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Ruth Keszia Whiteside
Manager, *People 1st Programme*

&

Della L. Perry
Co-Director, S.H.A.R.E

SHARE WA
22 Market St
GUILDFORD 6055
PH/FAX (08) 9279 7698
Email: share_wa@icenet.com.au

People 1st Programme
70 Roe St
NORTHBRIDGE 6003
PH (08)9227 6414
FAX (08)9227 6871
Email: pip@fpwa-health.org.au

Stereotype, Segregate and Eliminate: 'Disability', Selective Abortion¹, and the Context of 'Choice'

By Ruth Keszia Whiteside
&
Della L. Perry

'Prejudice is ... a form of shared mania that results in great hurt to the subjects of its madness. ... Its primary symptom is hatred of others, and those who are hated are at high risk for being hurt. The irrationality of hatred for others because of their race, nationality, religion, gender, social class or other characteristic can become all consuming. That irrationality has proven itself to be resistant to all reason and evidence contrary to its poisoned convictions. Prejudice, however, has often been elevated and dignified by powerful and influential people who have supported it in the name of reason and have advanced it in the name of science'.²

At the time this paper is being written, abortion laws are on the verge of being repealed in Western Australia. Whatever one's personal opinion about the desirability of any outcome, this is a significant opportunity for careful consideration of both implicit and explicit ideas, influences and issues which have framed the so-called 'abortion debate'. This is of course a difficult task, requiring us to reflect upon how our own values and attitudes are formed, and how these are influenced by, and in turn, influence, the world around us.

Working in affiliation with Family Planning Western Australia and within the *People 1st Programme* (which '*supports people with an intellectual disability in human relationships, self esteem and sexuality*' related issues), has posed and continues to pose some remarkable and confronting challenges. A particularly sensitive area, which also highlights the important connection between advocacy and education, revolves around the awkward intersection of biological/medical and sociological/philosophical perspectives upon '*normality*'. When

¹ Jennifer Fitzgerald offers a clear definition of the term 'selective' with regard to 'abortion' thus: '*Selective abortion is the practice of aborting a foetus on the basis of the characteristics which that foetus has, or is presumed to have. For example, in some countries, selective abortion takes place on the basis of the sex of the child. In many places, selective abortion is commonly used to avoid the birth of a child with an impairment*'. See: 'Selective Abortion and Wrongful Birth in Queensland: Veivers v. Connolly', in Fitzgerald & Leipoldt (1996), p.9. As implied here by the word '*presumed*', the criteria for 'selection' need not be 'objectively' measurable. In terms of the notion of 'selectivity' as a response to cultural influences or pressures, a disturbing if useful example exists in South Korea, where Professor Cho Hyoung of Ewha Women's University in Seoul '*estimates that up to 30,000 female fetuses, or one in two are aborted each year after tests to confirm their sex*', John Larkin, 'Gender imbalance alarms as abortion rate increases', *Sydney Morning Herald*, 11 November 1997. Preference for male children is also commonly recognised as a basis for infanticide and abortion in several other countries including India and China.

² J. David Smith, (1993), *Preface*, p.xiii.

speaking to medical practitioners for example, or when making presentations at community and public forums, is it both reasonable and instructive to express a sense of outrage about the past and present practices of '*selective breeding and weeding*' of both the unborn, and (in some times and places), newborn ? Should it, and will it, affect the sensibilities of those who would applaud the 'successes' of medical science in the attempted annihilation of genetically determined diseases, to be linked with their intellectual predecessors who firmly believed that '*feeble-mindedness*' was inextricably, (and biologically), intertwined with moral decadence, poverty and depravity:

[From around the beginning of the Twentieth Century], *Mental defectives and the feeble-minded were considered a threat to Western Society ... Pauperism, inebriety, prostitution and general social degeneracy were all attributed to the personal and biological defects of the feeble-minded. ... [T]he segregation of mental defectives was supported by a broad cross-section of the intelligentsia, which included conservatives, socialists, feminists and radicals. Many followers [of the 'science of Eugenics'], were reassured that social problems such as unemployment and delinquency were the result of poor breeding, rather than of defective social or economic arrangements*'.³

Is it unfair, or judgemental to even ask service providers if they have any knowledge of these issues, and/or if they have reflected upon the relationships between personal and social attitudes to, and perspectives upon, the *idea* or experience of 'disability'?!?

In community and public presentations should we worry about disturbing people or alienating their interest or engagement, by reminding them that one day, if we live long enough, we, or the people we love, will grow older and probably need some kind of care and support ? In Susan Wendell's opinion, such 'reminders' may be invaluable. She suggests for example that:

*'Aging is disabling. **Recognizing this helps us to see that disabled people are not "other", that they are really "us"**. Unless we die suddenly, we are all disabled eventually. Most of us will live part of our lives with bodies that hurt, that move with difficulty or not at all, that deprive us of activities we once took for granted or that others take for granted, bodies that make life a daily physical struggle*'.⁴

Can we truly claim to be fulfilling our own mandate (to support people accessing our services with experiences, strategies, skills and perspectives which might enhance and build up feelings of self esteem and self worth), *without* simultaneously challenging those histories,

³ Moira Fitzpatrick, (1988), pp.144 & 145. The subject broadly termed 'Eugenics' (or '*the study of so-called methods of improving the quality of the human race*') in Western history, is now well documented. For general background see Stephen Jay Gould (1981), and for a specific example of applied eugenics see J. David Smith, (1985). For a discussion which makes relationships between various forms of discrimination see D.L.Perry and R.K. Whiteside (1995), *passim*.

⁴ Susan Wendell, (1992), p.66. [bolding our emphasis]. While some might dispute the fact that aging *necessarily* implies difficulty, pain or 'disability', as Susan Wendell also comments this possibility is not merely a biological or physiological artefact, but is necessarily dependent upon social attitudes and ideas: '*Whether a particular physical condition is disabling changes with time and place, depending on such factors as social expectations, the state of technology and its availability to people in that condition, the educational system, architecture, attitudes toward physical appearance, and the pace of life. (If for example, the pace of life increases without changes in other factors, more people become disabled simply because fewer people can keep up the "normal" pace)*'. p. 67.

philosophies and practices which have reinforced '*disabilism*' (or negative and phobic ideas about disability), and which continue to express notions of 'perfection' as desirable or even possible. How can we be expected to promote the idea and experience of '*inclusiveness*' without questioning those scientific and medical practices enchanted with the deletion or devaluing of anything which, or anyone who, does not 'objectively' '*measure up*'? As Jennifer Fitzgerald has so passionately attested:

*'For people with a disability, giving up on the impossible goal of a perfect society is an essential baseline for guaranteeing their inclusion and acceptance in society. Giving up on the perfect self, at least the Western concept of perfect self, is the next step. For the goal of perfection locks people with disability in to fail. In a society which aims for perfection, people with disability will always fall short of the mark. In fact this goal locks everyone in to fail, for each of us, at some point in our life, whether through illness, old age or incapacity [will need some support]. [This then,] ... belies the Western myth of the perfect self and the perfect society'*⁵

While questions and issues such as these cannot be circumvented, or considered marginal, either in our work or in any of our social and personal relationships, nor can they be secondary considerations with regard to their implications for selective abortion.

Individualism and the Meaning of 'Choice'

The *People 1st Programme* has been founded upon feminist philosophies which acknowledge the *necessary* and interdependent relationships all of us have with each other.⁶ Although we work in an environment where funding is itself dependent upon the *label* of '*disability*', much of our time is (also ironically), spent challenging and disrupting the kinds of separation which such labelling seems to incur. We have found for example, that our concerted attempts to be as *inclusive* as possible, to offer services to family members, service providers and to the community at large, as well as to those deemed to have a disability, practically *and* politically challenges the notion of any *real* separation between any of us. Educational consultations almost always have better outcomes when people who live, work, recreate, and socialise together, are also included at some point (whether formally or informally), in the educational process.

Our *inclusive* approach is then, implicitly critical, both theoretically and practically,⁷ of those individualistic and individualising perspectives which regard a person in isolation from a social and material context.⁸ With loneliness and isolation also being expressed by many

⁵ Jennifer Fitzgerald, (1996), p.10 and *passim*.

⁶ This 'philosophy' which derives in many respects from 'feminist standpoint theory', also has strong links with most feminist perspectives which are concerned with the (often uneasy) relationship between institutionalised forms of knowledge 'truth' and reality and the nature of personal experience(s). For detailed discussion see Caroline Whitbeck, (1989), and Christine Overall, (1988). Similarly, our approach also subscribes to a *feminist ethics of care* which '*reflects a cumulative knowledge of human relationships, evol[ving] around [the] central insight, that self and other are interdependent*', see Carol Gilligan, (1982), p.74.

⁷ This connection can be usefully expressed by a Marxist perspective upon the term '*praxis*', where theory and practice are understood as so intertwined that they cannot be construed as separate entities.

⁸ It is pertinent that Wolf Wolfensberger's 'principle' of '*normalisation*' (or '*social role valorisation*'), has been critiqued for its '*cultural uniformity*' and for supporting prevalent ideologies of individualism – or a focus upon the individual rather than due consideration of their social context. Gillian Dalley has thus contended that in the

people participating in *People 1st Programme* activities,⁹ as both a cause and effect of great unhappiness, atomistic notions about 'independence' which do not acknowledge the need *we all must have* for the care and support of others, can add insult to injury. Micheline Mason puts this very well:

*'It has been assumed that all disabled people want to be as independent as possible, and few would question this. It is part of Western culture to see the need for help from others as a bad thing. All children are encouraged to leave behind signs of their dependence - breasts, nappies, bottles – as soon as possible. This continues into all aspects of 'growing up' ... It is not surprising then that this value judgement is extended into other areas of life until it becomes difficult for most people to admit that they need help or cannot manage alone. Loneliness and isolation are painfully common, but the connection between 'independence' and loneliness is seldom made. In fact, independence is a complete illusion even for the most able human being.'*¹⁰

This criticism of 'independence' is not then a diminishment of those invaluable personal skills and abilities each of us might like to utilise to negotiate diverse aspects of our lives, but it is another example of the need to call into question perspectives which imply that any of us can ever be truly separate or totally autonomous as human beings.¹¹ Everything we do, and everything we are, *necessarily* exists within a network of social expectations and interrelationships.

When attempting to reflect then, upon contemporary perceptions about selective abortion and 'disability', it seems relevant, to invoke considerations about a *context for choice*, rather than necessarily assuming the simple idea of individual *freedom of choice*. Jenny Morris has thus contended that for women '*choosing to have a disabled child*', the notion of choice is confounded by a spectrum of issues and attitudes which result in an '*emphasis upon ... the lack, not the availability of choice*.'¹²

'The most important constraints within which women 'choose' ... are the knowledge that society does not provide adequate resources for disabled people and the ignorance and prejudices which they [often], in common with most non-disabled people, hold about disability. ... Another problem ... [is that when] appealing to the rights of the individual in supporting the right of a woman to choose not to bear a disabled child is that, in giving her such a right, the individualist tradition also tends to place the responsibility for action entirely on

UK the '*dominant ideology has been one of individualism ... [with] ... an emphasis placed on privacy, independence, the separation of public and private domains, an acceptance of accompanying notion of gender division and women's subordination and the preaching of a creed of sturdy self-reliance. [She also proposes that when] ... Wolfensberger stresses that normalisation is a 'culture-specific' concept ... [which] supports the status quo and the dominant individualised ideology of care ...*' it has ambiguous features which may in fact be inimical to the interests of those it is intended to support, see Gillian Dalley (1992), pp.109 – 110.

⁹ Ruth Keszia Whiteside, 'Issues and Concerns as Indicated and Expressed by One Hundred Consumers of the *People 1st Programme*'s Educational Services', June 1997.

¹⁰ Micheline Mason, (Jan 1995), p.5.

¹¹ See Jennifer Fitzgerald for some examples of legal and related implications of social attitudes involving perceptions of '*Individualism and Individual Autonomy*', in 'Values in End-of-Life Decision-Making: Some Implications for People with a Disability, J. Fitzgerald and E. Leipoldt, *op. cit.*, p.5.

¹² See Jenny Morris, (1991), p.73, citing Sue Himmelweit, 'More Than A Woman's Right to Choose?', *Feminist Review* 29, Spring, 1988. [bolding our emphasis].

*the individual, with a concomitant denial of social or collective responsibility. Such a denial is manifestly against both the interests of women and disabled people'. ... If the responsibility is placed on the individual woman to exercise choice over whether or not to give birth to a disabled child, then the responsibility for choosing to bring up such a child also rests on her.*¹³

Regardless of the variety of feminism to which many women and pro-choice organisations subscribe, surely few would be comfortable with this conundrum, and yet there has been very little public discussion from these groups about this issue during the current abortion debate in WA. In an American context, Laura Hershey, a disability rights activist, attempting to find common ground with pro-choice groups with whom she also has considerable sympathy, stated the following:

*'Too often, when we object to positions that implicitly doubt the humanity of children born disabled, we are accused of being anti-choice. ... For the pro-choice movement, the fear is that questioning the motives and assumptions behind any reproductive decision could give ammunition to antiabortionists. ... Most pro-choice organizations do not favour the use of abortion to eliminate disabilities, but their silence leaves a vacuum in which fear of disability flourishes.'*¹⁴

During this debate, the often emotional and impassioned voices of people, (usually of course, women), who have recounted painful experiences from their past, including the trials and tribulations of raising a child with a disability, have appeared daily within letters to *The West Australian*. The grief, expressions of lack of support, the anger and regrettably the guilt, felt by many people, including those who are regarded or regard themselves as having a disability, expose the pressures and negative attitudes which have contextualised their experiences and their decisions.¹⁵ Those asserting the concept of 'a woman's choice' or those who prefer to focus upon a 'woman's (individual) responsibility or fault' might then be regarded as equally culpable in their inability to acknowledge the contingency of social, economic, political, emotional and other (often discriminatory) pressures. 'Choices' and decisions are not merely made 'privately', or within a vacuum, but are dependent upon the information, and range of options and supports any person *perceives* themselves to have, and *actually* has, at a particular point in time.¹⁶

'Medical Tragedy', Prenatal Screening and Selective Abortion.

¹³ Jenny Morris, *ibid.*, pp.73-4. [bolding our emphasis].

¹⁴ Laura Hershey, (1994), p.31.

¹⁵ One person wrote: 'I have muscular dystrophy. This affects many decisions in my life. It affects the way I dress, the furniture I buy, the clothes I wear, the type of job I do, the people I mix with and the decision to marry and have children. I fall and I can't get up. I am laughed at and ridiculed, denied employment, rejected by so-called friends, rejected because I am different and because people are scared of someone who is different. My mother didn't have the chance to have prenatal testing. I wish she had ... [!!!!]' 'Letters To The Editor', *The West Australian*, Saturday February 21 1998. It scarcely needs to be stated that this self deprecation indicts all of us.

¹⁶ Melanie James and Natalie O'Brien quote 'one Sydney clinic counsellor' as suggesting that 'one of the main reasons women cite for terminating pregnancies is lack of support', 'Reality and self-justification at odds in abortion stress debate', *The Australian*, Tuesday February 24 1998.

Clearly, there are many difficulties and ambiguities implicated in this discussion, (often regardless of the question of so-called 'abnormality')¹⁷ not least of which is reflected here in our attempts to express ourselves in the *least* loaded language. Even using the term 'disability' without, at the outset, appearing to conjure up the spectre of a homogeneous objectified group of '*dis*'-abled or '*less than*' persons is a problem.¹⁸ The 'them' and 'us' imagery, the stereotypically 'normal' lot and the 'others', (and there are ironically lots of categories of difference and otherness for each of us to avoid), is so entrenched in the perceptions of most of us that we rarely, unless confronted by some personal experience, consider the influential histories and bases of such ideas.¹⁹

We may believe ourselves to be enlightened and liberal, attempting to repress and overcome our prejudices, but the discomfort aroused by any form of difference (particularly if it is a *visible* form of difference)²⁰, which somehow reminds us of our own fragility and mortality, partly explains the attractiveness of belonging to the (albeit *imaginary*) 'in crowd'. From this safe, if artificial viewpoint, disability, disease and death can reside with other unfortunate individuals who are often viewed as victims of a 'medical tragedy.'²¹

¹⁷ We have yet to meet a 'perfect' or 'normal' child – including our wonderful own !

¹⁸ Professionals and service providers have themselves been indicted as culpable of such homogenisation and objectification by the: '*privileging of professional histories [which] maintains the membership of people with learning difficulties within a marginalised and stigmatised group ... confirm[ing] their identity as 'cases' rather than individuals*'. See Maureen Gillman, *et.al.*, (1997), p.683. For a critique of the involvement of psychology in the promotion and maintenance of 'racism and prejudice' which has numerous parallels with 'disabilism' see Ann Sanson *et.al.*, (1997). With regard to the issue of abortion generally, we are also uncomfortable with the unqualified use of the term 'foetus' which *pre-empts* the question of the humanity of the 'embryo'. We have used this term however, but with this consideration in mind, and where it has been adopted by particular protagonists in this debate.

¹⁹ Few people considering themselves to have confronted discrimination and prejudice(s), would make the kinds of confessions made by Phillip Adams in his *Introduction* to a publication about intolerance in Australia. Initially recalling an experience in the school playground as a five year old, and in his later perceptions as a mature man he wrote: '*[N]o sooner had we dealt with the reffo [refugee] ... than the same jeering, ugly circle formed around a kid with Down's Syndrome we'd found sitting quietly on a playground swing. Kids like that were called Mongoloids, and the name was almost enough. Despite his bewildered smile and obvious wish to be friendly, we bullied and terrified him. I felt shame then and I feel shame now, 50 years later. Yet when planning the International Year of the Disabled Person in the early 1980s I still felt, deep inside me, a primitive response to disability. These days I know how to repress such feelings in a nanosecond. And that's what we self-styled progressives do with vestigial prejudice – we censor it savagely, instantly, overlaying it with our more sophisticated considered response. But we are liars if we deny that old terrors no longer exist*'. See Phillip Adams, (1997), p.27.

²⁰ Sharon Dale Stone (1995), p.413 '*addresses the question of why it is that we tend to focus on visible disabilities and ignore the prevalence of invisible disability ... [by] argu[ing] that a focus on visible disabilities allows us to complacently ignore the widespread prevalence of disability in society*'.

²¹ Conversely, '[t]he social model ...[or] '*big idea*' of the disability movement ...[c]hallenges the traditional view of disability as medical tragedy, and replaces it with a view of disability as social oppression. In sociological terms, this is about arguing that disability is socially constructed not biologically determined', and if attitudes can be changed and sufficient supports and resources provided 'disability' as it is often perceived would simply not exist. See Tom Shakespeare, *et.al.*, (1996), p.2.

Any discussion of the contemporary application or 'option' of prenatal screening cannot either avoid the contextual issue of attitudes and values with regard to perceptions of disaster or tragedy about 'disability'. Whatever qualifications (or not) put on accessibility to abortion, it seems as if 'disability' or 'abnormality' occupies a special compartment all of its own. Laura Hershey has thus commented also, that in the US:

*'when a prenatal test reveals the possibility of a "major defect", as the medical profession puts it, the pregnancy almost always ends in "therapeutic abortion". The prospect of bearing a child with disabilities causes such anxiety that abortion has become the accepted outcome - even among [some] people who oppose abortion rights in general.'*²²

Similar attitudes appear to prevail in Australia when termination of pregnancy on the basis of 'abnormality' seems to be an issue with a separate agenda,²³ and where sometimes the avoidance of explication is regarded as a kind of resolution. In Western Australia for example, during the current 'abortion debate', Attorney General Peter Foss and the Coalition partyroom 'scrapp[ed]' an original element proposed in the Governments 'five-tier legislation' which permitted 'abortions for serious genetic defects'. It was reported he argued that 'terminations in cases of genetic defects would be sufficiently covered by the first two tiers of his Bill which also includ[ed] a vote for abortion on demand'.²⁴ Matt Price a journalist commenting upon this point suggested that '[t]he prospect of MPs defining the precise circumstances when the abnormal foetus could be terminated proved too frightening for all concerned'.²⁵

This circumvention or superficial neutralisation of a confronting issue, can of course, be rationalised various ways. Some might argue that in fact, *lack of reference to 'abnormality' altogether, is protective toward fetuses with a potential or existing disability, while others like 'prominent pro-life activist Richard Egan ... accused the Government of disguising its intention to "weed out Down syndrome and undesirable children"'*.²⁶ Whether one is sympathetic or not to Richard Egan and 'pro-life' or anti- abortion (depending on who is

²² Laura Hershey, *op.cit.*, p.27. In the UK '[i]n 1990 an amendment to legislation controlling human embryo research introduced a new limit for all abortions at 24 weeks except where the foetus was 'seriously handicapped'. Termination of a disabled foetus is now legal right up to the moment of birth', See Margaret Kennedy, (1995), p.11.

²³ 'Some major Australian hospitals will perform abortions post-20 weeks – half way through a pregnancy – but only where a lethal or disabling abnormality has been detected in the foetus'. In the same article it is also stated that: 'Late mid-trimester abortions garner great publicity and debate but, in truth, those performed so late, for other than foetal abnormalities, represent a tiny proportion of all abortions in Australia'. See Adrian McGregor, 'This man is on the frontier of Australian abortion practice ...', *The Weekend Australian Review*, July 26-27, 1997, p.1.

²⁴ Chip Le Grand and Natalie O'Brien, 'Abortion: MPs look into their hearts', *The Australian*, March 11, 1998, p.2.

²⁵ *ibid.*, Matt Price, 'Heavens are weeping, but for whom do tears fall?'

²⁶ Cited in Le Grand and O'Brien, *op.cit.*

doing the labelling) perspectives, there are clearly many other indications which also imply that the government's 'intention' or dismissal of this issue could, *by default*, endorse the continued 'elimination' of less than 'perfect' 'foetuses' or (potential) people in our society.²⁷

There is no doubt that the greater accessibility to prenatal screening presently offered throughout Australia has led to an increase in the numbers of pregnancies being terminated on the basis of a *detected* 'abnormality'. A report issued by the *Australian Institute of Health and Welfare* in 1997, entitled: *Congenital Malformations Australia 1993 and 1994*, showed (regardless of the problem of lack of reliable data for such terminations), an increase from '421 in 1991' to '700 in 1994' due to 'foetal defects'.²⁸ Although available figures do not reveal the full extent of terminations on the basis of foetal 'defects' in Australia, the trends are evident and have been recently discussed by various commentators including Roy Eccleston in an article entitled: 'Death Before Deformity'. In this he comments that:

*'According to estimates, national terminations for Down syndrome rose from 16, or less than 5 per cent of Down's births, in 1982 to 114, or more than a third in 1992 - and the figure has grown sharply since with wider testing. In Victoria alone in 1993, 61 Down's foetuses were diagnosed, and doctors say the vast majority would have been terminated. In South Australia in 1991, more than 70 per cent of foetuses with spina bifida (open spine) were terminated, compared with about 20 per cent in 1980. While specialists stress that most terminations are for serious problems this is not always the case. Professor Shaun Brenneke, the obstetrician in charge of the perinatal unit at Melbourne's Royal Women's Hospital says an ultrasound might spot a missing hand. "Is this sufficient justification for terminating a pregnancy?" [he asks].'*²⁹

Disability and disease seem to be inextricably intertwined in these scenarios with 'prevention' and 'treatment' somehow equated with termination.³⁰

²⁷ This raises the conundrum which frequently crops up in relation to funding and the acquisition of supports for people in our society who need them i.e.- if the term 'disability' is not explicated then it seems some important provisions cannot (or will not) be made. The dissolution of this terminology is not then merely semantic, but dependent upon the creation of a society which assumes collective responsibility for all its members.

²⁸ As reported by Naomi Mapstone in 'Neural defects decline in newborns: report', *Canberra Times*, March 1997.

²⁹ Roy Eccleston, 'Death Before Deformity', *The Australian Magazine*, January 20 -21, 1997, p.12.

³⁰ See for example an article entitled: 'Detecting fetal abnormalities', by Robert Williamson (Director of the Murdoch Institute for Research into Birth Defects), *Australian Family Physician*, Vol. 26, No. 3, March 1997. Although this article refers to both '*timely advice on the availability of antenatal diagnosis and the best possible care of any child affected by a genetic disease*', the entire discussion is only about identifying abnormality. Williamson also comments: '*With the various test protocols in use in Victoria, approximately half the Down Syndrome pregnancies which would come to term each year are identified antenatally after voluntary testing. The majority of these couples choose to terminate affected pregnancies, making it remiss not to discuss the risk of having a Down syndrome child with an older pregnant woman*' (p.247). In this short statement alone, the '*medical tragedy*' model is implicit and assumed in the notion that tests are 'voluntary', and that having a child with Down's syndrome is a 'risk'. While it might be expecting too much to ask medical practitioners to consider the implications of the medicalisation and disease model of 'disability', it is important to note the power and (unquestioning) subtlety of such perspectives.

'Foetal medicine specialist Janet Vaughan [has been reported to say] ... that when she rings doctors with the results of their patients' tests they often say, "Oh. Well have you told her what to do?" [She] say[s], "No that's not my job" Then they say, "Oh, so I've got to do it, have I"?'³¹

As the authors of a recent publication about the history of the social construction of intellectual disability in Western Australia were reported to comment:

'Genetic scientists wrongly depict intellectual disabilities as preventable diseases when they advocate testing in pregnancy ... [they] said disabled people and their families felt worthless when ethics were left out of the debate'.³²

Can we deny the ethical implications involved here, particularly when the preferred (and somehow *self-evident*) focus is upon *available technology*, rather than on any fundamental implications for the nature of our society and how we might expect to treat other people - and to be treated ourselves. With present methods of screening, such as 'chorionic villus sampling' to be superseded, (if continuing trials are successful), by blood tests³³ which can be performed earlier in pregnancy, also '*mak[ing] it easier to opt for a termination at six weeks, given the lack of foetal movement and a less stressful abortion procedure*', why should we worry? Perhaps we should celebrate this new test called '*PreScreen, developed by Flinders technology in Adelaide working with US company BMC*' ... [especially because] *[t]he test would be an enormous money spinner, as more parents took the opportunity to reduce the risk of abnormal offspring*'.³⁴

Without being able to explore the issue in any real depth here, *money* cannot at any point be subtracted from many of the issues we have discussed.³⁵ In the first place, pressures on governments to adequately fund health care systems are currently a source of great contention. The support and care of some people with disabilities does not in the current climate of economic rationalism, appear as a very attractive proposition. '**Choosing**' to have a child with a disability is also (apparently) tantamount to 'choosing' to support that child possibly well into adulthood, with very little assistance,- financial or otherwise. Screening for abnormality, particularly if all pregnant women take up the 'option' is also potentially a

³¹ Jane Wheatley, (1997), p.46.

³² Catherine Fitzpatrick, 'Warning on Foetal Testing', *The West Australian*, 3 December 1996. Publication referred to: Errol Cocks, *et.al*, (1996).

³³ A blood test called MSS or maternal serum screening is presently used to identify 'risk' of Down syndrome and Spina Bifida. See Wheatley, *op.cit.*, p.44.

³⁴ Roy Eccleston, 'Revolution in the wings for pre-natal testing', *The Weekend Australian*, Feb 26 – Mar 1, 1998.

³⁵ '*Seven senior doctors, including Institute of Child Health Research Founding Director, Professor Fiona Stanley [during the current 'abortion debate'] ... sent a letter to State MPs warning of the social [financial?] implications of curbing access to abortion. ... It said about 100 of the 9000 terminations in WA each year involved serious malformations of the foetus. "Whilst some of these children would die soon after birth, some would survive the disabilities and need services that are already stretched to the limit", the letter said.*' 'Doctors fear social backlash, *The West Australian*, Thursday, March 12, 1998, p.5.

very lucrative activity which will no doubt be supported by medical practitioners who might well also be fearful of legal implications of not facilitating a 'perfect' outcome.³⁶

In an article discussing 'Euthanasia and disabled children', Margaret Kennedy has recently argued:

Disabled children's lives are not valued in modern society. They are [often treated as] second class citizens. There is an unquestioned assumption that physical [and other forms of] disability ... means that life is not worth living. Those who support the legalisation of euthanasia focus the right to die on those who are either terminally ill or incurably disabled. The simple desire to die is not [generally] regarded as a sufficient qualification for euthanasia. This implies that sick and disabled people are 'right to want to die' and 'better dead'.³⁷

In 1914, one of the most prominent eugenicists in America, argued that:

The feeble-minded person is not desirable, he is a social encumbrance, often a burden to himself. In short it were better for him and for society had he never been born. Should we not then, in our attempt to improve the race, begin by preventing the birth of more feeble-minded'³⁸

Bearing in mind the confluence of issues of selective abortion, sterilisation and euthanasia with regard to negativisation of people with a disability,³⁹ it appears then doubtful that at this point in our 'history' we have come a very long way. For if the latter two issues are to be

³⁶ Legal implications with regard to 'rights' of parents and children are quite complex and according to Jennifer Fitzgerald, reflective of the 'principles of individualism and individual autonomy [which she suggests] have risen to new heights'. As Ms Fitzgerald argues: '[t]he personal freedom of parents to choose not to have a child with an impairment is upheld as an important reason in favour of selective abortion. This however, clearly begs the question: Who owns the child? In addition, it ... [has also been] argued that the child itself has a right 'not to be born', J. Fitzgerald and E. Leipoldt, *op.cit.*, p.5. For people with or without a disability who might be considering having a child, the implications could become horrendous: It was proposed for example, by Margery Shaw an American attorney and physician, that '[o]nce a pregnant woman has abandoned her right to abort and has decided to carry her fetus to term, she incurs a "conditional prospective liability" for negligent acts toward her fetus if it should be born alive ... A decision to carry a genetically defective fetus to term would be an example ... [in that] ... exposure to the mother's defective intrauterine environment caused by her genotype ... could ... result in an injured infant who might claim that his [sic] right to be born physically and mentally sound has been invaded'. Margery W. Shaw, 'The Potential Plaintiff: Preconception and Prenatal Torts', in Aubrey Milunsky and George J. Annas (eds), *Genetics and the Law 11*, New York, Plenum Press, 1980, pp.225-232, cited in, Ruth Hubbard and Elijah Wald, (1993), pp.25-26. Those doing the testing should also be wary however, as reported recently, parents of a 16 year old daughter are currently suing the 'estates of two dead doctors' for the inaccuracy of blood tests for rubella. After a recent re-test indicating results were positive not negative as originally reported in 1980, Mrs Harriton said 'if she had known she had rubella, she would not have continued with her pregnancy', *The West Australian*, Friday February 13, 1998.

³⁷ Margaret Kennedy, *op.cit.*, p.11.

³⁸ H.H. Goddard, *Feeble-Mindedness: its causes and consequences*, New York, Macmillan, 1914, p.558, cited in Christopher Kliewer and Stephen Drake, (1998), pp.99-100.

³⁹ See for example the work of Jennifer Fitzgerald (previously cited), who in our opinion, is the most outstanding contemporary Australian commentator on these and many of the other difficult ethical issues raised here.

resolved, then maybe Goddard might be considered 'correct' - perhaps potentially disabled people should never be born - but doesn't that, as we suggested at the outset include *all* of us?

*'If I were a mystic, I might assume a fundamental oneness of all living things;
[then] the burden of proof would rest with those who claim ... difference'*⁴⁰

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⁴⁰ Christine Overall, (1988), p.92.

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