

# Prenatal Bioethics, Advocacy, and the Requirement of a Third Moral Space

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## Abstract

*Well-publicised scientific advances in genetics and prenatal medicine have, over the past couple of decades, precipitated a sometimes heated discussion around prenatal diagnosis, genetic counselling and disability advocacy. Drawing on a variety of perspectives, attention is drawn here to a likely futures scenario occurring 'downstream' from current practices in prenatal medicine and advocacies surrounding it. The issue is not to apportion historical blame for what originates from a complex matrix of social causes and competing discourses such as medical beneficence and eugenics. The challenge is to shift the space and locus of inquiry from conflicting epistemologies and related values to questions of futures ontology. This involves a difficult transition from confrontational approaches to that of a dialogue about what it may come to mean to have been born with a disabling condition of genetic origin. The key to a third moral space is through finding apposite metaphors that open up prospects for fresh ways of thinking.*

**Keywords:** prenatal diagnosis, disability advocacy, moral space

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## Introduction

This paper addresses the question of how, in a futures context derived from perspectives surrounding clinical genetics, prenatal diagnosis and disability advocacy, there is a requirement for a third moral space. Just what this requirement is, and some of the reasons for it, shall be discussed here. In order to ground the paper in the current situation, attention is drawn, firstly to a chapter in a book entitled *The Sorting Society* (Sparrow, 2008), then to a keynote address concerning the ethics of prenatal diagnosis to the Australian Sonographers Association (Parker, 2006). Sparrow makes a sympathetic case for what he terms 'the expressivist critique' of prenatal bioethics. Parker's address to a select audience of medical sonographers re-asserts the beneficent right of genetic practitioners to proceed as planned, having withstood a failed 'expressivist objection' (Edwards, 2004) from what

has been termed 'the disability rights' (Parens & Asch, 1999) or 'social model of disability' perspective (Oliver, 1990 & 1996; Shakespeare & Watson, 1997). Attention is also drawn to an attempted rapprochement between medical and social models by British disability theorists (Shakespeare & Watson, 2002).

Analysed in terms of moral space, a proclaimed 'first' moral position—that of science—has prevailed over a 'second' and reactionary position, that of disability advocacy, which (on one possible account) has been obliged through the force of logic to find a middle ground. The present paper questions whether a middle ground has been achieved, and proposes that what has occurred is an instance of a more general 'parallax view', that is, 'constantly shifting perspective between two points between which no synthesis or mediation is possible. Thus there is no rapport between the two levels, no shared space...' (Zizek, 2006, p.4) An irreconcilable difference remains. The idea of 'third moral space' is crucial to the following account. A requirement for moral space arises in the first instance in the modern era as a response to an irreducible difference between pure philosophical discourse and the necessity for the political embodiment of thought. Moral space is neither properly philosophical (detached) nor truly political (engaged in action). And yet it invests the philosophical and the political with their only enduring source of dignity. Regardless of questions about the internal strengths and coherency of a position, or of making political decisions, there is always a space in which ideas are formulated and rehearsed with colleagues and/or allies prior to enactment in the political arena. But any moral space consensus quickly creates its antagonists. A third moral space is about remaining with the differences that ensue not about resolving them. It is about questioning how to deal with the fallout in a futures context.

In order to explicate how differentiated moral spaces have come about historically in the bioethics context and how a third space is required to come to pass in the future, it is necessary to engage in what might be termed 'futures archaeology'. This involves digging down through layers of language and public discourse to retrieve that which is necessary for thought on the matter to continue into the future. Fortunately at least some of the tools by which this can occur are available through futures research methods. For this reason, the current paper draws upon futures methodology including scenarios, forecasting and causal layered analysis (CLA) (Inayatullah, 2002).

As Inayatullah explains, in CLA the future is regarded as causally produced by human agents, and conceptually layered, which is to say the future comes about at a number of different epistemic levels, each level making significant contributions to our understanding. The layering ranges from surface or more apparent structures of language ('the litany'); to deeper levels ('the social causes' and 'the discourse or worldview'); eventually making its way into the largely unconscious realm that finds its expression in myths and metaphors. The idea in using CLA is to avoid conveniently compartmentalising the future into disciplinary areas, but rather to open it up, making it amenable for richer and more expansive inter-, multi- or trans-disciplinary investigations. In this paper, these layers are all represented, although they are not always expressly signalled. The goal of the paper is to open up a horizon of thinking towards the future that takes its inspiration from multiple sources and layered depths. Of course no inquiry such as this is exhaustive. The process here is not to find authorita-

tive voices from the past, or rest upon bygone certainties, but to find ways of thinking that can help illuminate the path to the future, contributing to similar efforts by others.

### **A Genetic Futures Scenario**

One probable genetic future, as anticipated from a trajectory based on an assumption of accelerated medical biotechnological innovation, is an increase in the numbers of people who, from birth, will carry a significant social stigma. This stigma is in addition to that which many people with disability now carry. These people will, as a result of learning about their own cultural and biological heritage, believe they ought never to have been born. They will be unmoved by efforts of genetic counsellors to convince them otherwise. They will be aware that the very same counsellors also inform people about the great advantages of genetics. Soothing them with the words that their parents or someone else unconditionally loves them *despite* their disability will appear as a glib effort of deception. They will not be put off from their belief by a counsellor saying that, yes they can see that being born has harmed them, but wait; there are ways around it, if they undertake prolonged therapy, or failing that, simply take this happiness enhancing drug. They will see right through the ruse. They will believe, deeply and implacably, in the face of all efforts to make the situation appear different, that their sheer existence is wrongful.

### **Starting from Personal Experience**

Different people arrive in the genetics field, including the area addressed by prenatal diagnosis, from a variety of directions. Any particular direction has a great bearing on how one perceives the situation. For clinicians the direction has come about through education in science and having a commitment to the goals of science. One of these goals is to find cures, or ways to avoid, the most serious of diseases and disabilities. Another direction is from prospective parenthood. The goals here are various. One of these may be to have children who do not have seriously disabling genetic conditions, adversely affecting their life prospects. Another possibility is that one simply wants to have a child with maximum medical support without realising beforehand the extent to which this support reaches.

My involvement in genetics was not through any of these routes. As such some may say that any involvement I have personally is not sufficiently acquainted with the 'lived experience' of disability either from a social or a medical perspective. I do not know whether this is so. What I can say is that hitherto, I may have been unjustifiably optimistic about prospects for a third perspective, insofar as such a perspective has been thought to be derived from a combination of 'the social model' and 'the medical model' of disability via an inquiry that involves people from these currently opposed positions respectfully, albeit critically, listening to each other. I rather think now that before any such positive 'third' perspective happens, a certain amount of negation with respect to both these prior perspectives must occur. Such perspectives require critique, not from the position of each other, but from a position on the outside of both. An outsider perspective involves anyone in making such a critique an unavoidable degree of

alienation. The journey to that space occurs over time, and for some, arriving at such a perspective is currently unthinkable. I shall explain how this space may nonetheless be accessed via an examination of some of the work that has currently been submitted for public examination.

Initially my acquaintance in the field of prenatal bioethics was through a disability advocacy organisation doing a wider range of work (1998-2003). The task I undertook was to raise concerns expressed by people with disability, family members and other advocates (e.g. Bridle, 1999; Fitzgerald, 1995; Newell, 2003), that genetics poses risks, not merely to the quality of life, the actual life, or the reputation of people with disability, but also to the kind of society and citizenry we are becoming. In short, the expressed concern is that we are at risk of becoming a monocultural society, having less than adequate regard for human diversity, that we are becoming consumerist in our approach even to the having of children, maintaining less reliance on virtues of compassion and the solidarities of community, and that disadvantaged minority voices are becoming silenced under the weight of expert opinion. For a time, I was one of the voices in Australia raising what was regarded as 'objections' to technologies such as prenatal diagnosis. The key terms that emerged out of this very broad range of concerns were 'disability discrimination' and 'eugenics' (Turnbull, 2000).

The use of these terms have been summarised in the literature as constituting either 'the expressivist critique' or 'the expressivist objection' to prenatal genetic diagnosis and related technologies. Both terms convey the idea that such technologies express a negative value judgement about the lives of people with disability. The expressivist objection is part of a wider critique that such technologies constitute a means by which various human types can be differentiated and subjected to discriminatory practices. Sparrow compares the position to similar critiques of racial or sex discrimination as a way of sorting people into unequal social groups. Many people nowadays voice strong moral opposition to processes of sorting between people on the basis of race. Moral opinion is more divided (particularly when eugenic practices in China and India are taken into account) over sorting on the basis of sex. When it comes down to the question of disability, however, the weight of moral opinion across many societies sides with the selection process. In the face of this most recent phase of growth in what he terms 'sorting technologies' Sparrow notes "it has been critics from within the disability community who have thought hardest about—and have raised some of the most forceful objections to—the development of the sorting society."

Sparrow develops a position that tries to understand the disability critique of prenatal genetics sympathetically, as an expression of political relations between unequal social groups. Typically, he says, policy makers who favour genetic technologies are non-disabled people. In order to provide a basis for a critique of social policy, Sparrow links questions of identity, not so much to the *science* of genetics, but to genetic scientific ideology. This is difficult terrain. He suggests that "both critics and proponents of the use of technologies of genetic selection must negotiate a difficult set of dilemmas surrounding the relationship between genes and identity." He argues that objecting to the use of genetic diagnosis from a position of disabled identity exposes an objector to the ideological view that genes are what most significantly determine personal identity. To hold to a genetic determinist position would be fall prey to the very assumption

made by the most vigorous proponents of genetics. Sparrow seeks to avoid this dilemma by endorsing the basic assumption of the social model of disability. He claims, contra genetic determinism

*It is social understandings that determine which conditions are contingent to, and which are constitutive of, personal identity. What sorts of social identity have a genetic component is itself a matter of political contestation. Genetic technologies and the debate surrounding them therefore play a central role in determining what the relationship is between genes and persons. (Sparrow, 2008, p. 125).*

This position enables a claim that disability advocates have consistently made about genetic diagnosis that the focus on genes draws attention away from the most important aspect of disability: societal prejudice, or negative social attitudes towards people with disability.

Sparrow's main claim is that a 'debate' surrounding genetic technologies paves the way into the future: an undecided future in which genetic constitution and human identity may or may not be correlative. If Sparrow is right, 'the expressivist critique' is an integral part of future discussions in relation to genetics and identity. He says

*Paying attention to the political dimensions of this negotiation lends strength to the expressivist critique in three ways. Firstly, it highlights important continuities and similarities between the "old" and the "new" eugenics, in particular, that the state which governs the modern sorting society is not neutral about the sorts of people who will be born in the future. Secondly, it draws our attention to the fact that the policies which the state adopts concerning the use of technologies of genetic selection express attitudes towards persons with disabilities which plausibly may be morally evaluated. Thirdly, it shows how the expressive content of these policies may be as much a function of the relations between the people who determine the policies as it is about their content. These lessons suggest that the expressivist critique may have more force and substance than is often appreciated. (Sparrow, 2008, pp. 126-127).*

Parker, on the other hand, straightforwardly poses the question of whether 'the expressivist objection' constitutes a good reason not to pursue genetic medicine as part of an effort to eliminate disability. His conclusion, valorising the normative goals of science, is that it does not. His argument, in a nutshell, is that whilst genetic intervention may be understood as a form of eugenics, and whilst this may be distressing to some people, even violating their sense of identity, the worthiness of the overall direction of genetic medicine outweighs these considerations. Parker argues, however, that there is no need for people's feelings to be harmed in the first place, according to his claim of a compatibility between two positions, (a) that the world would be a better place if no one in it were disabled and (b) the world would not be a better place if any particular disabled person did not exist. He maintains that efforts to prevent disability do not entail that actual living people with disability are not valued as persons. It would appear that he hopes, in this way, to bridge the gap between the positions of science and disability advocates, whilst acknowledging the difficulty of the task. He writes

*It has been said that the responses of bioethics and disability activists to each others' arguments concerning these issues has been a kind of civil war, a polemical rather than a critically argued interchange (Kuczewski & Kirschner, 2003). I hope this paper falls into the latter category. (Parker, 2008, p. 42).*

Parker clearly identifies himself as having a reasoned rather than a polemical voice. What his paper invites is a discussion aimed at creating a reasoned consensus of opinion. He invites advocates to consider the situation logically. For example he writes

*PD aims to prevent serious disability, and this aim is generally accepted across medicine. Taking certain vitamins during the antenatal period avoids the risk of the birth of a child with spina bifida, just as terminating a pregnancy does. The critical view should condemn both equally, but usually remains silent about the former practice (Parker, 2008, p. 50).*

The question is whether this logical bridge building effort can work as a means of reconciliation of opposed perspectives. Coming from the opposite direction, British disability advocates Shakespeare and Watson (2002) have questioned whether the social model of disability is an outdated ideology. They maintain that a rigid dichotomy between medical and social models is untenable. They say

*Many activists have opposed all attempts to reduce the incidence of genetic conditions. Yet, while we would ourselves have major criticisms of contemporary genetic rhetoric and practice, we cannot see a problem in seeking to avoid serious and debilitating conditions. The woman who takes folic acid in her pregnancy is being sensible, not being oppressive to people with spina bifida. While we would oppose blanket selective screening of all impairments, there are times where it seems appropriate and desirable to take advantage of genetic technologies. Impairments such as Tay-Sachs disease and anecephaly are both terminal and very unpleasant and most people would want to avoid them if at all possible. (Shakespeare & Watson, 2002, pp. 15-16).*

It would appear, then, that reconciliation between the two positions is *logically* possible. A remaining question concerns the moral assumptions embedded in these accounts. Whilst folic acid is a preventative for spina bifida, the only available prenatal preventative for Tay-Sachs disease and anecephaly is abortion. On Shakespeare's and Watson's side, there appears to be an embedded argument that treatment regimes have adverse effects on both women and disabled people and therefore should take the least adverse pathway from the perspective of both parties. If so that demonstrates sensitivity to women and to disabled people. On Parker's side, there appears to be an embedded argument to the effect that since both folic acid and abortion are, equally, ways of avoiding having a child with spina bifida, they are both equal from a moral point of view. The question of whether they are morally equal, however, is part of what is at issue. Answering that question, moreover, would involve talking to women and taking women's perspectives into account. And there is no prospect there for a consensus. It could well be a reasonable assumption that large numbers of women do not want to have to go through an experience of abortion if they can help it. It is a

traumatic event. Folic acid supplements hold no fears.

The remaining morally relevant issue involves what is, and is not, expressed in medical communication addressed primarily to pregnant women. Clinical handouts that address spina bifida typically talk about taking folic acid not having an abortion. This sends a clear signal that clinicians are somewhat sensitive to the potentially traumatic expressive content of their communication when it comes to dealing with pregnant women. It does not yet appear that there is similar degree of sensitivity to dealing with people with disabling conditions. In my experience as a disability advocate I have known people with spina bifida who are deeply troubled by the medical alignment of some spina bifida 'support' associations, in the way they offer advice. The advice includes statements about ways to avoid having a baby with spina bifida. These people say they have been traumatised to learn that their own 'support' association reinforces the medical message, and therefore feel a sense of betrayal. Until this matter is addressed any reconciliation between the positions is superficial at best. An irreducible difference remains: a parallax gap between medical and social disability perspectives.

Sparrow's argument likewise suggests that the expressivist critique does not lead easily towards reconciliation. It suggests that the value of such a critique is that it remains a powerful way of contextualising developments in genetics, by drawing attention to lack of disability representation in the bioethical arena where theories of ethics are discussed, the political arena where policies are made and communication is issued, and the clinical arena where practices are enacted. The issue remains one of the oppression of disabled people, not just because it offends some people's sense of identity, but because for example, people with disabilities or advocates are not invited to attend genetics or sonography conferences, or even to be present at such events. It is oppressive to have an important perspective such as this routinely disregarded. Instead of a harmonious reconciliation, there is ongoing tension demonstrated by Sparrow in his understanding of the situation as requiring a 'debate'.

Yet there is a problem embedded in Sparrow's story of the future being shaped via an ongoing 'debate' between two political opponents. First moral space, the space of science, has already attained a well-nigh indisputable position of right to correlate the causes of a very great range of disabilities with genetics or what happens prenatally. The voice of the opposition—that the causes of disability are social—is by comparison in a very weak position. The 'debate', from the perspective of the political victors, is over. 'The cause of science' has prevailed over 'the disability advocacy cause', and this is because the having and winning of a 'cause' depends politically on being able to justify a claim to know what causes what. As it stands at present, those who believe, in relation to the field of prenatal diagnosis, 'impaired genetics is what most significantly causes disabled identity' have won the contest in the hearts and minds of policy makers.

### **The Requirement in Doing Advocacy, for a Third Moral Space**

An alternative position is possible. The discussion so far has focused on the level of the ideological causes of opposition or possible reconciliation between different

social groups. Deeper levels of CLA open up a different kind of discussion, involving the mythologies (or, as some prefer to put it, the ontology) of human identity. From within this discussion it may become apparent that it is not a debate that will decide the future. For a start, the future, as imagined from within these mythologies, is not unitary. There are multiple futures (some congruent with current medical and social models and others that are not) and these will require or produce multiple moral spaces.

In 2002, the agency for which I worked, Queensland Advocacy Incorporated (QAI) hosted a conference entitled *Genetics and Disability: Exploring Different Spaces, Different Futures*. The opening paper which I delivered and was subsequently published in JFS was prospectively about a third moral space in which the voices of science and of various communities are not privileged (Turnbull, 2003). The conference aim was to produce an environment in which people from currently opposing perspectives listened to each other. The emphasis on space indicates that there are both contextual considerations and a locus of identity around which moral perspectives are created. The idea of 'third' is that, as a result of freely attending to another to whom previously there was an opposition, the possibility for an alternative perspective is opened up. The outcome of that conference was, at least for a time in a particular location (Brisbane, circa 2002, 2003), further and more deeply respectful discussions between disability advocates and, among others, genetic counsellors. Dr Parker was present at these gatherings and made valuable contributions to them.

In the Exploring Moral Space paper I focused primarily on contextual considerations and on opening up the prospect for a third moral space. Whilst such a prospect remains, an opportunity still exists for a deepening and enriching of the dialogue about these matters. The point is not so much about getting agreement. It is about getting respect. The problem with highlighting context is that on its own, there is an insufficient challenge to take up a focused discussion. In this paper I seek to extend that exploration by focusing on a particular locus of identity emerging on the futures horizon. The identity can best be appreciated at 'the discourse/worldview' and 'the myth/metaphor' levels of CLA.

## **A Worldview of Alienation and the Metaphor of a Diabolical Moment**

There lies before us a diabolical moment; whether it is of any consequence in world history is as yet undecided. In some ways the moment is itself insignificant. Whilst many discerning eyes are turned towards great events and momentous occasions, far fewer are aware of subtle changes that occur in places where privacy and confidentiality are upheld as sacrosanct values. Such places include clinics devoted to genetics. It is important to understand the root of this word 'diabolical'. The word in origin refers not to some kind of devilish person, but rather to change in which the direction is irrevocable (Gk bole=change). The prefix 'dia' has three possible meanings and each adds a layer of significance to the moment. It means alternatively, 'to pass through', 'complete', and 'a separation'. A diabolical moment is effectively a moment that some will pass through, during which their life is completely and irrevocably

altered, signalling a separation or a divergence from the direction of others. Whether we like it or not, the future for such people will be altered. But how, and in what way altered?

Medical science appears to have embraced the idea that genetics signifies a complete change in how medicine will be practiced and how people of the future will live, including what their life expectancies will be. In the medical utopian vision of the world, people of the future are not born with serious disabilities, such having been eliminated either before birth or prior to conception. The separation between healthy and disabled people will be achieved biologically, and prenatally. There are, it is claimed, over-riding reasons to believe that only good things are to be associated with this scenario. What is insidious, however, is the insinuation that such a goal is achievable. In a far more realistic scenario, but no less diabolical, only some will have been born as a result of direct genetic intervention. In order to get 'the privileged few' born in such a fashion, 'the many' will have been subjected to the pressure of a geneticised culture based around the idea of the rights of children to having an open future, that is, a future without impairments. The separation here will be social. Further, those who continue to be born as a result of being undetected prior to birth may well come to believe that their sheer existence is a violation of a universal moral code enshrined in this right. If so, they will have come to believe in the right to have been born via the agencies of genetics. The weight of this moral pressure may lead some of such people thinking of themselves as already dead, or as good as dead, beyond redemption.

The condition is not ultimately reducible to a form of social devaluation (as understood from a functionalist sociological perspective). That perspective has important insights to consider and strategies to offer many people. Not all conditions, however, can be adequately addressed by this level of analysis. In order to gain an adequate appreciation for the condition it is necessary to think in terms of worlds of experience disconnected from ideals of citizenship or belonging to a group from which can be drawn a sense of positive identity and support. Here one is confronted with strange metaphors used to describe situations of rarely spoken about ontological depth. Many contemporary discussions of genetics or disability do not speak to this depth or from an appreciation of it. The metaphor that beckons for investigation is of 'the completely alien' or 'the utterly estranged'. The metaphor cannot be understood by merely referring to 'otherness', as pertaining to those who are different, and because they are different, are devalued.

Familiar descriptions of otherness speak from biological or social perspectives implicitly signaling what responses are to be considered appropriate. For example someone with Down syndrome has 'trisomy 21', a genetic condition in which there are not two, but three versions of chromosome 21. The appropriate response in this linguistic formulation is medical, resulting in prenatal diagnoses seeking to avoid the birth of such children. Or the person suffers 'a significant social disadvantage'. The appropriate response in this linguistic formulation is social, including legislation around human rights, and advocacy and social action to remove disadvantage.

The utterly estranged is profoundly other; a far-removed otherness that connects with a sense of not being a person or being a non-person in human form. A related metaphor speaks of identification with the un-dead or the living dead. This, for many,

is an unfamiliar form of disablement. It is not merely biological or social; it is moral. It is a condition of being utterly disconnected from what a majority of people would say is a good life, not just socially, but ontologically. It is a depth from which normal conceptions of a good life would seem, not merely unattainable, but utterly out of the question, totally inappropriate, a hollow mockery of life itself.

It is in the face of such a scenario that people working in genetics and in disability advocacy alike, need to ask whether they have the conceptual equipment to deal with the prospective situation. The question is whether the medical or social models of disability, in their current formulations, based as they are on the notion of value including rights, are able to cope with a phenomenon of profound ontological alienation. In order to address this question, the challenge is to take time to draw aside from familiar roles, functions and patterns of professional conduct, and start to rethink the entire situation from a position, not of their own existence, but of the prospective existence of others, taking into account what we now know from a variety of lived experiences about such a condition.

Doing this would require setting up a moral space that does not already privilege science on the one side, or various communities signalling particular identifications such as 'the disability community' on the other. To be ontologically alienated is to be positioned on the outside of any of these, from the perspective of a radical self negation: an ontological disavowal. Perhaps those who have been trying to speak about matters of deepest concern to them, and have not been successful in getting others to listen, and consequently feel themselves somewhat socially alienated, may be able to position themselves alongside those whose *ontological condition* qualifies them as residents of such a space. Whether someone who is socially alienated can succeed in reaching out and making connections with another whose alienation goes much deeper, is quite another matter. It is in order to discuss the who, the what, and the how, of such scenarios, that a third moral space has been proposed.

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