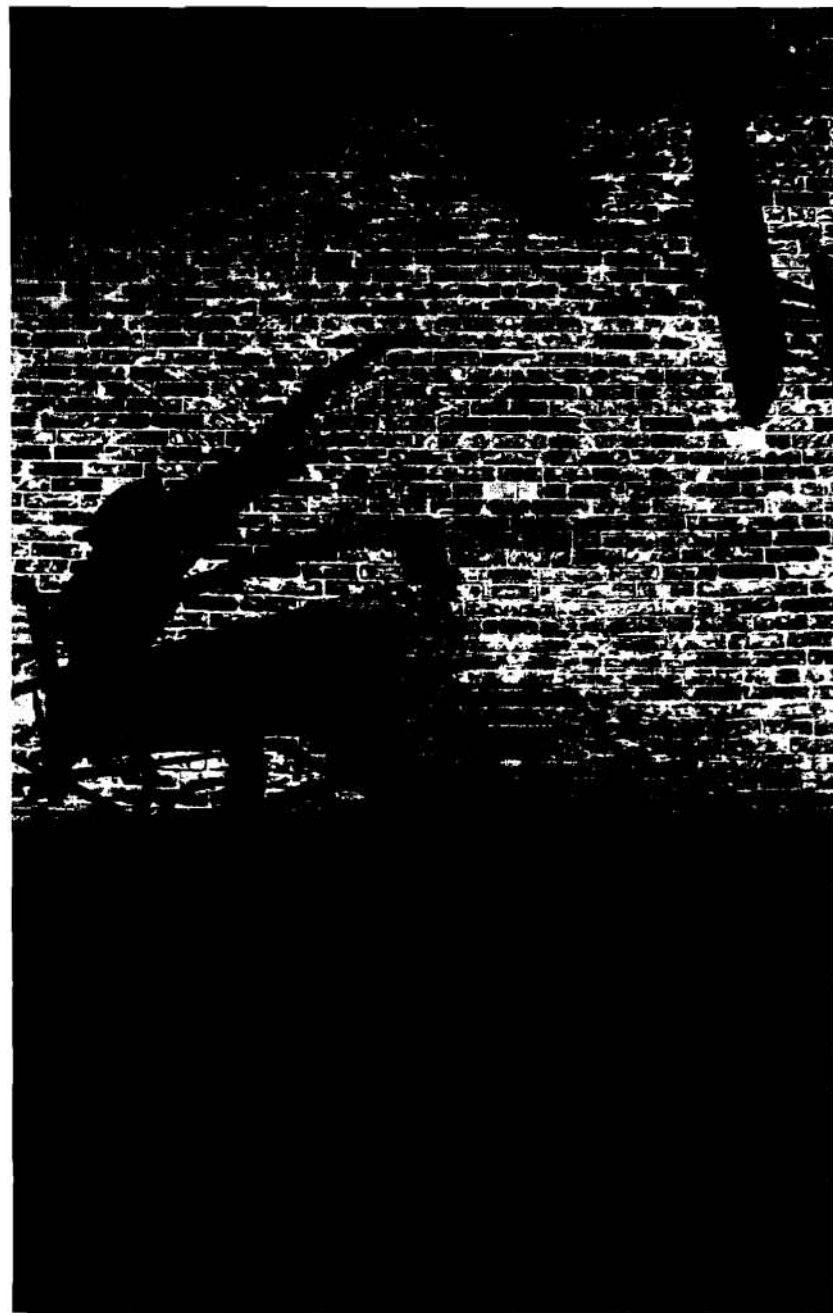


THANKS, BUT I'D RATHER BE DISABLED

If it's broke, do we necessarily have to fix it?

BY MARILYN HEAD



A WORLD FREE OF DISABILITY AND debilitating pain; the ability to regenerate diseased or impaired tissue; the option of screening out genetic disorders. This is the promising future foreshadowed in part by the emerging biotechnologies displayed in Te Papa's *Genetic Revolution* exhibition.

Yet, speaking at a forum held at Te Papa on International Disability Day, Australia's leading disability activist, Christopher Newell, expressed outrage at the systematic exclusion of the voices of those living with impairments. By focusing, he said, on the "dominant biomedical discourse" that equates absence of disability with the good life, the exhibition failed to address the most fundamental question: is delivering us from disability inherently a good idea?

"The absence of alternative narrations of genetics, particularly those that see biotechnology as inherently threatening to the worth of people with disabilities, is a rude reminder of the silent and silenced voices of the disabled," said Newell, who is associate professor of medical ethics at the University of Tasmania's school of medicine.

According to this way of thinking, the hidden subtext of the genetic revolution is the re-emergence of eugenics, albeit clothed in the language of "therapy" and "choice". Put bluntly, if disability in general is something damaged or broken that needs fixing, of what value are people living with impairments now? Are they also broken and damaged and therefore of less worth than other people?

It's an uncomfortable question, one rarely considered in the biotechnology debate, so firmly entrenched is the assumption that *of course* people "suffering" from disabilities would rather be without them: it's so obvious that they don't even have to be asked. Yet, without the voices of those directly concerned, Newell argues, "biotechnology risks being used as a form of social control – try replacing the word disability with race or gender and the danger is clear".

Pre-implantation genetic diagnosis (PIGD) and the subsequent screening of embryos for serious genetic disorders pose particular risks, he believes.

"It is one thing to have treatment for a medical condition, but another when genetic makeup is such a compelling tragedy as to remove the claim to life itself. And in screening out disability, are we also screening out quintessential human qualities such as courage, persistence and fortitude? Are we valuing technology above the inherent dignity of human life? Could biotechnology ultimately signal the end of genetic diversity?"

In affirming the right of disabled people to be full human beings, Newell draws on

his own lifelong experience of congenital physical impairment. He uses a wheelchair and is often hospitalised for an intensely painful spinal condition, yet he insists that disability is a social construct rather than just a physical condition. His book *Disability in Australia: exposing a social apartheid*, co-authored with Gerard Goggin, documents the routine oppressive treatment of people with disabilities whose basic human rights are flagrantly ignored.

"Society still makes decisions about the 'poor pathetic disabled' rather than embracing the diversity and dignity of human life and upholding universal values," says Newell. "We are not slaves to our conditions. Many of us with

not have EB. Hilary Stace, the mother of a child with autism, says, "I would not choose genetic testing (although I think mothers have a right to choose). There are so many people like Humphrey and my son who give so much in terms of teaching about compassion and the value of humanity. Just because their norm is not ours doesn't devalue it or them."

And Philip Patston, the ebullient gay comedian and training consultant who has cerebral palsy, on being asked if he would choose to have the motor neuron cells damaged at birth replaced as a result of stem cell research, quipped, "That's like asking someone Maori if they would like to be modified to become Pakeha. They

It is one thing to have treatment for a medical condition, but another when genetic makeup is such a compelling tragedy as to remove the claim to life itself. – Christopher Newell

hindsight and proper social support find a variety of benefits and insights through the challenges of disability. We have learnt what it is to be human; our impairments can become our strengths."

Newell's views are strongly endorsed by others with impairments who are "happy with the way they are" and "would never want to be any different". At the forum, panellist Dr Martin Sullivan spoke of how he felt used by scientists who invoked disability to justify sometimes highly controversial research. Humphrey Hanley, who has a severe form of the genetic skin blistering condition *Epidermolysis bullosa* (EB), would choose not to have gene therapy, rather than

might consider that life could be easier being Pakeha, but if their essential Maoriness is removed, what part is left?"

That people could choose to live with pain, or accept the possibility of having a physically impaired child, or even describe cochlear implants to mitigate deafness as being "instruments of oppression", is so extraordinarily at odds with the popular view of the disability community, espoused by such emblematic figures as Christopher Reeve and fellow supporters of biotechnology research, that clearly the bioethical debate has been less than inclusive – in the public arena at least.

"When citizens are removed from effective participation," says Newell, "we leave unexamined the social circumstances in which people make difficult decisions and unexamined the technologies which enable those decisions. We may see disability and the treatment of suffering as central to the shaping of biotechnology, but rarely do we explore or deconstruct the meta-ethical dimensions of what we are doing."

"Biotechnology by itself cannot deliver 'the good life'. There is a vital role for medicine in supporting all people, but disability does not need to be 'solved' so much as embraced as part of the diversity of the human condition."

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Disability activist Christopher Newell.



new frontiers

>> WHERE THE WEIGHT IS



If children live in what's thought by parents to be a dodgy area, the kids are more likely to be overweight, according to a study in the Archives of Pediatrics & Adolescent Medicine. University of Michigan researchers found that 17 percent of children living in neighbourhoods perceived as least safe by their parents were overweight, compared with only four percent of those living in the safest area. "In attempting to protect their children from harm," the authors say, "parents not only decrease the kind of physical activity that comes from playing outdoors in the neighbourhood but inadvertently increase the likelihood of sedentary activity that comes from staying indoors."

>> THINK IT AWAY

US scientists have been able to train a small group of people to think away pain. While they watched their brain's activity on functional magnetic resonance imaging (fMRI), the people in pain were asked to try to control the pain-regulating part of the brain by ignoring the pain or imagining a more benign sensation. All those involved managed to reduce their pain. As a result, the researchers believe that people can learn to "strengthen the function of a specific region of the brain and, through that change, the regions associated with the perception of pain". The report on the pilot study was published in Proceedings of the National Academy of Sciences.

>> BIG SCIENCE

High school students can vie to win six "Big Science" adventures around New Zealand in June, with an overall winner travelling to Antarctica to join the celebrations for International Polar Year in 2007. To take part, school teams must produce a five-minute video on a local science story – anything from a local place of scientific interest to the work of a local scientist. The competition, being organised by the Royal Society of New Zealand, closes on April 12. For more information, see <http://www.rsNZ.org/events/bigsci/>

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