

Alternative Futures of Genetics and Disability

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In this presentation, based on a speech presented to the Queensland Advocacy Incorporate Conference on "Genetics and Disabilities," Brisbane, October 7, 2002. I would like to map out the futures of genetics and disability with the intent to aid in the creation of a third moral space, as developed by David Turnbull, contesting both the technocratic and the rights approaches.

To do so, it is important to get a handle on the future: what its alternative meanings and uses are.

Foundational Approaches to the Future

Three approaches are foundational. They are: (1) the future as given, (2) the future as transcendental, and (3) the future as contested.

(1) The future as given—taken for granted. This is the commonly held view that there is a singular future that we must respond to. The future is often framed as what will the future be. More often than not technologies are seen to drive this future. Human agency tends to be removed from this approach except for those at the center of technological power.

(2) The future as transcendental—accepted because it is Allah's will. In this approach the future is not in our hands, we must submit to higher forces beyond our control. The goal is to go back to the original text and use it as a guide to understanding the future.

(3) The future as contested. The future here is seen as created by a variety of factors—pushes, pulls as well as weights (patterns of history, paradigms). The future is to be decolonized, challenged, rethought, and then an alternative future created.

I certainly prefer the third of these approaches, as

this allows human agency but is not so naive as to believe that 'you can be all that you can be' (the Western, and particularly postmodern American view of boundless opportunities)—there are limitations, whether because of structure, planetary resources, or even because of forces that are mysterious.

Of course, the new genetics challenges traditional notions of the nature of nature, so much so that, reports *Newsweek*, one Eric Sprague wants to inject himself with jellyfish proteins, a process that has made rats glow in the dark. "I just want to be glowing green. I've looked into being a human subject without much success thus far!"

What then are the uses of the future?²

Commonly, the future is considered a statement about the probability of an event or trend occurring in forward time, that is, we do not remember the future *per se*. However, as important as our constructions of the future, are the various uses of the future. These include the following:

First, the future is educational. The purpose of understanding the future is to develop a conceptual map, to be able to understand theories, methods and values. The future is often constructed as a fascinating idea, full of marvel and possibility.

Second, the future is strategic. Through scenario planning, it can be used to make better decisions. The implications of current trends can be inferred and these trends can thus be challenged: the future as a future impact statement. The future that is best can thus be consciously chosen depending on how one defines 'best'—the issue is, which future?

Third, the future is about capacity building. More

important than solely education—in terms of the internalization of knowledge—is developing the internal and external capacity to adapt to alternative futures. Thus, getting the future right in terms of the correct strategy is not as important as having the capacity to adapt, to find one's niche. Organizationally, this means being future active, moving from thinking about the future to capacity building for the future.

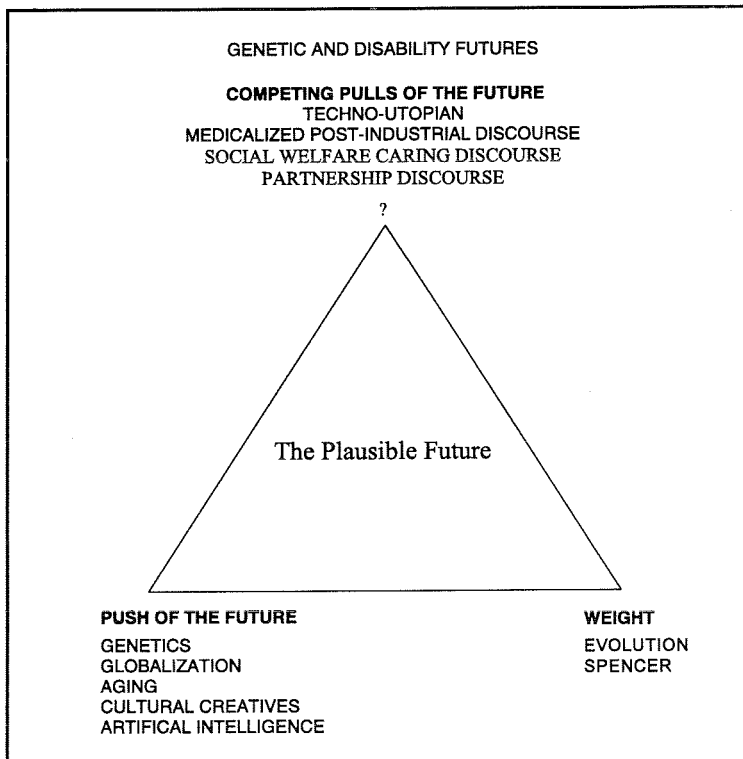
Fourth is memetic change. The future developed is a preferred one. It means spreading ideas and metaphors that encapsulate the desired future.

Fifth, and perhaps the most contentious, is the future as microvita change. Microvita is a term used by philosopher P. R. Sarkar to represent the basic stuff of the universe - being both matter and idea, body and mind, wave and particle.³ Microvita change is about living the future one desires, living in the future. It means that there is an inner dimension to our vision of the future. Real change comes about by being the future not just forecasting it, learning about, developing capacity or even meming it. One becomes the future one envisions.

Essentially, these divisions move the notion of the future as methods and mapping (educational) to an idea that empowers (strategy and capacity building) to an idea that transforms (memetic and microvita change).

Within this framework, I would like to map out the future. However, this is an open-ended map, in need of further development.

This map uses the futures tool, the futures triangle. The futures triangle maps three dimensions: the push of the future (new technologies, globalization, demographic shifts such as aging and migration), the pull of the future (competing images of the future: Gaia versus global tech versus collapse versus national realism, for example) and the weight of the future (what is problematic to change, deep structures). Taken together the triangle of the future presents a way to map the competing dimensions of the future. This is useful in that with a simple diagram the dialectics of the future can be understood. The future is not seen as fixed out there but as being created by various processes (and not being created because of historical patterns or weights).



Thus, what the triangle suggests is that the future is not created. There is a tension between the pushes—the technological imperative and costs associated with it—and the pulls and weights. The pushes appear to be neutral—but they are related to images.

The technocratic utopian pull is best exemplified by the movie *Gattaca*. In the Social Welfare Caring discourse, the most vulnerable are taken care of, but through bureaucratic means. Care is routinized. In the medicalized post-industrial image, the focus remains on profit. Genetics develops through the actions of large pharmaceuticals. However, it is post-industrial as the one size for all industrial paradigm that is challenged. Writes Sandy Edry:⁴

The problem with medicine's one-size-fits-all approach is that it doesn't account for the subtle variations in our genes that make each one of us unique. By 2012, though, your general practitioner may be better equipped. In what's being touted as the 'era of personalized medicine' newborn babies would have their genomes etched in microchips. The information would allow doctors to tailor drugs, diets and treatments to each person's particular genome, avoiding drug fatalities, zeroing in on disease-prevention strategies and helping us lead healthier lives.

I would thus not discount the image of the future. It appears the least tangible but in fact has tremendous impact on which future is actually created. The pull, argues Polak, influences the rise and fall of civilizations.⁵ Pulls that are positive and include agency can move us forward. Certainly pulls that have are negative and discount agency have the opposite result. We know as well from the health literature that one's image of future health and one's sense of agency are far more important than other factors—diet, exercise and even genes.

The pushes are well known. They are the drivers of the future. Which push often becomes dominant is dependent on the image of the future and the strength of the weights. For

example, gene research is dominant because of the hegemony of the techno-utopian image. The cultural creatives push is championed by those with a more spiritual partnership view of the future. The weight here is the evolutionary notion of competition and survival of the fittest.

Thus creating the future is a mixture of push, pull and weight. The weights are varied, including most certainly evolution, the fear of the other and the Spencerian overlay to gene research. What then are the alternative futures that emerge? I present these as scenarios, alternative possibilities.

SCENARIOS

1. CONTINUED GROWTH

Genetics and disability are defined in terms of increasing quantity of life, preventing diseases and enhancing human potential. Science remains corporatized. There is, however, resistance from all aspects of society—costs, rights, for example. Issues of equity are central here as well as 'rogue' nations developing gene warfare capacity. Other aspects of disease prevention remain. The main driver is globalization in its corporatist and governmentalist form.

2. TECHNOLOGICAL TRANSFORMATION

Human Evolution accelerated through genetics plus the artificial intelligence revolution, the 8th day of evolution. Essentially, this is the slippery slope from gene prevention to gene therapy to gene enhancement to germ-line intervention. With issues of equity arising, the state is likely to manage and control reproduction. Eventually there will be a full range of life forms, human, cyborg, gene-borgs, to mention a few. The main driver is technology, particularly the synthesis of genetic and artificial intelligence technologies.

3. COLLAPSE

Genetic experiments lead to mistakes and accidents. Germ-line intervention continues these mistakes across generations. It is not the 8th day of evolution but a return to the beginning. Humans have failed but Gaia continues.

Another species rises. The driver remains technology but the guiding weight is that of humanity going beyond its boundaries.

4. SOCIAL TRANSFORMATION

Post-normal science develops—action learning, participatory, public—along with social transformation. Gene therapy and therapeutic cloning is likely to be allowed but germ-line intervention is banned for another generation. The health model that develops is inclusive, ecological (Gaian-based), multi-door (geneticist plus GP plus homeopath plus massage therapist plus meditation plus diet and exercise). Writes Jennifer Fitzgerald:

Gene therapy continues, but people with disability advise scientists on crucial differences such as between the intention to enhance health and to eliminate disability. The voices of people with disability are central in this scenario ... What are needed are not only policies but value transformation that include their ways of knowing in creating gene futures.⁷

This scenario is the desire for a better world, a social utopia, being asserted by cultural creatives and others fatigued by 500 years of world capitalism.

5. RETURN TO PAST

Heroic science is stopped by the religious right. We—in OECD nations—all die at 70 in any case. Genetic science only for the select few. Strong global protocols against most forms of intervention. Efforts to return to traditional forms of medicine (family based, GP that listens, local traditions). Genetic experiments take off in non-regulated areas in the world. The drivers here are the technology revolution in the context of inequitable globalization.

But while the past may beckon many, it is the long term future that stares at us. Humans may be the first creatures to—through artificial intelligence and germ-line intervention—create their future successors.

CAUSAL LAYERED ANALYSIS

While scenarios focus on breadth, CLA moves to depth. It seeks to go beyond the litany

of the future. Forecasts are nested in the system. For example, the litany is that genetics will solve disabilities, either through predicting and then terminating foetuses that are abnormal or through gene therapy. Inappropriate genes can then be weeded out through germ-line intervention. Of course, not all disability is genetically linked. For example, cerebral palsy occurs when oxygen to the brain is cut off during the birth process. As well, traumatic brain injury has nothing to do with genetics (there might be a correlation with drug/alcohol use tendencies, but not this has not thus far been linked to genetics).

These forecasts are nested in the larger medical and health system; in this case, the technological, medical, corporate, governmental and other institutional relationships that define the future. The main concern of this system is cost to the society. Secondary are the costs and pain of relatives. Cost and pain of the disabled comes third.

Writes Robin Brandt, a futurist who has written on disability futures:

The medical and health system model makes the person with disability unable to participate in society except as a 'sick' person. Unable to participate in society in a responsible fashion, that they are constructed as not having responsibility, this also means they have no 'rights'. They are relieved of their responsibilities as a citizen! Additionally, because they are not able, they must be told what to do by the licensed, degreed and fully examined expert who makes plans or prescribes to the individual.⁸

Nested in the overall system are worldviews. In genetics, this is a Spencerian worldview—evolution of the fittest—but placed on the society. This view is reductionist, seeking to solve problems through technology instead of through social, political and consciousness change. Other worldviews include the spiritual new age, focused on transforming consciousness, the quality of life, and the industrial, focused on enhancing the quantity of life, and giving funds and social care to the disabled.

Beneath these levels are unconscious stories, or myths and metaphors. The disabled are the 'other' in this future, to be changed, transformed, but not as treated partners. Perhaps, Cyclops is the unconscious myth. Another myth is that of the geneticist as God or angel, giving life back to those that have been marked.

Changing the future requires intervention at all these levels: finding new litanies, rethinking the system, challenging worldviews and creating new metaphors. For example, in issues of quality in medicine, the litany is 70-100 thousand a year dying from medical mistakes in the USA. The litany response is 'train better doctors'. However, a move to the system level alerts us that it is the institutional relationships between nurse, surgeon, hospital cleaner, CEO that is likely to generate the problem; merely training better general practitioners will not solve it. No-fault systems, action learning and other quality enhancing measures are needed. But is that enough? A move to the worldview level suggests that it is the vertical relationship between surgeon and patient that is the problem—it is the nature of medicine itself that must be transformed. This means challenging the mythology not only of science and medicine, but also of modernity—the desire to live forever, and the search for perfection and progress.

Thus praxis must be at every level—A real challenge.

What then the future?

Which is your preferred future? Which future is probable? Which future must we avoid? What can be done? Is it possible to create a third moral space? What are our choices? And how will genetics define choice? As Graham Molitor argues, we could add a new chromosome pair to the human genome, "Designed to carry specific therapeutics and traits, these modules could be switched on or off, at the carrier's option, simply by taking a pill or an injection."⁹

A real challenge, indeed.

Appendix - Institute For Alternative Futures Scenarios

Four Scenarios for Genomics

A recent IAF project for the UK government's Economic and Social Research Council (ESRC) used multiple scenarios to explore the social science implications of the genomics revolution. These scenarios combined forecasts and key drivers of genomics into four alternative visions of genomics in 2015. The full text of these abstracts is available at: <<http://www.altfutures.com/pubs/esrc/esrc.htm>>

Genomics, Inc.—Genomics gains more public acceptance as better safety standards and new applications demonstrate the value of its applications. Mergers and alliances create a handful of 'Life-Science' conglomerates that operate on a global scale. Many individuals use genomics to identify their unique health risks and sensitivities. Untoward consequences are not significant.

Broken Promises—Genomics applications prove more difficult to develop than expected, and several prominent genomics accidents turn public opinion against genomic technology. Activists mobilize for stronger measures against the industry and further reduce public demand. Liability lawsuits severely diminish the industry and public pressure forces genomic patents into the public domain.

Out of Our Control—Genomic breakthroughs accelerate and the costs of research decline; throughout the developed world, applications are delayed in the approval processes. In the meantime, developing nations, particularly China, use unregulated field trials to rapidly advance and develop genomics applications. Miracle products create widespread public acceptance among those who can afford them, despite genomic accidents and uncertainties.

Genomics for All—Genomics is successfully implemented, with wise and participatory management of the risks and side effects. A consensus emerges not only on how genomics should be implemented, but also on the type of society that genomics should serve. Genomics plays an

important role in building a global society dedicated to improving equity and sustainability.

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Endnotes

- 1 Brook Larmer and John Ness, "Mad science," *Newsweek* (16-23 September 2002), 77.
- 2 For more on this, see Sohail Inayatullah, *Questioning the Future*. Tamsui, Tamkang University Press, 2002.
- 3 See Sohail Inayatullah, Understanding P.R. Sarkar: *The Indian Episteme, Macrohistory and Transformative Knowledge*. Leiden, Brill, 2002.
- 4 Sandy Edry, "Me-Too Medicine," *Newsweek* (16-23 September 2002), 76.
- 5 See Frederick Polak, *The Image of the Future* trans. Elise Boulding. San Francisco, Jossey-Bass, 1973.
- 6 www.culturalcreatives.org
- 7 Sohail Inayatullah and Jennifer Fitzgerald, "Gene Discourses: Politics, Culture, Law, and Futures," *Journal of Technological Forecasting and Social Change* (Vol. 52, 1996), 161-183. And: Jennifer Fitzgerald, *Include Me In: Disability, Rights and Law in Queensland*. Brisbane, Queensland Advocacy Incorporated, 1994.
- 8 Email. September 20, 2002.
- 9 Graham T.T. Molitor, "Redesigning Humans: Our Inevitable Genetic Future," *Journal of Futures Studies* (Vol. 6, No. 4, May 2002), 160.