2003.