BIOETHICS

# The Return of Eugenics in Australia

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In 1996, on the fiftieth anniversary of the Nuremberg medical trials, German doctors gathered together in conference. They commemorated this anniversary under the title "Medicine and Conscience" and reminded their medical peers throughout the world that the separation of biological power from a moral sense would always be a danger to the profession. "This history," they said, "should not be viewed as just happenstance in Germany at a certain period in time." The removal of conscience from medicine creates an amoral medical force, but worse still, a force that can be sent in any direction. "Medicine can be distorted by state; physicians must be above state-decreed strategies," they warned. When the *Journal of the American Medical Association* reported on this conference it concluded that society and politics under the Third Reich had distorted the "medical ethos". Almost fifty years earlier, the British Medical Association had similarly overlooked the prime responsibility of doctors and medical associations not to relinquish conscience. Endeavouring to explain eugenic atrocities under Nazism, they submitted a resolution to the World Medical Association in 1947, presenting medicine as something of a depersonalised entity which had become "an instrument in the hands of the state to be applied in any way desired by its rulers". The characterising spirit of a profession, however, cannot be changed from the outside. It arises from a deeper stability and from convictions that are held and shared. It will bear up against distortion by state or fashionable ideas or persons of power and influence without—or within. For an ethos to be "distorted", those who held it must have let go.

The Nuremberg medical trials were said to have given insufficient attention to the ideology of eugenics. It is not the duty of a trial, however, to penetrate a philosophy. Before doctors abandon their ethos and banish their characterising spirit, the duty lies with them to penetrate a new philosophy whose merchant they are about to become. In the case of all eugenics, past and modern, whether as forced sterilisation and execution then, or sifting the unborn population now, the spirit of beneficence is the first casualty. It must either be cast out or recast.

Eugenic concepts are shaped into a pleasing appearance of benignity and fellow-feeling on the outside but medicine will always know what is on the inside. A language makeover, even a values makeover, has trouble hiding death from those asked to produce it. "Tending to the production of fine offspring" is the dictionary shape of eugenics, but the marketed shape is a newly crafted compassion, and a cold optimism dressed up as hope. Together they absolve eugenic rationales, and create a context of permission. Germany's 1939 decision to kill malformed newborns was said at the trials to be in response to compassion for the parents, for relief for the incurably ill, and for reasons of genuine medical care. Its responsible and salvific shape came from calculation of cost. Posters had appeared around Germany of a young man straining under the load of two mentally handicapped persons below the statement, "A hereditarily sick person costs on average 50,000 Reichsmarks up to the age of 60". Preventing an individual with "bad genes" from living was protecting society from the burden of those genes.

Australians have not yet been asked what particular shape they would like eugenics to take here. It was claimed in 2003 that Australia led the world in Down syndrome screening. Professor Sheffield, clinical geneticist at the Murdoch Children's Research Institute, then

lamented, however, that there was still room for improvement. Some states in Australia had not maximised their detection methods. This decade has seen unprecedented pressure generated within obstetric medicine to close the gaps in foetal Down syndrome diagnosis and this pressure passes down the line into every cubicle in every antenatal clinic, every general practitioner's office and every family. Other countries, too, have started dusting up their figures and casting their screening nets further. Denmark proudly announced in the *British Medical Journal* in 2008 that it had only delivered to life thirty-one Down syndrome children the previous year.

Professional approval easily becomes a new orthodoxy. The New South Wales Department of Health introduced prenatal testing to the public as a medical development in the interests of the baby's health. Their promotional pamphlet for prenatal diagnosis was published and distributed to every hospital and general practice in the state in June 2001. Its heading, "Importance of checking your baby's health before birth", was stamped obliquely across a mother's pregnant abdomen like a checked entry visa in a passport. Launched with such a forcefully worded assurance of its place in the baby's care and wellbeing, prenatal diagnosis was inserted confidently into society.

The new "beneficence" of this ideology was simply an entry permit, or perhaps an exit permit, or maybe an accidental death somewhere in between. While implying a benefit, it did not dare refer to the fact that the testing death rate statistically towered over the rate of any clinical gain. It followed the same well-paved path of all eugenic propaganda. The unconditional love and generosity of parenthood not choosing this path was implied as neglect or some dreadfully disorganised oversight of the "important". Indifference to responsibilities for the health and wellbeing of these disabled children became the new compassion, and the elimination of these children became the new face of care. Preventive medicine was targeting their very lives, whose survival would now constitute a statistical blot on the aims of "best medical practice".

Conceptual assent, first by the medical profession and then induced in the public under the shape of medical care, silently initiates eugenics. From this point on, principled reasoning has been stamped with a "new" ideology and one medical ethos has been subtly and smoothly traded for another.

The enabling link between wanting only fine offspring and producing only fine offspring is the medical profession. From being receptive to eugenic goals of biological research and implementing the clinical process, to agitating for its uptake in professional and political spheres, doctors become the advocate of eugenics rather than the advocate of the mother and child, whose wellbeing it is their responsibility to guard. The two ideologies are not compatible. Even assuming that one has already rejected Hippocratic principles, the more enduring *primum non nocere* ideal—first do no harm—is countermanded both by the protocols of the prenatal testing process and by its objective, to decrease the births of Down syndrome children. Whenever this mirror is held up to the prenatal screening and testing program, there is always indignation from those working at its core. The language magic must not be broken. Opposing ideologies must be seen to be as one. Beneficence must be marked present as the value it ever was, rather than absent but impersonated. Andrew McLennan, speaking for the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), recently denied that prenatal testing was about ending the lives of babies with Down syndrome. "This is all about choice," he reportedly informed the *Sun Herald* in November, "it's certainly not about running a program to increase the terminations for abnormalities." So, after undergoing a process which has been recommended for all pregnant women in Australia by this College, at mammoth cost and incurring unacceptable mortality rates for the child (up to 1 in 33 procedural foetal mortality after Chorionic villus sampling of the child's placental tissue,

and up to 1 in 100 procedural mortality after sampling foetal cells from amniocentesis) to obtain a result that is apparently worth the jeopardy of one's child, the end objective is to gain information which can be safely and inexpensively obtained a few months later. It all seems a tad foolish. Is Doctor McLennan sure prenatal testing programs are not about terminations for abnormalities? Chuffed with the successes of Down syndrome screening in Australia in 2003, Professor Sheffield was quoted in *Australian Doctor* as pushing for a "national consensus" on Down syndrome screening: "We've been trying for years but there is resistance from politicians, so each state has to cope with their own allocations [for screening]". Those in the industry who are most clamorous for whole population foetal screening seem displeased that the Australian population has representatives in government. Equally contemptuous of governing systems, obstetrician Dr Lachlan de Crespigny was quoted in the *Sydney Morning Herald* in October 2009 self-righteously railing against New South Wales abortion laws, which had not permitted senior doctors to kill a thirty-two-week unborn baby with a brain abnormality. Once suspended from his own hospital for a similar activity, Dr de Crespigny seems intent on absolving himself by stirring support for the crime. His role in the abortion law reform legislation in Victoria was significant. Compelling doctors to act against conscience in securing the deaths of unwanted children reminds one of Nietzsche's criticism of the state as capable of "organised immorality".

The German Medical Association proposed a law for compulsory sterilisation, which became the Law for the Prevention of Hereditarily Diseased Offspring in 1933. Feeblemindedness was especially targeted, and every case of hereditary illness had to be registered. The program was so large that it transformed the medical syllabus. The profession had to undergo special training to recognise hereditary abnormality. Before modern genetics, this meant classifying the shape of patients' earlobes, their particular gait, and measuring the crescents at the bases of fingernails. Where diagnosis could not be found, "moral feeblemindedness" was declared of a person deemed to be totally without value to the community. Mothers tried to conceal their children's disabilities from doctors, and inmates of mental institutions and prisons hid answers to intelligence tests and tried to memorise them.

While beneficence is the first eviction from the new ethos, the second is truth. The Hippocratic code of practice holds more interest for historians now that the true oath has not been taken in medical schools for almost a generation. Medical students, green and wholly inexperienced, as a group now invent their own. The characterising spirit of medicine must be freed from its roots, and replaced each year. Once adrift it will handle better. None of the new editions or their starry-eyed graduand authors felt any chill earlier this decade when pregnancy was redefined as beginning on day six of the pregnancy. The mentored graduating oath at a Sydney medical school was busy declaring that "prejudice has no place in medicine" and the Royal Australian College of General Practitioners was busy, too, its spokesperson Dr Elizabeth Hindmarsh declaring that doctors who continue to hold that pregnancy begins at conception are prejudiced.

Dr Hindmarsh's condemnation arose in reference to doctors disinclined to terminate an early pregnancy with the "morning after pill". But it could equally have arisen in reference to any discussion of pre-implantation genetic diagnosis. This service is advertised to all couples, fertile and infertile alike. Its costly purpose is to have them produce multiple embryos under the usual IVF processes and then select the "normal" ones out for freezing or implantation. The others, "not transferred", end up in the plumbing.

Sydney IVF can now advertise its services for embryo quality checks under the banner of preventing "terminations". It seems new lives are not terminated at Sydney IVF, they are merely discarded. So exuberant is Sydney IVF to promote what it is not doing that it sometimes falls over its own language. One of its recent newsletters to GPs, complete with a free coffee bag, recently boasted of screening embryos for chromosome abnormality

“prior to conception using IVF with preimplantation genetic diagnosis”. Either Sydney IVF has moved from a glass dish to a crystal ball, or conception, too, is up for redefinition. One wonders about the importance of truth to Sydney IVF, as it elsewhere speaks of “the inevitability of miscarriage when chromosomes are abnormal”. Has this industry never seen a child with Down syndrome?

New mandatory definitions, reflecting a Stalinist attitude within the medical profession, also reflect a philosophical vacuum and a creeping two-dimensionality in our universities and colleges. Producing genetically clean offspring, however, is a murky business. Lies cast as truth and philosophy resting in the shallows reduce the visibility of slow sinister developments passing around us. That is useful to the operators of eugenics. The last thing they want is clarity, rigour or analysis.

From the late 1960s it has been increasingly possible to detect the chromosome and genetic disorders of a foetus. The commonest foetal chromosome abnormality, Down syndrome, is also known as Trisomy 21, since those born with this problem have three copies of chromosome 21 instead of two copies. Figures vary, but it usually affects about 1 in 800 live births. It is the most common abnormality associated with intellectual disability and accounts for 25 per cent of children with an IQ below 50. Most, however, will have an IQ in the range 35 to 70. Life expectancy after infancy is now about 60 years due to additional problems they may have such as heart defects, gastrointestinal malformations, increased frequency of leukaemia, epilepsy and increased susceptibility to infection. The fault arises during preparation of the mother’s egg, and the chance of this happening increases as she ages. During the last twenty years the proportion of pregnancies involving women over the age of thirty-five has increased from 5 per cent to 20 per cent, making Down syndrome one of the few congenital defects with an increasing prevalence. Due to this prevalence and the fact that Down syndrome babies don’t usually die young, testing the foetus for Down syndrome has been singled out for increasing attention by both medicine and state.

This prenatal diagnostic test of a baby’s chromosomes began as an offer to older mothers to have some amniotic fluid withdrawn from the womb through a needle and syringe, between weeks fifteen and seventeen of their pregnancy, so that foetal cells floating in it could be cultured and analysed. It was available to such mothers in the 1970s but not urged upon them. The diagnosis of chromosome abnormality can’t be made without tissue containing foetal genetic material—and the going is hazardous. Complications of invasive tests are not slight. Death or morbidity of the child is frequently the price paid for knowledge of a diagnosis which can never be reversed, at a human cost which is non-refundable. Despite its hazard it is still the most common method used to diagnose Down syndrome. Amniocentesis could be done at a later, safer time but it takes two weeks for the most accurate results of baby’s chromosome test (karyotyping) to be completed. At twenty weeks gestation a “termination of pregnancy” becomes a “neonatal death”, attracting inconvenient legal attention in most states and further delay negotiating ethics committees. The whole process has therefore to be squeezed in before twenty weeks gestation. The newer addition of chorionic villus sampling from the placenta, at around thirteen weeks gestation, has avoided this problem and that of privacy, but incurs a threefold increase in mortality.

Maternal age alone, however, was seen to pick up only 30 per cent of Down syndrome babies. The response of a medical profession already loosening its grip on its principles has since been to develop more and more sophisticated screening programs. Caring for them in the surgery while trying to kill them in the womb has not seemed incompatible or even insincere. Good and evil—like earlobes and fingernails—were about to be reclassified as population screening methods were devised and introduced. The unconditional love and generosity of parents towards these children becomes optional and avoidable; the provision of a community and its health system becomes better spent on detection and

elimination. During the last ten years population screening programs for Down syndrome have attached themselves noiselessly to antenatal care, for no purpose other than to reduce the numbers of these children.

Right now, across Australia, pregnant mothers are being offered their place in this screening program. It is an expensive statistical undertaking to systematically sort mothers and their unborn babies into one of two groups in the population. Information is collected relating to a measurement at the back of a baby's neck at twelve weeks by ultrasound, together with pregnancy protein levels in the mother's blood, her weight, ethnicity and age. A foetal software program interprets all this information (in what is commonly called the Combined First Trimester Screening Test) to assign a number to every pregnancy. This number assesses the risk of major chromosomal abnormality. It might be a 1 in 30 risk of Down syndrome or a 1 in 3000 risk, or a 1 in 300 chance of trisomy 13 or 18, which is also calculated. It's all about chances. RANZCOG suggests that all mothers with a "high risk" assessment (a risk of more than 1 in 250 or 1 in 300) be offered invasive tests to check if maybe, just maybe, despite the long odds calculated, this baby does have Down syndrome. These facts don't change but the language does and sometimes quite quickly. All these mothers are considered to have "screened positive" for Down Syndrome. A whopping 5 per cent of the pregnant population of Australia will get a screen positive result for Down syndrome—one in twenty pregnancies.

The gargantuan expense of this program is simply to march mothers to either the 95 per cent "screened negative" group where there is still Down syndrome (10 to 15 per cent false negatives) or to the 5 per cent group where more Down syndrome is likely to be scattered. For every hundred women who find themselves in this top 5 per cent grouping of the population only two of them will actually have a Down syndrome baby. That doesn't seem to bother anyone because the statistical net is arithmetically calculated and deliberately set to siphon off the top 5 per cent of the population for invasive testing.

The terms "high risk" and "low risk" were next favoured because the statistical grouping is so inexact. None the less, still only 2 per cent of those screening "high risk" or "higher risk" of Down syndrome will have a Down syndrome pregnancy. Some now favour the woman-centred approach of offering the mother invasive non-therapeutic diagnostic testing for a risk result at any level she is comfortable with, having already assailed her comfort with best medical practice recommendations of ultrasound, blood testing and resort to high-tech computer programs. A mother's choice of invasive testing for her child is often then encouraged along with misinformation. The "Genomics" section of the West Australian Department of Health in 2008 produced the resource "Prenatal Screening and Diagnostic Tests"—still distributed and still on their information website as of November last year—which assures all West Australian mothers that these prenatal screening tests, with a stated 1 in 300 cut-off for the high risk group, "tell us if Down syndrome is likely or unlikely". This is not true. Even those screening in the "increased risk" group for Down syndrome are hugely unlikely to have it. Just in case women are still too comfortable with their screening test result, this brochure next reassures them that their higher risk screening "does not mean there is definitely something wrong" with their baby, but such mothers "might consider further diagnostic testing".

Creating anxiety and herding more anxious mothers into invasive diagnostic testing with layers of language errors (which might be corrected in the next edition and have only been posted for two years) is unfortunate. West Australian mothers though are fortunate that their obstetricians are better at invasive testing procedures than those elsewhere in Australia. The brochure promises worried mums that the West Australian fatality rate for invasive diagnostic tests (amniocentesis and chorionic villus sampling lumped together) is less than 1 in 200. That's really good because RANZCOG figures now state a death rate of up to 1 in 33 babies tested by CVS and up to 1 in 100 babies tested by amniocentesis in November 2008, and 1 in 50 mortality from CVS in 2006. The West Australian

Department of “Genomics”, which assesses the economic burden of genetic disease, is responsible for this parent information resource, to help mothers through these difficult decisions.

Informed consent becomes non-existent for parents when information providers muddy the waters. Having been marched off to the left or off to the right, those parents assigned to RANZCOG’s 5 per cent group of potential undesirables are bewildered, hurried and hungry for knowledge of their situation. Reliable knowledge, however, is scant. Even the medical profession has not yet grasped that this population screening tool is not screening for Down syndrome, but for the *risk* of Down syndrome. The 5 per cent positive screening rate cast over the whole pregnant population collects such a large group because it means to identify even those with a slightly increased risk, even a 1 in 300 chance. What confuses people, and many doctors too, is that this is not a screening test for a problem, but a massive population net to see who is in the top 5 per cent bracket of risk for having a problem. This is unlike all other screening tests in medicine. In other areas of medical care, screening tests are designed “to separate those who probably have a specified disease from those who do not” (*Oxford Concise Medical Dictionary*).

It is the unique nature of these tests which leads them to be so poorly understood. After these programs were under way, the *Australian and New Zealand Journal of Obstetrics and Gynaecology* published a study on the level of knowledge and understanding that obstetricians and general practitioners, who regularly see pregnant women, have about prenatal screening and diagnostic tests. It found, first, that “47 per cent of obstetricians and GPs answered incorrectly, or were unable to identify that 5 per cent of women who undertake either a first or second trimester screening test receive an ‘increased risk’ result”; second, that among both obstetricians and GPs “only small correlations were found between perceptions of knowledge and actual knowledge levels”; and finally that close to one third of obstetricians and GPs answered incorrectly regarding the false positive rate of screening tests. Another survey of Australian health care professionals, allied to a tertiary level maternity hospital, found that less than 10 per cent were able to provide accurate information about prenatal screening tests.

This is of some concern when we consider that the information antenatal care providers give to parents will influence their decision for further hazardous, non-therapeutic tests. The *British Journal of Obstetrics and Gynaecology* has observed that “many health care professionals associated with antenatal care are not aware that detection rates and false positive rates vary with maternal age”. This knowledge is very important for all mothers assigned to the higher-risk group. Older mothers already know that they have a higher chance of carrying a Down syndrome baby because of their age. But they may not be informed of the increased weighting given to maternal age by the software that interprets their combined first trimester screening test. They may not be informed that the measurements of the baby’s neck ultrasound and of their own blood’s pregnancy proteins could be exactly the same as the results from a twenty-five-year-old mother, but their final personal risk calculation, from these same measurements, will be much higher. What they may think represents anatomical and biochemical evidence of Down syndrome is merely reflecting the maternal age risk they already knew. The rate of false positives climbs steeply with maternal age. At thirty-six years of age one in ten mothers will screen positive for Down syndrome. This is how the test is designed, to find 91 per cent of Down syndrome in this age group—provided they all consent to expose their babies to the invasive test. For every twenty-four of these mothers then agreeing to diagnosis, one will test positive for Down syndrome. The false positive rate is closer to 50 per cent for mothers in their mid-forties, in order to find 99 per cent of those with Down syndrome. Older mothers, after all, are now producing more than half the babies with Down syndrome.

One by one the professional colleges are closing ranks against these children. “Common Sense Pathology”, issued by the Royal College of Pathologists of Australia, stated in the

November 2007 issue that "Public health policy should be aimed at offering screening to all pregnant women regardless of age". Since cornering all these babies with the screening test has become awkward, three colleges—RANZCOG, the Royal Australian College of GPs, and the Human Genetics Society of Australasia—all recommend proceeding directly to amniocentesis or chorionic villus sampling for mothers over thirty-five years of age. In 2009 the *Australian and New Zealand Journal of Obstetrics and Gynaecology* published an article prefaced with the statement that prenatal detection of chromosome and gene abnormalities is an essential component of antenatal care.

For the population so screened and sifted, the public shape of eugenics is drawn in comforting language. "Woman-centred" care, "choices", "security", "peace", "psychological adjustment", even "spiritual preparation" are proposed as the ends which justify the hazardous means of eugenics. Is prayer like a catalogue? Can we now not even pray in uncertainty? What sort of spiritual preparation thrives from submitting another to danger for our own benefit? The underlying collegiate shape of eugenics is quite different and less focused on emotionally soothing words. When the College of Obstetricians looks at screening for Down syndrome it looks at the "benefit to cost ratio". This is an economic term in which the ratio should be greater than 1. The benefit-to-cost ratio of terminating, or exterminating, Down syndrome using combined first trimester screening is 1.57. The benchmark method compares the cost of screening with the cost of raising a Down syndrome child. "For consideration of national policy", we are told, "cost effective screening programs will be significantly compromised if the participation rate is low". Estimates are based on the fact that 80 per cent of screened positive women will accept a diagnostic test, and that 90 per cent of pregnancies diagnosed with Down syndrome will be terminated. "For a national policy for Down syndrome screening to be effective ... the costs of the screening program to detect a certain number of cases has to be balanced against the cost of managing missed or undetected cases in the population." It then adds that the monetary costs of transporting these mothers to facilities where they can receive "appropriate care" and of "ongoing grief counselling" should be considered.

Some things, however, are not considered in these policies. Each person is entitled to the social authority of state to sanction against intrusion upon his or her human dignity. When that state turns on the individual we have a state described by Nietzsche as the "coldest of cold monsters". The child's entitlement to society extends beyond state, and should not be locked out of the language of "woman-centred care". Everyone is entitled to social order (article 28 of the Universal Declaration of Human Rights) in which his or her rights and freedoms are fully realised. Similarly, each individual has a right to the medical services which give the means to life and meet his or her needs. Instead, these unfortunate children are attended to by "best medical practice", the despairing and deadly parasite on antenatal care.

These babies are being classified and measured once again as they lie under the drapes of false compassion and even false piety. Alone and voiceless, they are separated from the loving and life-giving wisdom of their parents by deception, poor information and ethical confusion. Marched off to the right, they enter that rarefied area of slightly complicated medicine where they are just out of reach of journalism, churches, non-medical academia and the rest of us. Yet words are their only defence. Words matter. The terminology used, however, can also kill. Most of these children will not be shielded from the pressure of compassionate health talk and will not be hidden from medicine by their mothers. They won't have a chance to help each other memorise the answers to IQ tests. The full exertions of a mother are again required of her to provide for the wellbeing and survival of her infant offspring.

The defendants and their lawyers at the Nuremberg medical trials made the point that physicians who, with Hitler, decided to kill malformed children were merely responding to the popular wish. Their defence was that they were merely technicians. In occupied

Holland, however, to its eternal credit the medical profession stood firm. They recognised that the "accomplishment of ... a public task" was without ethos. When the German authorities threatened to revoke their licences, Dutch physicians all handed them in. Propaganda, persuasion and then terror were used against them, as 100 Dutch doctors were sent to concentration camps. While Victorian doctors are threatened with de-registration for not performing the public duty, obstetricians elsewhere are intimidated by threats of lawsuits for wrongful life. If physicians in occupied Holland could stand firm and hold to their characterising spirit, separating curing from killing, could not doctors elsewhere? Obstetricians elsewhere?

In Australia we have moved well beyond the debate we haven't had and into a eugenics program rolled out across our country. Prenatal testing is poorly understood by the public and even by obstetricians and health departments, yet it is offered to all pregnant mothers. We have been complicit in a protocol which assumes that the contribution made by those with Down syndrome has insufficient value. It's not that we don't like them, we don't even know them; it's not that we are prejudiced, we're actually quite indifferent to them; it's most certainly not discrimination because we're well educated and enlightened, but it's because we think their lives will be onerous and unimportant. We don't care to give them the chance to think for themselves. Our generosity as a nation would prefer their chromosomes were "checked" early in the pregnancy and "choices" made for them. Worse still, we, as a medical profession, have worked out the procedures and decided the methods of execution. We have let go of our ethos in exchange for boasts of preventive care, when we could have held it tightly as one of our main tools. Like our new medical oaths and codes of practice, we welcome a language which gives ambience but no light.

Instead of sapping parents' confidence and courage we could be standing with them and their child, reminding the world of Mother Teresa's words, that the greatest disease in the West today is being unwanted, unloved and uncared for.

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