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Dear Sir,

Proposed Amendments to the Disability Discrimination Act

The first real issue with this inquiry is its timing. I only found out about it in the last week, thanks to the Warringah Council disability newsletter. It is to be anticipated that there will be little feedback, given the time of year the inquiry was called and the deadline for submissions. The Parliament should give serious consideration to amending its Standing Orders in each House, so that no inquiries can be initiated between November 30th and February 1st the following year. It can be taken as a given that everyone will be preparing for Christmas and annual leave during this time, and few if any will be thinking of legislative reviews.

In general, from my quick examination of the Bill on the Parliamentary info web site, it seems concerned with minor amendments and refinements. While acknowledging that amendments concerning carers and assistance animals are welcome, the whole premise of the Bill remains one where various “others” (be they employers, contractors or any number of other service providers) have to amend their environment to accommodate a person or persons with a disability.

As someone confined to a wheelchair by cerebral palsy I acknowledge that one can see vast changes over the 35 years of my own life. And it is not that I fail to welcome the clear progress that has been made. However, it is also fair to say that having sat on numerous access committees and lobbied government (at all levels) repeatedly,¹ this is

¹ See for example, my submission to the Henry Inquiry into tax reform, highlighting many of the anomalies in the tax system which operate as an active disincentive for many people on low incomes (and with disabilities) to enter the workforce. Note in particular, the questions raised over the Supported Wage

not something I want to be doing in 20 years from now. By then, I want to live in a world which says that it is discriminatory, as well as being a failure of medicine, science and public policy, for anyone to be living with any form of disability. If some people like Bono and Sir Bob Geldof believe they can make poverty and hunger history, why do we not aim to do the same with disability?

Part of the reason is that the ethos of the past twenty years at least, has been to convince people with disabilities, their families and the wider community that people with disabilities are “normal” and we can do “anything”. Firstly, in this day and age of ‘free choice’, ‘self-determination’ ‘tolerance’ and the like, trying to define what is ‘normal’ is a fraught process which some could say is discriminatory in and of itself. Secondly, it is unreasonable to say anyone can do “anything”. Regardless of who we are there are personal, financial and other limits on what we can do. And while it is true that many things can be overcome, one of my personal frustrations is that the public (and thus political and legal) perception of disability as a study of extremes. We are either portrayed as extremely needy and vulnerable (eg: service provider appealing for charitable donations) or as exceptionally praiseworthy and courageous (eg: Para Olympians). Depending on whose statistics you accept, up to 20% of the Australian population has a disability.² We do not all live life in the extremes popularly depicted.

However, we all have aspirations, many of which are not reflected in this Bill. Firstly, as stated earlier, I want to see in my lifetime an era emerge where it is seen as unacceptable for anyone to experience disability. Such an aspiration should be articulated in the legislation. Additionally, the focus of the Bill is reasonable adaptations made by others to incorporate people with disabilities into the wider (supposedly mainstream) environment. There is little or no suggestion of people with disabilities taking control of their own environment and declaring what they want, either individually or collectively. This was exactly the kind of point I was trying to make when writing to the Productivity Commission’s inquiry into Paid Maternity Leave.

The premise that the government would pay individual mothers and firms a subsidy, instead of using the money to encourage the redesign of employment so that people could work from home (in the age of internet, satellite and broadband technology) and thus have much more flexible work hours, in order to be with their family while still being productive, did not make sense to me.³ Similarly, part of me asks why we are still seeking to reasonably adjust the world for people with disabilities, instead of bringing the world directly to them through modern technology.

Also, if the Government were serious about disability it would begin taking more bold moves in science and research. To truly make disability history, the Government must

Scheme, which in my view, does not foster real sustainable work, but continued dependence on State welfare http://taxreview.treasury.gov.au/content/submissions/Adam_Johnston.pdf

² See the Australian Bureau of Statistics, *Disability, Ageing and Carers: Summary of Findings, Australia, 2003*, available at <http://www.abs.gov.au/Ausstats/abs@.nsf/e8ae5488b598839cca25682000131612/768ee722e31f6315ca256e8b007f3055!OpenDocument>

³ See generally, http://www.pc.gov.au/_data/assets/pdf_file/0018/80442/sub063.pdf

move against the churches in Australia. These institutions have, for far too long, held back the cause of stem cell research, in particular, embryonic stem cell research. While many will say the churches do many good charitable works, I do not see this as anywhere near adequate compensation for the opportunity cost of research which the churches have helped to ban in Australia.⁴

As such, it is time to stop talking about reasonable adjustment and start talking about how we can possibly, in all good conscience, continue to accept disability as part of the human condition, rather than eradicate it from our personal and communal experience of humanity. A failure to do so is a discriminatory act, and should be treated in this way. After all, the laying of sewerage pipes, the discovery of antibiotics and mass vaccination programs all led to greatly improved health and longevity in the Western World in the 18th, 19th and 20th centuries; stem cell and genetic technologies are the tools for continued human progress in this new millennium.⁵ I believe the churches are facing their greatest threat in over two millennia, and have said elsewhere:

“...The churches and their related charitable arms are generally held in high public esteem for their work with the sick, elderly, disabled and other marginalised groups in society. And there is no doubt that this esteem is merited. However, does stem cell technology represent a threat to that constituency, as people who were once ill and marginalised see the potential to be restored to mainstream life? The churches may well wonder whether many will continue to look to them for help, guidance and support, as stem cell science and other research progresses?...”⁶

People should not have to suffer sickness and disability for another’s moral comfort. Yet, in my view, by considering disability a normal and acceptable part of human experience which we should continue to adapt to, we are implicitly tolerating suffering. On this basis, I think the Bill should be widened, to not only consider discrimination against individuals, but discrimination against groups of people because of the second groups’ moral or ethical views. In this respect, one can sight the example of St. Johns College which offered some land to Sydney University in 2007 to build a research institute, on the proviso that no stem cell research be conducted at the institute.

I was so incensed by this, that I wrote a short paper.⁷ In essence, it appeared to me that words like “ethics” and academic research “guidelines” could readily be used to achieve pseudo-religious ends or “morals”. While I don’t object to anyone holding whatever

⁴ And the results speak for themselves, with esteemed Australian scientist Dr Alan Trouson going to California. See <http://www.abc.net.au/sundayprofile/stories/2221197.htm> Note that my response to the news of his departure was published in the Melbourne Age under the heading “Best hopes goes east” <http://www.theage.com.au/cgi-bin/common/popupPrintArticle.pl?path=/articles/2007/12/23/1198344881486.html>

⁵ See generally, my submission to the Senate Community Affairs Committee inquiry into the *Somatic Cell Nuclear Transfer (SCNT) and Related Research Amendment Bill 2006*, available at http://www.aph.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/leg_response_lockhart_review/submissions/sub53.pdf

⁶ Ibid., p. 3

⁷ See Appendix 1

moral views they like, when it effects the research decisions of a publicly funded, secular institution of higher learning, we should all be concerned. What other areas of research or inquiry might be stifled that may help ameliorate disability in one or more of its forms? I trust this helps to explain why I believe the Disability Discrimination Act should have a somewhat different focus today.

Yours faithfully,

Adam Johnston

Sunday, 11 January 2009