The Hon Josh Frydenberg MP

Treasurer

Member for Kooyong

24 October 2019

Dear Mr. Frydenberg

**Prebudget Submission**

in making this submission, I draw attention to the document I submitted last year. Many of my concerns remain outstanding and, while some potential income tax reforms have had their fate determined by the last election, there is still much to be done.

The issue of tax expenditures remains a complex and costly matter for the Commonwealth Government. The government could improve its financial position considerably by sealing many of the loopholes which allow so much revenue to allude the Commonwealth. Again, this is more widely discussed in the prior submission which I attach,[[1]](#footnote-1) so I will not labour the point.

Another issue which should be raised is a recent consultation undertaken by the Federal Department of Health on the development of stem cell and related research in Australia.[[2]](#footnote-2) As someone confined to a wheelchair by cerebral palsy for all my life, I am a passionate supporter of scientific research and development which leads to the cure of all forms of disability and chronic illness. While supporting and welcoming the progress of the Scientific Research Future Fund, much more needs to be done to translate discoveries in the lab into therapies for patients at the bedside

in this respect it saddens me that $22 billion can be spent on a National Disability Insurance Scheme (NDIS) that according to media reports I have heard, has been underspent.[[3]](#footnote-3) This does not of itself concern me – I would take the underspent and happily spend it on scientific research. I would also indicate that the NDIS does not really represent a pathway to a normal or ordinary life. In many ways it represents a life sentence; that is a life sentence depended on the church and charitable sector for the very means of living. You would think that in 21st century Australia and indeed in the rest of the Western world, we could be far more creative than rebadging welfare as insurance and thinking nobody would notice.

I noticed and, to quote that famous Yellow Pages advertisement which entered the Australian lexicon I am "not happy Jan!" If you look through the NDIS Rules for Supports for Participants, the NDIS administrative agency will not provide any funding for something likely to improve the functional capacity of an individual who is a member (or participant) in the scheme.[[4]](#footnote-4) This must be the height of cruelty and the most depressing regulatory instrument ever written. While the Agency might see a discrete dividing line between someone's health and disability (this being to the financial advantage of the NDIS) ask anyone who must live with a disability and, you will likely receive a very different answer. Certainly, in my own case I see no distinction between my health and disability – each interacts and effects the other. Indeed, cerebral palsy brings its own range of chronic conditions, which "helpfully multiply" as I age.

This is what makes the NDIS rules so cruel. People are condemned to live out their days with their disability being an ever-present companion. Is this good enough? Personally, I say no. While I may be too old to expect the science to have practical application to me, it should benefit future generations. Our government should not accept that people will live with disability or chronic illness – our emphasis should be the cure such conditions so that they become an oddity of the history books This is why I have included my submission on cellular research and, why the Treasury has been provided with a confidential file outlining my concerns regarding the care of people who are aged and disabled under the NDIS. While being a participant myself (because there is nowhere else to go for support and services) I remain deeply troubled by my own reliance on the charitable sector ongoing care. The establishment or re-establishment of a government provider at the state and territory level when it came to disability and aged care services would be most welcome, as this would engender more open and public scrutiny.

In summary:

1. Tax reform should continue and, the many loopholes which continue to permit tax expenditures should be closed. This would give greater certainty to the Commonwealth budget;

2. More emphasis should be placed on providing both financial and other relevant infrastructure support to Australia's research scientists. This should be given much greater prominence than it is receiving currently, even with the establishment of the Scientific Research Future Fund;

3. While we should still provide social care and support, programs like the NDIS are looking to the past and not the future. The government should be aiming to cure all forms of disability and chronic illness; I say this as someone with a disability and attendant chronic illnesses. The NDIS does not solve my problems or give me an ordinary life and, as stated above, the application of the science may come at a time after I have left this world. Nonetheless, it should be a far greater priority to ensure that future generations do not have to live with disabilities and chronic illnesses. Government planning and spending should reflect this objective. Sadly, I am not confident that it does this currently.

Yours faithfully,

Adam Johnston

1. See <https://consult.treasury.gov.au/budget-policy-division/2018-19-pre-budget-submissions/consultation/view_respondent?show_all_questions=0&sort=submitted&order=ascending&_q__text=adj&uuId=519819481> as at 24 October 2019 [↑](#footnote-ref-1)
2. See my submission, the document “my response.pdf” attached [↑](#footnote-ref-2)
3. NDIS underspend helps return budget to the brink of surplus, Pro-Bono, <https://probonoaustralia.com.au/news/2019/09/ndis-underspend-helps-return-budget-to-the-brink-of-surplus/> as 24 October 2019 [↑](#footnote-ref-3)
4. See highlighted text below:

Supports for Participants Rules

7.5     The NDIS will not be responsible for:

(a)     the diagnosis and clinical treatment of health conditions, including ongoing or chronic health conditions; or

(b)     other activities that aim to improve the health status of Australians, including general practitioner services, medical specialist services, dental care, nursing, allied health services (including acute and post-acute services), preventive health, care in public and private hospitals and pharmaceuticals or other universal entitlements; or

(c)     funding time-limited, goal-oriented services and therapies:

(i)      where the predominant purpose is treatment directly related to the person’s health status; or

**(ii)     provided after a recent medical or surgical event, with the aim of improving the person’s functional status, including rehabilitation or post-acute care**; or

(d)     palliative care.

<https://www.legislation.gov.au/Details/F2013L01063> as at 24 October 2019 [↑](#footnote-ref-4)