

# What Place is there for People with 'Serious' Genetic Conditions in a Geneticised World?

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*This paper discusses implications of geneticisation, including eugenics, with regard to possible future people with 'serious' genetic conditions such as Down syndrome.<sup>1</sup> Ethical dimensions of the relationship between possible future and actual people are explored. Dominant ethical theories do not adequately address this relationship for reasons to do with an ontological gap between these kinds of person. There is yet another kind of human being to consider - liminal beings. Important ethical possibilities emerge once liminality is embraced, and these provide a framework within which an ethical defense may be given of a place for people with such conditions.*

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*Human Identity in a Geneticised World*

At the commencement of the 21st century, the world is undergoing rapid geneticisation. One way of portraying geneticisation is through describing an emerging 'gene consciousness'. From everyday conversations and journalism through to erudite research, more and more people are talking in terms 'the genes responsible for' every deficiency of health and well-being and the potential for biotechnology to provide a remedy. Such language suggests that people are embracing a form of biotechnological determinism, at least as far as health is concerned. Yet even if genetic factors in health are being identified, human identity as a whole emerges from a wider range of sources other than biomedicine. This gives rise to an ethical tension between a biomedical view and a wider cultural perspective.

There is power in geneticisation, but there is also strong resistance to complete biomedical incursion, even among people closely linked to genetic science. Such resistance occurs in the wider population, and because of this, serious genetic conditions currently targeted for elimination are still likely to exist despite the geneticisation of the world. Those with human identity emerging in part from these conditions, have always within any historical system, whether it is religious or scientific, been placed at the margins. The marginalisation of people with serious genetic conditions occurred with its greatest systematic violence in the late 19th and early 20th century with the promulgation of eugenics. Proponents of contemporary eugenics claim that this no longer occurs in liberal countries, and medical science regards its contemporary interventions as therapeutic.

*Eugenics*

Eugenics (literally) means "good in birth", or "well born". Its originator, Francis Galton understood eugenics as the "science of improving stock - not only by judicious mating, but by whatever tends to give the more suitable races or strains of blood a better chance of prevailing over the less suitable than they otherwise would have had."<sup>2</sup> It is clear that 'eugenics', given a more contemporary rendition, refers to a biotechnological process producing a human being free of disabling conditions in order to give a person the competitive capacities needed in a contemporary and future world. Indeed any technology could be understood to be 'eugenic' if it has any part in this process. Therapeutic ge-

netics relates to the use of genetic means in diagnosing and overcoming human susceptibility to disease and disability. The therapeutic/eugenic distinction is therefore unsustainable. This distinction improperly defines eugenics out of existence without acknowledging that eugenics is a still a dominant genetic futures goal relating to biological advantages, not the particular means utilised in a bygone era.<sup>3</sup> Eugenics is not now about eliminating less-than-ideal human phenotypes and promoting others, using methods practiced in the early part of the 20th century.<sup>4</sup>

What is the position, ethically speaking, of people whose identity is derived at least in part, from a condition being targeted for eugenic elimination? Positive eugenics (in its most friendly form, the search for a cure of disease or disability) is not, unlike early 20th century negative eugenics, an attempt to deny to people with severe genetic conditions a place in the world. It is an attempt to prevent there being people to occupy the place to which people with such conditions have been routinely assigned. Contemporary and futurist eugenics (incorporating genetic enhancement) is based on an abhorrence of social marginalisation and an effort to prevent it through some form of human technology. The goal may still have something in common with Galton's Social Darwinism, that of using science to create competitive social advantages; even though the means are decidedly different. Nevertheless what is needed is an account that shows that both the goal and the means of contemporary and future eugenics (even if recast as therapy) is ethically defensible.<sup>5</sup> Such an account will begin to discuss the place of people with severe genetic conditions in a geneticised world. Obviously the form of eugenics that concerns some people is eugenic elimination: and this may equally occur through termination of pregnancy or through germline gene therapy.

### *What Lies Behind Eliminating Serious Genetic Conditions Such as Down Syndrome?*

In most public geneticised institutions there is a negative verdict concerning Down syndrome, and given the current failure to provide gene therapy, therapeutic terminations are recommended. The medical verdict relates at one level to the structure of the genome; in this instance there are 47, not 46 chromosomes.<sup>6</sup> However what must not be discounted is the characterisation by Dr John Down of the "Mongol idiot",<sup>7</sup> a clear reference to the now discredited 19th century belief that

Caucasian races, though highly evolved, sometimes had an offspring that was a throwback to a less evolved, intellectually inferior race. This stigma has lasted over a century and has resulted in the widespread incarceration and separation of people with Down syndrome from family and community.<sup>8</sup> On the back of this blatant prejudice has been delivered the almost invariable medical recoil from the medical treatment of people with this condition. That was until the 1980s. A spate of reforms across the western world made a failure to treat medical conditions in newborns with Down syndrome a form of child abuse.<sup>9</sup> The 'baby Doe' case in USA brought the issue of medical non-intervention to a head. As a response, the focus has been on eliminating "the problem" prenatally, with consistent reports of over 90% abortions in cases of positive prenatal diagnosis for the condition.<sup>10</sup>

The process of eliminating serious genetic conditions such as Down syndrome depends on maintaining a negative representation of an actual, current identity, even though those utilising such representations might not intend that they be stigmatising. Yet the portrayal of such a negative verdict may be itself a source of completely unwarranted harm to actual people, simply because it is not true. Certainly people with Down syndrome are in a state of heightened vulnerability due to being different from others, and much of this difference is contained in medicalised descriptions. But they also sufficiently like others need to be more accurately represented as being in a state of social ambiguity or liminality.<sup>11</sup> This is a state of being 'neither/nor', for example being neither fully independent, nor completely dependent and therefore having an ill-defined social place. Nevertheless greater understanding of developmental psychology and the introduction of early childhood intervention has enabled many children with the condition to take up valued social roles and form highly meaningful relationships in their communities.

Liminality, an 'in-between' state, potentially creating ambiguity and uncertainty given the cultures in which it occurs, also applies to fetuses. Fetuses with Down syndrome are therefore doubly liminal, yet as this paper explores, liminality is a state that poses a distinct set of ethical possibilities. Such possibilities may not be considered by ethicists adhering to a positivist framework of 'either/or,' such as human or non-human, person or non-person.

*An Ethical Defense of Therapeutic Genetics*

One contemporary argument that eugenic or therapeutic elimination (however it is framed) is ethically defensible is based on the premise that no actual people are eliminated, only possible future people are.<sup>12</sup> Therefore, the argument runs; there is still a place for people with conditions such as Down syndrome in the present, and although harm to these people require attention,<sup>13</sup> avoiding these should not override the eugenic/therapeutic goal.<sup>14</sup> This argument is sophisticated and complex, and needs to be considered in depth. Basically it seeks to minimise the ethical problem of doing harm to people in the present, whilst at the same time creating the conditions for benefiting people in the future. Because genetic and early prenatal intervention concerns possible future people, not actual people, some philosophers do not consider the values involved in their elimination as the same as those under previous eugenic eras. However whether this is actually achievable, and whether it involves the appropriate kind of moral agency and moral values, is not so certain.

*What Values are Relevant to Possible Future People?*

It is important to be clear about relevant values when considering actions towards possible future people. It is essential to consider what it is to which the value is attached. Is it something to do with the agents of the action, such as their intentions? Is it something about the action itself, such as its contemporary scientific or social character? Is it something to do with the consequences of the action?

People may intend that their actions have the highest possible value in regard to possible future people. The value of the actions themselves, insofar as their consequences are not actually realised, remains in the intentions of the agents or in their current significance. What is significant is that something is being done with some future state of affairs in mind. This might have enormous current significance for something like the stock exchange, but this is only because value is attached to speculation. Whether the actions have value as the cause of some future state of affairs as evaluated at that time, is still uncertain. What future possible people who become actual people might value is unknown. Perhaps these future values are irrelevant. What actual people say is good for possible future people is good for them, some might think. It may lead to the ultimate paternalism. Yet a positive account of 'the good' for

possible future people is fraught with ineliminable uncertainty. We do not know what “they” will say about what is good, so actual people cannot know if their intentions or their actions will have any positive significance as a value for possible future people.

What current people can assert at best is that some unspecified people will come to exist as a result of their actions, and that those people will form their own values. Any possible value of actions by actual people estimated by people of the future is in the consequences of the actions currently performed, as evaluated by “them”. This too is uncertain, because current people do not know what those consequences will be. In terms of genetic enhancement, for example, geneticists in the present era do not know what the life experiences of possible future genetically enhanced people will be. It might be altogether too sanguine to suppose that their life experiences would be better than those of non-genetically enhanced people in the present or in the future. Actual people must reject any self-belief in anything approaching omniscience about the future. It follows that no values of actual people are relevant to possible future people now, and none may be relevant in the future.

### *Relating these Considerations to Ethical Theory: Deontology and Consequentialism*

In terms of ethical theory, the situation with regards to possible future people seems to pose significant challenges. The theory of deontology,<sup>15</sup> which emphasises the intentions of moral agents, their rights to exercise their intentions (built up into individual life-plans) and their duties towards others who also have intentions is disqualified in relation to possible future people. Actual people’s intentions are irrelevant to possible future people, and what “their” intentions might be in the future is unknown. What is known is that possible future people have no intentions and have no other characteristics that could give them rights. Simply being a possible person does not confer an actual right. How can someone have a duty, therefore, towards some possible future person who does not have a corresponding right that needs to be protected? The only way to resurrect deontology would be to impute rights to future possible people. This would then impose corresponding duties on actual people. What these duties might be is a contentious issue. Would for example, a pregnant woman have a “duty” to abort a fetus with a severe genetic condition, on account of the putative “right”

of a possible future person to have a condition known as “genetic health”?

There does seem to be some currency in a notion of “the rights of future generations”, such as the right to a livable environment, or to inheriting a well-ordered and properly resourced society, but this seems to entail a generalised obligation on society as a whole. There might also be, in some generalised sense, a right to genetic health. But generalised societal obligations seem to be best handled within a consequentialist framework, rather than a deontological one with its explicit emphasis on individual rights and duties. Deontology as an ethic giving guidance to individuals, does not impose these kinds of duties on particular individuals with respect to possible future people. Indeed deontology maintains that actual people are free to conduct themselves without consideration for any putative rights of possible future people. This is one of the greatest problems with respect to the environment, as a parallel example, and the right of individuals to make a living has come at the expense of degrading the environment for future generations. The challenge to protect certain futures does not come from within deontological theory. It comes from consequentialism, the theory that makes harmful or beneficial consequences the primary consideration.

Geneticising the world seems to be ethically grounded in an attempt to make sure that certain harmful consequences of human action do not occur in so far as is possible. No individual rights though, are imputed to future possible people, and no corresponding individual duties placed on actual people. The consequentialist theory that seems most to apply is utilitarianism.<sup>16</sup> It produces in effect a limited kind of paternalism towards possible future people. Utilitarians do not invoke the formal structure of rights and duties to promote their views. What they seek to do is provide good reasons for the avoidance of certain harms and the pursuit of certain benefits. This may involve recommending actions that result in the elimination of possible future people with serious genetic conditions. While many utilitarian geneticists and ethicists may deplore eliminating actual people (because they also use deontological ‘rules of thumb’), they would contend that actions towards possible future people are a substantially different matter.

Surely, they might argue; possible future people are not harmed by present actions that eliminate them, at least in the same way as actual people are harmed. And if they are not harmed in this way, and possible future people who become actual people are the possible beneficiaries of our actions, then the value is one of eliminating harm and replacing it with some opportunity, at least, for benefit to occur. Of course rarely do

people are now being given information based on 'risk' assessments. This is the wrong kind of response, according to the summary of deontological values above. People may want support for any contingency, not to be told that support is only given to those bringing about one kind of future, the 'genetically healthy' one. This is to say that people may demand respect for all their life plans, even ones that do not produce the greatest advantages. People who invest strongly in a moral present that involves mutual support for a wide range of contingencies are not likely to accept a substantially different moral future in which equality is reinterpreted as a right to genetic competitiveness assigned to individuals and given a cost/benefit value to society. The moral present to which they may subscribe involves a belief that support within society is, or ought to be available, whatever the need. The future of geneticisation seems to require a belief that one had better act now to minimise reliance on anyone else, because others will be pre-occupied exclusively with their own interests.

A Social Darwinist future does not necessarily translate into outcomes acceptable to a utilitarian either. Here we must remember that, for the utilitarian, the value of an action is dependent on its outcomes. At present, we know that competitive advantage exists, and some interests always override others. The "greatest good for the greatest number" is always threatened by a great number of goods being appropriated by a minority. But in the future, genetic science will according to its biotechnologist proponents, have vindicated their position. The greatest good for the greatest number will have been achieved because something closer to genuine functional equality will have been achieved.<sup>22</sup> The competitive race will be such that less people than now will be disadvantaged. Yet this is a future that is entirely hypothetical. There is nothing in the methodology of genetic science to guarantee it. There is nothing substantiated in the entire history of ethics that claims that functional equality is even desirable.<sup>23</sup> The outcome that biotechnologists assume will occur, has not yet occurred, may never occur, and most likely would be undesired even if it did occur. It therefore cannot be endorsed as a value, using the criteria of value accepted by utilitarians.

The dual problem then, is that geneticisation seems to run counter to both deontology and utilitarianism, ushering in Social Darwinism made possible by utilitarian speculation. Theoretical approaches to ethics seem to be being ruled off the court even as some ethicists endorse the legitimacy of geneticisation. It is self-contradictory for an ethicist to apply deontology to possible future people, and almost self-contradictory for



a utilitarian to both be consequentialist and to assume knowledge of what the future holds. A utilitarian also has to be a projectivist.<sup>24</sup> A crisis of legitimacy has occurred, and genetic aims cannot be assumed to be ethically defensible. The assumption among proponents of geneticisation seems to be that “science’s rational intelligence” supplies its own sovereign morality.<sup>25</sup> Such intelligence is seriously compromised in an ethical sense by a deficient ontology: an insufficient attendance to the kinds of beings there are.

At issue are the basic ontological constructs by which genetics proceeds. A clear-cut distinction between actual people and possible future people has been assumed. This has thrown the entire ethical structure of rights, duties and the achievement of well-being into disarray. Important theoretical frameworks have been lost, making it difficult to negotiate ethics with respect to possible future people. It might pay to have a closer look at a different ontology to that which geneticists and some ethicists are presupposing.

### *Liminality: A Different Ontology*

Both contemporary science and much of ethics have ignored a category not captured by a focus on actual people and possible future people: liminal people. Liminal people have some characteristics of actual people and some characteristics of possible future people, but they do not have sufficient of either to be unambiguously one or the other. Liminal people are neither ‘just’ actual, nor ‘just’ possible. They are both actual and possible, without being fully either. Liminality is the most contested ontological category for humans. Few are satisfied with liminality; there is pressure to resolve it one way or another in favour of a much more distinct, definite, socially recognised category. This sociological fact reflects a positivist bias. We have all been taught to describe the world in terms of ‘either/or’, not ‘neither/nor’. If something is ‘neither/nor’, the inevitable question is asked, “but what is it?”

A fetus, for example, is neither fully ‘a person’, nor is it entirely ‘non-person’. Developmentally, a fetus is continuous with an actual person, and in this respect differs from possible future people lacking any developmental attributes. The difference is that a fetus is an actual embodied being even though it is within the body of a mother. According to contemporary science, a fetus is a non-person for some procedures (e.g. therapeutic termination); it is ‘a baby’ in cases in which some intra-uter-

ine procedure may save its life. Modern medicine reflects liminality. Medicine resolves liminality sometimes one way, sometimes another.

In effect, liminality is a state even more widely open to interpretation than most states of being. There are quite opposing ways of interpreting this state, and it therefore requires a resolution as to what sector, knowledge of it belongs. It comes down to a question of 'place' in a body of knowledge. The women's movement is quite clear about this in respect to fetal life. A fetus is 'in' a woman's body, irrespective of the ways in which medicine metaphorically externalises it, through ultrasound, or clinical descriptions for instance. What the women's movement has also recognised is that a woman is also 'in' a social and political order, and that women are vulnerable to patriarchal domination and oppression.<sup>26</sup> Social meanings strongly influence how a pregnant woman interprets her place within that order, and also the place of a fetus. The women's movement has attempted to give individual women a 'place' within a broader social movement, so that they can have greater freedom to decide the eventual 'place' for what the fetus will become. All this entails holding the liminal status of the fetus intact whilst these decisions are made. The movement claims a deontological position: no one other than the pregnant woman has the right to decide whether the fetus will be eventually person or a being whose possibilities for personhood can never be realised. Yet what the women's movement has encountered is that a woman is sometimes constrained in some measure by her connectedness with the fetus, felt and communicated through her body. Making the body a vehicle of knowledge validates the knowledge of individual women and gives individual women the right to exercise that knowledge. It also reintroduces a limited, non-universal form of deontology derived from embodied knowledge, not from some rational schema, and gives rise to the notion of fetal rights and wider social duties of others concerned primarily with the welfare of the mother. A fetus has a right to be considered, not in a fully developed 'actual person' sense, but in a liminal sense; communicated in ways best described by women. It makes possible the ethical space in which a woman may, even in the face of any medical diagnosis, place a greater emphasis on the 'personal' characteristics of her fetus than the 'non-person' aspects. This ethical space places actual duties, on for example, obstetricians and pediatricians.

The same argument applies also to liminal people with severe genetic conditions. There is knowledge concerning what is possible for people with some severe genetic conditions such as Down syndrome. This knowledge has originated within the community of people with disability. It also properly belongs within the community of women fac-

ing prenatal and genetic decisions in relationship to the liminal being of a fetus. For women facing geneticised decisions, such knowledge is important. This is storied knowledge. It is unlikely that it can be reduced to a set of generalised facts suitable to the textbook genre, to be digested by medical students, for example. This leads to a point that cannot be overemphasised. The place of people with severe genetic conditions is threatened by restricting access to the oral genre of stories. These are lived experiences told and retold within a community of mutually interdependent participants. In so far as geneticisation is part of a purely technocentric approach to managing human life, reducing both communal interdependence and all relevant knowledge to medical discourse, geneticisation acts against the place of people with severe genetic conditions in the world. At the level of genetic and prenatal practice, extreme sensitivity needs to be exercised, because any woman may have through her body, a connection to a liminal being, and this ontologically entails that geneticists and ethicists ought to recognise a world of liminal beings.

Whilst this defence of a place for people with severe genetic conditions such as Down syndrome rests on a particular embodied relationship between a woman and a fetus, and her place within a community awakened to certain possibilities, it does not however provide a defence against geneticisation as such. So long as no such relationship exists, and no liminal being exists, geneticisation finds no resistance from deontology. Yet liminality may be more pervasive than this.

The significance of liminality extends beyond the prenatal sphere. Storied knowledge works its way into deeper levels of consciousness throughout the community. The knowledge from within the community of people with disability enters a wider embodied consciousness, creating resistance to overriding geneticisation.<sup>27</sup> Some people refuse to take part in genetic testing. In contrast to a late term fetus, whose liminality borders on or overlaps actual personhood, this form of liminality borders on or overlaps possible future personhood. Genes too, may exhibit liminal qualities. Actual people may want to protect their genetic inheritability from scientific interference on behalf of possible future people. Genes are the liminal pathways between actuality and possibility. The combining of genes in human reproduction has for many people, a sense of the sacred, and this too is a contested, liminal zone. For many people there is a sense that biotechnology assumes too much of a right to interfere. The right to protect these liminal zones belongs to actual people, and this reintroduces deontology. It goes without say-

ing that all this is highly contested territory, but the heat of the contest may say something about the importance of the territory. At the heart of the contest is a debate over expertise.

### *A Story about "the Experts"*

Steven is a young man with Down syndrome. When he was born the doctors told his parents not to expect too much for him or of him. They were told for instance that he would always be a 'floppy' baby. He would never develop good muscle tone. He would always have an intellectual disability. Steven's parents did not believe what the doctors told them, but they knew it would take extra effort on their part to give Steven the best opportunities. The experts had abandoned them. I met Steven first of all through seeing a video in which he, as an 18-year-old, spoke to a group of parents of young children with Down syndrome. The gathering was at an early childhood intervention centre. What most impressed me about Steven was his sense of personal identity. He spoke with obvious enjoyment about his family, his childhood, his education, and his accomplishments. I subsequently met and spoke with Steven on several occasions. Each time he was eager to communicate, to tell me stories about his life. Some of these stories were about his girlfriend, a delightful young woman also with Down syndrome. Other stories were about surfing, and going to have lunch as an invited guest with the national champion football team, and meeting his favorite players.

At the very heart of geneticisation is the question of place for people such as Steven. In order for people with Down syndrome to have a place in a geneticised world, their own knowledge must have a place in the conversation, and medical knowledge must find a place for the adequate representation of social and experiential perspectives. This at least opens up space for a greater diversity of embodied expertise, and from this basis a greater diversity of human possibilities will be realised.<sup>28</sup>

### *Notes*

1. This condition has been chosen as an exemplar, because while it may be considered serious, it is not ordinarily fatal, and unlike anencephaly or Tay-Sachs disease, does not preclude considerable life prospects for a person given positive relationships along with some medical support. Therefore the question of place for a person with the

condition is a reasonable one.

2. Galton F, *Inquiries into Human Faculty and its Development*, London. J. M. Dent and sons, 1883.
3. See Agar N, Liberal Eugenics, Ch.18, in Helga Kuhse and Peter Singer (Eds.) *Bioethics: An Anthology*, Blackwell Philosophy Anthologies, 1999.
4. Including sterilisation, segregation, incarceration and killing. See Pfeiffer D, "Eugenics and Disability Discrimination" *Disability and Society*, 1994; 9(4), for an excellent historical analysis.
5. See for an example of such an attempt, Wikler D, "Can we learn from eugenics?" *Journal of Medical Ethics* 1999; 25(2): 183-194.
6. A discovery by Jerome Lejeune demonstrated the connection between Down syndrome and trisomy 21. See Ruth Schwartz Cowen, "Genetic Technology and Reproductive Choice: An Ethics for Autonomy," in Kelves DJ and Hood L, (Eds.) *The Code of Codes: Scientific and Social Issues in the Human Genome Project*, Harvard, 1992 (Pp. 260).
7. Mongolism was the name given to the condition of Down syndrome in public literature printed by at least one Brisbane hospital up until 1994.
8. There is a vast literature in which the names of Wolfensberger and Nirjie are prominent in arguing for the normalisation of living conditions.
9. See Fost N, "Decisions Regarding Treatment of Seriously Ill Newborns," *Journal of the American Medical Association*, 1999;281(21): 2041-2043.
10. See Parens E and Asch A., "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations" *Hastings Centre Report*, September-October 1999.
11. Liminality has been well described in the anthropology literature and has been applied in the field of disability to highlight the social uncertainty surrounding the position of people with disability. See Nicholaisen I, "Persons and Nonpersons: Disability and Personhood among the Punan Bah of Central Borneo." in Ingstadt B. and Whyte SR, *Disability and Culture*, 1995 University of California Press: Berkeley; Murphy R., Scheer J., Murphy Y., Mack R., "Physical disability and social liminality: A study in the rituals of adversity", *Social Science and Medicine* 1988; 26(2): 235-242.
12. Wikler says that 'the core notion of eugenics may be benign'. He says "No one objects in principle, according to this view, to using what we know of the science of heredity to improve the chances of future generations for achieving greater wellbeing". Wikler op cit.

13. Perhaps even amelioration through something like Social Role Valorisation. See Wolfensberger W., *A brief introduction to Social Role Valorisation as a high-order concept for structuring human services* 1992 (Rev. Ed.) Syracuse NY: Training Institute for Human Service Planning, Leadership and Change Agency (Syracuse University).
14. Wikler maintains that a "starting position" for eugenics is: "public policy in genetics, whether or not it is termed eugenics, ought not to infringe on personal liberty. But this does not necessarily call on us to avoid any risk of burdening some individuals for the sake of the genetic wellbeing of future generations. I am not personally persuaded, for example, that the threat of stigmatising the disabled requires us to abandon the effort to ensure that future generations are free from avoidable disability." Wikler then raises the matter of distributive justice, and whether providing for the "genetic wellbeing of the group" can be done fairly and justly. He simply acknowledges "it wasn't, last time it was tried", and in so doing finds himself trapped in an inescapable tension. I would suggest that there is an ineliminable problem for Wikler of the inevitability of injustice for people with disability in his tentative endorsement of eugenics. Wikler, *op cit*.
15. Deontology, articulated most influentially by Immanuel Kant, is one dominant ethical theory in the west applied usually to interpersonal and role-based relationships. It is concerned with rights, rules and duties, applied in the 'here and now'. Violations of duty always undermine respect. Complete loss of respect entails the breakdown of relationships and with it the social order that deontology presupposes. Deontology therefore requires a consequentialist view as well.
16. Utilitarianism is a consequentialist view that has become the dominant ethical theory in the west within public policy at least. Originating in the work of Jeremy Bentham and JS Mill its influence is detectable in every sphere of knowledge. The principle of 'the greatest good for the greatest number' and its reliance on the values of utility have found the perfect match in statistical approaches in which 'the norm' also captures 'the preferences of the majority'.
17. In balance the aggregate of benefits should outweigh harms, according to this theory. This has its roots in commonsense understanding of 'deferred rewards'. Often people have to put up a certain degree of pain to arrive at some pleasure that "makes it all worthwhile".
18. See Parfit D, *Reasons and Persons* 1984, Oxford: Oxford University Press.
19. These values are encapsulated in the mission statement of Queensland

Advocacy Incorporated “To promote, protect and defend, through advocacy, the fundamental needs and rights and lives of the most vulnerable people with disability in Queensland.” They are also encapsulated in key statements of the Disabled Peoples’ International Europe Declaration on bioethics and human rights. “Nothing about us without us”; “We demand that we are included in all debates and policy-making regarding bioethical issues”; “We must be the people who decide on our quality of life, based on our experiences”; “All human beings are born free and equal in dignity and rights”, “Biotechnology presents particular risks for disabled people. The fundamental rights of disabled people, particularly the right to life, must be protected”; “Disabled people must join together in solidarity to ensure our voices are heard in these life-threatening issues”. See Newell C, “The Right to live and be different: An exploration of the significance of the DPI Europe Declaration on bioethics and human rights”, *Interaction*, 2000; 13(3): 6-9.

20. John Harris writes in section II (entitled significantly for this paper, Our Genetic Future) in ‘Biotechnology, Friend or Foe?’ “I wonder why, if it is legitimate to try to educate our children to acquire the ability to do mathematics, is it not legitimate genetically to engineer into them a like ability. Why, ethically, might it be wrong to attempt something via genetic engineering that it is not wrong to attempt via what used to be called ‘social engineering’? There may, of course, be a good reason...” Harris’s openness to “a good reason” salvages his account from an implicit endorsement of the sovereignty of the competitive spirit. See chapter 12 in Dyson A and Harris J, *Ethics and Biotechnology* London. Routledge, 1994 (Pp. 221).
21. There is a clear echo here of Galton’s notion of giving “more suitable races or strains of blood a better chance of prevailing over the less suitable”. Galton op cit.
22. J. Hughes for example, contends that genetic science promotes equality scientifically by identifying and “eliminating congenital sources of illness and disability that create the most intractable forms of inequality in society.” Hughes, J. (1996) “Embracing Change with All Four Arms: Post Humanist Defence of Genetic Engineering”, *Eubios Journal of Asian and International Bioethics* 6: 94-101.
23. Functional equality rules out genius as well as intellectual impairment. A principle of status-equality, however, requires society to embrace the benefits and challenges of diversity, but enjoins society to ameliorate the harms that functional inequalities create. Some see genetics

as having a role in this. See Nicholas Agar op cit. p. 178 "Goods of genetic engineering must be allocated to an individual in a way that improves prospects associated with all possible life plans - most especially the worst off potential life plan." This principle may have merit concerning the cloning of somatic tissue for non-germline therapeutic purposes.

24. A projectivist being one who projects into the future some view as to what consequences will ensue from a course of action. The question then arises: is value given to the projection or the consequences? If the former, then the utilitarian is less of a consequentialist than we are led to believe.
25. Stewart Clegg argues that the connection between sovereignty and science goes back at least to the 17th century English philosopher Thomas Hobbes. He says "Hobbes' conception of sovereignty buttressed practical reasons for loyalty to a monarch with a model of moral reason. The premises of this moral order were founded on the universal claims of science's rational intelligence". Clegg S.R., *Frameworks of Power*, London. Sage, 1989 (Pp.24) Science's rational intelligence does not necessarily create an ethic to live by.
26. I hope in saying this that I have understood what I take to be one of the central pillars of feminism. Implicit in the word 'moral' for feminists, is a rejection of oppression; a position that unites feminists and disability activists, even if the practical details entail that moral tragedies still occur. See Sherwin S., *No Longer Patient: Feminist Ethics and Health Care*, Philadelphia. Temple University Press, 1992; Celeste Michelle Condit, *Decoding Abortion Rhetoric: Communicating Social Change*, 1990, University of Illinois Press, Urbana and Chicago; Asch A, Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy *American Journal of Public Health* November 1999; 89(11); Rapp R., *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, New York, Routledge 1999.
27. See Shakespeare T., Choices and Rights: eugenics, genetics and disability equity, *Disability and Society*, 1998; 13(5): 665-681; Shakespeare T, Arguing about Genetics and Disability, *Interaction*, 2000; 13(3): 11-14; Newell C., "Access to Opportunity or Oppression? An Australian Policy Analysis of the Ethics of the Cochlear Implant", *Interaction*, 2000; 13(3): 16-23; Wolbring G., Bio/gene Technology and the Disabled: The Unheard Voice, *Interaction*, 2000; 13(3): 25-31.
28. See Knox M., Mok M., Parmenter T.R., "Working with the Experts:



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