PRENATAL TESTING, EAST AND WEST

Regulating disabled foetuses in China and Australia

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apid developments in genetic technologies have created challenges for policymakers to adapt the regulatory system to account for new social and ethical concerns to the community. This article focuses on the economic, political, and social implications of prenatal testing for China and Australia.

Prenatal testing is a technology used to determine the physi(ologi)cal condition of a foetus before birth. Prenatal screening allows parents and physicians to exert more control over what was previously foreordained by nature. However, prenatal testing is problematic because current technology is not foolproof. Screening tests have a 5 per cent incidence of false positives and false negatives, while diagnostic tests have risks of miscarriage. Moreover, many diseases detected in prenatal testing are incurable. with the only preventive remedy being abortion. Thus, in the absence of gene therapy, prenatal testing has been criticised as tacitly encouraging abortion of disabled foetuses and discriminating against the disabled. However, I agree with Holm, who argues that aborting a disabled foetus does not translate into actual discrimination against existing disabled people, although it implies that the parents value the particular disability so negatively that they think that the world without the disabled child is preferable simply because it does not contain that child.2

In this article, I demonstrate that China, as a post-socialist country exhibiting capitalism with Chinese characteristics, is keen to directly regulate 'human bodies' due to the widespread acceptance in that country of the importance of 'quality birth' and the resultant perceived need to reduce the number of disabled people born. In contrast, Australia, as a Western liberal country, relies on a loose framework of guidelines and professional regulation to regulate genetic testing. Nevertheless, I show that due to a lack of informed consent and full understanding of prenatal testing, the Australian position leads to the same outcome as the Chinese position, ie increased abortions of disabled foetuses in society.

China: 'Quality Birth'

Prenatal testing in China: The Maternal and Infant Health Care Law

The Chinese government has been very concerned about 'quality births' and population issues. In 1979 the Chinese government introduced the Chinese Family Planning Policy, better known as the 'One Child

Policy'. In broad terms, this policy dictates that the majority of Chinese citizens should only have one child, and there should be social and economic incentives (longer maternal leave, subsidised education, health and housing) and disincentives (fines, social stigma) to achieve that goal. As part of a series of reforms aimed at tightening birth control in the early 1990s, the government introduced measures to strengthen marriage registration and premarital examinations.

On I June 1995, China introduced the Maternal and Infant Health Care Law ('MIHCL'). The law aims to 'ensure the health of mothers and infants and [to improve] the quality of the newborn population' while reducing the burden of disabilities.

Article 38 of the MIHCL defines serious diseases as 'target infectious diseases', 'genetic diseases of a serious nature' and 'relevant mental diseases', including conditions such as AIDS, gonorrhoea, syphilis, leprosy, schizophrenia, manic-depressive psychosis and other diseases 'medically considered inappropriate for reproduction'. A list of 'serious' genetic diseases was released in 1986 as the Ministry of Health Interim Guidelines by Category of Abnormal Conditions, prohibiting reproduction for people who were deaf by birth, were intellectually disabled, had uncured venereal diseases or had serious diseases which affected their eyesight.

Implementation details of the MIHCL were not released by the Chinese government as the policy was classified as sensitive. However, as the MIHCL was enforced as part of the 'One Child Policy', I will briefly examine the implementation of the broader population planning policy, drawing on literature by prominent academics in this area: Greenhalgh and Winkler, White and Scharping.³

Although the Chinese government has prohibited the use of coercion to carry out their policies since 1995, the incentives provided to local cadres to adhere to stringent birth quotas encourage them to use force. In the early 1990s, cadres responsible for birth planning launched coercive campaigns in several regions involving mass sterilisations, confiscating property and demolishing houses. For example, White reports that in Anhui in 1991, a 'shock' campaign contributed to a total of more than 1.2 million sterilisations and IUD insertions. In urban areas, enforcement was highly intrusive and involved health aides observing and managing the reproductive lives of Chinese citizens, including monitoring menstrual cycles and

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- 2. Søren Holm, 'The Expressivist Objection to Prenatal Diagnosis: Can it be laid to Rest?' (2008) 34 Journal of Medical Ethics 24.
- 3. Susan Greenhalgh and Edwin Winkler, Governing China's Population: From Leninist to Neoliberal Biopolitics (2005); Tyrene White, China's Longest Campaign: Birth Planning in the People's Republic, 1949–2005 (2005); Thomas Scharping, Birth Control in China 1949–2000: Population Policy and Demographic Development (2003).

accompanying women to the local health centre for sterilisations and abortions.

These hardline measures attracted criticism from the Western media. Due to strong international pressures, especially during the 1998 Beijing Eighteenth International Congress of Genetics Convention, which included discussions on eugenics and criticism of the MIHCL, China declared that it would clarify the ambiguities in the law.⁴

On 20 June 2001, the Chinese government promulgated the 'Measures for Implementation of the Law of the People's Republic of China on Maternal and Infant Health Care'. The decree made premarital testing voluntary, as Article 14 states that during the premarital examination, based on the physician's advice, the patient can voluntarily postpone marriage or take long-term contraceptive measures or ligation. Further, in 2003, the revised Marriage Registration Regulations abolished compulsory pre-marital physical examinations, a step described by the China Daily on 4 September 2003 as 'socially progressive' and showing 'improved respect for human rights'. The China Daily reported (21 May 2007) that the percentage of new couples who had premarital medical check-ups plummeted from 68 per cent in 2002 to 3 per cent in 2005. In contrast, Greenhalgh and Winkler state that about 70 per cent of pregnant women accepted prenatal testing for defective foetuses from 2001 to 2004. A further study found that Chinese couples terminated 96 per cent of pregnancies with sex chromosome abnormalities, a higher percentage than any other country.5 Thus it appears that the Chinese populace is unconcerned about premarital check-ups, but is more interested in prenatal testing, with a high likelihood of abortion if defects are detected.

The Chinese government has continued to show a strong interest in 'quality births' by monitoring infant defect rates and publicising the large cost of supporting infant defects. Jiang Fan, vice-minister of the National Population and Family Planning Commission ('NPFPC'), announced that a Chinese baby with physical defects is born every 30 seconds (China Daily, 31 January 2009). Previously, the Ministry of Health announced that birth defects accounted for 4 to 6 per cent of total births yearly, imposing a total annual cost of one billion yuan (Xinhua, 20 September 2006). The reports of rising birth defects were accompanied by strident statements by government officials supporting the reintroduction of compulsory pre-marital health checks to ensure the 'quality' of the population. In the same Xinhua report, Pan Guiyu, then deputy director of the NPFPC, called for the resumption of compulsory pre-marital tests, stating that the 2003 cancellation was a major cause of the rise in birth defects and could affect the 'quality' of the population.

Following the official pronouncements, the NPFPC released a regulation to facilitate the screening of newborn infants for birth defects to 'help reduce the incidence of debilitating conditions', which came into effect on 1 June 2009.

Therefore China has gone from strong regulation of genetic testing to relaxing the regulations and is starting to re-emphasise screening for birth defects. In addition, since the early 2000s, there has been a move away from coercive population planning methods towards providing incentives for compliance, as well as a shift in emphasis of the family planning policy from quantity to quality.

In order to understand the Chinese government's position, it is necessary to examine the concept of 'quality' which permeates governmental discourse.

Suzhi and the pursuit of quality

Quality or suzhi is a multifaceted concept with a range of meanings that has been used in a range of contexts, including family planning, national development and education.⁶ The much-debated concept of suzhi has been extensively researched by academics such as Kipnis, Anagnost and Jacka, and is a 'floating signifier' which even the Chinese find notoriously difficult to define.⁷ The word has been translated into 32 different English terms. Broadly, suzhi can be understood as a person's physical, intellectual and moral status, which incorporates elements of nature ('superior birth') and nurture (education) and contains elements of Confucian notions of self-cultivation, early modern Chinese anxieties about 'national characteristics', as well as Marxist efforts to create a new socialist order.

Kipnis shows that the rise of suzhi discourse during the post-Mao era was tied to a series of political, economic, social and cultural events, including the implementation of the population control policy and the centrality of nationalism to the Chinese Communist Party's ('CCP') self-legitimisation. The CCP's legitimacy rests on the premise of improving the condition of the population, and suzhi links disparate policies towards a national development plan.

Suzhi has been used strategically both in justifying increased state intervention in the private spheres and retreat in the public spheres. For instance, suzhi discourse was used to rationalise state intervention in the private sphere of individual reproduction to improve the population's quality. Conversely, in the public sphere, in post-socialist conditions where the government dismantled previous collective welfare benefits towards liberalisation, suzhi discourse was used to shift the onus of provision from the government to individuals by relating their well-being to their suzhi, with the state role being to support individuals towards achieving higher suzhi.

Further, suzhi has struck a chord in Chinese society at large due to the increasingly competitive nature of the Chinese populace. Greenhalgh and Winkler contend that in contemporary China, falling fertility created the rising desire for the 'quality child' on the part of parents, grandparents, educators and society — 'if the one-child norm is repressive, the norm of healthy, educated single child is seductive'. This implies that as the discourse of 'quality' is ingrained the fabric and belief structure of Chinese society, where the Chinese public self-regulate, their behaviours and goals may be

- 4. Gail Rodgers, 'Yin and Yang: The Eugenic Policies of the United States and China: Is the Analysis that Black and White?' (1999) 22 Houston Journal of International Law
- 5. Can Liao and Dong-Zhi Li, 'Pregnancy Outcome Following Prenatal Diagnosis of Sex Chromosome Abnormalities in Mainland China' (2008) 28 Prenatal Diagnosis 443.
- 6. Rachel Murphy, 'Turning Peasants into Modern Chinese Citizens: "Population Quality" Discourse, Demographic Transition and Primary Education' (2004) The China Quarterly 1, 2.
- 7. Ann Anagnost, 'The Corporeal Politics of Quality (Suzhi)' (2004) 16(2) Public Culture 189, 197. See also Andrew Kipnis, 'Suzhi: A Keyword Approach' (2006) China Journal 295; Ann Anagnost, National Pastrimes: Narrative, Representation and Power in Modern China (1997); Tamara Jacka, Rural Women in Urban China: Gender, Migration and Social Change (2006).
- 8. Rachel Murphy, 'Turning Peasants into Modern Chinese Citizens: "Population Quality" Discourse, Demographic Transition and Primary Education' (2004) The China Quarterly 1, 2.

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aligned with the government to reduce perceived 'low quality' births; thus disabled foetuses are more likely to be aborted.

Australia's approach: Liberal reproductive freedom

The Australian context: Piecemeal regulation

In Australia, prenatal testing is not explicitly legislated, which means that the law regulating doctor-patient consultations applies, ie the duty to take reasonable care in contract and negligence, including providing sufficient information to patients about medical procedures to enable them to make informed decisions.9 This is bolstered by legislation in states and territories (except the Northern Territory) which specifically address the issue of consent to genetic procedures.10

Further, privacy legislation concerning the collection, use, storage and disclosure of personal and health information can incidentally affect pre-birth reproductive choices. Information privacy is currently governed by a complex set of commonwealth, state and territory legislation.11 The Australian Law Reform Commission ('ALRC') has recommended that health information privacy be regulated under the general national system.

In the absence of comprehensive legal regulation, the Fertility Society of Australia has developed an accreditation scheme and established the Reproductive Technology Accreditation Committee ('RTAC') to monitor compliance. 12 The RTAC is responsible for producing guidelines defining the standards of clinical. scientific and technical practice in treatment and research provided by Australian infertility clinics. This self-regulatory mechanism ensures that the standard of treatment in Australian clinics is the responsibility of professionals providing the treatment. Non-compliance with the RTAC Code of Practice can lead to a review and possible suspension of a clinic's accreditation. There is significant financial incentive for clinics to be accredited as the Health Insurance Commission approval of patient fertility drugs is linked to this accreditation.

Despite the lack of direct legislation in the area of prenatal testing, there is legislation about assisted reproductive technology, ie methods used to achieve pregnancy by artificial or partially artificial means, which may involve genetic testing as part of the process. I will outline this briefly.

Due to constitutional limitations, Australia regulates assisted reproductive technology partly by state

legislation (New South Wales, Victoria, South Australia and Western Australia)13 and partly under the National Health and Medical Research Council's Ethical guidelines on the use of assisted reproductive technology in clinical practice and research (revised June 2007) ('NHMRC Guidelines').

The NHMRC Guidelines lay the ground rules for all states and territories about ethical practice in assisted reproductive technology. The Guidelines are the only source of regulation for states without specific legislation (Tasmania, Queensland, ACT and NT), and in states with legislation, the Guidelines are applicable as a guide via accreditation requirements for IVF clinics. However, in YZ v Infertility Treatment Authority Morris | held that the Guidelines do not have the same status as a statute and should not be interpreted or applied like a statute, emphasising that '[t]he guidelines are intended to be just that — guidelines'.14

In its Guidelines, the NHMRC outlines some ethical issues which should be considered in the evaluation of pre-implantation genetic diagnosis ('PGD'):

- · what counts as a serious genetic condition is controversial:
- there are different perceptions of disability; and
- the practice of selecting against some forms of abnormality may threaten the status and equality of opportunity of people who have that form of

This is an interesting contextual approach which recognises the perspectives of disability theorists — that the practice of selecting against disability may discriminate against those who currently have that disability.

However, this aspirational passage is followed by more prescriptive requirements restricting the use of PGD. The Guidelines state that PGD must not be used for:

- prevention of conditions that do not seriously harm the person to be born;
- · selection of the sex of an embryo except to reduce the risk of transmission of a serious genetic condition;
- · selection in favour of a genetic defect or disability in the person to be born.

These prohibitions may be seen as impinging on reproductive rights and freedoms. Further, the prohibition on selecting in favour of a disability implies that one of the main purposes of genetic testing is to

- 9. Rogers v Whitaker (1992) 67 ALIR 47; Malette v Schulman (1990) 67 DLR (4th)
- 10. Transplant and Anatomy Act 1978 (ACT); Patient Information and Consent to Medical Treatment Guidelines (NSW) and Guidelines for Newborn Screening (NSW); Criminal Code 1995 (Qld); Consent to Medical Treatment and Palliative Care 1995 (SA); Human Tissue Act 1983 (Tas); Guidelines for Newborn Screening (Nov
- II. For example, Privacy and Personal Information Protection Act 1998 (NSW); Health Records and Information Privacy Act 2002 (NSW); Health Records Act 2001 (Vic); Information Privacy Act 2000 (Vic); Health Records (Privacy and Access) Act 1997 (ACT): Health Services Act 1991 (Old): South Australian Health Commission Act Amendment Act 1987 (SA)
- 12. Helen Szoke, 'Regulation of Assisted Reproductive Technology: The State of Play in Australia' in Ian Freckelton and Kerry Petersen (eds), Controversies in Health Law (1999) 244
- 13. Assisted Reproductive Technology Act 2007 (NSW) and Assisted Reproductive Technology Regulations 2009 (NSW); Infertility Treatment Act 1995 (Vic) as amended by the recent Health Legislation (Infertility Treatment and Medical Treatment) Act 2006 (Vic): Reproductive Technology (Clinical Practices) Act 1988 (SA); Human Reproductive Technology Act 1991 (WA).
- 14. YZ v Infertility Treatment Authority [2005] VCAT 2655, [68].

15. Secretary of the Department of Health

and Community Services v JWB and SMB

(1992) 175 CLR 218

- 16. Simon Meagher, 'Prenatal Screening and Diagnosis: Recent Advances' (Paper presented at the Scientific, Medical, Ethical and Legal Aspects in Prenatal Screening and Diagnosis Conference, Melbourne, 17 August 1999) 14.
- 17. Norman Ford (ed), Scientific, Medical Ethical and Legal Aspects of Prenatal Screening and Diagnosis (1999) 35.
- 18. Susan Michie, Deana Smith and Theresa M Marteau, 'Prenatal Tests: How are Women Deciding?' (1999) 19 Prenatal Diagnosis 743.
- 19. Cate Nagle et al, 'Evaluation of a Decision Aid for Prenatal Testing of Fetal Abnormalities: A Cluster Randomised Trial' (2006) 6 BMC Public Health 96.
- 20. Carole Webley and Jane Halliday, Report on Prenatal Diagnostic Testing in Victoria 1999 (1999) Perinatal Data Collection Unit 1

eliminate disability and the choice to have a disabled child is not countenanced.

Indeed, in the NHMRC Guidelines, the reasons given in support of using genetic technologies include 'interest in reducing the economic and social costs of caring for the incurable' and '[h]ope for progress in the overall health and fitness of human society'. This implies that one of the goals of prenatal testing is to improve 'public health', ie to reduce the economic 'burden' of genetic diseases and to increase the general health of the population. This is akin to the 'quality population' concept in China. The Guidelines also list a reason which conforms to the 'reproductive freedom' argument, ie the 'belief that other people are not entitled to stop those who wish to use genetic technology'.

The 'reproductive freedom' principle was scrutinised in the case of *Re Marion*, where the High Court majority decided that court authorisation was required for sterilisation of a mentally incompetent child due to the fundamental right to personal inviolability, but specifically noted that there is no right to 'reproductive freedom'. ¹⁵ Thus reproductive freedom is not an absolute right; rather it is an interest which constrains society from interfering with the exercise of reproductive choice without justification. Appropriate justification is based on the 'best interests' of the individual, rather than the burden to society. This implies that in Australia the main focus is the interest of the individual, rather than the 'public health' argument of weighing up the interests of the individual and society.

Thus prenatal testing in Australia is regulated in a patchwork manner, with a heavy reliance on ethical guidelines and professional self-regulation. The main justification for prenatal testing is based on 'reproductive freedom' and to a lesser extent 'public health'.

Practice of prenatal testing in Australia

Prenatal testing in Australia aims to detect major foetal abnormalities and provide couples with prenatal options, usually with the intention to abort abnormal foetuses. The practice of prenatal testing comprises a preliminary screening test for a variety of abnormalities and, if the results show high risk, this is followed by genetic counselling and possibly a prenatal diagnostic test. If the result is positive, the couple is counselled again, and there is an option of terminating the pregnancy. I will examine each step in part, focussing on Victorian law.

Screening and diagnostic tests: Implications

In prenatal testing, there is an emphasis on informed choice and reproductive freedom. However, it is unclear whether these notions operate in Australian practice. Real choice is predicated on non-directive communication of accurate information to a comprehending agent, leading to autonomous action based on 'systematic processing', ie weighing the pros and cons of possible options.

The usual prenatal screening tests are a maternal serum alpha-fetoprotein screening test, performed between 15 and 20 weeks gestation, and an 18th week

ultrasound examination, where neural tube defects and chromosomal defects such as Down Syndrome are detected. The diseases tested for depend on technology available, rather than policy considerations. Results of screening tests only measure risk levels and do not foresee with certainty whether a foetus is defective, thus a further diagnostic test is necessary for clarification. The usual prenatal diagnostic techniques are amniocentesis and chorionic villus sampling. These are highly invasive and carry a 0.5 per cent and 1 per cent chance respectively above the background risk of a miscarriage. These numbers seem negligible but, for a background risk of 30 per cent, an additional 1 per cent is significant.

Physicians tend to offer screening tests whether or not they believe it is clinically valuable as they fear legal action. 17 Since it is considered 'standard practice', failure to screen may lead to litigation. In addition, evidence shows that physicians do not give information in a manner conducive to systematic decision-making, as screening is often presented as 'routine' and for 'reassurance', not requiring decisions. 18 The possibility of further risky diagnostic tests and abortion as the only 'treatment' is frequently not raised at this juncture. Ford reports research which shows that during the 18th week ultrasound, many women thought the doctor was merely 'taking pictures' of the baby. In Victoria, information provided about prenatal testing options is not uniform, as some women receive verbal or written information, while others receive no information at all. 19 Therefore it seems that for screening tests, women do not realise they are being tested, or accept the test to appease the physician, which is incompatible with 'informed choice'. However, diagnostic tests may involve more systematic decision-making, as these are presented as conferring benefits and risks.

In Victoria, prenatal tests are offered to women in high-risk groups, ie advanced maternal age (over 37 in Victoria), or if the indication falls within the Prenatal Diagnosis Policy of the Human Genetics Society of Australasia. In the private system, women may have these procedures regardless of risk. The government funds the majority of prenatal testing costs through Medicare rebates. The fact that the tests are readily available and made affordable by the government for targeted groups may signify that the government supports reproductive freedom. Conversely, the public health influence might be operating: to increase the health of the population through preventive measures.

From diagnosis to abortion: Implicitly sanctioned?

There were 5 550 prenatal diagnostic tests performed in Victoria in 1999 (8.7 per cent of Victorian women giving birth), of which 4.4 per cent had an abnormality.²⁰ Abortion rates following positive diagnostic testing vary across diseases, but the 1998 Annual Report of the Consultative Council on Obstetric and Paediatric Mortality and Morbidity reported that approximately 80 per cent of foetuses with Down Syndrome were aborted following a positive diagnostic test. In 1998, 50.7 per cent of foetuses with chromosomal abnormalities were aborted before 20 weeks, but this

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is probably understated since no mandatory reporting for abortion exists in Victoria.

Genetic counselling: Direction of non-directiveness?

Genetic counselling is a communication process to assist couples in making decisions about genetic disorders. The practice of genetic counselling is based on non-directiveness, ie the counsellor should 'objectively' disseminate information. The stress on non-directiveness originated from the desire to repudiate coercive eugenics, and is grounded in a faith in the capacity of humans to make enlightened knowledge-based decisions. However, doubt exists on whether non-directiveness is effective, desirable or even possible in practice.21 Sociologists have recognised that no human behaviour or speech, including scientific research, is free from value judgments.²² If so, directive methods should be acceptable if explicitly acknowledged, as unacknowledged and unintended directiveness may be more manipulative. The ethos of genetic counselling may be misguided, thus leading to unintended consequences.

Genetic counsellors often have to convey complex information to their patients within a short timeframe in order for patients to make major life decisions. The counsellor presents information about the 'burden' of condition, ie risks and severity of the condition in terms of probabilities of genetic defects, which are negative medical terms. There is little or no emphasis on the positive aspects of having a disabled child. For instance, a study of women who had given birth to a child with Down Syndrome or other disabilities strongly affirmed their love for, and commitment to, the child and asserted how much these children enriched their lives.²³ Thus, there may be unintended pressure from genetic counsellors to abort abnormal foetuses. Even without overt pressure to terminate, abortion is the expected course of action, as there is no alternative besides inaction.

To sum up, Australia loosely regulates prenatal testing, which leads to significant confusion amongst clinicians, parents and potential parents. Informed choice seems to be lacking in the practice of prenatal testing in Australia. Subsequently there may be covert and overt pressures to abort an abnormal foetus, as well as implicit societal and governmental support for this practice. This results in most women undergoing prenatal testing and the majority of abnormal foetuses being aborted.

China versus Australia: East versus West

The prenatal testing policies in China and Australia seem prima facie very different. The Chinese government seeks to regulate all aspects of the reproductive process, including premarital screening and prenatal testing, where the Australian government has loose regulation of genetic testing, with piecemeal laws and a high reliance on professional self-regulation and NHMRC Guidelines. The Chinese laws are also more expansive, as the laws include sterilisation for carriers of broadly defined 'serious' diseases and the Guideline Standards contain eight pages of 'serious genetic diseases', including venereal diseases and intellectual disability.

The concept of the State intruding into the intimate lives of its citizens and directly planning their births may seem alien to Western liberal democracies. However, as Sigley argues, the Chinese conception of self includes the physical self and ethical self as holistic elements of a single entity which is self-regulating and readily accessible to others. Intervention by others is a crucial factor in formulations on how Chinese citizens would conduct themselves to increase their 'quality' — the boundary between public and private, state and society do not exist in the same way as Western liberal democracies.24

Chinese policies are expressed to be towards the goal of a 'quality population', while Australia practises the principles of 'reproductive freedom' and, to a lesser extent, 'public health'. Although both the 'reproductive freedom' and 'public health' rationales have been noted in the NHMRC Guidelines, the predominant rationale for prenatal testing is generally focussed on 'reproductive freedom'.

The 'public health' argument is akin to the 'quality population' concept in China, as both are geared towards reducing the number of disabled people in the population, due to societal costs of supporting the disabled, coupled with the goal of a healthier population. However, the 'quality population' concept in China incorporates richer dimensions including Confucian concepts, Chinese nationalism and Marxist socialism, which makes it distinctly Chinese. On the other hand, the 'reproductive choice' notion, which is more common to Western liberal countries, has not been adopted in China. The Australian policy thus focuses more on the interests of the individual and upholding the right of reproductive freedom. In this sense, the Chinese policy seems to conform to the

- 21. Shoshana Shiloh, 'Decision-making in the context of genetic risk' in Theresa Marteau and Martin Richards (eds), The Troubled Helix: Social and psychological implications of the new human genetics (1996); Susan Michie et al, 'Nondirectiveness in Genetic Counselling: An Empirical Study' (1997) 60(1) American Journal of Human Genetics 40.
- 22. Aliza Kolker and B Meredith Burke, Prenatal Testing: A Sociological Perspective (1994) 43.
- 23. Ioan Hume, 'Disability, Feminism and Eugenics: Who has the right to decide who should or should not inhabit the world?" (Paper presented at the Women's Electoral Lobby National Conference, University of Technology, Sydney, 26 January 1996) 2.
- 24. Gary Sigley, Governing Chinese Bodies: Population, Reproduction and the Civilising Process in Contemporary China (PhD Thesis, Griffith University, 1996) 101.

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'true' eugenic motive of eliminating defective genes from the population. However, I argue that the 'public health' reasons may manifest indirectly in Australia in the practice of prenatal testing, as exhibited by the funding, design and implementation of prenatal screening, which may implicitly take into account economic savings generated by avoiding the birth of disabled children, compounded by biased genetic counselling.

Initially, it seems that China's policy is more controversial than the Australian one due to the coercive element in the MIHCL, which has since become voluntary. However, although reproductive freedom in Australia is based on voluntary choices, the current permissive attitude towards prenatal screening and selective abortion, together with the high value placed on perfection, inadvertently leads to eugenic consequences. Radical individualism does not take into account the fact that individual actions may have inadvertent social consequences. 'Rational' choices of individuals in aborting abnormal foetuses collectively have population effects, even without state intervention. When the scope of politics in reproductive testing is reduced, market power takes over, and one social power is replaced by another. Although there are ideological differences, the final outcomes of both the policies are similar: an increase in the abortion rate of disabled foetuses. Moreover, the Chinese reproductive policies have undergone shifts over the years, which have led to the elimination of the coercive element of the policies.

However, as the concept of 'quality' strongly permeates contemporary Chinese society, 'liberalised' individuals choose to act in accordance with the government's population policies, rather than exhibiting the previous strong resistance to population control. Thus, contemporary China exhibits the same liberal characteristics as Australia. The main difference is the mode of regulation, as the Chinese government is more intent on regulating intimate aspects of Chinese bodies, while the Australian government is content with loose regulation.

The similarity in attitudes between Australian and Chinese parents may also be a result of the popular preference of giving birth to healthy children. This preference seems 'natural' and reflects the desire to give birth to a child who will have the opportunity to have the 'best life'. However, this assumption is based on preconceptions that a disabled person will have a poor quality of life, and will increase the burden on parents and society, which are essentially the 'reproductive freedom' and 'public health' arguments discussed here. The Chinese government has further reinforced this preference by instilling the heterogeneous concept of 'quality' into its populace. Nevertheless, this seemingly 'natural' view can be challenged by the example of the deaf American lesbian couple who selected a donor to produce a deaf baby on the basis of their 'reproductive freedom', as they saw deafness as defining their cultural identity and wanted their children to share their culture.²⁵ This produces a conflict between 'reproductive freedom' (the couple's reproductive choice to select for deafness) and 'public health' (the utilisation of scarce resources to care for deaf people), which is not easily resolved.

To sum up, although initially the Chinese and Australia regimes of regulating disabled foetuses appear to be extremely different, due to China's liberalisation and the failed outcomes of informed choice in Australia, the outcome of both modes of regulation are similar: an increase in abortion rates in the respective countries. Therefore in charting future paths towards effectively regulating emerging reproductive technologies, it is prudent to analyse the ideals, practices and outcomes of a mode of regulation, as well as the wider social context. It is the first step towards understanding others as well as ourselves.

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25. Julian Savulescu, 'Deaf Lesbians, "Designer Disability," and the Future of Medicine' (2002) 325 *British Medical Journal* 771.

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